University Library



A gateway to Melbourne's research publications

Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:
Hayes, Laura

Title:
Hope and recovery in a family treatment for schizophrenia: a program evaluation of a family psychoeducational intervention

Date:
2014

Persistent Link:
https://hdl.handle.net/11343/40751

Hope and recovery in a family treatment for schizophrenia: A program evaluation of a family psychoeducational intervention

Laura Maree Hayes

Submitted in total fulfilment of the requirements of the degree of Doctor of Philosophy

May 2014

Department of Psychiatry

The University of Melbourne

Abstract

A focus on recovery is increasingly widespread in practice and policy in services for people with schizophrenia and their families. Recovery principles suggest that hope is integral to recovery, which can occur (and implicitly hope can improve) independent of the symptomatic severity of mental illness. However, there is little research on this or recovery-focused services in general. This is a concern for services wishing to evaluate the provision of recovery-focused practices. Unless the relationship between hope and recovery is investigated broadly, the understanding and evaluation of recovery is compromised.

Over 50 RCTs demonstrate the effectiveness of family psychoeducation (FPE) in reducing relapse in consumers and burden in carers. Although not studied previously, FPE appears well suited to improve hope and recovery because it develops purpose and support within families.

This study investigated (1) the trajectory of hope, recovery and symptoms across an FPE program; and (2) the usefulness of a hope model which defined hope as the positive expectancy of achieving goals through optimism and self-efficacy. Emergent hope, in contrast, emphasises the beginning of hope as the "tiny fragile spark" in the midst of adversity.

Method: The study used a mixed-methods, quasi-experimental design with consumers and relatives selected for FPE suitability, compared to TAU, conducted in community mental health centres in disadvantaged suburbs. Assessments conducted before and after 10 months of FPE or TAU included: hope, consumer functioning and symptoms; and carer distress and burden. Treatment satisfaction was assessed in participants from the treatment cohort.

Results: 62 consumers and 63 carers were recruited across treatment and TAU cohorts; most consumers had persistent symptomology and fifty percent had co-morbidities. Average hope in consumers and carers was significantly below

community norms. Higher symptoms were correlated with reduced hope. There were no changes over time in outcomes and no significant differences between FPE and TAU groups. Carers expressed some hopes in terms of positive expectancy and self-efficacy, but also discussed hopes without optimism for their attainment. Consumers did not express their hopes in terms of goals, motivation and planning. However, in the absence of objective changes, participants reported high levels of satisfaction with FPE.

Conclusion: These results emphasise the lack of hope in consumers with severe and enduring mental illnesses and the need for new ways to address this important problem. The lack of treatment effect for FPE could not be attributed to low statistical power; the findings suggest there are considerable challenges in restoring hope and achieving recovery for this group of consumers. The study demonstrates the difficulties in translating evidence from successful efficacy trials into effective recovery-based programs.

Hope was not independent of symptoms, consistent with other research, but not the recovery paradigm. A nuanced reading of recovery narratives suggests that while recovery can occur despite the persistence of symptoms, it is not a given. In the early stages of recovery and low levels of hope, symptoms can dominate positive expectancies. As a mix of optimism and efficacy, expectancy hope showed limited relevance, as it could not account for carer hopes expressed in the face of considerable adversity. Lower hope levels might be better assessed using emergent models of hope.

These findings encourage closer attention to the successful implementation of FPE in routine practice, more research into the relationship between hope and recovery, and the need for suitable models and measures of hope to evaluate recovery-focused services.

Declaration

This is to certify that:

(i) The thesis comprises only my original work towards the PhD except were indicated in the preface.

(ii) Due acknowledgement has been made in the text to all other material used.

(iii) The thesis is fewer than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

Signed……..

Preface

The present study has been undertaken in conjunction with an effectiveness evaluation of the Building Family Skills Together (BFST) program carried out by the author on behalf of the investigator group at the Psychosocial Research Centre, University of Melbourne. The members of the investigator group included Associate Professor Carol Harvey, Associate Professor John Farhall, Associate Professor Amaryll Perlesz, Brendan O'Hanlon, Associate Professor Graeme Hawthorne, David Juriansz and Noel Renouf. The measures used in a concurrent effectiveness evaluation were utilised in the present research in addition to instruments specifically for this PhD study.

Acknowledgements

I would like to acknowledge the generous mentoring and supervision of Associate Professor Graeme Hawthorne and Associate Professor Carol Harvey, and am saddened that Associate Professor Hawthorne could not complete his supervision of this thesis due to illness.

I am grateful to Professor Helen Herrman and Professor David Castle who have provided supervision in 2013.

I would also like to acknowledge the excellent work of the research team led by Associate Professor Carol Harvey, Associate Professor John Farhall, Associate Professor Amaryll Perlesz, Brendan O'Hanlon, Associate Professor Graeme Hawthorne, David Juriansz and Noel Renouf who developed and guided the outcomes evaluation of this most important intervention to support families and consumers living with mental illness.

Thanks also go to the consumers and carers who generously gave their time for the research interviews, and shared their experiences openly.

I would also like to thank my family for their support of my PhD.

Table of Contents

Abstract **3**

Declaration **5**

Preface **7**

Acknowledgements **9**

Table of Contents **11**

List of tables **16**

List of figures **17**

List of abbreviations and acronyms **19**

Chapter 1: Introduction **24**

1.1 Introduction to the study **24**
1.2 Structure of the report **30**
1.3 Schizophrenia: Definition and diagnosis **30**
1.4 Contemporary experience of living with psychosis in Australia **33**
1.5 Brief history of treatments for schizophrenia **34**
1.6 Family treatments for schizophrenia **35**
1.7 Use of the term consumer **38**

Chapter 2: A critical review of hope for carers and consumers **41**

2.1 The importance of hope **41**
2.2.1 Early approaches to hope – Emergent Hope 44
2.2.2 Cognitive approaches to hope 45
2.2.3 Hopelessness 46
2.2.4 Snyder's Hope theory 48
2.2.5 Measuring hope: the Snyder Hope Scale 50
2.2.6 Findings regarding the Snyder Hope Scale 51
2.3 Critiques of Snyder's model **53**
2.3.1 Hope, optimism and the construct of control 53
2.3.2 Hope and negative and positive affect 60
2.3.3 The Snyder Hope theory and the phenomenology of hope 62
2.3.4 Content validity of the Snyder Hope Scale 63
2.3.5 Other research on hope 64
2.3.6 Conclusion: hope and it's measurement 66
2.4 Hope and recovery for consumers **67**
2.4.1 Definitions of recovery 67
2.4.2 The development of the concept of recovery 70
2.4.3 Tensions and debates regarding recovery 71
2.4.4 Phased models of recovery and hope 72
2.4.5 Evidence relating hope and recovery 74
2.5 Hope for caregivers and family members **80**
2.5.1 Hope and caregiver burden 81
2.5.2 Carers and the "holding of hope" 82
2.6 Hope in contemporary mental health treatment for families **83**
2.6.1 Predictions for hope in treatment 83
2.6.2 Further research into hope for carers and consumers 85
2.7 Conclusion **86**

Chapter 3: Behavioural Family Therapy 89
3.1 The Behavioural Family Therapy model 90
3.1.1 Background and influences 90
3.1.2 Contemporary Behavioural Family Therapy treatment 92
3.1.3 Hope and BFT 98
3.2 Research outcomes for BFT and family psychoeducation 99
3.2.1 Early studies from the 1980s and 1990s 100
3.2.2 Five crucial characteristics of the early studies 103
3.2.3 Family psychoeducation and expressed emotion 105
3.2.4 Sparse and rich comparison treatments 111
3.2.5 Acute and persistent conditions 115
3.2.6 Family psychoeducation for specified groups 117
3.2.7 BFT in contemporary practice – questions remaining 119
3.3 BFT in action - Building Family Skills Together 121
3.3.1 The need for a family intervention 121
3.3.2 Implementation activities 122
3.3.3 Adaptations of BFT for this program 124
3.3.4 Challenges in implementation 124
3.4 Evaluation of the BFT program and research questions 126
3.4.1 Expected outcomes from prior research 126
3.4.3 Program logic 129
3.4.2 Hypothesis questions 132

Chapter 4: Evaluation methodology 136
4.1 Evaluation questions and hypotheses 136
Section 4.2: Study Design 138
4.2.1 Quasi-experimental method 138
4.2.2 Minimum treatment requirements 141
4.2.3 Pre and post testing time frame 141
4.2.4 Mixed methods approach 142
4.2.5 Threat analysis 143
4.2.6 Power analysis 150
Section 4.3: Materials, Setting and Participants 152
4.3.1 Catchment area profiles 152
4.3.2 Service descriptions 154
4.3.3 Participants 156
4.3.4 Measures 158
Section 4.4: Study procedures 170
4.4.1 Ethics 170
4.4.2 Recruitment procedures 170
4.4.3 The research interview 178
4.4.4 Working with participants of non-English speaking background 179
4.4.5 The follow-up interview 180
4.4.6 Risk management and adverse events 180
Section 4.5: Data analysis 181
4.5.1 Data entry and data management 181
4.5.2 Data analysis 181
4.5.3 Qualitative data analysis 185

Chapter 5: Consumer results 188
5.1 Consumer participants and participation rate 188
5.2 Small number strategy 190

5.3 Examination of base-line results 194
5.3.1 Comparing demographic measures in treatment and comparison groups at baseline 194
5.3.2 Distribution of pooled data for outcome measures at baseline 194
5.3.3 Comparing outcome measures for treatment and comparison groups at baseline 197
5.3.4 Effect of differences in demographic and outcome variables for treatment and comparison groups at baseline 198
5.4 Examination of follow-up results 201
5.4.1 Demographic match of treatment and comparison groups at follow-up 201
5.4.2 Distribution of pooled data for outcome measures at follow-up 202
5.4.3 Comparing outcome measures for treatment and comparison groups at follow-up 204
5.5 Differences between the Snyder Hope Scale at follow-up, adjusted for base-line scores 205
5.6 Subsidiary analysis - differences between individual items in the Snyder Hope Scale 206
5.7 Hope and recovery analysis 208
5.7.1 Hope and symptoms 208
5.7.2 Hope as a precursor recovery variable 209
5.8 Comparison of Consumer hope scores with other groups 209

Chapter 6: Carer results 216
6.1 Carer participants, participation rate and demographics 216
6.2 Small numbers strategy 218
6.3 Examination of base-line results 219
6.3.1 Comparison of demographic measures in treatment and comparison groups at baseline 219
6.3.2 Distribution of pooled data for outcome measures at baseline 220
6.3.3 Comparing outcome measures for treatment and comparison groups at baseline 223
6.3.4 Summary of examination of baseline measures 224
6.4 Examination of follow-up results 224
6.4.1 Comparing demographic measures in treatment and comparison groups at follow-up 224
6.4.2 Distribution of pooled data for outcome measures at follow-up 225
6.4.3 Comparing outcome measures for treatment and comparison groups at follow-up 227
6.3.4 Summary of examination of follow-up measures 228
6.5 Differences for the Snyder Hope Scale at follow-up, adjusted for base-line scores 228
6.6 Subsidiary analysis - differences between groups for individual items in the Hope Scale 229
6.7 Hope and wellbeing analysis 230
6.7.1 Hope and burden 231
6.7.2 Hope as a precursor to improved wellbeing 231
6.8 Hope in the family context 232
6.9 Hope in carers in comparison other carer studies 233

Chapter 7: Qualitative analysis of the hope interview 238
7.1 Introduction 238
7.2 Methods 239
7.3 Consumer results 240

7.3.1 Goals for consumers 241
7.3.2 Motivation for goal achievement in consumers 245
7.3.3 Consumer planning for goals 247
7.3.4 Consumer summary 250
7.4 Carer results 250
7.4.1 Carer goals 251
7.4.2 Carer motivation 256
7.4.3 Carer planning for goals 260
7.4.4 Carer summary 262
7.5 Summary and conclusion 262

Chapter 8: Satisfaction with BFST: Exit interview 267
8.1 Engagement 267
8.2 Psychoeducation and skill acquisition 268
8.3 Generalisation of therapy acquired skills and education 272
8.4 Other changes 275
8.5 Conclusion of sessions 276
8.6 Summary 277

Chapter 9: Discussion and conclusion 279
9.1 No change to outcomes 280
9.1.1 No observed effect of treatment 281
9.1.2 Treatment fidelity 286
9.1.3 Measurement failure 290
9.1.4 Statistical validity - Small numbers 295
9.1.5 Satisfaction with treatment: exit interview findings 296
9.1.6 Conclusion: treatment effect not detected 296
9.2 Hope and the recovery paradigm 298
9.2.1 Hope across the course of treatment 298
9.2.2 Hope for consumers 298
9.2.3 Hope for carers: burden and coping 301
9.2.4 Hope and the family: relational hope 302
9.2.5 Expectancy hope in carers and consumers 303
9.2.6 Hope in comparison to community, carer and consumer groups 305
9.2.7 The Snyder Hope Scale, hope and recovery 306
9.3 Strengths and limitations of the study 308
9.3.1 Strengths and weaknesses in the statistical validity of the study 308
9.3.2 Strengths and weaknesses in the internal validity of the study 311
9.3.3 Strengths and weaknesses in the construct validity of the study 313
9.3.4 Strengths and limitations in the external validity of the study 315
9.3.4 Strength and weakness of the qualitative analysis 316
9.3.5 Summary of strengths and weaknesses 317
9.4 Implications 318
9.4.1 Implications for program evaluation and effectiveness of BFT 318
9.4.2 Implications for hope and the recovery paradigm 321
9.5 Questions for further research 323
9.6 Conclusion 326

List of references 333

Appendices 362

Appendices Section 1: Questionnaires 363
Appendix 1.1 Consumer baseline questionnaire 363

Appendix 1.2 Consumer follow-up questionnaire 378
Appendix 1.3 Carer baseline questionnaire 394
Appendix 1.4 Carer follow-up questionnaire 417
Appendix 1.5 Case manager baseline questionnaire 442
Appendix 1.6 Case manager follow-up questionnaire 446

Appendix 2: Telephone recruitment script 450

Appendices Section 3: Participant information and consent 454
Appendix 3.1 Participant information and consent for carers in treatment Area Mental Health Service 454
Appendix 3.2 Participant information and consent for consumers in the treatment Area Mental Health Service 462
Appendix 3.3 Participant information and consent for carers in comparison Area Mental Health Service 471
Appendix 3.4 Participant information and consent for consumers in comparison Area Mental Services 479

Appendices Section 4: Invitation to research 490
Appendix 4.1 Flyer for comparison group consumer and families 490
Appendix 4.2 Flyer for staff at comparison sites 492
Appendix 4.3 Flyer for treatment group consumer and carers 496
Appendix 4.4 Flyer for treatment group case managers 498

Appendix 5: Script for Case managers 502

Appendix 6: Supplementary table to Chapter 5 503

Appendix 7: Supplementary table to Chapter 6 504

Appendix 8: Semi-structured interview on hope 505

Appendix 9: Exit interview with consumers and carers 506

Glossary 508

List of tables

Table 2.1: Contrasting emergent and expectancy hope 50
Table 2.2: Snyder Trait Hope Scale with 4 point response set, arranged by subscale 53
Table 2.3: Positive psychology domains and correlations with Snyder Hope Scale 56
Table 2.4: Negative affect and hopelessness correlations with Snyder Hope Scale 58
Table 2.5: Positive psychology domains and the concept of perceived control 59
Table 3.6: Summary of successful family psychoeducation studies for consumer outcomes, where EE status was not reported..... 109
Table 3.7: Summary of successful family psychoeducation programs and outcomes 127
Table 4.8: Threats to Statistical Conclusion Validity 147
Table 4.9: Threats to internal validity 148
Table 4.10: Threats to construct validity 149
Table 4.11: Threats to external validity..... 150
Table 4.12: Sample size calculation for the Snyder Hope Scale 151
Table 4.13. Coverage of Local Government Areas by Area Mental Health Services and site offices. . 153
Table 4.14: Catchment area demographic profiles. 154
Table 4.15 Operationalisation of domains and selected instrument for the questionnaire 160
Table 4.16: Summary of consumer instruments..... 168
Table 4.17: Summary of Carer instruments..... 169
Table 4.18: Recruitment statistics by site for consumer 176
Table 5.19 First Principal Components Analysis of Snyder Hope Scale at base-line with all scale items included. 192
Table 5.20 Final Principal Components Analysis of Snyder Hope Scale at base-line with items 1, 10 and 12 removed. 193
Table 5.21: Consumer demographics 195
Table 5.22: Consumer baseline descriptive statistics for pooled treatment and comparison groups 197
Table 5.23 Examination of consumer baseline scores for treatment and comparison groups 198
Table 5.24: Consumer t-tests for effect of accommodation type on baseline measures..... 199
Table 5.25: Two-way ANOVA on LSP at baseline for consumer. 200
Table 5.26: Consumer correlation matrix for DAI at baseline. 200
Table 5.27: Consumer t-tests for relation of Drug Attitude Inventory with demographic variables .. 201
Table 5.28: Loss to follow-up rates for consumers across treatment and comparison groups..... 203
Table 5.29: Consumer follow-up descriptive statistics pooled from treatment and comparison groups 204
Table 5.30: Examination of consumer follow-up measures for treatment and comparison groups... 205
Table 5.31: Consumer follow-up scores adjusted for baseline scores across treatment and comparison groups 206
Table 5.32: Consumer follow-up scores adjusted for baseline scores across treatment and comparison groups for individual Snyder Hope Scale Items 207
Table 5.33: Consumer correlation matrix between baseline Hope and other baseline variables 208
Table 5.34 Snyder Hope Scale studies in comparison to consumer scores from the present study ... 213
Table 6.35 First Principal Components Analysis of Snyder Hope Scale for carers at base-line with all Scale items included. 219
Table 6.36: Carer Demographics 221
Table 6.37: Carer baseline descriptive statistics 222
Table 6.38: Examination of carer baseline scores for treatment and comparison groups..... 223
Table 6.39: Loss to follow-up in treatment and comparison groups for carers 225
Table 6.40: Carer follow up descriptive statistics 227
Table 6.41: Carer follow-up measures compared by treatment group 228
Table 6.42: Carer follow-up scores adjusted for baseline across treatment and comparison groups. 229
Table 6.43: Post-test scores adjusted for pre-test scores across treatment and comparison groups for individual Hope Scale Items..... 230
Table 6.44: Carer correlation matrix between baseline SHS and other baseline variables 231
Table 6.45: Carer and Consumer Hope and Family Functioning correlations at base-line..... 233

Table 6.46 Summary of Snyder Hope studies with comparison to carer scores from the present study 235
Table 7.47: Number of hope qualitative interviews. 241
Table 7.48: Number of hope qualitative interviews for carers. 251
Table A.49: Principal components analysis of the WHOQOL for consumers 503
Table A.50 Principal components analysis of the WHOQOL for carers 504
Table A.51: Questions for consumer and carer on goals in the hope interview, summarised from the questionnaires in Appendix 1. 505
Table A.52: Questions for consumer and carer in treatment group only, on treatment satisfaction, summarised from the questionnaires in Appendix 1. 506

List of figures

Figure 1.1 Family psychoeducation, variants and implementation. 29
Figure 2.2: Schematic diagram of the construct of control identifying agents, ends and means (from Skinner (Skinner, 1996)) 56
Figure 3.3: Evaluation logic for BFT intervention (based on Rossi, p 95 (Rossi, Lipsey, & Freeman, 2004) 131
Figure 4.4: Flowchart of recruitment for comparison group 171
Figure 4.5: Flowchart of recruitment for treatment group 172
Figure 5.6: Treatment Consumers' response rate 189
Figure 5.7: Comparison consumers' response rate 190
Figure 5.8: Histogram of Snyder Hope Scale distribution for consumers at baseline 196
Figure 5.9: Histogram of Snyder Hope Scale distribution for consumers at follow-up 203
Figure 6.10: Treatment Carers' response rate 217
Figure 6.11: Comparison carers' response rate 218
Figure 6.12: Histogram of Snyder Hope Scale distribution for carers at baseline (pooled from treatment and comparison groups). 221
Figure 6.13: Histogram of carer Snyder Hope Scale distribution at follow-up (pooled from treatment and comparison groups) 226
Figure 6.14: Histogram of Family Assessment Device distribution at follow-up (pooled from treatment and comparison carer groups) 226

List of abbreviations and acronyms

ACT	Assertive Community Treatment
AMHOCN	Australian Mental Health Outcomes and Classification Network
AMHS	Area Mental Health Service,
ANCOVA	Analysis Of Co-Variance, a statistical procedure.
BASIS-32	The Behaviour and Symptom Identification Scale, 32-item
BFST	Building Family Skills Together
BFT	Behavioural Family Therapy
BHS	Beck Hopelessness Scale
BPRS	Brief Psychiatric Rating Scale
CALD	Culturally and Linguistically Diverse (communities).
CATT	Crisis Assessment and Treatment Team
CBT	Cognitive Behavioural Therapy
CCT	Continuing Care Team
CFI	Camberwell Family Interview
CTO	Community Treatment Order
DAI	The Drug Attitude Inventory:
df	Degrees of Freedom
ECI	The Experience of Caregiving Inventory
ECINEG	The Experience of Caregiving Inventory Total Negative Experiences Subscale
ECIPOS	The Experience of Caregiving Inventory Total Positive Experiences Subscale
EE	Expressed Emotion
EOI	Emotional Over Involvement
FA	Factor Analysis
FAD	The Family Assessment Device
FADGF	The Family Assessment Device General Functioning Scale
FEP	First Episode Psychosis
FI	Family Intervention
FoG	Family of Origin
FPE	Family Psychoeducation
FS	Friendship Scale
GHQ	General Health Questionnaire
GHQ-28	General Health Questionnaire -28 item version
GP	General practitioner
IC	Individual Counselling
ID	Intellectual Disability
K-R	Kuder-Richardson measure
LGA	Local Government Area
LoS	Length of Stay
LOT	The Life Orientation Test
LSP	The Life Skills Profile
m	Mean
MFG	Multi-Family Group
MST	Mobile Support Team

n	Number
NESB	Non-English Speaking Background.
NGO	Non Government Organisations (Rehabilitation services)
p	Probability
P&K	The Pai and Kapur Family Burden Scale
PCA	Principal Component Analysis
POMS	The Profile of Mood States
POPE	Patient Only Psychoeducation
QoL	Quality of Life
QOLTOT	Total WHOQoL score
r	Pearson correlation
RCT	Randomised Control Trial
RFS	The Role Functioning Scale
SD/sd	Standard Deviation
SE	Standard Error
SEIFA index	Socio-Economic Index for Areas
SHS	Snyder Hope Scale
STORI	Stages of Recovery Inventory
T-R	Test-Retest reliability
TAU	Treatment As Usual
TMD	Total Mood Disturbance
TNA	Total Negative Affect
TPA	Total Positive Affect
WHOQOL-Brèf	The World Health Organisation Quality of Life Brèf Version

Chapter 1 Introduction

Chapter 1: Introduction

1.1 Introduction to the study

Hope is defined as the expectation or desire for positive events in the future, or having some grounds or intimation that something good may happen (Pearsall, 1999).

There have been a number of descriptions of hope in the psychological and psychiatric literature over the past 50 years, but two main approaches can be discerned. Firstly, there is nascent hope, where hope first "emerges" but attainment of the desired event or goal is uncertain and the means to achieve the goal is unclear (P.E. Deegan, 1988; Menninger, 1959). This is often described as the first step in recovery from mental illness; the "ray of hope" or the "fragile flame of hope". It is a first inspiration in changing or improving one's life from adverse circumstances and in this thesis entitled "emergent" hope (P.E. Deegan, 1988; Menninger, 1959). The second approach conceptualises hope as a generalised expectancy that goals can be achieved, an approach developed in the cognitive psychology literature, described in this thesis as "expectancy hope" (Snyder et al., 1991; Stotland, 1969). This cognitive approach, extended by Snyder with the Snyder Hope Scale (Snyder, et al., 1991), defines hope as a positive expectancy combining motivation and planning to attain goals (Snyder, 2002).

Expectancy models of hope have been operationalised with validated instruments and widely used in research, but conceptualisations of emergent hope, while common in narrative accounts of recovery and transformation, are not frequently examined in empirical research.

Hope has frequently been suggested as an important component of recovery for people living with serious mental illness (Bellack, 2006; Bonney & Stickley, 2008; Campbell-Orde, Chamberlin, J., & Leff, 2005; Czuchta & Johnson, 1998; Darlington & Bland, 1999; A. B. Hatfield & H. P. Lefley, 1993; Kopelowicz, Liberman, Ventura, Zarate, & Mintz, 2005; R. P. Liberman, 2002; Robert Paul Liberman, Kopelowicz, Ventura, & Gutkind, 2002; Noiseux & Ricard, 2008;

Noordsy et al., 2002; Ralph, Kidder, Muskie, & Phillips, 2000; Rudnick, 2008; Silverstein & Bellack, 2008; Snyder, Lehman, B, & Monsson, 2006). Recovery is defined as the capacity to have a meaningful, purposeful life with hope for the future (A. B. Hatfield & H. P. Lefley, 1993; Lefley, 1997; Kim T. Mueser, 2012). The return of hope is often seen as the vital first step on the road to recovery (P.E. Deegan, 1988). Case studies (Darlington & Bland, 1999), qualitative research (Czuchta & Johnson, 1998; Noiseux & Ricard, 2008) and literature reviews (Bellack, 2006; Bonney & Stickley, 2008; R. P. Liberman, 2002; Robert Paul Liberman, et al., 2002; Noordsy, et al., 2002; Rudnick, 2008; Silverstein & Bellack, 2008; Snyder, et al., 2006) in the recovery literature describe hope as integral to the beginning and continuation of the recovery process. In an international review of recovery, 105 separate conceptualisations of recovery were identified. Eighty-five of these unique recovery models identified hope as fundamental to the recovery process (Slade, Leamy, et al., 2012).

However, the definition of hope in the context of recovery is somewhat imprecise, but seems to incorporate hope in both in the emergent and expectancy sense. In its most general sense, hope in recovery is described as a "belief in the possibility of recovery" (Slade, Leamy, et al., 2012) or as a determination to get better (Beate Schrank & Slade, 2007). It is described as "the small and fragile flame" (P.E. Deegan, 1988p. 14) that is the precursor to "taking control of one's own life" (P.E. Deegan, 1988; Lefley, 1997) and overcoming despair. As well, developing personal goals and feeling confident they can be attained are the hallmarks of mature hope and established recovery (Copic, Deane, Crowe, & Oades, 2011).

A focus on hope and recovery is an increasingly widespread approach to policy and practice for people living with schizophrenia and their families (Department of Health, 2011). Currently there is little rigorous research that explores possible links between hope and recovery in clinical practice (Slade, 2010; Slade, Leamy, et al., 2012) in spite of the frequent reference to hope in the recovery literature. This is a concern for services wishing to evaluate their efforts to provide recovery-focused practices. Unless the relationship between

hope and recovery can be investigated broadly, the understanding and evaluation of recovery is compromised.

Given the challenges to hope in the situation of serious mental illness it is also important to understand what interventions are helpful for improving hope and recovery. People living with schizophrenia often report high levels of hopelessness, defined as a loss or lack of hope (Bellack, 2006; Bonney & Stickley, 2008; Campbell-Orde, et al., 2005; Czuchta & Johnson, 1998; Darlington & Bland, 1999; A. B. Hatfield & H. P. Lefley, 1993; Kopelowicz, et al., 2005; R. P. Liberman, 2002; Robert Paul Liberman, et al., 2002; Noiseux & Ricard, 2008; Noordsy, et al., 2002; Ralph, et al., 2000; Rudnick, 2008; Silverstein & Bellack, 2008; Snyder, et al., 2006). Given the potentially serious impacts of schizophrenia on all aspects of life including the impact of stigma, the length of illness (often a lifetime), it's effect on interpersonal relations and often inadequate access to support and services (McGorry, 2005), it is understandable that consumers live with long term hopelessness about their situation along with their family members (Hoffmann, Kupper, & Kunz, 2000).

The provision of evidence-based interventions can provide powerful tools for consumers as they strive for personally important goals that are part of hope and recovery (Kim T. Mueser, 2012). The Building Family Skills Together (BFST) program is an intervention for people living with schizophrenia and their carers designed to help families meet the challenges of living with a severe mental illness.

The Building Family Skills Together program has been adapted from Behavioural Family Therapy (BFT) developed by Ian Falloon and colleagues in the UK (I. R. H. Falloon, 1988b; I. R. H. Falloon, Boyd, & McGill, 1984) (see Figure 1.1). Behavioural Family Therapy is a type of family psychoeducation. A large number of randomised controlled trials indicate Behavioural Family Therapy (BFT) and other family psychoeducation (FPE) interventions are highly successful in reducing relapse in people living with schizophrenia, and decreasing burden and stress in family members (F. Pharoah, Mari, Rathbone, & Wong, 2010).

Building Family Skills Together (BFST) may be particularly helpful in restoring hope in consumers and families as it encourages goal setting and goal achievement that are the heart of hope. The BFST program focuses on developing a number of areas related to goals and hope:

- Skills in goal setting (G. Fadden & Gair, 2004),
- Improving interpersonal relations that often enhance opportunities to achieve goals (G. Fadden & Gair, 2004),
- Problem solving that helps people overcome barriers to goal achievement (G. Fadden & Gair, 2004),
- Enhancing family functioning so that the family works together to achieve group and individual goals (G. Fadden & Gair, 2004),
- Giving individuals and families constructive feedback that improves skills and consequent feelings of competency (G. Fadden & Gair, 2004).

This study aimed to investigate (1) the course of hope, recovery and symptoms and the relationship between them during and after a family psychoeducation program; and (2) the usefulness of the Snyder Hope Scale to assess hope in the recovery context.

This thesis investigated hope through both quantitative and qualitative approaches to the assessment of hope, and considered the relationship of hope to other recovery outcomes such as social engagement and quality of life. Levels of hope, as measured by the Snyder Hope Scale, were assessed before and after attending a treatment for families and consumers at a community mental health service. It was hypothesised that hope would increase for participants in the programme, observable in the development of personal goals, increased motivation to achieve goals, and increased ability to problem solve challenges in attaining goals. Other recovery measures such as interpersonal relations and quality of life were also predicted to improve.

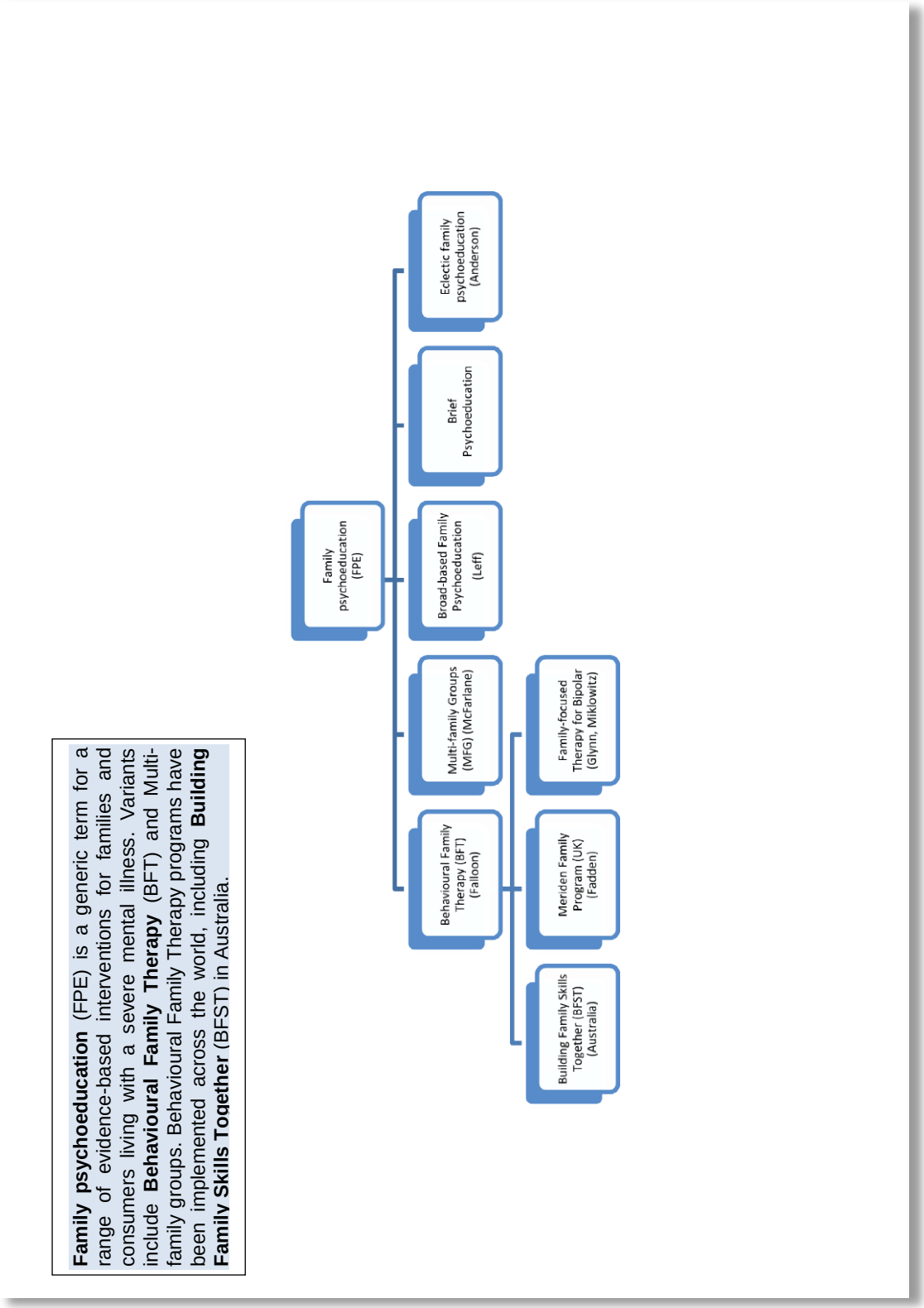
Although both emergent and expectancy accounts of hope may play a role in recovery, this research focused on the role of expectancy hope in recovery, as measured by the Snyder Hope Scale. However, the relevance of the Snyder model of hope, with its focus on “high hope” was assessed for its relevance to

consumers and carers who may be living with very low levels of hope given the mental health challenges in their lives.

A number of concepts from the literature regarding hope and recovery were also explored. Narrative accounts of recovery imply that recovery can occur independent of the level of symptoms, and that the return of hope is a forerunner of full recovery (W. Anthony, 1993; P.E. Deegan, 1988; Sandra G. Resnick, Fontana, Lehman, & Rosenheck, 2005). These “axioms of recovery” were critically examined.

It also considered hope, burden and wellbeing in carers, to understand if hope in carers is independent of the level of burden, and if increased hope can lead to increased wellbeing in carers.

Figure 1.1 Family psychoeducation, variants and implementation.



1.2 Structure of the report

The literature review in Chapter 2 introduces the concept of hope and its relevance to serious mental illness and recovery. It notes there are a number of different definitions and uses of the concept of hope, and some challenges in its measurement. In Chapter 3 the rationale and development of family psychoeducation treatment is examined. Outcomes for family psychoeducation trials over 40 years are reviewed. Finally, the potential for BFT to improve hope (beside other outcomes) for families and consumers living with schizophrenia is discussed through a program logic approach.

In Chapter 4, the details of the study methodology are set out, comprising qualitative and quantitative data collection before and after the BFT intervention. Hope is explored through questionnaires and interview data. This is followed by Chapters 5, 6, 7 and 8 which present the results of the qualitative and quantitative analyses. Chapter 9 discusses these results, and conclusion.

The rest of this introductory chapter discusses the definition of schizophrenia and provides a brief introduction to the history of medical, psychological and family treatment for schizophrenia.

1.3 Schizophrenia: Definition and diagnosis

Consumers were recruited to the study from 2006 to 2009, under ICD-10 (World Health Organization, 1992, 2008)/DSM IV (American Psychiatric Association, 2000) criteria, which will be elaborated below. Since recruitment, the DSM classification schemes have been updated with the publication of DSM-V (American Psychiatric Association, 2013). The most notable changes from DSM-IV to DSM-V criteria will be briefly described also.

An essential characteristic of schizophrenia and related disorders is the presence of psychotic symptoms (American Psychiatric Association, 1994). The group of related disorders includes diagnoses such as Schizophreniform Disorder, Delusional disorder and Schizoaffective disorders, psychotic disorder due to a general Medical condition, substance-induced psychosis, brief

psychotic disorder and shared psychotic disorder (American Psychiatric Association, 1994).

The main diagnostic psychotic symptoms are delusions, hallucinations and thought disorder. Delusions are beliefs that are logically and factually false, but are maintained in spite of reasoning and reference to evidence (Reber, 1985). Hallucinations are perceptual experiences that are vivid and real subjectively, but no physical stimulus exists (for instance seeing or hearing things that aren't there) (Reber, 1985). Thought disorder incorporates thought echo, thought insertion or withdrawal or thought broadcasting (World Health Organization, 2008).

Other psychotic symptoms include disorganised behaviour or speech (speech that is incoherent, or with loosening of associations (Reber)), catatonic behaviour (a stupor-like state with extreme immobility) and negative symptoms (American Psychiatric Association, 1994).

Negative symptoms include the reduction or loss of normal functions resulting in apathy and low motivation, affective flattening (emotional expression losing range and intensity), alogia (loss of fluency and productivity of speech and thinking) and avolition (inability to initiate goal-directed behaviour) (American Psychiatric Association, 1994). Negative symptoms are associated with much of the disability associated with schizophrenia (American Psychiatric Association, 1994).

Schizophrenia in DSM-IV is defined as at least six months of disturbance with a minimum of one month of acute symptoms, these being two or more of: delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour and negative symptoms (American Psychiatric Association, 1994, 2000). Under ICD-10, only 1 month of disturbance is the required criterion (World Health Organization, 2008). If the delusions are bizarre, or the hallucinations take the form of a running commentary or two voices in conversation, then a second criterion need not be met as well (American Psychiatric Association, 2000). The special single criterion attribution has been removed from DSM-V (American Psychiatric Association, 2013).

Diagnostic criteria also include social or occupational dysfunction levels that are below pre-morbid levels in one or more areas such as work, relationships or self-care. The presence of mood disorders, the effects of a psychoactive substance, a general medical condition or the presence of a developmental disorder form exclusionary criteria (American Psychiatric Association, 1994).

Schizophrenia usually develops between the late teens and mid-30s. Often females diagnosed with schizophrenia will have later onset, better prognosis and more emphasis on mood disorder (American Psychiatric Association, 1994). The lifetime prevalence is 0.5 to 1%, although there is thought to be regional variation (American Psychiatric Association, 1994; Kendall & Zealley, 1989). The 12 month treated prevalence in Australia in 2010 was 2.1/1000 (V. Morgan et al., 2012).

Historically, there have been two approaches to the diagnosis of schizophrenia, one emphasising the long-term decline, the second, more focused on the cross-sectional assessment of particular psychotic symptoms (Kendall & Zealley, 1989). The first is associated with Kraepelin who identified a syndrome which he named 'dementia praecox' in 1896 which gathered together various syndromes previously described in the 19th century: démence précoce, with severe intellectual decline starting in adolescence reported by Morel in 1852; hebrephrenia described by Hecker in 1871 as a "silly" deterioration; catatonia described by Kahlbaum in 1874, and in 1891; and "simplex syndrome" described by Pick as a simple deterioration in functioning with a minimum of symptoms (Kendall & Zealley, 1989). Kraepelin also regarded the emotional and motivational aspects as important features of schizophrenia with serious, irreversible personality changes (Kendall & Zealley, 1989). He noted a syndrome marked by paranoia, but without the emotional and motivational deterioration and labelled this paraphrenia (Kendall & Zealley, 1989).

The term 'schizophrenia' was first used by Bleuler at a lecture at a meeting of the German Psychiatric Association in 1908 and published in 1911 (Fusar-Poli & Politi, 2008), critiquing Kraepelin's assumptions of mental deterioration (dementia) and youthful onset (praecox) (Fusar-Poli & Politi, 2008; Kendall & Zealley, 1989). Bleuler described some of the essential symptoms of

schizophrenia as “loosening of associations, disturbances of affectivity, ambivalence, and autism”. Bleuler also suggested that schizophrenia was not inevitably incurable, thus de-emphasising the focus on decline (Fusar-Poli & Politi, 2008).

1.4 Contemporary experience of living with psychosis in Australia

A recent epidemiological study showed a 12-month treated prevalence for psychosis of 4.5 people per 1000 in Australia, with approximately 68% of these diagnosed with schizophrenia, schizoaffective disorder, or delusional disorder (Galletly et al., 2012). The other 32% included Bipolar (mania) (18%), depressive psychosis (4%) and other (10%). Sixty percent were male.

In-depth interviewing of a random sample from the epidemiological survey demonstrated the considerable challenges for people living with psychosis in Australia. Three-quarters of the males and half of the females had never been married or had de facto partnerships. One quarter of females had dependent children living with them at home (V. Morgan, et al., 2012).

Only one fifth of respondents had current employment and over half lived in rental accommodation. Thirty percent lived in supported housing or the family home and 5% were homeless. Two-thirds were current smokers, and approximately 50% met criteria for lifetime alcohol abuse/ dependence and 50% met criteria for lifetime drug abuse/dependence (Galletly, et al., 2012).

One third had had an inpatient admission for their mental health concerns in the previous year, with one fifth of the total sample having an involuntary admission. Twenty percent were on a community treatment order at some time in the previous year. Over 70 % of the sample had received case management over the previous year from a non-government organisation or public mental health service (A. Morgan et al., 2012).

Many lived with chronic physical ailments, well in excess of community norms. For instance, 20% had diabetes (community levels of 6%), epilepsy rates were 7% (community rates of 1%), and half met criteria for metabolic syndrome (V. Morgan, et al., 2012).

Only half stated that they were satisfied with "life as a whole" compared to 81% when the question was asked of the general population. However, three-quarters of interviewees believed their circumstances would improve over the following year (V. Morgan, et al., 2012).

1.5 Brief history of treatments for schizophrenia

Until the post World War II era, treatment for schizophrenia met with only mild success with a mix of physical treatments and attempts at psychotherapy. From World War I to the 1940s, the physical treatments consisted of deep sleep therapy, electro-convulsive therapy and lobotomies (Shorter, 1997).

The discovery of psychotropic medication in the 1950s was a significant breakthrough which brought great changes to the treatment and management of serious mental illness. The effective use of medication appeared to empty the institutions and assert the biological paradigm as the causal explanation for schizophrenia (Cawte, 1998; Shorter, 1997).

In evaluating the history of treatment for schizophrenia the received wisdom regarding the exclusive role of drug treatment in clearing the asylums should be questioned in a contemporary evaluation of their legacy. Although psychotropic medication is often seen as pivotal in reducing inpatient numbers and underpinning the trend to deinstitutionalisation (for instance see Cawte and Shorter above) there are arguments that suggest psychosocial factors were also important. Inpatient numbers per capita were falling in the U.K. before the introduction of psychotropic medication (Goodwin, 1989). Increased availability of community treatment occurred due to social, economic and political factors such as the patient rights movement in the USA and legislation such as the 1963 mental health act of the Kennedy administration as much as the use of the new medications (Scull, 1986). The lower cost of community treatment versus hospitalisation also convinced governments to restrict inpatient treatment (Scull, 1986). In Australia, the most rapid period of deinstitutionalisation occurred later, in the 1990s (Singh, 2008).

In Britain, the Mental Treatment Act of 1930 initiated unlocked wards and introduced psychiatric institutions that were accountable and open (Shorter,

1997). On the open wards, group work was developed, therapeutic communities were set up and the healing power of the milieu was explored (Shorter, 1997).

In the 1940s, individual psychotherapies derived from psychoanalysis, looked at psychopathologies in the patient's family of origin as the cause of schizophrenia (McGorry, 2005). In spite of the family of origin being seen as a causative factor, treatment was still focused on the diagnosed individual. Although concepts such as the "schizophrenogenic mother" developed by Frieda Fromm-Reichmann (Fromm-Reichmann, 1948) are unacceptable today (Shorter, 1997), at the time, these psychoanalytically derived therapies were progressive since they emphasised listening to the "patient", and understanding of the patient's experience. They offered hope for improvement (Menninger, 1959). However, evidence for the effectiveness of individual psychoanalytically-based psychotherapy for schizophrenia has not been strong (McGorry, 2005).

Contemporary practice recommends both biological and psychosocial treatments (Kreyenbuhl, Buchanan, Dickerson, & Dixon, 2010; McGorry, 2005; Kim T. Mueser, Deavers, Penn, & Cassisi, 2013; National Institute for Health and Clinical Excellence, 2009). There is increasing acknowledgment that medication, while effective for symptomatic relief, does not provide total rehabilitation, is not effective with all cases and non-adherence continues to be a concern (McGorry, 2005). A range of Cognitive-Behavioural therapies (CBT), cognitive remediation and psychoeducational strategies have emerged over the past 50 years to augment the effect of medication, help manage persistent symptoms and assist with rehabilitation (McGorry, 2005). Treatments to enhance vocational and social re-engagement such as vocational support and social skills training are also important. All these treatments are essential in the effective treatment of schizophrenia and are recommended in integrated treatment guidelines (McGorry, 2005).

1.6 Family treatments for schizophrenia

An important approach to the treatment of schizophrenia has been family therapy. Developments between the two World Wars in humanising ward treatment in hospitals discussed above, progress in group therapy, the child

guidance movement and the development of marriage guidance counselling all anticipated the family therapy movement.

Many research groups were active at this time, but the research in the 1950s by the Palo Alto group into communication patterns in families with a member living with schizophrenia led to some particularly striking concepts that provided strong theoretical impetus to treat families and not just the "patient" (Broderick & Schrader, 1981).

The research by Lidz, Wynne, Bateson, Bowen and others generated ground breaking and influential theories and ideas that furthered the therapeutic practice and produced the first identifiable "family therapies" (Bloch, Hafner, Harari, & Szmukler, 1994; Broderick & Schrader, 1981; Burbach, 1996). These early theories of family and schizophrenia looked at the family as the cause and origin of the illness. Therapists and researchers started to see the family as the unit of investigation and treatment (Broderick & Schrader, 1981; Guerin, 1976)

These early researchers identified and labelled various "dysfunctional" family patterns focusing on intra-familial dynamics and communication. For instance, Lidz suggested that intra-familial dynamics caused schizophrenia and that an ineffective father figure was a precipitating factor in schizophrenia (Burbach, 1996). Wynne identified a number of characteristics in families with a member diagnosed with schizophrenia such as pseudo mutuality, (where families "rigidly adhere to the shared illusion that they all have the same expectations" (p 114) and communication deviance (communications that are problematic to understand and make shared meanings in a family difficult). Bateson introduced the concept of the "double-bind", a form of "habitual contradictory communication sequences" (Burbach, 1996) (p 113), which entangled the family members in contradictory communications.

Two threats to the family therapy movement emerged by the 1960s and 1970s. The first was that research failed to demonstrate the validity of many of the theories underpinning family therapy. The mechanisms described were hard to operationalise for research. For instance "double bind communications" of Bateson were difficult to define for a study protocol. Also, there was no specificity – families with so-called schizophrenogenic patterns produced no

children with schizophrenia and families with no identifiable pathology had symptomatic offspring (Burbach, 1996). In time, these therapies also came to be seen as very “family blaming” and disempowering to the families who were increasingly asked to manage the care of the family member with the mental illness in the community (Leggatt, 2001).

During the 1960s, in response to observations that some people frequently relapsed while others remained stable after hospital discharge, researchers in the U.K. developed the concept of Expressed Emotion (G Brown, 1985; G Brown & et al, 1972), which included dimensions such as hostility, critical comments and emotional over-involvement. The presence of EE was observed to be stressful for the person with mental illness, leading to an increase in the risk of relapse. Hostility was defined as a negative attitude to the family member with a mental illness; emotional over-involvement as an overly concerned and intrusive approach to the family member; critical comments were defined as negative and judgemental comments about the person with mental illness, such as accusations of laziness, rudeness or disruptive behaviours. The family treatments that have developed from the EE concept have utilised a skills-based and educational approach to minimise EE behaviours, and increase more helpful family interactions.

This was a major break with the originators of family therapy where the family was seen as the *cause* of the illness. In contrast the concept of EE and the stress- vulnerability theory of Zubin and Spring in 1977 (Zubin & Spring, 1977), incorporated the concept of biological susceptibility and led to more practical educational approaches to working with families. Although the EE/stress-vulnerability approach can still be utilised in a manner critical of families (Hatfield, Spaniol, & Zipple, 1997), it has tended to focus on engaging and collaborating with families (Leggatt, 2001). This approach is often called family management or family psychoeducation (FPE) in contrast to that of family therapy described above (Burbach, 1996). One particular approach to family management – Behavioural Family Therapy - is the focus of this study, and is discussed in Chapter 3.

1.7 Use of the term consumer

There are many terms that are used to describe the person living with a serious mental illness such as schizophrenia.

Phrases such as “person with schizophrenia”, which emphasise the person first and diagnosis second, are preferable compared with phrases such as “people suffering from schizophrenia” which make an assumption about a person’s reaction to their diagnosis. “Person living with schizophrenia” is another preferred option. In the past the term “schizophrenic” was used, but as this term “places the person last”, it is used infrequently today (E. F. Torrey, 2011).

The word “patient” was historically used to describe someone with a mental illness receiving treatment and is still used in medical contexts, but less so in psychiatric and counselling settings today. It is associated with a more paternalistic approach by professionals, implying that the person being treated is passive and makes no independent choices, all knowledge and expertise being with the person delivering treatment. It implies a dependent relationship in the person attending for treatment and is considered to foster the “sick role” (Damodoran, 2000).

However, the term “patient“encapsulates some realities that the terms “client” or “consumer” do not. It reflects acute need when a person is in treatment and the legal reality of the inequities of the relationship (Jager, 1999; Plastow):

> *The use of ‘client’ reflects an assumed equality in the relationship. However, the inherent inequality between psychiatrists and patients is recognised in the ethical and legislative restrictions placed on relationships between psychiatrist and patient (Jager, 1999) p 180.*

In surveys of attendees at medical and psychiatric services it appears treatment setting influences preferences regarding form of address. In any medical setting (i.e. inpatient and outpatient), there is a high preference for the term client (over 80% in studies) (R. Elliott, 1993; Nair, 1998). In inpatient psychiatric settings the preference for the term ‘patient” is about 55%, 15 – 26% prefer client and 8-9% prefer consumer (Chris Lloyd, King, Bassett, Sandland, & Savige, 2001; K.T. Mueser, Webb, Pfeiffer, Gladis, & Levinson,

1996). In psychiatric outpatient services, the preferred term was client (41%) with 35% preferencing the term consumer and only 11 % patient (Chris Lloyd, et al., 2001). However, more recent studies indicate that the term patient may be resurgent, because it equalises psychiatric and medical illness (Simmons, Hawley, Gale, & Sivakumaran, 2010).

The alternatives to the term “patient” are the terms “client” or “consumer”. While the terms “consumer” and “client” derive from the discourse of recovery and empowerment for people living with mental illness, they also have the unfortunate association with the discourse of economics and managerialism (Plastow, 2010).

This thesis will refer to service recipients as consumers, as the participants in the study were all outpatients at the time of the study and this study focuses on recovery, a key concept associated with the term consumer (W. Anthony, 1993; Young & Ensing, 1999). Although consumers of mental health services are not always in a position to be autonomous consumers, picking and choosing services in the same way one chooses a new TV, it still reflects an aspiration by service providers and recipients to respect choices, work collaboratively, and break down power differentials.

Chapter 2: A critical review of hope for carers and consumers

Chapter 2: A critical review of hope for carers and consumers

Hope is defined as the expectation of positive events in the future.

There have been a number of conceptualisations of hope over the past 50 years. Firstly, there is nascent hope, often described as the first step in recovery, the "ray of hope" or the "fragile flame of hope". It is a first inspiration in changing or improving one's life from adverse circumstances and entitled here "emergent" hope (P.E. Deegan, 1988; Menninger, 1959). The second conceptualisation of hope is as a generalised expectancy that goals can be achieved, an approach popularised in the cognitive psychology literature, described here as "expectancy hope" (Snyder, et al., 1991; Stotland, 1969). Another approach to hope, taken up more widely in nursing, especially in the oncology and palliative care arenas, attempts to draw on both emergent and expectancy hope (Farran, Herth, & Popovich, 1995) but these integrative hope schemas while showing potential have not been widely used and lack theoretical underpinnings. The following review follows the threads of the two main concepts of hope, emergent hope, and expectancy hope with a brief review of "integrative hope".

2.1 The importance of hope

Hope has frequently been suggested as an important component of recovery for people living with serious mental illness (Bellack, 2006; Bonney & Stickley, 2008; Campbell-Orde, et al., 2005; Czuchta & Johnson, 1998; Darlington & Bland, 1999; A. B. Hatfield & H. P. Lefley, 1993; Kopelowicz, et al., 2005; R. P. Liberman, 2002; Robert Paul Liberman, et al., 2002; Noiseux & Ricard, 2008; Noordsy, et al., 2002; Ralph, et al., 2000; Rudnick, 2008; Silverstein & Bellack, 2008; Snyder, et al., 2006). Case studies (Darlington & Bland, 1999), qualitative research (Czuchta & Johnson, 1998; Noiseux & Ricard, 2008) and reviews (Bellack, 2006; Bonney & Stickley, 2008; R. P. Liberman, 2002; Robert Paul Liberman, et al., 2002; Noordsy, et al., 2002; Rudnick, 2008; Silverstein & Bellack, 2008; Snyder, et al., 2006) in the recovery literature all describe hope as the starting point in the recovery process. Hope in the context of recovery

is described as “the small and fragile flame” (P.E. Deegan, 1988p. 14) that is the precursor to “taking control of one’s own life” (P.E. Deegan, 1988; Lefley, 1997) and overcoming despair. Hope overcomes the bleak and limiting prognoses that can be associated with a diagnosis of a mental illness (Bonney & Stickley, 2008; Patricia E. Deegan, 1997); a part of regaining hope is the restoration of the belief in one’s self and one’s future (Bonney & Stickley, 2008).

Hope has also been implicated in positive expectancies about treatment, such as the placebo effect and the so-called “common-factors” approach. Hope has a long history in psychiatry and psychology, being seen as an important ingredient in the therapeutic relationship, alleviating despair, and giving the necessary motivation to work towards positive outcomes (Clarke, 2003; Korner, 1970; Menninger, 1959).

Nearly fifty years ago, Frank (J. Frank, 1968) wrote extensively about the therapeutic factors common to treatments, and similar effect sizes in improved outcomes across a variety of therapies. One of the important factors he identified was hope linked to improved expectations of help and the provision of positive experiences, which “heighten hopes, and enhance his sense of mastery, interpersonal competence or capability” (J. Frank, 1968) p 357. Hope, as a positive expectancy for treatment, has been formalised as one of the common factors purported to underlie all effective treatments. Hope in this context includes the impact of the knowledge one is undergoing a treatment and specific expectancies regarding the belief in the efficacy of the treatment.

Research over the last 20 years has also promoted hope as one of the many facets of positive psychology, with hope associated with positive outcomes in sport, academic achievement, health and wellbeing (Snyder, 2002).

Conversely, hopelessness has been linked to poorer health outcomes (Aaron T Beck, Weissmann, Lester, & Trexler, 1974; Gottschalk, 1985) and increased risk of suicide (Aaron T Beck, et al., 1974; R. E. Drake & Cotton, 1986; Paul H. Lysaker, Salyers, Tsai, Spurner, & Davis, 2008). People living with schizophrenia are often reported to be living with high levels of hopelessness

and high risk of suicide (Bassman, 2000; Bengtsson-Tops & Hansson, 1999; Paul H. Lysaker, Davis, & Hunter, 2004; Paul H. Lysaker, et al., 2008; White, McCleery, Gumley, & Mulholland, 2007).

Thus, the presence of hope has been associated with the benefits of recovery, as a driver for therapy success, and is linked with many other positive outcomes; and a lack of hope has been linked with serious negative risks including suicide.

Hope can also assist caregivers in coping with the burden of care (Bland & Darlington, 2002; Lazarus, 1999). Furthermore, the role of family has been identified as significant in maintaining hope and assisting recovery (Bassman, 2000; Bland & Darlington, 2002; Bonney & Stickley, 2008; Czuchta & Johnson, 1998; Darlington & Bland, 1999; Flaskas, 2007; C. Flaskus, I. McCarthy, & J. Sheehan, 2007; A. B. Hatfield & H. P. Lefley, 1993) for consumers.

Despite the commonly cited link between hope, recovery and consumer mental health, this relationship has not been extensively studied with quantitative or prospective investigations (Slade, Leamy, et al., 2012). Neither has the role of hope in alleviating burden and supporting the family role in recovery been the focus of extensive rigorous empirical evaluation (Cutcliffe & Herth, 2002; Kylma, Juvakka, Nikkonen, Korhonen, & Isohanni, 2006; Silverstein & Bellack, 2008; Slade, Leamy, et al., 2012) Rather, it has been explored in qualitative studies or methodologies such as focus groups (Noordsy, et al., 2002), clinical impressions (Mead & Copeland, 2000), narrative accounts (Bassman, 2000; P.E. Deegan, 1988) or field studies without comparison groups (Littrell & Herth, 1996). This has produced a rich foundation of qualitative material, which requires extension with further quantitative study. In one of the few studies that take a quantitative approach to recovery, there has been a focus on hope's opposite, hopelessness. Lysaker et al, used a measure of hopelessness, not hope (Kylma, et al., 2006; Paul H. Lysaker, Buck, Hammoud, Taylor, & Roe, 2006; Paul H. Lysaker, Campbell, & Johannesen, 2005; Paul H. Lysaker, et al., 2004; Paul H. Lysaker, Roe, & Yanos, 2007; Paul H. Lysaker, et al., 2008) (reported in detail in Section 2.2.3).

Unless the relationship between hope and recovery can be investigated broadly, the understanding and evaluation of recovery is compromised. There is a need for further research in the area that helps us understand the course of hope and recovery for consumers living with severe and persistent mental illness, and understand how hope may contribute to the ongoing improvement in the lives of consumers and carers.

2.2.1 Early approaches to hope – Emergent Hope

Emergent hope was introduced to the psychiatric literature in the post World War II era by authors such as Frankl (Frankl, 1963) and Menninger (Menninger, 1959). Menninger wrote about hope and its relationship to initiating a return to health in patients, and inspiring doctors in their work. Presaging the notion of recovery in 1959, Menninger wrote about psychiatric diagnoses "destroying hope" with their negative prognoses compared to treatment that might:

> *Attempt to understand the man [sic], how he has become what he is, what goes on inside of him, what goes on around him, and how these interact. By observing…we can discover what in his world is good for … [the patient] and what is unbearable, what damage he inflicts on himself and others and what potentials within him remain undeveloped. And here enters in hope, for we acquire, then a rationale for therapeutic intervention (Menninger, 1959)* p 488.

Menninger described the therapeutic endeavour in a manner very similar to contemporary accounts of recovery as:

> *Replacing therapeutic nihilism with constructive effort, to replace unsound expectations – first with hope, and then with sound expectations…What can we do better than dispel…false expectations – good and bad – and then light for them a candle of hope to show them the possibilities that may become sound expectations? (Menninger, 1959, p. 490).*

Frankl wrote about his experiences of the Nazi concentration camps during World War II, observing that survivors managed to nurture hope, whereas the

loss of hope was a precursor to succumbing to illness and death (Frankl, 1963). Hope was often relational – keeping alive the dream of seeing loved ones again - and was strongly aligned with finding purpose and meaning in life, even within the dire circumstances of the "death camps". This concept of hope has been influential in later transcendent approaches to hope (Callan, 1989).

In this sense, emergent hope is different to many other positive psychology concepts. As Fredrickson writes:

> *Hope is not your typical form of positivity. Hope is the exception, it comes into play when our circumstances are dire - things are not going well or at least there is uncertainty about how things will turn out (Fredrickson, 2009).*

The significant aspects of emergent hope are: the presence of adversity, the importance of relationships and hope as the first step in a return to health. Emergent hope matches the commonly understood meaning of hope, where "only hope is left" or being "hopeful despite the odds" (P.E. Deegan, 1988, p. 14) or "a tiny fragile spark of hope appeared and promised that there could be something more than all of this darkness" (Bruininks & Malle, 2005; P.E. Deegan, 1988, p. 14; Tong, Fredrickson, Chang, & Lim, 2009). However, emergent hope has remained largely based in narrative and descriptive accounts of hope, rather than developing a more empirical basis.

2.2.2 Cognitive approaches to hope

Stotland outlined expectancy hope in the first cognitively based definition of hope in 1969, who defined hope as "expectations of goal attainment" (Stotland, 1969). This definition of hope focused on core characteristics of "temporality, desirability and expectancy" and the expectancy of success (Nunn, Lewin, Walton, & Carr, 1996) – it was about the future (temporality), about personally valued goals (desirability) and appraisals of likelihood (expectancy). While it appeared restricted (J. Miller & Powers, 1988), the advantage of the narrower definition was that presumably the core mechanisms of hope were emphasised and more readily operationalised.

In a number of clearly articulated propositions, Stotland theorised that hope consisted of valued goals, and the expectancy that the goal would be achieved. Stotland suggested that as desired goals were perceived as more attainable, and of greater importance, then positive feelings and increasing motivation to achieve the goal were present. When goal attainment was threatened, but the goal remained important, the dominant affect was anxiety. To avoid anxiety, Stotland outlined four main strategies in the short term. Firstly, goals may be devalued or given up, resulting in apathy or hopelessness. Secondly, goals may be shifted to short-range, easier targets. Thirdly, activities (cognitive and behavioural) may be undertaken to increase the likelihood of achieving the goals in spite of the initial threat to attainment. Finally, in the long run, goals may be shifted, refined or changed (Stotland, 1969).

Expectancy hope (i.e. hope defined as the expectation of goal attainment) has a significant difference to emergent hope. Where Frankl and Menninger described emergent hope as providing focus and motivation when expectancy is low, Stotland suggests that hope is maintained where expectancy is high.

In terms of temporality and desirability, the definitions are similar. Frankl and Menninger make clear that hope is focused on the future as does Stotland and all make clear that hope is about valued outcomes.

Stotland's definition clarifies the meaning of both hopefulness, and hopelessness. They are not mirror opposites. Hope is the positive expectation that goals will be met, but hopelessness is a consequence of giving up or devaluing goals – implying that goals have existed but are lost.

2.2.3 Hopelessness

Stotland's cognitive theory of hope quickly led to the development of new instruments to measure it (Farran, et al., 1995). The absence of hope was examined by Beck and operationalised with the Beck Hopelessness Scale (BHS). Beck defined hopelessness as negative expectancy and a core feature of depression (Aaron T Beck, et al., 1974). Three factors were identified in establishing the construct validity of the BHS; firstly lack of positive feelings

about the future, secondly, presence of bleak expectations for the future and thirdly a loss of motivation.

Although not directly stated, interpretation of the BHS items suggests that negative expectancy is the expectation of a lack of positive events (with associated low levels of positive affect (Headey & Wearing, 1992)), rather than the presence of adverse events (associated with high negative affect (Headey & Wearing, 1992)).

Later studies showed that high scores on the BHS correctly identified 91% of completed suicides in a group of hospitalised consumers followed up over 10 years. While sensitive, it is not specific, as a large percentage of people who did not complete suicide over the time period also showed a high score as well (A. T. Beck, Steer, Kovacs, & Garrison, 1985). Another study with consumers diagnosed with schizophrenia showed that hopelessness was linked to the perception that major life goals were not obtainable due to having schizophrenia, and that hopelessness is the aspect of depression most predictive of suicide (R. E. Drake & Cotton, 1986). This research suggests that it is not just a "lack" of positive events that is a feature of hopelessness, but the "loss" of positive events that is at the core of a hopelessness crisis, which adds a narrative aspect to hope and hopelessness.

Other research on consumer groups showed negative expectations (measured with the BHS) were associated with poorer social skills at work and an avoidant coping style (Davis, Lysaker, & Nees, 2003). While some studies have shown positive and negative symptoms are not correlated with hopelessness (Paul H. Lysaker, et al., 2004) other studies do show a correlation (Paul H. Lysaker, et al., 2008; White, et al., 2007).

The BHS has been used in contemporary research into severe mental illness (SMI), for instance, by Lysaker (Paul H. Lysaker, et al., 2006; Paul H. Lysaker, et al., 2005; Paul H. Lysaker, et al., 2004; Paul H. Lysaker, et al., 2007; Paul H. Lysaker, et al., 2008) and has satisfactory psychometric properties for the measurement of hopelessness (Aaron T Beck, et al., 1974). In a number of studies on military veterans in the USA, Lysaker found less hopelessness was

associated with lower levels of positive symptoms, better coping, (Paul H. Lysaker, et al., 2005) (Paul H. Lysaker, et al., 2007), less negative symptoms and less alienation (Paul H. Lysaker, et al., 2008). However, the theory and research around the BHS is less clear as to the exact definition of *hope* and whether low scores on the scale represent high hope or low hopelessness. Thus, it cannot be used with confidence to measure the presence of hope.

2.2.4 Snyder's Hope theory

In the late 1980s and early '90s positive psychology constructs became the focus of wider academic study (Steed, 2002) and concepts such as hope, optimism, wellbeing and self-efficacy became well known (M. E. Seligman & Csikszentmihalyi, 2000). Seligman wrote Learned Optimism (1998) (M. E. P. Seligman, 1998) and the Handbook of Positive Psychology, edited by Snyder and Lopez (2002) (Snyder & Lopez, 2002) was published. In this context hope moved from the recovery concepts of Frankl and Menninger or the clinical concept of hopelessness of Beck and became part of the study of positive psychology. Building on the cognitive focus of Stotland, hope became an operationalised psychological concept with the publication of the SHS in 1991 (Snyder, et al., 1991).

Snyder developed Stotland's approach to hope (being the expectation of goal achievement), and defined hope as the "perception that goals can be met" (Nunn, et al., 1996; Snyder, et al., 1991). Snyder described three components of hope: having desirable goals (for instance, a cure for an ailment); the motivation and determination to meet goals (entitled "agency hope"; for instance, the motivation to undergo treatment and belief in a cure); and the capacity to generate means to attain these goals (referred to as "pathways hope"; for instance, making plans to search out treatments and practitioners) (Snyder, 1995, 1999a, 1999b; Snyder, 2000a, 2000b; Snyder, 2002; Snyder, 2000c; Snyder et al., 2005; Snyder & Feldman, 2000; Snyder et al., 2000; Snyder, et al., 1991; Snyder, et al., 2006; Snyder, Parenteau, Shorey, Kahle, & Berg, 2002; Snyder, Rand, & Sigmon, 2002; Snyder et al., 1996; Snyder & Taylor, 2000). Agency hope can be likened to "will power" and pathways hope to "way power" (Snyder, et al., 1991). Snyder's "agency hope" was a

combination of two aspects of Stotland's theory of hope: the perception of the probability of goal attainment, and the importance of the goal. As a refinement of Stotland's theory, Snyder's hope theory can be defined as another expectancy hope theory.

As Snyder explains it, the additional concept of pathway hope was unique to his concept of hope and provided a number of advances on other hope theories. Firstly, the addition of "pathways" as part of hope linked hope with behaviour. Secondly, attention to pathways purportedly enabled discrimination between hope and other positive states such as optimism or total positive affect (TPA) (Nunn, et al., 1996; Stotland, 1969). Thirdly, the behavioural aspects of pathways hope linked in theories of stress and coping (Lazarus, 1999).

Snyder theorised about how hope and coping operated in high hope persons (Snyder, 2002). When goal achievement is disrupted, then coping is activated. A person high in hope was predicted to choose more productive pathways including coping strategies, and put them into action. After initial disappointment, the high hope person would re-energise and try new pathways to achieve a goal, thus selecting a more "problem solving" coping style. Empirically, the theory has been validated in studies that have shown high hope correlated with greater levels of problem-solving coping styles (Snyder, 2000c). The links to stress and coping are important to the understanding of hope and carer burden discussed later.

The inclusion of personal goals also links hope to values and meanings, since the generation of personal goals includes reference to what is important to a person (Weingarten, 2007).

In contrast to emergent hope, Snyder's version of expectancy hope is a more generalised phenomenon, described as a personality trait and occurring in many situations. Emergent hope is more specifically a phenomenon of adversity. As with Stotland, Snyder's version suggests hope is highest when expectancies are high, whereas emergent hope suggests hope is what persists when expectancies are low (see Table 2.1). It is also unclear how hopelessness is defined in the Snyder model, as Snyder refers to "low hope" rather than hopelessness (Snyder, 2002; Snyder, et al., 1991).

2.2.5 Measuring hope: the Snyder Hope Scale

Snyder published a scale simultaneously with developing his theory of hope (Snyder, et al., 1991). The scale consisted of 12 questions, 4 items regarding agency hope, 4 items regarding pathways hope and 4 filler items not included in the total of subscale calculations. All were positively keyed (see Table 2.2).

The original version measured "trait hope", a stable enduring dimension of personality (Snyder, et al., 1991). Other versions of the scale measured "state hope" (Snyder, et al., 1996), transient experiences of hope. The adult trait version of the SHS is also in use with a 5 point (Moraitou, Kolovou, Papasozomenou, & Paschoula, 2006) and 8 point response set (Snyder, Lapointe, Crowson, & Early, 1998). There is also a measure for hope in children (Snyder et al., 1997).

Table 2.1: Contrasting emergent and expectancy hope

	Emergent Hope	Expectancy Hope
Definition	Positive goals that emerge in situations of adversity	Expectations ones goals will be achieved
Authors	Menninger Frankl Frank	Stotland Beck (Hopelessness) Snyder
Expectancy (adversity)	Specifically pertains to low expectancy/adverse situations	High hope is a phenomena of high expectancy
Social aspects	Relationships important	Relationships not considered
Temporality	Future oriented	Future oriented
Desirability	Strongly desired	Strongly desired
Generality	Emerges in particular situations	Trait (but fluctuations can be measured in a 'State' scale)
Empirical findings	Descriptive and narrative	Quantitative, correlations

The psychometric properties of the dispositional version of the SHS have been reported as sound, with an internal consistency of $\alpha = 0.82$ for the 8pt scale, and $\alpha = 0.77$ for the 4 pt scale averaged from 74 articles which reported such statistics. A test-retest correlation of 0.80 was averaged from 17 articles reporting on reliability. The scale and its variants have been widely used with more than 300 published studies since 1991 (Hellman, Pittman, & Munoz, 2012).

2.2.6 Findings regarding the Snyder Hope Scale

Findings regarding the factor structure vary. Some find a clear 2 factor structure (Creamer et al., 2009; Sun, Ng, & Wang, 2012; Venning, Eliott, Kettler, & Wilson, 2009), others do not (Ahmed & Duhamel, 1994; Babyak, Snyder, & Yoshinobu, 1993; Moraitou, et al., 2006; Steed, 2002) or consider there is little unique variance explained by the Pathways or Agency items above the general factor Hope in factor analysis (Brouwer, Meijer, Weekers, & Baneke, 2008). Steed found cross loading of items such as "I can think of many ways to get out of a jam", "I energetically pursue my goals" and "I meet the goals that I set for myself" (Steed, 2002). This was interpreted as "conceptually meaningful", as the cross loading reflected the potential for the items to be interpreted as pathways as well as agency items (Steed, 2002). Correlations between the pathway and agency subscales have been reported as $r = 0.39$ to 0.57 ($p<0.05$) (Snyder, et al., 1991; Snyder, Parenteau, et al., 2002).

Correlational findings regarding the SHS and demographic measures are widely published. Venning reported slightly lower hope with younger compared to older adolescents in Australia (Venning, et al., 2009). Hope was lower for older subjects (Moraitou, et al., 2006) within a mature aged sample. In a community sample, lower hope was found in older subjects (54-65 years old), and those separated/divorced and widowed (T. C. Bailey & Snyder, 2007). These correlations with age suggest that hope increases throughout adolescence, peaking in young adults, and then diminishes gradually through the rest of life. However, other samples have shown no effect for age (Creamer, et al., 2009).

Studies indicate hope is higher for those living with partners (Creamer, et al., 2009; Moraitou, et al., 2006). School completion and employment were associated with higher hope (Creamer, et al., 2009). Gender has not been associated with different levels of hope (Creamer, et al., 2009; Snyder, et al., 1991).

High SHS scores have been associated with more success academically (controlling for intelligence, previous grades and self-esteem) (Snyder,

Wiklunds, & Cheavens, 1999) higher sports ability (Curry & Snyder, 2000), higher health literacy (Snyder & Feldman, 2000) increased pain tolerance (Snyder, et al., 2005) and better psychological adjustment (Kwon, 2002).

Convergence with other positive psychology domains such as optimism, self-esteem, coping, problem solving, self-efficacy and subjective wellbeing have been extensively reported (see

Table 2.3) Correlations are moderate and generally consistent (i.e. in the range of r=0.50 to 0.60). Correlations with negative affect (depression and anxiety) and hopelessness range from 0.42 to 0.58 (inverse). Exceptions are very high variability in correlations with TPA (ranging from 0.3 to 0.74) and TNA (recorded as low as 0.18) (see Table 2.4).

This suggests consistent construct validity for the SHS, and the foregoing moderate correlations indicate appropriate convergence without redundancy.

Table 2.2: Snyder Trait Hope Scale with 4 point response set, arranged by subscale

Subscale		*Definitely false*	*Mostly false*	*Mostly True*	*Definitely True*
P	I can think of many ways to get out of a jam.	○	○	○	○
P	There are lots of ways around any problem.	○	○	○	○
P	I can think of many ways to get the things in life that are most important to me.	○	○	○	○
P	Even when others get discouraged, I know I can find a way to solve the problem.	○	○	○	○
A	I energetically pursue my goals.	○	○	○	○
A	My past experiences have prepared me well for my future.	○	○	○	○
A	I have been pretty successful in life.	○	○	○	○
A	I meet the goals that I set for myself.	○	○	○	○
F	I feel tired most of the time.	○	○	○	○
F	I am easily downed in an argument	○	○	○	○
F	I worry about my health.	○	○	○	○
F	I usually find myself worrying about something.	○	○	○	○
A=agency subscale P=pathways subscale F= filler item					

2.3 Critiques of Snyder's model

Three main aspects of Snyder's model of expectancy hope and hope scale have been criticised. Firstly, it is suggested there is poor theoretical differentiation with other positive psychology concepts such as optimism (Aspinwall & Leaf, 2002). Secondly, it is suggested that the links to affect are poorly described and integrated. And thirdly, questions have been raised about the observed phenomenology of hope and the Snyder construct of hope.

2.3.1 Hope, optimism and the construct of control

Hope can be considered one of many theoretical constructs populating the positive psychology field (M. E. Seligman & Csikszentmihalyi, 2000) and

meaningful differentiation and integration of these constructs is of interest. In spite of potential overlap in domains and the extensive reporting of the correlations between hope and other domains (see

Table 2.3 and Table 2.4) there is a lack of consolidation of research findings related to hope, optimism and other positive psychology constructs (Aspinwall & Leaf, 2002; Skinner, 1996).

Underlying many of the theories for obtaining “the good life” is the construct of control. An outline of an integrated theory of the construct of control (Skinner, 1996) was used in this thesis as a framework to compare and contrast hope with other related theories. Perceived control is the expectancy that outcomes can be controlled, either through the agency of self or another (Skinner, 1996).

The construct of control has several dimensions, but only two concern us here. One dimension distinguishes between agents, means and ends. Agents refers to the persons or groups who exert control, means refers to the pathways through which control is exerted, and ends refers to the goals and outcomes over which control is exerted.

Agent-means relations describe the extent to which potential means are available to the agents exerting control. Means-ends relations describe the relation between potential means and the desired (and undesired) ends. Agent-ends relations refer to the extent an agent can control or produce a desired end or prevent a negative one (Skinner, 1996) (see Figure 2.2).

The second dimension refers to something outside the domain of perceived control itself; it is the potential consequences of control. For many theories, this is the most important or observable aspect - for instance, where there is high perceived control, the consequences are optimism, motivation, active coping, sustained problem solving etc. Loss of perceived control leads to pessimism, avoidance and ineffective coping and problem solving (Skinner, 1996).

Clearly, expectancy hope maps fairly well onto the concept of control, where agency hope is an agent-ends and agent-means concept (i.e. the ability of self

to achieve a desired end (goal) and ability of self to execute a particular response), and pathways hope is a means-end concept (i.e. it about making plans (the means) to achieve goals (ends)) (Aspinwall & Leaf, 2002)(see Table 2.5). For the second dimension, the consequences of control, Snyder's Hope theory fits the general model again: if there is high hope, the consequences are theorised to be positive emotional states and active "goal pursuit" and low hope leads to giving up and pessimism.

Figure 2.2: Schematic diagram of the construct of control identifying agents, ends and means (from Skinner (Skinner, 1996))

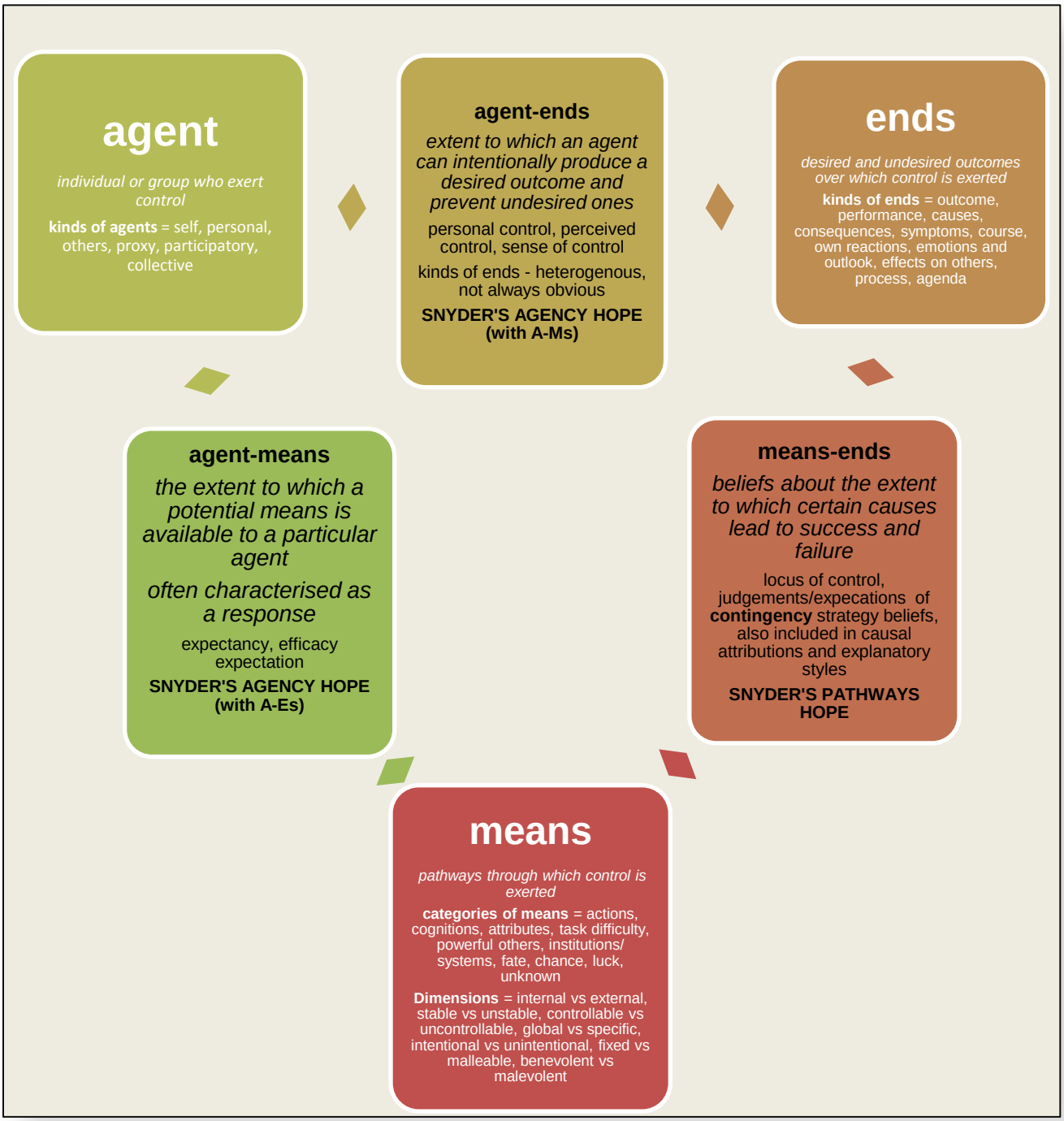


Table 2.3: Positive psychology domains and correlations with Snyder Hope Scale

Concept	Scale	Author (s)	Snyder Hope Scale correlation	Additional findings and comments
Expectancy of success (optimism)	GESS	Fibel and Hale (Fibel & Hale, 1978; Hale, Fiedler, & Cochran, 1992)	0.55(Gibb, 1990), 0.54(Holleran & Snyder, 1990) 0.57 (Steed, 2002)	SHS made significant contribution to variance in problem-solving coping beyond the GESS
Optimism (Seligman)	Attributional Style Questionnaire	Peterson et al (Peterson et al., 1982)	No data identified	
Optimism	Life Orientation Test (LOT)	Scheier & Carver (Scheier & Carver, 1985)	0.60 (Gibb, 1990) 0.50 (Holleran & Snyder, 1990) 0.55 (Magaletta & Oliver, 1999) 0.50 (Anderson, 1988) 0.50 (Harris, 1988) 0.50 (Munoz-Dunbar, 1993) 0.50 (Snyder, et al., 1991) 0.62 (Steed, 2002)	SHS made significant contribution to variance in problem-solving coping and difficulty of personal goals beyond the LOT. Negative life stress and hope predict unique variance in the level of mental health symptoms, over the LOT (Holleran & Snyder, 1990)
Self Esteem	Rosenberg Self Esteem scale	Rosenberg (Sears, 1986)	0.58 (Gibb, 1990)	
Problem - focused coping	Ways of Coping Checklist	Folkman and Lazurus ((Folkman & Lazarus, 1985)		Hope makes independent contribution to problem focused coping when anxiety/neuroticism controlled, or TPA & TNA controlled, or LOT or GESS controlled. When TPA or TPA controlled, hope makes independent contribution to active coping (Holleran & Snyder, 1990; Sigmon & Snyder, 1990; Snyder, et al., 1991)
Emotion focused coping	Ways of Coping Checklist	Folkman and Lazurus (Folkman & Lazarus, 1985)		
Problem Solving	Problem Solving Inventory	Heppner and Patterson (Heppner & Petersen, 1982)	-0.62 (Gibb, 1990),	(Lower scores = higher problem solving)
Self – efficacy	Self-efficacy scale	Sherer, et al (Sherer, Maddux, & et al, 1982)	0.59 (Magaletta & Oliver, 1999)	
Subjective Wellbeing	General Wellbeing questionnaire	Wheeler, (Wheeler, 1991)	0.60 (Magaletta & Oliver, 1999)	SHS only makes 3% contribution to GWBQ after LOT and SES (Magaletta & Oliver, 1999)
Total positive affect (TPA)	Positive and Negative Affect Scale (PANAS)	Watson and Tellegen (D. Watson, Clark, & Tellegen, 1988)	0.3 (Sigmon & Snyder, 1990) 0.55 (Snyder, 2002) 0.74 (Steed, 2002)	

All correlations significant at $p < 0.05$ level

Table 2.4: Negative affect and hopelessness correlations with Snyder Hope Scale

Concept	Scale	Author (s)	Snyder Hope Scale correlation	Comments
Total Negative affect (TNA)	Positive and Negative Affect Scale (PANAS)	Watson and Tellegen (1988) (D. Watson, et al., 1988)	-0.18 (Sigmon & Snyder, 1990) -0.52 (Steed, 2002)	
Anxiety/ Neuroticism	State-Trait Anxiety Inventory	Spielberger (1970) (Spielberger, Gorsuch, & Luchene, 1970)	-0.58 (Holleran & Snyder, 1990)	When control for anxiety/neuroticism, hope makes independent contribution to problem-focused coping (Sigmon & Snyder, 1990; Snyder, et al., 1991)
Anxiety/ Neuroticism	Taylor Manifest Anxiety Scale	Taylor (1953) (Taylor, 1953)	-0.47 (Holleran & Snyder, 1990)	
Hopelessness (Beck)	Beck Hopelessness Scale (BHS)	Beck, Weissman, Lester, Trexler (1974) (Aaron T Beck, et al., 1974)	-0.51(Gibb, 1990)	Correlation of -0.51 with TPA (Snyder, et al., 1991)
Depression	Beck Depression Inventory	Beck (1961) (A.T. Beck, Ward, Mendelson, J., & Erbaugh, 1961)	-0.42 (Gibb, 1990; Snyder, et al., 1991)	
All correlations significant at $p < 0.05$ level				

Many other theories also map onto the construct of control. This allows for the various related theories to be clearly compared and contrasted.

Optimism shows particular theoretical and empirical overlap with expectancy hope. Optimism theories tend to be theories of overall control, that goals will be met, irrespective of agency or means (Carver & Scheier, 2002; Fibel & Hale, 1978; Steed, 2002), As Carver and Scheier state, optimism is “an overall sense of confidence about the outcome” p 288 (Carver & Scheier, 2002, p. 288). In terms of the construct of control, the emphasis is on agent-ends – with means and agency unspecified.

Thus, hope and optimism are similar in that they both focus on goal achievement. Optimism is the more general case, without specifying means, or agents. In contrast, Snyder emphasises personal agency and personal means and the Snyder Hope theory incorporates a focus on pathways, the specification of ways to achieve a goal. It is the focus on pathways, and the addition of pathways items in the Snyder Hope Scale (SHS), that provides some unique predictive power to the SHS.

Table 2.5: Positive psychology domains and the concept of perceived control

Concept	Agent-means	Means-ends	Agent-ends	Potential consequences of perceived control	Orient-ation
Hope – Snyder (Snyder, et al., 1991)	Agency hope "will power" – personal agency only	Pathways hope "way power"	Agency Hope "will power"	Hopeful thinking leads to positive emotional states, and low hope thinking and thwarted goals leads to negative emotions.	P G
Hope – Stotland (Stotland, 1969)	NA	NA	Goals will be met	Increases in goal probability and importance leads to greater motivation and positive feeling. If goal attainment threatened then anxiety is felt	P G
Hopeless--ness (Aaron T Beck, et al., 1974)	Loss of motivation	NA	Goals will not be met/ bleak negative future	Depression and helplessness as a result goals unobtainable, lack of positive feelings about the future	P G
Optimism/ expectancy of success (Fibel & Hale, 1978) (Scheier & Carver, 1985)	Can be self or other - no particular agent specified	Means not important, as long as effective - no particular means specified	Optimism is the belief that goals will be achieved, but neither agency nor means are specified	Optimism is the confidence of goal attainment, and motivates people to stay engaged in goal pursuit	P G
Self – efficacy (Bandura, 1977,)	Efficacy expectancy (original definition)	Outcome expectancy	Efficacy expectancy has been more recently described in agent-ends terms (Skinner, 1996)		P or R, S
Problem Solving (Heppner & Petersen, 1982)	Agent, means and ends not part of problem solving, but antecedent to problem solving			Sustained problem solving and action orientation if perceived control is maintained, Withdrawal escape and passivity if control is perceived as impossible	
Coping (Folkman & Lazarus, 1985)	Agent, means and ends not part of coping theory, but antecedent to coping			Appraisal of situation as controllable and adequate resources leads to information seeking, strategising, planning and constructive coping. Appraisals of low control lead to poor coping efforts, e.g. escape, pessimism, passivity.	
Orientation to time and generality P= Prospective = Retrospective, G = General, S = Specific					

Another similar theory is Bandura's theory of self-efficacy. Self-efficacy (Bandura, 1977,) theory describes an agent-means aspect (efficacy expectancy) and a means-end aspect (outcome expectancy), which is obviously similar to Snyder's agency and pathways hope components (see Table 2.5). The implication of this structural similarity is that findings about self-efficacy and hope may be interrelated and research in either field might be usefully combined. These differences may be resolved empirically rather than theoretically (Skinner, 1996). Correlations between the Self Efficacy Scale and the SHS are moderate (Magaletta & Oliver, 1999)(see

Table 2.3) which suggests some overlap, but given the theoretical similarity, a higher correlation might be expected. However, the correlations may reflect particular operationalisations of the scales, which may not reflect the underlying constructs accurately.

In conclusion, the expectancy theory of hope is not structurally unique, but has nuanced differences from other similar theories such as optimism and self-efficacy, all based on the construct of control. This means that many of the findings relating to the SHS could be associated with the construct of control in general, rather than hope per se. The expectancy conception of hope appears to be strongly linked to optimism and self-efficacy, i.e. "I expect to be successful (optimism) and I know how I will achieve it (self-efficacy)" could be a statement of expectancy hope.

Since Snyder's construct overlaps with self-efficacy and optimism it covers domains that would be relevant to therapeutic change, such as goal setting, agency and other aspects of positive functioning.

2.3.2 Hope and negative and positive affect

In Snyder's account of hope, affect is described as a "side effect" of the cognitive aspects of hope, whereas contemporary accounts of affect suggest that affect can drive cognition (Aspinwall & Leaf, 2002; C. Smith, Haynes, Lazarus, & Pope, 1993) and therefore presumably can influence hope. In addition, links to Total Positive Affect, and homeostatic affect mechanisms are

not articulated in spite of consistent reports of moderate to high correlations between hope and affect (Steed, 2002).

Hope measurement has been criticised for being contaminated with positive affect and negative affect (Nunn, et al., 1996; T. W. Smith, Pope, Rhodewalt, & Poulton, 1989; Steed, 2002). Snyder made clear that goal attainment will be associated with positive affect, so some correlation of TPA and hope would be congruent with Hope theory. Snyder reports correlations of $r2 = 0.30$ ($p<0.001$) with positive affect items on the Positive and Negative Affect Scale (D. Watson, et al., 1988) and correlations of $r2 = -0.18$ ($p<.05$) with negative affect items (see

Table 2.3)(Snyder, et al., 1991) which are not unduly large. The correlations also suggest that there is a greater link to positive affect rather than negative affect. Steed (Steed, 2002) compared the Life Optimism Test (LOT), the Generalised Expectancies for Success Scale (GESS), the SHS and the Hunter Opinions and Personal Expectations Scale (HOPES). Correlations between all these instruments, stress and coping style were reduced when total positive affect (TPA) and total negative affect (TNA) were taken into account, indicating the associations between optimism and hope with coping may actually be due to "contamination" with affect.

There is also a question regarding Snyder's proposition that positive affect *results* from the hope cognitive set, but might it actually be the *basis* from which the positive cognitions spring (Aspinwall & Leaf, 2002; Robert Cummins, 2010; Meehl, 1990; C. Smith, et al., 1993)?

Given there has been little prospective or longitudinal data collected on the SHS, the question has not been settled empirically. However, other research (not in the hope area itself) indicates that emotions impact on goal selection, goal pursuit, decision-making, managing feedback, and monitoring goal progress (Aspinwall & Leaf, 2002).

Research into subjective wellbeing (SWB) also indicates that SWB is based on a homeostatically derived core affect, that is normally stable, positive and

genetically controlled (Robert Cummins, 2010). Consequently, if this core affect is the basis of our cognitive schemas, then the suggestion that hope is trait like, is most likely because the hope cognitive schema is based on this homeostatic core affect. In summary, the Snyder model of hope does not incorporate the more recent research insights into affect, behaviour and self-regulation (Aspinwall & Leaf, 2002).

2.3.3 The Snyder Hope theory and the phenomenology of hope

A third critique of the Snyder model of hope relates to its relevance to lay person accounts of hope (Tong, et al., 2009); the absence of reference to hope and relationships (Horowitz, 2008; J. Miller & Powers, 1988); absence of links with adversity; and the importance of hope when no "pathways" are available (i.e. when there is "nothing to do but hope" and "only hope is left") (Tong, et al., 2009) and the relationship to hopelessness. Also, it is unclear how hopelessness, emergent hope and expectancy hope are linked.

2.3.3.1 Hope and relationships

Snyder emphasises *personal* agency in the Hope theory and Scale, yet this is neither intrinsic to the control construct underlying the hope theory, nor congruent with many accounts of hope in literature and research (Aspinwall & Leaf, 2002; Bruininks & Malle, 2005; Flaskus, McCarthy, & Sheehan, 2007; Frankl, 1963; Tong, et al., 2009). This is especially pertinent in this study of a family intervention, as will be explained in section 2.5, and Chapter 3. As Frankl observed, holding goals and hopes about family members was vital for survival in the adverse circumstances of the concentration camps. Positive relationships and the experiences of agency through joint effort also inspire and augment hope (Aspinwall & Leaf, 2002; Flaskus, et al., 2007). Individuals also look to others for approval of goals and efforts to achieve them (Aspinwall & Leaf, 2002). Most important in the context of families, is the hope one holds for significant others. This is often a situation when there is little control over outcomes as they depend on the other person for their fulfilment (Averill, Catlin, & Chon, 1990; Bruininks & Malle, 2005; Tong, et al., 2009).

It is unclear why Snyder only theorised about hope related to the individual, and all versions of the scale refer only to personal goals, actions and motivations.

The emergent concept of hope more clearly accounts for hope and relationships. However, it is reasonably easy to extend Snyder's scheme to incorporate goals for other persons without violating the structure of the expectancy concept.

2.3.3.2 Hope adversity, and the link to recovery

As much of the foregoing has suggested, Snyder's expectancy hope does not fully account for the significance of adversity, whereas it is central in emergent hope. In the commonly understood meaning of hope, hope is invoked as the link between adversity and advantage. For instance Professor Cornell West has stated:

> *There's a difference between hope and optimism. Now optimism is based on the facts, looks pretty good out there, things are going to get better. Whereas hope says, It don't look good at all, but whether we take the leap of faith to create new visions based on possibilities that become contagious, to encourage people to engage in heroic actions always against the odds, no guarantee whatsoever, that's hope (West, 1999).*

This kind of "hope in adversity" is the motivating force used by activists such as Lech Wałęsa, who entitled his biography "A way of hope" (Walesa, 1987). This view of hope sharply demarcates expectancy hope and optimism; "hope in adversity" is maintaining goal focus when expectancies are low and optimism is unwarranted, whereas optimism and expectancy hope is based on positive expectancies (Bruininks & Malle, 2005; Tong, et al., 2009). However, both concepts of hope are relevant to recovery, and the challenges of mental illness.

Snyder does suggest that persons with high hope will show more constructive coping when goal achievement is threatened. However, hope as he has defined it relies on high perceived control, that is high motivation and clear contingencies (i.e. links between actions and outcomes). Hope in the situation of true adversity offers little but deep desire to attain the end goal (Tong, et al., 2009). Hope is belief a goal can be attained, whereas optimism/ expectancy hope is confidence it can be attained. Another way of characterising the

differences is to describe Snyder's expectancy hope as a theory of control, whereas emergent hope is a theory of "non-control".

2.3.4 Content validity of the Snyder Hope Scale

Although Snyder's model of hope clearly states it concerns perceptions of the future, some statements in the Snyder instrument are about a current appraisal (e.g. "There are lots of ways around any problem"), or past appraisals (egg "I have been pretty successful in life" and "My past experiences have prepared me well for my future") (Carver & Scheier, 2002).

In addition, it has also been suggested that agency items measure a sense of "prior success" rather than agency itself. Items such as "I have been pretty successful in life" and "My past experiences have prepared me well for my future" are examples (Carver & Scheier, 2002).

Factor analysis has also revealed that the agency and pathways subscales do not emerge as statistically robust factors in a number of studies (Ahmed & Duhamel, 1994; Babyak, et al., 1993; Moraitou, et al., 2006; Steed, 2002), suggesting that items do not clearly reflect the underlying construct.

The critiques and findings imply that the SHS does not accurately operationalise Snyder's theory. It has been suggested that the pathways items appear to measure the pathways concept more precisely, but the agency items (e.g. "My past experiences have prepared me well for my future" or "I have been pretty successful in life") do not clearly represent the agency concept (Carver & Scheier, 2002). This may have implications for studies that use the SHS, as the interpretation of the findings may be inconclusive.

2.3.5 Other research on hope

In the wider psychology field, the meaning of hope varies widely (B. Schrank, Stanghellini, & Slade, 2008; Wein, 2005). Some definitions have taken a very broad view. Both Miller (J. Miller & Powers, 1988) and Herth (Herth, 1992) use a broader view of hope, based on Dufault and Martocchio's (Dufault & Martocchio, 1985) definition that:

> *Hope is a multi-dimensional dynamic life force characterised by confident yet uncertain expectation of achieving a future good …which is realistically possible and personally significant" (p 380)*

Miller (J. Miller & Powers, 1988) defines hope as having ten critical elements including affiliation, avoidance of "absolutising", personal meaningfulness, transcendence and "renewed spiritual self" and mental and physical activation. Schrank, in a recent review of the literature, developed a summary definition of hope as a:

> *Future orientated expectation …[sometimes based in a difficult present] of attaining personally valued goals, relationships or emotional states (p42)(B. Schrank, et al., 2008, p. 42)*

where the attainment will be meaningful, subjectively realistic and requiring internal and external resources (B. Schrank, et al., 2008). These approaches are often described by their authors as "integrative" (Farran, et al., 1995; Herth, 1992; J. Miller & Powers, 1988; Beate Schrank et al., 2012).

In this view, hope exists on the emotional, cognitive, behavioural and environmental planes compared to the definitions by Stotland and Snyder which are strictly cognitive. Also, the views of Miller and Herth are derived more from the area of hope in cancer treatment and terminal illness palliative care (Farran, et al., 1995; J. Miller & Powers, 1988). The integrative approaches quite rightly suggest that the cognitive definitions of Stotland and Snyder miss significant aspects of hope and try to incorporate both emergent and expectant views of hope. Some emphasise a religious or spiritual focus that may limit the acceptability of the scales for some respondents. For example, in the Nowotny Hope Scale one item is "My religious beliefs help me most when I feel discouraged" (Nowotny, 1989).

However, the integrative definition has not been consolidated with and differentiated from other psychological theories, such as optimism, the control construct and affect, a similar critique to that made of the Snyder theory of hope.

Other hope scales (Farran, et al., 1995) have not been so widely used, providing little guidance for benchmarking (B. Schrank, et al., 2008). The SHS has been employed over a number of years and with a diverse range of communities and thus remains one of the most widely applicable hope measures (Steed, 2002). Thus, although integrative hope measures show potential to encapsulate hope comprehensively, the SHS has shown adequate psychometric quality, has been widely used and so provides benchmarking potential. Furthermore, it shows overlap with concepts such as optimism and self-efficacy, which are highly relevant in clinical situations.

2.3.6 Conclusion: hope and it's measurement

Hope has been part of the literature regarding mental health and therapy since the middle of the twentieth century. There appears to be two approaches to hope, one described here as emergent hope, and the other expectancy hope.

Emergent hope describes the hope that "emerges" as the first step towards recovery in the midst of adversity. Emergent hope also focuses on relationships, as interpersonal relationships sustain hope in difficult circumstances. Emergent hope is an atheoretical construct, with largely narrative descriptive accounts. It is this approach to hope that matches commonly understood lay notions of the term (Bruininks & Malle, 2005; Tong, et al., 2009).

Expectancy hope is based on the construct of perceived control, where hope is defined as the expectancy that goals can be met. Snyder theorised that hope consists of agency (a belief that one can achieve goals and that one can implement the means to achieve goals) and pathways (the belief that one can devise suitable means to achieve a goal). This expectancy model of hope combines optimism (i.e. the belief that goals will be achieved) and self-efficacy (one believes they know how to achieve goals) based on the construct of control. Expectancy hope does not deal with the notion of adversity, and implies that hope functions mostly in situations of high expectation. The widely known SHS is an expectancy hope measure and is extensively used with good convergent evidence and psychometric properties. At 12 questions it has low burden for respondents.

A third approach to hope, entitled here as “integrative”, so called because it is developed from an amalgam of the hope literature (Benzein & Saveman, 1998; Beate Schrank, Woppmann, et al., 2012), is less widely used at present; does not have a theoretical basis yet; and differentiation from other concepts has not been established.

In conclusion, the SHS is a useful measure of positive orientation, and its links to the construct of control make it valuable in the context of therapy. However, it is unclear if it can capture the layperson/emergent account of hope; whether it is relevant to situations of adversity; and how it describes the importance of relationships. The next section explores how the SHS and the expectancy theory of hope may be relevant to the concerns of recovery for consumers and burden for carers.

2.4 Hope and recovery for consumers

Recovery is broadly defined as “living as well as possible” (South London and Maudsley NHS Foundation Trust, 2010) with a minimum of the symptoms of mental illness (Slade, Leamy, et al., 2012). Hope has been frequently described as one of the core components of a recovery approach to the treatment of mental illness (Slade, 2010; M Slade, 2012). Currently, there is great interest in the concept of recovery with many publically funded mental health services moving to a recovery-based service (i.e. providing services in a manner consistent with recovery values, and encouraging the recovery process in consumers) (Department of Health, 2011; Ramon, Healy, & Renouf, 2007; M Slade, 2009; M. Slade, 2012; M Slade, 2012).

2.4.1 Definitions of recovery

Recovery has no unitary definition, but in recent years a number of review articles of the literature have established a consensus (Bellack, 2006; Bonney & Stickley, 2008; R. P. Liberman, 2002; Noordsy, et al., 2002; Rudnick, 2008; Silverstein & Bellack, 2008). Two main approaches to the concept of recovery exist, one from the scientific literature, and the other from the consumer literature (Bellack, 2006; Silverstein & Bellack, 2008).

In the scientific approach to recovery, set criteria in areas such as remission, stabilisation of symptoms, psychosocial rehabilitation, improved vocational activities, additional social connections and independent living are defined (Bellack, 2006; Kopelowicz, et al., 2005; Robert Paul Liberman, et al., 2002). While these criteria may vary across different contexts, the general concept is that recovery is the restoration of role functioning and not just symptom control and this is an advance on the limited focus on symptom reduction. Hope has not been prominent in this area of research. This approach to "recovery" has also been characterised as "clinical recovery" (Slade, Leamy, et al., 2012), or "service-based recovery" (Beate Schrank & Slade, 2007; Secker, Membrey, Grove, & Seebohm, 2002) "recovery from" mental illness (Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008; Slade, Bird, et al., 2012) or an "outsider perspective on recovery" (C. Brown, Rempfer, & Hamera, 2008).

The second approach to recovery is derived from the consumer-oriented literature, case studies and qualitative surveys (Bellack, 2006). This typifies recovery as a process (Robert Paul Liberman & Kopelowicz, 2005), rather than a fixed end point, and delineates a number of important characteristics that contribute to recovery. Recovery is not about symptom remission, or "cure", but the capacity to have a meaningful, purposeful life with hope for the future (A.B. Hatfield & H.P. Lefley, 1993; A. B. Hatfield & H. P. Lefley, 1993; Lefley, 1997).

> *Recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of the disability…to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution" (P.E. Deegan, 1988, p. 11), p 11.*

In this view, hope can be seen as an integral part of recovery (Bellack, 2006; Bonney & Stickley, 2008; Czuchta & Johnson, 1998; P.E. Deegan, 1988; Noordsy, et al., 2002; Slade, 2010; M Slade, 2012; Snyder, et al., 2006) and the return of hope is believed to be the turning point in the recovery journey and is subsequently followed with a "willingness to act" and take control of one's life (P.E. Deegan, 1988; Lefley, 1997).

In contrast to the scientific definition of recovery, this approach to recovery is characterised as “personal recovery” (Slade, Leamy, et al., 2012), “social recovery” (Secker, et al., 2002), “user-based recovery” (Beate Schrank & Slade, 2007) “recovery in’ (Davidson, et al., 2008) mental illness (Slade, Bird, et al., 2012) or an “insider perspective on recovery” (C. Brown, et al., 2008). The consumer vision of recovery argues forcefully in humanitarian terms for more enlightened treatment and practice, consideration of the consumer as a human being, and the restoration of hope in the treatment of mental illness, all leading to better outcomes.

The consumer approach to recovery does not exclude the use of scientific evidence to deliver effective treatment. In fact, the use of evidence-based treatments is an essential part of delivering recovery-oriented services and optimal outcomes (P. W. Corrigan & Ralph, 2007; Kim T. Mueser, 2012). Family-based psychoeducation (the focus of this program evaluation) is thus consistent with recovery-oriented services.

The suggested characteristics for treatment settings that are consistent with recovery values (Bellack, 2006; Substance Abuse and Mental Health Services Administration, 2005) are:

- Hope – the message that recovery can and does occur
- Self-direction – consumers make their own choices
- Individualised treatment – treatment is tailored to the individual
- Empowerment – consumers have authority over their own lives
- Holism – recovery occurs on many levels of a person’s life
- Strengths based – recovery is based on building on strengths, not focusing on deficits
- Peer supported – consumers supporting each other is important for recovery

- Respect – between the consumer and service providers, and consumers and the rest of society is important
- Responsibility – consumers are responsible for their own care and recovery.

How these characteristics and values, combined with evidence-based treatments, impact on the recovery process for consumers, and outcomes for their carers has not been established empirically (Sandra G. Resnick, et al., 2005).

2.4.2 The development of the concept of recovery

The popularity of recovery-focused policy and practice has increased over the past two decades, with a number of antecedents (Ramon, et al., 2007). One of the original statements defining the contemporary recovery movement was in 1993 by William Anthony (Michaela Amering & Schmolke, 2009; W. Anthony, 1993; Roberts & Wolfson, 2004). This statement proposed that recovery can occur "even though the illness is not cured" (p.525) and is a way of living a satisfying, hopeful and contributing life" (p. 526) and suggested that the vision of recovery could and should be the guiding force in mental health services going forward (W. Anthony, 1993).

Deegan (P.E. Deegan, 1988), in the five years previous, had written a very moving account of her personal journey from being overwhelmed and hopeless, though to regaining a meaningful life (Ramon, et al., 2007; Roberts & Wolfson, 2004) (see quotes above). These and other narrative accounts of people living with severe mental illness and the journey to personal recovery, made significant contributions to the concept of personal recovery (Copic, et al., 2011; Mike Slade, 2009).

Broader social movements also laid the foundations for the widespread acceptance of the recovery concept – the so-called "recovery movement" (Barber, 2012). One was the consumer movement in the USA in the 1970s and 1980s which demanded empowerment for service users and a collaborative approach to treatment (Ramon, et al., 2007; Roberts & Wolfson, 2004; Turner-Crowson & Wallcraft, 2002). Another was deinstitutionalisation (W. Anthony,

1993; Ramon, et al., 2007; Roberts & Wolfson, 2004) which promised autonomy and self-determination for people living with mental illness away from institutional care. However, in its implementation and the withdrawal of custodial care, it became clear that mere symptom relief was not sufficient in itself to deliver the promise of independence and fulfilment.

In addition, longitudinal studies showed that long term outcomes for people diagnosed with severe mental illnesses such as schizophrenia were not as pessimistic as generally accepted and that a substantial percentage would see complete remission or at least substantial restoration of functioning (Barber, 2012; McGorry, 2005; Ramon, et al., 2007; Roberts & Wolfson, 2004). It was also suggested that recovery and functional gain were reliant on effective treatment based on optimism, positive expectancy for the future and stigma reduction (Barber, 2012). Poorer outcomes might be the result of a self-fulfilling prophesy of the incurability of severe mental illness, and the presence of social barriers that caused disability (W. Anthony, 1993; P.E. Deegan, 1988; Ramon, et al., 2007; Roberts & Wolfson, 2004).

2.4.3 Tensions and debates regarding recovery

Although discussion regarding recovery is mostly constructive, debate and tensions are still apparent.

Firstly, there is a question regarding who “owns” recovery? Is it service users or service providers? (Pilgrim, 2008; Ramon, et al., 2007) Who should lead the implementation and planning of recovery-based services, and refine the understanding of recovery? Traditionally, policy is defined by government bureaucracies and implemented by mental health services with consultation from consumers and carers. Recovery-based services may challenge the top-down approach, and demand a more collaborative method (Roberts & Wolfson, 2004).

Secondly, although the promotion of recovery within services is welcome, how a service effectively implements a “recovery oriented” practice is unclear (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006; Department of Health, 2011; Ganju, 2003). If autonomy and self-determination are to be encouraged, how does this impact on the management of risk and clinical governance for

services (Davidson, et al., 2006; P. Deegan, Rapp, Holter, & Riefer, 2008; Department of Health, 2011; Ramon, et al., 2007; Roberts & Wolfson, 2004)? What about services for people who "don't want to recover" or "don't achieve recovery" (Davidson, Lawless, & Leary, 2005; Davidson, et al., 2006; Ramon, et al., 2007; Turner-Crowson & Wallcraft, 2002)? This concern may emerge from confusion between the clinical and personal notions of recovery (outlined above) (P.E. Deegan, 1988; Mike Slade, 2009)), where people assume recovery is "not for them" since they still have symptoms (i.e. they have not clinically recovered), whereas personal recovery is available for all (Ramon, et al., 2007; Roberts & Wolfson, 2004; Beate Schrank & Slade, 2007). Does encouraging recovery and self-determination mean more or less services and support are provided (Davidson, et al., 2006; Ramon, et al., 2007; Roberts & Wolfson, 2004)?

There are also questions related to service delivery regarding the most appropriate interventions and activities that promote hope and recovery for consumers (Davidson, et al., 2006; M Slade, 2009), the methods to train practitioners to work in a recovery-oriented practice, and the optimal support, supervision and management practices within a service.

Thirdly, although recovery research is an exciting new area, there are both opportunities and challenges to research in the area. Tasks that exist are in areas such as developing and testing satisfactory recovery measures, and understanding (and measuring) the sub-process of recovery. If recovery is a process, not just an outcome, then how will that process be observed and documented in research procedures? If recovery is a deeply personal and individual journey, then how is this incorporated in research methodologies that seek to generalise, average, group and summarise? (Ramon, et al., 2007)

2.4.4 Phased models of recovery and hope

Although frequently described as integral to recovery, the definition of hope in this context is imprecise. In its most general sense, hope in recovery is described as a "belief in the possibility of recovery" (Slade, Leamy, et al., 2012) or as a determination to get better (Beate Schrank & Slade, 2007). It involves committing to change, focusing on strengths not weaknesses, looking forward,

being optimistic, and having self-belief (Beate Schrank & Slade, 2007). Salyers & Macy (Salyers & Macy, 2005) referred to hope in recovery as "hope for a better life" (p 101), whilst Resnick et al (Sandra G. Resnick, et al., 2005) described it as hope for the future and hope for achieving one's goals. Noordsy et al (Noordsy, et al., 2002) described hope in recovery as hope for positive change.

These descriptions of hope allude to hope as a "trigger" for recovery and also hope maintaining the trajectory of recovery (Beate Schrank, Bird, Rudnick, & Slade, 2012). In this sense hope could be referred to in both its emergent sense (i.e. as a trigger), and its expectancy/optimistic sense (expectation of maintaining progress to recovery).

Narrative syntheses of personal accounts and qualitative studies of recovery have suggested that recovery has stages or phases, which is congruent with the notion that recovery is a process or a journey (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). The recovery stages have been loosely based on the model of change by Prochaska and diClemente (Leamy, et al., 2011; Prochaska & diClemente, 1982).

Generally, these 'phase models' include a number of stages: the pre-contemplation stage, characterised by demoralisation and dependence; the contemplation stage characterised by a first awareness of the possibility of recovery and the 'spark of hope'; the preparation stage with preliminary strengthening and building of determination; and the action stage typified by learning and discovery; and finally, the maintenance and growth stage exemplified by living beyond disability with self-reliance and active coping (Retta Andresen, Peter Caputi, & Lindsay Oades, 2006; Andresen, Caputi, & Oades, 2010; Andresen, Oades, & Caputi, 2003; Leamy, et al., 2011).

One model developed in Australia is Andresen's stages of recovery model (SRM) measured with the Stages of Recovery Inventory (STORI) (Retta Andresen, et al., 2006; Andresen, et al., 2010; Andresen, et al., 2003). The five stages proposed are Moratorium, Awareness, Preparation, Rebuilding and Growth. Correlation studies on the STORI indicate that scores on other self-assessed recovery measures increase across the STORI classification phases

(Andresen, et al., 2010). This does not necessarily indicate that qualitatively distinct phases exist, but does suggest a promising area for further research. In related research, it was shown that active goal pursuit and significantly improved levels of hope were only found in the Preparation stage of recovery (Copic, et al., 2011).

The stages model of recovery may have a resonance with the concepts of emergent and expectancy hope, with emergent hope characterising hope in the early phases of recovery, and expectancy hope related to later stages in the recovery journey.

The concept of emergent hope being followed through with more constructive thinking and action has been described previously (Kylma, et al., 2006):

> *Hope is not a bolt of lightning: it is a turning point that must be quickly followed by willingness to act. (P.E. Deegan, 1988, p. 14)*
>
> *Replacing … unsound expectations – first with hope, and then with sound expectations… p 490 (Menninger, 1959, p. 490)*

Hope in "maintaining recovery" seems to parallel expectancy hope and optimism, in that it refers to focusing on "potential positive outcomes" (i.e. optimism) and positive expectations of goal achievement (i.e. hope). The return of a general sense of personal control is implied. Tooth et al suggest that regaining sense of personal control ("a determination to get better") was most important to recovery (Tooth, Kalyanasundaram, Glover, & Momenzadah, 2003).

These models suggest that there are qualitative changes in the components and sub-process of recovery (Retta Andresen, et al., 2006; Andresen, et al., 2010; Andresen, et al., 2003; Copic, et al., 2011; Leamy, et al., 2011). For instance hope, as a component of recovery, moves in each stage, from hopelessness, to awareness of sources of hope, to utilising sources of hope, to developing a sense of personal agency to finally a sense of optimism and well-being (Retta Andresen, et al., 2006)

More precise definitions and measures of hope in recovery will be necessary to develop the paradigm, link it to existing findings, and support ongoing research.

2.4.5 Evidence relating hope and recovery

Currently there is little rigorous research that explores possible links between hope and recovery in clinical practice (Slade, 2010; Slade, Leamy, et al., 2012) in spite of the frequent reference to hope in the recovery literature. This is acknowledged as part of the general circumstance in which research on the consumer model of recovery is lacking (Bellack, 2006). It may also be the result of a lack of a rigorous definition of hope in the recovery context, as well as problems with the general construct and measurement of hope discussed in Section 2.3. While the reliance on narrative accounts for understanding recovery is accepted as appropriate for understanding a consumer-driven perspective (Tooth, et al., 2003), more rigorous empirical understanding of hope and recovery is needed to support evaluation of recovery-based services (M. Slade, 2012; M Slade, 2012).

In an international review of recovery, 105 separate conceptualisations of recovery were identified. Eighty-five of these unique recovery models identified hope as integral to the recovery process (Slade, Leamy, et al., 2012). Hope was one of five major recovery processes, the other four being connectedness (support and community engagement), identity (rebuilding a positive self-identity and overcoming stigma), meaning in life (improved quality of life and meaningful experiences) and empowerment (personal responsibility and control) (Slade, Leamy, et al., 2012).

Resnick et al (Sandra G. Resnick, et al., 2005), seeking an empirical conceptualisation of recovery, selected suitable items from a questionnaire battery for a factor analysis and obtained a four factor solution. The four recovery factors were hope, empowerment, knowledge and life satisfaction. The items in the questionnaire battery that measured hope were 2 optimism items endorsing positive expectations for 2 yrs and 5 yrs into future, and 2 hope items endorsing positive evaluations of current mental health compared to

mental health 2 yrs and 5 yrs previously (i.e. a trajectory of past and future improvement in mental health).

There is some literature outlining the situation for the person living with schizophrenia and the challenge of hopelessness (Hoffmann, et al., 2000; Kylma, et al., 2006; Paul H. Lysaker, et al., 2006). In fact, increasing insight can lead to higher levels of hopelessness, possibly due to increased levels of internalised stigma (Paul H. Lysaker, et al., 2007). Hopelessness may have a profound effect on the person living with a serious mental illness:

> *When the patient perceives the disorder and its consequences to be beyond his control, feels helpless, and has given up expecting to influence it's course positively, thereby abandoning responsibilities and active coping strategies. Thus once established, hopelessness may become a central limiting factor in the efficacy of treatment and rehabilitation* (Hoffmann, et al., 2000, p. 148).

Conversely, the instillation of hope is an integral part of recovery. Thus, research regarding hope is especially pertinent in the situation of serious mental illness, since people living with schizophrenia are identified as a group particularly challenged by hopelessness, in addition to the putative link between hope and recovery.

Two specific implications from the consumer model of recovery will be investigated in this study. Firstly, that hope can exist and recovery can occur independent of level of symptoms (W. Anthony, 1993; Rudnick, 2008); and secondly, that the emergence of hope is a precursor to the full experience of recovery (W. Anthony, 1993; M Slade, 2012).

2.4.5.1 Hope, recovery and symptoms

The consumer vision for recovery asserts that hope and recovery can occur, irrespective of level of symptoms of mental illness (W. Anthony, 1993; Rudnick, 2008). It is clearly possible that consumers can maintain recovery and hope in areas such as developing meaning and purpose in life, forging social connections, and establishing a set of values, even if symptoms are persistent or recurrent. However, the reality for many consumers may be that persistent

or recurrent symptoms challenge optimism and hope and deplete the energy required for recovery, a point of view more compatible with scientific views of recovery that assert that recovery is based on the reduction of symptoms (Robert Paul Liberman & Kopelowicz, 2005).

Research generally supports the view that persistent symptoms can impact negatively on a recovery orientation, but some studies show no relationship between hope and symptoms.

Resnick (Sandra G. Resnick, et al., 2005), reported above, demonstrated that the perception of improvement mental health in the past, and the expectation of improvement in the future is integral to the recovery orientation. In another study, Resnick et al (S. G. Resnick, Rosenheck, & Lehman, 2004) found that hope was independent of psychotic symptoms, but negatively correlated with depression symptoms, alcohol problems and medication side effects, stating:

> *The most important finding of this study was that severity of symptoms, especially depressive symptoms, was strongly and negatively related to all … components of recovery orientation…. Some proponents of the recovery movement have emphasised that recovery can occur despite the presence of psychiatric symptoms…. Our findings instead suggest that the severity of psychiatric symptoms, which is most commonly associated with a biomedical perspective of mental illness, may be significantly and negatively related to recovery orientation (S. G. Resnick, et al., 2004, p. 545)*

In a series of papers, Lysaker et al found the following correlations between hopelessness (Beck Hopelessness Scale (BHS)) and symptoms: greater hope correlated with lower negative symptoms (Paul H. Lysaker, et al., 2008), increased insight and perceived stigma correlated with lower hope (Paul H. Lysaker, et al., 2007), higher hope correlated with lower positive symptoms (Paul H. Lysaker, et al., 2005), and finally, hope was unrelated to positive and negative symptoms (Paul H. Lysaker, et al., 2004). All studies were conducted on virtually the same population of middle-aged veteran clinic clients, mostly male and diagnosed with schizophrenia or schizoaffective disorder. White et al also found an inverse correlation between hope (BHS) and symptoms, and

hope and depression (White, et al., 2007) (i.e. hope increased as symptoms and depression decreased).

Landeen et al found no correlation between hope and symptoms in a sample of 100 consumers with schizophrenia (Landeen, Pawlick, Woodside, Kirkpatrick, & Byrne, 2000). Andresen found recovery self-report measures to be independent of the functional and symptom measures, but moderately correlated with psychological distress (Andresen, et al., 2010).

In summary, lowered mood, depression and distress would appear to lower hope and impede recovery, more than the direct symptoms of psychosis, although this is not a universal finding. Since high rates of depression co-occur with serious mental illnesses such as schizophrenia, the impact of depression on hope and recovery could be widespread (V. Morgan, et al., 2012).

2.4.5.2 Hope as a precursor to full recovery

A second implication of the recovery model for hope is that hope is understood as the first step in the process of recovery. There are numerous qualitative and narrative studies that describe nascent hope as the beginning of the road to recovery (Bellack, 2006; Bonney & Stickley, 2008; Czuchta & Johnson, 1998; Darlington & Bland, 1999; P.E. Deegan, 1988; Lefley, 1997; R. P. Liberman, 2002; Robert Paul Liberman, et al., 2002; Noiseux & Ricard, 2008; Noordsy, et al., 2002; Rudnick, 2008; Silverstein & Bellack, 2008; Snyder, et al., 2006), but this author could not locate any quantitative prospective studies that investigated this assertion.

There are a number of theoretical models that explicitly define hope as the first active step after a stage of despair, inaction and withdrawal. The concept of recovery phases discussed above suggests that the re-awakening of hope is the turning point from pre-contemplation to contemplation of recovery (Retta Andresen, et al., 2006; Leamy, et al., 2011).

There is little empirical research that shows the relationship between recovery and hope through correlations between hope and either primary (i.e. measures explicitly designed to measure recovery) or secondary measures (i.e. those designed to cover domains related to recovery such as social connection or

quality of life) in people with severe mental illness. Noordsy et al (Noordsy, et al., 2002) write about hope as one of three major components of recovery, this observation being based on "clinical observations, focus groups with consumers and consumer-professional interactions" (p318), Mead and Copeland describe their personal experiences of regaining hope (Mead & Copeland, 2000) and other narrative accounts of rehabilitation describe the return of hope as pivotal to personal recovery (Bassman, 2000; P.E. Deegan, 1988). Littrell and Herth (Littrell & Herth, 1996) found improvement in hope levels in consumers treated with pharmacotherapy and a comprehensive psychosocial program. However, there was no control group, and no analysis taking into consideration the effect of covariates such as changes in symptom levels. There is some research on psychotherapy in the general population and student groups (e.g. see (Snyder, 2002)) which shows hope increases across the duration of a psychotherapy treatment.

Given the minimal data on measuring hope in relation to recovery, and the widespread implementation of recovery-based services and the need for evidence of their effectiveness, more research into hope and recovery is warranted (Australian Health Ministers Conference, 2009; Department of Health, 2011). Since there is minimal quantitative or prospective literature supporting the case for recovery, the rationale for such person-oriented treatment would be strengthened if there were studies employing rigorous evaluation research designs investigating how recovery "processes" such as hope contributed to recovery "outcomes" (Slade, Leamy, et al., 2012). The study of hope and recovery is already beginning with the compilation of compendiums with suggested instruments for recovery measurement (Campbell-Orde, et al., 2005; Ralph, et al., 2000). However, there is little current research showing exactly how hope is related to improvement in outcomes in mental health treatment (Bellack, 2006; Silverstein & Bellack, 2008; M Slade, 2012).

Given the foregoing discussion on theories of hope and hope measurement, the SHS is a candidate for such research given its wide usage to date and adequate psychometric qualities. Although the relationship of both emergent and expectancy hope to recovery is worthy of empirical investigation, currently,

there is no instrument available to measure emergent hope. The only scale that explicitly measures expectant hope is the SHS. The SHS, by including a Pathways (that is, a means-ends or "way power" concept) subscale, incorporates coping and problem solving. In addition, through the underlying concept of perceived control, the Snyder Hope construct overlaps with important and relevant constructs such as self-efficacy and optimism. This makes it an excellent candidate for empirical exploration of the hope in the context of recovery for consumers.

2.5 Hope for caregivers and family members

The term "burden" is commonly used to describe the challenging nature of caring for a family member with a serious mental illness (Schene, Tessler, & Gamache, 1994). This has been recognised since the era of de-institutionalisation, when families took an increasing role in the care and supervision of their mentally ill relative (Schene, 1990). Two types of burden have been described – objective burden, which encompasses the adverse effects in the household such as financial loss or general disruption and behaviours that are disturbing to others; and subjective burden, namely, what family members feel about the demands and to what extent they *feel* burdened (Hoenig & Hamilton, 1966). More recently, theories of appraisal have suggested firstly, that all burden is essentially "subjective" since we cannot separate assessment of demand from appraisal and secondly, that caregiving incorporates both negative and positive aspects. Terms such as "caregiving" or "caregiving experience" are suggested alternatives (G. I. Szmukler et al., 1996) although the term burden encapsulates the often debilitating nature of the tasks and challenges (Laura Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, in submission).

Caregivers can feel considerable burden in caring for a family member diagnosed with a serious mental illness (Baronet, 1999; Department of Human Services, 2004; Ohaeri, 2003; Schene, 1990; Schene, et al., 1994; Schene, van Wijngaarden, & Koeter, 1998; Victorian Auditor General's Office (Australia), 2002) and the demands of caregiving have been associated with negative mental health effects for carers (Laura Hayes, et al., in submission). In recent

research in Australia, over one third of carers reported symptoms of psychological distress or substance use disorder in the previous 12 months, and just under half had at least moderate distress levels (Pirkis et al., 2010).

Carers' hopes are frequently centred on their consumer relative and hope may play a role for caregivers and family in two main ways. Firstly, hope may assist in coping with carer burden; and secondly, carers may assist consumers to maintain their hopefulness.

2.5.1 Hope and caregiver burden

Hope may help carers in coping with caregiving burden and conversely, hopelessness may affect the carer and further contribute to caregiver burden (Kylma, et al., 2006).

Lazarus and Folkman developed the concept of coping in the 1970s (Folkman & Lazarus, 1985). They proposed that there are a number of ways of coping (practical, emotional, detachment and faith/hope) that mediate the level of stress experienced by people in a challenging situation. Szmuckler and colleagues (G. I. Szmukler, et al., 1996) have found that a sense of mastery, in the sense of feeling confident to problem solve when challenges are presented, can increase psychological wellbeing in carers. This is corroborated by the findings of Noh (S. Noh & Turner, 1987) who showed that mastery was the most powerful predictor of burden and distress in relatives of recently discharged psychiatric patients. Bland and Darlington (Bland & Darlington, 2002) in a qualitative study found that hope was central to the coping process in families. MacInnes and Watson (MacInnes & Watson, 2002) found caregivers rated hopelessness as their second most severe burden (after incidents of violence).

All these studies suggest that hopefulness, and related concepts such as mastery/efficacy help carers to manage caregiving burden and conversely, that hopelessness is perceived as a significant part of burden. Hope in this context fits the definition of expectancy hope, with a focus on behaviours such as planning, pathways and constructive, high-agency coping skills.

The SHS, incorporating aspects of optimism, efficacy and problem solving would appear to be an excellent measure to assess hope and coping for burdened carers. Previous research with the SHS has shown that people high in hope can manage periods of extreme stress and burden more effectively, as higher hope predicts constructive rather than passive reactions to threats to goal attainment (Snyder, 2002; Snyder, et al., 1991).

2.5.2 Carers and the "holding of hope"

The second role of hope for carers may be in helping maintain their consumer relative's hope, described as being a "holder of hope", a role also shared with therapists and treatment teams (M. Amering & Schnolke, 2009; Flaskas, 2007; Peter McKenzie, 2007). This is a remarkable challenge for carers as they live with chronic adversity and the ongoing challenges of caring in the long term. Sometimes carers have neither reason to be optimistic (i.e. have positive expectancy), nor is it clear how any particular goals will be achieved. What appears to maintain hope against the odds is the relational aspects of hope for carers, as they nurture their own hopes for the future of their relative.

> *Hope may be what people hold when the odds of success are slim or when the means to goal attainment are outside their control. (Aspinwall & Leaf, 2002, p. 281)*

Holding hope for their relative may help carers to maintain their efforts in very difficult circumstances over long periods of time (Aspinwall & Leaf, 2002; Tong, et al., 2009).

"Holding hope" is not easy, as hope in carers often wavers as the future prospects for their relative rise and fall. Tuck et al (Tuck, du Mont, Evans, & Shupe, 1997), in a qualitative study on nine families, found hope could fluctuate, with falling hope associated with a re-experiencing of loss and grief. In another qualitative study in Sweden, Pejlert (Pejlert, 2001) observed that fluctuating hope was a feature of the parent carer experience, also a clinical observation made by Perlesz in the case of families where a member was recovering from acquired brain injury (Perlesz, 1999). Karanci found that about 50% of caregivers in a Turkish sample were hopeful about the future for their mentally ill relative (Karanci, 1995). George and Howell (George & Howell,

1996) found that rehospitalisation was often a source of hope as it was a place to stabilise and return to health.

More research in the area of the role of carers in maintaining consumer hope is undoubtedly warranted, as carer-inclusive practices are implemented as part of recovery focused treatments.

2.6 Hope in contemporary mental health treatment for families

The foregoing has discussed emergent hope as a first step from adversity to renewal, and expectancy hope as a belief that goals can be attained. Both aspects of hope are important in the clinical situation, but expectancy hope may have broader applications in the practical effectiveness of programs and treatment.

2.6.1 Predictions for hope in treatment

In terms of the expected trajectory of hope in the treatment situation, the recovery model suggests that emergent hope is a critical first step in improvement, and subsequent changes would be markers of continuing recovery and increasing expectancy hope. The expectancy model of hope would suggest that at the beginning of treatment, people have low hope, and effective treatment would be directed at helping a person set goals and improving positive expectancies for them (Cheavens, 2000).

Aspects of treatment that would enhance emergent hope and promote the first steps to recovery are those that:

- Develop a positive vision of the possibilities and potential within a person
- Maintain the vision of hope for a person at points of time when the person cannot do so themselves (P. McKenzie, 2006; Menninger, 1959; Ruvelson, 1990; Weingarten, 2000).
- Build on strengths, rather than focus on deficits (Czuchta & Johnson, 1998).

These aspects would appear to be associated with attitudinal factors in service provision. Empirical evidence is unclear if these therapeutic characteristics

enhance or create emergent hope, although anecdotal evidence suggests both. If emergent hope is present, then do further stages of recovery inevitably ensue? It seems effective intervention and support is required to develop emergent hope into a fuller recovery although evidence is lacking.

Aspects of treatment that would enhance expectancy hope are those that:

- Help a person to develop their own goals (not impose goals on them) (Bellack, 2006; Darlington & Bland, 1999)
- Assist a person in developing agency and strategy competencies to achieve these goals.
- Introduce skills in problem solving to overcome barriers in the execution of goals (Snyder, 2002; Snyder, et al., 2000; Snyder, et al., 1991; Snyder, Michael, & Cheavens, 1999; Snyder, Parenteau, et al., 2002).

These aspects of treatment are related to the provision of active, practical interventions for consumers and their families. While there is evidence that improvements in expectancy hope will lead to a range of better outcomes (see above research related to the SHS), there is little prospectively derived evidence showing the course of hope over a treatment program.

The foregoing suggests that hope would appear to have both mediator and moderator effects in measuring treatment outcomes (Baron & Kenny, 1986; Frazier, Tix, & Barron, 2004). By this it is meant that hope may have effects in mediating between treatment type and outcomes, as a possible mechanism through which treatment influences recovery outcomes. Hope may also have moderator effects since the levels of hope at the beginning of treatment may interact with the effects of treatment. For instance, treatment of people with low hope may be more or less effective compared to treating people already high in hope.

Family treatments offer specific opportunities for enhancing hope. Family therapists have written extensively about the instillation of hope in the family system that is part of the healing that occurs in a family in therapy (Flaskus, et al., 2007; P. McKenzie, 2006; Perlesz, 1999). Family treatments can enhance

relations within the family (Bassman, 2000) and allow families to support each other's goal setting and achievement efforts. Carers and family members can play a role in maintaining a positive vision of the future when the consumer is temporarily overwhelmed.

In particular, psychoeducational family interventions would appear to have a significant role in promoting hope and recovery (Glynn, Cohen, & et al, 2007). Family psychoeducation supports consumers and family members' in setting goals (G. Fadden & Gair, 2004; I. R. H. Falloon, et al., 1984). In addition they focus on building skills in problem solving that supports goal attainment (I. R. Falloon, 2000; I. R. H. Falloon & Pederson, 1985).

There is little research about family psychoeducation and hope. However, Snyder's goal orientated approach to hope may integrate very well with aspects of contemporary manualised family treatments which focus on skills such as problem solving and goal setting. The role of emergent hope is less clear.

2.6.2 Further research into hope for carers and consumers

The SHS is a popular measure of hope, but it is unclear if it adequately captures the notion of emergent hope and the associated adversity and relational concepts. On the other hand, the notion of expectancy hope draws on a solid base of empirical findings, and combines important concepts such as optimism and self-efficacy. Although the emergent account of hope is germane to the further investigation of hope and recovery, at present there is no instrument for its measurement and the concept is not fully operationalised.

This literature review has outlined a number of areas where the narrative accounts of hope and recovery are rich, but quantitative accounts are lacking:

- Levels of hope are described as rising across a course of treatment, but this has rarely been investigated in prospective studies. This study planned to look at hope in carers and consumers before and after a family treatment

- Narrative accounts of recovery suggest that hope (and recovery) can occur irrespective of symptom levels, and that hope is the initial step on

the road to recovery. This study planned to analyse if hope is an independent predictor of symptoms in consumers and how hope at the beginning of treatment might predict other measures of "full recovery" at follow-up. In other words, does hope have a mediating effect on recovery outcomes and are the level of symptoms a moderator of recovery achievement?

- Descriptive accounts of caregiver burden suggest that hope has a role in improving coping and reducing burden, and improving caregiver wellbeing in general. This study planned to investigate if caregiver hope at baseline is related to burden and other measures of caregiver wellbeing. In other words does hope have a mediating effect on improved caregiver burden and wellbeing from FPE treatment?

- The relational aspects of hope are often remarked upon, but research is uncommon. How carer and consumer levels of hope interact has not been explored previously. Carers are often characterised as the "holders of hope" for their consumer relative: this research proposed to investigate the hopes, goals, motivation and plans of consumers and carers and the impact of family relationships on hope.

- It is widely presumed that consumers and carers live with reduced hope; this research planned to benchmark carer and consumer hope levels with other groups, such as consumers with physical health issues and other community groups.

2.7 Conclusion

The foregoing literature review outlines the importance of hope and its putative relation to recovery. The terms "emergent" and "expectancy" hope have been used in this discussion as a descriptive heuristic to emphasise two traditions of hope in the literature. The significant aspects of emergent hope include the presence of adversity, the importance of relationships and the role of hope as the first step in a return to positive living. Emergent hope matches the more

commonly understood meaning of hope. Emergent hope is distinct from other positive psychology constructs, due to its activation in highly adverse situations.

Expectancy hope, most fully theorised by Snyder, incorporates three focal components: having desirable goals; the motivation and determination to meet goals or “agency hope”; and the capacity to generate means to attain these goals, referred to as “pathways hope”. The SHS has been widely used and validated although concerns remain over the integration of hope theory with contemporary models of affect, the role played by interpersonal relationships, and the significance of adversity. How expectancy hope may endure in the situation of severe and persistent mental illness presents something of a conundrum where there is on-going adversity, and low expectancy for a change in health status.

The measurement of expectancy hope, and connected domains such as optimism, self-efficacy, coping and problem solving would be a useful outcome to investigate since it covers domains that would be relevant to therapeutic change, that is - goal setting, agency and contingency which are important aspects of positive functioning.

There is widespread interest in hope and recovery due to the implementation of recovery frameworks for mental health treatment (Australian Health Ministers Conference, 2009; Department of Health, 2011). Since empirical research in this area is only recently developing, it is very important to have reliable measures of all aspects of recovery, which includes a relevant measure of hope. This study was designed to address multiple questions using quantitative and qualitative methods to explore hope experienced by consumers diagnosed with schizophrenia and their carers. It also explored how family functioning and the relational context might influence hope in family members. Finally, it looked at hope in the context of treatment outcomes, and how hope influences recovery outcomes.

Chapter 3: Building Family Skills Together: A Behavioural Family Therapy program

Chapter 3: Behavioural Family Therapy

This chapter introduces the Behavioural Family Therapy (BFT) model as a type of family psychoeducation intervention, and discusses putative links to the enhancement of hope in carers and consumers. Research outcomes for BFT and other family psychoeducational interventions are critically assessed in regards to contemporary practice in the mental health field. Next, the implementation of BFT for this current study is explained. Finally, the program evaluation of the BFT program and research questions are presented.

BFT is one of a range of family psychoeducation (FPE) programs that were developed within the expressed emotion (EE) paradigm and the stress-vulnerability model. The common attributes of family psychoeducation programs include: sessions over 6 months or more; the presence of the consumer in most sessions; a mix of modules on relapse prevention, information provision and skills training in coping, stress management, communication, problem solving, goal setting etc.; and validation through research trials (Grainne Fadden, 1998). BFT has traditionally had a focus on communication skills and problem solving and is carried out with single families (I. R. H. Falloon, et al., 1984). Other models include McFarlane's multi-family group model, which as it's name implies is a FPE carried out with a small number of families brought together in a group setting (W. R. McFarlane et al., 1995). Another variant is Barrowclough and Tarrier's "Behavioural family approach" (Tarrier et al., 1988). Leff et al. (Leff, Kuipers, Berkowitz, Eberlein-Vries, & Sturgeon, 1982) developed "broad-based family psychoeducation" (see Figure 1.1).

BFT seeks to impart knowledge, social and personal skills that enable families and consumers to work more effectively with the challenges of living with schizophrenia. The aim of BFT is to reduce stress for the person living with schizophrenia thus decreasing the risk of relapse. With improved mental health in their relative, and better coping skills, there is decreased burden for family members. One of the main mechanisms hypothesised for these changes is via reduction in so-called "high EE" behaviours such as hostile or critical

comments and emotional over-involvement, replacing them with improved communication, better problem solving and increased social engagement.

The Building Family Skills Together (BFST) program was an implementation strategy for a BFT intervention initiated to bring an effective family intervention to a group of consumers of an Area Mental Health Service (AMHS), a community mental health service for adults aged 18 to 64 living in Melbourne, Australia. As described in Chapter 1, BFT is one of several family psychoeducation interventions (FPE or FI); that is, it is a manualised, evidence-based treatment to assist consumers and families living with severe mental illness.

3.1 The Behavioural Family Therapy model

3.1.1 Background and influences

BFT incorporates a number of treatment and research paradigms. An early influence on the development of BFT was the explicitly behavioural program developed by Liberman in 1970 involving behavioural therapy in schizophrenia (Robert Paul Liberman, 1970). Behavioural therapy with families involved detailed analysis of target behaviours (usually difficult behaviours) and the design of interventions using operant conditioning techniques. These techniques required very precise focus on particular behaviours and overall changes to family functioning only came about as secondary to the change in the target behaviours. Instead of targeting problem behaviours, BFT uses behavioural methods to assess the presence of *constructive* behaviours and uses reinforcements to increase them. The other aspect adapted from behaviour therapy is the use of identified and operationalised goals and outcomes (I. R. H. Falloon, et al., 1984).

A second influence was the British research into the area of relapse and expressed emotion in schizophrenia. Research in the 1960s and 1970s at the MRC Social Psychiatry Unit by George Brown and colleagues, found an association between high expressed emotion (EE) in families and high rates of relapse in relatives with schizophrenia (G Brown, 1985; G Brown & et al, 1972). Expressed emotion was defined as critical or hostile remarks about a

family member with schizophrenia, and emotional over-involvement with them, mitigated by the presence of warmth towards the family member (Chambless, Bryan, Aiken, Steketee, & Hooley, 1999; Vaughn & Leff, 1976). In order to decrease critical and hostile comments and emotional over-involvement, and reduce intra-familial stress for the consumer (I. R. H. Falloon, 1988a, 1988b; I. R. H. Falloon, et al., 1984), BFT included some components of social skills training for families, including expressing feelings and making requests in a more positive and less critical manner, and positive reinforcement of constructive behaviours.

Consonant with the EE research, Zubin and Spring in the US developed a stress-diathesis model integrating biological and environmental factors in the course of serious mental illness (Zubin & Spring, 1977). According to their model, symptoms and consequent disabilities for people living with schizophrenia can be seen as the result of stressors interacting with an underlying vulnerability. They proposed two sources of vulnerability, inborn and acquired. Inborn vulnerability is genetically based, and expressed in neurophysiology and internal environment. The inborn vulnerability could be mitigated with medication use. Acquired vulnerability results from early life events such as traumas, medical complications, and family experiences. Stressors are defined as major life events that require substantial adjustment and re-organisation. The interaction of stressors and vulnerabilities (inborn and acquired) in an individual leads to unique mental health outcomes for each person. Low vulnerability individuals can manage high levels of stress without mental illness, but high vulnerability individuals can only manage low levels of stress.

Personal coping, attitudinal change, improved competence and increased social supports can decrease vulnerability in a susceptible person. Thus treatments in four areas may improve symptoms (I. R. H. Falloon, et al., 1984):

- Underlying biological vulnerability may be improved, via medication or by decreasing physiological stress (e.g. decreasing drug or alcohol use) (I. R. H. Falloon, et al., 1984)

- Stressful life events or day-to-day tension may be decreased (e.g. via decreased EE type events in the home or improved environment) (I. R. H. Falloon, et al., 1984).
- Support (social and professional) may be improved for instance by allocating a case manager, or enlisting family support (I. R. H. Falloon, et al., 1984)
- Personal coping may be improved by increasing skills in problem solving, and in social skills (I. R. H. Falloon, et al., 1984).

This model integrates the EE research with other treatment modes, including a rationale for medication use.

While the behavioural paradigm provided powerful tools for change, and the EE research gave a focus to some particular changes within families that might be targeted, there was no intervention that provided protection from extra-familial stress and life events, and provided rehabilitation beyond avoiding relapse. In the 1980s, Falloon, Boyd and McGill developed a comprehensive program to be carried out in the family home (I. R. H. Falloon, et al., 1984) called Behavioural Family Therapy. This was aimed at improving the situation for all the family, and had an emphasis on problem solving, and not just positive communication. This model thus incorporated a new understanding of the stress-diathesis model for mental illness (Zubin & Spring, 1977) and a fuller psychosocial perspective on treatment.

3.1.2 Contemporary Behavioural Family Therapy treatment

The BFT program utilised at the two Area Mental Health Services (AMHS) that were the treatment sites for this study, was a contemporary version of BFT which consisted of manualised skills and education provided to families in their home, using specific methods such as role play, worksheets, record keeping and family homework (G. Fadden & Gair, 2004). In introducing families to the program, it was described as a “course”, so the emphasis was on skills and learning, rather than implying the family had “problems” that needed to be fixed. The practitioner was likened to a “coach” walking alongside the family, rather than the “expert” leading the way (B. O'Hanlon, 2008).

There are two unique aspects to BFT: (1) the philosophy and attitudes with which the work is done, and (2) the special components or modules that families and practitioners work on together.

3.1.2.1 The BFT philosophy and approach

BFT incorporates progressive attitudes to the treatment of consumers and their families. These positive attitudes are helpful in the engagement of families as they contribute to establishment of rapport and trust. These attitudes are explicitly set out in the training manual (G. Fadden & Gair, 2004).

Firstly, the practitioners approach the family with a "positive attitude", and confidence in the BFT treatment (G. Fadden & Gair, 2004). Not only does this provide a constructive role model for the family, but increases engagement and commitment to the sessions. This positive attitude underpins all the other principles.

A second aspect is that the "expertise and skill of the family is acknowledged" (G. Fadden & Gair, 2004). The families' "expertise" in dealing with issues every day, often over a number of years, is validated. The practitioner provides an additional unique set of skills, and the consumer, family and practitioner can collaborate, combining all their knowledge and expertise.

Thirdly, the "actions of the family are seen as their best effort to manage the situation within the limits of their resources" (G. Fadden & Gair, 2004). This attitude can relieve blame and guilt from family members, who have been trying their best with limited resources and understanding over long periods of time. Without this attitude, family sessions can feel like a "blame-fest" (Anonymous carer, 2009).

A fourth attitude is to "distinguish between the actions of the family and their intentions" (G. Fadden & Gair, 2004). Often families intend to be helpful to the relative with mental health issues, but the actual action ends up being unhelpful. By thinking clearly about intention versus outcome, the family can start to make new choices about the means they use to achieve their desired ends, by incorporating new coping methods and problem solving.

A final vital attitude acknowledges “every family has its own culture” (G. Fadden & Gair, 2004). This means that the practitioner respects and accepts the family’s values and way of functioning. Cultural and religious beliefs are not needlessly challenged.

Sessions are often carried out in the home. The benefits of sessions in the family home are that it is convenient for the family, increases adherence (Leff et al., 1990) and family members who might resist attendance may be drawn into sessions (I. R. H. Falloon, et al., 1984). It is also believed that the skills learnt will generalise more readily when they are practiced in the home, which is a “real life” environment, rather than at the clinic, which may seem artificial (I. R. H. Falloon, et al., 1984). This means that the skills learnt are more likely to be actually used and practiced after the session has been concluded.

3.1.2.2 Engagement

During the process of engagement, the practitioner establishes a relationship with the family using the above principles as guidance. Engagement involves families in a discussion about BFT sessions: what is involved, what are the expected outcomes, what are the family’s main issues and concerns that might be addressed in the sessions. Engagement sessions are a “getting to know” process, for practitioner and family members, as well as a time to educate the families about BFT and what can be expected.

Some families may express reluctance to proceed with BFT sessions and suggestions to resolve any unnecessary impediments to engagement are provided in the manual (G. Fadden & Gair, 2004). One can consider engagement as a process underlying the entire sequence of sessions because engagement concerns the maintenance of relationships between the family and practitioner that is required for family work to continue. However, engagement as a formal phase is considered completed when the family decides to commit to the BFT program.

3.1.2.3 Assessment

Once the family has committed to start BFT, the next step is an accurate assessment of the family both as individuals and as a whole. This happens in the first few sessions.

Initially there are individual interviews with family members including the consumer. Each family member is asked about background information, their understanding of the consumer's mental illness, the impact of the mental illness on themselves, their daily living circumstance, daily living pattern and their personal goals. Often a rapport between practitioner and family members is established during this process (I. R. H. Falloon, et al., 1984). The family members feel they are being listened to (often for the first time), and their voice is being valued in itself, and not as an adjunct to the consumer. They are given space to set goals relevant to themselves. At this stage, individuals are asked to set some concrete goals to be achieved by the completion of the intervention.

The family as a whole is also assessed. In one assessment, the family is asked about how they solve problems and achieve goals together. Detail is elicited on family discussions, who gets involved, how progress is assessed, problem solving skills and attitudes to consensus or compromise.

In another assessment of family problem solving, the family as a whole is asked to come together to solve a problem and the practitioners observe the family's strengths and assess areas where additional skills could be learnt. The family are asked to set some concrete goals to be achieved by the completion of the intervention.

After the assessment phase, the education and skills learning occur.

3.1.2.4 Family education about schizophrenia and relapse

The purpose of information sharing is to give the consumer insight, understanding of their experiences, help the family understand the experience of the consumer and for the practitioner to understand the needs of the family (G. Fadden & Gair, 2004). It is also recognition of, and sharing of the expertise of consumers and family members.

Often the information sharing is against a background where discussion of mental illness has been quite minimal. This could have been for a variety of reasons: the family may have been worried that discussion might reinforce unusual ideas or behaviours in the consumer. Health-care professionals may have given little psychoeducation because: they were concerned that the information might confuse the family; they lacked confidence to manage the discussion; or they worried the information might upset the family or make things worse (G. Fadden & Gair, 2004).

The information sharing sessions do not consist of the practitioner as "expert" giving a standard "talk" to families and handing over pamphlets. The discussion is tailored to the family's needs. The consumer becomes the "expert" and explains his/her own symptoms to the family. This can be a very powerful experience for families, as they hear what it is like to live with "voices" or delusions and other symptoms of schizophrenia, often for the first time (G. Fadden & Gair, 2004).

The family also discuss and agree on a list of early warning signs and are encouraged to record this on paper. This will also include a list of agreed on actions and persons to contact should there be impending signs of a relapse (G. Fadden & Gair, 2004).

3.1.2.5 Communication skills

The communication skills are: expressing positive feelings and giving positive feedback, active listening skills, expressing negative feelings and making requests for change. All these skills are acquired in a similar sequence of activities. Firstly, the benefits of a skill are discussed, then the family identify their existing use of the skill, the components of the skill are then explained, then actual practice of the skill with role-play and feedback occurs, with homework on the skill undertaken between sessions. The practitioner should also be a role model for the skill in sessions (G. Fadden & Gair, 2004).

Expressing positive feelings involves a direct verbal communication informing a person that the speaker is pleased with something that person as done. This

helps the family focus on positive things and notice helpful things done by each other.

Making a positive request involves using assertive language to make a constructive request for behaviour change. This helps the family to increase their efficiency at resolving issues and achieving goals (G. Fadden & Gair, 2004).

Expressing unpleasant feelings involves talking about negative feelings such as unhappiness, frustration, anxiety or anger without blaming. This helps the family resolve problems, increases intimacy and facilitates problem solving (G. Fadden & Gair, 2004).

Active listening is the skill of listening to a person in a conscious manner, discussing their concerns and clarifying problem areas and ideas. When active listening occurs, the speaker has an opportunity to clarify their thoughts and feelings, and the listener is fully aware of the issues and concerns of their family member. Again, this is helpful for the family in solving problems and achieving goals (G. Fadden & Gair, 2004).

All these skills are alternatives to high EE behaviours such as hostility, criticism and emotional over-involvement. Without necessarily emphasising what families are doing “wrong”, the training in new skills provides alternatives for effectively communicating concerns, and articulating difficult feelings without blame, resentment or aggression.

The use of constructive communication skills leads easily to the next step: problem solving.

3.1.2.6 Goal setting and problem solving skills

Goal setting and problem solving are the core skills to be imparted in BFT, although they are based on mastering the skills and information of previous modules (I. R. H. Falloon, et al., 1984). Goal setting and problem solving follows a six step methodology. Firstly, the problem is identified and put in clear terms. Secondly, all possible solutions are listed without censoring or discussion. Thirdly, each solution is evaluated. Fourthly, the best solution (or

combination of solutions) is then selected. The final two steps are, fifthly, planning to implement the solution, and lastly, reviewing the implementation. In BFT, the family learns how to perform these steps together (I. R. H. Falloon, et al., 1984).

The use of the term goal setting is a constructive re-framing term for problem solving. Both use the six steps, but the term "goal setting" implies a focus on what is to be achieved and "problem solving" a focus on what will be reduced or eliminated. In practice, many "problems" can be reframed as "goals", for instance the problem of "how to stop the house being disorganised" for the family, can be reframed as the goal of "how do we keep the house orderly" (G. Fadden & Gair, 2004). All family members can benefit from separate and joint initiatives to support their chosen goals. Falloon contends that the extended benefits of learning goal setting and problem solving are that goals can be set in relation to rehabilitation and recovery for the consumer family member, not just for the reduction of relapse (I. R. H. Falloon, et al., 1984). This is because the consumer and family not only learn how to avoid stress, but learn a low-stress method to achieve new goals.

3.1.2.7 Termination and booster sessions

The end of formal sessions may be difficult for some families who appreciate the support and structure of family sessions. The practitioner focuses on "handing over" to the family, so they can become independent in the use of the skills, and their goal setting endeavours. Booster sessions are available in the months after cessation of regular sessions. This enables the family to reinforce and fine-tune the skills they have learnt, and the practitioner may provide extra help where the family still feels challenged (G. Fadden & Gair, 2004).

3.1.3 Hope and BFT

BFT has many characteristics that could improve hope for participants. The goal setting clearly introduces a link between Snyder's theory of hope (where high hope is the expectation that goals will be met) and BFT (Snyder, et al., 1991) (See Chapter 2, Sections 2.2, and 2.3). Setting a desirable goal is the first component of hope, whilst finding ways to achieve goals, through problem solving, is synonymous with Snyder's "Pathways Hope". The family working

together and the presence of the practitioner/coach can assist with motivation and encouragement for goal achievement, augmenting “Agency Hope” and increasing the likelihood personal success. Improved goal setting and problem solving can enhance recovery for consumers as they begin working on personal goals.

For carers, hope may be enhanced through the reinvigoration of personal goals, problem solving may improve coping, thereby reducing perceived burden and carers may learn constructive ways to assist their consumer relative regarding the consumer’s hopes and goals. Observing recovery in their consumer relative may also contribute to increased carer hope.

Other hope instilling strategies in BFT include (G. Fadden & Gair, 2004; Kylma, et al., 2006):

- Building positive relations in the family, which may be a goal in itself, can help consumers and carers to support each other’s goals and minimise conflict that undermines goal-related activities.
- Encouraging the autonomy of family members to follow personal goals.
- Information about schizophrenia that is provided may form the basis of realistic goals and hopes for family members.

Falloon suggested that problem solving/goal setting had a unique emphasis in BFT approaches to FPE (I. R. Falloon, 2000). Hope, with its focus on goal striving, and the suggested role for hope in initiating recovery, may be an important intermediary through which FPE works. Goal setting activities may improve hope, which then in turn, impacts other outcomes such as coping, improved social engagement and well-being in carers and consumers.

3.2 Research outcomes for BFT and family psychoeducation

The trials described below report on many studies covering a number of family psychoeducation (FPE) variants. Generally, BFT has been differentiated from a multi-family group or from other single-family psychoeducational interventions (referred to below as “generic family psychoeducation”) when describing the interventions. Although the term multi-family group is sometimes used to specify the particular intervention developed by McFarlane (W. R. McFarlane,

Lukens, et al., 1995), this literature review uses the term to describe any family psychoeducation intervention where more than one family forms a therapeutic group for treatment. Some studies describe group interventions for multiple families where the consumers do not attend. They are called relatives groups (RGs) in the literature review. All studies are randomised control studies (RCTs) unless stated otherwise.

3.2.1 Early studies from the 1980s and 1990s

The first waves of studies for family psychoeducation were conducted in the 1980s and 1990s and were highly successful. Their outcomes have been widely cited.

Falloon's (I. R. Falloon et al., 1982) 1982 study compared 18 consumers receiving BFT at home, to 18 consumers receiving clinic-based individual supportive management. They were a young group (average age 25) living with high EE families (ascertained with the Camberwell Family Interview (CFI)) all living with parents, and emerging from recent relapse. Clinical exacerbation (defined as re-emergence of positive symptoms for over a week) was significantly reduced, as were days in hospital after an intervention of 9 months duration. Symptom remission was obtained in a significantly greater proportion of the BFT group. Although the BFT group had greater clinical contact, it is unclear by how much. Medication adherence was greater in the BFT group, suggesting that part of the effect of BFT was through this route, but improvements could not be attributed to medication alone.

A later Falloon study showed similar results (I. R. Falloon et al., 1985). Thirty-six consumers (and their families) were randomised to two conditions, BFT or TAU for 2 years. Participants were young and from high EE or stressed families of origin and recently admitted to hospital and stabilised. Medication adherence, and intensity of contact with services were matched for the two groups. Both groups showed improvement over time, but assessments at 9 months and 24 months showed significant reduction in relapse and remission in symptoms for the BFT cohort compared with TAU. Falloon et al. concluded that one of the ways that relapse was avoided in the BFT group was the early recognition of relapse symptoms and fast effective treatment, whereas in the

TAU cohort, contact was made with the service after the relapse was well established and little could be done to prevent it.

Another early study was by Hogarty and colleagues in 1986 (Hogarty et al., 1986). This randomised control study compared individual skills training, family stress management or both, with a medication only condition. Participants were recruited after a hospital admission. All families were classified as high EE on the CFI. The combined family and individual treatment reduced relapse to nil. Family therapy alone, or individual skills training alone both had similar relapse rates, midway between the combined treatment condition and medication only rates. Medication adherence in all groups was associated with improved outcomes. However, the level of contact was a confounder in the findings, as it increased with every additional treatment.

This study showed that the effects of family and individual treatments were additive, and that maintenance medication is the "necessary foundation" for psychosocial interventions (Hogarty, et al., 1986). Results over 2 years were not as impressive, and the authors suggested that family psychoeducation might work best in the recovery phase, and not in the long term.

Another pioneering study was by Leff and colleagues (Leff, et al., 1982) in an RCT comparing 12 consumers receiving family psychoeducation over 9 months with 12 consumers receiving TAU. These were an older group compared to the previously described studies, averaging 35 years old, recruited at admission to hospital for treatment of a relapse, and living with high EE families (50% with parent carers). Relapse was reduced from 50% to 9% in the treatment group, along with expressed emotion (EE). Both groups were maintained on medication. Over 2/3 of concurrent admissions during the trial period were excluded from the study due to the consumer not living in the family residence, low EE or low contact with a high EE family, which suggests a very selective group were studied.

Tarrier's 1988 study (Tarrier, et al., 1988) controlled for the effects of level of contact and medication. BFT for 9 months in a high EE group reduced relapse significantly compared to minimal psychoeducation or TAU interventions. The

study group was similar to that of Leff (Leff, et al., 1982) and recruited at admission to hospital for treatment of relapse.

Wallace and Liberman's 1985 study (Wallace & Liberman, 1985) showed a significantly higher rate of social skills, and a (non-significant) reduction in relapse when BFT was compared with a general health program conducted over 9 weeks on an inpatient unit. All participants were from families with at least one high EE member.

Another early inpatient study compared a brief intervention of family crisis support with standard treatment in first episode psychosis (Goldstein, Rodnick, Evans, May, & Steinberg, 1978). Subjects who received adequate medication and family treatment had no relapses over the 6 month follow-up period, whereas low medication, no family treatment consumers had 48% relapse rates. For the intermediate groups, receiving low levels of medications, and family treatment or high levels of medications /no family treatment, the relapse rate was similar at about 20%. This was against a background rate of 45% relapse conventionally. Although a short treatment, the striking results may be attributable to the fact this was a treatment naive group. No measure of EE was made.

Three other early studies that achieved considerable improvement in outcomes were undertaken in China. In these studies, the authors made substantial efforts to adapt the intervention to suit families' needs in China, where treatment via counselling was not standard, and treatment with only medication the norm (Xiong et al., 1994).

Xiong (Xiong, et al., 1994) reported reduction in hospital readmission and length of stay and employment improved at 12 and 18 months following a comprehensive family intervention carried out post-admission. Family burden was also reduced. This was one of the few early studies to measure family outcomes (beyond an assessment for EE). Medication adherence was similar across the two groups. The consumer group was unusual in having a high proportion of married participants (56%). There was no selection for high EE (not measured), and the TAU condition was sparse - consisting of 2 or 3 outpatient visits for medication assessment only.

Zhang (Mingyuan. Zhang, Heqin, & Co-Authors., 1993), studying a large group (n=2,298), similar in profile to Xiong, showed significant improvement in recovery, disability, symptoms, working, family burden and medication adherence in favour of family treatment over 12 months. Medication and family intervention had independent and additive effects on outcomes. Again, cultural adaptations were considered important, and TAU was very sparse.

The third Chinese RCT looked at male-only first episode consumers, receiving family psychoeducation after hospital admission (M. Zhang, Wang, Li, & Phillips, 1994). Relapse rates were greatly improved in the family treatment group. Symptoms and functioning for consumers in the treatment group who did not relapse, improved compared to TAU group at 18 months. As in Xiong (1994) (Xiong, et al., 1994) and Zhang (1993) (Mingyuan. Zhang, et al., 1993), there was no selection on the basis of family functioning, there was great attention to cultural adaptation in the intervention and there was a minimal comparison treatment averaging 2.8 outpatients visits for medication management only.

3.2.2 Five crucial characteristics of the early studies

In these efficacy studies, there appeared to be a number of similar characteristics. The studies were all based on the stress-vulnerability model of schizophrenia and the EE research. They were mostly conducted on fairly homogenous groups where drug and alcohol abuse or intellectual disability and most other co-morbidities were excluded. Given the selectiveness of the inclusion criteria and RCT design, they tended to be efficacy studies. Most studies made improvements over and above the benefits of medication, and often suggested that improved medication adherence was one of the pathways to reduced relapse (Leff, et al., 1982; Schooler et al., 1997; Tarrier, et al., 1988; Tarrier et al., 1989; Xiong, et al., 1994; M. Zhang, et al., 1994). These early studies garnered impressive results on only small samples of 20 to 30 consumers in the treatment group (although for exception see (Mingyuan. Zhang, et al., 1993)). They also focused on outcomes of relapse and rehospitalisation and there was little or no interest in family outcomes except the measurement of EE.

There appeared to be five consistent characteristics:

- Firstly, the family psychoeducation interventions were successful with families where there was evidence of high EE (usually assessed via the CFI) (I. R. Falloon, et al., 1982; I. R. Falloon, et al., 1985; Hogarty, et al., 1986; Leff, et al., 1982; Tarrier, et al., 1988) (although for exceptions see (Goldstein, et al., 1978) (Xiong, et al., 1994; Mingyuan. Zhang, et al., 1993; M. Zhang, et al., 1994)).
- Secondly, the comparison treatment was very minimal or sparse usually defined as "routine care", but consisting of infrequent sessions for medication management only (Xiong, et al., 1994; Mingyuan. Zhang, et al., 1993; M. Zhang, et al., 1994).
- Thirdly, the intervention was provided just after a crisis that had resulted in hospitalisation (I. R. Falloon, et al., 1982; I. R. Falloon, et al., 1985; Hogarty, et al., 1986; Leff, et al., 1982; Randolph et al., 1994; Tarrier, et al., 1988; Xiong, et al., 1994; M. Zhang, et al., 1994).
- Fourthly, the intervention was adapted to the cultural and phase-specific needs of the families and the consumer (Goldstein, et al., 1978; Xiong, et al., 1994; Mingyuan. Zhang, et al., 1993; M. Zhang, et al., 1994).
- Finally, all interventions were substantial, lasting a number of months, and over a number of sessions (except (Goldstein, et al., 1978)).

To what extent could these crucial characteristics be varied and still achieve success? What other outcomes could be achieved with these interventions? Which aspects of the intervention were critical to success? Follow-up studies have since scrutinised the performance of BFT and related family psychoeducation interventions by varying one or more of the characteristics of the participant groups or the intervention, to explore these questions. This later group of studies has tended to focus on a broader range of outcomes such as employment or functioning.

3.2.3 Family psychoeducation and expressed emotion

The studies reviewed above were carried out primarily with high EE families. Later studies were carried out on families with varying levels of EE, or without EE being assessed. Very little evidence exists that categorically demonstrates effective FPE treatment on low EE groups.

Girón et al. (Girón et al., 2009) studied family psychoeducation in a naturalistic setting, but with rigorous exclusion criteria, selecting for high EE families. A two year program resulted in significantly fewer positive and negative symptoms, improved social role and relations, less family burden, reduction in clinical relapse and a trend to lower hospitalisation, compared to individual counselling with TAU.

In another study of a high EE group, Rund et al. (Rund et al., 1994) in Norway, obtained significantly lower EE, reduced relapse (12% in the treatment group versus 67% in the TAU condition) and non-significant trends in reduced inpatient time and improved functioning. The clinical group was young consumers with first episode psychosis on long-term inpatient stays.

Leff (Leff, et al., 1990) compared BFT with a multi-family group treatment in a high EE sample with comparable results for relapse, showing both types of family intervention had similar outcomes. Relapse rates were about half of rates “consolidated from previous research” on TAU families. These three studies confirmed that family psychoeducation was effective with high EE families.

This author found only one partly unsuccessful study concerning high EE families. Tomaras et al. (Tomaras et al., 2000) in Greece, selected high EE families from a group of chronic consumers entering a rehabilitation program and reported reduction in relapse of 50% at the end of the 1 year concurrent multi-family group program, with differences becoming non-significant another year later. They suggested that the fairly rich comparison treatment “crowded out” the effect of the multi-family group, which comprised infrequent sessions, even though it was over a year in length. Also, the results may have been attenuated by the chronicity of the consumer group.

There are a number of intervention studies on low EE families. Linszen (Linszen et al., 1996) conducted a family psychoeducation intervention with consumers with first episode psychosis and their families. The comparison condition (individual psychoeducation) was as effective as the BFT intervention. However, consumers in low EE families undergoing family psychoeducation had raised relapse rates compared to low EE families in the comparison condition. The paper reported statements by families in the BFT cohort that skills training interfered with the discussion of grief, and families felt the implication of doing skills training was that they were defective in their relationships. Three major limitations of the study were: the comparison treatment was not sparse; not all families were high EE; and the program was not 'phase specific' i.e., not specifically adapted to the needs of consumers with first episode psychosis and their families. It is of concern that the intervention actually created more stress in some families.

Telles (Telles et al., 1995) (also described in the section on cultural adaptation later) was another unsuccessful trial set in the USA, with immigrant families with low EE (measured by the CFI) who were living with a family member with schizophrenia. Increased relapse rates were found in the non-acculturated group, with acculturation measured by the Acculturation Scale for Mexican-Americans (Cuellar, Harris, & Jasso, 1980) a validated and widely used measure. Medication adherence showed no relationship to time to relapse. In the more acculturated group, medication adherence, not intervention status predicted time to relapse. The study participants were recruited after recent relapse.

In a third study on low EE families, Garety et al. (P. A. Garety et al., 2008) found no effect for a family intervention averaging 14 sessions over a year with 1 and 2 year follow-up. A quarter of participants did not receive a minimum dose (less than 6 sessions). Families were assessed with the CFI, to establish low EE. Garety et al. concluded the family trial was underpowered, and was unable to draw any definitive conclusions about any particular subgroups. However, it was suggested that FI across the board might not be warranted where families are low EE and receive a relatively high level of psychoeducation in standard treatment already.

These successful high EE/ unsuccessful low EE studies augment the findings of the original BFT studies that were mainly carried out on high EE families.

Two studies in the 1990s achieved positive outcomes with mixed high and low EE groups. Barrowclough (Barrowclough et al., 1999) compared 24 families receiving a tailored family intervention with 35 families receiving treatment as usual (TAU) with 50% high EE across both groups, measured with the CFI. The relapse rate was 46% in the TAU group, and 24% in the treatment group at 6 months, which approached statistical significance (p = 0.056): there was no effect on symptoms. Outcomes for high and low EE subgroups were not reported separately. There was also a significant reduction in carer needs, but not carer distress and burden. It was not reported how EE status affected outcome.

The second study was by Randolph et al. (Randolph, et al., 1994). This study reported a clinic based BFT treatment with veterans recently admitted to hospital, from both high and low EE families (status established with the CFI). Exacerbations (presence of moderately severe symptoms in one or more measures of psychotic symptoms) were significantly decreased in the treatment group (14.5%) compared to 55% in the comparison group. The BFT treatment was equally beneficial to both high and low EE families, and baseline EE levels had no association with number of exacerbations. There was no difference in symptom levels in the absence of exacerbation i.e. there was probably a floor effect in symptoms between relapse so the treatment effect was specific to exacerbation. The Randolph (Randolph, et al., 1994) and Barrowclough (Barrowclough, et al., 1999) studies suggest that EE status is not crucial to successful outcomes in family interventions.

However, success for the mixed group may actually be due to improvement in the high EE group only. McCreadie et al. (R.G. McCreadie et al., 1991) reported mixed results in a field study across a service area with stabilised consumers in the community. Only 50% of families approached were interested in family BFT and multi-family group treatment. The refusal and consenting groups did not differ in EE status (50% high EE), age, or kinship type. The only difference was that refusers had significantly lower relapse rate at baseline. Of

the treatment group, only 50% actually attended any sessions. The treatment attendee group was approximately 50% high EE. McCreadie et al. argued that the loss to follow-up rate indicated that family psychoeducation was not popular with many families. The intervention did not change EE rates in families, but relapse decreased after the intervention. According to this author's calculations, this was entirely due to a reduction in relapse in the high EE group, suggesting that relapses were stable in the low EE group (high EE group number of relapses fell from 13 to 4, low EE group relapse stayed at 4). The treatment group as a whole reported very high levels of satisfaction with the treatment. This study suggests that there may be appropriate self selection by families in and out of family treatment and reinforces that BFT works most effectively in high EE families for reducing relapse. The study is obviously limited by the lack of a control group.

Bellack et al. (Bellack, Haas, Schooler, & Flory, 2000) raised doubts about the role of EE and skills training in family psychoeducation in a study of communication outcomes in BFT and multi-family group interventions. In a small study of 77 families, not selected on the basis of EE, there was no change in an omnibus communication skills measure, which included problem-solving behaviour and critical and over-involved behaviour (i.e. same as the EE concept), either over time or between groups. Communication outcomes failed to predict symptoms or time to relapse. Bellack et al. suggested that the families did not learn the skill or failed to apply the skill learnt. They suggest caution in generalising from this result, hypothesising that in exclusively high EE groups the outcome might be different. This study may indicate that EE is a very precise construct, and that the omnibus measure used here, while encompassing EE, actually diluted it, so no effect was recorded.

A number of studies have assessed groups where no EE status was measured, and were thus carried out on a presumably mixed group. In a preliminary report on a 12 month BFT intervention, Magliano et al. (Magliano et al., 2005) reported: decreases in symptoms and improvement in functioning in consumers; a reduction in carer burden; and an improvement in coping and social support in carers. There was no assessment of families concerning their EE status. The significance of these results cannot be assessed fully as there

was no control group. A 2006 study by Magliano et al. (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006b) using a wait-list control, reported

Table 3.6: Summary of successful family psychoeducation studies for consumer outcomes, where EE status was not reported

Study	Intervention
Barrowclough, 2001 (Barrowclough et al., 2001)	Drug and alcohol adaptation
Berglund, 2003 (Berglund, Vahlne, & Edman, 2003)	BFT
Bradley, 2006 (Bradley et al., 2006)	Multi-family group
Brooker, 1994 (Brooker et al., 1994)	BFT
Buchkremer, 1997 (Buchkremer, Klingberg, Holle, Schulze Monking, & Hornung, 1997)	Family psychoeducation
Chien, Chan, 2006 (Chien, Chan, & Thompson, 2006)	Multi-family group
Dyck et al. 2002 (Dyck, Hendryx, Short, Voss, & McFarlane, 2002)	Multi-family group
Falloon , 2004 (I. R. Falloon et al., 2004)	BFT and optimal treatment
Gleeson 2010 (Gleeson et al., 2010)	Relapse prevention for 1st episode psychosis
Goldstein 1978 (Goldstein, et al., 1978)	Relapse prevention
Hornung, 1999 (Hornung, Feldmann, Klingberg, Buchkremer, & Reker, 1999)	Generic family psychoeducation
Kopelowicz, 2012 (Kopelowicz et al., 2012)	Multi-family group
Kulhara, 2009 (Kulhara, Chakrabarti, Avasthi, Sharma, & Sharma, 2009),	Family psychoeducation
Magliano, 2005 (Magliano, et al., 2005)	BFT
Magliano 2006 (Magliano, et al., 2006b)	BFT
Mak, 1997 (Mak, Wong, Ma, & Fung, 1997)	BFT and multi-family group
McFarlane, 1995 (W. R. McFarlane, Link, Dushay, Marchal, & Crilly, 1995)	Multi-family group
McFarlane, 2012 (W. McFarlane, Lynch, & Melton, 2012).	Integrated treatment
Nordentoft, 2006 (Nordentoft et al., 2006)	Integrated treatment
Schooler, 1997 (Schooler, et al., 1997)	BFT
Xiang, 1994 (Xiang, Ran, & Li, 1994)	Multi-family group
Xiong, 1994 (Xiong, et al., 1994)	Family psychoeducation and multi-family group
Zhang, 1993 (Mingyuan. Zhang, et al., 1993)	Multi-family group
Zhang, 1994 (M. Zhang, et al., 1994)	Family psychoeducation

improvement in social relationships, job interest and global functioning in consumers as well as burden in carers, after a BFT treatment. There was no difference in symptoms over time or between groups. However, the statistical conclusions were unconvincing since within group t-tests were used for the treatment and comparison groups separately, rather than F-tests comparing the two cohorts over time. Overall, this author believes there was no treatment effect in this study.

Some large studies suggest that family treatments are an important component of treatment. In a worldwide study (n=603) examining the effects of 2 years of optimal treatment (which includes medication, family psychoeducation, assertive community treatment (ACT) social and occupational rehabilitation, and cognitive behavioural therapy (CBT) for specific symptoms) there were significant reductions in impairment, disability and carer stress (I. R. Falloon, et al., 2004). Similarly, Mc Farlane et al. report integrated treatment for first episode psychosis produced significantly better results than conventional treatment (W. McFarlane, et al., 2012). Other successful studies where EE status is not reported are summarised in Table 3.6 (most are described in more detail later in this chapter).

For studies that report an overall effect on a group but where EE status has not been assessed, it is unclear what their significance is for the EE hypothesis. On one hand, it is probable that the group includes a mix of high and low EE and a positive result means that the intervention has been effective on all levels of EE. However, it does not eliminate the possibility that the overall effectiveness was due to substantial changes in the high EE subgroup only (i.e. similar to the McCreadie (R.G. McCreadie, et al., 1991) study).

In summary, a number of studies have been successful with high EE families (except for Tomaras (Tomaras, et al., 2000). There are also a number of studies that have been unsuccessful with low EE groups (P. A. Garety, et al., 2008; Linszen, et al., 1996; Telles, et al., 1995). This would suggest that EE status is highly relevant to the success of a family psychoeducational intervention. However, some studies have been successful with specified

mixed high and low EE groups (Barrowclough, et al., 1999; Randolph, et al., 1994). Also, many studies have been successful with groups with unspecified EE status, presumably mixed (Barrowclough, et al., 2001; Bradley, et al., 2006; Brooker, et al., 1994; Chien, et al., 2006; Dyck, et al., 2002; I. R. Falloon, et al., 2004; Gleeson, et al., 2010; Hornung, et al., 1999; Kopelowicz, et al., 2012; Kulhara, et al., 2009; Mak, et al., 1997; W. R. McFarlane, Link, et al., 1995; Nordentoft, et al., 2006; Schooler, et al., 1997; Xiang, et al., 1994). The issue is of concern, since some low EE groups in family treatment have had increased relapse after treatment (Linszen, et al., 1996).

In conclusion, for some family psychoeducation interventions such as multi-family groups, generic family psychoeducation or relapse prevention programs, there are a number of successful studies where the groups are presumably mixed EE status. However, for BFT, with the specific inclusion of communication skills training, there is evidence that it may be unhelpful in low EE families. Interestingly, even though EE status seems important to the effectiveness of interventions, the Bellack study casts doubt on EE as the *mechanism* through which change is effected.

3.2.4 Sparse and rich comparison treatments

Three classic studies that had very minimal comparison treatments were Xiong (Xiong, et al., 1994), Zhang (Mingyuan. Zhang, et al., 1993), Zhang (M. Zhang, et al., 1994) described previously. In these studies, family treatment was compared to a very low-contact medication-monitoring regime. In these circumstances the family treatment was highly effective in comparison, although results could have been due to the differences in contact intensity as much as modality.

Later studies that show significantly improved outcomes for family psychoeducation compared to a sparse treatment include Nordentoft et al. (Nordentoft, et al., 2006), Xiang et al. (Xiang, et al., 1994), and Dyck et al. (Dyck, et al., 2002), described below.

A later study with a minimal comparison treatment was Nordentoft et al. (Nordentoft, et al., 2006), a 2 year integrated treatment for ultra-high risk cases that included a multi-family group family intervention, in comparison to a

minimal case-management condition. Transition to schizophrenia at 2 years was reduced from 48% in the comparison group to 25% in the treatment group.

Xiang et al. (Xiang, et al., 1994) conducted a study in rural China comparing a "mutual family support group" with a low-contact medication only condition. The family intervention significantly enhanced working ability and treatment adherence, reduced symptoms and social disturbance in consumers, and improved the care that families offered their relative. Xiang et al. (Xiang, et al., 1994) suggested that family treatment is not a "luxury" add-on for services to incorporate when extra resources are available but essential for the best use of scarce treatment funds. In this group it improved adherence and addressed stigma in a powerful way.

In the study of Dyck et al. (Dyck, et al., 2002), a 2 year multi-family group intervention was compared to a minimal TAU condition, with significant decreases in rehospitalisation by 12 months for the family treatment group.

When comparing family interventions with a minimal TAU condition, the level of contact may be an issue since the participants in the family treatment condition are receiving a great deal more clinical contact, and this may be a factor in changed outcomes rather than modality of treatment.

When contact intensity is matched, then both treatment conditions tend to be considered "rich". Girón (Girón, et al., 2009) (described in Section 3.2.3) was successful with a family intervention on top of individual counselling compared to TAU; Gleeson (Gleeson, et al., 2010) (described below in section 3.2.6) was successful with relapse prevention versus TAU that included case management, groups and employment support for instance. However, Garety et al. (P. A. Garety, et al., 2008) (described in Section 3.2.3) suggested that no treatment effect was seen for their study because the rich comparison treatment "drowned out" any impact of the family intervention.

If we understand that the positive outcomes of even the most effective and focused treatments are partially the result of "common factors" such as the therapeutic relationship, external factors and expectancy, then the specific outcomes of any one treatment technique are quite minimal (Hubble, Duncan,

& Miller, 1999b). Some authors suggest just 15% of overall outcome improvement is due to specific techniques (Hubble, et al., 1999b). Thus, additional treatments can only offer marginal effectiveness, as the first treatment is already supplying sufficient "dosage" of the "common factors", and for the second treatment, the "common factors" are saturated and do not make any further contribution to outcomes.

Thus, family interventions and BFT will have diminishing effects if added to already rich treatments, and their comparative advantage is diminished if they are judged against other high quality programs. However, programs directed to target groups such as high EE groups may still deliver significant improvements above those offered by generic treatment.

3.2.4.1 Comparing different family interventions

Another type of comparison between "rich treatments" is between two different types of family intervention.

Generally, when BFT and multi-family groups are compared, the results are similar. In Schooler (Schooler, et al., 1997) and Zastowny (Zastowny, Lehman, Cole, & Kane, 1992), Leff (Leff, et al., 1990) (described below) both conditions were similarly effective. In Montero (Montero et al., 2001) (described below), BFT was slightly more effective than a MFG.

Schooler and colleagues (Schooler, et al., 1997) found no difference over two years between supportive family management and a more intensive BFT regime. Subjects were a group of consumers who had had a recent relapse, all residing in their family of origin. However, a subgroup on standard medication and supportive family management achieved a relapse rate of 31% compared to the standard medication/BFT group of 19% (difference is statistically not significant). Consumers who were "unstable" at the beginning of the study were eliminated, which is the sub-group that might have shown even better results for the BFT intervention. Schooler et al. indicate that the results for both family interventions achieved outcomes that were superior to medication alone. No measures of EE or family functioning were included. This study reinforces

Hogarty's (Hogarty, et al., 1986) assertion that adequate medication is the "necessary foundation" for psychosocial interventions.

Zastowny et al. (Zastowny, et al., 1992) compared BFT and a supportive family intervention in 30 young consumers at high risk for relapse with following a recent admission. General functioning, social adjustment and relapse rates improved in both groups of consumers, whilst family conflict, knowledge of mental illness, family burden, EE and problem solving all improved in both groups of carers.

Leff (Leff, et al., 1990) compared BFT with a relatives group in an RCT including a total of 23 families, all high EE. Relapse rates at 2 years were virtually the same (33% and 36% respectively) compared to a control group with a 75% relapse rate. Sessions were provided with the same frequency in each condition, although adherence was less in the relatives' group condition. EE was reduced in both treatment groups.

McFarlane et al. (W. R. McFarlane, Dushay, Stastny, Deakins, & Link, 1996) compared a multi-family group and crisis family intervention treatment in 68 consumers, all receiving additional assertive community treatment. Few significant differences were found in the outcome variables, with the multi-family group having higher employment rates during the study. Rehospitalisation, symptoms, and treatment participation for consumers all improved in both conditions, as did burden, family functioning and adjustment in carers.

Montero et al. (Montero, et al., 2001) compared BFT in the home, with a clinic based multi-family group, in an RCT with 87 participants. Two-thirds of participant families met criteria for high EE. There were no significant differences for relapse rates at 12 months, but BFT was superior on social functioning, medication dose reduction and symptoms. EE was reduced in both groups, but more so in the BFT group. Results were not analysed separately for high and low EE families. Psychological distress (GHQ-28) did not reduce in relatives, but knowledge about schizophrenia did improve in both groups.

Thus, BFT or multi-family groups may have slight superiority compared to each other, depending on the characteristics of the treatment groups. For instance, BFT may be more effective with high EE families (Montero, et al., 2001), but multi-family groups are superior for first episode psychosis (W. McFarlane, et al., 2012).

3.2.5 Acute and persistent conditions

All but one of the "classic" studies were carried out on consumers who had recently relapsed (the exception is Zhang, 1993 (Mingyuan. Zhang, et al., 1993)). The majority of more recent studies, where the relapse status of participants is reported, have included groups with recent relapses and mostly with positive results. Successful acute studies (subsequent to the classics) were those by Girón (Girón, et al., 2009), McFarlane (W. R. McFarlane, et al., 1996), Rund (Rund, et al., 1994), Schooler (Schooler, et al., 1997), Zastowny (Zastowny, et al., 1992) and Montero (Montero, et al., 2001) (all described previously), Gleeson (Gleeson, et al., 2010), Kopelowicz (Kopelowicz, et al., 2012) (both described in Section 3.2.6 below), and Berglund (Berglund, et al., 2003).

In a small RCT in Sweden, Berglund et al. (Berglund, et al., 2003) achieved positive results for a BFT treatment conducted on an inpatient unit. Relapse rates, family attitudes to the consumer, carer burden and distress, and medication use all improved in the treatment group. Consumers were in hospital at an acute phase of the illness, albeit the course of illness was persistent (average of 9 years since diagnosis).

Acute studies that were not effective include those of Garety (P. A. Garety, et al., 2008), Linszen (Linszen, et al., 1996), and Telles (Telles, et al., 1995) (all described previously) where the relevant factors may have been EE status (see discussion of these papers above).

A number of studies of family psychoeducation have also been effective in treating consumers with long term and/or stabilised conditions. They are the studies of Brooker (Brooker, et al., 1994), Buchkremer (Buchkremer, et al., 1997), Hornung (Hornung, et al., 1999), Tomaras (Tomaras, et al., 2000), McCreadie (R. G. McCreadie, 2001) (described previously) Bradley (Bradley, et

al., 2006) (described below), Kulhara (Kulhara, et al., 2009) and Mak (Mak, et al., 1997) (described next section).

Bradley et al. (Bradley, et al., 2006) adapted a multi-family group treatment for Vietnamese-speaking family groups in long-term community treatment. Symptoms and relapse rates were reduced at 12 and 18 months follow-up, but carer burden did not decrease significantly.

Buchkremer et al. (Buchkremer, et al., 1997) and Hornung et al. (Hornung, et al., 1999) reported on 2 year and 5 year outcomes respectively for a study comparing 4 levels of treatment. The clinical group were outpatients with persistent symptoms and prominent negative symptoms who were stabilised at the beginning of the study. The most intensive treatment included CBT, family treatment, medication and general psychoeducation; the least intensive was case-management and medication; and intermediate treatment levels had a selection of these components. All modalities were provided for 8 months. The most intensive treatment had a 26% reduction in relapse compared to the least intensive at 2 years (significant, $p<0.050$). At one year the reduction was only 9%, showing that some of the benefits in terms of relapse can be delayed. At 5 years the relapse rate in the intensive group was 42%, and 69% in the least intensive group (significant, $p<0.05$), again showing lasting benefits for intensive interventions which include families.

Tomaras et al. (Tomaras, et al., 2000) (described above), while reporting a reduction in relapse at Year 1 (not sustained at 2 year follow-up), suggested that the chronicity of the consumer group minimised changes, especially with outcomes such as symptomology or disability, which exhibited a “floor effect” in the stabilised group. It is unclear why Buchkremer et al. showed sustained improvement, while Tomaras et al. did not.

Negative results for family psychoeducation in chronic subjects were obtained by 2 studies only: Magliano et al. (Magliano, et al., 2006b), described above, and McDonnell et al. (McDonell, Short, Berry, & Dyck, 2003).

McDonell et al. (McDonell, et al., 2003) reported an RCT comparing a multi-family group intervention over 2 years with TAU with no reduction in carer

burden for either group. Burden was increased when family members became more aware of consumer suicidal ideation. The authors attributed the lack of change to the long-term nature of the illness.

This suggests that overall; FPE can be effective with acute, recently relapsed consumers and first episode psychosis, as well as consumers who are stabilised or with longer-term conditions. However, the effects may be different for the acute compared to the chronic groups. For instance, relapse and symptoms may not change in the chronic group, as there are floor effects (Tomaras, et al., 2000).

3.2.6 Family psychoeducation for specified groups

Family interventions originated in the USA and UK and have been conducted in many countries across the world, with migrant and non-migrant participants, and with different clinical subgroups, many with positive results. For instance, four studies have been conducted successfully in China (i.e. Xiong (Xiong, et al., 1994), Xiang (Xiang, et al., 1994), Zhang (Mingyuan. Zhang, et al., 1993), Zhang (M. Zhang, et al., 1994)). However, successful implementation in different situations requires appropriate adaptation.

In an unsuccessful adaptation, Telles et al (Telles, et al., 1995) (summarised previously) conducted a trial with Latino immigrant families in the USA over one year and found increased relapse rates in the non-acculturated group. Telles et al. suggested that the BFT program included “exercises that are culturally dystonic…that are experienced as intrusive and stressful” (Telles, et al., 1995, p. 478). This is of particular concern since BFT is aimed at reducing intra-family stress.

However, a more recent trial of multi-family groups amongst Mexican Americans (Kopelowicz, et al., 2012) suggested that adaption to the specific needs of a cultural group can be successful. In a group of consumers struggling with medication adherence, three interventions were compared: a multi-family group focused on medication psychoeducation; a generic multi-family group; and a TAU group. The medication multi-family group obtained statistically significant improvement in medication adherence and decreased hospitalisations. Increased medication adherence accounted for one third of

the reduction in hospitalisation. This study shows the potential adaptability of family psychoeducation to particular cultural situations and specific clinical challenges.

In a moderately successful trial adapting family psychoeducation for Chinese families in Hong Kong, Chien et al. (Chien, Norman, & Thompson, 2004) conducted a 6 month trial comparing a multi-family group, TAU and a consumer only psychoeducational condition. The multi-family group was superior to consumer only psychoeducation and TAU in terms of carer burden and family functioning and length of consumer hospitalisation (in days) but no change overall occurred family support service use.

Mak et al. (Mak, et al., 1997) adapted BFT for a Hong Kong population. Knowledge and social disability were improved in the treatment group and employment levels were maintained whereas they fell away in the comparison group. High satisfaction for both consumers and carers was obtained.

Kulhara et al. (Kulhara, et al., 2009) adapted family psychoeducation for an Indian population with a low intensity (monthly session) intervention for 9 months compared to TAU. Disability and symptoms improved significantly in the treatment condition, as did caregiver social support. Carers reported high satisfaction with the intervention. Relapse, caregiver burden and coping showed no change. However, the loss to follow-up rate was high in both conditions (approximately 50%).

Montero (Montero, et al., 2001) adapted family psychoeducation for Spain and Nordentoft (Nordentoft, et al., 2006) for Norway (all described above) that were all successful adaptations to countries beyond USA and UK. In addition Bradley et al. (Bradley, et al., 2006) used a multi-family group format with success for Vietnamese-speaking immigrants in Australia.

The study of Linszen (Linszen, et al., 1996) (described above) might also be seen as an unsuccessful adaptation to consumers with first episode psychosis. In contrast a successful adaptation for consumers with first episode psychosis was Gleeson et al. (Gleeson, et al., 2010). The intervention decreased relapse compared to TAU, but no treatment effect was observed for families in the

areas of caregiving experience, distress and EE. In particular EE seemed to spontaneously reduce in both groups. The authors suggested that monitoring of EE is preferable to immediate treatment. The treatment implication is that relapse prevention should be universally available, but not social skills training or problem solving (hallmarks of treatments such as BFT) unless a high stable level of EE is observed.

In another adaptation by Barrowclough et al., family psychoeducation was used in an integrated approach for co-morbid substance abuse disorders with schizophrenia (Barrowclough, et al., 2001). The integrated treatment included motivational interviewing, CBT and a family intervention, compared to TAU. General functioning and days abstinent from drugs or alcohol improved, and positive symptoms, and episodes of symptom exacerbation decreased significantly for the integrated treatment condition. This integrated treatment was planned in response to expectations that the co-morbid consumers would have particular needs, in that they were poorly motivated to change substance use initially, that symptoms may be a factor in maintaining drug and alcohol use, but substance use may aggravate symptoms, and that family stress is a particular issue in co-morbidity.

In summary, many studies have successfully adapted family psychoeducation to different cultural and clinical situations, which shows its essentially flexible nature. However, successful adaptation is not a “given” and in some cases has failed. These failed cases are salutary for practitioners in planning the implementation of family psychoeducation in novel settings.

3.2.7 BFT in contemporary practice – questions remaining

It contrast to the earlier successful studies, it would appear that less definitive results for family psychoeducation have been attained when:

- Treatment is not offered selectively (P. A. Garety, et al., 2008) to families with the specific constellation of EE characteristics. This conclusion is similar to that of previous overviews such as the review of Fadden (Grainne Fadden, 1998).

- The comparison or control treatment is matched for contact time or includes another effective modality. For instance in Garety et al. the comparison treatment is quite rich (P. A. Garety, et al., 2008) compared to the sparse support offered in the three Chinese studies (Xiong, et al., 1994; Mingyuan. Zhang, et al., 1993; M. Zhang, et al., 1994).
- The family treatment is in addition to already rich treatment and the so-called “common-factors” are saturated, such that the additional specific effects of family interventions are lost. The lack of additive effects may be especially marked in clinical groups experiencing smaller treatment effects such as low EE groups (P. A. Garety, et al., 2008).
- Relapse and rehospitalisation are used as outcome measures within current treatment communities. These measures are less sensitive to change when low rates of hospitalisation occur, and consumers in long-term case management live with more persistent symptoms and disability (P. A. Garety, et al., 2008); that is, there are floor effects in the relapse/rehospitalisation measures.
- Adaptations to specific clinical groups such as those from diverse cultural communities, first episode, or drug and alcohol dependence co-morbidity groups is possible, and is often, but not always successful.
- Intensive family psychoeducational interventions, be they multi-family groups, or single family interventions, offer similar efficacy in general, but may have slight differential superiorities for specific clinical groups such as first episode consumers.

Changes to service delivery have changed the characteristics of those consumers who have long term contact with services and are thus more likely to access longer term treatment such as BFT and other substantial family psychoeducational treatments (Hamden, Newton, McCauley-Elsom, & Cross, 2011). Reduction in long-term case management and its replacement with short-term episodic care for many has meant that the residual consumer group in long term contact with services has more severe and refractory symptoms and is less responsive to many modes of treatment. Therefore, although many trials of BFT and family psychoeducation have been successful in the past, a

question remains regarding their effectiveness with contemporary consumer groups in Australia.

In addition, most of the studies reported above did not include participants with co-morbid drug and alcohol issues, intellectual disability, depression, anxiety or other disorders. They were efficacy studies.

Questions also remain as to the mechanisms by which family psychoeducation works. Although reduction in EE has been shown to have a relationship to improved outcomes (Leff, et al., 1982), this is not a universal finding (Bellack, et al., 2000). Exactly how family psychoeducation reduces EE is also unknown. Another suggested mechanism is via improved medication adherence (I. R. Falloon, et al., 1982; Schooler, et al., 1997).

As services seek to improve recovery outcomes and not just reduce relapse, then the role of hope, as an initial step in recovery is an area of increasing interest. It is a logical area for exploration, since hope is clearly linked to BFT practices such as goal setting and problem solving, as well as attitudinal aspects such as the optimistic role of the practitioner. It may have an important role as a mechanism by which family psychoeducation can impact recovery processes and other outcomes,

3.3 BFT in action - Building Family Skills Together

3.3.1 The need for a family intervention

As the foregoing literature review shows, the evidence amassed since the 1980s suggested that overall, family psychoeducation programs such as BFT are effective in reduction of relapse in consumers, and burden in their carers (I. R. Falloon, et al., 1982; I. R. Falloon, et al., 1985; I. R. H. Falloon, et al., 1984; I. R. H. Falloon & Pederson, 1985; Pilling et al., 2002; Pitschel-Walz, Leucht, Bauml, Kissling, & Engel, 2001). Clinical guidelines in the UK, USA and Australia state that family psychoeducation should be an essential part of contemporary treatments for schizophrenia (Kreyenbuhl, et al., 2010; McGorry, 2005; National Collaborating Centre for Mental Health, 2002).

A group of researchers and practitioners saw a substantial gap between evidence and practice in the area of family inclusion and the provision of family psychoeducation at an AMHS in Melbourne. Reference to clinical practice at the AMHS indicated no therapy of this type was being done. There was very little inclusion of family members in any type of ongoing therapy or consultation resulting in considerable concern for consumers and carers (C. Harvey, O'Hanlon, & Leggat, 2004a). After consideration of the clinical requirements and access to expertise and training, BFT was selected as the family program to implement. Building Family Skills Together (BFST) was the name given to the program that provided BFT throughout the selected AMHS.

3.3.2 Implementation activities

In order to make family sessions available, there was a need to train practitioners; provide mentoring and support for those practitioners, and ensure organisational support (P.W. Corrigan, Steiner, McCracken, Blaser, & Barr, 2001; C. Harvey & O'Hanlon, 2013; C. Harvey et al., 2007).

The BFST implementation strategy had a number of priority areas: firstly, identifying and working with barriers at an organisational level; secondly providing training to all staff in the CCT; thirdly, mentoring staff and supporting them in incorporating BFST into their clinical repertoire; and fourthly, developing plans to make BFST a sustainable practice (C. Harvey, O'Hanlon, & Leggat, 2004b; C. Harvey & O'Hanlon, 2013; C. Harvey, et al., 2007). Deliberations on implementation were kept confidential from the researcher (the author) in order to minimise undue influence on the objective evaluation of the program.

Local practitioners on the implementation team received training from Dr Grainne Fadden at Meriden in the U.K. in 2005 as an initial step. Further funding enabled Dr Fadden to travel to Melbourne and train another BFT expert practitioner, and a small number of staff at the AMHS in 2006.

Staff were trained in BFST through a five day program developed by the Meriden Family Programme in the UK (G. Fadden & Heelis, 2011). While comprehensive, and incorporating active training methods such as role-play and feedback, the training programme cannot offer in-depth skill development,

albeit skill acquisition is enhanced with a previous understanding of cognitive behavioural techniques (I. R. H. Falloon, 1988b; I. R. H. Falloon, et al., 1984; Kavanagh et al., 1993).

Reference to implementation experience in other services and the literature showed that after training practitioners in BFT, there was a slow adoption of family work and few families were seen by each practitioner (G. Fadden, 1997; Kavanagh, et al., 1993). Factors such as support and mentoring of practitioners by BFT trainers were anticipated to help facilitate the use of the intervention with families. This also improved practitioner skill and fidelity. With this knowledge, the BFST program undertook to "embed" family intervention experts in the AMHS to enhance deployment of the family intervention (C. Harvey, et al., 2004b).

As a follow-up to training, mentoring sessions were offered to BFST trainees in the work place. Attendance was optional. These sessions offered support in engaging families, as well as problem solving around challenges in starting and continuing sessions.

Sustainability plans were made in order to support BFST after the embedded BFST expert had completed their placement in mid 2008. This was done by developing a core group of expert BFST practitioners via designation of "champions" (i.e. enthusiastic case managers who conducted BFST with a number of families) and ensuring a portfolio holder, with designated time allocation, to promote and sustain BFST throughout the AMHS network.

Further funding was obtained from The Buckland Foundation to support an outcomes evaluation of the BFST program. The present study is linked to this outcomes evaluation. The evaluation protocol is detailed in Chapter 4.

3.3.2.1 Implementation site – A community mental health service

The setting and details of the mental health service are described in depth in Chapter 4.

The continuing care team (CCT) was chosen as the team to implement the family intervention. This was because the consumers engaged with this team

were relatively stable symptomatically, and usually worked with the case-manager for a time period that matched that needed for a family intervention (C. Harvey, et al., 2004b).

3.3.3 Adaptations of BFT for this program

The most important adaptation required was to meet the needs of the population born outside Australia. The major strategy was to use interpreters for all sessions where families were more familiar with a language other than English. Sometimes, bilingual case managers worked with families from their own cultural background to enhance the cultural relevance of sessions.

3.3.4 Challenges in implementation

Implementation is a complex task (D. Fixsen, Naoom, Blase, Friedman, & Wallach, 2005) and no longer seen as one of passive diffusion, but one of active processes (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004).Effective implementation of evidence based techniques present a challenge beyond the development of successful interventions (Ganju, 2003; Woolf & Johnson, 2005)

The challenges of implementing and translating evidence based interventions into effective programs in the field relate to the fact that interventions in the human services sector are complex (D. L. Fixsen & Blase, 2009; Magnabosco, 2006). To be effective, the implementation of a program cannot be a “one-off” procedure, but is instead a lengthy process that occurs in stages and incorporates a number of core components (D. S. Elliott & Mihalic, 2004; D. L. Fixsen & Blase, 2009; Morrison, 2004; W. C. Torrey et al., 2001). The stages involved cover pre-implementation, preparation, action and sustainability phases (D. Fixsen, et al., 2005), Across these stages, core components need to be applied to achieve “high fidelity practitioner behaviour” (D. L. Fixsen & Blase, 2009). This incorporates a wide range of activities (Magnabosco, 2006) such as attention to staff selection, training, coaching, consultation, performance assessment, decision supportive data systems, and facilitative administration and leadership (D. L. Fixsen & Blase, 2009).

The agents who lead the implementation (called implementors or purveyors) need to develop their experience via feedback (D. L. Fixsen & Blase, 2009) Building implementation capacity and science and the expertise of implementors is lagging behind the knowledge we have regarding the efficacy of interventions (D. S. Elliott & Mihalic, 2004; Ganju, 2003). Family psychoeducation programs may be the most difficult intervention to implement due to their complexity, their "newness" to practice and the difficulties of assessing fidelity (compared to employment programs or assertive community treatment for instance) (Magnabosco, 2006).

Socially complex interventions are also more difficult to evaluate in the field for a number of reasons (Wolff, 2000). In randomised controlled trials it is assumed that there is a standardised intervention (for instance a medication to be delivered). However, in socially complex environments such as a mental health service, where the intervention is itself complex, then standardisation and fidelity are issues, especially in regard to such aspects as: dose; activities and practice behaviour within sessions; motivation of staff; engagement of staff in training, supervision, mentoring and learning (Wolff, 2000).

In particular, two of the main challenges likely to have impacted the program evaluation were low rates of family engagement and maintaining practitioner skill and fidelity.

Previous research has found that the average number of families seen by a BFT-trained case manager is 1.4 to 1.7 (G. Fadden, 1997; Kavanagh, et al., 1993). Thirty-one percent of case managers trained in BFT reported challenges in finding "suitable" families, another 25% found logistical difficulties, such as insufficient time, or difficulty arranging sessions in work hours also impacted engagement (G. Fadden, 1997).

Conversely, the other challenge to engagement identified in studies was that many families were uncertain whether to proceed with the intervention, and this was a considerable barrier for case managers (G. Fadden, 1997). Reported barriers for families to attend family sessions included factors such as stigma or pre-existing time commitments. In addition families may be resigned to the burden of caring for their mentally ill relative, or unwilling to "rock the boat" in

terms of how the family functions and thus not accept the offer of family psychoeducation (L. Dixon et al., 2001).

Another challenge was in maintaining fully trained staff when there was substantial staff turnover (Woltmann et al., 2008). It was thus difficult to maintain a core of expert staff that would act as a repository of knowledge and skills for the service. However, these factors, while important, were not measured in the outcomes evaluation, but acknowledged as potential factors impacting the skill and fidelity of treatment, and potentially treatment outcomes.

Concern has also been expressed regarding the background training required for practitioners to adequately assimilate the required skills from the one week training (Kavanagh, et al., 1993). However, there is evidence that many professional groups in mental health teams are capable of delivering BFT. In the study of Brooker et al. (Brooker, et al., 1994), community psychiatric nurses were trained to deliver the intervention to 34 consumers and families. In the quasi-experimental trial where BFT treatment for 6 months was compared to treatment as usual, positive and negative symptoms and social functioning significantly improved for consumers, and distress reduced and mental health literacy improved significantly for carers in the treatment group at 6 months.

3.4 Evaluation of the BFT program and research questions

The expected outcomes were determined after considering prior research, and program impact theory (Rossi, et al., 2004). In the case of a BFT intervention, the body of prior research (outlined in Chapter 2 and this Chapter previously) was substantial and provided a clear guide as to the expected outcomes.

3.4.1 Expected outcomes from prior research

The major outcomes indicated by previous research were: decreased relapse and related decrease in hospitalisations, increased medication adherence, reduced medication dose, decreased positive and negative symptoms, improvements in social functioning, global functioning, employment and knowledge of schizophrenia, for consumers (F. Pharoah, et al., 2010; Pilling, et al., 2002). Table 3.7 provides a summary of the positive outcomes from the studies reviewed in this literature overview.

Table 3.7: Summary of successful family psychoeducation programs and outcomes

Study	Improved consumer outcome	Improved carer outcome
Barrowclough, et al., 1999 (Barrowclough, et al., 1999)	Clinical relapse	Carer needs
Barrowclough, et al., 2001 (Barrowclough, et al., 2001)	General functioning, Positive and negative symptoms, Relapse Exacerbation, Days abstinent from alcohol	
Berglund, Vahlne & Edman, et al., 2003 (Berglund, et al., 2003)	Medication dose, Relapse,	Family resignation/ rejection, Distress & burden
Bradley, et al., 2006 (Bradley, et al., 2006)	Symptoms, Relapse	
Brooker, et al., 1994 (Brooker, et al., 1994)	Positive and negative symptoms, Social functioning,	Distress (GHQ), Knowledge about Schizophrenia
Buchkremer, et al., 1997 (Buchkremer, et al., 1997)	Relapse	
Chien, Chan et al., 2006 (Chien, et al., 2006)	Consumer functioning	Burden (P& K)
Dyck, et al., 2002 (Dyck, et al., 2002)	Relapse	
Falloon, et al., 1982 (I. R. Falloon, et al., 1982)	Relapse (clinical exacerbation), days in hospital, Symptom remission	
Falloon, et al. 1985 (I. R. Falloon, et al., 1985)	Relapse (admissions and exacerbations), Major episodes, Total remission	
Falloon, et al. 2004 (I. R. Falloon, et al., 2004)	Mental impairment, Disability, Full recovery	Carer stress
Girón, et al., 2009 (Girón, et al., 2009)	Positive and negative symptoms, Social role, Employment, Hospitalisations	Family burden
Gleeson, et al., 2010 (Gleeson, et al., 2010)	Positive symptoms, Relapse	
Goldstein, et al., 1978 (Goldstein, et al., 1978)	Relapse	
Hazel, et al., 2004 (Hazel et al., 2004)		Carer distress
Hogarty, et al., 1986 (Hogarty, et al., 1986)	Relapse	
Hornung et al., 1999 (Hornung, et al., 1999)	Relapse and rehospitalisation at 2 and 5 yrs	
Kulhara, et al., 2009 (Kulhara, et al., 2009)	Symptoms, Disability	Support, Satisfaction
Leff, et al., 1982 (Leff, et al., 1982)	Relapse	
Magliano, et al., 2006 (Magliano, Fiorillo, Malangone, De Rosa, &	Global functioning, Social relationship, Job interest, Maintenance of social interests, Management social conflicts	Burden

Study	Improved consumer outcome	Improved carer outcome
Maj, 2006a)		
Magliano, et al., 2005 (Magliano, et al., 2005)	Symptoms, Disability	Burden, Coping, Social network
Mak, et al., 1997 (Mak, et al., 1997)	Disability, Employment	Knowledge, Satisfaction
McFarlane, et al., 1996 (W. R. McFarlane, et al., 1996)	Relapse (rehospitalisation), Symptoms, Treatment participation, Employment	Burden, Family function, Social adjustment
McFarlane, et al., 2000 (W. R. McFarlane et al., 2000)	Employment	
McFarlane, Lynch & Melton, 2012 (W. McFarlane, et al., 2012)	Relapse, Symptoms, Functional outcomes especially employment	
Montero, et al., 2001 (Montero, et al., 2001)	Disability, Medication, Symptoms	
Nordentoft, et al., 2006 (Nordentoft, et al., 2006)	Transition to Schizophrenia	
Randolph, et al., 1994 (Randolph, et al., 1994)	Exacerbation	
Rund, et al., 1994 (Rund, et al., 1994)	Relapse, EE, Satisfaction	
Tarrier, et al., 1988 (Tarrier, et al., 1988)	Relapse in High EE families	
Xiang, Ran & Li, 1994 (Xiang, et al., 1994)	Symptoms, Social disturbance Knowledge about illness, Working ability, Treatment adherence	Ability to offer appropriate care
Xiong, et al., 1994 (Xiong, et al., 1994)	Rehospitalisation, Relapse Symptoms and clinical measures Employment, Medication adherence	
Zhang, Heqin & Co-Authors 1993 (Mingyuan. Zhang, et al., 1993)	Recovery, Symptoms, Disability, Working, Medication, Treatment adherence	Burden
Zhang, et al., 1994 (M. Zhang, et al., 1994)	Symptoms, Functioning, Relapse and Time to relapse	

For carers, the improved outcomes were: needs addressed, increased coping, improved social networks and social adjustment, improved knowledge of mental illness, decreased burden, resignation, distress and stress (Grainne Fadden, 1998; F. Pharoah, et al., 2010)(and see summary in Table 3.7). Measures of family functioning showed improvement with family psychoeducation, but had not been frequently studied (Pilling, et al., 2002).

Research regarding hope and BFT had not been undertaken before, but related study in the area of hope and psychotherapy, and on hope and schizophrenia suggested hope had a close relationship to recovery and was possibly quite low in consumers with schizophrenia. Hope was also logically and theoretically linked to family psychoeducation because of goal setting activities and optimistic practitioner attitudes embedded in the intervention. Hope was potentially a mediator of FPE outcomes. The impact of hope levels at the outset on treatment outcomes (i.e moderator analysis) was unclear, but extremely useful in determining the most appropriate candidates for FPE (Frazier, et al., 2004; MacKinnon, 1994).

3.4.3 Program logic

Standard program logic systematically describes the sequence of inputs (i.e. people and resources), activities, and proximal, intermediate and distal outcomes for programs (Rossi, et al., 2004). The program theory for the BFST program is outlined in Figure 3.3 below.

The proximal outcomes describe the immediate changes that might be expected from attending BFST sessions. These are the skills and educative experiences that families take with them “as they walk out the door” after sessions. For BFST, it was hoped families would finish sessions with increased knowledge of mental illness, and skills training in communication and goal setting/problem solving, and better knowledge and plans for relapse prevention (I. R. H. Falloon, et al., 1984; Rossi, et al., 2004).

Intermediate outcomes are the second set of changes from sessions, as skills learnt in sessions are applied in everyday life. In the case of BFST, carers and consumers utilise the communication and goal setting skills at home, actually start achieving some goals, and start applying some of the knowledge about mental illness and relapse prevention. EE in the family decreases (I. R. H. Falloon, et al., 1984). Hope should improve. Intermediate outcomes involve the generalisation of the skills learnt in sessions to the rest of a person’s life (Rossi, et al., 2004).

Distal or long-term outcomes are realised as the result of success at the intermediate and proximal level (Rossi, et al., 2004). For BFST, as

communication, problem solving and hope improves and EE decreases, consumer functioning should improve and carer burden decrease. Overall, quality of life and social participation should improve (I. R. H. Falloon, et al., 1984).

The foregoing is only a theoretical model for the effects of BFST. No research was identified that demonstrated the mechanism or sequence of events by which family psychoeducation works. One partial mechanism may be through better medication adherence (I. R. H. Falloon & The Optimal Treatment Project Collaborators, 1999). However, in a didactic program such as BFT, the proximal outcomes must clearly also include the learning of the skills and information that are taught and shared in sessions.

However, the most important message from program logic is that to achieve the distal outcomes that are usually the actual target of an intervention (e.g. improved quality of life (Priebe, Oliver, & Kaiser, 1999)) proximal and intermediate goals must be achieved along the way. If skills and knowledge are not acquired, nor practiced outside of sessions, or not in deficit, then improved quality of life might not be achieved. The mediation analysis regarding hope is thus quite significant, since it provides crucial information on a possible mechanism through which family psychoeducation works – through the improvement in hope and expectations regarding goal achievement (Baron & Kenny, 1986; Frazier, et al., 2004; MacKinnon & Dwyer, 1993).

Measuring proximal and intermediate goals except for hope, in this program evaluation was not undertaken since they were not valuable outcomes in themselves and at the time of instrument selection (2006), no operationalised measures were available. (More recently, measures such as the Questionnaire of Family Functioning (Roncone et al., 2007) have been published which do measure the level of communication skills in the family). Extra measures would also have been more burdensome for participants to complete in assessments.

However, an exit interview to gauge satisfaction with the family intervention included some questions about learning and use of skills and knowledge of mental illness, so some qualitative information was obtained on the proximal and intermediate outcomes.

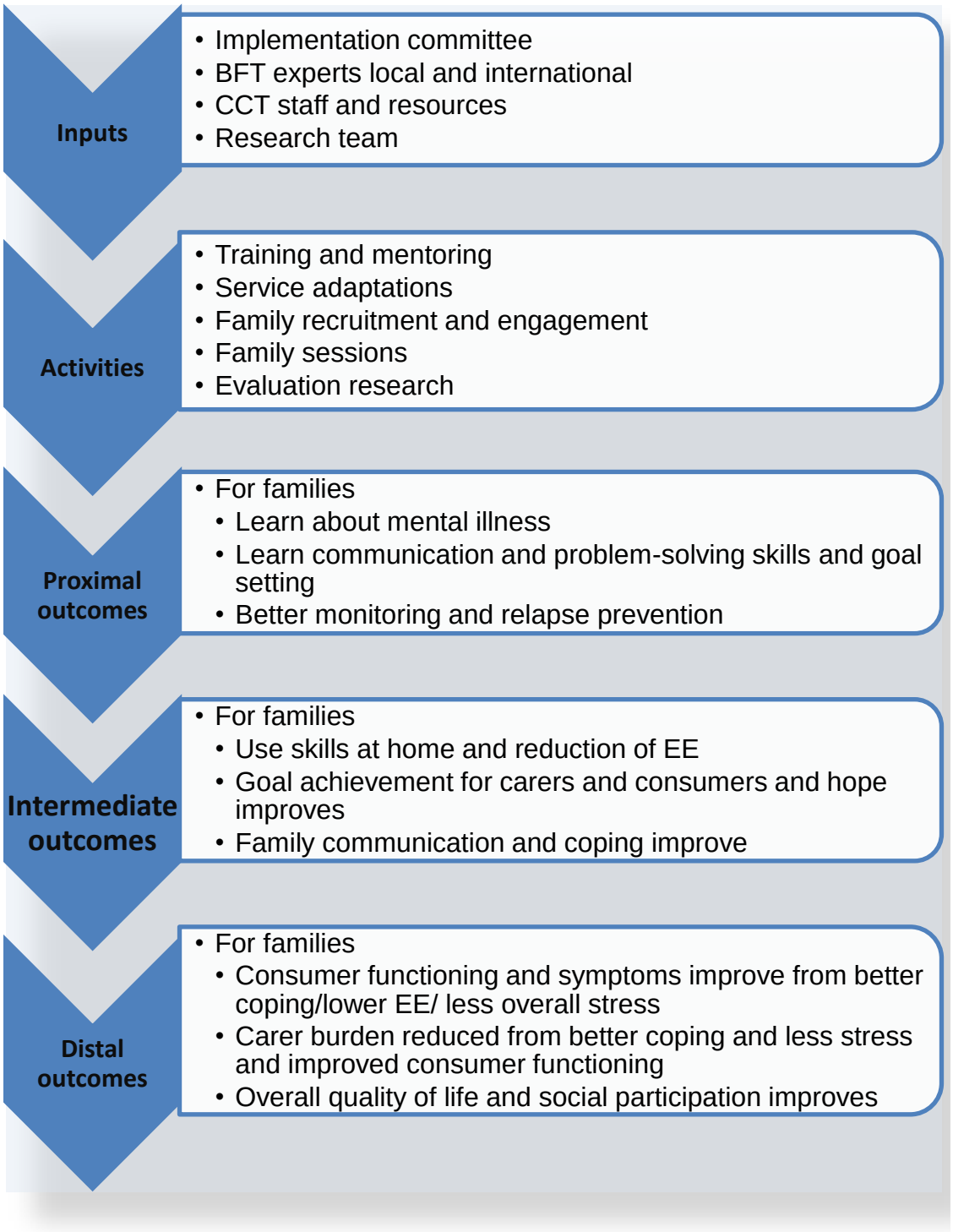


Figure 3.3: Evaluation logic for BFT intervention (based on Rossi, p 95 (Rossi, Lipsey, & Freeman, 2004)

3.4.2 Hypothesis questions

The review of the literature in Chapter 2 identified hope and recovery as vital aspects of contemporary treatment, but as yet hope, in the context of recovery has not been clearly operationalised. It seemed likely that Snyder's operationalisation of hope into goals, agency and pathways would provide some interesting findings in relation to consumers living with schizophrenia and their carers. However, the Snyder Hope Scale was considered to be possibly deficient in measuring some aspects of hope, in particular, "emergent" aspects of hope, aspects of adversity and the significance of relationships to hope. The trajectory of hope, over a course of treatment had rarely been studied, but was worthy of empirical study as hope and its relationship to other recovery measures was of growing interest in an era of recovery-based services.

BFT, and related family psychoeducational interventions have excellent evidence as to their effectiveness, but the literature review suggested that better outcomes were obtained when high EE groups were targeted, and the intervention was appropriately adapted for illness phase, and cultural background. In addition, outcomes such as relapse have been very well researched, but recovery outcomes such as hope, role functioning, social connection and quality of life have not. BFT is a relevant treatment for the examination of hope and recovery since it focuses on goal setting, which is a central part of hope and recovery, and encourages consumers to work together with their carers and support team (P.E. Deegan, 1988; Kim T. Mueser, 2012).

The main aim of this doctoral research was to examine the course of hope in consumers and carers receiving BFT treatment, in comparison to a group receiving case management only. Subsidiary questions looked at hope in relation to symptoms (consumers) and burden (carers), similarities in the levels of hope within a family and the role of hope as a precursor to other recovery based outcomes. This was an exploration of some of the tenets of the recovery model (see Chapter 2). Consumer and carer hope were compared to levels in other reported groups, such community, consumer and other carer groups.

The hypothesis of this research was:

1. That the BFST program would significantly improve hope in consumers and caregivers when compared with a case management only group (treatment as usual or comparison group) over 10-months.

Subsidiary research questions were:

2. Following the logic of the recovery paradigm, were symptom levels at baseline a moderator of hope (and recovery)? Was hope a predictor of improvement in other measures of recovery, such as social connection, role functioning and quality of life for consumers and thus a mediator of the effectiveness of family psychoeducation?

3. Was hope a predictor of improvement in burden and other measures of wellbeing for carers, such as social connection or quality of life and thus a mediator of the effectiveness of family psychoeducation for carers?

4. Was consumer hope at follow-up predicted by hope in carer family member, self-assessed family functioning, or treatment type? Was carer hope at follow up predicted by: hope in consumer family member, self-assessed family functioning, or treatment type? In other words, were aspects of the family environment mediators of hope for carers and consumers?

5. Was hope, at baseline, in both treatment and comparison groups (consumer and family caregiver) less than levels reported in previous studies?

6. What goals do consumers and carers have, how did they assess the likelihood of achieving their goals and had they made plans for achieving their goals (qualitative analysis)? Did the discussion of goals, agency and pathways relate to consumers' and carers' hopes for the future?

7. Were the treatment group satisfied with the BFT treatment? Which sessions had the most impact (qualitative exit interview)?

Chapter 4: Evaluation Methodology

Chapter 4: Evaluation methodology

4.1 Evaluation questions and hypotheses

This research was an examination of hope and recovery for people living with schizophrenia, and their carers, in the context of a recovery-focused family psychoeducational program, the Building Family Skills Together (BFST) program based on Behavioural Family Therapy (BFT). As argued in the previous chapters, very little quantitative or prospective research in the domain of hope in people diagnosed with schizophrenia and their families has been done previously, despite hope often being considered an important aspect of treatment and recovery (Kylma, et al., 2006; C. Noh, Choe, & Yang, 2008). The available research showed that people diagnosed with schizophrenia live with higher levels of hopelessness and demoralisation compared to the community at large (Hoffmann, et al., 2000). It was unclear whether levels of hope in consumers with schizophrenia differs from consumers with other diagnoses or whether hope in carers of people living with schizophrenia differs from caregivers of people with other disabilities.

The present study investigated hope, using quantitative and qualitative methods, for a group of consumers and family caregivers, before and after a BFT intervention. The results were compared with another group of families who did not receive BFT sessions.

Concurrent with the PhD study and outcomes evaluation were two other research programmes. One was a study into the overall levels of family work carried out in the Area Mental Health Services (AMHS) involved in the study led by Dr John Farhall, examining any changes due to the implementation of the BFST program (J. Farhall, Goldstone, Harvey, O'Hanlon, & Hayes, 2010). The second was another PhD using a participatory action research method and qualitative analysis of the implementation of the BFST program, with an exploration of training, mentoring of staff and the experience of BFST participant families undertaken by Brendan O'Hanlon (B. O'Hanlon, 2013; B. O'Hanlon, C. , Harvey, & et al, 2012; B. O'Hanlon, Perlesz, & et al, 2007).

The PhD study on hope was conducted in conjunction with an outcomes evaluation of the BFST program. The outcomes evaluation was focused on comparing pre- and post- treatment assessments for consumers and one key family member. The outcomes evaluation domains of measurement for the consumer were: symptoms and behavioural problems, attitudes to medication, quality of life, social connection, service utilisation and research. The outcomes domains of measurement for the family member were: quality of life, social connection, psychological distress and emotion, caregiving experience and burden. Many aspects of the research protocol were determined for the outcomes evaluation by the research investigator group (named in the acknowledments).

Additional measures were included for the purposes of the PhD project. They were measures of hope, family functioning and treatment satisfaction. The same measures were used for consumers and family members. These additional measures were chosen in order to investigate the following hypothesis and research questions.

The primary hypothesis of this research was:

1. That the BFST program would significantly improve hope in consumers and caregivers when compared with a case management only group (treatment as usual or comparison group) over 10-months.

Subsidiary research questions were:

2. Following the logic of the recovery paradigm, were levels of hope in consumers independent of the levels of symptoms? Was hope a predictor of the other measures of recovery, such as social connection, role functioning and quality of life for consumers?

3. Was hope a predictor of burden for caregivers? Was hope a predictor of the other measures of wellbeing for carers, such as social connection or quality of life?

4. Was consumer hope at follow-up predicted by hope in carer family member, self-assessed family functioning, or treatment type? Was carer

hope at follow up predicted by: hope in consumer family member, self-assessed family functioning, or treatment type?

5. Was hope, at baseline, in both treatment and comparison groups (consumer and family caregiver) less than levels reported in previous studies?

6. What goals do consumers and carers have, how did they assess the likelihood of achieving their goals and had they made plans for achieving their goals (qualitative analysis)? Did the discussion of goals, agency and pathways relate to consumers' and carers' hopes for the future?

7. Were the treatment group satisfied with the BFT treatment? Which sessions had the most impact (qualitative exit interview)?

In order to answer the above questions, the following study design was employed.

Section 4.2: Study Design

4.2.1 Quasi-experimental method

A quasi-experimental design (D. T. Campbell & Stanley, 1966; Cook & Campbell, 1979) was chosen, using a group of similar consumers and their families who did not join the BFST program as a comparison. Although the findings of a quasi-experimental trial may be less robust than a fully randomised design, there were valid reasons to choose a non-randomised design (Foussias & Remington, 2010; M. Marshall et al., 2000; Pajonk, 2005; Wells, 1999).

Firstly, the purpose of the research was to examine the construct of hope, in what was essentially an effectiveness study. Randomised controlled studies have established BFT as an effective intervention for assisting consumers and their families previously (F. Pharoah, et al., 2010). This study did not seek to replicate these findings, but to examine this particular implementation of a BFT program. As such, the research needed to examine outcomes in the program while preserving usual care conditions (Pajonk, 2005).

To do this, the inclusion criteria at the treatment site were broad, and all consumers with a relevant diagnosis were eligible, no treatment was delayed due to research protocols, and the normal range of other services were available, all typical features of an effectiveness study (Fleischhacker & Goodwin, 2009).

Randomisation to a comparison group or wait list would not deliver usual care. In contrast it would have created a treatment environment that was not typical, in that the normal array of adjunct services may have been withheld and access to treatment personnel may have been rigid, in order to enforce control conditions (Pajonk, 2005; Riedel, Strassnig, Muller, Zwack, & Moller, 2005; Rothwell, 2005). In addition, families on a waitlist may have been discharged from the service before they received treatment, raising ethical concerns about the research denying families the best available treatment.

As discussed earlier (Chapter 3), the implementation model chosen for the BFST program was to deliver the program in one team, at one Area Mental Health Service. It was decided not to implement the service on a small scale or only partially, owing to the need to provide training efficiently, set up effective mentoring groups, and for system-wide changes to be made to support family work (for example, changes to work hours and time-in-lieu systems).

In addition, randomised control methodologies can be expensive to use (Aveline, Shapiro, & et al, 1995; Bottomley, 1997; Elkin, Shea, & Watkins, 1989; C Lloyd & Bassett, 1997) when such financial resources were not available for this study.

Another concern with the quasi-experimental method was the question of treatment contamination. If a wait-list or non-BFST group from the treatment site was used as a comparison group, then it was possible their treatment would not truly be “treatment as usual”, as their case managers could be conducting BFST sessions on other consumers at the same time, and this might influence the treatment carried out on the comparison group. This reinforced the decision to choose a comparison group from a site where there was no BFST program. By the same token, consumers of any BFT trained

clinician working at a comparison site, even though there was no BFST program in operation, were excluded from joining the comparison group.

Given these circumstances, the only satisfactory way to obtain a comparison group was to choose a quasi-experimental design.

4.2.1.1 Research threats with a quasi-experimental design

The major threats to the quasi-experimental design concerned the non–equivalence of groups at baseline, differences in instrumentation, the inadequate control and/or measurement of external influences (e.g. local history), and maturational processes (Cook & Campbell, 1979) (for definitions and explanation of threats, see Section 4.2.6 below). However, careful management of these threats minimised their impact on the validity of the outcomes study (Pajonk, 2005; Summerfelt & Meltzer, 1998; Wykes, Steel, Everitt, & Tarrier, 2007).

Both the treatment and comparison groups were drawn from the consumer lists of community mental health centres (within the Continuing Care Teams or CCTs) in the northwest of Melbourne. The selection of comparison families from adjacent area services was an appropriate choice to maximise the potential for equivalent groups. All these centres were within a larger health organisation that administered the entire region. The centres provided similar services to communities that were well matched demographically, which increased the likelihood that similar groups would be drawn from across the centres. The consumers and their families at the comparison AMHS would have been eligible for the BFST program if it had been available at their AMHS.

Finally, each service may have been influenced by the particularities of the history at each site (Chen, 1990). However, recruitment over an extended period of time (3 years) reduced the impact of any time-limited events (Cook & Campbell, 1979), as only a few recruits were probably influenced at any point in time. The research into the level of family work at the AMHSs included reviewing important events and “history” at both treatment and comparison sites. This allowed a judgement to be made regarding the impact of site-specific events (J. Farhall, et al., 2010).

4.2.2 Minimum treatment requirements

For the purposes of the study, families were considered not to have had a minimum effective dose if they had less than 6 sessions before treatment ceased. These families were still followed-up at 10 months if they were agreeable, and included in the analysis.

For most cases, six sessions covered engagement sessions and individual assessments of each family member. Some families started preliminary sessions in information sharing and relapse planning within the six sessions (see Chapter 3 for more details on the components of a BFT treatment).

The six session criterion was based on evidence regarding the minimum number of sessions required to elicit changes for the family and consumer (Pitschel-Walz, et al., 2001; G. Szmukler et al., 2003). Although duration was an important aspect of treatment dose as well (Pilling, et al., 2002), a pragmatic decision was made to set the minimum dose based on the number of sessions not duration. This criterion was set by the program evaluation investigator group, and adhered to for the PhD study.

4.2.3 Pre and post testing time frame

BFT treatment was usually administered for approximately nine months. Consequently, the follow-up interview was planned for 10 months after the base-line assessment, to accommodate any longer treatment durations, and allow changes from treatment to be consolidated. Some treatment durations were shorter than 9 months due to early termination or fast progress in the program. These families were still interviewed at 10 months. It is arguable that all treatment families should have been interviewed one month after treatment was concluded, whenever that may have been. However, this would preclude a meaningful comparison with the comparator group, as assessment duration could not easily be matched between the two groups.

In picking the study time frames there were a number of risks. Changes for BFST participants may have occurred before or after the assessment period. However only two assessments were conducted (pre- and immediate post-) due to practical concerns regarding research resources and participant burden.

4.2.4 Mixed methods approach

A mixed methods approach was utilised, as both quantitative and qualitative data would contribute valuable information to answer the research questions (Bryman, 1984; Cook & Campbell, 1979; Moffatt, White, Mackintosh, & Howel, 2006; Price & Taylor, 2008; Steckler, McLeroy, Goodman, Bird, & McCormick, 1992). Quantitative data was of primary interest because it provided high-grade evidence to answer research questions.

However, additional qualitative protocols were also warranted because outcomes from mental health interventions are complex and require diverse methods to study and understand them (Baum, 1995; Moffatt, et al., 2006; Price & Taylor, 2008; Steckler, et al., 1992). Since the examination of the potential link between hope, recovery and a BFT intervention was novel, qualitative data could provide insight into this area. Although the primary research questions about hope were essentially quantitative, useful insight into the hope and personal goals of participants could be obtained by open-ended questions. Thus both quantitative and qualitative data could make useful contributions to answering the research questions (Patton, 2002).

Along with qualitative data on hope, treatment satisfaction and carer burden were also investigated via semi-structured interviews. Given this was the first outcomes study of a BFT intervention in the Australian health care system, some qualitative “satisfaction with treatment” data was of interest, in order to add richer detail to the quantitative outcomes data (Steckler, et al., 1992). The issue of carer burden also warranted further attention, since the carer experience has been less well researched and reported inconsistently (Pilling, et al., 2002).

It has been argued that quantitative and qualitative data are fundamentally incompatible and the techniques for collecting such data come from research paradigms that are incommensurable (Baum, 1995; Bryman, 1984; Kuhn, 1984; Price & Taylor, 2008). However, this argument confuses philosophical positions about research and knowledge, with discussions of practical strategies for data collection (Loveland, Randall, & et al, 2005; Patton, 2002). The data gathered in this study did not cross paradigms because both

qualitative and quantitative data were utilised in a manner consistent with the scientific method (Gower, 1997). The qualitative data were collected in short interviews that were highly structured, with standardised questions. The qualitative data has been used to understand more about the quantitative data, and to interpret the quantitative findings.

4.2.5 Threat analysis

The four main types of threat to the validity of the research protocol, following Cook and Campbell (Cook & Campbell, 1979), were threats to the validity of statistical conclusions, threats to internal validity, threats to construct validity and threats to external validity. The threats are summarised in to Table 4.8 to Table 4.11 and the major threats and some moderate threats are discussed in the text, and minor threats documented in the tables.

4.2.5.1 Statistical validity threats

Threats to statistical validity refer to concerns about the statistical procedures of a study, for instance the level of power or choice of measure. Threats are listed in Table 4.8. In this study, the major threat was low numbers, leading to low statistical power. Recruitment strategies were reviewed to maximise numbers, but were limited by the number of families entering treatment in the case of the treatment group.

Another threat to the statistical validity of this study was the heterogeneous nature of the target population in terms of their age, family relationship, ethnicity and education. Demographic markers of this heterogeneity were collected (for example age, level of education, length of illness, country of birth, family constellation around consumer). However, given the small numbers, not all factors could be controlled via statistical methods without reducing statistical power even further.

4.2.5.2 Internal validity threats

The second major group of threats related to internal validity, which concerned the plausibility of the conclusions of the research, the demonstration of causal relationships and the elimination of alternative causes. Internal validity threats are summarised in Table 4.9. Many of the threats consequent to the quasi-

experimental design such as the non–equivalence of groups at baseline and the inadequate control and/or measurement of external influences (e.g. local history) were in this category. The threat of non-equivalent groups, discussed previously, was managed by recording demographic characteristics in order to analyse and statistically control for differences if necessary.

The inadequate control of external influences, and their interaction with selection was of concern for the quasi-experimental design. Firstly, the researcher maintained a log recording all significant events at each site in order to provide some documentation of such events. The second study, concurrent with the present study, also investigated the level of family work at each site over the time of recruitment and documented significant events at each of the sites (John Farhall, Campbell, Harvey, di Benedetto, & O'Hanlon, 2007; J. Farhall, et al., 2010). While not enabling control of external influences, this information was utilised in the interpretation of results.

Other threats were maturational processes and differences in instrumentation.

Maturation and its interaction with selection was another threat to the internal validity of the research design. Any changes over the time period of the study may be due to the natural history of the mental illness, or other developmental factors within the consumer or carer. Proxy measures for these maturity variables were collected and used in this study and groups were checked for equivalence. The proxy measures were "time since diagnosis" for natural history, and age for other developmental factors. While maturity processes could not be controlled, examination of whether groups were well matched helped to minimise potential differences in maturation between treatment and comparison groups.

Instrumentation threats relate to changes in measurement over time due to changes in observer scoring and/or changes in the meaning of instruments for participants. Inconsistency in instrumentation was of concern where the researcher was non-blind to treatment condition and study phase, as the researcher's scoring could be biased by this knowledge. Inconsistency of scoring was minimised as only one researcher undertook pre- and post-testing for treatment and comparison groups and exactly the same questionnaire was

used at both time points. The researcher was trained in the consistent use of the interview measures in order to minimise this threat.

It was conceivable that participants would interpret questionnaires differently at pre- and post-testing time points. This could have been due to a more defensive test-taking attitude at pre-testing, which relaxed at follow-up. The researcher maintained a neutral stance, neither too friendly nor too detached, to minimise such reactions from participants. The extent to which this occurred, however, was unknown.

Another major threat to internal validity was that observed differences in groups could be due to selection bias and not changes due to different treatment. This threat was managed by ensuring recruitment criteria were implemented in the same way at treatment and comparison sites. Also, as previously discussed, participants were recruited from the same type of services in demographically similar areas. In order to investigate this concern, at the conclusion of recruitment, both groups were compared on age, gender, education and employment. It was expected that there would be no statistically significant differences.

4.2.5.3 Construct validity threats

Threats to construct validity relate to concerns about the relationship between the research measurement and underlying constructs. Construct validity concerns are summarised in Table 4.10.

The two major construct validity threats were treatment interactions and generalisability across constructs. Treatment interactions are of concern in an effectiveness trial when consumers are the recipients of multi-modal treatments, including medication, case-management, job and vocational services. All additional treatments and groups were recorded for both treatment and comparison groups over the 10 months between assessments. However, the only consistent extra treatment was BFT for the treatment group consumers.

The second threat to construct validity, generalisability across constructs concerns the differing impact of the treatment on different constructs. Previous

research has shown that BFT is effective in reducing relapse in consumers and burden in carers. The use of additional outcome measures for the study, presumes that positive changes will be generalised to other constructs. This is a major risk in examining novel outcomes such as hope. However, measures of relapse and burden were still included in the study design.

4.2.5.4 External validity threats

External validity concerns the generalisability of a study to other populations, settings and times, given the internal or causal validity was acceptable. In the case of an effectiveness study such as this, generalisability may be quite high, since it the evaluation was set in a realistic clinical setting. However, there was no randomised selection, so it possible that the samples joining the research are not representative of the population attending the clinics.

Generalisability is also mitigated by the early enthusiasm of clinicians in the program and their response to the attention of the researchers (Hawthorne effect) leading to unusual results. However, since recruitment occurred over 4 years, the novelty effect was less likely to be sustained. External threats are outlined in Table 4.11.

Table 4.8: Threats to Statistical Conclusion Validity

Threat	Application in present design	Importance of threat	Management of threat
Low statistical power (Type II error)	Small sample size obtained	Major threat	Review barriers to recruitment. Pursue small numbers statistical strategy
Violation of statistical test assumptions	Statistical tests chosen may not be appropriate for the particular data to be analysed	Moderate threat	For normal data, use parametric tests, for non-normal data, use non-parametric tests or normalise data
Fishing/error rate	Large number of hypotheses and variables used	Moderate threat	Bonferroni adjustment could be used, but see text for arguments against such a procedure
Reliability of measures	Measures chosen could have low reliability	Moderate threat	Reliable, valid measures used. Psychometric properties of instruments researched
Reliability of treatment implementation	With a wide variety of therapists, with varying training, experience, philosophy and confidence carrying out the treatment it was most likely that treatment fidelity was variable	Major threat	Each implementation site had a single trainer/mentor often doing co-therapy – this would homogenise treatment at each site to an extent. Mentoring and supervision groups provided Treatment duration and total number of sessions measured.
Random irrelevancies	Extraneous variables may affect outcomes	Minor threat	Wide variety of demographic and treatment variables recorded. Researcher log was kept to document any significant events
Random heterogeneity of respondents	Groups highly variable on such factors as age, ethnicity, education, family constellation etc	Major threat to determining treatment effects	Wide range of respondent characteristics were measured – e.g. age, living circumstances, work, medication, to cover many sources of heterogeneity. However, since the group size was small, only one or two demographic variables could be used as co-variables

(Types of threat taken from Cook and Campbell (Cook & Campbell, 1979) and Hawthorne (G. Hawthorne, 2007))

Table 4.9: Threats to internal validity

Threat	Application in present design	Importance of threat	Management of threat
History	Events which affect outcomes, but not part of treatment	Moderate	Included questions on major life events and other therapies undertaken
Maturity	Observed changes were due to increased maturity of subjects	Minor	Ensure the treatment and comparison groups were matched on major demographics to ensure maturational changes were similar across groups
Instrumentation	Changes in calibration of instruments or in scores given by observers	Moderate	All interviews by same researcher increased consistency. Researcher was well trained in consistent use of questionnaires
Statistical regression	High and low scores at one time, would regress to mean at a later observation point	Minor	Data preparation included testing for outliers using Mahalanobis Distance calculation
Selection	Differences in the characteristics of treatment group versus comparison group	Major	Major demographic factors were being measured for both groups and post hoc analysis carried out to check groups were equivalent
Mortality or loss to follow-up	Different rates of loss to follow-up from treatment and comparison groups	Moderate	Compare rates of loss to follow-up between treatment and comparison group.
Ambiguity about direction in causal influence	If a correlation exists, it is not always clear if causality was implied and in what direction	Minor	Pre-test post-test design affords some insight into causal process
Diffusion or imitation of treatments	Possibility of comparison group getting more family treatment due to hearing about BFT and the BFST program in course of research	Minor	Ensured that any BFT trained clinicians from comparison services were not source of recruited families
Compensatory equalisation of treatments (by staff)	Comparison services may have altered the level of family treatment knowing they were being compared to the BFST service	Minor	In theory very likely that services would compete, but in reality, the limitations imposed by resources available would mean there was little effective change or equalisation in services
Compensatory rivalry by respondents	Comparison families may be motivated to do better knowing they would be compared to a group getting "special treatment"	Minor	Minimal information was given to comparison families about the BFST treatment, and there was little likelihood of contact between treatment and comparison families
Demoralisation of comparison group	Comparison families may do worse because they know they were not receiving extra family sessions	Minor	Comparison and treatment families did not meet. Descriptions of family treatment were very minimal for comparison group

(Types of threat taken from Cook and Campbell (Cook & Campbell, 1979) and Hawthorne (G. Hawthorne, 2007))

Table 4.10: Threats to construct validity

Threat	Application in present design	Importance of threat	Management of threat
Inadequate explanation of constructs	All instruments need constructs that are adequately defined	Moderate	Well defined constructs and valid measures were used, but operationalisation of hope in this context was problematic
Mono-operation bias	Potential outcomes may be missed, or not measured effectively, because operationalised with single measure	Moderate	A comprehensive suite of outcome measures was selected with plenty of overlap – e.g. the psychological wellbeing scale on the WHOQOL would overlap with the GHQ-28 and the POMS
Mono-method bias	All quantitative data collected in the same way, with very similar question and answer format	Moderate	Mixed methods employed with some data obtained through interview (qualitative).
Hypothesis guessing within experimental conditions	BFST program families were told that relapse rates and family wellbeing should improve after treatment	Moderate	Researcher interviews conducted in as neutral a manner as possible. Some data was relatively objective e.g. admission
Evaluation apprehension	Some respondents may be anxious about "assessment" and try to present as healthy or coping well Some respondents may be inhibited to answer questions honestly if family members present	Moderate	Interviewer reassured respondents that there were no "right " or "wrong" answers. Interviewer made sure family members did not see each other's answers and provided private spaces for questionnaire completion and interviews
Experimenter expectancies	The interviewer may be biased in interviewing families from treatment and comparison families, particularly at the post-treatment phase	Moderate	Interviewer attempted to remain neutral in interviews
Levels of constructs	Constructs could be measured at a range where there was little impact on outcomes	Moderate	Possible that constructs not measured at levels where change occurred
Interaction of testing and treatment	Possibility that testing can sensitise families in treatment.	Minor	Owing to the difficulty in getting adequate numbers already, there would be no separate cell of cases that had the post-treatment evaluation only.
Treatment interactions	Where multiple treatments occur, it is unclear which has been effective	Major	All cases, both treatment and comparison were recipients of many modalities of treatment. The one consistent difference was that one group would get BFT.
Generalisability across constructs	Treatment may have different effects on the various constructs, so all should be measured	Major	The constructs selected for testing were relatively untried for the BFT intervention and possibly did not capture outcomes of the intervention

(Types of threat taken from Cook and Campbell (Cook & Campbell, 1979) and Hawthorne (G. Hawthorne, 2007))

Table 4.11: Threats to external validity

Threat	Application in present design	Importance of threat	Management of threat
Interaction of selection and treatment	Potential for treatment and comparison groups to be systematically different from each other	Major	Post hoc testing of group equivalence was undertaken
Interaction of setting and treatment	Can the study generalise from an outpatient public mental health setting to other treatment settings?	Moderate	Clear descriptions of setting taken. The choice of clinic to carry out the BFST program was not random
Artificiality of the study setting	The setting of the treatment may be contrived and not "real world"	Minor	The present setting was very much in the everyday delivery of mental health treatment and was clearly not artificial
Hawthorne effect	A novel treatment enthuses researchers and therapists and subjects respond to the extra attention	Moderate	Possible to analyse if any response difference in earlier recruited cases to later recruited cases, but with small numbers sub-group analysis not undertaken
Interaction of history and treatment	Data collected when another special event was happening and try to generalise data to time when this event isn't happening	Minor	Recruitment over 4 years decreased the influence of any one event
Interference of prior treatments	Previous treatments still have an effect on participants. In doing research on a group that tend to have a long history of treatment and illness, there were many previous treatments that may be affecting present observations	Major	Problem of studies on schizophrenia is that heterogeneous prior treatments affect current functioning of participants leading to greater error in measurement (Spaulding, 1992)
Measurement contamination	Where the assessor knows the treatment group and this affects subjective parts of the assessment.	Major	The assessor was not blinded, nor were participants

(Types of threat taken from Cook and Campbell (Cook & Campbell, 1979) and Hawthorne (G. Hawthorne, 2007))

4.2.6 Power analysis

4.2.6.1 Power calculations for critical effect size

Power calculations were made for the primary outcome of hope. Power calculations, based on the expected changes in the Snyder Hope Scale indicated that 28 cases within each group would give 80% power to avoid Type II error (where a real difference in pre- and post- results would not be detected statistically) (statistical formula from Davison, 1986 (Davison, Fayers, Nunn, Venables, & Newman Taylor, 1986)).

The calculations are presented in Table 4.12 below.

The estimated effect size was derived from outcomes of previous research with the Snyder Hope Scale. An effect size of 0.70 was achieved for psychotherapy consumers reported by Irving et al (Irving et al., 2004) where improvement in

hope scores between pre- and post-treatment testing was approximately two thirds of a standard deviation (Irving, et al., 2004). Also, Snyder et al (Snyder, et al., 1991) reported an effect size difference of 0.71 between people in treatment (inpatient) and USA college samples.

Baseline results obtained a mean of 23 (M = 23) and standard deviation of 4 points (SD = 4) for the Snyder Hope Scale. To achieve an effect size of around 0.70 in this study, in line with Snyder et al (Snyder, et al., 1991) and Irving et al (Irving, et al., 2004), it was assumed that a change of three points (an effect size of 0.75) would be achieved. This would be a moderate effect size.

Although previous research has shown significant results for groups of approximately 30 (I. R. Falloon, et al., 1982; I. R. H. Falloon & Pederson, 1985), this may not provide sufficient power in an effectiveness study. In small scale randomised control studies (RCTs) many extraneous influences can be controlled. However, in effectiveness studies, there can be more uncontrolled factors, so it has been suggested that power needs to be increased to show main effects (Fleischhacker & Goodwin, 2009; Foussias & Remington, 2010; Pajonk, 2005). Furthermore, research into family interventions has shown effect sizes have been decreasing over time, presumably as TAU improves relative to the family treatment condition (Pilling, et al., 2002).

So, the impact of a heterogeneous sample and decreasing comparative treatment effect strongly suggested that more than 28 participants in each group would be required. However, as discussed in recruitment methods below, recruitment to the trial was slow, and limited by the numbers actually treated in the program. This is a dilemma for real-world effectiveness studies, where treatment implementation is limited by the size of the service. Therefore, the planned recruitment of 30 participants for each cohort was achievable given the service size. However, it was still possible that this would provide insufficient power for eliminating Type II errors.

Table 4.12: Sample size calculation for the Snyder Hope Scale

Power calculations

Equation: $2N = \frac{4\sigma^2(z\alpha + z\beta)^2}{d^2}$

Where 2 N = total number of subjects, σ = standard deviation, $z\alpha$ = 1.96, with α = 0.05, and two-sided test, and $z\beta$ = = normal deviate for the power (0.84 with 80% power) and d = specified difference between the means. Formula from Davison et al (1986) (Davison, et al., 1986)

Hope at Baseline	Observed mean (M1)	23.00
	Observed SD (SD1)	4.00
Hope at Follow-up	Expected mean (M2)	20.00
	Expected SD (SD2)	4.00
σ		4.00
$z\alpha$, with significance level α= 0.05		1.96
$z\beta$ with 80% power (1-0.80 = 0.2)		0.84
d		3.00
Therefore number needed in each group was calculated to be:		28

Section 4.3: Materials, Setting and Participants

4.3.1 Catchment area profiles

All participants were drawn from urban and suburban areas in northwest Melbourne. To reduce identifying information the Local Government Areas (LGAs) and the service sites were identified by number only. LGAs are geographic areas that are under the control of a single local council. LGA1 and LGA2 were the areas where participants receiving the BFST program were drawn from, and LGA 3 to 6 were the areas where the comparison group were drawn from. The source of catchment area profile data is the Australian Bureau of Statistics 2006 Census (Australian Bureau of Statistics, 2007).

At the time of the study, Area Mental Health Services (AMHS) provided mental health services across designated LGAs through a number of site offices. There were five sites across the six LGAs and they were assigned a number code (1 to 5), again, to protect the privacy and identity of participants. Sites 1 & 2 represented the two treatment sites servicing LGA1 and LGA2 respectively,

under the administration of one AMHS (Treatment AMHS). Sites 3, 4 & 5 were the three comparison sites. Sites 3 and 4 serviced LGA3 and LGA4 respectively under the administration of another AMHS (Comparison AMHS 1), and Site 5 serviced two LGAs, LGA5 and LGA6 under the administration of a third AMHS (Comparison AMHS 2) (see Table 4.13).

Table 4.13. Coverage of Local Government Areas by Area Mental Health Services and site offices.

Area Mental Health Service	Treatment AMHS		Comparison AMHS 1		Comparison AMHS 2	
Serviced by	Site 1	Site 2	Site 3	Site 4	Site 5	
LGA	1	2	3	4	5	6

LGAs 1 and 3 covered urban areas with some areas of gentrification (for instance, the percent of professionals across these LGAs were 26.1 and 25.5, respectively). They extended northwards to well established suburbs with a relatively high percentage of overseas born from established CALD communities (percentage born overseas were 39.8 and 40.2, respectively), and less affluent lifestyles (Australian Bureau of Statistics, 2007).

LGA 2, 4 and 6 were outer urban LGAs. These were areas of rapidly expanding suburbia, with substantial numbers of young families (percentage of households consisting of a couple with children was approximately 55% in each area, and median age 32, 34 and 31 years, respectively). The percentage of people born overseas was slightly less than Sites 1 and 3 and the communities in these areas were more recently established CALD communities in Australia (Australian Bureau of Statistics, 2007).

LGA 5 was among the most disadvantaged LGAs in Melbourne (Australian Bureau of Statistics, 2007). It had a very high percentage of persons born overseas (just over 50%), and high unemployment rates.

Each LGA pair forming the three AMHS's were well matched on overall demographics and economic profile, which made them suitable for drawing comparison groups for the purposes of a quasi-experimental design.

See Table 4.14 for LGA profiles.

It should be noted that many of the areas from which participants were drawn had been identified as areas of multiple and serious disadvantage, affected by factors such as low income, early school leaving, long term unemployment, low work skills, high levels of forensic history, and low community engagement (Vinson, 2007). This would have implications for the complexity of required treatment and the opportunity for change for participants in treatment and usual care groups.

Table 4.14: Catchment area demographic profiles.

Area Mental Health Service	Treatment AMHS		Comparison AMHS 1		Comparison AMHS 2		Australian average
LGA	**1**	**2**	**3**	**4**	**5**	**6**	
Serviced by	**Site 1**	**Site 2**	**Site 3**	**Site 4**	**Site 5**		
Population	135,764	147,781	128,067	124,647	168,215	78,912	
Males n (%)	65,925 (48.6%)	73,138 (49.5%)	62,223 (48.6%)	61,761 (49.5%)	83,460 (49.6%)	39,352 (49.9%)	49.4
Median age	36	32	36	34	35	31	37
% Born OS	40	34	40	38	51	30	29
% LOTE home	45	42	46	47	59	30	21
% Married	44	53	43	56	51	54	50
% Family	43	56	44	56	52	55	45
% Unemployed	6	7	6	6	9	6	5
% Professional	26	11	25	12	12	13	20
% Home/mortgage	62	74	59	76	72	78	65
Income ($/week)	413	403	399	406	358	505	466
SEIFA	987	965	972	978	930	1010	1000

Source: Australian Bureau of Statistics Census 2006 (Australian Bureau of Statistics, 2007)
% Born OS = % overseas born
% LOTE home = % Speak Languages Other Than English at home
% Family = % couple families with children
% Home/mortgage = % own home or mortgage
Income = Median household income ($/week)
SEIFA = Socio-Economic Indexes for Areas – Index for Relative Socio-Economic Disadvantage 2006

4.3.2 Service descriptions

All the sites and AMHS belonged to a single administrative network and provided a similar range of services across their respective region at the time of

data collection. One type of service is provided by what were known as Continuing Care Teams (CCTs). The services of the CCTs are explained further below. All sites had CCTs at the time of recruitment. The investigator group implementing the BFST program chose the CCTs because they treated consumers for a sufficient duration required to carry out a BFST treatment, and consumers were generally adequately stabilised to engage in such an intervention.

Continuing Care Teams (CCTs) were nested in a range of mental health services that were provided by Area Mental Health Services at the time of the research. These services were for adults aged 18 to 64 years.

Within a continuum of care, acute services such as inpatient care, and crisis and assessment teams were provided. Longer term and intensive rehabilitation and care for people with substantial psychiatric disability were available at the Community Care Units (residential) and through Mobile Support Teams who provide assertive case management in the community. People with less disability associated with their mental health problems were treated via the CCTs; people with high prevalence disorders such as depression and anxiety, were managed through Primary Mental Health care teams that also provided consultation to primary health-care practitioners (e.g. General Practitioners (GPs)). A person being managed by the service might move from high to low intensity treatment, to final discharge, as their mental health improved. Some consumers at the service were on Community Treatment Orders (CTOs), meaning they had obligatory medication and treatment that was legally enforced under mental health legislation through one of the community teams.

4.3.2.1 The Continuing Care Team (CCT) model of care

The CCTs provided medium term treatment for consumers who had a severe mental illness (SMI) and could be managed in the community with relative independence. Criteria set by the Department of Human Services (now called the Department of Health)(the funding body) included:

- All registered consumers had a case manager

- A multi-disciplinary team reviewed all consumers at three monthly intervals at minimum.
- The services and treatments that were provided to CCT consumers included case management, medication, and access to crisis assessment and inpatient services if a crisis or deterioration should occur.
- All consumers were aged 16 to 64, lived within the designated geographical area, required case-management and were not able to access other suitable services in the community. After discharge from the CCT, many consumers were managed by GPs (with consultation support from the AMHS) in the community.

4.3.2.2 Mobile Support Team

Two treatment participants were in treatment with the Mobile Support Team at the time of recruitment. The Mobile support team (MST) provided intensive support to consumers in their homes as well as clinic-based support. Visits occurred as often as daily, and staff provided care from early in the morning until late in the evening, including weekends and public holidays. MST programs were based on the model of Assertive Community Treatment (L Dixon, 2000; C Harvey, H. Killaspy, Martino, & Johnson, 2011), which refers to actively managing consumers and following up with consumers who have not initiated contact. MST care was typically provided long term and was intensive and assertive in nature.

4.3.3 Participants

Participants were all drawn from CCT clinics at the 5 sites except for two treatment participants being treated by the Mobile Support Team while completing BFST sessions.

4.3.3.1 Inclusion and exclusion criteria

The inclusion criteria were intentionally broad reflecting the needs of implementation and effectiveness research. The implementation required the treatment to be available to all consumers who had family contact, including families of non-English speaking backgrounds and all family constellations. The

research criteria were the same as the treatment criteria, so if consumers met criteria for the program, they met criteria for the outcomes evaluation.

Participants were eligible to join the research if they were:

- Under case-management in a Continuing Care Team (CCT) in an AMHS at time of recruitment. A small number of cases (n=2) came from the Mobile Support Team (MST) due to particular needs of those families.
- A primary diagnosis of schizophrenia, schizoaffective disorder, delusional disorder or other psychotic disorder. Additional co-morbidities such as substance abuse or depression were acceptable and were noted.
- Living with family or in regular face-to-face contact with family (minimum weekly contact).
- CALD/NESB consumers were included and interpreters were arranged as needed.
- In addition to the above criteria, consumers and families from treatment sites were required to be involved in BFST sessions with their case-manager.

Exclusion criteria were:

- Any other primary diagnoses. A diagnosis of an affective disorder with psychotic features did not qualify for study inclusion. As noted above, secondary diagnoses or co-morbidities such as drug and alcohol abuse and depression were acceptable.
- For the comparison group, cases were excluded if the case-manager had undergone BFT training because of potential “contamination” issues, for example, normal treatment by these case managers could inadvertently include elements from BFT.
- For comparison cases, the family should not have been taking part in any alternative type of formal family program at the AMHS, such as Multi-Family Group interventions or Family Consultations. However,

participating in informal family meetings occurring as part of routine care was not an exclusion criterion.

These broad criteria meant that a diverse range of consumers could join the treatment program and, potentially, the research. Their age range, the duration of their mental illness, their co-morbidities, intellectual ability, ethnic identity, English language ability, whether the consumer lived with the family or not, and family constellation around the consumer were all highly varied. This meant that the treatment and comparison groups were quite heterogeneous, which was the "real world" of the effectiveness study.

It should be noted that a demographically variable group was likely to have high statistical variance as well (i.e. high standard deviation or variance). The effect would be to decrease power and lead to higher threats to statistical validity (see power analysis section above) (Davison, et al., 1986; Spaulding, 1992).

4.3.4 Measures

Selection of domains and instruments for measuring outcomes was based on a number of criteria. A domain for measurement was chosen if it met some of the following criteria:

- It had shown consistent sensitivity to change in previous research on BFT;
- It appeared to be a logical outcome of the intervention, according to program logic;
- In order to broaden the understanding of FPE outcomes, some were chosen because they were less frequently studied in previous research on family interventions, but some evidence of their relevance was available.
- If the instrument had sound psychometric properties
- If appropriate clinical or community norms were available, and/or cut-points for interpreting scores on the instrument.

For instance, as burden and experience of caregiving for family members has been shown to be sensitive to change in previous research (F. Pharoah, et al., 2010), but has been less frequently examined in family psychoeducation studies (Pitschel-Walz, et al., 2001) then reliable instruments measuring this domain were of interest. Similarly, quality of life, medication adherence, daily functioning, disability and role functioning have been infrequently studied in the context of family interventions, and yet shown to be sensitive to change (F. Pharoah, et al., 2010). A summary of the domains assessed and the measures used is presented in Table 4.15.

No specific recovery measure was chosen for this research, in spite of the emphasis on recovery. This decision was based on a number of reasons. Firstly, at the time of instrument selection (in 2006), the range of instruments that measured recovery and were psychometrically validated was extremely limited (Burgess, Pirkis, Coombs, & Rosen, 2010). Those that were available (such as the Recovery Assessment Scale (Giffort, Schmook, Woody, Vollendorf, & Gervain, 1995)) had not been tested for sensitivity to change (Burgess, et al., 2010), a crucial property for this research. Secondly, the addition of another measure would have contributed to further participant burden which was already substantial given the range of measures planned. Thirdly, a number of measures of functional recovery were selected instead (for instance role functioning or quality of life) as they had clearer links with the expected outcomes of an FPE program.

Table 4.15 Operationalisation of domains and selected instrument for the questionnaire

Concept	Definition of concept	Chosen instrument	Operationalisation
Hope	The expectation of goal attainment (Stotland, 1969)	Snyder Hope Scale ((Snyder, et al., 1991)	Measures agency hope (i.e. positive expectations) and pathways hope, (i.e. the ability to plan pathways to achieve goal) (Snyder, et al., 1991)
Family functioning	Family functioning identified with 6 dimensions, problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control	The McMaster Family Assessment Device: General Functioning Scale (FADGF) (Epstein, Baldwin, & Bishop, 1983)	The 60 item FAD covers all 6 dimensions with 6 subscales. The FAD General Functioning (FADGF) scale does not have a direct correspondence with each dimension, but had inter-correlation with the scale over all, indicating a coverage of the general areas identified
Function and disability	Function and disability assessed for the impact of mental illness on treatment and rehabilitation needs. It is part of assessment on four levels: 1. pathology, (e.g. nervous system lesions) 2. impairment, (psycho-physiological symptoms linked to pathology such as negative and positive symptoms) 3. disability and function (restriction in normal activities due to impairment) 4. handicap (societal disadvantage such as unemployment).	The Life Skills Profile (LSP) (Rosen, Hadzi-Pavlovic, & Parker, 1989)	Scale measures self-care, turbulence (offensive or difficult behaviour to others, drug use) social withdrawal and amotivation, bizarre or odd ideas/speech, poor medication/treatment adherence
Role functioning	Functioning in main role domains in adult life	The Role Functioning Scale (RFS) (Green & Gracely, 1987)	Rates role performance in main areas of adult role responsibility; personal self/care, cognitive/affective functioning, social/familial relationships, and vocational/educational.
Burden	Consequences experienced by carers and family in caring for relatives with mental illness (but also includes non-family carers). Objective burden relations to the observable disruption to the family and household, and subjective burden is the feeling of burden being carried	The Family Burden Scale (Pai & Kapur, 1981)	The scale reviews the effects of caring for consumer on finances, home routine, family leisure, family interaction, physical health of family members, mental health of family members and subjective burden (suffering). These areas were said to cover the domains most frequently affected by caring for a person with a mental illness

Concept	Definition of concept	Chosen instrument	Operationalisation
Caregiving	Appraisal of the demands of caring for a mentally ill person, incorporating coping and mediating factors (e.g. social support)	The Experience of Caregiving Inventory (ECI) (G. I. Szmukler, et al., 1996)	High score on the scale predicts psychological distress, mediated by coping strategies as expected. Measures loss, dependency, difficult behaviours, negative symptoms, stigma, working with mental health services, effects on family and positive aspects of caring
Psychiatric outcomes/Daily functioning	Symptoms and functioning affected by psychiatric illness and generally the focus of improvement for psychiatric treatment	The BASIS-32 (S.V. Eisen, Grob, & Klein, 1986)	Behavioural focus, assesses a mixture of impairment and function, rather than function alone
Medication adherence	Adherence to prescribed medication regimen	The Drug Attitude Inventory (DAI) (Hogan, Awad, & Eastwood, 1983)	30 True/False questions about how a consumer feels when on medication, but not what a consumer knows, or believes about medication. It forms a useful predictor of medication adherence
Mood state	Mood state is a person's subjective feelings, affect, mood or emotion	The Profile of Mood States (POMS) (Bech, 1993; McNair et al, 1991; Moore et al, 1991)	The scale measures six identifiable mood states; Tension / Anxiety; Depression / Dejection; Anger / Hostility; Vigour / Activity; Fatigue / Inertia; Confusion / Bewilderment
Psychological distress	Psychological distress is the feeling of worry, strain and being overwhelmed by demands	General Health Questionnaire (GHQ-28)	The GHQ measures distress in somatic symptoms, inability to carry out one's normal functions, feelings of distress and sadness, and thoughts of self-harm and suicide.
Quality of Life	Individual's perception of their position in life in the context of culture and value systems and in relation to their goals, expectations, standards and concerns	The WHOQOL-Brèf	26 questions on: Physical health; Psychological health; Social situation; Home environment; Does not seek person's explicit comparison to own values, or for comparison with others, but asks for personal assessment of 'satisfactions' in above areas
Social Isolation	Felt social isolation is living without companionship, social support, or connectedness, being an outsider, isolated, feeling loneliness, and low levels of social contact	Friendship Scale (G. Hawthorne, 2006).	Scale measures issues around getting In touch with others, feeling separate, feeling isolated, feeling alone and friendless and ease of relating to others. Measures perceived social isolation, not objective or actual social isolation

4.3.4.1 Self Report Instruments

Instruments that were completed by the consumer and carer via self-report are described below. All measures were used twice, once at baseline and again at follow-up, with both groups.

The following measures were utilised exclusively in the PhD and were completed by both carer and consumer:

The **Snyder Hope Scale (SHS)** is a twelve item scale developed to measure hope, conceptualised as the "expectation of goal achievement" (Snyder, et al., 1991). Four items on the scale each measured "agency" hope (the motivation and expectation of goal achievement) and "pathways" hope (the capacity to generate pathways to goals), and four items were "fillers". The SHS offered superior psychometric properties compared to other hope scales (Ahmed & Duhamel, 1994; Babyak, et al., 1993; Staats, 1989; Steed, 2002) (see discussion in Chapter 2), low participant burden, and extensive population and clinical norms (Snyder, 2002; Snyder, et al., 1991) (although mainly with American populations, see Chapter 5, Table 5.34).

Family Assessment Device General Functioning Scale (FADGF) (I. V. Miller, Epstein, Bishop, & Keitner, 1985.) is a 12 item scale based on the McMaster conceptualisation of healthy family functioning. High scores indicate higher levels of family dysfunction such as poor role clarity, higher conflict, less emotional intimacy and poor problem solving. The FADGF is highly correlated with the full 60 item Family Assessment Device (FAD) scale, and is an effective brief measure of family functioning (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990; I. V. Miller, et al., 1985.). It was selected because it was relevant to targeted outcomes of family intervention (F. M. Pharoah, Mari, & Streiner, 2004), and offered low participant burden (Byles, Byrne, Boyle, & Offord, 1988), availability of clinical and population norms and ease of interpretation (I. Miller, Bishop, Epstein, & Keitner, 1990).

The following measures were utilised in the PhD analysis and also formed part of the concurrent outcomes study and were completed by both carer and consumer:

The **Friendship Scale (FS)** is a six item scale that measures social isolation (G. Hawthorne, 2006). Each question has a five-item response set (1=almost always/ 2=most of the time/ 3=about half the time/ 4=occasionally/ 5= not at all). The scale range is 6 to 30 with high scores indicating high levels of connectedness and friendship. With only six items it has low participant burden as well as good psychometric properties and population norms for the Australian community (G. Hawthorne, 2006; G Hawthorne, 2008).

The **World Health Organisation Quality of Life Questionnaire, brief form (WHOQoL-Brèf)** measures quality of life in four domains; physical, psychological, social relationships and environment (The WHOQOL Group, 1998b; WHOQoL-Group, 1998). It has 26 questions with varying 5 level response sets. Subscale scores were converted to a percent scale. Higher scores indicated better quality of life. Population norms were available for Australian samples (G Hawthorne, 2008).

The carer completed the following instruments only. The instruments covered domains relevant to carer mental health and amenable to change from interventions. They were:

The **Experience of Caregiving Inventory (ECI)** (66 items) (G. I. Szmukler, et al., 1996) rated the concerns and experiences of carers in the areas of stigma, getting professional care for their relative, loss and grief, concerns about behaviour and supervision. Each item asks carers to assess the occurrence of thoughts regarding a concern as Never/Rarely/ Sometimes/Often/Nearly Always in the past month. Instead of an exclusive focus on negative burden, the ECI (Stuckey, Neundorfer, & Smyth, 1996; Stull, Kosloski, & Kercher, 1994; Webb et al., 1998) measured some constructive outcomes of caregiving such as increased sense of agency and positive experiences with the consumer and other helpful people. The ECI was developed in Australia, with carer groups similar in background to the present study, and had good ecological validity with items based on an analysis of carers' actual descriptions of the caregiving experience (G. I. Szmukler, et al., 1996). At 66 items, it generates considerable participant burden.

The **Profile of Mood States (POMS)** (McNair, Lorr, & Droppleman, 1981) consists of 65 one-word items. Questions were rated Not at all/ A little/ Moderately/Quite a bit/ Extremely for presence of that mood state in the past week, which is sufficient to demonstrate consistent mood, but short enough to reflect recent changes and treatment effects (McNair, et al., 1981). The mood states measured were Tension - Anxiety, Depression - Dejection, Anger - Hostility, Vigour - Activity, Fatigue – Inertia and Confusion-Bewilderment. Subscales were combined (reversing the scoring of the Vigour subscale) to obtain a single measure of overall emotional turbulence, a "global estimate of affective state" (McNair, et al., 1981) (p 9), called the Total Mood Disturbance Score (TMD).

The **General Health Questionnaire (GHQ-28)** (Goldberg & Williams, 1988) (28 items) measured depression, anxiety and psychological distress. The scale was scored using the "GHQ" method, which has been used for norming and validity testing for the GHQ-28 (Goldberg & Williams, 1988). It uses a dichotomous response scale which focuses on 'pathological deviations' where responses of 'less than' or 'no more than usual' were scored '0' and 'rather more' and 'much more than usual' were scored '1'. Scores of 5 or more indicated a high possibility that clinically diagnosable depression or anxiety is present (Goldberg & Williams, 1988).

Consumers completed the following instruments:

The **Behaviour and Symptom Identification Scale – 32 item (BASIS – 32)** (S.V. Eisen, et al., 1986), is a 32 item instrument that covers a range of behavioural and symptom areas. It can discriminate between consumer informants with different diagnoses, but has low correlations between ratings of a consumer informant and those of a family informant (Susan V. Eisen, Dill, & Grob, 1994; S.V. Eisen, et al., 1986; S.V. Eisen, Wilcox, Leff, Schaefer, & Culhane, 1999). It shows sensitivity to changes in consumer mental health and functioning (S.V. Eisen, et al., 1986; S.V. Eisen, et al., 1999). The BASIS-32 has been widely used in public mental health services (State Government of Victoria, 2009).

The **Drug Attitude Inventory (DAI)** is a scale that measures attitudes to medication use, including opinions about side effects, symptom control, relapse prevention and personal choice about treatment. It was highly predictive of medication adherence (Hogan, et al., 1983). It consists of 30 statements rated true or false by the respondent.

Demographic questions were administered. These were gender, age, country of birth and ethnicity, relationship status, educational attainment, employment status, housing, relationship between consumer and carer and level of contact between carer and consumer.

Concurrent with data collection from the carer and consumer, case managers completed two questionnaires regarding the consumer. They were:

The **Life Skills Profile (LSP)** is a16-item scale rated on a four-point response set to measure functional difficulties (lower scores representing greater difficulty). The full 32-item scale has five subscales: self-care, non-turbulence, social contact, communication, and responsibility (Rosen, et al., 1989). The shorter 16-item version used in the present study does not contain the communication subscale. It has been used with Australian community mental health service samples and has acceptable reliability and validity (Hambridge & Rosen, 1994; Keller & Hayes, 1998; Parker, O'Donnell, Hadzi-Pavlovic, & Proberts, 2002; Parker, Rosen, Emdur, & Hadzi-Pavlovic, 1991; Trauer, Duckmanton, & Chiu, 1995, 1997).

The **Role Functioning Scale (RFS)** (Green & Gracely, 1987) has 4 scales, which rates role performance in the areas of adult role responsibility; personal self/care, cognitive/affective functioning, social/familial relationships, and vocational/educational areas.

Treatment and medication information was obtained from case histories and the clinic computerised data bank. The information obtained was:

- Diagnosis and co-morbidities.
- Number and duration of hospital admissions for the 12 months before the baseline interview and 10 months before the follow-up interview.

- Number of crisis assessment and treatment team (CATT) attendances for the 12 months before the baseline interview and 10 months before the follow-up interview.

- Number of minor crises/relapses defined as noticeable exacerbations of symptoms necessitating a review with change of treatment plans and /or medication, for the 12 months before the baseline interview and 10 months before the follow-up interview

- Number of service contacts (face-to-face) for the 12 months before the baseline interview and 10 months before the follow-up interview

- Medication type and amount (in Chlorpromazine equivalents). Only medication prescribed was recorded, medication actually used was not probed.

- Number of BFST sessions (for treatment cohort).

Service use information was not analysed for the PhD and was collected for the purposes of the outcome study only.

4.3.4.2 Data collected via semi-structured interview

Further data was collected via semi-structured interview. Both consumers and carers, in treatment and comparison groups, completed short interviews on hope, focusing on their goals for the upcoming year, their enthusiasm for and confidence with these goals, and strategies and plans to achieve these goals. These questions were directly based on Snyder's conceptualisation of hope. These were administered at baseline and follow up. Field notes were taken at the time of the interview and later transcribed into a database for analysis. The areas of goals that were probed were general goals, goals related to family members, and goals related to current treatment. See Appendix 8 for the interview schedule.

Carer burden was further explored in the **Family Burden Interview (Pai & Kapur or P&K)** (Pai & Kapur, 1981), a semi-structured interview that covers some of the main areas of carer burden, including financial concerns, effects on daily routines, leisure time, mental and physical health of family members

(26 items). The interviewer (LH) assigned scores of 0 = No burden, 1 = Some/moderate burden and 2 = Severe burden according to interviewee reports, at the conclusion of the interview. The interview was carried out at baseline and follow up, for carer only. Field notes were taken in most interviews. For six baseline and seven follow up interviews, the interview was taped as well and later transcribed.

At the follow-up interview, a short interview was also administered to carer and consumer of the treatment group only, to obtain views on treatment satisfaction, skills learnt, and changes for self and family after the intervention. Field notes were taken at the time of the interview. See Appendix 9 for the interview schedule.

The instruments are summarised in Table 4.16 and Table 4.17 and the full assessment schedule for carer and consumer, at baseline and follow-up are in Appendix Section 1.

Table 4.16: Summary of consumer instruments

Outcome	Measure	Informant
Demographic	Socio-demographic data	Consumer
Hope	Snyder Hope Scale (Snyder, 1991) (Snyder, et al., 1991)	Consumer
	Qualitative Hope interview	Consumer interview with researcher
Family Functioning	The McMaster Family Assessment Device: General Functioning Scale (FADGF) (Epstein 1983) (Epstein, et al., 1983)	Consumer
Social engagement	Friendship Scale (Hawthorne, 2006) (G. Hawthorne, 2006)	Consumer
Satisfaction with life, quality of life	The WHOQOL-Brèf (The WHOQoL Group, 1998) (The WHOQOL Group, 1998a)	Consumer
Physical health	The General Health Question	Consumer
Medication adherence and use	The Drug Attitude Inventory (DAI) (Hogan 1983) ((Hogan, et al., 1983)	Consumer
	Medication	Case note review (Outcomes evaluation only – not used for PhD)
Daily functioning and symptoms	The BASIS-32 (Eisen, 1986) (S.V. Eisen, et al., 1986)	Consumer
	The Life Skills Profile (LSP) (Rosen 1989) (Rosen, et al., 1989)	Case manager
	The Role Functioning Scale (RFS) (Green 1987) (Green & Gracely, 1987)	Case manager
Relapse and treatment	Relapses, admissions	Case note review and computer records (Outcomes evaluation only – not used for PhD)
Treatment satisfaction	Interview with researcher	Consumer interview with researcher - Treatment group only

Table 4.17: Summary of Carer instruments

Outcome	Measure	Informant
Demographic	Socio-demographic data	Carer
Hope	Snyder Hope Scale (Snyder, 1991) (Snyder, et al., 1991)	Carer
	Qualitative Hope interview	Carer interview with researcher
Social engagement	Friendship Scale (Hawthorne, 2006) (G Hawthorne, 2008)	Carer
Family functioning	The McMaster Family Assessment Device: General Functioning Scale (FADGF) (Epstein 1983) (Epstein, et al., 1983)	Carer
Satisfaction with life, quality of life	The WHOQOL-Brèf (The WHOQoL Group, 1998) (The WHOQOL Group, 1998a, 1998b)	Carer
Physical health	The General Health Question	Carer
Psychological distress	General Health Questionnaire (GHQ-28) (Goldberg, 1988) (Goldberg & Williams, 1988)	Carer
	The Profile of Mood States (POMS) (McNair, 1991) (McNair, et al., 1981; Moore, Stambrooke, Peters, & Lubusko, 1991)	Carer
Caregiver experience and burden	The Experience of Caregiving Inventory (ECI) (Szmukler 1996) (G. I. Szmukler, et al., 1996)	Carer
	The Family Burden Scale (Pai and Kapur, 1991)(Pai & Kapur, 1981)	Carer interview with researcher
Treatment satisfaction	Interview with researcher	Carer interview with researcher - Treatment group only

Section 4.4: Study procedures

4.4.1 Ethics

Ethics approval for the research was obtained from Melbourne Health (Project Number 2006.027, Application Date 9.8.2006) and The University of Melbourne Human Research Ethics Committee (ID # 0830546 dated 23 October 2008).

The research procedures and protocol were designed and carried out in a manner consistent with the Helsinki Declaration (World Medical Association, 2008).

The protocol was designed to ensure consent was freely given and occurred separately from the pre-existing clinical relationship. Given a level of dependence by the consumer and family on a clinician in a therapeutic relationship, a situation could arise that consent might be given under duress if a clinician sought consent for research directly. Thus clinicians could not be involved in the research consent procedure (World Medical Association, 2008).

Another consideration was the protection of consumer and carer privacy. To manage duress and privacy concerns, case managers asked if contact details of potential participants could be passed on to researchers after the consumer or family member agreed, and then the researcher could seek consent with them independently of their clinical relationships.

4.4.2 Recruitment procedures

Participants were recruited from five sites in urban and suburban Melbourne described previously, where they were receiving case management. The researcher had no direct access to any consumers, since they were engaged in confidential psychiatric treatment. The process of identification of eligible families was different for treatment and comparison groups, but the recruitment methods were the same. Comparison group families' recruitment is shown in **Figure 4.4**. The flow chart of recruitment procedures for treatment group families is depicted in **Figure 4.5**.

Figure 4.4: Flowchart of recruitment for comparison group

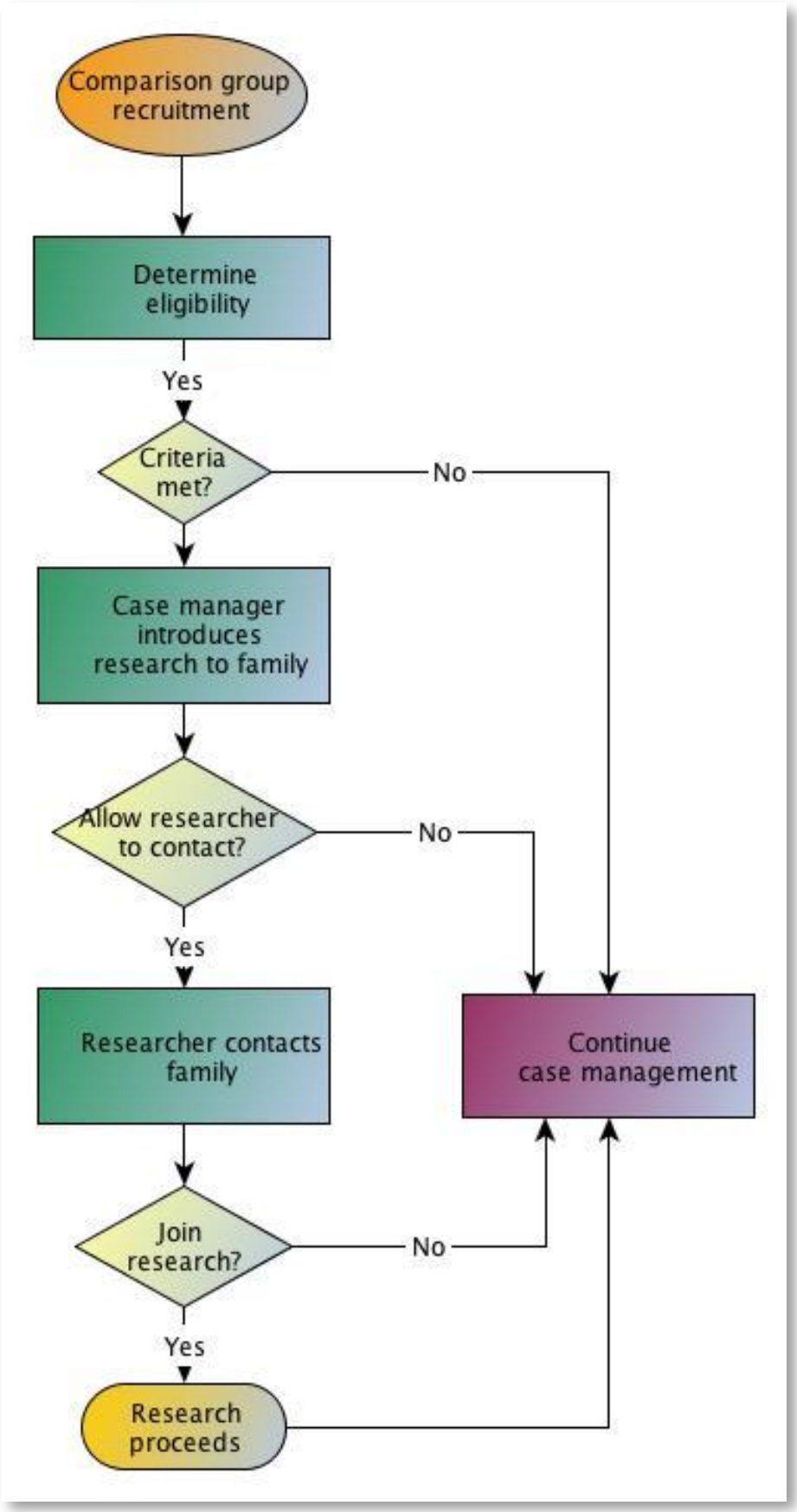
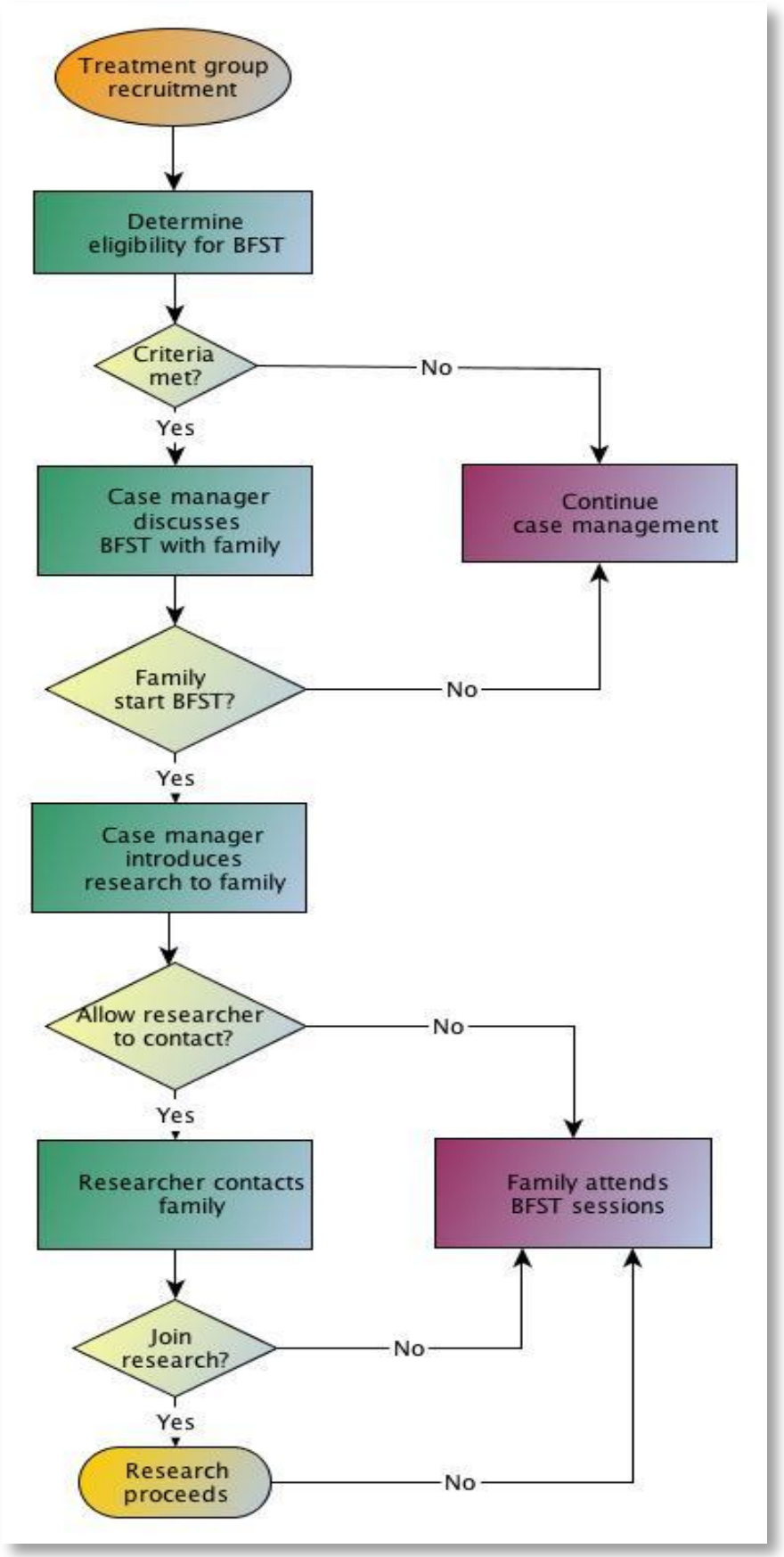


Figure 4.5: Flowchart of recruitment for treatment group



4.4.2.1 Identification of eligible consumers and families

Families participating in the BFST program were selected for treatment on clinical grounds only, not on their suitability for research. Once a consumer and their family committed to attending BFST sessions at Clinic 1 or 2, they were considered eligible for the outcomes and PhD research. The case manager asked if they consented to the researcher contacting them. If they gave their verbal consent to be contacted, then their names and phone numbers were passed to the researcher. The case manager did not ask them to join the research, only if contact details could be passed on to the researcher. This protected the privacy of the putative participants and was a requirement of the ethics approval. It also removed the need for treating clinicians to be involved with consent procedures for the research.

For the comparison group the procedure differed, since consumers were not receiving BFST sessions, so that identifying those eligible occurred another way. The researcher reviewed the de-identified case list with the case managers of the comparison services, deciding which cases met the inclusion criteria. Consumers and their families met eligibility criteria if they were under case management in a CCT, had a diagnosis of schizophrenia or other psychotic disorder and were living with or having regular face-to-face contact with family (see 4.3.3 Participants). If the case manager was trained in BFT, their case list was ineligible, in order to avoid treatment "contamination" (see 4.3.3.1 Inclusion and exclusion criteria).

The case manager then had a list of eligible candidates to be approached. On average, two or three suitable cases would be identified per case manager. The case manager then contacted the eligible consumers and their families, briefly explained the research and asked if contact details could be passed to the researcher. Case-managers were provided with an information flier (see Appendix 4.1) for consumers and families, which briefly outlined the research and this flier could be handed to consumers and families. This meant that information was given to consumer and families in a consistent manner.

The researcher also made suggestions on introducing the research to the consumers and families of case managers. The suggested script focused on a

brief explanation of the research, with a request for verbal consent for the researcher to contact them. On obtaining this verbal consent (for initial contact only), the case manager passed on the contact details to the researcher as set out in the ethics agreement. See Appendix 5 for the script details.

While still protecting privacy, case managers could also provide risk assessment information to the researcher so that interviews could be scheduled for the clinic rather than the home if appropriate. Case managers could also advise the researcher if deferral of an interview was necessary due to relapse or crisis. This was the case for both treatment and comparison participants.

4.4.2.2 Recruitment

Once the contact details were passed to the researcher, the researcher then made contact with the consumer and/or family via telephone call. The script for this call is appended (See Appendix 2). In this telephone call, the researcher provided their name, role and institution. The research was briefly introduced, and the requirements of participation were explained. If the consumer or family agreed to proceed, an appointment was made for the research interview. Written consent was obtained at the beginning of the research interview.

4.4.2.3 Consent

The interview began with a brief explanation of the research. Then the "Participant information and Consent Forms" were reviewed (included in Appendix Section 3). The researcher summarised the main points, then the participants either read the forms or the researcher read them to them. It was made clear that participants could withdraw at any time, and that whether they participated or not would make no difference to their treatment, and that confidentiality would be maintained at all times. The requirement of a follow-up interview was also clarified. Any questions were answered.

When the researcher and participants were satisfied that the demands of the research were adequately understood and the consumer was competent to consent, the consent forms were signed. The researcher confirmed that consumers and carers adequately understood the research, by asking them to

explain what they believed the research demands were (Sieber, 1992). The issue of competence mainly related to the consumer. The researcher relied on clinical judgement at the time, and also on case manager assessments of current mental state.

For the consumer, consent was obtained for additional data collection. Firstly, consent was requested to access medical records for information on medications, and secondly consent was requested to access computerised databases (CMI-RAPID) held by the AMHS. This was to ascertain the amount and type of services accessed by a consumer (days in hospital, case manager contacts etc).

Since the BASIS-32 was administered as a routine outcome measure at each AMHS, consent was also obtained from the consumer to feedback the results of the BASIS-32 instrument to case managers. This would save the consumer completing another BASIS-32 with their case manager.

Extra copies of the participant information form and photocopies of the consent form were returned along with a thank you letter after the interview was concluded. The consent form included a form for rescinding consent, in case participants decided to withdraw consent at any time.

Table 4.18: Recruitment statistics by site for consumer

Cohort	Site	Start BFT*	Asked	Agree contact	Contact	Base-line	Lost	Follow-up	In CM
		n	n	n	n	n	n	n	n
BFST	1	32	26	24	19	19	4	15	12
	2	21	16	15	12	11	3	8	6
TAU	3	-	20	13	13	10	3	7	6
	4	-	21	12	11	9	3	6	4
	5	-	41	20	19	13	2	11	11
Totals			124	84	74	62	15	47	39

* Cases with diagnosis of schizophrenia only

Ask = Consumers approached by case managers; Agree contact = agree to contact; Contact = contacted to join research; base-line = interviewed at baseline; Lost = lost to follow-up because not contactable or declined interview at follow-up; Follow-up = completed follow-up questionnaires; In CM = still in case-management at follow-up.

4.4.2.4 Barriers to recruitment

Barriers to recruitment to the research program differed between the treatment and case-management only groups. Barriers for the treatment group occurred at the level of treatment uptake and have been discussed in Chapter 3 on the BFST program and it's implementation. Information on the particular barriers in this cohort was not collected in the outcomes or the PhD study, but some qualitative data was collected within the linked study conducted and reported by O'Hanlon (B. O'Hanlon, 2013). From Table 4.18, it can be seen that a response rate of 71% (30/42) was achieved for the treatment group.

For the comparison group, barriers occurred at two stages in the procedure: firstly, case managers identifying and contacting eligible consumers and their families to explain the research and asking if contact details could be passed to the researcher; and secondly, at the stage when consumer and family joined the research after researcher contact. A response rate of 39% (32/82) was achieved for the comparison group.

The following difficulties with this procedure were identified and recorded in the research log pertaining to recruitment (Sharkey, Savulescu, Aranda, & Schofield, 2010):

- Case-managers reported they had insufficient time to assist with recruitment;
- Case-managers reported eligible families in crisis, consumer unwell or otherwise not appropriate for research at this time;
- Case managers misunderstood the eligibility criteria;
- Case manager misunderstood research aims and feared that they would be evaluated rather than the treatment; and
- Case managers had no eligible consumers (e.g. specialised in another diagnosis, or none of case manager's clientele lived with family).

Activities described in the following section were undertaken to reduce the identified barriers. Although recruiting in this manner made the process more complex it was essential for protecting consumer and family privacy.

4.4.2.5 Activities to enhance recruitment

Considerable effort was required to enlist the case managers in the recruitment effort, at both the treatment and comparison sites (Howard, de Salis, Tomlin, Thornicroft, & Donovan, 2009; Sharkey, et al., 2010; J. M. Watson & Torgerson, 2006). At the commencement of the evaluation, there were meetings and presentations with each CCT. The presentation included an introduction to the BFST program and information on BFT. The positive effects of BFT on relapse and carer burden were explained. The evaluation procedures were discussed, including the role of case-managers in the recruitment procedures. Flyers were handed to case managers outlining the research (see Appendix 4.2).

The researcher used a number of methods to minimise the recruitment demands on case-managers. Flyers for families and suggestions on approaching consumers and families were given to case managers as detailed above in the eligibility section.

4.4.2.6 Identification of eligible consumers and families

The researcher made numerous visits to the comparison sites, with fortnightly contact from January 2007, to the end of March 2008. This built personal relations with case managers, and also provided ongoing opportunity for the researcher to review de-identified case-lists and identify eligible consumers.

During meetings with case managers the researcher reviewed the case managers' understanding of eligibility and answered any questions about the research. Any misunderstandings were clarified. Case managers were also "coached" in conducting conversations with consumers and families about the research, with emphasis that they were not responsible for obtaining consent and to only ask if contact details could be passed to researchers. This ensured that consent procedures were clearly separated from clinical relationships.

The major concern was that recruitment of comparison cases was very slow. The recruitment of treatment cases was also very slow and limited by the number of cases that entered treatment. As a result recruitment to both cohorts was not high, although ultimately met criteria set for minimum numbers obtained from power calculations.

4.4.3 The research interview

Most interviews took place in the participant's home. Managing the risks inherent in home visiting is discussed below (in section 4.4.6 Risk management and adverse events). In the majority of cases, the researcher met with the consumer and family member simultaneously as they were living in the same residence (n=48). Otherwise, separate appointments were made where the consumer and carer lived apart. In some cases, the researcher met at the local CCT clinic (n=16). This was mostly to convenience participants, since the research appointment could be made before or after a routine visit to the clinic. In one case, the researcher met the family at the clinic because of documented risk for home visiting.

After written consent was obtained (see Section 4.4.2.3 Consent), participants were given the questionnaire booklet to complete. Mostly, carers were able to complete it independently. About half of the consumers completed the

questionnaire independently as well. For the remainder, the researcher facilitated the completion of the questionnaire. Facilitation usually required the researcher reading the questions and answer options to the participant. Often the participant looked on, so they could read alongside.

The carer questionnaire usually took about 45 minutes, and the consumer questionnaire about 40 minutes.

If the carer and consumer were able to complete the questionnaires independently, the carer, consumer and researcher all sat in the same room to do the questionnaires since the researcher was on hand to help both of them. For the interview component or when participants chose to do the questionnaire via interview, the researcher obtained a private space to ensure the interviewee could answer independently.

The researcher then completed the brief interview of the qualitative questions on hope with the consumer. Once the consumer questionnaire and interview was completed, then the researcher interviewed the carer about the challenges of caring (the Pai and Kapur Burden of Care interview) and the qualitative questions on hope. It took approximately 20 minutes to complete the interview, and 20% (1 in 5) of interviews were taped (with consent) on a small unobtrusive digital recorder and later transcribed. For all other participants, field notes were taken during the interview.

At the conclusion of the interviews, the researcher thanked the family and a thank you letter was sent to the consumer and carer soon after the interviews, with copies of consent forms enclosed.

4.4.4 Working with participants of non-English speaking background

As was discussed in the profiles of the recruitment sites, there were sizeable NESB/CALD communities in the AMHS catchment areas. Interpreters were used to ensure all families had access to treatment and were able to participate in the research if they chose. The interpreters came from an interpreter service that routinely provided interpreter staff to AMHS, and had previous experience in working with mentally ill people of NESB.

Where interpreters were required, they attended the family interview with the researcher. The participant information and consent forms were completed in a three-way conversation between participant, interpreter and researcher. The questionnaire was completed with the interpreter translating the questionnaire from English into the participant's first language, and the participant responding according to the response set given for each question. The interpreter would complete the questionnaire booklet for the participant. The researcher supervised the process.

Because this process was slow, the research meeting was quite lengthy and increased participant burden. Some sections of the questionnaire were not completed in these circumstances, especially the open-ended interview sections of the questionnaire.

Interpreters were used with 2 consumers and 3 carers. Although a much higher percentage of participants were born overseas, their level of English was proficient enough to enable the research interview to occur without interpreters.

4.4.5 The follow-up interview

The researcher made phone re-contact with the consumer and carer to book the follow-up interview conducted 10 months after the initial interview.

At the time of follow-up, 44 (92%) were still in case-management with 8% discharged from the AMHS. Discharge destinations included rehabilitation services, private psychiatrists and primary health-care practitioners (usually General Practitioners). The follow-up interview followed the same procedures as the baseline interview, except for one extra set of questions for the treatment cohort, regarding treatment satisfaction. In all other respects the interview was the same as before and the same for both treatment and comparison group.

4.4.6 Risk management and adverse events

In cases where the researcher noticed that the carer had high scores on the GHQ-28, very low scores on the WHOQoL-Brèf, or showed signs of distress in an interview, the researcher referred them to their relative's case manager or

carer consultants at the AMHS either at the time or by follow-up phone call. Four carers were distressed or had extreme scores on their questionnaires and were referred to Carer Consultants at their service (2 treatment group and 2 comparison group).

One consumer who became distressed during interviews was referred to their case manager. These procedures were agreed to in the ethics proposal and also explained in the Participant Information and Consent Form (Appendix 4.3).

The researcher conducted interviews in participants' homes, which presented potential risks associated with threatening situations occurring in a non-clinical environment, without back up from other staff. The researcher followed standard protocols for the AMHS for home visits, such as: informing office staff of interview schedule and destination, advising when interview completed, and obtaining risk assessment advice from case managers before attending participants' homes. At no time did a threatening situation occur.

Section 4.5: Data analysis

4.5.1 Data entry and data management

Interviews booklets were checked at the time of interview, and again shortly afterwards, to reduce missing data. Contact data was entered on an Excel spreadsheet to track interview dates, cohort, site and contact details. The identifying data in this file was destroyed at the end of the final follow-up interviews.

Questionnaire data, identified only by a number, was entered directly onto an SPSS data file (SPSS, 2007) for analysis. Ten percent of questionnaire data was checked for error in data entry as a verification procedure. Negligible errors were noted.

4.5.2 Data analysis

Data preparation: Missing values within scales were imputed by horizontal mean imputation (G. Hawthorne & Elliott, 2005). No attempt was made to impute categorical missing data (e.g. gender). Skew was assessed and non-normal data was transformed using appropriate transformations. Where

transformation was used, the descriptive statistics were presented before transformation for readability, and statistical procedures carried out on transformed data. If data could not be normalised, then non-parametric statistics were used.

Data analysis: Categorical data is reported as frequencies with percentages. Scale reliabilities were reported using Cronbach α. Effect sizes were calculated with Cohen's d. Cohen's classification of effect size was as follows: scores of d=0.20 indicate a small effect, d=0.50 a moderate effect and d=0.80 a large effect (J. Cohen, 1988).

Pearson correlations were calculated to show correlations between scales. Chi-square was used with categorical data. Parametric statistics (*t*-test, ANOVA, Pearson correlation and regression analysis) were used in analyses for normal data or normalised data.

Two-tailed statistical probabilities were used because there were little or no previous studies in the area to support directional (one-tailed) hypotheses.

Level of significance: Level of significance was set at $p < 0.05$, with no Bonferroni adjustment (Perneger, 1998; Rothman, 1990). The Bonferroni adjustment is appropriate where the universal null hypothesis is relevant. The universal null hypothesis in this instance would be that the treatment and comparison groups were equal on all variables. The universal null hypothesis was not tested in the present analysis. Instead, hypotheses about individual variables were tested.

Setting the level of significance lower with a Bonferroni adjustment, while decreasing Type I error, would also increase Type II error (accepting the null hypothesis when it was not true). Both Type I and II errors are equally important in clinical research, since Type I errors lead to accepting ineffective treatments and Type II errors lead to the potential rejection of an effective treatment. A Bonferroni adjustment would lead to an unacceptable imbalance between the two types of error (Perneger, 1998).

The strategy was to report all significance testing at the 0.05 level, the number of tests carried out and their context (Rothman, 1990).

Statistical analyses were performed using SPSS Version 16.0.1 (SPSS, 2007).

Hypothesis testing: In order to test the following hypotheses, the following data analyses were undertaken.

4.5.2.1 Primary research hypothesis

1. That the BFST program would significantly improve hope in consumers and caregivers when compared with a case management only group (treatment as usual or comparison group) over 10-months.

An ANCOVA was performed using Snyder Hope Scale pre- and post-scores, comparing treatment and comparison groups. Demographic measures were used as co-variates. A two-tailed test was used, since there was insufficient evidence from previous studies to support a one-tailed hypothesis.

4.5.2.2 Subsidiary research questions

2. Following the logic of the recovery paradigm, were levels of hope in consumers independent of the levels of symptoms? Was hope a predictor of the other measures of recovery, such as social connection, role functioning and quality of life for consumers?

A regression was planned to analyse the effects of the predictor variables, changes in consumer hope, treatment type and selected demographics, onto the criterion variable, changes in consumer recovery outcomes. A two-tailed test was used, since there was insufficient evidence from previous studies to support a directional (one-tailed) hypothesis. As explained in Chapter 5 and 6, the planned regression was abandoned for (two-tailed) correlation procedures instead.

3. Was hope a predictor of burden for caregivers? Was hope a predictor of the other measures of wellbeing for carers, such as social connection or quality of life?

A regression was planned to analyse the effects of the predictor variables, changes in carer hope, treatment type and selected demographics, onto the criterion variable, changes in carer burden. A two-tailed test was planned, since there was insufficient evidence from previous studies to support a directional

(one-tailed) hypothesis. As explained in (2) above, the planned regression was abandoned for (two-tailed) correlation procedures instead.

4. a. Was consumer Hope at follow up predicted by: hope in carer family member, family functioning, or treatment type?

A regression was planned to analyse the effects of the predictor variables, changes in carer hope, changes in family functioning (consumer version), treatment type and selected demographics, onto the criterion variable, changes in consumer hope. A two-tailed test was planned, since there was insufficient evidence from previous studies to support a directional (one-tailed) hypothesis. As explained in (2) above, the planned regression was abandoned for (two-tailed) correlation procedures instead.

4. b. Was Carer Hope at follow up predicted by: hope in consumer family member, family functioning, or treatment type?

A regression was planned to analyse the effects of the predictor variables, changes in consumer hope, changes in family functioning (carer version), treatment type and selected demographics, onto the criterion variable, changes in carer hope. A two-tailed test was planned, since there was insufficient evidence from previous studies to support a directional (one-tailed) hypothesis. As explained in (2) above, the planned regression was abandoned for (two-tailed) correlation procedures instead.

5. Was hope, at baseline, in both treatment and comparison groups (consumer and family caregiver) less than levels reported in previous studies?

Pre-treatment hope scores were compared to previously published studies using an independent samples *t*-test. The hypothesis was two-tailed because this is a more rigorous criteria, although there is some evidence that consumers, and to a lesser extent, carers live with low hope and hopelessness.

6. What goals do consumers and carers have? How do they assess the likelihood of achieving their goals and had they made plans for achieving

their goals? Did the discussion of goals, agency and pathways relate to consumers' and carers' hopes for the future?

See qualitative analysis below (Section 4.5.3 Qualitative data analysis below). Interview data was analysed by qualitative methods.

4.5.3 Qualitative data analysis

Qualitative data, recorded in the field with notes and digital recorder, were handled two ways. Digital recordings were professionally transcribed into Word documents, and the researcher transcribed field notes.

Both sources of the textual material were then analysed together in Excel spread sheets for the thematic analysis (Howitt & Cramer, 2008a). The researcher re-read all the data and made an initial coding. The coding was primarily based on categorisations arising from this initial reading. From the coding, themes were identified. Refinement of themes led to some re-coding and enhancement of themes in an iterative process.

Finally, a definitive list of themes were defined and labelled, with textual material assigned as supporting evidence.

Chapter 5: Consumer results

Chapter 5: Consumer results

5.1 Consumer participants and participation rate

Sixty-two consumers were recruited to the study, 30 of whom were receiving BFST and 32 treatment as usual. Forty-five were male and their average age was 36 years (SD=12). Forty-nine were born in Australia. Thirty-three were receiving a disability support or old age pension, thirteen were working at least part-time, ten were unemployed, five were studying, and one was a homemaker. For those not working, the average time since work was 11.6 years (SD =10.3, n=36). Thirty-three had completed high school, thirteen primary school only, eleven had a college or university degree and five had a trade certificate. Forty-four consumers had never married and were single, thirteen were partnered, and five were divorced, separated or widowed. See Table 5.21 for a summary of consumer characteristics.

The 62 participants were recruited from 124 consumers that were approached by case managers, giving a recruitment rate of 50% overall (62/124) (see Figure 5.6 and Figure 5.7).

For recruitment of the BFST treatment group, forty-two families receiving BFST were approached by their case manager and invited to join the research. Thirty-nine consumers agreed to contact from the researcher. The researcher contacted thirty-one of these consumers with eight withdrawing from BFST treatment before contact occurred. Thirty treatment consumers joined the research, with one refusal; 23 consumers completed post-questionnaires as well. This gave a response rate of 71% for BFST consumers (30/42). See Figure 5.6 for details of the recruitment attrition rates for the treatment group.

Eighty-two comparison families were approached by their case managers. Forty-five families agreed to be contacted by the researcher. The researcher contacted forty-three of these families and was unable to contact two families. Thirty-two consumers of these families joined the research and completed the baseline testing and of these, 24 completed the post testing as well. This gave

a response rate of 32/82, or 39% for comparison consumers. See Figure 5.7 for details of the recruitment attrition rates for the comparison group.

Overall, sixty-six families participated in the BFST research. In fifty-nine families, both carer and consumer took part in the interviews and in three families only the consumer participated (two treatment and one comparison) and in four families only the carer joined the research (two each treatment and comparison).

Figure 5.6: Treatment Consumers' response rate

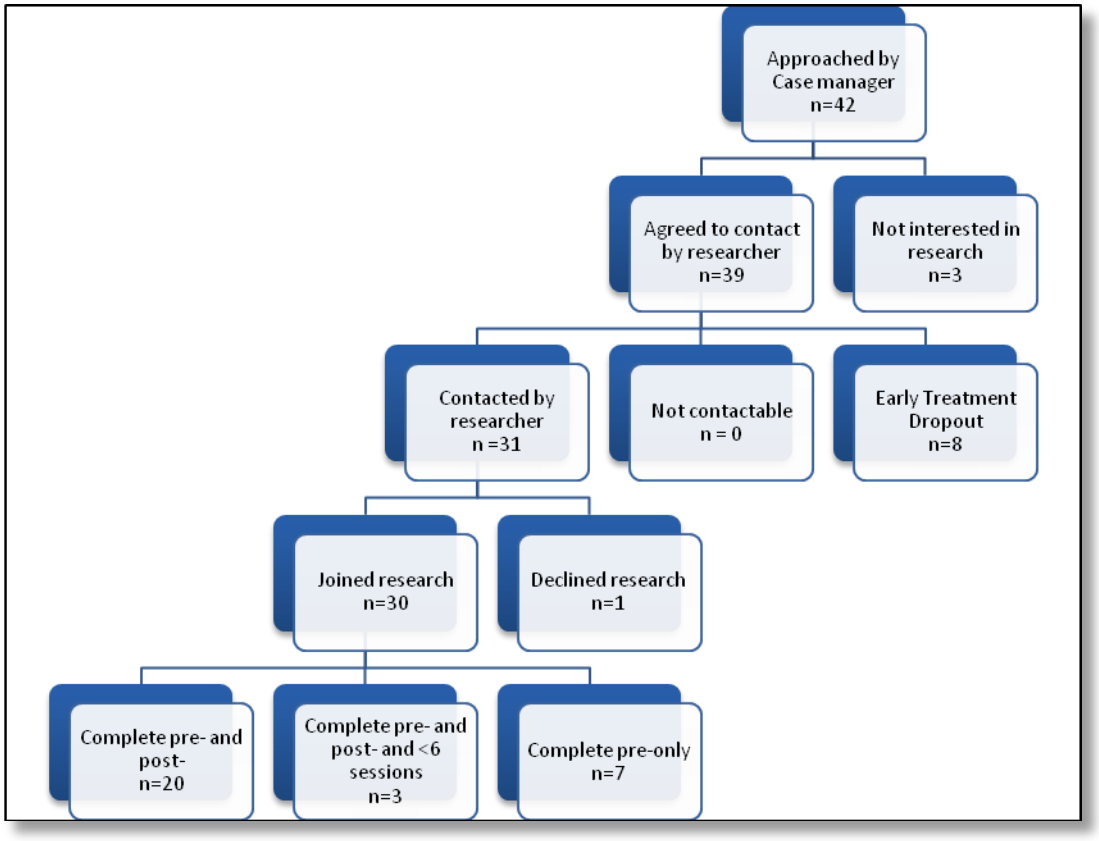
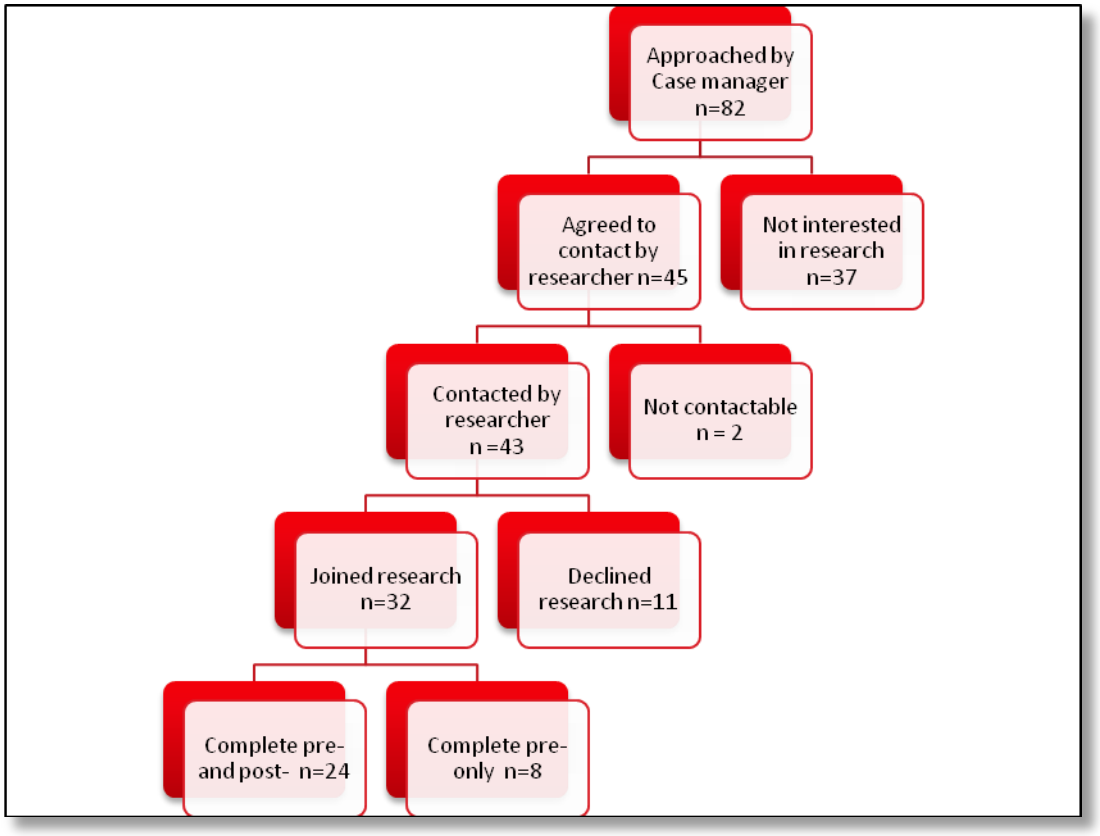


Figure 5.7: Comparison consumers' response rate



5.2 Small number strategy

Since there were a large number of variables in the analysis compared to a small number of participants, one objective of the statistical analysis was to reduce the number of variables in consideration. One method of doing this was to report total scale scores and not subscales.

The conventional model for the Snyder Hope Scale consists of two subscales. The Agency subscale is comprised of four items measuring the motivation to achieve goals (items # 2, 9, 10, 12); the Pathways subscale (another 4 items) measures the ability to generate plans and alternative methods to achieve goals (Snyder, 2002) (items # 1, 4, 6, 8) (see Table 5.19 for item content). The remaining four items of the 12 item scale are filler items (# 3, 5, 7, 11).

For the Snyder Hope Scale, although previous analyses have shown strong loadings into the two subscales (Creamer, et al., 2009; Snyder, et al., 1991) other authors have argued that the extra variance thus explained is minimal, and that a one-factor solution is adequate (Brouwer, et al., 2008). The structure

of the Snyder Hope subscales was further examined to see if the one-factor solution was feasible with the current data.

Correlation between Total Hope, and the subscales was calculated and found to be very high (Pearson Correlation = 0.88, *p*=0.00 for Total Hope and Agency Hope, and Pearson correlation = 0.91, *p*=0.00 for Total Hope and Pathways Hope, n=55, calculations on normalised data, see Section 5.3.1 below).

A Principal Component Analysis showed that all items loaded on the principal factor >0.30, and that 11/12 items loaded >0.60 suggesting a uni-dimensional scale. Items # 1, 3 & 10 cross-loaded onto a second factor, and items # 4, 10 & 12 onto a third factor. However, most of these cross-loading items loaded highest on the first factor, with two exceptions, items # 10 and 12. Item #10 loaded highest to factor 2, and item #12 loaded marginally higher to factor 3. These may have been bloated specifics rather than real factors (Cattell, 1978). Seventy-three percent of total variance was explained with the 8 items across three factors. See results in Table 5.20.

Although the necessary number of cases for an Factor Analysis (FA) is conventionally considered to be 300 or so cases, (Comrey & Lee, 1992; Tabachnick & Fidell, 2001) more recent commentators have suggested that much smaller numbers will yield valid results for a Principal Component Analysis (De Winter, Dodou, & Wieranga, 2009). De Winter et al (De Winter, et al., 2009) summarises a number of studies that suggest that samples between 50 and 100 cases are adequate for PCA.

The model was retested in an iterative process, removing cross-loading items one at a time. The final model (summarised in Table 5.20) comprised the surviving 5 items with items 1 (“I can think of many ways to get out of a jam”), 10, (“I have been pretty successful in life”) and 12 (“I meet the goals that I set for myself”) removed. A single factor solution was obtained and total variance explained was reduced to 59%. All five items remaining had high loadings onto the single component obtained.

Table 5.19 First Principal Components Analysis of Snyder Hope Scale at base-line with all scale items included.

CONSUMER BASELINE				
Snyder Hope Scale Component Matrix				
Item number	**Scale Items Italics = Agency items Green highlight = Pathways**	**Component**		
		1	**2**	**3**
1	I can think of many ways to get out of a jam.	.60	-.49	-.05
2	*I energetically pursue my goals.*	.76	-.28	.18
4	There are lots of ways around any problem.	.74	.27	-.47
6	I can think of many ways to get the things in life that are most important to me.	.74	.30	-.24
8	Even when others get discouraged, I know I can find a way to solve the problem.	.80	-.25	-.05
9	*My past experiences have prepared me well for my future.*	.66	.22	-.19
10	*I have been pretty successful in life.*	.31	.76	.48
12	*I meet the goals that I set for myself.*	.64	-.15	.68

nb: Items 3, 5, 7, and 11 were filler items and were eliminated from scale computation
Total Eigenvalues for Component 1 = 3.62, % Variance explained = 45%
Total Eigenvalues for Component 2 = 1.18, % Additional variance explained = 15%
Total Eigenvalues for Component 2 = 1.05, % Additional variance explained = 13%
Principal components Analysis, No rotation.
Factor 1 =45% of variance explained, Eigenvalue = 3.62
Factor 2 =15% of variance explained, Eigenvalue = 1.18
Factor 3 =13% of variance explained, Eigenvalue = 1.05
Total variance explained= 73%
Kaiser-Meyer-Olkin = 0.73
Bartlett's test Approx Chi-Square = 159.4, df = 28, Sig <0.001

The choices in analysing the Snyder Hope Scale were then: either proceed with the conventional Total Hope Scale; use the one factor Hope Scale obtained above with the 3 items deleted; or, do concurrent analyses with both. On balance, the conventional Total Hope Scale was considered most useful, since the results could be compared with other studies, notwithstanding the unsatisfactory psychometric properties of the scale that were found with this group of participants. The one factor scale explained a reduced amount of total variance, and would have produced results that were not easily interpretable. Given that the factors in the full model did not replicate the conventional Snyder Hope Scale Agency and Pathways structure, the use of these subscales would be questionable.

Table 5.20 Final Principal Components Analysis of Snyder Hope Scale at base-line with items 1, 10 and 12 removed.

CONSUMER BASELINE		
Component Matrix		
Item number	**Scale Items** ***Italics = Agency items*** **Green highlight = Pathways**	**Component**
		1
2	*I energetically pursue my goals.*	.73
4	There are lots of ways around any problem.	.82
6	I can think of many ways to get the things in life that are most important to me.	.80
8	Even when others get discouraged, I know I can find a way to solve the problem.	.79
9	*My past experiences have prepared me well for my future.*	.70

nb: Items 3, 5, 7, and 11 were filler items and were eliminated from scale computation.
Items 1,10 & 12 withdrawn from principal components analysis
Principal components Analysis, No rotation.
Eigenvalue for Component 1 = 2.93, % Variance explained = 59%
Total variance explained= 59%
Kaiser-Meyer-Olkin = 0.78
Bartlett's test Approx Chi-Square = 93.96, df = 10, Sig <0.001

A Principal Components Analysis was also performed on the WHOQOL to see if it was appropriate to sum the subscales to obtain a total quality of life measure for use with inferential statistics. Although a seven factor solution was obtained, all but one item loaded onto the first factor >0.30. The one item below the 0.30 threshold was only marginally so, (0.28), and thus a single factor solution was considered justifiable for use in the analysis, given the considerable constraints due to small numbers. (See Appendix 6 for the WHOQOL PCA results). All but 5 of the items in the WHOQOL had cross-loadings onto other factors, usually more than one. Thus no clean factor solution emerged.

The BASIS-32 does have subscales but it is commonly used as a scale total, so was not further analysed and only the total score used.

5.3 Examination of base-line results

5.3.1 Comparing demographic measures in treatment and comparison groups at baseline

The chi-square statistic was used to check the equivalence of the treatment and comparison groups at baseline where data was dichotomised and there were more than five participants in each group. Fisher's exact test was used where data was divided into three groups or there were less than five in any cell.

Testing of demographic variables at baseline revealed no significant differences between comparison and treatment groups by age, gender, education, region of birth, partnership status, and diagnosis. Groups only differed on the index of accommodation, with the treatment group more likely to be living in a group home (supported accommodation) (Fisher's Exact test, p=0.03). This was likely to be a chance finding (Bellucci, Glaberman, & Haslam, 2002). Thus, although group allocation was not randomised, two substantially matched groups were recruited. See Table 5.21 for details.

5.3.2 Distribution of pooled data for outcome measures at baseline

The results for the Snyder Hope Scale were examined in a histogram of the scores at baseline (Figure 5.8). The distribution was uni-modal, and kurtosis was minimal (Kurtosis statistic = .06, SE = .63). There was some negative skew, indicating that while some consumers scored adequately on the Snyder Hope Scale, there were a number whose score was very low. The ratio of skew/standard error of skew was -2.10 (see Table 5.22), considered to be a significant skew, and inferential statistics using the Hope Scale were calculated with transformed data.

Table 5.21 presents mean and standard deviation of the Snyder Hope Scale and secondary outcome variables (namely, Behaviour and Symptom Identification Scale (BASIS-32), Drug Attitude Inventory (DAI), the Family Assessment Device (FAD), the Friendship Scale (FS), the Life Skills Profile (LSP), the Role Functioning Scale (RFS), and the World Health Organisation

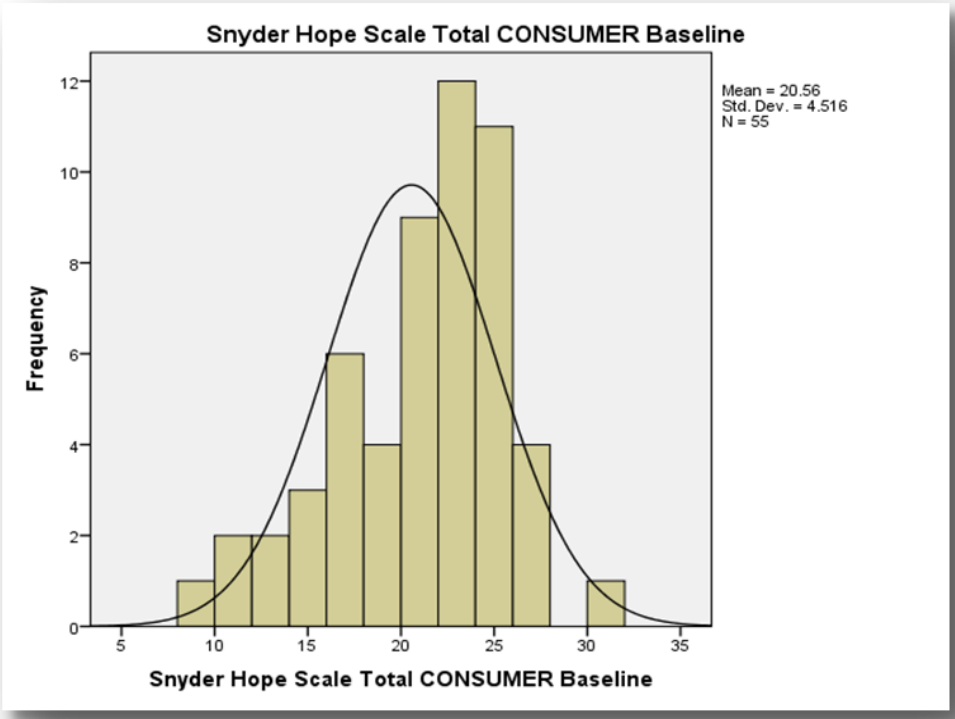
Quality of Life Total Scale (QOLTOT)) at baseline (pooled from treatment and comparison groups).

Table 5.21: Consumer demographics

		CONSUMER		
Demographic	**Category**	**Treatment**	**Comparison**	**Statistic**
Age	Young[3]	19	15	0.19[1]
	Old	11	17	
Gender	Male	22	23	0.90[1]
	Female	8	9	
Education completed	Primary	7	6	0.94[2]
	Secondary	16	17	
	Post secondary	7[4]	9[5]	
Work status	Active role	13[6]	6[7]	0.09[2]
	Unemployed	3	7	
	Pensioner	14[8]	19[9]	
Region of birth	Australasia	25	24	0.42[1]
	Overseas	5[10]	8[11]	
Accommodation	Own home or rental	10	17	0.03[2]
	Family home	15	15	
	Group home	5	0	
Partnership status	Never married	23	21	0.45[2]
	Married/de facto	6	7	
	No current partner	1[12]	4[13]	
Diagnosis	Schizophrenia	20	26	0.19[2]
	Schizoaffective DO	10	6	

1 Two tailed significance of chi-square statistic
2 Significance of Fisher's Exact Test
3 Age dichotomised at 34/35 years
4 Comprised 3 trade certificate, 3 college certificate, 1 university completed
5 Comprised 2 trade certificate, 5 college certificate, 2 university completed
6 Comprised 2 full-time, 8 part-time work, 1 home maker, 2 students.
7 Comprised 1 full-time, 2 part-time work, 3 students.
8 Comprised of 1 retiree, 13 pensioners.
9 Comprised of 4 retirees, 15 pensioners.
10 Comprised 2 born in Europe, 1 born in Asia, 2 born in Middle East
11 Comprised 3 born in Europe, 3 born in Asia, 1 born in Middle East, 1 born in South America
12 Comprised 1 Separated
13 Comprised 3 Divorced, 1 Widowed

Figure 5.8: Histogram of Snyder Hope Scale distribution for consumers at baseline



The BASIS-32 was significantly skewed, as was the Drug Attitude Inventory (DAI) and the Life Skills Profile (LSP). Analyses with these variables were performed with transformed data. The Family Assessment Device (FAD), Friendship Scale (FS), Role Functioning Scale (RFS) and the Total WHOQoL Quality of life (QOLTOT) were not skewed.

All scales were uni-modal, except for the Role Functioning Scale, which was bimodal, indicating a low functioning and a high functioning cluster in the consumer participants. The Family Assessment Device (FAD) and the Drug Attitude Inventory (DAI) both showed significant positive kurtosis (leptokurtic). The FAD had a noticeable peak of scores between 2 and 2.25, with 30 scores taking these central values. No adjustment was made for kurtosis.

Table 5.22: Consumer baseline descriptive statistics for pooled treatment and comparison groups

CONSUMER BASELINE				
Measure	**N**	**Mean**	**SD**	**Skew/ Skew SE ratio**
Snyder Hope Scale[1]	55	20.6	4.5	**-2.10**
BASIS-32 Total[1]	61	1.0	0.8	**2.93**
Drug Attitude Inventory[1]	62	20.2	4.2	**-4.17**
Family Assessment Device	60	2.1	0.4	1.44
Friendship Scale	62	15.8	5.4	-1.55
Life Skills Profile[1]	56	51.1	6.1	**-2.71**
Role Functioning Scale	56	17.5	4.7	-0.30
WHOQoL Total Quality of life	61	56.7	16.9	-0.53

1. Skewness ratio in bold indicates greater than +/- 1.96, and scale was transformed for inferential statistical calculations.
BASIS-32 - Behaviour and Symptom Identification Scale
WHOQoL = World Health Organisation Quality of Life Scale

5.3.3 Comparing outcome measures for treatment and comparison groups at baseline

Examination of baseline scores for the outcome variables of Snyder Hope Scale (SHS), Behaviour and Symptom Identification Scale (BASIS-32), Drug Attitude Inventory (DAI), the Family Assessment Device (FAD), the Friendship Scale (FS), the Life Skills Profile (LSP), the Role Functioning Scale (RFS), and the World Health Organisation Quality of Life Total Scale (QOLTOT) showed that treatment and comparison groups were well matched for all these variables, except for the DAI (see Table 5.23). The treatment group showed a more adherent attitude to medication use (M=21.4, SD=3.4) compared to the comparison group (M=19.2, SD= 4.6, t=2.08, p=0.04). It is unclear why there would be differences in attitude to medication between the two groups, and again this was likely a chance finding (Bellucci, et al., 2002).

Table 5.23 Examination of consumer baseline scores for treatment and comparison groups

CONSUMER BASELINE							
Measure	**Category**	**N**	**Mean**	**Std. Deviation**	**t-statistic[2]**	**df**	**Sig. (2-tailed)[2]**
SHS[1]	Treatment	25	20.7	4.6	-0.23	53	0.82
	Comparison	30	20.4	4.5			
BASIS-32[1]	Treatment	29	0.9	0.8	-0.85	59	0.40
	Comparison	32	1.1	0.9			
DAI[1]	Treatment	30	21.4	3.4	-2.08	60	**0.04**
	Comparison	32	19.2	4.6			
FAD	Treatment	28	2.2	0.5	0.45	58	0.66
	Comparison	32	2.1	0.4			
FS[1]	Treatment	30	15.9	5.4	-0.23	60	0.82
	Comparison	32	15.7	5.5			
LSP[1]	Treatment	28	52.4	5.0	-1.44	54	0.16
	Comparison	28	49.9	7.0			
RFS	Treatment	28	17.3	4.9	-0.28	54	0.78
	Comparison	28	17.7	4.6			
QOLTOT	Treatment	29	56.2	15.2	-0.24	59	0.81
	Comparison	32	57.2	18.5			

1 Mean and standard deviation reported untransformed, t-test carried out and reported on transformed data.
2. Independent groups t-test statistic and p-value
SHS = Snyder Hope Scale
BASIS-32 - Behaviour and Symptom Identification Scale
DAI = Drug Attitude Inventory
FAD = Family Assessment Device
FS = Friendship Scale
LSP = Life Skills Profile
RFS = Role Functioning Scale
QOLTOT = World Health Organisation Quality of Life Total Scale

Overall, although a RCT protocol was not in place, the two groups were well matched and the exceptions that were considered in subsequent analyses were the differences in accommodation and attitude to medication (DAI).

5.3.4 Effect of differences in demographic and outcome variables for treatment and comparison groups at baseline

The impact of significant differences in accommodation type between the treatment and comparison groups was investigated further using t-tests, comparing the Snyder Hope Scale and secondary outcome variables for the supported (living with family or in a group home) and independent living (own or rented housing) groups of consumers. No significant differences were detected for the Snyder Hope Scale (SHS), the Behaviour and Symptom

Identification Scale (BASIS-32), the Drug Attitude Inventory (DAI), the Family Assessment Device (FAD), the Friendship Scale (FS), the Role Functioning Scale (RFS), and the World Health Organisation Quality of Life Total Scale (QOLTOT) on data pooled from treatment and comparison groups. For the Life Skills Profile (LSP), independent living consumers were rated lower on average (less life skills, M=48.7, SD=7.3, n=24) than supported consumers (greater life skills, M=52.9, SD=4.2, n=32, t = 2.33, df =37.55, *p*=0.03) by their case-managers (see Table 5.24). This suggests that living with support enhances life skills in this group of consumers.

Table 5.24: Consumer t-tests for effect of accommodation type on baseline measures

CONSUMER BASELINE	
Measure	***p*-value***
Snyder Hope Scale	ns
Behaviour and Symptom Identification Scale-32	ns
Drug Attitude Inventory	ns
Family Assessment Device	ns
Friendship Scale	ns
Life Skills Profile	.03
Role Functioning Scale	ns
World Health Organisation Quality of Life Total Scale	ns
**p*-value only reported for t-tests, t statistic and df reported in text for Life Skills Profile	

The relationship between the LSP and accommodation type was further examined in a 2-way ANOVA, with LSP as the dependent variable and accommodation and treatment type as the two independent variables. No significant interaction was detected at the *p*=0.05 level (see Table 5.25).

This testing showed that differences in accommodation status between treatment and comparison groups did not have any detectable confounding influence on LSP outcomes in this analysis, and there was no need to consider it as a covariate in further analyses.

Table 5.25: Two-way ANOVA on LSP at baseline for consumer.

		Independent living							
		Treatment			Comparison			ANOVA	
Measure		**n**	SD	M	**n**	SD	M	F^2	p^2
LSP[1]	Independent	9	6.7	51.1	15	7.6	47.3	1.48	0.23
	Supported	19	4.0	52.9	13	4.8	52.8		

1 Mean and standard deviation reported untransformed, t-test carried out and reported on transformed data.
2. Independent groups F-ratio statistic, and significance of p-value (2 tailed), where the df = 1,
LSP = Life Skills Profile

The relationship between medication adherence (DAI) and other outcomes and demographic measures were tested with correlation analyses and t-tests. Table 5.26 shows the Pearson correlations of the DAI with the SHS, and the secondary outcome variables. The DAI had virtually no correlation with the SHS at baseline. It also had little or no correlation with the BASIS-32, FS, the FAD and QOLTOT. There was a significant but small correlation with the scales completed by case managers – the Life Skills Profile (LSP) and the Role Functioning Scale (RFS).

Table 5.26: Consumer correlation matrix for DAI at baseline.

		CONSUMER BASELINE						
		SHS	BASIS	FS	FAD	LSP	RFS	QOL TOT
DAI	*r*	.08	.06	-.02	.12	**.35****	**-.28***	-.12
	p	.57	.66	.86	.37	**.01**	**.04**	.36
	n	55	61	62	60	**56**	**56**	61

r = Pearson Correlation
p = Sig. (2-tailed)
SHS = Snyder Hope Scale
BASIS - Behaviour and Symptom Identification Scale
DAI = Drug Attitude Inventory
FAD = Family Assessment Device
FS = Friendship Scale
LSP = Life Skills Profile
RFS = Role Functioning Scale
QOLTOT = World Health Organisation Quality of Life Total Scale

T-tests for base-line DAI against demographics, showed that membership of any particular demographic group did not result in significant differences in the DAI (see Table 5.27).

Table 5.27: Consumer t-tests for relation of Drug Attitude Inventory with demographic variables

CONSUMER BASELINE							
Measure	**Age**	**Gender**	**Educa-tion**	**Work Status**	**Country of Birth**	**Accommo-dation**	**Partnership status**
DAI	ns*	ns	ns	ns	ns	ns	ns

DAI = Drug Attitude Inventory
* *p*-value only reported for t-tests, reported as ns (not significant) if above 0.05.

In conclusion, small differences between groups at baseline regarding accommodation type and attitudes to medication showed no impact on the Snyder Hope Scale. Therefore, scores of the SHS at baseline did not need any adjustment for these potential confounds. Differences in scores of the DAI at baseline between comparison and treatment groups did not interact with demographic variables. Therefore, ANCOVA analyses for the DAI will be sufficient to adjust for the baseline differences.

Analysis of base-line demographics showed that comparison consumers were more likely to live independently. Analysis of the pooled data for the LSP and accommodation type showed significantly poorer life skills in independently living consumers. This relationship was no longer significant when treatment group was included in the analysis, which meant no adjustment was required for the following ANCOVA analyses. However, there was a small correlation between the LSP, RFS and the DAI, but this had no impact on planned analyses.

5.4 Examination of follow-up results

5.4.1 Demographic match of treatment and comparison groups at follow-up

Forty-seven consumers, 23 from the treatment group and 24 from the comparison group, completed follow-up questionnaires, 10 months after baseline data was obtained. The chi-square (or Fisher's exact test where applicable) was used to ascertain if the treatment and comparison groups were still equivalent at follow-up. If loss to follow-up rates differed across the two

groups, or drop outs were of a particular demographic profile, then group equivalence would not have been maintained.

Chi-square testing on loss to follow-up rates were performed for three major demographic measures; gender, age and diagnosis as well as cohort (treatment versus comparison). Loss to follow-up rates were even across the groups, with seven out of 30 participants in the BFST group, and seven out of 31 comparison participants, not completing follow-up questionnaires (see Figure 5.6 & Figure 5.7).

Loss to follow-up rates across treatment and comparison groups, male and female consumers, older and younger consumers, and diagnostic groups were not significantly different; results are summarised in Table 5.28. As loss to follow-up rates were matched across cohort and major demographic variables, no further testing was undertaken.

5.4.2 Distribution of pooled data for outcome measures at follow-up

The distribution of the Snyder Hope Scale at follow-up was examined via a histogram (see Figure 5.9). There was some negative skew (not significant, see Table 5.29), and no statistically significant kurtosis (Kurtosis statistic = .318, SE = .695).

Table 5.28: Loss to follow-up rates for consumers across treatment and comparison groups

CONSUMER							
		Loss to follow-up			Statistics		
		Yes	No	Total	Value	df	Significance
Gender	**Female**	4	13	17	.01[1]	1	.94
	Male	11	34	45			
	Total	15	47				
Age group	**Old**	9	19	28	1.76[1]	1	.19
	Young	6	28	34			
	Total	15	47				
Diagnosis	**Schizophrenia**	10	36	46			.51[2]
	Other psychosis	5	11	16			
	Total	15	47				
Study cohort	**Treatment**	7	23	30	.02[1]	1	.88
	Comparator	8	24	32			
	Total	15	47	62			

1 Chi-square statistic
2 Fisher's Exact test

Figure 5.9: Histogram of Snyder Hope Scale distribution for consumers at follow-up

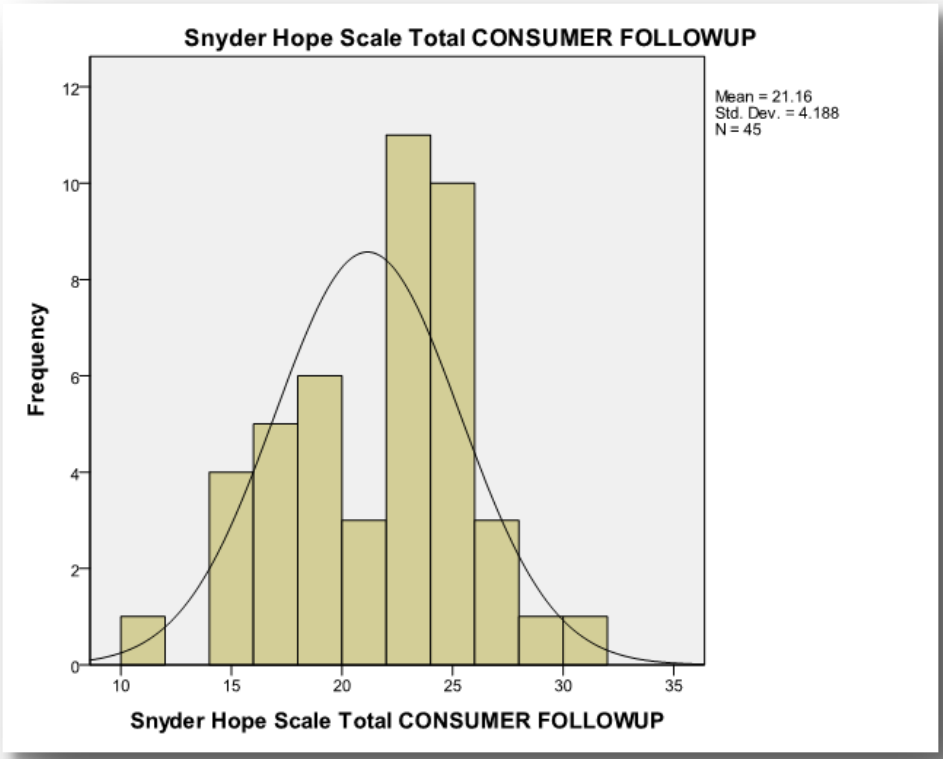


Table 5.29 presents means and standard deviations from outcome variables at follow-up pooled from treatment and comparison groups. Examination of the scales showed the BASIS-32, Drug Attitude Inventory, Friendship Scale, and

the Life Skills Profile all had a Skew/Standard Error of Skew ratio greater than ±1.96 so these scores were normalised before performing inferential statistics. The Drug Attitude Inventory, Friendship Scale, and the Life Skills Profile had a negative skew and the BASIS-32 a positive skew.

The distributions of the Family Assessment Device (FAD) and the Life Skills Profile showed significant positive kurtosis (leptokurtic), both showing large peaks at the modal score. The Role Functioning Scale was no longer bi-modal. No adjustment was made for kurtosis.

Table 5.29: Consumer follow-up descriptive statistics pooled from treatment and comparison groups

CONSUMER FOLLLOW-UP				
	Follow-up			
	N	**Mean**	**SD**	**Skew/ Skew SE ratio**
Snyder Hope Scale[1]	45	21.2	4.2	-1.11
BASIS-32 Total[1]	47	.9	.9	**3.47**
Drug Attitude Inventory[1]	46	19.5	4.7	**-2.48**
Family Assessment Device	47	2.2	.5	1.27
Friendship Scale	48	16.8	5.5	**-2.36**
Life Skills Profile[1]	40	53.4	5.7	**-3.09**
Role Functioning Scale	39	18.7	5.0	-0.64
WHOQoL Total Quality of Life	47	60.7	15.2	-0.84

1. Skewness ratio in bold indicates greater than +/- 1.96, and scale was transformed for inferential statistical calculations.
BASIS-32 - Behaviour and Symptom Identification Scale
WHOQoL = World Health Organisation Quality of Life Scale

5.4.3 Comparing outcome measures for treatment and comparison groups at follow-up

There was no significant difference in scores at follow-up (unadjusted for baseline) for the Snyder Hope Scale between treatment and comparison groups. This was also the case for the secondary outcomes of BASIS-32, DAI, FS, LSP, RFS and QOLTOT (see Table 5.30).

In conclusion, examination of the data collected at follow-up showed that loss to follow-up was even across demographic groups and treatment cohorts (see Table 5.28). Follow-up outcome measures, unadjusted for baseline showed no

significant differences between treatment and comparison groups (see Table 5.30).

Table 5.30: Examination of consumer follow-up measures for treatment and comparison groups

CONSUMER FOLLOW-UP							
Measure	**Category**	**N**	**Mean**	**Std. Deviation**	**t-statistic[2]**	**df**	**Sig. (2-tailed)[2]**
SHS[1]	Treatment	23	21.1	4.2	0.04	43	0.97
	Comparison	22	21.2	4.3			
B-32[1]	Treatment	23	0.9	0.8	0.01	45	1.00
	Comparison	24	1.0	1.0			
DAI[1]	Treatment	23	20.7	4.1	-1.69	44	0.10
	Comparison	23	18.3	5.0			
FAD	Treatment	23	2.1	0.4	-1.51	45	0.14
	Comparison	24	2.3	0.5			
FS[1]	Treatment	23	17.4	5.3	-0.70	46	0.49
	Comparison	25	16.3	5.8			
LSP[1]	Treatment	21	54.5	5.1	-1.10	38	0.28
	Comparison	19	52.3	6.1			
RFS	Treatment	20	19.3	5.4	0.74	37	0.47
	Comparison	19	18.1	4.7			
QOLTOT	Treatment	23	61.8	14.3	0.49	45	0.63
	Comparison	24	59.6	16.2			

1 Mean and standard deviation reported untransformed, t-test carried out and reported on transformed data.
2. Independent groups t-test statistic and p-value
SHS = Snyder Hope Scale
B-32 - Behaviour and Symptom Identification Scale
DAI = Drug Attitude Inventory
FAD = Family Assessment Device
FS = Friendship Scale
LSP = Life Skills Profile
RFS = Role Functioning Scale
QOLTOT = World Health Organisation Quality of Life Total Scale

5.5 Differences between the Snyder Hope Scale at follow-up, adjusted for base-line scores

The effect of BFST treatment compared to case management only (i.e. TAU) in the comparison group was analysed using the ANCOVA statistical test. For the Snyder Hope Scale, the only covariate was Snyder Hope at base-line, with treatment type as the independent variable, as the foregoing analysis indicated no other variables or demographic measure impacted on Snyder Hope scores. There was no significant difference in the Snyder Hope Scale between the two groups at follow-up after adjustment for scores at baseline (see Table 5.31).

Table 5.31: Consumer follow-up scores adjusted for baseline scores across treatment and comparison groups

CONSUMER FOLLOW-UP								
	Treatment			Comparison			ANCOVA	
Scale	**n**	**m[1]**	**sd[1]**	**n**	**m[1]**	**sd[1]**	**F**	**Sig.[2]**
Snyder Hope Scale	19	20.7	4.3	21	21.2	4.4	0.27	0.61
Basis-32	22	0.9	.8	24	1.0	1.0	1.41	0.24
Drug Attitude Inventory	23	20.7	4.1	23	18.3	5.0	0.20	0.66
Family Assessment Device	21	2.1	.4	24	2.3	.5	1.58	0.22
Friendship Scale	23	17.4	5.3	25	16.3	5.8	0.16	0.69
Life Skills Profile	20	54.6	5.3	17	52.1	6.5	0.01	0.94
Role Functioning Scale	19	19.1	5.6	17	18.7	4.4	0.02	0.90
Quality of Life Total Scale	22	62.3	14.4	24	59.6	16.2	0.21	0.65

1.Mean and standard deviation at follow-up, adjusted for scores at base-line.
2. df = 1

Similarly there was no significant difference between treatment and comparison groups for the BASIS-32, FAD, FS, RFS and QOLTOT, also reported in Table 5.31. None of these variables were affected by demographic confounding at baseline or follow-up and no further adjustment or analyses were required.

ANCOVA's for the DAI, LSP are also reported in Table 5.31, showing no significant differences in outcomes between treatment and comparison group. While differences in the DAI scores for treatment and comparison groups were detected at baseline, the ANCOVA analysis adjusted for this, and no further analysis was required.

Accommodation status, which was not equivalent between groups at baseline, was not related to any differences in baseline outcomes except for the LSP, with independently living consumers having lower life skills. However, further investigation showed that the differences were not significant once treatment group was considered, and there was no need to consider it as a confound in this analysis (see Section 5.3.4).

5.6 Subsidiary analysis - differences between individual items in the Snyder Hope Scale

Since the overall Snyder Hope Scale showed no differences between groups, across time, a subsidiary analysis was undertaken, examining outcomes for the

individual items in the Snyder Hope Scale, reported in Table 5.32. No single item showed significant changes between treatment and comparison groups at follow-up, adjusted for baseline scores.

Table 5.32: Consumer follow-up scores adjusted for baseline scores across treatment and comparison groups for individual Snyder Hope Scale Items

CONSUMER FOLLOW-UP								
	Treatment			Comparison			ANCOVA	
Hope item	n	M[1]	SD[1]	n	M[1]	SD[1]	F	Sig.[2]
1	21	2.4	.81	24	2.8	.90	.05	.83
2	20	2.6	.76	23	2.5	.90	.18	.67
4	21	2.5	.81	24	2.5	.88	.01	.92
6	21	2.8	.60	23	2.9	.92	.74	.39
8	20	2.6	.76	24	2.8	.64	1.41	.24
9	21	2.9	.91	23	2.7	.83	.61	.44
10	21	2.7	.73	23	2.5	.85	.51	.48
12	21	2.7	.96	24	2.5	.72	.85	.36

1.Mean and standard deviation at follow-up, adjusted for scores at base-line.
2. df = 1

5.7 Hope and recovery analysis

The analyses related to hope and the recovery paradigm were devised to track changes over time (e.g. hope at baseline predicting levels of secondary recovery variables at follow-up). However, the previous analysis indicates there were no significant differences between groups and over time. Accordingly, the following analyses were carried out across results pooled from both BFST treatment and TAU comparison groups at baseline. Baseline data was chosen since this provided the greatest number of participants.

For this analysis, firstly, data were examined for suitability on the criteria of normality, and linearity. The normality of outcome measures was determined in Section 5.3.1 above, and where data were skewed, the required analyses were carried out with transformed data. Linearity was assessed through examination of scatter plots and was not detected for any variable.

5.7.1 Hope and symptoms

One tenet of the recovery paradigm is that recovery can occur irrespective of the level of symptoms (Patricia E. Deegan, 1997) (see Chapter 2). The plan to test this hypothesis was to examine the correlation of changes in the Snyder Hope Scale (a measure of recovery) over the ten months of the study, with changes in the BASIS-32 (as a measure of daily functioning and symptom concerns as a proxy for symptoms) over the same time period. Given the correlation between changes in hope and changes in “recovery” measures was meaningless in the absence of changes, a correlation matrix was calculated between hope and all other measures at baseline. Baseline measures were chosen because this covered all participants.

This showed high to moderate negative correlations between the SHS and BASIS-32, reported in Table 5.33. This shows that as symptoms (BASIS-32) increase, hope (SHS) decreases.

Table 5.33: Consumer correlation matrix between baseline Hope and other baseline variables

CONSUMER HOPE RECOVERY CORRELATION MATRIX

		B32	FS	FAD	LSP	RFS	QOL TOT
Baseline SHS	r	-.67**	.60**	-.33*	.02	.02	.68**
	p	0.00	0.00	.01	.87	.87	.00
	n	55	55	55	50	50	55

r = Pearson Correlation
p = Sig. (2-tailed)
SHS = Snyder Hope Scale B32 = Basis-32 DAI = Drug Attitude Inventory. FAD = Family Assessment Device . FS = Friendship Scale. LSP = Life Skills Profile. RFS = Role Functioning Scale. QOLTOT = World Health Organisation Quality of Life Total Scale.

5.7.2 Hope as a precursor recovery variable

The recovery literature suggests that hope is the “precursor” recovery variable; the first step towards recovery is the improvement in hope, which is followed by changes to other recovery markers such as social engagement or daily activities (P.E. Deegan, 1988).

The planned analysis was for a multiple regression of hope at baseline as a predictor variable for other recovery variables at follow-up. Since there was no significant change between baseline and follow-up and treatment and comparison groups, the analysis was simplified to correlations between variables at baseline and the regression analysis and its implied causality was abandoned. The secondary recovery variables were the Family Assessment Device, Friendship Scale, Life Skills Profile, Role Functioning Scale and the World Health Organisation Quality of Life Total Scale. Baseline measures were chosen because this covered all participants. There was moderate correlations between hope and social connection (FS), and Total Quality of Life (QOLTOT) (both positive) and a small negative correlation with family functioning (FAD). See Table 5.33.

5.8 Comparison of Consumer hope scores with other groups

Consumer hope scores were compared with population norms and with other relevant consumer groups (i.e. consumers with other mental health diagnoses, or other types of chronic illness).

For this purpose, a literature search was undertaken using a multi-database search tool, with the term “Snyder Hope Scale” and the terms “population” and “norms” which yielded 3 articles. The search was repeated using only the term “Snyder Hope Scale” which yielded 51 academic journal articles from the databases Academic Search Complete, Arts & Humanities Citation Index, Business Source Complete, China/Asia On Demand, CINAHL, Computers & Applied Sciences Complete, DBPIA, Education Research Complete, ERIC, Humanities International Complete, JSTOR Arts & Sciences IV, Korean Studies Information Service System (KISS), MasterFILE Premier, MEDLINE, PsycARTICLES, Psychology and Behavioural Sciences Collection, Science Citation Index, ScienceDirect, Social Sciences Citation Index and SocINDEX with Full Text. In addition, bibliographies were searched for any relevant articles discussing hope, yielding a total of 256 articles. Abstracts were obtained for all of these articles and examined for relevance. Thirty-eight articles were retained that reported hope measures. On reading the full text, articles were discarded if they used alternative hope measures such as Snyder Children’s Hope Scale, the State Snyder Hope Scale, the Herth Hope Index, the Miller Hope Scale, or the Beck Hopeless Scale. Articles were also discarded if they used the Adult Dispositional Snyder Hope Scale but did not use the 4-point response set, or used the Adult Dispositional Snyder Hope Scale, but did not report means and standard deviations. Finally, a set of 10 articles remained that reported means and standard deviations for the Snyder Hope Scale with a four-point likert scale. No articles reported population norms.

Hope results from these 10 studies are summarised in Table 5.34. There were 12 different groups reported across the 10 studies. Six out of the 12 groups were university students[1], (three from the USA (Bronk, Hill, Lapsley, Tallib, & Finch, 2009; Chang & Banks, 2007; Snyder, et al., 1991) one each from India (Dogra, Basu, & Das, 2011), Iran (Babaie, Jain, & Cardona, 2011) and Kuwait (Abdel-Khalek & Snyder, 2007)). One group was an adolescent group with chronic illness (Buran, Sawin, Brei, & Fastenau, 2004), and another three were

[1] One of these groups was tested before commencing university

adult consumer samples (one each with psychosis (Copic, et al., 2011), trauma (Snyder, et al., 1991) and an inpatient group (Snyder, et al., 1991)). The psychosis group was reported in an Australian study by Copic, Deane et al. with a convenience sample was tested on their recovery orientation(Copic, et al., 2011). Low recovery orientation, where no action is taken to improve or self-manage mental health was described as moratorium or awareness level, and was contrasted with higher levels of recovery orientation described as preparation, rebuilding and growth stages. The findings showed that Hope increased as recovery increased. Another Australian sample was a cohort of patients admitted to a trauma service in a hospital (Creamer, et al., 2009). Although this group had experienced traumatic injury, they were not a PTSD group. The one study reporting hope in the general community, was from the USA (T. C. Bailey & Snyder, 2007), and provided hope scores stratified by age and marital status, with 29 to 56 participants in each subgroup. Hope in the older age group (55-64 years old) was significantly less than the three younger age groups (25-34, 35-44, 45- 54 years old).

T-tests (2-tailed) were used to determine if differences in Snyder Hope Scale scores between the consumer group and the study groups were statistically significant. Without population norms available, the comparisons are not definitive, but provide a guide to what may be typical scores for the Snyder Hope Scale in various groups.

See Table 5.16 for t-statistics, *df* and significance (*p*) for all tests. Hope scores for the consumer group were well below those for all the university student groups. They were also significantly below all age groups in the Bailey & Snyder study, and the married or never married groups. Scores were also significantly less than for the adolescent chronic illness group, the Australian trauma group, and the Snyder et al trauma stress group and inpatient group, and the high-recovery orientated consumers in Copic, Deane et al.

There were only 3 subgroups where there was no significant difference in the hope scores. Two were the Australian ‘low recovery orientation’ consumers in Copic, Deane et al. (moratorium and awareness consumers) and the third was

the separated/divorced and widowed subgroup in Bailey and Snyder's USA community study.

In general, comparisons to community based groups showed the consumers in the present group were much lower in hope, the only exception being separated/divorced/ widowed community persons in Bailey and Snyder.

Compared to other consumer groups, (recent traumatic physical illness, chronic physical illness or other mental illness) the present consumer group was much lower in hope as well, except for 'low recovery' consumers in Copic, Deane et al.

Table 5.34 Snyder Hope Scale studies in comparison to consumer scores from the present study

Study	Sample population	Subsample/ Subscale	n	M	SD	t[1]	df
Present	Consumers community mental health clinic – Australia, baseline	Total scale	55	20.6	4.5		
		Agency	59	9.9	2.5		
		Pathways	56	10.5	2.6		
	Carers	Total scale	56	23.2	4.1	3.20**	109
Abdel-Khalek & Snyder (Abdel-Khalek & Snyder, 2007)	Kuwaiti university students		323	24.33	3.09	7.62***	376
Babaie et al (Babaie, et al., 2011)	Pre-university students Iran		1027	25.6	3.5	10.16***	1080
Bailey and Snyder (T. C. Bailey & Snyder, 2007)	Community persons NOT at college - USA	25-34 years old	38	26.39	3.8	6.49***	91
		35-44	51	25.94	3.02	7.12***	104
		45-54	56	25.52	3.38	6.52***	109
		55-64	34	23	5.29	2.69**	87
		Married	142	25.57	3.3	8.52***	195
		Never married	44	25.29	4.65	5.08***	97
		Separate/divorce/widow	29	22.07	5.46	1.32	82
Bronk et al (Bronk, et al., 2009)	University students and residents of mid-west USA town	Adolescent group - agency	153	12.53	1.91	8.19***	210
		Adolescent group - pathways	153	12.82	1.99	6.85***	207
		Emerging adult - agency	237	12.93	1.69	11.09***	294
		Emerging adult - pathways	237	12.58	2.51	5.54***	291
Buran (Buran, et al., 2004)	Adolescents with chronic illness, hospital clinic convenience sample	38% 12-14yo, 35% 15-18yo, 27% 19-21yo, 58% female	66	23.2	3.92	3.40***	119
Copic et al (Copic, et al., 2011)	Sample of convenience at community clinic - consumer with psychotic disorder , Australia	Stage of recovery - Moratorium	13	19.2	5.36	0.97	66
		Awareness	12	20.16	6.24	0.29	65
		Preparation	14	23.6	3.52	2.32*	67
		Rebuilding	22	22.8	3.2	2.09*	75
		Growth	16	25.44	4.48	3.79***	69
Chang (Chang & Banks, 2007)	259 students from a USA university, mean age 18.4	European American - Agency	46	11.74	1.96	4.06***	103
		European American - Pathways	46	11.76	1.74	2.81**	100
		African American - Agency	30	12.07	2.53	4.32***	87
		African American- Pathways	30	13	1.58	4.81***	84
		Latino - Agency	33	12.67	2.13	5.31***	90
		Latino - Pathways	33	12.54	1.25	4.22***	87
		Asian American - Agency		12.13	2.16	4.75***	103

Study	Sample population	Subsample/ Subscale	n	M	SD	t[1]	df
		Asian American - Pathways	46	11.61	1.6	2.53*	100
Creamer et al (Creamer, et al., 2009)	Patients admitted to a trauma service in a hospital - Australia	73% male, mean age 38.4, SD 13.7	1025	26.27	3.68	11.00***	1078
Dogra (Dogra, et al., 2011)	711 university students in Kolkota		711	24	3.9	6.16***	764
Snyder et al (Snyder, et al., 1991)	Kansas University Student	Study 1	955	25.64	2.93	11.98***	1008
		Study 2	635	25.29	3.08	10.38***	688
		Study 3	475	25.27	3	10.29***	528
		Study 4	875	25.08	3.07	10.16***	928
		Study 5	641	25.36	2.91	11.06***	694
		Study 6	339	25.24	2.81	10.30***	392
	Traumatic stress centre - outpatients	Consumer	97	22.6	4.35	2.69**	150
	State hospital - Kansas USA,	Consumer	109	23.11	4.45	3.40***	162

1 t = T-test statistic on independent groups
2 *p* = statistical significance of t-test statistic, * = p<.05, ** = p<.01, *** = p<.001.

Chapter 6: Carer results

Chapter 6: Carer results

6.1 Carer participants, participation rate and demographics

Sixty-three carers were recruited to the research, 30 from the treatment group and 33 from the comparison group. The overall recruitment rate was 51% (63/124).

Fifty carers were female and their average age was 61 years (SD±12). Thirty-two had completed high school, twenty-two had a post-school qualification and six had completed primary school but not high school (data missing for 3). Eleven were working full-time, sixteen working part-time, seventeen were retired on an old age or disability support pension, twelve did home duties, five were unemployed and one was studying (data missing for one case). Forty-one were born in Australia. Thirty-four were married or in de facto partnerships, eighteen were separated or divorced, nine had never married and two were widowed. Thirty-seven were a parent to the consumer, fifteen were partners, nine were siblings and two were adult offspring. Forty-eight were residing with the consumer.

In recruiting participants for the BFST treatment group, forty-two families receiving BFST were approached by the case manager to join the research. Forty carers agreed to be contacted by the researcher. The researcher then contacted thirty-one carers with the remainder withdrawing from BFST treatment before researcher contact occurred. Thirty treatment carers joined the research and one declined, with 24 carers completing post-questionnaires. This gave a response rate of 71% for BFST carers (30/42). See Figure 6.10 for details of the recruitment attrition rates for the treatment group.

Eighty-two comparison families were approached by case managers. Forty-five families agreed to be contacted by the researcher. The researcher contacted forty-three of these families and two were uncontactable. Thirty- three carers of these families consented to join the research and started baseline testing and 28 completed post testing as well. This gave a response rate of 40% for

comparison carers (33/82). See Figure 6.11 for details of the recruitment attrition rates for the comparison group.

Figure 6.10: Treatment Carers' response rate

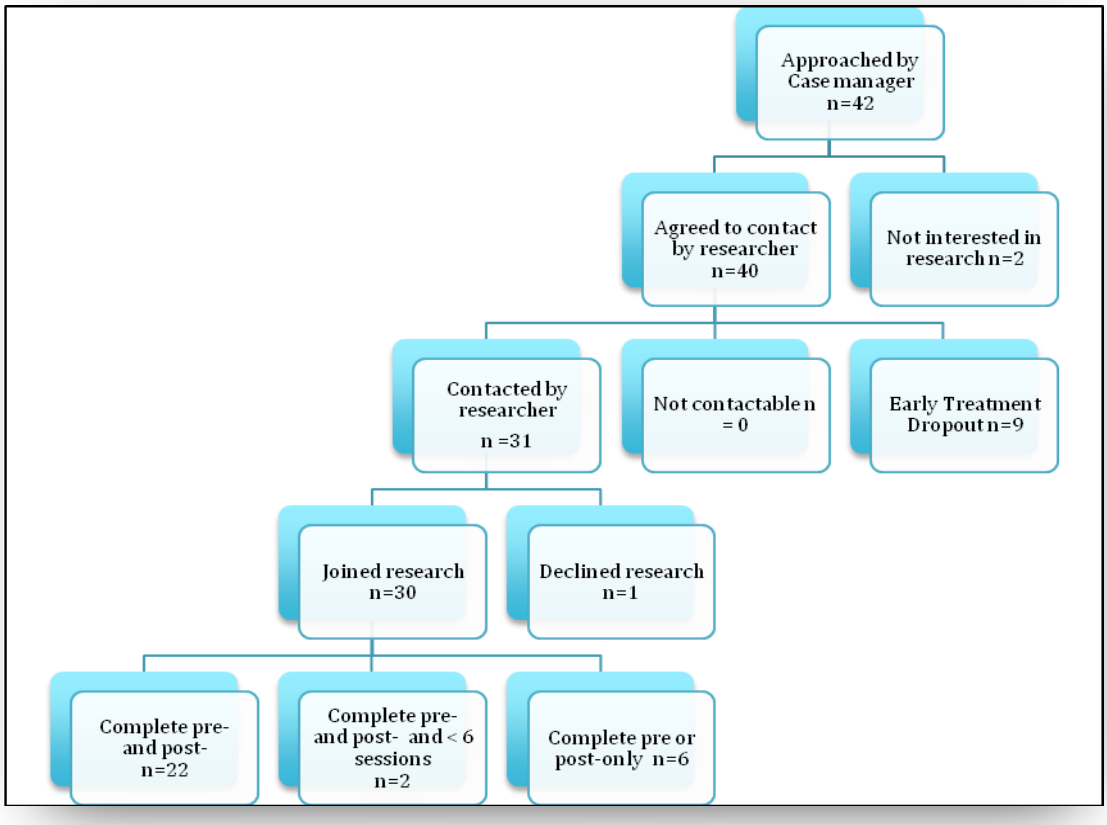
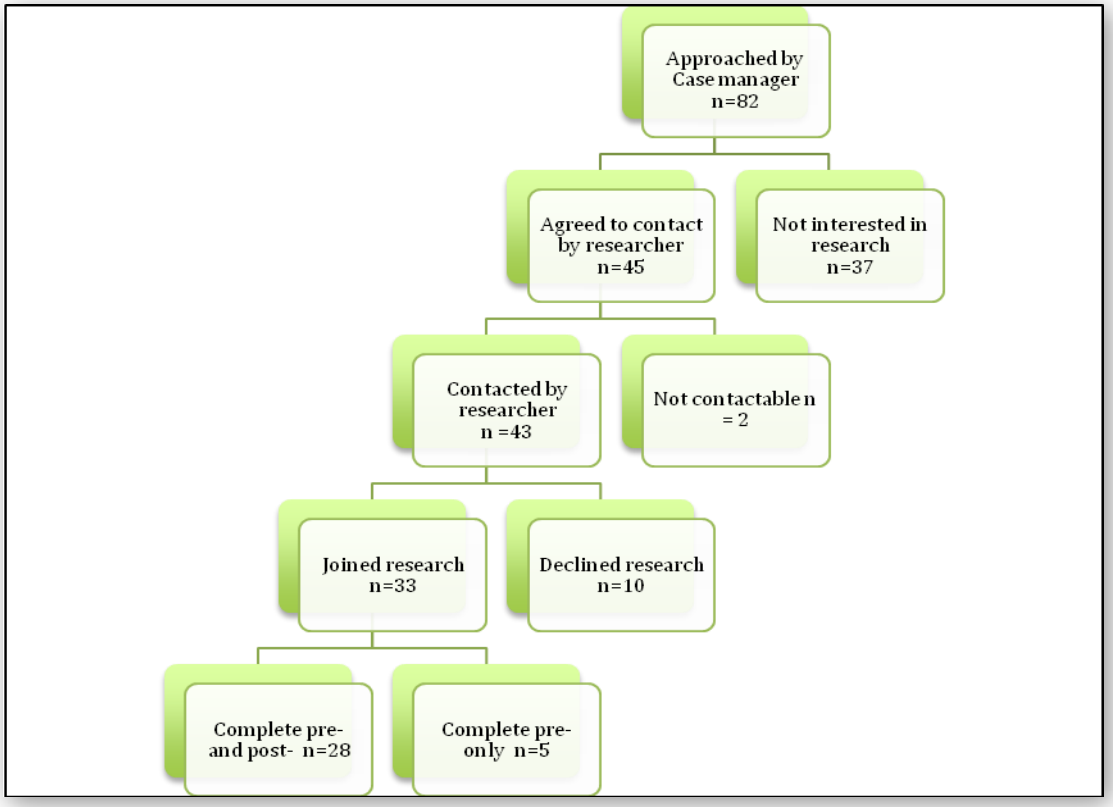


Figure 6.11: Comparison carers' response rate



6.2 Small numbers strategy

The factor structure of the Snyder Hope Scale and the World Health Organisation Quality of Life Scale (Bréf) was examined as part of a strategy to minimise the number of variables and sub-scales in the analysis. The statistical strategy for the carer analysis was the same as for the consumer (see Chapter 5). As noted previously, due to the large number of variables compared to the number of cases, scale totals were used rather than subscales. To assess if this was appropriate for scales with a subscale structure, the Snyder Hope Scale and the WHOQoL, factor analysis was undertaken for these scales.

A Principal Component Analysis (PCA) of the Snyder Hope Scale showed that all items loaded on the principal factor >0.30 and produced a uni-dimensional scale (see Table 6.35). Total variance explained was 52%. Therefore, not using the Agency and Pathways subscales for the Snyder Hope Scale was justified and the scale total was used in subsequent analyses.

Table 6.35 First Principal Components Analysis of Snyder Hope Scale for carers at base-line with all Scale items included.

Component Matrix		
Item number	**Scale Items** ***Italics = Agency items*** **Green highlight = Pathways**	**Component**
1	I can think of many ways to get out of a jam.	0.61
2	*I energetically pursue my goals.*	0.84
4	There are lots of ways around any problem.	0.52
6	I can think of many ways to get the things in life that are most important to me.	0.79
8	Even when others get discouraged, I know I can find a way to solve the problem.	0.70
9	*My past experiences have prepared me well for my future.*	0.63
10	*I have been pretty successful in life.*	0.89
12	*I meet the goals that I set for myself.*	0.74

nb: Items 3, 5, 7, and 11 were filler items and were eliminated from scale computation
Principal components Analysis, No rotation.
Eigenvalue Factor 1 = 4.19, % variance explained = 52%.
Total variance explained= 52%
Kaiser-Meyer-Olkin = 0.82
Bartlett's Test of Sphericity = 197.7, df = 28, p< 0.001

The WHOQOL was similarly analysed with a PCA (for details see Appendix 7). All items loaded moderately onto the first factor, the smallest loading being 0.46. Seven factors were obtained and the majority of items cross-loaded onto one or more factors. Thus a single factor solution, while not perfect, was considered justifiable in order to reduce the number of variables in use.

6.3 Examination of base-line results

6.3.1 Comparison of demographic measures in treatment and comparison groups at baseline

The chi-square statistic was used to examine the equivalence of the demographic measures between treatment and comparison groups at baseline. Due to sparse data, the data were dichotomised or trichotomised prior to analysis.

Testing of demographic variables at baseline revealed no significant differences between comparison and treatment groups on gender, age group, education, work status, region of birth, accommodation type, partnership status, relation to consumer (kinship) and whether their consumer relative lived with them. This indicated the groups were demographically equivalent at baseline. See Table 6.36 for details.

6.3.2 Distribution of pooled data for outcome measures at baseline

The carer results for the Snyder Hope Scale (SHS) were examined in a histogram (see Figure 6.12). There was no skew, no kurtosis and the distribution was uni-modal. Means and standard deviations for the SHS at baseline are presented in Table 6.37, along with results for secondary outcome measures, Experience of Caregiving Negative (ECINEG) and Positive (ECIPOS) scales, Family Assessment Device (FAD), Friendship Scale (FS), General Health Questionnaire (GHQ), Pai and Kapur Family Burden Interview (P&K), Profile of Mood States (POMS) and the Total WHOQoL score (QOLTOT). Results were pooled from treatment and comparison groups. The FS, the POMS and the GHQ were skewed, and inferential statistics using these scales were calculated with transformed data. None of the distributions of the scales showed kurtosis except for the GHQ, which had a pronounced peak at the lowest score of ‘0’ (no distress) and a flat tail towards higher scores (high levels of psychological distress). All scales were uni-modal.

Table 6.36: Carer Demographics

CARER				
		Treatment	**Comparison**	**Statistic**
Age	Young[1]	16	16	0.70[2]
	Old[1]	14	17	
Gender	Male	7	6	0.61[2]
	Female	23	27	
Education completed	Primary	1	5	0.29[3]
	Secondary	16	16	
	Post secondary	12[4]	10[5]	
Work status	Work active	15[6]	12[7]	0.63[3]
	Unemployed	2	3	
	Home-based	13[8]	17[9]	
Region of birth	Australasia	22	19	0.19[2]
	Overseas	8[10]	14[11]	
Accommodation	Own home[12]	20	22	0.92[3]
	Rental[12]	8	7	
	Family[12]	2	3	
Partnership status	Never married	5	4	0.83[3]
	Married/de facto	15	19	
	No current partner	10[13]	10[14]	
Carer relation to consumer	Father or mother	15	22	0.36[3]
	Partner or spouse	8	7	
	Offspring/sibling	7[15]	4[16]	
Live with consumer	Yes	23	25	0.93[2]
	No	7	8	

1 Age dichotomised at 63/64 years
2 Two tailed significance of χ^2 statistic
3 Fisher's Exact Test
4 Comprised 2 trade certificate, 5 college certificate, 5 university completed
5 Comprised 2 trade certificate, 6 college certificate, 2 university completed
6 Comprised 8 full-time, 7 part-time work
7 Comprised 3 full-time, 9 part-time work
8 Comprised of 7 home makers, 1 retiree, 5 disability support pensioners
9 Comprised of 5 home makers, 1 student, 1 retiree, 10 disability support pensioners
10 Comprised 5 born in Europe, 1 born in Asia, 2 born in Middle East
11 Comprised 8 born in Europe, 4 born in Asia, 1 born in Middle East, 1 born in South America
12 Own home is living in home, rental is rental home, "family" is living in family home with parents.
13 Comprised 8 Divorced, 2 Separated
14 Comprised 2 Divorced, 6 Separated, 2 Widowed
15 Comprised 7 siblings
16 Comprised 2 siblings and 2 adult offspring
Note: Where cells do not add to 63 for any demographic domain, there is missing data for some cases

Figure 6.12: Histogram of Snyder Hope Scale distribution for carers at baseline (pooled from treatment and comparison groups).

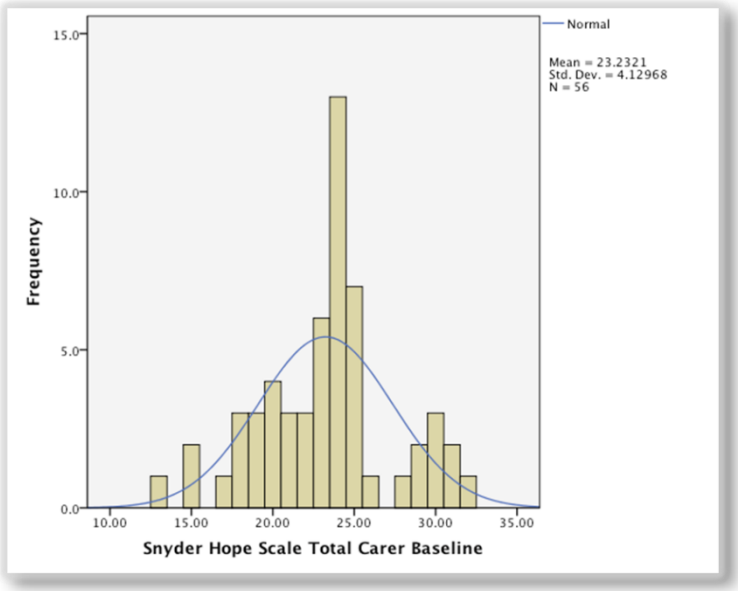


Table 6.37: Carer baseline descriptive statistics

CARER				
	Base-line			
	n	**Mean**	**SD**	**Skew/ Skew SE ratio**
Snyder Hope Scale Total	56	23.2	4.1	-0.13
ECI Total Negative /100	60	43.9	17.1	-0.22
ECI Total Positive /100	60	69.6	13.9	-0.69
Family Assessment Device	56	2.2	0.4	0.60
Friendship Scale[1]	61	17.6	6.0	**-2.03**
Total GHQ[1]	60	6.6	6.3	**4.68**[2]
Pai & Kapur Total burden	57	20.9	8.7	-0.71
POMS Total Mood Disturb[1]	60	41.6	30.7	**2.27**
WHOQoL Total QoL	61	63.1	14.6	-0.36

1 Skewness ratio in bold indicates greater than +/- 1.96, and scale was normalised for inferential statistical calculations.
2 Kurtosis statistic = 1.60, SE = 0.61, ratio = 4.58
ECI = Experience of Caregiving Inventory
GHQ = General Health Questionnaire
P& K = Pai and Kapur Family Burden Interview
POMS = Profile of Mood States
WHOQoL = World Health Organisation Quality of Life scale
SD = Standard Deviation
SE = Standard Error

6.3.3 Comparing outcome measures for treatment and comparison groups at baseline

Examination of baseline scores for all outcome variables (SHS, ECINEG, ECIPOS, FAD, FS, GHQ, P&K, POMS and QOLTOT) showed that the scores for treatment and comparison groups were not significantly different for any measure, where group differences were tested with the t-test. See Table 6.38 for details of t-score, degrees of freedom and significance.

Table 6.38: Examination of carer baseline scores for treatment and comparison groups

Measure	Category	N	Mean	SD	t	df	Sig. (2-tailed)
Hope	Treatment	26	23.4	4.8	0.34	64	0.74
	Comparison	31	23.1	3.6			
ECINEG	Treatment	28	46.4	14.3	0.62	68	0.64
	Comparison	32	42.7	19.4			
ECIPOS	Treatment	28	60.8	12.7	0.68	68	0.60
	Comparison	32	68.3	16.1			
FAD[1]	Treatment	26	2.2	0.6	0.36	67	0.73
	Comparison	33	2.2	0.4			
FS[1]	Treatment	29	17.1	6.4	0.62	69	0.64
	Comparison	32	18.0	4.6			
GHQ	Treatment	29	6.1	7.8	-0.72	60	0.48
	Comparison	31	6.0	4.6			
P&K	Treatment	26	23.1	9.2	1.77	66	0.08
	Comparison	31	19.1	8.0			
POMS[1]	Treatment	29	47.6	32.0	1.62	68	0.14
	Comparison	31	36.9	28.8			
QOLTOT	Treatment	29	60.8	14.8	-1.14	69	0.26
	Comparison	32	66.1	14.1			

1. Mean and standard deviation reported untransformed, t-test carried out and reported on transformed data.
ECINEG = Experience of Caregiving Inventory Negative Subscale
ECIPOS = Experience of Caregiving Inventory Positive Subscale
FAD = Family Assessment Device
FS = Friendship Scale
GHQ Sum = General Health Questionnaire Summative
P&K = Pai & Kapur
POMS = Profile of Mood States
HOPE = Snyder Hope Scale
QOLTOT = World Health Organisation Quality of Life Total scale

6.3.4 Summary of examination of baseline measures

No demographic or outcome measure at baseline was significantly different between treatment and comparison groups. The pooled distributions were uni-modal and only three measures (GHQ, POMS and FS) were skewed and normalised data used for inferential statistics. No further analysis was required.

6.4 Examination of follow-up results

6.4.1 Comparing demographic measures in treatment and comparison groups at follow-up

Fifty-two carers, 24 treatment and 28 comparison participants, completed follow-up questionnaires 10 months after baseline data was collected. One other treatment carer completed the Pai and Kapur interview only at post-treatment as well. For “lost to follow-up” analysis only, this participant will be considered as part of the lost to follow-up group i.e. only one set of data completed.

Chi-square (or Fishers Exact Test if necessary) was used to test loss to follow-up across study cohort, and the major demographics of gender, age, and kinship to consumer. Results (summarised in Table 6.39) indicated that follow-up occurred evenly across cohort, age, gender and kinship groups. As follow-up was matched across groups and major demographic variables, no further testing was undertaken. Loss to follow-up rates are also summarised in Figure 6.10 and Figure 6.11.

Table 6.39: Loss to follow-up in treatment and comparison groups for carers

		Loss to follow-up			Statistics		
		Yes	No	Total	Value	df	Significance
Gender	**Female**	8	42	50			0.68[2]
	Male	3	10	13			
	Total	11	52				
Age group	**Old**	5	26	31	.08[1]	1	.78
	Young	6	26	32			
	Total	11	52				
Kinship to consumer	**Parent**	5	32	37	.97[1]	1	.33
	Other	6	20	26			
	Total	11	52				
Study cohort	**Treatment**	6	24	30	.26[1]	1	.61
	Comparator	5	28	33			
	Total	11	52				

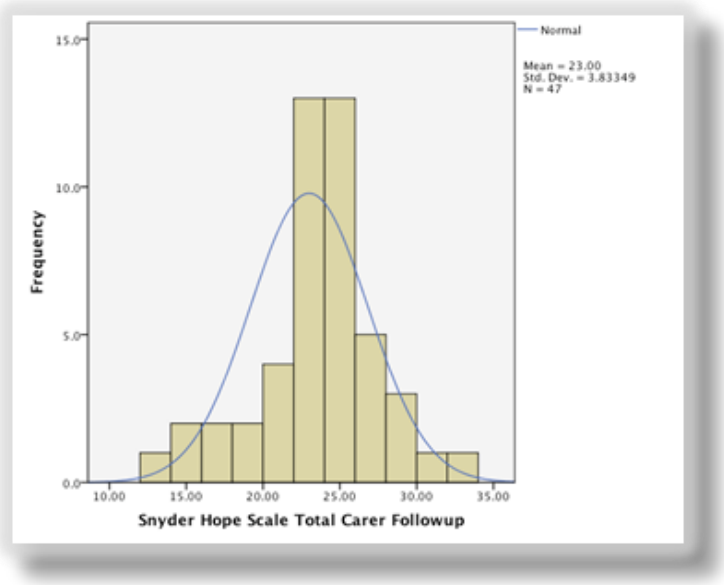
1 Chi-square statistic
2 Fisher's Exact test, no value was calculated

6.4.2 Distribution of pooled data for outcome measures at follow-up

The distribution of the Snyder Hope Scale, pooled from treatment and comparison groups at follow-up was examined via a histogram (see Figure 6.13). It was uni-modal, with no skew and no kurtosis.

Means and standard deviations for the Snyder Hope Scale and all other outcomes at follow-up were summarised (same analysis as for baseline) and presented in Table 6.41. The distributions for the Family Assessment Device (FAD) and the GHQ were skewed, and these scores were normalised before inferential statistics were performed.

Figure 6.13: Histogram of carer Snyder Hope Scale distribution at follow-up (pooled from treatment and comparison groups)



The FAD also showed significant kurtosis, with a sizable peak at the mode, and flat narrow tails in the positive and negative directions (see Figure 6.14). All scales were uni-modal at follow-up.

Figure 6.14: Histogram of Family Assessment Device distribution at follow-up (pooled from treatment and comparison carer groups)

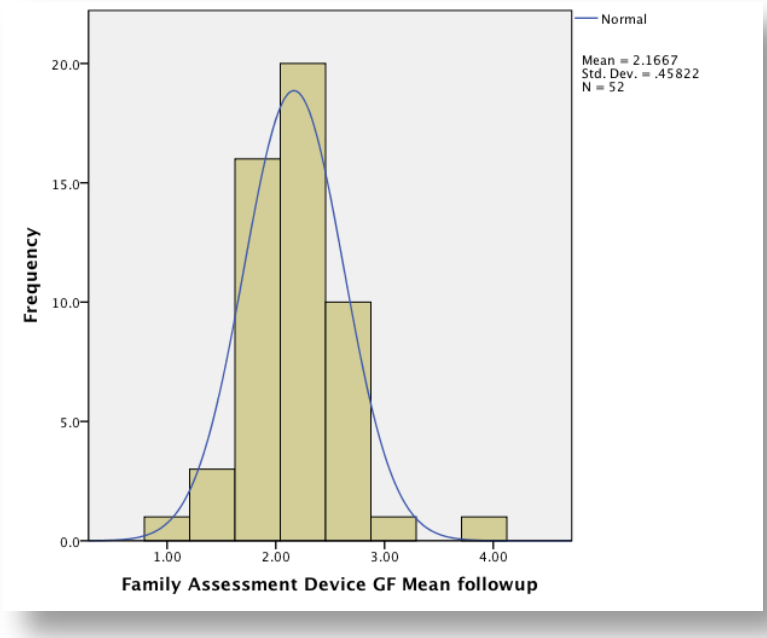


Table 6.40: Carer follow up descriptive statistics

CARER FOLLOW-UP				
	N	**Mean**	**SD**	**Skew/ Skew SE ratio**
Snyder Hope Scale Total	47	23.0	3.8	-1.28
ECI Total Negative /100	60	42.4	16.6	-0.34
ECI Total Positive /100	60	66.1	14.3	0.20
Family Assessment Device[1]	62	2.2	0.6	**2.86**
Friendship Scale[1]	62	17.3	4.7	-1.32
Total GHQ[1]	60	6.6	6.2	**2.96**
Pai & Kapur Total burden	42	16.8	9.4	0.84
POMS Total Mood Disturb[1]	60	42.7	31.8	1.88
WHOQoL Total QoL	60	63.1	14.8	0.87

1 Skewness ratio in bold indicates greater than +/- 1.96, and scale was normalised for inferential statistical calculations.
2 Skewness ratio in bold indicates greater than +/- 1.96, and scale was not normalised.
ECI = Experience of Caregiving Inventory
GHQ = General Health Questionnaire
P& K = Pai and Kapur Family Burden Interview
POMS = Profile of Mood States
WHOQoL = World Health Organisation Quality of Life scale
SD = Standard Deviation
SE = Standard Error

6.4.3 Comparing outcome measures for treatment and comparison groups at follow-up

Differences in outcome measures at follow-up between treatment and comparison cohorts were tested with t-tests (unadjusted for base-line). Results are presented in Table 6.41, showing no difference in follow-up scores for SHS and the secondary outcomes of ECINEG, ECIPOS, FAD, FS, GHQ, P&K, POMS and QOLTOT.

Table 6.41: Carer follow-up measures compared by treatment group

Measure	Category	N	Mean	Std. Deviation	t-statistic[2]	df	Sig. (2-tailed)[2]
SHS	Treatment	22	23.0	4.1	0.08	46	0.94
	Comparison	26	23.0	3.6			
ECINEG	Treatment	23	41.7	12.7	-0.28	48	0.78
	Comparison	27	43.0	19.6			
ECIPOS	Treatment	24	67.0	12.9	0.88	48	0.39
	Comparison	26	63.4	16.6			
FAD [1]	Treatment	24	2.1	0.6	-0.28	60	0.78
	Comparison	28	2.2	0.4			
FS [1]	Treatment	24	17.1	4.9	0.03	60	0.97
	Comparison	28	17.4	4.6			
GHQ [1]	Treatment	22	6.3	6.6	-0.60	48	0.62
	Comparison	28	6.9	6.1			
P&K	Treatment	17	16.4	9.3	-0.21	40	0.84
	Comparison	26	16.0	9.6			
POMS [1]	Treatment	23	41.0	30.2	-0.32	48	0.76
	Comparison	27	44.0	33.6			
QOLTOT	Treatment	23	63.7	14.4	0.27	48	0.79
	Comparison	27	62.6	16.3			

1. Mean and standard deviation reported untransformed, t-test carried out and reported on transformed data.
2. Independent groups t-test statistic and p-value
ECINEG = Experience of Caregiving Inv. Negative Subscale
ECIPOS = Experience of Caregiving Inv. Positive Subscale
FAD = Family Assessment Device
FS = Friendship Scale
GHQ Sum = General Health Questionnaire Summative
P&K = Pai & Kapur
POMS = Profile of Mood States
SHS = Snyder Hope Scale
QOLTOT = WHO Quality of Life Total scale

6.3.4 Summary of examination of follow-up measures

Testing of loss to follow-up and outcome measures at follow-up revealed no significant differences between treatment and comparison groups. Therefore, testing of changes across time and between treatment and comparison groups (see following section) required no further adjustment for potential confounders.

6.5 Differences for the Snyder Hope Scale at follow-up, adjusted for base-line scores

The effect of BFST treatment compared to "treatment-as-usual" (TAU) (comparison group) was analysed using the ANCOVA statistic, with the SHS at follow up as the dependent variable, treatment type as the independent

variable, and SHS at baseline as the covariate. No other variables were considered as covariates as the foregoing analysis showed that there were no confounding measures. There was no significant difference in the SHS between the BFST treatment and comparison groups at follow-up after adjustment for scores at baseline (see Table 6.42).

Table 6.42: Carer follow-up scores adjusted for baseline across treatment and comparison groups

	CARER FOLLOW-UP							
	Treatment			Comparison			ANCOVA	
Scale	**n**	**M[1]**	**SD[1]**	**n**	**M[1]**	**SD[1]**	**F**	**Sig.[2]**
Snyder Total Hope	20	23.1	4.3	23	22.9	3.8	0.18	0.67
ECI Total Negative /100	22	41.4	12.9	26	42.0	19.3	0.69	0.41
ECI Total Positive /100	23	57.5	12.9	25	54.1	15.6	0.24	0.63
Family Assessment Device	22	2.1	0.5	28	2.2	0.4	0.18	0.68
Friendship scale	24	17.1	4.9	27	17.9	4.0	0.09	0.76
General Health Questionnaire	22	5.3	6.6	26	5.7	5.8	0.12	0.73
Pai & Kapur Total Burden	16	14.3	8.3	23	16.4	9.8	1.08	0.31
POMS Total Mood Disturbance	23	41.0	30.2	25	43.0	34.5	0.78	0.38
Quality of Life Total	23	63.7	14.4	26	63.3	15.0	0.78	0.38

1. Mean and standard deviation at follow-up, adjusted for scores at base-line.
2. df = 1

Similarly, there were no significant differences for the ECINEG, ECIPOS, FAD, FS, GHQ, P&K, POMS and QOLTOT using the same analysis strategy (see Table 6.42).

6.6 Subsidiary analysis - differences between groups for individual items in the Hope Scale

With the overall Snyder Hope Scale showing no differences between groups and across time, a subsidiary analysis was undertaken, examining outcomes for the individual items in the Snyder Hope Scale, reported in Table 6.43. No single item showed significant changes between treatment and comparison groups at follow-up, adjusted for baseline scores.

Table 6.43: Post-test scores adjusted for pre-test scores across treatment and comparison groups for individual Hope Scale Items

CARER FOLLOW-UP								
	Treatment			Comparison			ANCOVA	
Hope item	n	m[1]	sd[1]	n	m[1]	sd[1]	F	Sig. [2]
1	22	3.0	0.7	26	3.0	0.5	0.22	0.64
2	22	2.9	0.7	25	2.8	0.6	0.06	0.81
4	21	3.1	0.5	25	2.9	0.6	0.30	0.59
6	22	2.9	0.8	25	2.9	0.6	0.28	0.60
8	22	3.0	0.4	25	2.8	0.6	0.52	0.47
9	21	2.9	0.8	26	3.0	0.8	0.10	0.75
10	21	2.8	0.8	26	2.7	0.7	0.02	0.90
12	22	2.7	0.8	26	2.7	0.6	0.25	0.62

1.Mean and standard deviation at follow-up, adjusted for scores at base-line.
2. df = 1

6.7 Hope and wellbeing analysis

Further analyses were planned regarding hope and its relationship to other outcomes for carers. These research questions were similar to the recovery hypotheses for the consumer. The consumer research questions were that hope is independent of the level of symptoms, and that hope is a "precursor" recovery variable; that is, improvements in hope occur preliminary to improvement in other recovery markers. The related carer research questions were that carer burden is independent of hope and that improvement in hope is a precursor to improvement in other carer outcomes such as social engagement or quality of life.

However, similar to the consumer analysis, there was no effect of treatment or time. Accordingly, instead of regressions across groups and time, data was pooled from treatment and comparison groups for correlations of baseline results for the following analyses.

Before correlations were calculated, data was examined for suitability on the criteria of normality and linearity. Examination of scattergrams (not included) showed no evidence of curvilinear relationships. Normality of distribution was established in Section 6.3.2 previously, and where data were skewed, the required analyses were carried out with transformed data.

6.7.1 Hope and burden

The notion that levels of hope are unrelated to carer burden was tested by examining the correlation of hope (SHS), burden (Pai and Kapur) and the experience of caregiving (ECIPOS & ECINEG). Although no literature was identified regarding this putative relationship, it was suggested that changes in hope over time would be independent of the level of burden. This analysis was simplified to baseline correlations since there were no net changes to the Snyder Hope Scale, the Pai & Kapur or the Experience of Caregving Inventory. The use of correlations allowed for some exploration of the hope hypotheses, even if conclusive results could not be derived, similar to the procedure with the consumer analysis.

Table 6.44 shows the correlation results. There was no significant correlation between the SHS and the ECIPOS, ECINEG or the P&K. Levels of the Snyder Hope Scale had no relation to levels of burden or the experience of caregiving (positive and negative).

Table 6.44: Carer correlation matrix between baseline SHS and other baseline variables

CARER HOPE CORRELATION MATRIX

		ECINEG	ECIPOS	FAD	FS	GHQ	POMS	P &K	QOLTOT
Baseline Hope	*r*	-0.18	0.25	-.41**	.64**	-.62**	-.41**	0.09	.60**
	p	0.18	0.06	0.00	0.00	0.00	0.00	0.53	0.00
	n	56	56	56	56	55	55	51	56

r = Pearson Correlation
p = Sig. (2-tailed)
Hope = Snyder Hope Scale; ECINEG= Experience of Caregiving Inventory Negative Subscale; ECIPOS = Experience of Caregiving Inventory Positive Subscale; FAD = Family Assessment Device; FS = Friendship Scale; GHQ = General Health Questionnaire; P& K = Pai and Kapur Family Burden Interview; POMS = Profile of Mood States; QOLTOT = World Health Organisation Quality of Life Total Scale.

6.7.2 Hope as a precursor to improved wellbeing

The literature, although not definitive, suggested that a rise in hope in carers can lead to an improvement in their wellbeing measures such as social engagement or quality of life.

The planned analysis was for multiple regression of hope at baseline as a predictor of wellbeing outcomes at follow-up. A number of constraints to this analysis were observed as for the previous analysis, due to non-significant changes over time and between groups. Again, instead of a regression and its implied causality, a correlation between the SHS at base-line and other wellbeing measures at baseline was conducted.

Following the strategy established for the analysis of consumer results, the data was screened prior to correlation analysis.

The normality of the outcome measures was determined in Section 6.3.1 above and where required, analyses was undertaken with transformed data. Linearity was assessed though an examination of the scatter plots and was no concerns were detected for any variable.

Correlation between baseline hope and other measures are summarised in Table 6.44. There were moderate positive correlations between hope, social connection (FS) and total quality of life (QOLTOT) (the same as for consumers, see Chapter 5, Section 5.7)(i.e. as hope increased, social connectedness, and quality of life improved). There was a moderate negative correlation between hope and psychological distress (GHQ) (i.e. as hope increased, psychological distress reduced). There was a low negative correlation between hope, and family functioning (FAD) (same as consumer) and total mood disturbance (POMS)(i.e. as hope increased, family functioning improved and total mood disturbance was reduced).

6.8 Hope in the family context

Hope was also analysed in relation to family relationships by examining a correlation matrix for consumer and carer hope and consumer and carer family functioning.

Table 6.45: Carer and Consumer Hope and Family Functioning correlations at base-line

CONSUMER and CARER HOPE and CORRELATION				
		Carer FAD	Consumer HOPE	Consumer FAD
Carer HOPE	*r*	**-0.41****	-0.02	-0.15
	p	**.00**	.91	.32
	N	**56**	54	49
Carer FAD	*r*		-0.20	-0.02
	p		.14	.87
	N		56	51
Consumer HOPE	*r*			**-0.33***
	p			**.01**
	n			**55**

r= Pearson Correlation
p= Sig. (2-tailed)
Hope = Snyder Hope Scale
FAD = Family Assessment Device

The correlation matrix (Table 6.45) showed that there were small negative correlations between baseline hope and baseline family functioning for carers and the same for consumers respectively, but no relationship between carer hope and consumer hope, nor carer family functioning and consumer family functioning. That is, for consumers and carers individually, as their rating of family functioning improved (i.e. FAD reduced), hope (SHS) increased. Carer hope and carer rating of family functioning had no correlation with their consumer relatives' rating of hope and family functioning, and consumer ratings of both hope and family functioning were unrelated to their carer's ratings.

6.9 Hope in carers in comparison other carer studies

Hope in other groups such as consumers, other carer groups and the general community was compared with the hope scores of the present carer group. Although there are many studies on carer outcomes, only one study was identified that used the Snyder Hope Scale with a carer group. The results from 10 of the studies identified in the literature search described in Chapter 5 were re-used for the carer comparison, plus the carer study. The study t-tests (2-tailed) were used to determine if there were significant differences in Snyder Hope Scores for each group as was done in the consumer analysis.

T-tests showed that the hope scores for carers were significantly higher than their consumer relatives. Results, in Table 6.46, showed that Carer Hope was

significantly lower than many of the university student groups (Abdel-Khalek & Snyder, 2007; Babaie, et al., 2011; Bronk, et al., 2009). The exception was the Indian university students (Dogra, et al., 2011) and some of Chang & Banks (Chang & Banks, 2007) students (only Latino and African-American Pathways scores were significantly higher). Carer hope was significantly less than the community groups surveyed in Bailey and Snyder (T. C. Bailey & Snyder, 2007), except for the older group and the separated/divorced/widowed group, where carer hope was similar. Carer hope was not significantly different to that of the chronically ill adolescents (Buran, et al., 2004), greater than the low recovery consumers, similar to the high recovery consumers in Copic, Deane et al. (Copic, et al., 2011), less than the trauma patients in Australia (Creamer, et al., 2009), and similar to Snyder's outpatient and inpatient groups (Snyder, et al., 1991). Scores were significantly lower than younger carers and not significantly different to middle-aged carers in the carer sample (Ferraro & Neisius, 2002). The average age of the older sample in Ferraro & Neisius was 43 years (sd±16), which was demographically similar to the current sample, although it was a small number of carers and recruitment method and care type were not specified.

In summary, carer hope scores were less than many people living in the community, and similar to the hope scores of groups facing significant long term challenges, such as some consumer groups, and people with chronic illness and those recently separated or widowed. However, Bailey and Snyder's results show that hope may decrease with age. Given the older average age of the carer group, then it may be the demographic variable of age, not just the role of carer that partly explains the lessened hope in this group. This is also supported by comparison to hope in other carers, where younger carers scored significantly more than carers in this sample on the SHS.

Table 6.46 Summary of Snyder Hope studies with comparison to carer scores from the present study

Study	Sample population	Subsample/ Subscale	n	M	SD	t[1]	df
Present	Carers of Consumers community mental health clinic – Australia, baseline	Total scale	56	23.2	4.1		
		Agency	56	11.4	2.4		
		Pathways	57	11.7	2.0		
Abdel-Khalek & Snyder (Abdel-Khalek & Snyder, 2007)	Kuwaiti university students	130 males average age 21.55 (± 2.66) years 193 females average age 21.04 (±2.47) years	323	24.33	3.09	2.40*	377
Babaie et al (Babaie, et al., 2011)	Pre-university students Iran	306 males, 721 females average age 25.6 (±3.5) years	1027	25.6	3.5	4.95***	1081
Bailey and Snyder (T. C. Bailey & Snyder, 2007)	Community persons NOT at college - USA	25-34 years old	38	26.39	3.8	3.81***	92
		35-44	51	25.94	3.02	3.90***	105
		45-54	56	25.52	3.38	3.27**	110
		55-64	34	23	5.29	0.20	88
		Married	142	25.57	3.3	4.24***	196
		Never married	44	25.29	4.65	2.39*	98
		Separated/divorced/widow	29	22.07	5.46	1.07	83
Bronk et al (Bronk, et al., 2009)	Uni students and residents of mid-west USA town	Adolescent group - agency	153	12.53	1.91	3.53***	207
		Adolescent group - pathways	153	12.82	1.99	3.6***	208
		Emerging adult - agency	237	12.93	1.69	5.58***	291
		Emerging adult - pathways	237	12.58	2.51	2.46*	292
Buran (Buran, et al., 2004)	Adolescents with chronic illness, hospital clinic convenience sample	38% 12-14yo, 35% 15-18yo, 27% 19-21 yo, 58% female	66	23.2	3.92	1.00	120
Copic et al (Copic, et al., 2011)	Sample of convenience at community clinic - consumer with psychotic disorder, Australia	Stage of recovery - Moratorium	13	19.2	5.36	2.99**	67
		Awareness	12	20.16	6.24	2.11*	66
		Preparation	14	23.6	3.52	0.34	68
		Rebuilding	22	22.8	3.2	0.34	76
		Growth	16	25.44	4.48	1.89	70
Chang (Chang & Banks, 2007)	259 students from a USA university, mean age 18.4	European American - Agency	46	11.74	1.96	0.77	100
		European American - Pathways	46	11.76	1.74	0.16	101
		African American - Agency	30	12.07	2.53	1.21	84
		African American- Pathways	30	13	1.58	3.07**	85
		Latino - Agency	33	12.67	2.13	2.51*	87
		Latino - Pathways	33	12.54	1.25	2.18*	88
		Asian American - Agency		12.13	2.16	1.60	100
		Asian American - Pathways	46	11.61	1.6	0.22	101
Creamer et al (Creamer, et al., 2009)	Patients admitted to a trauma service in a hospital - Australia	73% male, mean age 38.4, SD 13.7	1025	26.27	3.68	6.04***	1079

Study	Sample population	Subsample/ Subscale	n	M	SD	t[1]	df
Dogra (Dogra, et al., 2011)	711 university students in Kolkota		711	24	3.9	1.47	765
Ferraro & Neisius (Ferraro & Neisius, 2002)	20 young and middle age carers in the community, care type not specified	Young	10	26.1	2.8	2.14*	64
		Middle age	10	24.9	2.7	1.26	64
Snyder et al (Snyder, et al., 1991)	Kansas University Student	Study 1	955	25.64	2.93	5.90***	1009
		Study 2	635	25.29	3.08	4.72***	689
		Study 3	475	25.27	3	4.68***	529
		Study 4	875	25.08	3.07	4.34***	929
		Study 5	641	25.36	2.91	5.13***	695
		Study 6	339	25.24	2.81	4.68***	393
	Traumatic stress centre - outpatients	Consumer	97	22.6	4.35	0.84	151
	State hospital - Kansas USA,	Consumer	109	23.11	4.45	0.13	163

1 t = T-test statistic on independent groups
2 *p* = statistical significance of t-test statistic, * = p<.05, ** = p<.01, *** = p<.001,

Chapter 7: Qualitative analysis of the hope interview

Chapter 7: Qualitative analysis of the hope interview

7.1 Introduction

The aim of the semi-structured interview was to understand more about the goals of consumers and carers, how confident they were in pursuit of these goals, and if they had made plans to achieve these goals. The interview provided insight and detail about hope beyond the quantitative data from the Snyder hope scale (Patton, 2002).

Both the Snyder hope scale and the semi-structured interview used the terms "goals" rather than hope. Snyder's theory of hope defines hope as the expectation of goal achievement (Snyder, et al., 1991). The use of the term "goals" in the interview matched the terminology of the Snyder Hope Scale, and was a strategy to explore the thinking behind answers to the Snyder Hope Scale.

After completing the demographic and outcome measures, consumers and carers were asked about their goals for the next year, and how confident they were of attaining these goals. They were also asked about plans or sub-goals to achieve their targets. This follows Snyder's tri-partite conceptualisation of hope as goal directed thinking, agency (motivation and confidence) and pathways (methods and steps to achieve goals).

Consumers were asked about three types of goals, firstly in reference to their life in general, secondly goals for the rest of the family and thirdly goals for their treatment (BFST or case management) for the next twelve months.

Carers were asked very similar questions about goals, motivation and plans for themselves, then a different second question, regarding hope for their consumer relative, and a different third question, about their goals for their consumer relatives' treatment (BFST or case management).

The semi-structured hope interview schedule is appended in Appendix 8.

7.2 Methods

A thematic analysis methodology was used to analyse the interview data. For all interviews, field notes were taken during the interviews. These were transcribed to an Excel computer file and then grouped into meaningful categories, with separate analyses for carer and consumer interview data.

Initial descriptive categories for coding emerged naturally from the questions used in the semi-structured interviews (for instance grouping goals about personal life together). Further analytic concepts for coding were arrived at with subsequent reviews of the data (Browne, 2003; Charmaz, 2000, 2005), but were not significantly dissimilar to the original coding. At baseline, differences between treatment and comparison groups were not evident as only a small number of consumers from the treatment group were interviewed and the data was not sufficient to show trends. Less data was collected at baseline since the additional interview protocol was not finalised until later in 2007. The additional interview protocol was developed later than the quantitative assessment in response to two emerging issues: recruitment was proceeding much more slowly than expected and more qualitative data was required as part of the small numbers strategy and: secondly, the researcher observed that responses to the Snyder Hope Scale (SHS) seemed unsatisfactory. It was observed that instead of truly responding with how much the respondent behaved similar to the statement, they instead recorded with how much they *agreed* with the statement. The interview was planned to assess in more detail the participant's actual goals, motivation level, and plans.

Data was collected from a wider range of participants at follow-up, and differences between treatment and comparison groups at follow-up, where discernible, were identified and reported in the results. Overall, the impression was that there was not a great deal of difference in goals between baseline and follow-up (although this may be partly due to sparse data at base-line) and between the treatment and TAU groups at follow-up. This would be congruent with the quantitative findings for the hope measures and other outcome results. Therefore, most comments incorporated in this chapter are not identified by

group or assessment phase. However, where differences were observed, they are reported in the relevant section.

Although there is some reference to quantity throughout this section (e.g. “many” or “few”) there is no attempt to quantify responses. Strictly quantified data may have been misleading since data was collated across assessment phase and cohort, therefore counting up numbers of comments would not be informative.

Interviewees were not invited to reflect extensively on the themes of hope, goal-setting, motivation and planning. Instead, a specific range of responses were sought on a number of defined questions from all participants. The short structured interview emphasised the researcher as the interview guide, and kept the focus on particular topics. The selected topics were consistent for all interviewees. This approach placed limitations on some of the traditional qualities of qualitative research such as researcher reflexivity, defined as the researcher’s awareness of his/her preconceptions, reflections on actions, and reporting of such (Fossey, Harvey, McDermott, & Davidson, 2002), and permeability, defined as researcher responsiveness to the research observations and information (Fossey, et al., 2002). Some qualitative methods suggest longer unstructured interviews (Bryman, 1984; Fossey, et al., 2002). Using a short structured interview with all participants was aligned with an emphasis on the researcher’s own hypotheses regarding expectancy hope, the research question to be answered using the interview data (Baum, 1995; Bryman, 1984) and the purpose of enhancing the quantitative methodology (Steckler, et al., 1992).

7.3 Consumer results

Twenty-one out of 60 consumers were interviewed at baseline about their goals; five were from the comparison group and sixteen from the treatment group. At follow-up, 40 out of 47 consumers who completed post-treatment interviews were interviewed about hope, as summarised in Table 7.47.

Table 7.47: Number of hope qualitative interviews.

	Consumer	
	Pre	Post
Treatment	16	18
Comparison	5	22

7.3.1 Goals for consumers

7.3.1.1 Goals about wellbeing

The first theme for goals was related to becoming well, and reducing unpleasant symptoms, physically and mentally.

A number of consumer participants reported goals regarding physical fitness such as getting exercise, losing weight, giving up smoking, getting better sleep and more relaxation.

There were a variety of goals relating to their mental illness. Some desired to have a better understanding of their illness. Consumers wished to minimise medication use, but also attain effective symptom control through its use. Other positive goals were “getting better”, “getting to a level where I feel good” and “finding a way to enjoy life” or “love and happiness”. Moving constructively towards discharge meant working with the case manager and looking forward to meeting a new private psychiatrist.

Other mental illness related goals could be categorised as “maintenance” goals related to minimal “check-in” types of treatment such as seeing the case-manager “once a fortnight, just check in”, or visiting their health professional “every three weeks for a check up”. Some “maintaining” goals were about minimising change in the service delivery context, such as:

> *I hope I don’t change case manager or doctor again as it always changes and then I have to tell my story again and again, and they don't take me seriously, maybe, that's how I feel.*

Other goals were mostly about reducing unpleasant mental health problems such as reducing panic attacks, working through sadness, work regarding voices, anxiety, or avoiding hospital and not committing suicide.

Consumers who were in the treatment group tended to have goals around psychoeducation (i.e. learning more about schizophrenia for instance) than the comparison group.

Compared to baseline, follow-up goals incorporated more ideas about the requirements of living post-discharge (for instance treatment moving from case management to care from a GP) and the steps to undertake for this to happen (e.g. establishing referrals, stabilising medication etc).

7.3.1.2 Goals about study and work

A second major theme with a large number of goals was studying and working, with many consumers having goals about courses they wished to attend, or jobs to obtain. Consumers often nominated courses they wished to study, frequently TAFE courses, and courses relating to potential employment. At baseline the study plans were somewhat vague, but study plans were quite detailed and specific at follow-up, especially in the treatment group.

The desire to get a job, full or part-time was common. Not many consumers had a specific job or industry in mind, for example, only specifying “get into full time work”, or “get back to work again”. For a few consumers already in work, the goal was to remain in work, increase the amount of work or improve work performance. Just two consumers mentioned they explicitly had a goal not to work, one saying:

> *They [family and case-manager] suggested part time work, but I'm not ready, too tired, so maybe next year*

There was no obvious difference in work goals for treatment type or before or after phases, and plans did not incorporate a lot of detail.

7.3.1.3 Goals regarding leisure

Engaging in more pleasurable activities was another common theme for goals. A few consumers spoke of indulging in a hobby they already enjoyed, for example, ‘gardening, I love gardening’ but mostly they discussed taking up a

hobby, e.g. “buy a guitar this week and take lessons”. Many consumers mentioned the desire for travel in the future. One consumer suggested “occasional drug use - to give some life back into me - to get an interest back” as a way to provide some fun and stimulus. Some hobbies involved nurturing creativity such as to “keep working on my music, I sing and make music” or “continue writing on my book” and “take studio time more seriously and artistic skills more seriously”.

Another aspect of leisure was to improve social connections and to “go out more often”. Many consumers mentioned developing more friendships through being more open to connecting to people or using existing networks such as neighbourhood houses, or at work. A few mentioned developing social networks through the efforts of Non Government Organisation (NGO) programs.

Starting a romantic relationship was less frequently mentioned. One consumer spelled out the difficulties of this:

> *I wouldn't mind having a relationship with someone in the near future, but to put my problem on someone else is unfair.*

7.3.1.4 Goals related to family

Another major set of goals related to family themes (there was a specific prompt on this in the interview). Four major themes emerged, which were separation and individuation, improving family connections, resolving family conflict and, strain in family relationships. In particular the comparison group were less likely to have goals around family issues.

Many consumers described goals relating to independent living. For instance “getting my own house” and “over next couple of years, to move out” “I want to be more independent and find a place for myself”. Some consumers were not ready for total independent living, needing help to tolerate any time alone, i.e.

> *I’m working with the doctor to stay home by myself, to achieve this at least, during day and night.*

Many consumers described goals about strengthening family ties, usually through more regular contact, e.g. “see my sister regularly” or “keep getting together, keeping in touch, being closer” or:

> *[My daughter] lives in Ocean Grove, and can't visit at the moment [due to illness] so I'll look forward to her getting better and being able to visit.*

Other goals related to wanting the best for other members of the family: “[I] want them to have good health” “ I'd just like us all to be well” “[My] goal is to raise the kids proper and give them the best education” or for family members to overcome their own challenges for example “I'd like Mum to get back to the old life instead of Meals on Wheels” “get my daughter on top of things, because she's depressed at the moment” or “I hope my Mum meets someone [i.e. new partner]”.

Other goals related to the resolution of conflict or relationship difficulties such as “get along better with Mum” or “improve how we function, if we can improve on that” “I want them to say thanks for things to each other”.
Some alluded to the difficulties related to living with a serious mental illness, for instance, “that my dad might understand my schizophrenia, and that they [therapists] would explain [to him]”.
Some of the more poignant comments included descriptions of family strain

> *I hope that I wouldn't stress out my parents for maybe a year, and then we could talk about the past like my childhood. There is hidden stress, but when I bring it up, the past, she [my mother] gets very stressed. I tried to be good for a year and when I spoke to her, there was stress, a wall, a barrier.*
>
> Or:
>
> *Mum sticks with me you know. And they don't want to see me sad faced, they like to see me chirpy and I don't know why I get down.*

7.3.1.5 Practical goals

A few consumers suggested practical goals around financial stability and housing such as “improving financial situation” “[get] money to invest in a house” or “trying to save money”.

Finally, some consumer stated they had no goals, and this was somewhat more common for the comparison group.
Some had had a previous negative experience with goal setting, “I don't make any other goals, I've been through it too many times before”. Others had no stated goals, but implicitly, there was a plan to maintain the present situation:

> *Not many plans - keep up by myself to a certain level, satisfied enough to have a few things going, that's OK - I haven't much of an agenda, but it's enough for me, things, I can keep up, that’s O.K.*

Others preferred to “take things as they come” or “play it by ear. It's hard to make arrangements, things happen”.

7.3.2 Motivation for goal achievement in consumers

Comments about motivation were graded into three levels, representing high, medium and low motivation. Roughly a third of comments were in each category. There were no observable differences between the treatment and comparison groups.

Where consumers mentioned they felt very confident, making an effort and excited, the comments were rated as reflecting high motivation. Where consumers were high in motivation about their goals, they frequently mentioned they felt energised, for example “I feel lots of energy, confident about finishing”, or “yes, putting a lot of energy in, I'm hoping to 'pull them off'”, or “Yeah, I'm putting energy into these, I'll try my best, I try to fight depression and get a hold of myself” and “‘I will be putting as much energy as I can into my goals“.

Another characteristic of consumers who were high in motivation was their enthusiasm for the expected outcome, for example, “I am excited about working part-time while studying a course because it will be a real change in

my life" or "very interested in this one [i.e. this goal]". A consumer in the treatment group stated, "My family and I hope my goals will be reached. My family will be excited if I am also excited" indicating how families can be helpful in the goal setting process.

Medium motivation was expressed in similar terms such as feeling confident, making an effort, or energised, but to a lesser intensity. For instance "I'm putting some energy into it, but I'm pretty normal at the moment" or "I'm starting to put in a bit of effort" or statements that were more bland and generic such as "yeah, I'm committed". One thing that seemed to lessen motivation was less confidence the goal was achievable e.g., "[I'm] confident, need to be realistic about it… I'm determined, but I'll see how it goes" or "my lack of happiness [may prevent me from achieving goals]" or "50-50 really, it will happen, or it won't".

Moderate motivation also occurred when the consumer had goals involving other people that were not mutually held, for example:

> *I try to prepare my Dad for an old age home, even though he doesn't want to be in one*

Or

> *[Getting on with Mum] is the big goal, and we're close, but she's stressed and we can't talk and I hide away because I feel stressed too*

Or

> *I help out around the house and I'd like appreciation being shown for this.*

Low motivation occurred when consumers didn't believe a goal could be attained, e.g.:

> *I'm not sure I can make any difference, I make plans and have ideas and I just can't get it done, even the simplest things.*

Or "yeah, not likely to get to school, to get qualifications and get a good job".

Consumers expressed low motivation due to low energy:

> *I try to but when I come back after the meeting I get stressed out and tired and when I've finished with a session I've had enough for the day, [I'm] not energetic about it, it's like last year, I'll do it next year.*

Other statements were rated as low motivation when the consumer expressed neutrality about the goal. As before, another factor associated with less motivation, was less confidence about the outcome, e.g. "don't know [if it will be a success]".

7.3.3 Consumer planning for goals

Snyder suggested a number of elements to planning for goal achievement and these were considered in the analysis of consumer comments regarding plans for their stated goals. Snyder focused on the number of steps goal-makers outlined, inclusion of alternative strategies, planning for setbacks, and inclusion of dates, time lines and deadlines (Snyder, 2002; Snyder, et al., 1991).

Overall, the plans made by consumers were simple, and limited to one or two steps, with few mentions of time frames or deadlines. This related to the nature of the goals of course, many of which did not require elaborate planning.

However, for goals such as obtaining a job, a more detailed plan would be warranted. There were a large number of plans related to obtaining work or study, commensurate with the number of goals in this area. Given the complexity of rejoining the work force, and the long-term nature of the endeavour, the job hunting strategies were minimal.

Job related planning included ideas such as "if I want to do mining, I'll have to go to [interstate]" "Studying a field of employment I'm interested in". Some more detailed statements were "as soon as my car registered [and] using an agency who aren't very good, so get car and go around and visit factories, - easy to get a job, but I lose concentration…do resume drops" or "I got my first aid certificate, applied for "working with children" check and I've written my resume, I contacted YMCA about volunteer work".

Forward planning can be a problem for people living with schizophrenia so there was a particular interest in analysing the comments regarding more complex planning. Some of the more detailed plans included goal setting "jargon" that may reflect some coaching by another person, for instance a case-manager, family member or BFST therapist. In particular, goals related to the consumer's treatment (both BFST and comparison groups) were mostly rated as high in planning and strategy, which may reflect the efforts of case-managers in working with consumers. For instance;

> *Doing travel training with a carer, they help me learn about tickets, where to get on, where the stop is, mainly practical skills training,*

Or

> *These are goals I already have experience with. I would only need to work around time management. Strategies would include finding other places to study besides only at home and also waiting until I am fully recovered from the illness and ready to be working and studying again*

Or

> *Till I move, then I'll sort out what's happening, then get a job, 4 hours a day, 2 days a week, I've done all the steps, I've put my name down, and we'll see if I get it.*

In contrast, one consumer despaired of improving their life, because they could not create any plan of action:

> *I want to get out of this shit hole, but I don't see the door out of this room.*

Some consumer statements that were proffered as plans were really motivation statements, such as "being my own person and making up my own mind" or "just have to try" or "stick with it, and don't give up", "stay focused, talking positive to myself".

Planning for wellness or fitness was popular, and indicated that consumers often had at least one simple strategy for maintaining mental health or increasing fitness. Examples were "keep taking the tablets, like it or not - make sure I have taken them", or "deep breathing, trying to relax etc" or "get my

doctor to increase the medication that I take". Some considered how to cope with setbacks in their planning:

> *Yes, I might be set back if another breakdown occurs, but that should not happen as long as I'm on medication.*

Most of the fitness plans related to gym attendance or an exercise plan, e.g. "I've got the tablets (to lose weight) and sometimes I go for a walk" or "gym - getting the card for the leisure centre".

There were only a few plans for increasing social contact or hobbies. One consumer suggested, "get in touch with other people" and another:

> *Ring more people, being social. And go to hospital and visit people and keep doing art.*

However, these plans lacked specificity, had no strategy for setbacks and did not include any improvement in skills. This is problematic given that many consumers had goals in this area and social isolation is a major concern for people living with schizophrenia (Morgan et al., 2011).

Plans for independent living included some practical strategies for skill development, e.g. "working with budgeting so I can move out", "[developing] skills in cooking and cleaning" or "practising staying home by myself for a short time at first, then building it up". One consumer mentioned that family sessions had helped with planning:

> *To move out of home…my goals haven't changed [since the beginning of BFST sessions] it helped me to get some steps.*

Plans for family cohesion were more common in the BFST group, as would be expected;

> *In the family meetings, one of the things was to have a house meeting, once a week and we had our first one and it worked well,*

Or

> *Meetings - sit down and have a proper dinner and talk over what's happening - we are now closer as a family which we never were before.*

The overall impression is that BFST consumers were able to generate more detailed plans across a wider range of goals. In regards to maintaining mental health, both groups had some clear strategies. There were no clear differences between baseline and follow-up.

7.3.4 Consumer summary

Consumers had goals around improving mental and physical health, study and work, leisure, family and practical issues such as housing and financial matters.

Treatment consumers tended to have more goals around psychoeducation, more detailed plans for study and for other goals overall, and more likely to have goals related to family issues, such as improved family cohesion. Motivation for goals was similar between groups, and confidence in ability to achieve goals and enthusiasm for the goal increased motivation. Comparison consumers more commonly stated they had no goals. The overall level of planning was basic for both groups.

7.4 Carer results

The carers were asked similar questions to the consumers, but differences in their focus highlighted the asymmetries in the carer-consumer relationship, with emphasis on the carer's mindfulness of their consumer relative. The initial question however, was about the carer's own goals for the next year, and the motivation and planning around these goals. This was exactly the same question asked of the consumers.

The second question was about the carer's goals for their consumer relative, so the focus was not on the carer at all. In contrast, consumers were asked a more general question about their goals for their family, which tended to be inclusive of the consumer. Motivation and planning was elicited as before.

The third set of goals related to their consumer relative's treatment. Comparison group carer's were asked about their goals, hopes and expectations of working with the consumer's case manager. Treatment group carers were asked about their goals for BFST sessions. In the post-treatment assessment, they were asked if there were any goals "as a result" of BFST sessions, or developing from BFST sessions.

The carer and consumer interview data was analysed independently, and different themes emerged for carer goals compared to consumer goals. This is presumably linked to the different emphasis in the questions, as well as the different experiences of the two groups. The difference in themes between consumers and carers is reflected in the different subheadings in the goal, motivation and planning analyses.

Table 7.48: Number of hope qualitative interviews for carers.

	Carer	
	Pre	Post
Treatment	14	14
Comparison	3	19

Seventeen out of sixty three carers at baseline were interviewed about hope (three comparison group and 14 treatment group), and 33 carers out of 53 carers at follow-up were interviewed about hope (14 comparison group and 19 treatment group). See Table 7.48.

7.4.1 Carer goals

7.4.1.1 Carer personal goals

Carers' personal goals covered work or study, more leisure, some goals for the family in general, and goals to "have goals" about themselves.

Carers had modest and few goals for themselves, for instance, to "maintain my life - my health, my family, my home to continue, that's my life" or "minimise stress and keep healthy". Carers in the treatment group reported that BFST had helped them think more about their personal goals. For instance, treatment carers mentioned that they did not previously focus on themselves; "it's a bit hard to think of something for yourself, I want to put myself a bit further up on the tree [in the future]". A carer in the treatment group commented she was "asked what are your goals for next 5 years, [which] really got me thinking". Another carer from the treatment group mentioned they "would not do anything of this before [BFST]" as goals for themselves were neglected. Some carers did not believe they had time for themselves; "I would like time to do the things I'd like to do, but I'd rather have my son alive".

About a third of carers had some kind of goal around work or study at post treatment. For a few carers, the aim was to return to work or study for instance, “I'd like to go back to work, just part-time - I'll do some volunteer work too”. For others it was to change work conditions or improve qualifications, e.g. “doing extra courses through job” or “Certification for work next year”.

Carers had many and varied goals for relaxation, including holidays, taking up tennis and gym, doing some art and craft, joining the local footy team, and meeting people. Another carer had a goal to “go on holiday [but] my main concern [is] what could happen to her [i.e. consumer] when I'm away and in general”, showing the constraints in achieving personal goals.

A few carers had major goals around buying a new house. Some had some renovation ideas. Others wanted to pay off debts or get off government income support to improve financial stability.

7.4.1.2 Carer goals for their consumer relative

Most of the responses regarding goals for their consumer relative were from the second question. Carers reported as many, if not more, goals held for their consumer relative compared to goals held for themselves. The goals held for consumers did mirror the goals that consumers held for themselves, for instance, developing independence, greater social links, obtaining work or avoiding relapse.

There were some comments regarding goals for the family in general, mainly in response to the third question (goals for BFST or case management) and mainly from the treatment group. Goals included better communication, learning about each other, and new skills, and “keep being a happy family”. For treatment group carers, question two elicited goals individually focused on the consumer, but question three elicited more goals around the family as a whole.

For comparison group carers, goals for the consumer relative came in response to question two and three as well.

A major concern for carers was to improve the social life for consumers: “I want him to engage in some kind of social activity” or

> *I've been working on social things with him. Otherwise he's in the house, and loses perspective on things and gets things out of wack.*

More social life for the consumer could lead to better social opportunities for the whole family, e.g. “[For consumer] to socialise, so we can all socialise” or “going out a bit more, because he [consumer] was going out and had a girlfriend and not feeling left out when we do things”. A better social life was seen as part of recovery, even though there was no total remission possible

> *We know she'll never be well, but [could be] enjoying better quality of life - more social outings, e.g. coffee, shopping and other things.*

A related goal was to develop more independence for the consumer as part of rehabilitation and maintenance of wellbeing. For instance,

> *Plan to put him on a ministry of housing with someone independent and responsible and it has to be done, to have stability*

Or “more independence, and he's crying out for that”. Carers saw this as planning for the future, when they could no longer do the caring role

> *To be able to manage, to cope with life by herself, what will happen when we're gone, how will she cope.*

Some carers also had goals regarding consumer occupation. They articulated the complexity of this task:

> *He has been talking about full-time employment and finding the pathway towards that seems difficult. I think he's capable if he was offered a job, but someone needs to understand how he would present at an interview, and put in a lot of work to get something back.*

Many carers expressed goals that their relative could get better. It was here that the word “hope” was used in relation to their goals, a term not used elsewhere.

Hopes for [consumer] for her to be herself again, to come to herself again, whether it's the medication or something

Or

Hope Mum takes medication, gets back on her feet and looks after herself and then I could do my own thing a bit more

And

I haven't given up, I think he'll eventually get a job, and even meet the right person.

One carer discussed the holding of hope simultaneous with accepting reality:

It would be like for every mother, that he would have a fulfilling life, meet a partner, have kids, and we're waiting for a medication that will help him overcome the state he's in that we also accept you're in it, so get on with it.

Maintaining mental health and hoping things don't get worse was also important for carers. Goals included "[That he] stays the way he is, that would be good" or "that he stays the way he is at the moment, because he was not too good a few months ago" or 'I hope her health stays the same".

Carers expressed anxiety about the prospects of another relapse:

My hope is that [the consumer] won't break down again, it was horrifying, and I don't want to see that again. As good as things are, the best that can be expected is OK, I can cope, but if he regresses, that's when I feel anxious.

The tempering of hope was discussed in relation to goals of maintenance:

[We had] huge hopes when she started her job, but now hopes for health and improvement – there is no hope, hopes for maintaining is there, quality of life has improved lately.

7.4.1.3 Carer goals in relation to mental health services

There was a distinct difference in goals in relation to mental health services at follow-up between treatment and comparison groups, with treatment group carers expressing more confidence in liaison and collaboration with services, than comparison group carers. For instance a treatment group carer commented:

> *We've come a long way, so if we finish, that's far enough, it would be good to have catch-ups in the future.*

In contrast, comparison carers stated

> *A bit of contact with the case manager would be Good! No contact with previous case manager at all.*

Or

> *The service will be temporary and pushing people to GPs and private work, so I'm getting private backup - we'll be discharged within the year, so making plans ahead.*

In the main, comparison carers were not involved with case-managers, but did observe, that the case managers were working on goals with consumers. For example:

> *Case managers tend to come and check and solve a few things, like to contact the solicitor, the state trustees etc*

Or

> *The girl from NEAMI came for a walk with him and they just had a coffee and I'd like more of that. The case manager talks about doing a course, or something. He also talks about living independently - but [consumer] doesn't want to at the moment.*

Other carers were not involved with treatment "[Consumer] goes by himself". Satisfaction was expressed "I just feel so blessed with his treatment and the help and assistance they give" or "I'm happy with what they are doing, they're doing the best they can".

For treatment carers, there were still concerns about practicalities in treatment regimes for instance “co-ordination of [consumer’s] care who's in control?” or

> *Does he continue with case manager? For how long? I hope she works with him on getting him work*

Or “it's been pretty good, the change over in case manager” and

> *Its questions about whether medication may have caused the [side-effects]… but reluctant to fiddle with medication because he is so stable at the moment.*

7.4.1.4 No Goals

A few carers had no goal, or minimal goals to maintain the status quo. For instance “take each day as it comes” or “No goals, work, keep going. And pay bills” or “keep things the same”. Some carers felt goals were difficult:

> *To survive, not too many [goals] it encroaches on this, some tiny goals are there.*

One treatment carer felt demoralised by goal setting

> *No, I "failed" in BFST goal setting - I want to be "happier" e.g. too esoteric, practical goals? Lose weight, more arts and crafts - my husband was very practical and achieved his goals that were learn guitar and join choir.*

7.4.2 Carer motivation

7.4.2.1 Carer motivation for personal goals

Carers who were rated as having high motivation for their own goals used a similar vocabulary to consumers, with words such as “confident” “effort”, “energy” and “excitement”. Examples of high goal motivation are “working very hard to put money into the home loan” or “I'm putting a lot of effort into this, it's a good outlet” and “lots of energy, excited and pretty confident”. High motivation was linked to belief that goals could be achieved, for instance “yeah, that's definite” or “confident of achieving that”.

Another type of motivational statement in carers that was not apparent in consumers illustrated the pressure of necessity and duty. For instance “just gotta keep going, just gotta get the strength … and you've got to be there” or

> *Duty, keeps me going, self-belief and the idea I've got something to contribute*

One carer said hope was her motivation:

> *I used to pray a lot, but sometime I stopped believing in God … the family and husband are close. Don't let myself sit down, work till when I go to sleep, I'm tired and I sleep. And hoping…*

Some carers expressed a moderate or ambivalent motivation. Examples are “yeah, I'm confident, it WILL happen, I’m giving it 50% energy” or “definitely happen, but I’m a bit reluctant, because of how I'll cope with it all”. Some carers expressed mixed feelings about how their goals had been overwhelmed by the demands of previous caregiving:

> *I wish when I was young I got into sport, because Mum was unwell, and I missed out on it, would have been good to be encouraged [adult offspring carer]*

Or

> *At the start of year, I realised I was at the end of the road and now I get on with things, can't spend 24/7 looking after him.*

Carers with low motivation for personal goals mainly expressed this as making no effort to affect outcomes, for instance “we'll see what happens” or “just take it as it comes, can't do anything to affect this” or ”whatever happens, happens” or “see what's evolving, there’s things to sort out”. One carer indicated that the demands of caregiving were in the way of personal goal achievement: “It’s really hard at the moment, when she gets better maybe”.

7.4.2.2 Carer motivation for their goals for their consumer relative

Carer motivation for their goals regarding their consumer relative, were rated high, medium and low motivation (similar categories as for motivation for their personal goals).

High motivation statements resulted from the observation of consumer readiness. For instance “he's [consumer] ready to fill his life in now, before he wasn't interested, yeah confident” or “he's doing that a lot himself with his counsellor - yeah he can do it.” Others felt confident in their own ability to manage the situation:

> *I think I can control these things if anything goes wrong. I think I can help her. Other family members don't help so I know now I can do it.*

Others expressed confidence in success from effort and energy “as much as it takes” “Feeling excited and confident” or “lots of energy going into this” and “yeah, every scrap of energy I put into this”.

A sense of necessity was expressed in these statements “we need to do something different, can't go back to how it was, it didn't work” and

> *It's a real concern that he can manage, I won't be here forever. When I achieve that goal, I'll have peace of mind*

And “No, I won't give up till I die”, which clearly indicate the deep and desperate layers of motivation for carers.

Ambivalent motivation, but with the stirrings of hope were expressed by one carer at the end of BFST sessions:

> *I'm feeling freer, and I don’t have that constant worry, I wouldn't call it a "burden"… I think I'm at the point where I believe things can change, but I don't want to be optimistic, I'll be cautious, I’ll see what happens*

Other statements expressing ambivalence about achieving goals for their consumer relative acknowledged that the outcome was dependent on the consumer’s own motivation and ability. For instance “try to be encouraging, but in the end, it's up to [consumer], and she can pull the pin” “He'll talk about it

and I'll encourage him, but remind him it takes time" or "yeah, he'd like it too". Other carers used the term hope, for example "we hope the family gets closer" or "I hope it can happen" or"

> *There's not a drug out at the moment but as he is, I can't see him married at the moment. There are always miracles, and there are hopes and dreams.*

A large number of carers expressed low motivation and confidence that their goals for their consumer relative could be achieved – often due to the fact that the outcome was not in their control but in the consumer's. Treatment and comparison group carers equally shared this attitude. For instance:

> *We don't know how to do things, its up to S. to pull her socks up, we can't make it happen, so we'll give up*

Or

> *I'm worried that he's not doing anything, and not straight away, but in a year or so, he'll breakdown because he's not doing anything, and all he does is negative thinking*

Or

> *He [consumer] just doesn't have the energy or motivation to get going at moment*

Or

> *You can only suggest so much, and try to convince her about getting out, but she's not interested - so I'm starting to give up on it.*

Carers also expressed some frustration with services not able to help them

> *I've stepped back a lot of the time since leaving [the area mental health service]. It used to be good having a case manager you could phone them in a crisis, but now the [non government rehabilitation service] guy is not as available*

Or

> *They try as hard as she can, but how many clients does the case manager have on the books and how much time does she have.*

There appeared to be little difference in motivation for personal goals, or goals for the consumer relative between treatment and comparison carer groups.

7.4.3 Carer planning for goals

7.4.3.1 Carer planning for personal goals

Carers were able to generate many plans for their personal goals. Although not complex, they were practical and relevant.

Plans for obtaining or changing work included undertaking training, consulting with senior colleagues, and checking job advertisements. Planning for improved health included exercise plans, and joining events such as fun-runs. Housing and finance plans included budgeting, paying off home loans and savings plans. Hobby and recreational goals were achieved by joining lessons (e.g. for writing or music), getting passports for travel etc.

Carers who were passive about goal achievement did little planning, deferred actions and remained contemplating goals. For instance “In the winter when I have more time, I'll get into it” or “No particular plans, but work on problems before they get out of hand” or “just day by day” and “talking about it for a while, and made a few plans, but I don't get around to it sometimes”.

7.4.3.2 Carer planning for goals for their consumer relative

A large amount of planning and strategy went into the goals carers held for their relative, perhaps more than for the carer’s personal goals. For instance, where there was a goal to help the consumer lose weight,

> *When we go out, we have coffee or lunch, and we encourage positive moves [to diet] e.g. if she chooses Subway over KFC, take her to Homyped to help her out and keep her comfortable on her feet. Clothes shopping we give her positive feedback over things, give her a gift card rather than chocolate etc*

Or

The challenges are: here [in the family home] he doesn't pay rent, finding a flat mate that he can get on with, who does he share with, he doesn't want to go far away and then need to change case manager at the centre, this goal is my goal now [to live independently], he's got plans to get a job, getting medication right, right dosage, the right doctors and right case managers

Or

If I see something in the paper, I'll show him - ask him each day about what he's doing – case manager is working with him on that too.

Some carers were less active in their plans: "No, I just hope it happens" or "it's step by step and taking things as they arise". This did not mean abandoning the goals, for instance:

We keep 'hands around' but not 'hands on', so we help him a lot, and help him with the house, and not just let it all go.

For some carers, planning was difficult because they didn't know how they could help, or felt blocked by the consumer. For instance "I think about it every night, but how to get there is very hard" or "How, I don't know" or "The problem is that [consumer] is the stumbling block" or "I try to suggest but she's not interested". Other carers felt support services let them down, e.g.

Depends on his job agency, but they just send him to any job, and he's set on a baking job, and they just put them to anywhere, and don't make a real effort

Or

"[Consumer] hasn't seen psychiatrist for a few weeks, but a session is planned for this Thursday, They don't understand about the music

And

No meeting with the case manager this year so it's very hard.

Overall, the treatment carers seemed more confident in making plans to achieve goals compared to carers in the comparison group who tended to be more passive.

7.4.4 Carer summary

Carers had modest goals for themselves, relating to working and studying, leisure, and regaining self-focus. Some treatment group carers reported that BFST sessions has "given them permission" to think about personal goals again. BFST carers tended to have more goals around the family in general, as well as goals for their consumer relative. Carers from both groups were particularly concerned to improve their relative's social connections. Carers spontaneously mentioned hope in relation to goals for their consumer relative, especially regarding hopes for a normal job and long term relationship.

BFST carers expressed more confidence regarding treatment, and liaison and collaboration with service providers.

Carer motivation varied from high to low, and also incorporated a sense of duty and necessity that was not evident in consumers. Motivation for personal goals and goals for their consumer relative were similar, and was even across treatment and comparison groups.

Carers were more sophisticated at planning than their relatives, and put a large amount of effort into planning for goals related to their relative. Treatment carers were more confident in planning than comparison group carers.

7.5 Summary and conclusion

Carers and consumers had a wide range of goals relating to improvement in their personal lives in the areas of health, hobbies, socialising, work and home life. While many consumers had positive motivation, a substantial number lacked confidence in their ability to achieve their goal and had few plans in place. Many consumers had goals around positive family relationships, but also being able to live independent of their families. Discussing goals did not elicit any mention of hopes.

Some differences were noted between treatment and comparison consumer participants. Treatment consumers had more goals related to learning about their illness through psychoeducation than the comparison group, and had more detailed plans for study in the future, more likely to have goals around the family, and less likely to have no goals than the comparison group. Motivation between the two groups was very similar. The treatment group were able to make more detailed plans for their goals and in particular for family cohesion.

Differences between comparison and treatment carers were observed. Treatment group carers reported that BFST sessions had helped them think more about having personal goals; they had more goals for the family as a whole and expressed more confidence in liaison and collaboration with services. Motivation and confidence was similar between treatment and comparison group carers. Treatment group carers seemed more skilled than comparison group carers in making plans to achieve their stated goals.

These observations would be totally congruent with the aims and objectives of BFST, which is to help families with goals, think about goals as a family team and spend time in planning goal achievement. What is interesting is that motivation and confidence was not discernibly different between the two groups. A long experience of not achieving goals may have led to a sense of resignation that means both groups had low confidence about goals.

However, overall, there was much more similarity than difference between the two groups, in terms of types of goals, reasons for motivation level, and in ability to formulate goals.

Carers (following a prompt) had many goals for their consumer relative, with detailed plans and positive motivation. However, some carers expressed frustration around their inability to influence outcomes for their family member. Interestingly, when discussing the goals for their relative, carers spontaneously used the word “hope”. Carers used the term hope in relationship to outcomes they couldn’t plan for, and could not have confidence for success (for instance “Hopes for ….her to be herself again”). This use of the word hope takes up one of it’s meanings in the concept of emergent hope, that hope often occurs as a stated goal, but without confidence in goal achievement (i.e. no agency) and

without plans (i.e. no pathways). It also indicates the link between hope and adversity, in that strong hopes can be held even when there is no personal control over the situation and no planning is possible (Tong, et al., 2009) and also, how hope can be held more intensely for another person, than for oneself (Aspinwall & Leaf, 2002).

Carers discussion of their goals for their consumer relative indicate that they accept the symptoms and challenges of their consumer relative, but aim for the best quality of life possible in the circumstances.

In contrast, the language of goals did not tap any “hopes” in consumers. This does not mean they do not have hopes; only that talking about goals did not make a connection to hope for them. For carers, the language of goals only really sparked a discussion of hope in relation to their consumer relative. One interpretation is that hope is how people describe dealing with adverse circumstances (i.e. a serious mental illness), whereas goals are a more global positive approach to life.

What do the interview responses mean for understanding more about the Snyder Hope Scale results and the quantitative assessment of hope? The scale purports to measure constructs related to goal setting and achievement, which are the Snyder model of hope components of goals, motivation and pathways. The discussion of goals, motivation and pathways did not elicit any talk of personal hopes, except in one situation, that of carer’s talking about ”hopes” for their relative. When carers did talk about their hopes for their relative, they did not mention high confidence or clear pathways to these goals/hopes, rather, stated that the way forward was unclear and uncertain. In contrast, Snyder asserts that in high hope situations, there is no lack of motivation or planning (Snyder, et al., 1991). This could mean that when carers discuss their hopes for their consumer relative, that they have low hope according to Snyder’s measure, in spite of the presence of goals, or that Snyder’s construct is different to the phenomenon observed in carers that carers describe as hope.

Chapter 8: Satisfaction with BFST: Exit interview

Chapter 8: Satisfaction with BFST: Exit interview

Participants in the BFST group were interviewed at the end of treatment about their experiences of participating in family sessions. Carers and consumers were interviewed separately (see Chapter 4: Methodology). The semi-structured interview (see Appendix 9) covered aspects of their relationship to the Behavioural Family Therapist, the experience of working with their family and changes and learning from doing the sessions.

Responses to the interview were collated and thematically arranged, rather than grouped according to stimulus question, which allowed for linking of common experiences across various participants.

8.1 Engagement

Some carers and consumers talked about the ambivalence they felt before they started BFST sessions. For instance:

> *I was quite ambivalent about doing it because I thought it might stir up a hornet's nest, and rock the boat, that we were used to the easy path, and we'd all do things individually.* Carer, female, 49 year old

> *I was unsure at first, then I realised it was better to discuss it all together,* Consumer, male, 28 year old

Participants were reassured by the positive experiences in early sessions.

> *The first sessions (the individual assessment) were really good and when you left the room you felt better*. Carer, female, 41 years old

Participants mentioned a number of factors that contributed to families feeling comfortable in sessions:

- A positive relation to therapists e.g.

  The therapists really listened to you and were helping you, not just as an extra to the patient. Carer, female, 58 years old

  They agreed with what I said, and they accepted what I said. Consumer male, 25 years old

- A “light touch” in sessions, a sense of humour, e.g.

  It was like having a chat, … No big revelations, but it was easy going and a bit of fun and we'd laugh in the sessions. Carer, female, 55 year old

  Got along very well, jokes with [male therapist] and [female therapist] Consumer male, 38 years old

- Being patient and understanding, e.g.

  The [explanations] were very good, if we weren't sure they would always explain it and go back to material from the week before. Carer, female, 52 years old

Disruption to the regularity of sessions or difficulty with session times was a concern and reflects some of the challenges of implementation in a busy mental health centre:

> *We would like a longer program because it stopped and started, lost a lot of momentum* Carer, female, 52 years old
>
> *Early on we had difficulties (a bereavement) and then someone was sick and on holidays etc, and that slowed down things at the start.* Carer, female, 54 years old
>
> *The main thing that became a problem was having the session during working hours - it was hard to get a suitable time.* Consumer male, 24 years old
>
> *Good, but it was a bit stop/start at the beginning and I felt annoyed.* Consumer female, 23 years old

8.2 Psychoeducation and skill acquisition

BFT sessions included skills training, role-plays and “homework” to enhance learning. This could be challenging for some participants, both as a result of feeling self-conscious and cognitively challenged.

> *The role-plays etc make me nervous, but they were OK.* Carer, female, 54 years old

> *There were a few awkward moments, like role-playing. [But] the role-playing is the most important because you learn from it.* Consumer male, 31 years old

> *Maybe sessions less frequently, but go on for longer; it happened kind of quickly. It would have given me more time to organise my thoughts before the next session and give me more time to sort out my goals.* Consumer male, 28 years old

> *Needed more or longer sessions; there were too many topics in a short time and I need to learn slowly which might be quite common in people with medication, one topic a week is enough.* Consumer female, 31 years old

For some families, talking intimately about their challenges was awkward, but rewarding.

> *It was confronting, we only brought up things that we found difficult.* Carer female, 54 years old

> *To start, it was a little awkward, for [the consumer], the focus on 'his illness', and I brought it in that it was about my attitudes as well, not just about him.* Carer female, 32 years old

> *It was hard to talk about the addiction, I felt ashamed, in front of mum and dad and siblings.* Consumer female, 24 years old

Most consumers were not concerned about privacy, but for some there were concerns about moving from individual to family therapy, or meeting therapists in the home.

> *I had no problems with confidentiality; I wasn't scared to begin family sessions. I wanted them to know about the side effects [of my medication].* Consumer male, 25 years old

> *At first it was 'iffy' about what to say and what not to say. A few times I've said a few things to my CM that were absolutely private, and I didn't know how to manage that.* Consumer female, 38 years old

> *I wasn't concerned about privacy, but they found it embarrassing.* Consumer male, 18 years old

> *In the beginning it was a shock to have them in my house, but in the end I liked it.* Consumer, female, 45 years old.

Although understandably ambivalent in anticipating the discussion of difficult issues, the increase in family intimacy led to some of the most important breakthroughs for families. The forum for a lot of this helpful discussion was the "information sharing" sessions, where consumers could talk directly about their own experiences of symptoms and mental illness and carers learnt more about their relative's experiences.

Some families independently told stories of the growth of mutual understanding in sessions. For instance a carer explained what she learnt:

> *[Consumer] talked about her feelings, and her symptoms and her experiences, for her to open up to the family was a turning point and a high point.* Carer female, 52 years old

Her consumer relative explained the experience from her point of view:

> *In one of the early sessions, the therapist asked me to explain my symptoms, and I told my mum I thought she had been the devil, and she was amazed, and I realised it was just silly thoughts, just symptoms and I got the insight just by talking about it. The sessions brought relief and understanding, the family understands the illness and what I've been through and the symptoms, the hospital, about the anger and the physical stuff (i.e. aggression) there were some issues I was uncomfortable about, but my case manager said we have to talk about them.* Consumer female, 24 years old

Some of the learning was educative:

I understand my relative better, and understand the illness. I'm more aware and caring. Carer male, 54 years old

There is a greater acceptance of the symptoms; he doesn't talk a lot about them. Consumer male, 40 years old

[We learnt] a lot of what is going on for [our] son, understanding more about the voices etcetera. We are more relaxed because we understand it a lot more; we understand how he sees things and we are accepting he has a mental illness. Carer female, 53 years old

We didn't realise she hears voices ALL THE TIME, it's sad to think this goes on all the time, so [the consumer] did a CBT course. We have more understanding of [our consumer relative] and what she goes through … it was good to hear about her feelings, as she doesn't always express herself. Carer female, 55 years old

Some consumers learnt more about their own illness:

I learnt about the illness, and about the 'negative symptoms' and I had heard of them, but never had it explained, so now I understood about negative symptoms and the depression and the whole thing. Consumer, male, 34 years old

We've learnt something about my diagnosis, about listening better and having an open mind for a person's thoughts and feelings, that it mightn't be important to me, but it is to them. Closeness is important, see things from their eyes. Consumer, female, 45 years old

Sometimes the sharing led to more emotional breakthroughs with insights for both carers and consumers:

There were some emotional times, and it was between my husband and my daughter it was important, just a shift, a clearing of the air. Carer female, 49 years old

I understand more about my relatives, Mum was stressed about her mum [being unwell] and dad was busy at work, and it impacted on

mum's personality, and I understand that because of family sessions. Consumer male, 18 years old

I'm feeling more able to talk about my feelings; about feeling anxious and depressed and irritated. Consumer, male 31 years old

Yeah, yeah [we understand each other better], the more you talk, the better, it's painful but it's helpful. Carer female, 55 years old

One participant spoke eloquently about living with the painful feelings in his family

There was a moment when I realised it was really good we all talked together about feelings and mental illness, and everyone just expressed their opinion. It's tough for them [my parents] I think they are used to it now, that I have schizophrenia, and they are moving on. They learnt some things about me; some in the family still have to learn a lot more - like my brother and sister. Consumer, male 28 years old

Another consumer from a CALD family described how his father did not know about the diagnosis or understand about schizophrenia until for the first time the interpreter was organised and things were explained:

The interpreter was really good to speak to my parents, it was unbelievable because they [the interpreter and the therapists] explained what my illness was, they didn't understand what was going on [till then]. Consumer, male 35 years old

8.3 Generalisation of therapy acquired skills and education

Families described the implementation of the BFST skills in their own lives – both successful and unsuccessful.

We learnt to do problem solving together I realised I had the skills from work so I realised I could apply those skills at home. Carer, female, 47 years old

It was hard to get the time for the 1/2 hour meetings, to do our homework and we just didn't. Carer, female, 54 years old

My daughter and husband had a breakthrough, and did problem solving and it worked. Really doing lots of positive feedback and saying thank you, it lightened the mood at home, (we probably went through a phase of over doing it and being too nice) made us all more aware of how we got along, brought back some of the joy, some of the niceties again. Carer, female, 49 years old

Often the strategies they discussed, we did in an informal way beforehand anyway. For example solving problems or expressing feelings. Asking for what you want clearly, was a new skill because that gets caught up in other things and setting boundaries - saying no. Carer, female, 55 years old

There was [a key moment] when we did the problem solving, and that was a revelation, because we had a few large goals set out and worked out ways of achieving them, then "let's start doing stuff" it was quite energising. Carer, male, 40 years old

Practical changes from sessions were varied and tailored to each family's particular issues.

I'm more aware of the talking voices problems; it's helped. It's been good; I get extra help now to deal with the voices, like going for a walk or listening to music. Consumer, male 38 years old

Got a lot of things organised, like meals on wheels, got a cleaner organised, organised the district nurse. Consumer, male 35 years old

Carers' burdens were not as pressing after the sessions:

I got a sense of importance, that you matter, the patient goes in and gets treated and the carer is pushed aside. I felt important and validated. Carer, female, 58 years old

I've put things in place such as wills because of worries about the future and what will happen when I'm gone. Carer female, 58 years old

> *I accept his illness now, and just get on with it - I go out and walk or something. I didn't use to, I stayed in all day and it drove me nuts.* Carer, female, 54 years old

> *The "weight" on my shoulders has changed.* Carer, female, 54 years old

There was evidence of reduction in unhelpful communications, similar to "hostile and critical comments" (high EE):

> *Learning about expressing positive and negative feelings, was very helpful, that's what made me stop and think before I speak… Probably made me stop before I open my mouth, I stop and think, instead of just blurting it out. He (consumer) does get hurt feelings yeah, I would recommend it, not just because you've got a family member who is unwell, but because it is the basics.* Carer, female, 54 years old

Independently the consumer in the same family made the comment:

> *There is not so much tension now, or if there is, we just try and joke about it. There was tension and we didn't get along, and now we do, fights aren't so often. I feel a bit happier if there is less tension.* Consumer, male, 18 years old.

Another carer said:

> *Had I not had the sessions, I would still have thought yelling would help when in fact it makes it worse.* Carer, male, 61 years old

Other carer comments seemed to reflect a lessening of high emotional over-involvement (another aspect of high EE):

> *Everything is much less of a hassle, because [my consumer relative] has taken more control of things. I'm quite happy to give that to her.* Carer, female, 54 years old

> *During the program, they asked, what are you doing for yourself, what are your plans? And I had plans but never did them. Now I make sure I do a few things for myself.* Carer, female, 54 years old

Carers mentioned they had learnt to deal with exacerbations and made plans with their consumer relative:

> *Had a relationship with the case manager, because of the BFST sessions, and when my [son] became unwell it was easy to manage the situation.* Carer, female, 58 years old

> *We developed very good cards that summarised all the contact details of carers. And a wellness gauge that helped with decisions about who to contact if she was starting to feel down.* Carer female, 55 years old

8.4 Other changes

Other changes were more diffuse, unexpected or indirect, but still important.

> *I think clearer and I'm not crying any more.* Consumer, male 31 years old

> *I have got a new job, and that's been good.* Carer, male, 40 years old

> *He sleeps better too. I couldn't cope with his late afternoon wake ups again. It's been improving gradually. The family sessions helped because he could report in.* Carer, female, 55 years old

Social engagement in consumers improved:

> *He's started TAFE, that was from BFST, and has done really well, and he gets good marks and it increases his self-esteem.* Carer female, 32 years old

> *He's doing things he's never done before; he watched the news and current affairs and taking notice of politics. Same with the football, he watches it with me, and [doing] footy tipping which is confidence building.* Carer female, 58 years old

> *I noticed I WAS getting better; because then I could do the things that I said I would, before I wouldn't get things done.* Consumer, male 25 years old

8.5 Conclusion of sessions

Although comments were favourable overall, there were still some reservations and concerns for participants at the conclusion of sessions.

> *There is still a question in my mind about [our consumer relative] not being drawn out enough - whether we should just not talk and let him, or whether we should have said something.* Carer female, 49 years old

> *In my opinion BFST helps 60%, the rest it doesn't change. It helps, but it does not cure, it does not fix the person.* Carer male, 61 years old

> *We didn't learn any "facts and figures" about schizophrenia, we had already read the books, and perhaps it would be more benefit to people who don't understand. It was hard to get across to the therapists that why are you working on us, not him. We were doing sessions when he was unwell, so there was no point to the discussions because he was paranoid and there were things in his head.* Carer, female, 41 years old.

Some participants found the termination phase challenging

> *I didn't have many connections before the course started and I felt down when it was over, I had a "negative backlash".* Carer female, 58 years old

> *It was a bit of a let-down at the end, a follow up after 6 months would have been good, even a brief one.* Carer male, 40 years old

> *I wish to continue with sessions.* Carer male, 61 years old

Participants noted that a more rigid style, not adapted to the family atmosphere was inhibiting. Some families did not like particular aspects of BFST or find them helpful.

> *There wasn't time for some stuff, especially the positive stuff. There was a very dry way of talking; we would like a more energised way of speaking, a bit more motivating.* Carer male, 40 years old

> *The role plays didn't really work for us, tailoring to the family was better, rather than going through the textbook.* Carer, female, 54 years old

It felt a bit difficult [working with the family] it felt a little uncomfortable and formal, and there were hard things to talk about. It was a bit stiff sometimes. Carer, female, 55 years old

The family meetings at home didn't help. Carer, female, 54 years old

8.6 Summary

In summary, it was quite stressful for families as they started sessions, not knowing exactly what the process would entail and early positive experiences in sessions were important to create engagement.

Practical problems in schedules and continuity did have some negative impact on treatment. Surprisingly, confidentiality was not a concern for most consumers.

It is notable that, although BFT focused on “skills” and “problem solving” and structured activities in sessions, it was the more “therapeutic” outcomes that had the most impact. That is, the things that touched carers and consumers, and were reported as “breakthroughs” and experiences of lasting impact, were the times when a more profound understanding of other family members emerged, when therapists and families experienced moments of profound rapport, and when individuals gained insight into themselves. The skills learning certainly gave families better communication tools which enhanced these experiences, and they also provided activities which provided a safe “container” for these more profound interactions. The two sets of quotes from carer and consumer in the same family convey the interaction of the practical skills learning and the therapeutic outcomes.

Some of the benefits reported included practical changes in routines and symptom management, reduced carer burden, reduction in negative communication styles, more independent functioning in consumers, better understanding of symptoms, better relapse management, and better social engagement of consumers.

Chapter 9: Discussion

Chapter 9: Discussion and conclusion

This research investigated hope and recovery in an effectiveness trial for a family psychoeducation program. Hope levels (measured with the Snyder Hope Scale (SHS)) in families completing family psychoeducation sessions were compared with carers and consumers receiving treatment as usual (TAU). There was no significant difference in hope and other outcomes between the two groups at baseline or follow-up, and no change in hope levels between baseline and follow-up for both groups; that is, no effect for treatment or time. Due to a null treatment effect and small numbers, mediator and moderator analyses were not performed. However, exit interviews showed that satisfaction with the intervention was high, and participants in the BFST program could point to positive changes as a result of sessions.

The recovery literature suggests that improvement in hope and recovery in consumers may be independent of changes in symptoms (W. Anthony, 1993; P.E. Deegan, 1988), but this research found that hope, measured by the Snyder Hope Scale (SHS), was correlated with the symptoms and functioning experienced by consumers. In contrast, hope was independent of burden experienced by carers.

Hope had moderate correlations with other recovery markers such as social connectedness and quality of life for both carers and consumers at baseline. There was no correlation between hope levels in carers and hope levels in consumers in the one family.

Levels of hope in carers and consumers were found to be significantly less than in many other groups reported in studies using the Snyder Hope Scale (Abdel-Khalek & Snyder, 2007; Babaie, et al., 2011; T. C. Bailey & Snyder, 2007; Bronk, et al., 2009; Buran, et al., 2004; Chang & Banks, 2007; Copic, et al., 2011; Creamer, et al., 2009; Dogra, et al., 2011; Ferraro & Neisius, 2002; Snyder, et al., 1991).

The Snyder model of hope defines hope as a goal directed cognitive set, energised by the sense of successful determination in meeting goals

(motivation or agency) and the perception of successful means to achieve the goal (plans or pathways). A discussion of goals, agency and pathways, components of the Snyder model of hope, showed that consumers had goals around achieving stable mental health, and increased social engagement through work, study and friendships. Carers had goals around decreased stress, improved lifestyle for their consumer relative, and financial stability. Agency was low in both carers and consumers, especially when the goal did not seem attainable, and was not highly valued. Pathways were very simple and probably not adequate for some of the more complex goals, such as seeking employment. There were not substantial differences between treatment and comparison consumers in goals, agency and pathways. When discussing goals, agency and pathways consumers did not refer to hope, or mention their "hopes". Carers from the treatment group had somewhat more goals and pathways than comparison carers, but motivation was similar across both groups. However, carers did specifically mention the hopes that they held for their consumer relative when discussing their goals, agency and pathways.

This chapter will discuss the possible reasons for the null findings for the outcome evaluation, possible explanations for the findings regarding hope and recovery, and explore the usefulness of the Snyder definition and operationalisation of hope. The strengths and limitations of the study and the study methodology will also be reviewed. Implications for program implementation and evaluation of the effectiveness of family psychoeducation, and hope and the recovery paradigm will be discussed. Finally, questions for further research will be suggested, before the conclusion.

9.1 No change to outcomes

There was no significant change observed in hope and other outcomes for the treatment and comparison groups over the duration of the study. In other words, over 10 months of Behavioural Family Therapy (with case-management), or case-management only, there were no significant changes for consumers and carers in measures of hope, daily functioning, caregiver burden and experience, psychological distress, social isolation, or quality of life. This means that: (1) BFT did not appear to provide significant benefits beyond

case management only (no observed treatment effect); and (2) neither treatment resulted in measurable improvement in outcomes for consumers and their family carers (no effect for time).

9.1.1 No observed effect of treatment

There are a number of possible explanations for the lack of observed treatment effect. The literature (see Chapter 2) demonstrated that family psychoeducation is an efficacious treatment and its efficacy is supported by meta-analyses and systematic reviews. There are nearly 50 RCTs to demonstrate the value of family psychoeducation (F. Pharoah, et al., 2010; Pilling, et al., 2002; Pitschel-Walz, et al., 2001) notwithstanding a small number of negative results reported.

The findings of this study indicate, however, that Behavioural Family Therapy, a variant of family psychoeducation (see Figure 1.1) was not an effective treatment with this cohort of consumers and families. Four characteristics of this cohort may be particularly relevant: (1) they were not definably a high EE group; (2) they were a group of consumers with chronic and severe illness and no recent relapses; (3) over half had co-morbidities; and (4) fifty percent of families had CALD backgrounds. It is plausible that the treatment might be ineffective in a group with these particular characteristics, or that a usual “dose” of BFT was inadequate and a longer or more intensive treatment was required.

9.1.1.1 Impact of expressed emotion (EE)

While the evidence for the effectiveness of FPE with high EE families is very strong, it is unclear for low EE families (Grainne Fadden, 1998; P. A. Garety, et al., 2008) (also see review in Chapter 3). There was no measurement of EE in this group and presumably, like other family psychoeducation studies where EE was measured but not used for selection criteria (e.g. (Hornung, et al., 1999; R.G. McCreadie, et al., 1991; Montero, Asencio, Ruiz, & Hernandez, 1999; Randolph, et al., 1994)), they were not all high EE families. Notwithstanding this, family interventions are recommended for the treatment of schizophrenia regardless of EE status (L. B. Dixon et al., 2010). Therefore, with a group of mixed high and low EE, the overall changes to outcomes may not have significant. The families that were high EE may have experienced more benefits from BFT, but it is possible that this could not be demonstrated with

the measures that were selected, and the small sample size precluded sub-groups analyses.

In this researcher's personal observation, some families showed a range of EE behaviour with aspects of EE behaviour in some families observably modified. These families independently reported improvement and great satisfaction with outcomes. For instance, where families were emotionally over-involved (one component of EE) one carer noted, "*M. [consumer] has taken more control of things. I'm quite happy to give that to her"*, indicating that the carer no longer felt they had to be in control of their consumer relative. In families where the researcher observed that hostile or critical comments were of concern, the researcher noted that carers reported a new repertoire of communication skills that replaced high EE style interactions. Interview statements such as *"[BFT] probably made me stop before I open my mouth, I stop and think, instead of just blurting it out. He (consumer) does get hurt feelings"* are evidence of such changes. This reinforces the findings from the literature that high EE may be modified with benefits for family functioning, but the effects are unclear for low EE families.

9.1.1.2 Chronicity

The second characteristic of this cohort that may have rendered an otherwise efficacious treatment ineffective was the long term and severe nature of mental illness for consumers with a ceiling level of functioning reached. Similar arguments have been put forward for the ineffectiveness of some Assertive Community Treatment (ACT) programs in the UK as ceiling effects in consumers mean that treatment cannot make any further improvement (T. Burns, 2007a, 2007b; T Burns et al., 1999).

Although evidence supports the fact that BFT has been effective with consumers with long-standing disorders (Barrowclough, et al., 2001; Bradley, et al., 2006; Brooker, et al., 1994; Buchkremer, et al., 1997; Dyck, et al., 2002; Girón, et al., 2009; McDonell, et al., 2003; Xiang, et al., 1994), it has often been deployed after a crisis when functioning is recovering. BFT may not be effective with consumers who are stable without a recent crisis, as was the case in this study. Some treatment guidelines suggest that family treatments for relapse

prevention are most effective in the recovery phase after a relapse (L. B. Dixon, et al., 2010).

There is evidence that the level of disability and chronicity in consumers receiving case management in Australia may be increasing (Hamden, et al., 2011; Olesen, Butterworth, & Leach, 2010; Pols & Oak, 2011; Rosenberg, Hickie, & Mendoza, 2009). With the move to shorter-term (episodic) treatment, consumers with higher functioning or greater capacity for recovery have shorter periods in case management. With the short treatment duration for such consumers, family psychoeducational treatments of the calibre of BFT are not easily administered to these consumers and their families, because there is not enough time for a nine month treatment. Therefore, the group that is in case management for longer durations and are thus able to participate in a nine month family psychoeducation are a group of consumers with chronic and treatment resistant symptoms that may have poorer prospects for improvement. Even if BFT and family psychoeducation in general can be effective with stabilised but chronically unwell consumers with long standing diagnoses (i.e. about ten years as in many studies described in Chapter 3), it is arguable that the long term consumers in AMHSs in Victoria in the early 21st century are a different group and outcomes for family psychoeducation treatments in this group are not predictable from the current evidence base.

9.1.1.3 Co-morbidities

The third characteristic of this sample that may have contributed to the null result was the presence of co-morbidities in approximately 50% of the sample (including drug and alcohol issues in 20% intellectual disability in 5% and depression in 10%). This is different to many of the efficacy studies that explicitly excluded drug or alcohol abuse or dependence, intellectual disability, or other diagnoses such as depression and anxiety. One of the few studies that described successful treatment of a group with drug and alcohol issues included a raft of additional treatments such as motivational interviewing and cognitive behavioural therapy as well as FPE in an integrated treatment program (Barrowclough, et al., 2001). Such adjunct treatments for co-morbidities were not included in this program.

9.1.1.4 Adaption to cultural and linguistic diversity

Finally, there is the concern that BFT was not adapted to the particular constituency of cultural and linguistic diverse (CALD) consumers in this catchment area. As Telles (Telles, et al., 1995) suggests, the communication skills taught in BFT can be quite inappropriate in some cultures and training in this area exacerbates stress instead of reducing it. Thus cultural adaptation of BFT is a necessity for culturally and linguistically diverse populations (Kulhara, et al., 2009; Xiong, et al., 1994). Program evaluations of other BFT programs in the same geographic area of Melbourne have demonstrated that cultural adaptation is complex and subtle but achievable with demonstrable improvement in outcomes (Psychosocial Research Centre, 2010).

There was no assessment of cultural adaptation in the program evaluation but cultural sensitivity was a focus in training and implementation (C. Harvey, et al., 2004b). For instance, the use of interpreters in BFT sessions provided some families with the first adequate psychoeducation they had ever experienced and there is evidence of its significance in the exit interviews. The uptake of the intervention with CALD families in this service was high and proportional to the rates of overseas born in the community in general, which again suggests its general acceptability to CALD families. Thus there is reason for cautious optimism regarding adaptation of the program for local CALD communities at the AMHS who accessed the program.

However, in-depth interviews with participants undertaken as part of the implementation research program revealed that families from a CALD background found some aspects of the program unsuitable to their cultural circumstances. In particular, goal setting and the suggested communication skills did not make sense, or suit families from non-Anglo-Saxon backgrounds (B. O'Hanlon, 2013).

It is difficult to assess the impact of CALD background on outcomes and satisfaction overall, as again, subgroup analysis is precluded by small numbers, and no particular measures or observations of acculturation and program adaptation were made. Since the uptake was proportional for this group, then certainly the interest in family interventions and the positive impact

of learning about mental illness is evident from exit interviews. However, if the core skills of BFT are regarded as inappropriate in some families, then the ultimate effectiveness of the intervention must be in question for some participants of CALD background.

9.1.1.5 Duration

Given the severity and complexity of illness among consumer participants there is the possibility that there was an insufficient "dose" of BFT for this particular group. Usual treatment length for BFT is about 9 months, but adaptation to a particular family means that this is a guideline, not a prescription (G. Fadden & Gair, 2004). Much of the previous research has concentrated on groups with much less complexity. Given the severity, chronicity, stability, co-morbidities and cultural challenges of this cohort as explained above, this group might require long term support in order to match the changes achieved in previous research. For instance, Falloon reports on programs of *2 years* of integrated treatment achieving success (I. R. Falloon, et al., 2004), and Barrowclough *12 months* of integrated treatment with additional support for co-morbid drug use (Barrowclough, et al., 2001).

Some evidence that treatment may have been of insufficient length exists in the exit interview material, where families stated they hadn't sufficiently learnt the required skills, or still needed support. Other evidence of insufficient duration is in the 'hope' interview, when some carers and consumers had plans that lacked specificity and had no strategy for setbacks. This suggests that there had not been enough time to learn the skills and goal setting thoroughly enough to apply them readily in their day-to-day lives.

9.1.1.6 Rich comparison treatment

Another possible explanation for the lack of observed treatment effect was because the TAU intervention was quite rich and of similar effectiveness to BFT (Linszen, et al., 1996; Shawyer et al., 2012; Tomaras, et al., 2000). This may be particularly so when the additional effects of the family treatment may be reduced due to the particular difficulties of this cohort. However, this explanation is not satisfactory when the lack of a time effect is considered. If there are no changes over time in the TAU group as well, then rather than

considering that TAU is a “rich” treatment, it is arguable that it is another ineffective treatment. However, it does suggest the possibility of treatment “saturation” (P.A. Garety, Fowler, & Kuipers, 2000; Hubble, Duncan, & Miller, 1999a), as discussed in literature review in Chapter 3, such that any additional treatments beyond case management would be unlikely to show additional benefits.

9.1.1.7 Reasons for no change across time in either group

There was no difference across time for both groups in this study. Some of the reasons for this may be related to the issues discussed above regarding lack of treatment effect for a group of significant chronicity and co-morbidity.

The current results can be contextualised against the published results for outcome measures in the Victorian mental health system over the past few years. The average effect size of change between admission and discharge in the BASIS-32 (a self-report measure for consumers regarding symptoms and functioning) for ambulatory consumers for 2008 to 2011 is -0.57 (n=419, M=0.9 SD = 0.8 at admission and n=443, M=0.5 SD = 0.6 at discharge). Between reviews (3 months time period) the average change in the BASIS-32 is zero (SD = 0.4, n=120 effect size not calculable from the available data). Therefore, moderate changes to symptoms and daily problems (BASIS-32) over an entire episode of care occur in the mental health care system for consumers with a diagnosis of schizophrenia. However, changes *within* an episode of care for the BASIS-32 across the review periods of 3 months are very small.

Thus participants in this study, who were in case management for a minimum of 10 months, the duration of the study, were a group receiving longer treatment. Like the “review group” in the AMHOCN data, they may also show the least or slowest changes. This may support the contention that the recruits to the study lived with persistent and severe symptoms, and had reached a ceiling level of functioning.

9.1.2 Treatment fidelity

Potentially, BFT treatment is readily adaptable to the types of problems described above, such as chronicity or co-morbidities, because the BFT

philosophy suggests that every family has it's "own culture" that should be respected and incorporated in treatment planning (G. Fadden & Gair, 2004). However, such adaptations require skilful, thoughtful and experienced practitioners (Kavanagh, et al., 1993).

Thus the lack of treatment effect could have been because BFT treatment was not carried out properly – i.e. there was poor treatment fidelity, or it was carried out ineptly with poor contextual sensitivity. This could be due to a number of implementation factors such as inadequate training, inexperience of practitioners and/or insufficient workplace support.

The research program ensured treatment fidelity through (1) consistent training methods for all staff using validated training methods, (2) supervision and mentoring groups for all staff and (3) co-therapy treatment with the case manager and embedded BFT expert from the Bouverie Centre. In addition, there was a qualitative action research program and PhD research by O'Hanlon (B. O'Hanlon, 2013; B. O'Hanlon, C. , et al., 2012; B. O'Hanlon, et al., 2007) that focused on issues of implementation and treatment quality. Since there was no quantitative measure of treatment fidelity in this program evaluation,then it is not possible to draw definitive conclusions on fidelity, except to note it is a challenging issue in the implementation of such a complex intervention (D. L. Fixsen & Blase, 2009; Magnabosco, 2006; Wolff, 2000).

9.1.2.1 Training

There is some possibility that treatment quality was low because of insufficient training. The five day training program (based on the Meriden Family Programme training manual (G. Fadden & Gair, 2004)) offered to staff may not have been adequate to develop high-level skills. This is especially so when many staff did not have a background in cognitive behavioural therapy or family work on which to build (Kavanagh, et al., 1993; Magnabosco, 2006).

Kavanagh (Kavanagh, et al., 1993) raised questions about fidelity and competence and demonstrated that even when therapists stated they felt confident with family psychoeducation, in testing they did not recall the required material. He suggested that while therapists can "get by" in this circumstance,

the practice is likely to be rigid, rather than a “flexible adaptation” for complex cases. In contrast, Brooker (Brooker, et al., 1994) achieved positive results with a team of nurse practitioners raising the possibility that non-specialised staff can be trained to deliver family psychoeducation. However, Brooker’s study was not a service wide scheme. Instead staff applied specifically to be training and to participate in the trial.

In addition, modern adaptations of BFT may be a simplified version of the original successful interventions. Falloon’s texts on behavioural family interventions “Handbook of behavioural therapy” (1988)(I. R. H. Falloon, 1988b), and “Family Care of Schizophrenia” (1984)(I. R. H. Falloon, et al., 1984) have a more detailed approach to assessment and treatment planning compared to the Meriden manual. This would mean that contemporary expectations of skill levels are lower, and the results achieved in earlier trials of BFT are not achievable since they were to some degree due to more intensive training and higher skill levels.

The inadequate goal planning strategies apparent in the hope interview suggest that consumers and carers either did not benefit in this regard from training sessions, or did not transfer or retain skills learned. This could be due to poor coaching by inadequately trained staff, although duration and intensity of the intervention (see 9.1.1.5 above), and participants’ cognitive, emotional and social circumstances may also be factors.

This has implications for implementation of service wide schemes such as the one studied in the current project. It may be desirable to ensure staff have an option to participate or be given incentives and recognition for so doing. One strategy adopted in this project was for case managers to have actual field exposure to BFT before training, so that the training program was more meaningful.

9.1.2.2 Therapist experience

Secondly, it may have been difficult for clinicians to gain experience or sufficient confidence, when only seeing one or two families a year (G. Fadden, 1997; Grainne Fadden, 1998; Kavanagh, et al., 1993). This is different to other,

more successful models and implementations where a group of practitioners focus on family treatments only (Burbach & Stanbridge, 1998; Psychosocial Research Centre, 2010). These successful models allowed staff to concentrate on delivering family treatments, via specialisation of the service, or specialisation within the service.

Although practitioners were mostly experienced case managers, the specific skills of BFT may have not been adequately developed, especially if the training was not extensive. Kavanagh (Kavanagh, et al., 1993) has also suggested that without a background in cognitive and behavioural therapies, the required techniques may be quite difficult to master. This point was reinforced by Magnabosco who found that FPE required novel skills in the community mental health setting (Magnabosco, 2006).

A number of studies have found that practitioners with generalist duties usually see one or two families a year at most, and many therapists do not ever engage with family work after training (G. Fadden, 1997; Grainne Fadden, 1998). Reported difficulties with family sessions include heavy workloads, difficulties combining family work and general caseload, and no time allowance to carry out family sessions (Magliano, et al., 2005). Increased confidence in conducting family sessions can be the result of lengthier training (i.e. up to a year) and constructive management policies that are supportive of family work and allowing time for family work (R. Bailey, Burbach, & Lea, 2003).

Practitioners were supported in enhancing their skills via regular workplace mentoring sessions and the appointment of BFST champions, along with the opportunity for co-therapy with the embedded BFT expert and other case managers. While some practitioners saw several families over the course of the data collection period, some practitioners saw one or two families only. Thus the skill levels may have been quite varied in the practitioner group.

9.1.2.3 Service wide issues

Thirdly, there were difficulties in carrying out a long-term intervention in the AMHS setting due to staff changeover, and sessions delayed due to staff that were sick or on holiday leave. It was also difficult to arrange regular meetings

when a number of family members and co-therapists were involved, and some family members worked or had regular commitments (see participant comments in Chapter 8) and (L. Hayes, Harvey, & Farhall, 2013; B. O'Hanlon, 2013)). Although some solutions were implemented (such as after-hours sessions) lack of continuity was clearly an issue for some families in the exit interview. Another structural issue was the general demands of a busy caseload competing with opportunities to deliver family treatments. These issues have been cited as common concerns for the implementation of family interventions in mental health settings (R. Bailey, et al., 2003; A. S. Campbell, 1999; G. Fadden, 1997, 2006; Kavanagh, et al., 1993; Magliano, et al., 2005) and when sessions are infrequent, practitioners are also slow in developing skills in family interventions. Thus, although the service was very supportive of the family intervention, the daily reality of case management may have decreased the regularity of sessions and thus decreased their effectiveness.

9.1.3 Measurement failure

Measurement failure refers to the failure to detect a program effect due to the inadequacies of measurement and monitoring used in the program evaluation design. Whereas the previous section discussed the possibility that no change actually occurred from treatment (because the treatment was inadequately implemented, the treatment duration was too short, was insufficient for this particular group, or the treatment group was not amenable to change), this section discusses the possibility that change did occur, but was undetected by the measurement regime of this study. Three main sources of measurement failure are discussed: (1) measurement occurred at irrelevant time points, (2) inappropriate measures were used, or (3) the measures were insensitive to the level of change that occurred.

9.1.3.1 Measurement process did not sample at appropriate time points

A possible explanation for lack of observed treatment effect is that changes occurred before or after measurement points.

The BFT group may have shown changes very early in treatment that occurred before the first assessment was made. This is possible since the baseline

assessment usually occurred after one or two preliminary BFT sessions when the request to participate in the research occurred.

However, if changes occurred before baseline assessment, it also implies (an unlikely possibility), that the BFT group was actually not well matched with controls and improvements before their initial assessment masked this. The more likely explanation is that if changes occurred, it was for both groups equally, early after admission to case-management (J. D. Frank, 1968; Kellner & Sheffield, 1971), rather than just before baseline assessment. Thus both groups had reached a ceiling in functioning by the first assessment.

In addition, changes may have occurred after the final assessment. Firstly, initial changes from the program such as improved skills and knowledge may have taken some time to work through to changes in quality of life or social isolation. Thus assessments directly after the conclusion of sessions may have been too early to show positive changes. Secondly, changes might have been observable in particular situations when stressors re-occurred. This is evidenced in a statement by one carer in the BFT group who stated "[I] *had a relationship with the case manager, because of the BFST session, and when [my son] became unwell it was easy to manage the situation".* These families may be able to resolve these stressors and potential relapse situations more effectively than non-BFT families. These sorts of changes would not necessarily be identified since there was no assessment of coping skills. Also, as many families might face their first crisis after the follow-up assessment, they might not realise that their coping strategies had improved. It was the researcher's personal observation that non-BFT family carers were less confident about managing in the future whereas the BFT family carers, while still preferring to have the back-up of ongoing clinical care, felt that they had some skills and options to manage crises in the future.

9.1.3.2 Changes occurred in domains that were not assessed

The selection of instruments used in this study tended to prioritise global recovery outcomes that would be expected to improve in the long term, and not immediate outcomes. The global recovery domains that were measured, such as quality of life, were important, relevant outcomes and the proper focus for

measuring participant wellbeing. However, a BFT program would not be expected to impact quality of life directly. Hope was an intermediate outcome, linking the immediate and long-term outcomes (see the program logic from Chapter 3).

The use of long term, intermediate and immediate measures in program evaluation can help to provide understanding about the mechanisms of a particular intervention. For instance, if one was assessing a meditation course, it is understood that participants might desire improved overall quality of life as a result of meditating. However, to achieve that, the student needs to learn the skill properly, and be motivated to practice it regularly. A comprehensive assessment of a course would therefore need to assess if the skill was properly learnt, and also if it was practiced regularly, as well as assess any ultimate effect on quality of life. In other words the program evaluation should logically tap the chain of expected changes and improvements from beginning to end.

For this program, the program logic that was developed (based on the literature (I. R. Falloon, 2003)) proposed that families learnt new skills in communication, problem solving and goal setting etc, and then practised them day-to-day at home. High EE behaviours such as hostile comments or emotional over-involvement would reduce in frequency (I. R. Falloon, 2003). Ultimately it was hoped that as EE and related intra-family stress decreased, the consumer's mental health would improve, and carer burden therefore decrease. In addition, the carer would directly benefit from their own goal setting, positive communication, subsequent improved hope, coping and functioning. The result should have been improved quality of life and social connections (see Chapter 3 for a diagram of the BFT program logic).

In this instance, baseline skills, the extent of skill learning and skill generalisation was not assessed. When measures such as quality of life were not changed, it was impossible to assess if this was because the skills were not adequately learnt, they were not adequately practiced at home, or even that the skills were not in deficit in the first place. On the other hand, changes to skills may have occurred, but did not eventually lead to changes in hope or quality of life. In the current evaluation, only the exit interview data suggests the

possibility that some changes did occur, but these may not have been extensive. For instance some families reported using communication skills, but this may not have been consistent, or in the minority of families.

It is also possible that proximal changes occurred, but the impact on distant measures such as quality of life were "swamped" due to other factors impacting on quality of life. In particular, in this group who were generally living with economic disadvantage (Australian Bureau of Statistics, 2007), there would be no protective influence from the vagaries of life through the use of economic resources. In disadvantaged families, such as the present group, exogenous stressors that cannot be deflected by the use of economic resources (Robert Cummins, 2010; Headey & Wearing, 1992) could more easily overwhelm positive impacts.

Given some of the observations and qualitative changes documented, it is possible that change did occur, but not in the domains assessed. There is qualitative evidence that BFT families reported a great deal of improvement in the understanding of their relative's mental illness and high satisfaction with treatment. Neither of these domains was assessed in the quantitative battery. Studies such as those of Mak et al (Mak, et al., 1997), Kulhara et al (Kulhara, et al., 2009), Merinder et al (Merinder et al., 1999), Posner et al (Posner, Wilson, Kral, Lander, & McIlwraith, 1992), McCreadie et al (R.G. McCreadie, et al., 1991) and treatment guidelines (L. B. Dixon, et al., 2010) indicate these are consistent areas of improvement in FPE programs even if there is little or no change to outcomes such as symptoms or relapse.

9.1.3.3 Sensitivity to change

Changes in families in this study may not have been detected because the instruments selected were not sufficiently sensitive to detect the level of change that occurred. Instruments used in the program evaluation varied in their sensitivity to change.

The version of the Hope scale used was the Trait version, which by definition attempts to assess stable personality attributes. The State version may have been more sensitive to change. The drawback of the State version is that it is

less widely used and the benchmarking comparison would have been much reduced.

Some instruments were reasonably sensitive to changes, such as carer distress (GHQ), which has been particularly worded to distinguish recent changes in distress from long-term levels of distress (Goldberg & Hillier, 1979; Goldberg & Williams, 1988).

The relapse measurement for minor relapses may have been unsatisfactory as it relied on case-manager reports at the end of 10 months and case-history review (data collected but not analysed for the PhD). Case-managers could have forgotten minor relapses or not understood criteria. Case-history reviews relied on interpretation of notes that did not always include the study criteria in descriptions of crises (e.g. did not explicitly document changes to symptom levels). Previous studies used a clinical interview tool such as the Positive and Negative Symptom Scale (PANSS) or Brief Psychiatric Rating Scale (BPRS) (I. R. Falloon, et al., 1982; Leff, et al., 1982) at the time of the putative deterioration to confirm the relapse.

Hospitalisation was also used as an objective measure of relapse in earlier studies (data collected but not analysed for the PhD). In contemporary mental health care, access to hospital beds is much more restricted with much higher hurdles for access to inpatient treatment (Groom, Hickie, & Davenport, 2003; McGorry, 2005; Victorian Auditor General's Office (Australia), 2002). This means that hospitalisation as a measure only denotes very extreme levels of symptoms. There is a floor effect on length of stay (LoS), as hospitalisation days are at very low levels already, and possibly cannot be reduced any further (a similar argument has been put forward for recent studies of Assertive Community Treatment that do not show effect, see (T. Burns, 2007a, 2007b). This makes length of stay and admission data insensitive markers of functional change in contemporary consumers of mental health services.

Quality of life is often assumed to be a stable construct (Atkinson, 1982; Robert Cummins, 2010; Headey & Wearing, 1992). If so, large changes in life circumstances would be needed for change to be detected. In this population, a decreased quality of life may have been well established after many years of

living with a serious mental illness. As suggested above, the financial situation of families in the study was often difficult, and many carers reported financial burden, living in some of the areas in Melbourne with high disadvantage as assessed by SEIFA scores (Australian Bureau of Statistics, 2007). It has been suggested that adequate financial resources provide a buffer and support for maintaining quality of life (R Cummins et al., 2007). Thus while improvements in quality of life due to cognitive and emotional changes may have occurred, this group may be very vulnerable to other external stressors which BFT could not control or reduce.

Given that all measures, both sensitive and not sensitive, showed no change, then it is unlikely that there were changes that went undetected due to the insensitivity of measures. Rather, it suggests that no change occurred in the domains selected for assessment.

9.1.4 Statistical validity - Small numbers

Finally, no treatment effect may have been recorded due to small numbers and low power in this study. The sample size was small (n=62 consumers across two groups), limiting the power of the study. However, the observed changes were so small that even a much larger group of thousands of cases would not have given significant change results. For instance, power calculations for the Snyder Hope Scale, with means 21.2 (±4.3) at baseline and 21.1 (±4.2) at follow-up, alpha = 0.05, and 80% power showed 37,929 cases would be needed in each group to show significant differences (Davison, et al., 1986).

In contrast, many studies have shown significant results with groups the same size, but with more homogenous samples (for example (I. R. Falloon, et al., 1982; Gutierrez-Maldonado, Caqueo-Urizar, & Ferrer-Garcia, 2009)).

Achieving adequate recruitment numbers for effectiveness studies from a limited pool of service users remains a challenging issue. If only a minority of families using a service take up a particular type of intervention, such as Behavioural Family Therapy, at any one time there will be small numbers coming forward for research assessment. Therefore, for clinical effectiveness studies offering a specialised intervention in a limited pool of consumers, there will inevitably be a struggle for adequate numbers. In contrast, for efficacy

studies, the more rigorous control of selection criteria and treatment conditions means such small numbers may be adequate.

9.1.5 Satisfaction with treatment: exit interview findings

In spite of little change to outcome measures, BFT families who completed an exit interview expressed high satisfaction with the intervention and could point to identifiable changes in coping strategies, communication styles and plans for the future.

What might explain high satisfaction and no objective changes? Firstly, in an interview situation, families may feel grateful for the support, and satisfaction came from this rather than any actual improvements (Wilson, 2011). In addition, participants may have wished to please the interviewer, by mentioning positive things and hiding any criticisms. Also, the families that completed the exit interview may have been more satisfied than the families who did not wish to be followed up, and thus stated satisfaction was not balanced by comments from less satisfied families.

Some other reasons for the exit interview findings are also possible. The satisfaction and subjective improvements observed may not have been sufficient to overcome adverse socioeconomic circumstances, and the long term nature of the families' adversities. In addition, if the intervention was not of sufficient duration, then changes may not have been consolidated. The high satisfaction, and reports of positive rapport with practitioners suggest that family psychoeducation has an important role to play in the treatment of severe mental illness and the support of carers and families, but further adaptation for the Australian mental health system is required.

9.1.6 Conclusion: treatment effect not detected

It seems unlikely that real change in outcomes did occur, but went undetected. Similar research protocols implemented by the same research group in an alternative BFT program have measured quite sizable changes to these domains (Psychosocial Research Centre, 2010). In this other program consumers achieved significant improvement in symptoms, social connection, quality of life and family functioning, and carers, reduced burden. However, the

consumer group in this second program had different diagnoses (one third had schizophrenia, one third bipolar and one third major depression) and staff in this program worked exclusively in BFT treatment. This suggests that there were no methodological or measurement issues in the present study, but rather lack of treatment effect, due to the severity, complexity and persistence of mental illness in consumers (including a high level of co-morbidities) and their CALD status, and lack of EE specificity in family selection. Also, staff expertise may have been limited in some cases, by lack of specialisation in family treatment, due the generalist demands of case management.

Given the previous discussion regarding the selection of long-term rather than immediate measures, it is possible that minor positive changes did occur within immediate domains, but were not measured, and were small, not sufficiently consistent and not widespread. Some participants could clearly outline changes that were congruent with the skills they had been taught as part of the program in the exit interview. Whether these changes were sustained or enacted broadly enough throughout participants' lives is unknown. It is also unclear how profoundly these changes needed to be enacted, or for how long, to bring about such global attitudinal changes as might be measured in instruments such as the Snyder Hope Scale. It also appears that changes were not universal in the treatment group, thus overall, there were no significant changes in measures.

While the selection of measures does not allow any definitive statement on the reasons for the lack of treatment effect, the review of outcome studies for family psychoeducation suggests that treatment group characteristics may be most relevant. In particular, the level of EE in the families in this sample, the long term/stable nature of mental illness in this sample, the high rates of co-morbidity and the severity of disability in this group may all be pertinent characteristics. A more intensive or longer program may have been warranted in this situation. It is also possible that some case managers involved in giving treatment did not receive sufficient training or experience in delivering the program to become proficient.

9.2 Hope and the recovery paradigm

The primary research question hypothesised that hope would increase in consumers and carers from baseline to follow-up after treatment from an effective family intervention. However, no such increase was detected. Other hypotheses regarding the course of hope during a family treatment were unable to be answered satisfactorily, since there were no significant differences between treatment groups and across time. Planned regressions, with implications for the mediating and moderating role of hope in FPE outcomes were abandoned, and correlations were used instead. Base-line correlations between hope and other outcome measures, coupled with the qualitative interview material showed that consumer symptoms were inversely related to hope and recovery, and that consumers did not relate the concepts of goals, agency and pathways to their hopes.

In spite of the limitations to the analysis, the results, with the inclusion of the qualitative interview material, provide some basis for understanding more about hope and recovery for consumers, hope and burden for carers and hope in the context of family relations. The results also present some directions for the translation of narrative accounts of recovery into empirical research programs. They supply some insight into the relevance of the concepts of emergent and expectancy hope to recovery and it's measurement.

9.2.1 Hope across the course of treatment

Hope and all other outcomes did not change from baseline to follow-up assessment. This finding, alongside the moderate correlations with other recovery markers at base-line indicate that the Snyder Hope Scale scores were generally aligned with scores of wellbeing and mental health, and were higher if wellbeing and social relations were better, and were lower as distress (in carers), and symptoms (in consumers) increased. Burden for carers was independent of hope levels.

9.2.2 Hope for consumers

The lack of change across the course of treatment means that there can be no definitive conclusions about the dynamics of hope over a treatment cycle. It

does suggest that the course of expectancy hope is probably not unique, showing no changes over time, similar to other outcome measures.

The consumer interview data showed there was a lot of similarity between the treatment and BFT groups, especially in terms of types of goals. Goals included typical aspirations such as better mental and physical health or occupational and social satisfaction. The plans made by consumers were simple, and limited to one or two steps, with few mentions of time frames or deadlines.

BFT consumers were somewhat clearer about goals and making plans at interview. However, the differences were minimal and probably not substantial enough and/or not sufficiently widespread throughout the group to influence other outcomes such as quality of life or felt social support.

The statistical analysis for the first “recovery hypothesis” showed that hope and consumer symptoms were inversely related at baseline. There was a moderate negative correlation between hope and symptoms with hope decreasing as symptoms worsened.

These results are somewhat contrary to the most common understanding of the recovery paradigm, which suggests that hope can be independent of symptoms (S. G. Resnick, et al., 2004). This result may reflect the measures chosen rather than providing evidence against commonly received notions of the recovery paradigm. Rather than a “pure” measure of symptoms, the BASIS-32 measured problems with mood, relationships, daily living, as well as anxiety and psychotic symptoms. As has been suggested, the Snyder Hope Scale probably taps constructs such as optimism and self-efficacy, rather than just hope. Thus the observed relationship between the Snyder Hope Scale and the BASIS-32 may reflect the association between general functioning and optimism and expectancy, rather than symptoms and hope.

The correlation between the BASIS-32 and the Snyder Hope Scale is congruent with other research that shows hopelessness is associated with lowered affect and psychological distress (Andresen, et al., 2010; R. Beck et al., 2001; S. G. Resnick, et al., 2004), and symptoms of schizophrenia

(Hoffmann, et al., 2000; Paul H. Lysaker, et al., 2005; Paul H. Lysaker, et al., 2008; White, et al., 2007) although some studies have found this not to be the case (Landeen, et al., 2000; Paul H. Lysaker, et al., 2004).

Other research in hope and recovery suggests that symptoms have more impact at different times in the recovery journey (Copic, et al., 2011). Narrative accounts may be interpreted this way too. Research into the "stages of recovery" show that at low levels of recovery, consumers may feel more dominated by symptoms (Copic, et al., 2011). Anthony suggests that recovery can occur even though symptoms are unchanged or relapses occur "People…can recover even though the physical nature of the illness is unchanged" (W. Anthony, 1993, p. 532) and "individuals who experience intense psychiatric symptoms episodically can also recover" (W. Anthony, 1993, p. 532). However, he also suggests that as the recovery process continues, "symptom frequency and duration appear to have been changed for the better…More of one's life is lived symptom free" (W. Anthony, 1993, p. 532). Deegan discusses living with recovery, and still having a psychiatric disability (Patricia E. Deegan, 1997) and reports that "my symptoms may look the same or even worse" (Patricia E. Deegan, 1997, p. 21) in recovery. This suggests that the interaction of hope and symptoms varies as recovery progresses and in different individuals. In early or absent recovery, consumer hope is related to symptom levels, but as recovery progresses, hope (and related optimism and efficacy) is more resilient in the face of symptoms. If we conclude that the consumer participants in this research are a low recovery group (evidence for this is discussed in Section 9.2.6), then the results support at least the first part of this model.

No conclusions about increases in hope as a forerunner to "full recovery" could be drawn from this analysis, but the data in this research suggested that expectancy hope did not have a unique trajectory. Although hope may have an important mediating role in FPE outcomes, due to its links to goal setting and problem solving activities, and the pertinence of hope and recovery to family interventions, the relevant analyses could not be performed. The correlations between hope and other recovery outcomes may be the result of various connections between domains. They may be all influenced by another variable

such as positive affect and there is some evidence for this (Aspinwall & Leaf, 2002; Robert Cummins, 2010; Meehl, 1990). Another possible linkage might be the positive cognitions that are part of expectancy hope are similar to the positive attitudes inherent in constructive relationships, better family functioning and better quality of life. The correlation between the Snyder Hope Scale and other life domains such as quality of life is similar to previous findings with the Snyder Hope Scale (Snyder, 2002).

9.2.3 Hope for carers: burden and coping

In contrast to the findings concerning consumers, there was little correlation between carer expectancy hope (SHS) burden (P&K) and negative experience of caregiving (ECINEG). Correlation with Positive Caregiving Experience (ECIPOS) was low but nearly significant. Hope had positive correlations with wellbeing measures such as friendship and total quality of life, (similar to consumers) and negative correlations with family (dys)function (FAD), distress (GHQ) and total mood disturbance (POMS). The interview on hope showed that some carers in the BFT group appeared more articulate in describing their goals and some carers stated that BFT sessions had provided the impetus for personal goal setting that had long been absent.

It might be predicted that hope would decrease as negative challenges increase, as was seen for the consumer. However, the finding that burden and hope are not correlated suggests that caregivers can nurture hope, independent of the level of burden and the difficulties within the caregiving experience. The independence of these measures may relate to issues of caregiver resilience, where carers maintain hope in spite of their difficulties because they are motivated to do the best by their mentally unwell relative. There is evidence for this in the carer hope interview where carers discuss the necessity to maintain hope for their consumer relative. This is not dissimilar to Frankl's discussion of hope that helps people to transcend and cope with difficult situations by the creation of meaning (Frankl, 1963).

The independence of burden (P&K) and the Snyder Hope Scale may also be impacted by divergent data gathering methods, since the researcher scored the P&K from a semi-structured interview, whereas the Snyder Hope Scale was

self-rated. This means that the lack of correlation may be an artefact of scoring method, not a real difference in the domains. However, the Negative Experience of Caregiving (ECINEG) was another self-rated scale, and it too, did not correlate with the Snyder Hope Scale. This suggests that the lack of correlation is more likely to be due to independence of the domains, and not data collection methodology.

9.2.4 Hope and the family: relational hope

There were small negative correlations between baseline hope and baseline family functioning for carers as for consumers, with increasing hope correlated with better family functioning (decreasing FAD scores). This may be partially a function of affect, because with a more positive outlook carers and consumers may have endorsed hope items more optimistically and taken a more constructive view of the family. Also, as positive expectancy rises (with increased Snyder Hope Scale scores), then carers and consumers may have felt more confident about how family members carried out role responsibilities, problem solving, and made emotional and behavioural responses in the family. Statistically speaking, the low correlation between hope and the FAD for carers may be due to the kurtosis of the FAD scale, reflecting a reduced range of scores, and thus limiting the possible extent of correlation.

Consumer hope and family functioning had no relationship to carer measures of hope and family functioning within a family dyad. It might be predicted that a family culture would provide consistency on many instruments, especially an instrument rating family functioning (Knafl et al., 2009). On the other hand, divergent scores within a family can indicate family difficulties, even if individual scores are not over the clinical threshold, or average out within a family to below the threshold (Akister & Stevenson-Hinde, 1991). Divergent scores, reflecting different views within the family, can contribute to family strain (Akister & Stevenson-Hinde, 1991) so the unrelated scores may reflect family strain and difficulties in both the BFT and TAU groups. The independence of Snyder Hope Scale scores within a family indicated that optimism and expectancies within a family vary substantially. It may reflect the very different

perspectives that carers and consumers have in regards to their expectations in life.

Does the independence of carer and consumer hope indicate there is no relational hope? It is difficult to determine this from the analysis of the Family Assessment Device and Snyder Hope Scale scores, especially since the Snyder Hope Scale focused on individual goals and motivation, without the opportunity to report on goals and hopes for other people. Relational hope is much more about the content of the goals rather than any quantification of hope levels.

The analysis of the interview on hope may be more relevant to this question. The carers' discussions of their hopes and goals for their consumer relative were a demonstration that hope can include goals for other people, and suggests that hopes for a person one cares about deeply can be held more intensely than for oneself (Aspinwall & Leaf, 2002).

Consumer goals regarding their family reflected more diverse issues, such as independent living, reducing strain and conflict, regularising contact patterns, and improved wellbeing of family members. Consumers did not express such ideas as "hopes". The difference between consumer and carer goals was partially attributable to differences in the questions, since consumers were asked about goals for the family in general, whereas carers were asked more specifically for their goals regarding their consumer relative.

Also, the qualitative data suggested that BFT encouraged families to be more aware and supportive of each other's goals. Thematic analysis showed that carers and consumers had better awareness of each other's needs after BFT, and felt they had a more collaborative relationship and a better connection with services. These observations would be totally congruent with the aims and objectives of BFT, which is to help families with setting goals, to think about goals as a family team and to spend time planning goal achievement together.

9.2.5 Expectancy hope in carers and consumers

The results of the hope interview provide some insight into the nature of hope. The most relevant aspect of the carer interview was when they reflected on

their goals for their consumer relative. They suggested many goals for their consumer relative and spontaneously used the term “hope”. Sometimes the answers conveyed a sense of agency (i.e. motivation) and pathways (i.e. planning), in accordance with Snyder’s model of hope. Some goals did not include a positive expectancy or pathways (parts of expectancy hope). There were expressions of hope without plans, and without expectation for success (for example “Hopes for ….her to be herself again”).

The carers’ discussion of their hopes for their consumer relative was a demonstration of the link between hope and adversity (Frankl, 1963), that strong hopes can be held even when there is no personal control over the situation and no planning is possible (Tong, et al., 2009). This is similar to narrative descriptions of hope as “ only hope left”, “hopeful despite the odds”, and the “tiny fragile spark of hope” (Bruininks & Malle, 2005; P.E. Deegan, 1988; Tong, et al., 2009), and the importance of holding goals related to others (Frankl, 1963). This matched what has been characterised in this thesis as emergent hope, that is, relational aspects were paramount, positive expectation was not necessary, hope was maintained in the face of adversity and no planning was necessarily apparent.

At the same time, although aspects of “emergent hope” were prominent, the discussion of goals did lead to spontaneous mention of hope. Therefore, some aspects of the expectancy model may be relevant to the understanding of hope.

This is in contrast to consumers, with low hope, where discussion of goals did not trigger revelations of hopes. This could be interpreted in a number of ways. Firstly, it could be that the expectancy model of hope (i.e. hope as the expectation that goals will be met through motivation and planning) did not correspond to how consumers understand their personal hopes. This means that the expectancy model of hope is an inappropriate operationalisation of hope, at least for this group.

It is possible that the cognitive/expectancy model of hope may not be entirely appropriate for populations such as people who are living with schizophrenia, and dealing with cognitive and executive functioning difficulties. For instance,

subjectively, the author observed that many consumer participants answered questions on the Snyder Hope Scale on the basis of how much they *agreed* with the statement, rather than how much they felt the statement actually *described* them. For example, in response to a statement such as "There are lots of ways around any problem" a very common response was for the participant to say, "Of course, I agree...[there are many ways to solve a problem]." Even after prompting for an answer that was more self-descriptive, it was difficult for participants to apply the statement to examples from their own lives. This suggests that consumers did not readily apply the concept of problem solving and goal setting to their own situation, and the language of goals was quite alien to them.

Alternatively, it may be that the low levels of consumer hope meant that *any* approach to the discussion of hope, direct or indirect, would have produced limited results. That is, it is difficult to gain insight into the phenomenon of hope by the study of participants living with low or no hope.

It has also been suggested that "goal pursuit" is only active at higher levels of hope and recovery (Copic, et al., 2011). This means that the expectancy model of hope may be relevant to consumers further along the "recovery journey", but for this low hope group, the expectancy model of hope was inappropriate and positive expectancies were not activated.

9.2.6 Hope in comparison to community, carer and consumer groups

Hope levels in consumers were very low compared with the general community. Carers also had lower hope than the general community. The expectancy model of hope would predict that consumer and carer hope would be lower than that of the general community. This important finding suggests that there are considerable challenges in restoring hope and achieving recovery for this group of consumers and emphasises the need for new ways to address this significant problem.

In another study of hope and recovery, it was shown that hope varied with recovery orientation (R. Andresen, P. Caputi, & L. Oades, 2006). The average

level of hope among consumers in this current sample matched the levels of hope in no (moratorium) or low (awareness) recovery orientation consumers in Copic et al (Copic, et al., 2011) and they had significantly less hope than other consumers with higher levels of recovery (see Table 5.16). Although both samples were "samples of convenience" and generalisation from the studies is difficult, it does suggest that the consumers in this study were demonstrably low in recovery orientation.

Carer hope was also lower than many other community groups, but similar to another middle aged sample (T. C. Bailey & Snyder, 2007), and a middle-aged carer group (Ferraro & Neisius, 2002) (the average age of carers in this study was 61 (SD±12 years)). It appears demographic factors as well as the caregiver role, may be impacting carer levels of hope. However, the low levels of hope in carers indicate the need for consideration of their psychological state in a family inclusive treatment plan.

9.2.7 The Snyder Hope Scale, hope and recovery

The findings regarding expectancy hope and the Snyder Hope Scale suggest it does not have any unique predictive qualities for recovery outcomes in consumers, apart from general associations with positive functioning, although definitive analyses were not possible given the lack of change from baseline to follow-up. The interview on goals did not elicit any discussion of hope, which may mean consumer hope was so low that it was impossible for consumers to conceptualise hope, or that existing consumer conceptualisations of hope do not incorporate expectancies.

The results for the carers show that the expectancy hope model partially corresponds to their conceptualisation of hope for their consumer relative, but aspects of emergent hope were also relevant. Adversity, low expectancies and relationships were clearly important parts of the hopes expressed for their consumer relative.

The results of this research suggest that at low hope (i.e. at levels found in this consumer group), expectancy hope is a poor conceptualisation of the hopes that may be present.

At moderate levels of hope (as observed in carers in this study), expectancy hope is a partial conceptualisation of hope. Moderate hope may be qualitatively different phenomenon from low hope, with observable levels of motivation, but no pathways and the presence of adversity. It appears to incorporate both emergent and expectancy aspects of hope.

Snyder's model appears to be a model of high hope/optimism only. This means that only persons that are consistently high in hope (and optimism) will exhibit measurable levels of motivation and pathways for goals and may be able to discuss these in the language of goals, motivations and pathways.

Although the meaning of hope in recovery is not well defined in the literature, it seems that both emergent and expectancy aspects are important and relevant. If the Snyder Hope Scale only partially operationalises the domain of hope, then it may have limited usefulness in the study of recovery. It can probably discriminate low and high levels of expectancy hope, which may have some use, although, it is not a unique measure of positive attitudes and self-efficacy. As was demonstrated with this group of consumers, who displayed low hope and recovery, scores on the Snyder Hope Scale, and discussion of goals, motivation and pathways can tell us very little about the presence of emergent hope. Some of the consumers and carers who had low scores on the Snyder Hope Scale may have had some level of emergent hope, but they are not identifiable from the use of the Snyder Hope Scale or the hope interview.

An example from the study may clarify the application of emergent and expectancy hope in treatment. At post-treatment, a consumer stated his goals of moving out of home,

> *Before I never mentioned [my goal of getting my own apartment], I never thought it could happen, so when sessions happened I mentioned it and we started figuring how to do it. I feel a lot happier having this goal every time I think about it ….it's a fair bit of work… [I'll achieve it] with help... [BFT sessions] helped me to get some steps.*

Qualitatively, this consumer had moved from emergent hope to expectancy hope, and BFT sessions had clearly helped this process (although no pre-

treatment interview on hope was conducted to corroborate this). This family were observably one of the "success stories" of the program: they reported high satisfaction and could readily identify changes from the program. Perhaps the presence of emergent hope (i.e. the goals that were "never mentioned") at the beginning of the program was part of the reason for their success.

Although conclusions of this kind are speculative since there was no specific assessment of emergent hope, the identification of emergent hope may assist in selecting individuals and families who are in a position to benefit from interventions. Just as importantly, interventions might be developed that can support the creation of emergent hope for those living without hope.

9.3 Strengths and limitations of the study

Overall, this study tried to reconcile the opposing issues of managing validity threats with the need for a realistic field study of family treatments with consumers living with persistent and serious mental illness. Apart from the limitations imposed from small numbers, many validity threats were minimised. However, there is a great challenge in effectiveness studies with heterogeneous groups, which demand large numbers for sufficient power, yet are often carried out in clinical services where the study size will be limited by the numbers attending the clinic.

The study strengths' were the use of mixed methods of data collection (qualitative and quantitative data) and a well-executed quasi-experimental design that enabled a program evaluation of a realistic field trial.

The limitations were small numbers, lack of proximal measures, non-blinding and lack of randomisation in selection and group allocation.

9.3.1 Strengths and weaknesses in the statistical validity of the study

Threats to statistical validity refer to concerns about the statistical procedures of a study, and the validity of statements about the association of variables (see Chapter 4, Section 4.2.5.1 and Table 4.1) (Cook & Campbell, 1979).

9.3.1.1 Low statistical power

The original power calculations suggested that if a moderate effect size of 0.7 was obtained due to the BFT intervention, then approximately 30 families were needed for each cohort (BFT and TAU) (see Section 4.2.6). This figure was attained for this study.

However, the effect size obtained was much smaller than predicted and there may have been concerns that there was insufficient power for a real difference between groups to detected statistically. However, as the second set of power calculations for the Snyder Hope Scale showed (see Section 9.1.4), an extremely large sample size would have been required to show any treatment differences for the effect size that was actually obtained; the inability to make a significant finding was due to the lack of overall treatment effect, rather than lack of power.

The participants recruited to the study were also heterogeneous, being highly variable on such factors as age, ethnicity, education and family constellation. A larger number of participants may have allowed for more covariates to be used in analyses enabling the location of sub-groups for whom there was a treatment effect or for the effects of other variables to be co-varied out. In particular, variables such as number of treatment sessions, or treatment complexity (i.e. presence of co-morbidities) or level of hope, may have discriminated the families who benefitted from those who did not. With small recruitment numbers, the ability to identify a treatment-responsive subgroup via a moderator analysis was not possible.

Using one-on-one interviews to complete the questionnaires ensured low rates of missing data and maximised return rates (i.e. compared to mail out questionnaires for instance). This meant that the number of cases that could not be included in analyses due to missing data was negligible.

9.3.1.2 Other threats to statistical conclusion validity

Variations in treatment delivery can increase variability in measures and decrease the chance that true differences are detected. However, as discussed previously, standardised training, careful supervision and mentoring were

implemented to support the intervention, which assisted the maintenance of fidelity during the research period. A potential weakness of the research was the lack of formal measures of fidelity, which may have provided more evidence regarding variations in treatment variation. This may have also provided vital feedback regarding the implementation process for purveyors and skill development for practitioners (D. L. Fixsen & Blase, 2009; Morrison, 2004; W. C. Torrey, et al., 2001). However, this may not have been viable in this study, as it may have required more research resources, more demands on case managers, and perhaps intrusion into family sessions for observations. Some variation in treatment fidelity is to be expected as naturally part of a field trial.

A large number of measures were used in this research program. This is positive in that a wide range of outcomes could be observed. However, this means that multiple comparisons were made. The Bonferonni adjustment was not made. This was because the Bonferonni adjustment is only appropriate when the universal null hypothesis (which states that outcomes for treatment and comparison groups were equal for all variables) is relevant. Instead for this study, hypotheses about individual variables were tested and the Bonferonni adjustment was not made. It should also be noted that as many test results were not significant at the $p = 0.05$ level (i.e. were above 0.05), then reducing that threshold would not have impacted on the number of reportable results.

Most data were normally distributed, and if not, were readily “normalised” for statistical tests.

In conclusion, the main threat to statistical validity was the low participant numbers, reducing the statistical power of the study, although the planned numbers of participants were recruited to the study. As noted, the absence of a treatment effect meant that even substantial increases in numbers, and consequently of power, would not have led to a significant result. However, it may have facilitated moderator analyses to demonstrate which consumers and carers may have benefitted most from treatment. Although formal measures of treatment fidelity were not made, the viability of these is questionable given the

resources available for the research. Finally, multiple comparisons were carried out but there is justification for not making the Bonferonni adjustment.

9.3.2 Strengths and weaknesses in the internal validity of the study

Internal validity concerns the plausibility of the conclusions of the research; the demonstration of causal relationships and the elimination of alternative causes (see Chapter 4, Section 4.2.5.2 and Table 4.2) (Cook & Campbell, 1979).

9.3.2.1 Randomisation versus quasi-experimental design

The quasi-experimental method was highly effective in delivering matched groups, but without a randomised design the possibility of bias in group allocation cannot be logically eliminated. Although the groups were not randomly assigned they were demographically identical, and very well matched on attributes tested by the outcomes questionnaires, with no important differences at baseline. The only difference was that treatment group consumers had more medication adherent attitudes at baseline. Given the range of measures, it is arguable that this is a random difference, rather than reflecting a systematic difference between the two groups.

It is likely the groups were well matched due to a number of related factors. Firstly, they came from demographically similar geographic areas in the north, west and northwest of Melbourne. Secondly, they were recruited from CCT clinics, where consumers of similar chronicity and mental health status were being treated. Thirdly, at the level of the individual case manager, the process of assessing the case list for consumers eligible for BFT *or* the BFT research was essentially the same. That is, a case manager assessing their case list for a potential comparison group recruit, would have made the same short list of two or three consumers, as they would have if they were assessing their case list for a BFT candidate.

The use of the ANCOVA statistical test, rather than F-test statistic was appropriate when no assumption of group equivalence could be made.

The alternative was to recruit families on a clinical basis, but randomise to “immediate treatment” or “wait-list” conditions. However, this would have had implications for implementation as well. Many consumers would not be in case

management for over 18 months (i.e. wait for 9 months and then treatment for 9 months) and thus many on the wait list condition would miss treatment all together. Also, the implementation required all the resources and organisational support to be fully utilised to achieve good performance and enhance sustainability. If the intervention was to be implemented "half-strength" then skill building and maintenance (discussed in Section 9.1.2 above) would be further challenged.

The multi-site approach (one treatment area mental health service (AMHS) and 2 comparison AMHSs) is a commonly used method for effectiveness studies. It made the study feasible with restricted resources, and within a realistic clinical setting, with the real-life diversity of a community mental health clinic. As discussed in Chapter 4, this was the only reasonable implementation strategy for the intervention program, given budget constraints, resource allocation, implementation issues, and the realities of time limited treatment durations in community clinics.

9.3.2.2 Loss to follow-up

Uneven loss across the treatment and comparison groups would have made follow-up comparisons invalid. About 25% did not complete follow-up assessments, but the numbers lost to follow-up were equal across groups and matched for demographic characteristics. This demonstrates that the groups remained demographically matched at follow-up and the group comparisons were meaningful.

However, the participants lost to follow-up may have had outcomes much better or much worse than the group that stayed within the study. Presumably the outcomes of the "lost to follow-up" group were similar across treatment and comparison groups, given their demographics were similar. This may have impacted the changes observed across time. If participants lost to follow-up left treatment due to enhanced mental health, then overall improvements in the study group may have been underreported. Analysis was carried out on an intention to treat basis with all the follow-up results that were obtained.

9.3.2.3 Proximal measures

The lack of proximal measures (i.e. measures that assess domains directly impacted by FPE) means that no firm conclusion can be drawn regarding the reasons for treatment failure in this study (see earlier discussion regarding the concept of proximal measures in Chapter 3 regarding program logic, and in Section 9.1.3.2 in this chapter). It is unclear if the families in the BFT program learnt the skills or information properly, enacted the skills or retained information, or whether the skills and information were in deficit initially.

Hope, is an important intermediate outcome because it is a logical product of FPE due to goal setting modules and its relevance in assessing recovery outcomes. Hope was measured, but analyses regarding hope as an intermediate/mediating variable were not undertaken due to lack of treatment effect and small numbers. It is also unclear whether enhanced skills and information would make any impact on long-term outcomes such as social isolation or quality of life. Although the program logic developed for this program evaluation has suggested a plausible chain of causality, and it is sensible given the components of many successful FPE programs, the use of recovery outcomes such as quality of life, was an exploration of new territory regarding possible outcomes for family psychoeducation (I. R. Falloon, 2003).

In summary, this study has acceptable internal validity even though a second tier strategy for group assignment (i.e. quasi-experimental, RCT being first tier) was used. Lack of proximal measures means that further analysis explaining the lack of causal effect was not possible.

9.3.3 Strengths and weaknesses in the construct validity of the study

Threats to construct validity relate to concerns about the relationship between the research measurement and underlying constructs (see Chapter 4, Section 4.2.5.3 and Table 4.3) (Cook & Campbell, 1979).

9.3.3.1 Choice of measures

One strength of the study was the wide range of outcome measures that were used that were related to clinically relevant domains such as hope, social

isolation, distress, role functioning and quality of life. These measures generally had sound psychometric properties, and some had norms or benchmarks for meaningful comparison (e.g. the Friendship Scale (G Hawthorne, 2008), the WHOQOL (G. Hawthorne, Herrman, & Murphy, 2006), or the General Health Questionnaire (Goldberg & Williams, 1988)).

Although these measures were likely candidates for improvement from a family psychoeducation program, previous research in family psychoeducation interventions has focused on relapse as a primary outcome, and outcomes regarding quality of life and social support are not common (F. Pharoah, et al., 2010) (see literature review in Chapter 3). This research represents an important broadening of the study of the possible outcomes of family psychoeducation.

Not all of the issues raised in the literature review regarding the nature and measurement of hope, and the relation of hope to recovery were answered by the study results. This is partly due to the fact outcomes did not change between baseline and follow-up, due to treatment failure, which meant planned regressions for hope could not be carried out. The qualitative hope data suggested that the expectancy model of hope did not sufficiently capture important aspects of hope relating to adversity and relationships (see Section 9.3.5 below). Another approach to exploring the empirical measurement of hope and recovery may have been to utilise a selection of different hope and recovery measures concurrently in order to compare their validity, or to extend the hope interview by including questions on emergent hope.

9.3.3.2 Experimenter and participant expectancies

Researcher expectancies may have influenced results, especially since the researcher was not blinded to group allocation. These possibilities cannot be discounted since the interviewer had multiple roles in co-ordinating contact with families, data analysis and conducting the interviews. However, since the null hypothesis was not rejected, and the results for both groups are the same, there seems no evidence of bias.

In clinical studies such as these, it is very difficult to implement a placebo treatment in the comparison condition that matches for attention and expectancy and might enable participants to be blind to the condition to which they have been allocated. However, recently, placebo conditions such as "befriending" have shown promise for control groups. Interestingly, these neutral placebo treatments have proven so effective that they have become validated treatments in themselves (Shawyer, et al., 2012). In this study, the provision of high quality case management to the TAU cohort represents a fairly well matched comparison treatment in terms of attention and contact hours.

9.3.4 Strengths and limitations in the external validity of the study

External validity concerns the generalisability of this study to other populations, settings and times, given the internal or causal validity was acceptable (see Chapter 4, Section 4.2.5.4 and Table 4.4) (Cook & Campbell, 1979).

9.3.4.1 Naturalistic field setting

A great strength of the study was the naturalistic field setting. Although this introduced many challenges to managing bias, the outcomes of this study could be readily applied to other community treatment settings where the implementation of a family psychoeducation program is being considered. The critical aspects of the setting for this study were the chronic and severe nature of mental illness in the consumer group, the outpatient setting, and the skill level of the clinicians. This is particularly important, as the literature review of family psychoeducation studies showed that many were conducted in hospital settings after acute episodes, and with specialised or highly supervised staff. As mental health treatment is increasingly carried out in outpatient settings with generic mental health case-workers, and with consumer groups living with severe and long term disability, then there is a need to review the effectiveness of treatments in such outpatient settings.

9.3.4.2 Convenience sampling

Randomised selection in research studies ensures that results can be generalised to the population group that was sampled. In this study, randomised recruitment did not occur. Instead it was essentially a sample of

convenience, as case managers contacted eligible consumers as best they could. There were no randomisation procedures to ensure every eligible consumer had an equal chance of being selected to join the research.

As this was a program evaluation and an effectiveness trial, rather than an efficacy trial, then a purely randomised approach to selection was not necessarily appropriate. A fully randomised method of recruitment for the research would have interfered with the therapeutic/clinical nature of selecting families for BFT treatment outlined in Figure 4.2 (Chapter 4). Allowing the clinical selection of participants meant that the program was evaluated as it functioned normally within the clinic. This is an important part of the treatment process that should not have been changed for the research program.

Generalisability is potentially reduced by the convenience/clinical sampling methodology. However, although not random, the recruitment sampling was *replicable* – the comparison group was a very similar sample to the treatment group. As has been discussed earlier, case managers were remarkably consistent in assessing their case lists for candidates for BFT or the BFT comparison group. This suggests that generalisation to other potential family therapy programs implemented in community mental health services is quite high.

9.3.4 Strength and weakness of the qualitative analysis

The qualitative analysis provided some useful descriptive insights which augmented the understanding of the quantitative findings in terms of the types of goals, the level of motivation and sophistication of planning. It also provided evidence of high satisfaction with the intervention in spite of no improvement in carer and consumer outcomes. The interview was highly structured and limited to exploring pre-defined themes on the expectancy approach to hope (i.e. goals motivation and planning), and the experience of BFST sessions for the treatment group. This approach was appropriate to provide answers to the well-defined research questions regarding goal-striving and treatment in relation to the structured intervention (Baum, 1995; Bryman, 1984).

The qualitative methodology and findings were limited by a reductive qualitative strategy and the shortcomings of this approach were highlighted in the situation

of the unanticipated outcome regarding lack of treatment effect. If outcomes had been positive, then the quantitative analysis would have yielded adequate information regarding hope and recovery. With a lack of positive quantitative findings there was more reliance on the qualitative analysis for insights into the program outcomes in relation to hope. A more reflexive approach to the qualitative methodology may have yielded better insights into the broader nature and experience of hope, low hope or hopelessness, and treatment experiences. Possibly more exploration of the theme of emergent hope may have developed.

In hindsight, the opportunity to further develop the theoretical understanding of emergent hope via more extensive engagement with participants and their stories was missed. However, given the extensive quantitative undertaking, and the procedures and methodologies used to support this, a further rigorous qualitative methodology was not viable in terms of researcher and participant resources. Another researcher was already conducting some in-depth interviews with selected participants in relation to implementation so more in-depth interviews would have been burdensome. In summary, a limited qualitative approach was planned in response to specific research questions and finite researcher and participant resources. Given the outcomes obtained however, a more reflexive qualitative strategy may have been desirable in the absence of positive quantitative findings.

9.3.5 Summary of strengths and weaknesses

In conclusion, although many threats were apparent, the careful management of the study minimised the effect of these threats. The methodologies employed (e.g. quasi-experimental group allocation) mean that the possibility of bias cannot logically be eliminated. However, since no differences between groups were discovered, then there is little evidence of bias. The strength of the study lies in the naturalistic field setting, although this had implications for sampling and allocation procedures. The small numbers precluded a deeper analysis of participant characteristics and outcomes, but appropriate numbers were recruited to the study given initial predictions of effect size.

The study was designed to assess the construct and measurement of hope and recovery as well as the effects of BFT on a wide range of outcomes. The study of hope was innovative and enhanced by both qualitative and qualitative analyses, and the contrasting of carer and consumer experience. The results were limited by the use of a single quantitative measure of hope, and a relatively narrow range of qualitative interview questions that could be accommodated within the study resources.

9.4 Implications

9.4.1 Implications for program evaluation and effectiveness of BFT

Clearly, a major implication for this study is in the translation of efficacious interventions into practical and effective treatments that are available for widespread use. Although many promising techniques for treatment have been demonstrated in RCTs under controlled conditions, there is a pressing need for them to be evaluated and adapted for use in community treatment regimes (D. S. Elliott & Mihalic, 2004; D. L. Fixsen & Blase, 2009; Ganju, 2003; Woolf & Johnson, 2005). As this study indicates, there are considerable challenges in conducting field studies to evaluate them (Wolff, 2000). These challenges include the management of quasi-experimental research designs, adequate recruitment, and high variability in treatment fidelity and participant characteristics. However, the knowledge gained by field studies is invaluable in assessing the viability of potential treatments in real world settings. Possible approaches to overcome constraints are related to the implementation of evidence-based interventions and enhancing their evaluation.

Supporting the fidelity of treatment in field studies is demanding, and this study managed those challenges though consistent training, mentoring and co-therapy strategies. Other challenges remain. Recent research has suggested that high staff turnover and financial duress within services can decrease the quality of training and supervision of staff and the quality of the work that it is possible to carry out (Robert E. Drake & Deegan, 2008; Woltmann, et al., 2008). This means there is a constant demand to train and mentor new staff, and that trained staff do not stay long enough in a job to develop the skills necessary to deliver the family intervention confidently and competently. This

has implications for the sustainability of complex interventions such as family psychoeducation in the public sector.

Subsequent experience with other models of implementation by the research team suggests that clinicians whose duties allow them to spend significant work time seeing families develop more confidence, can make more sophisticated adaptations, and can respond more strategically to family dynamics while delivering the skills training and psychoeducation (Burbach & Stanbridge, 1998; Psychosocial Research Centre, 2010). This suggests that complex interventions might be best delivered by practitioners who specialise, rather than expecting every case manager in a service to deliver sessions. However, given the importance of families for consumer mental health (I. R. Falloon, 2003) and the demands on care-givers (L. Hayes, et al., 2013; L. Hayes, Harvey, Hawthorne, & Perlesz, 2007; Laura Hayes, et al., in submission), family-sensitive practice, generic skills in family interviewing, skills in basic family education regarding mental illness and other family support aptitudes would still be required in all staff.

This study also raises questions about adapting family psychoeducation to groups of consumers with a profile of more persistent disability. This may mean longer treatment, more intensive treatment or more adjunctive treatments are required to augment the family intervention. Evidence from integrative treatments for schizophrenia suggest that a wide range of treatments may be required that are tailored to the needs of individual consumers (Kim T. Mueser, et al., 2013). The use of family intervention specialist teams, as described above, may also enhance this adaptation.

While the hallmark of family psychoeducation is its adaptability to the family culture, in practice matching intervention with family constellation and CALD background is complex (Glynn, et al., 2007; Psychosocial Research Centre, 2010). Earlier studies of family psychoeducation (e.g. (I. R. Falloon, et al., 1985; Leff, et al., 1982)) were aimed at consumers with parent or spouse carers. However, working with couples and families where consumers have their own children is a growing area of need (A. Morgan, et al., 2012), and demand will be growing for family psychoeducation adaptations to support

them. In addition, working with families where people were born overseas is common in Australia given 29% of the Australian population is born elsewhere (Australian Bureau of Statistics, 2007). Development of systematic adaptations to these requirements rather than relying on idiosyncratic versions should be a priority.

Extensive survey of the family psychoeducation and BFT literature did not uncover any clear guidelines as to which families or which consumers benefit most from family interventions except for high EE families (see Chapter 3). It suggests that more research might be needed for understanding which families will benefit most from family psychoeducation and attention to moderator analyses. Given the severity and complexity of mental illness in this cohort, then longer treatments may be required for similar populations.

Program logic established a plausible chain of improvements from immediate to long-term, but this has not been validated empirically. Close attention to program logic would be useful to enhance the internal validity of program evaluations. In this study, as no significant changes in long-term outcomes were observed, it was difficult to interpret this finding without information regarding immediate outcomes. Earlier attention to program logic as suggested by program evaluation protocols (Rossi, et al., 2004) is recommended to assist in the choice of proximal measures. These in turn can indicate the stages of change and give clues about the reasons for the effectiveness or ineffectiveness of the program. The development of standardised instruments with strong psychometric properties to measure proximal outcomes is a priority.

It is not clear which components provide the crucial effectiveness in family psychoeducation interventions. This implies the need for research comparing interventions that include different components and modules and further research on mediating factors. Qualitative research that explores the subjective experience and changes resulting from sessions would also be important (L. Hayes, et al., 2013). The obvious benefit of enhanced knowledge of effective components would include improved treatments for families and the

ability to focus training for practitioners on the more effective aspects of the intervention.

The use of structured interviews for qualitative analysis seems a particularly appropriate approach to evaluating recovery-based outcomes, obtaining details as to effective components, and empirical evidence of the chain of improvements. As self-report measures for recovery have only recently been developed and many aspects of their validity are yet to be established the use of structured interviews will enhance its measurement. Also, recovery programs may have unintended outcomes, and qualitative approaches can be a way to understand unexpected outcomes. In addition, the response bias, such as that observed in answers to the Snyder Hope Scale, may also affect some of the positively worded recovery scales, so that participants' answers reflect agreement with the recovery statements, rather than critical self-assessment. Finally, interviews and qualitative data collection allow the authentic voice of carers and consumers to be heard in the assessment of recovery programs and provide insight into the reasoning behind their responses (S. Marshall, Crowe, Oades, Deane, & Kavanagh, 2007; Ramon, et al., 2007). Therefore, it is recommended that research protocols examining complex interventions and recovery-based programs include structured interviews to be used for qualitative analysis. As well this interview material can be scored to allow for quantitative insights.

9.4.2 Implications for hope and the recovery paradigm

The results of this study emphasise the lack of hope in consumers with severe and enduring mental illnesses and the need for new ways to address this important problem. This has implications for the implementation of recovery-orientated services, as it has been argued that hope is an integral part of recovery (M Slade, 2012). If hope is very low among consumers and their family members, then the process of recovery may be impeded.

While hope arguably plays a central role in the initiation of positive change in people's lives, it is surprising that theories and measures of hope lack consolidation and integration (Aspinwall & Leaf, 2002). The notion of hope has been widely utilised in the recovery movement as a vague "positive future".

This study has attempted to clarify an approach to hope integrating concepts from the literature, but also starting to link hope to more rigorous theories such as the concept of control. The results have shown that Snyder's account of hope and the measurement of positive expectancy can be integrated with the concepts of efficacy and optimism, but the link to emergent hope is unclear.

The question regarding whether hope is a precursor of recovery could not be answered definitively in the present study. Hope was shown to have positive correlations with recovery outcomes such as quality of life and decreased social isolation. However, its role as a causal force in improvement in these domains remains an open question.

The results suggest that the Snyder Hope Scale has limitations for further empirical research into recovery, as it does not operationalise emergent aspects of hope that have been shown to be relevant to hope in this research. Especially when expectancy hope is low, then emergent hope may be more important. At intermediate levels of hope, as for the carers in this study, then both emergent and expectancy hope may be apparent. It is possible that at high hope levels, then expectancy hope is dominant. This would match a "staged model", similar to the "stages of recovery model" (R. Andresen, et al., 2006). Further research into a staged model of hope may improve understanding of hope, develop a more nuanced approach to it, and widen the appreciation of the links between hope, recovery and treatment.

The correlation between hope and symptoms in consumers is a point worthy of consideration as recovery models are implemented throughout Australia. The correlation suggested that as symptoms increase, hope decreases. Other research has shown links between lowered hope and depression as well (Andresen, et al., 2010; R. Beck, et al., 2001; S. G. Resnick, et al., 2004) and this may be a widespread problem as epidemiological surveys show that consumers living with psychosis in Australia have co-morbid depression at a rate of 25% and a life-time rate of depression of 80% (A. Morgan, et al., 2012). How hope may be instilled and endure in the situation of severe and persistent mental illness and depression presents something of a challenge where there is low hope and expectancy for a change in health status. It does suggest that

"being hopeful" and engaging in recovery is not a simple task of "just being positive". This also points to the fact that better methods for symptom resolution are still a priority and although the notion that recovery can occur despite ongoing symptoms may still hold true, these findings might suggest that decreased symptomology may still be important

The question of the precise nature of the relationship between emergent hope, expectancy hope, and the notion of hope implicated in recovery is raised in this study. No definitive answers are obtained but it is identified as an important topic for further study. It remains an important area for research as the recovery model becomes a more popular approach to service delivery. However, there is a suggestion that even at low levels of expectancy hope, then the presence of emergent hope can still lead to better outcomes after treatment engagement.

The results of this study emphasise that hope is not a simple construct. Its qualities vary in situations of hopelessness, low hope and high hope. Therefore its role in recovery and treatment is not simple. This research and the literature survey identified that hope is an important yet poorly operationalised concept, that is often linked to the process of recovery in ill-defined ways, and with little empirical investigation to date.

9.5 Questions for further research

More research regarding hope and recovery is warranted. Research is especially needed on translating the promises of narrative accounts of recovery into substantiated programs of effective treatment for people living with severe and persisting disability and set in the real world of state funded services. Even in relatively well-resourced places such as Victoria, clinical staff time and training are limited and do not reach the levels achieved in experimental settings. Areas for particular focus are:

- The development of new, or the re-evaluation of existing hope measures that are suitable for the assessment of hope in recovery. These hope measures would need to capture the varying qualities of hope, including both emergent and expectancy hope. One methodology that may be

useful is the application of semi-structured interviews that can be subsequently scored. This is the methodology used for measures such as the Camberwell Family Interview, which allows for highly reliable assessments of family functioning and can capture subtle but definable characteristics of the construct under examination.

- Further exploration of emergent hope as a predictor of therapeutic success. The narrative accounts of hope strongly suggest that the emergence of hope is the critical first step in recovery and can thus lead to more successful engagement with treatment. Empirical assessment of this concept would be useful for predicting consumers and families who could benefit most from treatment. Potentially, treatments like BFT would be most helpful as they assist consumers and families with developing the plans and motivation from their emergent goals. This does not mean that consumers and families living with low, or no hope should not be offered treatments but it does mean that different types of treatment may be more useful for these groups. More research into the role of carers in maintaining consumer hope is undoubtedly warranted, as carer-inclusive practices are implemented as part of recovery focused treatments.

- The overlap in the constructs of expectancy hope, perceived control and optimism suggests that more critical thinking about positive psychology is warranted. Psychologists have a role to play in the integration of the theoretical underpinnings for constructs such as hope.

- The null result for this treatment program was unexpected, given the number of positive studies reported in the literature for family psychoeducation. A more critical review of the literature unearthed questions about translating these efficacy studies into effectiveness studies and implementing such a treatment program. More research into family psychoeducation that takes account of family EE status, CALD background, and chronicity of consumers' mental illness is required. The optimum length and intensity of the intervention must be investigated in community settings where symptom severity and

perseverance may vary from groups included in previous effectiveness studies.

- While the research did not focus on program implementation, the results emphasise the importance of evaluating the implementation of efficacious treatments in real world services for people living with severe and persistent disabilities. The service wide approach to implementing a family intervention may have led to inadequate skill development among case managers, many of whom worked with only one or two families a year. Further research into optimal implementation models is warranted. Research into the implementation of short term family psychoeducation, including information sharing and relapse prevention only, may be useful as these sessions seemed to have the most positive impact with a wide range of participants. They require less complex clinical skills, are widely applicable, and there is good evidence that they are effective with a diverse range of groups (Grainne Fadden, 1998). It is relevant to ensure that all practitioners are equipped with basic communication skills and readiness to work with families. Child and adolescent services already work systematically with families across the service and these services could provide additional appropriate practice models.

- As a corollary, more research into the inclusion of families and carers at mental health services and attention to carer mental health is important. Investigation of practice models that support family engagement is also essential.

- The extent of consumer and carer involvement in design and implementation of the training program and its evaluation needs to be considered. Participation of these groups in all stages of program implementation and research is becoming the norm in many places and its value established (Boote, Telford, & Cooper, 2002; Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). In this study the use of exit interviews provided an important source of feedback and in depth interviews were conducted by another researcher associated with the BFST project as well (B. O'Hanlon, 2013). The use of carers and

consumers as consultants and members of research reference groups (Lammers & Happell, 2004; C. Lloyd & King, 2003) are examples of what could be done in the future to assist implementation and evaluation.

9.6 Conclusion

This study raises multiple questions about the effective implementation and assessment of recovery-orientated services. Firstly, the study result raises questions about the most effective way to implement interventions in the field when they have been shown to be effective in RCTs and other highly controlled efficacy trials. In this instance, the effectiveness of family psychoeducation with groups of consumers with longstanding and severe disorders and with complex presentations including co-morbidities and CALD backgrounds presented unique challenges not examined in previous research. Family psychoeducation may require adaption to meet these particular needs, and modifications may include longer or more intensive programs and/or the addition of multi-family group formats. Attention to both immediate and long-term outcomes may help to understand more about effective “ingredients” and the pathways for positive outcomes. The best modes for staff training and deployment are also important concerns.

This research also demonstrated that consumers and carers live with very low levels of hope. The capacity for services to support consumers in initiating and maintaining their process of recovery is challenging but obligatory in this context. While services are encouraging “recovery attitudes” in staff and promoting a message of hope and optimism (Department of Health, 2011), it is equally significant for staff to be able to tolerate hopelessness and to work from the existing situation of the consumers and their families (Flaskas, 2007; Flaskus, 2007; P. McKenzie, 2006; Peter McKenzie, 2007; Ruvelson, 1990).

Although this program was not objectively successful in changing outcomes for families, this is not a reason to abandon family interventions in community mental health settings. The high level of satisfaction with the BFT program and the difficulties that some carers and consumers had on cessation of sessions suggest that there is a high demand for family involvement in recovery focused

mental health treatment. Clearly there are practical concerns that remain in engaging families, but given the mental health challenges carers face themselves, it is essential that family-inclusive practice remain a priority.

This research also raised questions regarding the adequacy of existing models of hope and recovery for the purposes of research and evaluation of recovery-orientated services. Some particular questions were the primacy of hope in the recovery process, the links between hope, recovery and symptoms, and the comprehensive measurement of hope. Staged models of hope that take account of the narrative processes behind hope levels may be rich areas for further investigation.

Even if the Snyder Hope Scale is an imperfect measure of hope, measuring only expectancy hope, is there any need for a better assessment? It performed adequately, in the sense that correlations with other scales were mostly as predicted. Many of the questions unanswered regarding hope were due to lack of changes in hope across the treatment program. The Snyder Hope Scale showed appropriate variability across the carer and consumer samples. Is there any need for another measure for hope?

However, if we have regard for the narrative accounts of recovery from consumers and others, there is common description of a pivotal moment when the possibility of a better life was conceptualised – the moment of hope emerging. For the possibility to become reality, then motivation, positive expectancies and plans were required to make the “dream into reality”. However, the initial process was one of a tiny “ray of hope” emerging. To properly implement recovery focused services, then an understanding of nascent hope is most important, as recovery focused services must help create and strengthen this emerging hope, before helping to build it to expectancy hope.

This research has made important contributions in a number of areas. It has started to develop a clinically relevant model of hope and addressed empirical questions about hope and the link to recovery. It has shown how FPE is potentially linked to hope through its goal setting and coaching practices and through enabling family members to understand and support each other and

more generally through its recovery oriented approach. The concepts of emergent and expectancy hope and the role they play in recovery (P.E. Deegan, 1988; Menninger, 1959; Beate Schrank, Bird, et al., 2012) make important contributions to the development of an empirical model of hope and recovery. This research also utilised a novel technique to evaluate the Snyder Hope Scale by using qualitative material collected via interview.

Narrative accounts of recovery imply that recovery can occur independent of symptom improvements, and that the return of hope is a forerunner of full recovery (W. A. Anthony, 1993; P.E. Deegan, 1988). This research found that hope and symptoms are not independent of each other in consumers, which suggests that a more nuanced approach to the possibilities for recovery when symptoms are prominent should be considered.

Part of understanding more about emergent hope will be the development of an adequate operationalisation and measurement for it. The use of conventional quantitative measures with their closed response sets may be inadequate to capture this subtle phenomenon. Emergent hope is not a trait, nor a behaviour; it has a narrative aspect, as it is part of a life story that unfolds over time. A suggestion for developing the assessment of emergent hope would be the use of semi-structured interview techniques, with regard to a staged model of hope, similar to those developed for recovery (R. Andresen, et al., 2006).

This research demonstrated that both consumers and carers live with significantly lowered hope, quality of life and social inclusion. The challenge is to design and evaluate treatment programs that offer real possibilities for improved hope and recovery, social participation, respect and dignity for people living with serious mental illness and their families. This is of particular interest for the consumers who joined this study and who lived with severe and persisting disability. Optimal treatment regimes may require more intensive and extensive adaptations of existing interventions in addition to new methods of treatment.

This research also developed a more nuanced account of family psychoeducation, through in depth analysis of multiple trials in an effort to understand the poor treatment response in this study. Although family

psychoeducation is recommended for all consumers who have family contact (L. B. Dixon, et al., 2010; Kreyenbuhl, et al., 2010; McGorry, 2005; National Collaborating Centre for Mental Health, 2002; Scottish Intercollegiate Guidelines Network, 1998), the literature review in this thesis would seem to suggest that more attention should be paid to appropriate adaptations for illness phase, level of expressed emotion, cultural background, co-morbidities, family constellation, and stability and persistence of symptoms in adopting recommendations in the field. It also suggests that while efficacy studies are important for establishing the potential usefulness of interventions, effectiveness studies are required to understand the practical effects in the field.

Although this study did not find positive outcomes for the specific family intervention program investigated, it is still important to provide support for carers through family sensitive practices and other evidence-based supports. New possibilities for the provision of evidence-based family interventions might include a wider range of programs that meet the range of family needs. For instance, short programs focusing on education regarding mental illness and relapse prevention might be widely available, with longer programs offered more selectively to families with higher levels of stress. Programs tailored to specific concerns might be developed, such as those directed at first episode psychosis, or families where the parent has a mental illness. A mix of single-family sessions and multiple family sessions might also be offered.

This study shows the complexity of psychosocial interventions and their implementation. However, it also suggests that these interventions meet a particular set of needs that, at this stage, cannot be met with medication alone. These particular needs range from rehabilitative needs, the need for increased social engagement through work and study, the requirement for information on mental illness and relapse prevention and the need to alleviate family burden. One of the most important needs underlying all these is the necessity of hope for the journey of recovery.

List of references

List of references

Abdel-Khalek, A., & Snyder, C. R. (2007). Correlates and predictors of an Arabic translation of the Snyder Hope Scale. *Journal of Positive Psychology, 2*(4), 228-235.

Ahmed, S. M. S., & Duhamel, P. (1994). Psychometric properties of the Scale of Individual Differences--Measure of Hope. *Psychological Reports, 74*(3, Pt 1), 801.

Akister, J., & Stevenson-Hinde, J. (1991). Identifying families at risk: Exploring the potential of the McMaster Family Assessment Device. *Journal of family therapy, 13*(4), 411-421.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental health disorders (DSM-IV)* (Fourth ed.). Washington DC: American Psychiatric Association.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental health disorders (DSM-IV-TR)* (Fourth ed.). Washington DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental health disorders (DSM-V)* (Fourth ed.). Arlington, VA: American Psychiatric Publishing.

Amering, M., & Schmolke, M. (2009). Recovery in mental health: reshaping scientific and clinical responsibilities.

Amering, M., & Schnolke, M. (2009). *Recovery in mental health: Reshaping scientific and clinical responsibilities*. UK: Wiley Blackwell.

Anderson, J. R. (1988). *The role of hope in appraisal, goal setting and expectancy.* University of Kansas, Lawrence.

Andresen, R., Caputi, P., & Oades, L. (2006). Stages of recovery instrument: Development of a measure of recovery from serious mental illness. *Australia and New Zealand Journal of Psychiatry, 40*, 972-980.

Andresen, R., Caputi, P., & Oades, L. (2006). Stages of recovery instrument: development of a measure of recovery from serious mental illness. *Australian and New Zealand Journal of Psychiatry, 40*(11-12), 972-980.

Andresen, R., Caputi, P., & Oades, L. G. (2010). Do clinical outcome measures assess consumer-defined recovery? *Psychiatry research, 177*(3), 309-317.

Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australasian Psychiatry, 37*(5), 586-594.

Anonymous carer. (2009). Personal communication from carer, conversation dated 1 March 2009. Melbourne.

Anthony, W. (1993). Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11-23.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990's. *Psychosocial Rehabilitation Journal, 16*(4), 11-23.

Aspinwall, L. G., & Leaf, S. L. (2002). In search of the unique aspects of hope: Pinning our hopes on positive emotions, future orientated thinking, hard times and other people. *Psychological Inquiry, 13*(4), 276 - 288.

Atkinson, T. (1982). The stability and validity of quality of life measures. *Social Indicators Research, 10*(2), 113-132.

Australian Bureau of Statistics. (2007). 2006 Census. Retrieved 1 May 2010

Australian Health Ministers Conference. (2009). *Fourth National Mental Health Plan: an agenda for collaborative government action in mental health 2009-2014.* Canberra: Commonwealth of Australia.

Aveline, M., Shapiro, D., & et al. (1995). Building research foundations for psychotherapy practice. In M. Aveline & D. Shapiro (Eds.), *Research Foundation for Psychotherapy Practice* (pp. 301-322). Chichester: Wiley.

Averill, J. R., Catlin, G., & Chon, K. K. (1990). *Rules of hope*: Springer-Verlag Publishing.

Babaie, E., Jain, S., & Cardona, B. (2011). Comparative study of hope and happiness among the children of veterans and non-veterans. *Education, 2*, 419-428.

Babyak, M. A., Snyder, C. R., & Yoshinobu, L. (1993). Psychometirc properties of the Hope Scale: A confirmatory factor analysis. *journal of research in personality, 27*(154-169).

Bailey, R., Burbach, F. R., & Lea, S. J. (2003). The ability of staff trained in family interventions to implement the approach in routine clinical practice. *Journal of Mental Health, 12*(2), 131-141.

Bailey, T. C., & Snyder, C. R. (2007). Satisfaction with life and hope: a look at age and marital status *Psychological Record, 57*(2), 233-240.

Bandura, A. (1977,). Self-efficacy: Toward a unifying theory of behavioral change *Psychological Review, 84*(2), 191-215

Barber, M. E. (2012). Recovery as the new medical model for psychiatry. *Psychiatric Services, 63*(3), 277-279.

Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(6), 1173.

Baronet, A.-M. (1999). Factors associated with caregiver burden in mental illness: A critical review of the research literature. *Clinical Psychology Review, 19*(7), 819-841.

Barrowclough, C., Haddock, G., Tarrier, N., Lewis, S. W., Moring, J., O'Brien, R., et al. (2001). Randomized controlled trial of motivational interviewing, cognitive behavior therapy, and family intervention for patients with comorbid schizophrenia and substance use disorders. *Am J Psychiatry, 158*(10), 1706-1713.

Barrowclough, C., Tarrier, N., Lewis, S., Sellwood, W., Mainwaring, J., Quinn, J., et al. (1999). Randomised controlled effectiveness trial of a needs-based psychosocial intervention service for carers of people with schizophrenia. *British Journal of Psychiatry, 174*, 505-511.

Bassman, R. (2000). Agents, Not Objects: Our Fights to Be. *Journal of Clinical Psychology, 56*(11), 1395-1411.

Baum, F. (1995). Researching public health: behind the qualitative-quantitative methodological debate. *Soc Sci Med, 40*(4), 459-468.

Beck, A. T., Steer, R. A., Kovacs, M., & Garrison, B. (1985). Hopelessness and eventual suicide: a 10-year prospective study of patients hospitalized with suicidal ideation. *Am J Psychiatry, 142*(5), 559-563.

Beck, A. T., Ward, C. H., Mendelson, M., J., M., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4*(June), 53-63.

Beck, A. T., Weissmann, A., Lester, D., & Trexler, B. (1974). The measurement of pessimism: the hopelessness scale. *Journal of Consulting and Clinical Psychology, 42*(6), 861-865.

Beck, R., Perkins, T. S., Holder, R., Robbins, M., Gray, M., & Allison, S. H. (2001). The Cognitive and Emotional Phenomenology of Depression and Anxiety: Are Worry and Hopelessness the Cognitive Correlates of NA and PA? *Cognitive Therapy & Research, 25*(6), 829.

Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: Concordance, contrasts, and implications. *Schizophrenia Bulletin, 32*(3), 432-442.

Bellack, A. S., Haas, G. L., Schooler, N. R., & Flory, J. D. (2000). Effects of behavioural family management on family communication and patient outcomes in schizophrenia. *Br J Psychiatry, 177*, 434-439.

Bellucci, D. M., Glaberman, K., & Haslam, N. (2002). Computer-assigned cognitive rehabiliatation reduces negative symptoms in the severely mentally ill. *Schizophrenia Research, 59*, 225-232.

Bengtsson-Tops, A., & Hansson, L. (1999). Clinical and social needs of schizophrenic outpatients living in the community: the relationship between needs and subjective quality of life. *Social Psychiatry & Psychiatric Epidemiology, 34*(10), 513.

Benzein, E., & Saveman, B. i. (1998). One step towards the understanding of hope: a concept analysis. *International Journal of Nursing Studies, 35*(6), 322-329.

Berglund, N., Vahlne, J. O., & Edman, A. (2003). Family intervention in schizophrenia--impact on family burden and attitude. *Soc Psychiatry Psychiatr Epidemiol, 38*(3), 116-121.

Bland, R., & Darlington, Y. (2002). The nature and sources of hope: perspectives of family caregivers of people with serious mental illness. *Perspect Psychiatr Care, 38*(2), 61-68.

Bloch, S., Hafner, J., Harari, E., & Szmukler, G. I. (1994). *The Family in Clinical Psychiatry*. U.K.: Oxford University Press.

Bonney, S., & Stickley, T. (2008). Recovery and mental health: a review of the British Literature. *Journal of Psychiatric and Mental Health Nursing, 15*(2), 140-153.

Boote, J., Telford, R., & Cooper, C. (2002). Consumer involvement in health research: a review and research agenda. *Health policy, 61*(2), 213-236.

Bottomley, A. (1997). To randomise or not to randomise: methodological pitfalls of the RCT design in psychosocial intervention studies. *Eur J Cancer Care (Engl), 6*(3), 222-230.

Bradley, G. M., Couchman, G. M., Perlesz, A., Nguyen, A. T., Singh, B., & Riess, C. (2006). Multiple-family group treatment for English- and Vietnamese-speaking families living with schizophrenia. *Psychiatr Serv, 57*(4), 521-530.

Broderick, C., & Schrader, S. (1981). The history of professional marriage and family therapy. In A. S. Gurman & K. D.P. (Eds.), *Handbook of Family Therapy*. New York: Brunner-Mazel.

Bronk, K. C., Hill, P., Lapsley, D., Tallib, T., & Finch, H. (2009). Purpose, hope and life satisfaction in three age groups. *The journal of Positive Psychology, 4*(6), 500-510.

Brooker, C., Falloon, I., Butterworth, A., Goldberg, D., Graham-Hole, V., & Hillier, V. (1994). The Outcome of Training Community Psychiatric Nurses to

Deliver Psychosocial Intervention. *British Journal of Psychiatry, 165*, 222-230.

Brouwer, D., Meijer, R. R., Weekers, A. M., & Baneke, J. J. (2008). On the dimensionality of the Dispositional Hope Scale. *Psychological Assessment, 20*(3), 310-315.

Brown, C., Rempfer, M., & Hamera, E. (2008). Correlates of insider and outsider conceptualizations of recovery. *Psychiatr Rehabil J, 32*(1), 23-31.

Brown, G. (1985). The discovery of expressed emotion: induction or deduction? In J. P. Leff & C. Vaughn. (Eds.), *Expressed emotion in families : its significance for mental illness*. New York: Guilford Press.

Brown, G., & et al. (1972). Influence of family life on the course of schizophrenic disorders. *British Journal of Psychiatry, 121*, 241-258.

Browne, J. (2003). Grounded theory analysis: coming to data with questioning minds. In V. Minichiello, G. Sullivan, K. Greenwood & R. Axford (Eds.), *Handbook of research methods for nursing and health science*.

Bruininks, P., & Malle, B. (2005). Distinguishing Hope from Optimism and Related Affective States. *Motivation & Emotion, 29*(4), 324-355.

Bryman, A. (1984). The debate about quantitative and qualitative research: a question of method or epistemology. *British Journal of Sociology., 35*(1), 75-92.

Buchkremer, G., Klingberg, S., Holle, R., Schulze Monking, H., & Hornung, W. P. (1997). Psychoeducational psychotherapy for schizophrenic patients and their key relatives or care-givers: Results of a 2-year follow-up. *Acta Psychiatrica Scandinavica, 96*(6), 483 - 491.

Buran, C. F., Sawin, K. J., Brei, T. J., & Fastenau, P. S. (2004). Adolescents with myelomeningocele: activities, beliefs, expectations, and perceptions. *Developmental Medicine & Child Neurology, 46*(4), 244-252.

Burbach, F. R. (1996). Family Based Interventions in psychosis - an overview of and comparison between family therapy and family management approaches. *Journal of Mental Health, 5*, 111-134.

Burbach, F. R., & Stanbridge, R. (1998). A family intervention in psychosis service integrating the systemic and family management approaches. *Journal of Family Therapy, 20*, 311-325.

Burgess, P., Pirkis, J., Coombs, T., & Rosen, A. (2010). *Review of Recovery Measures*: Australian Mental Health Outcomes and Classification Network.

Burns, T. (2007a). Evolution of outcome measures in schizophrenia. *Br J Psychiatry Suppl, 50*, s1-6.

Burns, T. (2007b). Hospitalisation as an outcome measure in schizophrenia. *Br J Psychiatry Suppl, 50*, s37-41.

Burns, T., Creed, F., Fahy, T., Thompson, S., Tryrer, P., & White, I. (1999). Intensive versus standard case management for severe psychotic illness: A randomised trial. *Lancet, 353*(9171), 2185-2189.

Byles, J., Byrne, C., Boyle, M. H., & Offord, D. R. (1988). Ontario Child Health Study: reliability and validity of the general functioning subscale of the McMaster Family Assessment Device. *Fam Process, 27*(1), 97-104.

Callan, D. B. (1989). Hope as a Clinical Issue in Oncology Social Work. *Journal of Psychosocial Oncology, 7*(3), 31-46.

Campbell-Orde, T., Chamberlin, J. C., J., C., & Leff, H. S. (2005). *Measuring the promise: A compendium of recovery measures, Volume II,* . Cambridge, MA: Evaluation Center.

Campbell, A. S. (1999). *Behavioural Family Therapy Training: a regional evaluation*. Birmingham, UK: Partnership for Developing Quality.

Campbell, D. T., & Stanley, J. C. (1966). *Experimental and quasi-experimental designs for research* (2nd ed.). Chicago R. McNally.

Carver, C. S., & Scheier, M. F. (2002). The hopeful optimist. *Psychological Inquiry, 13*(4), 288 - 290.

Cattell, R. (1978). *Scientific use of factor analysis in behavioral and life sciences.* New York: Plenum Press.

Cawte, J. (1998). *The last of the lunatics*. Melbourne: Melbourne University Press.

Chambless, D. l., Bryan, A. D., Aiken, L. S., Steketee, G., & Hooley, J. M. (1999). The structure of expressed emotion: a three-construct representation. *Psychological Assessment, 11*(1), 67-76.

Chang, E. C., & Banks, K. H. (2007). The Color and Texture of Hope: Some Preliminary Findings and Implications for Hope Theory and Counseling Among Diverse Racial/Ethnic Groups. *Cultural Diversity & Ethnic Minority Psychology, 13*(2), 94-103.

Charmaz, K. (2000). Grounded theory: objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.). Thousand Oaks: Sage Publications.

Charmaz, K. (2005). Grounded theory in the 21st century. In N. K. Denzin & Y. S. Lincolm (Eds.), *The Sage handbook of qualitative research* (3rd ed.). Thousand Oaks: Sage publications.

Cheavens, J. (2000). Hope and depression: Light through the shadows. In C. R. Snyder (Ed.), *Handbook of hope : theory, measures & applications*. San Diego, Calif.: Academic Press.

Chen, H.-t. (1990). *Theory-driven evaluations*. Newbury Park, Calif: Sage Publications.

Chien, W.-T., Chan, S. W. C., & Thompson, D. R. (2006). Effects of a mutual support group for families of Chinese people with schizophrenia: 18-month follow-up. *The British Journal of Psychiatry, 189*(1), 41-49.

Chien, W.-T., Norman, I., & Thompson, D. R. (2004). A randomized controlled trial of a mutual support group for family caregivers of patients with schizophrenia. *International Journal of Nursing Studies, 41*(6), 637.

Clarke, D. (2003). Faith and hope. *Australasian Psychiatry, 11*(2), 164-168.

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences*. Hillsdale, NJ: Lawrence Eribaum Associates.

Cohen, R. J., Swerdik, M. E., & Smith, D. K. (1992). *Psychological testing and assessment* (2nd ed.). Mountain View, California: Mayfield Publishing Company.

Comrey, A. L., & Lee, H. B. (1992). *First course in factor analysis* (2nd ed.). Hillsdale, N.J.: Lawrence Erlbaum Associates.

Cook, T. D., & Campbell, D. T. (1979). *Quasi-Experimentation: Design and Analysis for Field Settings*. Chicago, Illinois: Rand McNally.

Copic, V., Deane, F. P., Crowe, T. P., & Oades, L. G. (2011). Hope, Meaning and Responsibility across Stages of Recovery for Individuals Living With an Enduring Mental Illness. *Australian Journal of Rehabilitation Counselling, 17*(2), 61-73.

Corrigan, P. W., & Ralph, R. O. (2007). Introduction: recovery as consumer vision and research paradigm. In R. O. Ralph & P. W. Corrigan (Eds.),

Recovery in Mental Illness: Broadening our understanding of wellness. Washington D.C: American Psychological Association.

Corrigan, P. W., Steiner, L., McCracken, S. G., Blaser, B., & Barr, M. (2001). Strategies for disseminating evidence-based practices to staff who treat people with serious mental illness. *Psychiatric Services, 52*(12), 1598-1606.

Creamer, M., O'Donnell, M., L. , Carboon, I., Lewis, V., Densley, K., McFarlane, A., et al. (2009). Evaluation of the Dispositional Hope Scale in injury survivors. *Journal of Research in Personality, 43*, 613-617.

Cuellar, I., Harris, L. C., & Jasso, R. (1980). An acculturation scale for Mexican American normal and clinical populations. *Hispanic journal of behavioral sciences*.

Cummins, R. (2010). Subjective Wellbeing, Homeostatically Protected Mood and Depression: A Synthesis. *11*(1), 1-17.

Cummins, R., Hughes, J., Tomyn, A., Gibson, A., Woerner, J., & Lai, L. (2007). *The wellbeing of Australians: carer health and wellbeing.* Melbourne: Deakin University.

Curry, L. A., & Snyder, C. R. (2000). Hope takes the field: Mind matters in athletic performances. In C. R. Snyder (Ed.), *Handbook of hope : theory, measures & applications*. San Diego, Calif.: Academic Press.

Cutcliffe, J., & Herth, K. (2002). The concept of hope in nursing 2: hope and mental health nursing. *Br J Nurs, 11*(13), 885-889, 891-883.

Czuchta, D. M., & Johnson, B. A. (1998). Reconstructing a sense of self in patients with chronic mental illness. *Perspectives in Psychiatric Care, 34*(3), 31.

Damodoran, S. S. (2000). What's in a name? . *Australian and New Zealand Journal of Psychiatry, 34*(4), 698-699

Darlington, Y., & Bland, R. (1999). Strategies for encouraging and maintaining hope among people living with serious mental illness. *Australian Social Work, 52*(3), 17 - 34.

Davidson, L., Lawless, M. S., & Leary, F. (2005). Concepts of recovery: competing or complementary? *Current Opinion in Psychiatry, 18*(6), 664-667.

Davidson, L., O'Connell, M., Tondora, J., Styron, T., & Kangas, K. (2006). The top ten concerns about recovery encountered in mental health system transformation. *Psychiatric Services, 57*(5), 640-645.

Davidson, L., Schmutte, T., Dinzeo, T., & Andres-Hyman, R. (2008). Remission and recovery in schizophrenia: practitioner and patient perspectives. *Schizophrenia Bulletin, 34*(1), 5-8.

Davis, L. W., Lysaker, P. H., & Nees, M. A. (2003). Coping style and hopelessness as predictors of social function at work in schizophrenia. *Schizophrenia Research, 60*(1, Supplement 1), 15.

Davison, A. G., Fayers, P. M., Nunn, A. J., Venables, K. M., & Newman Taylor, A. J. (1986). Number of patients required in lung function studies. *Thorax, 41*, 830-832.

De Winter, J. C. F., Dodou, D., & Wieranga, P. A. (2009). Exploratory factor analysis with small sample sizes. *Multivariate Behavioral Research., 44* (2), 147-181.

Deegan, P., Rapp, C., Holter, M., & Riefer, M. (2008). Best practices: a program to support shared decision making in an outpatient psychiatric medication clinic. *Psychiatric Services, 59*(6), 603-605.

Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal, 11*(4), 11-19.

Deegan, P. E. (1997). Recovery and Empowerment for People with Psychiatric Disabilities. *Soc Work Health Care, 25*(3), 11 - 24.

Department of Health. (2011). *Framework for recovery-oriented practice*. Melbourne: State Government of Victoria,.

Department of Human Services. (2004). *Summary of the 2003-2004 survey of consumer and carer experience of Victorian public adult mental health services.* Melbourne: Victorian State Government.

Dixon, L. (2000). Assertive Community Treatment: Twenty-five years of gold. *Psychiatric Services, 51*(6), 759-765.

Dixon, L., MacFarlane, A. C., Lefley, H. P., Lucksted, A., Cohen, M., Falloon, I., et al. (2001). Evidence-based practice for services to families of people with psychiatric disabilities. *Psychiatric Services, 52*(7), 903-910.

Dixon, L. B., Dickerson, F., Bellack, A. S., Bennett, M., Dickinson, D., Goldberg, R. W., et al. (2010). The 2009 schizophrenia PORT psychosocial treatment recommendations and summary statements. *Schizophr Bull, 36*(1), 48-70.

Dogra, A. K., Basu, S., & Das, S. (2011). Impact of Meaning in Life and Reasons for Living to Hope and Suicidal Ideation: A Study among College Students. *SIS Journal of Projective Psychology & Mental Health, 18*(1), 89-102.

Drake, R. E., & Cotton, P. G. (1986). Depression, hopelessness and suicide in chronic schizophrenia. *The British Journal of Psychiatry, 148*(5), 554-559.

Drake, R. E., & Deegan, P. E. (2008). Are assertive community treatment and recovery compatible? Commentary on "ACT and recovery: Integrating evidence-based practice and recovery orientation on assertive community treatment teams". *Community Mental Health Journal, 44*(1), 75-77.

Dufault, K., & Martocchio, B. C. (1985). Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions. *Nurs Clin North Am., 20*(2), 379-391.

Dyck, G. D., Hendryx, M. S., Short, R. A., Voss, W. D., & McFarlane, W. R. (2002). Service use among patients with schizophrenia in psychoeducational multiple-family group treatment. *Psychiatric Services, 53*(6), 749-754.

Eisen, S. V., Dill, D. L., & Grob, M. C. (1994). Reliability and validity of a Brief Patient-Report Instrument for psychiatric outcome evaluation. *Hospital and Community Psychiatry, 45*(3), 242-247.

Eisen, S. V., Grob, M. C., & Klein, A. A. (1986). BASIS: The development of a self-report measure for psychaitric inpatient evaluation. *The Psychiatric Hospital, 17*(4), 165-171.

Eisen, S. V., Wilcox, M., Leff, H. S., Schaefer, E., & Culhane, M. A. (1999). Assessing behavioral health outcomes in outpatient programs: Reliability and validity of the BASIS-32. *The Journal of Behavioral Health Sciences & Research, 26*, 5-17.

Elkin, I., Shea, M. T., & Watkins, J. S. (1989). National institute of mental health treatment of depression colloborative research programme: general effectiveness of treatments. *Arch Gen Psychiatry, 46*, 971-982.

Elliott, D. S., & Mihalic, S. (2004). Issues in disseminating and replicating effective prevention programs. *Prevention Science, 5*(1), 47-53.

Elliott, R. (1993). Consumerism and public psychiatry. *Hospital and community psychiatry, 44*, 5.

Epstein, N., Baldwin, L., & Bishop, D. (1983). The McMaster Family Assessment Device. . *Journal of Marital and Family Therapy, 9*, 171-180.

Fadden, G. (1997). Implementation of family interventions in routine clinical practice following staff training programs: A major cause for concern. *Journal of Mental Health, 6*(6), 599-612.

Fadden, G. (1998). Research update: psychoeducational family interventions. *Journal of Family Therapy, 20*(3), 293-309.

Fadden, G. (2006). Training and disseminating family interventions for schizophrenia: developing family intervention skills with multi-disciplinary groups. . *Journal of Family Therapy, 28*(1), 23-38.

Fadden, G., & Gair, F. (2004). *Behavioural Family Therapy Training Workbook* (3rd ed.). U.K.: Meriden: The West Midlands Famly Programme.

Fadden, G., & Heelis, R. (2011). The Meriden Family Programme: lessons learned over 10 years. *J Ment Health, 20*(1), 79-88.

Falloon, I. R. (2000). Problem solving as a core strategy in the prevention of schizophrenia and other mental disorders. *Aust N Z J Psychiatry, 34 Suppl*, S185-190.

Falloon, I. R. (2003). Family interventions for mental disorders: efficacy and effectiveness. *World Psychiatry, 2*(1), 20-28.

Falloon, I. R., Boyd, J. L., McGill, C. W., Razani, J., Moss, H. B., & Gilderman, A. M. (1982). Family management in the prevention of exacerbations of schizophrenia: a controlled study. *New England Journal of Medicine, 306*(24), 1437-1440.

Falloon, I. R., Boyd, J. L., McGill, C. W., Williamson, M., Razani, J., Moss, H. B., et al. (1985). Family management in the prevention of morbidity of schizophrenia. Clinical outcome of a two-year longitudinal study. *Archives of General Psychiatry, 42*(9), 887-896.

Falloon, I. R., Montero, I., Sungur, M., Mastroeni, A., Malm, U., Economou, M., et al. (2004). Implementation of evidence-based treatment for schizophrenic disorders: Two-year outcome of an international field trial of optimal treatment. *World Psychiatry, 3*(2), 104-109.

Falloon, I. R. H. (1988a). Prevention of Morbidity in Schizophrenia. In I. R. H. Falloon (Ed.), *Handbook of behavioural therapy*. New York: The Guilford Press.

Falloon, I. R. H. (Ed.). (1988b). *Handbook of behavioural therapy*. New York: The Guilford Press.

Falloon, I. R. H., Boyd, J. L., & McGill, C., W. (1984). *Family Care of Schizophrenia: A problem solving approach to the treatment of mental illness*. New York: The Guilford Press.

Falloon, I. R. H., & Pederson, J. (1985). Family management in the prevention of morbidity of schizophrenia. The adjustment of the family unit. *British Journal of Psychiatry, 147*, 156-163.

Falloon, I. R. H., & The Optimal Treatment Project Collaborators. (1999). Optimal treatment for psychosis in an international multisite demonstration project. *Psychiatric Services, 50*(5), 615-618.

Farhall, J., Campbell, J., Harvey, C., di Benedetto, M., & O'Hanlon, B. (2007). *What family work is done by mental health clinicians? An examination of family contacts with staff of continuing care teams.* Paper presented at the TheMHS Conference 2007: 2020 Vision - Looking towards excellence in mental health care in 2020, Melbourne, Australia.

Farhall, J., Goldstone, E., Harvey, C., O'Hanlon, B., & Hayes, L. (2010). *Can you see the ripples? Preliminary results from an assessment of the wider impact of establishing behavioural family therapy in continuing care teams.* Paper presented at the TheMHS Conference, Sydney NSW.

Farran, C. J., Herth, K. A., & Popovich, J. M. (Eds.). (1995). *Hope and hopelessness : critical clinical constructs*. Thousand Oaks, Calif.: Sage Publications.

Ferraro, F., & Neisius, L. (2002). Caregiving in Young and Middle-Age Adults. *Psychology and Education, 39*(3/4), 22-24.

Fibel, B., & Hale, W. D. (1978). The Generalized Expectancy for Success Scale: A new measure. *Journal of Consulting and Clinical Psychology, 46*(5), 924.

Fixsen, D., Naoom, S. F., Blase, K., Friedman, R. M., & Wallach, F. (2005). *Implementation Research: A Synthesis of the Literature* (No. 231). Florida: University of South Florida, Louis de la Parte Florida Mental Health Institue, National Implementation Research Network.

Fixsen, D. L., & Blase, K. A. (2009). Implementation: The missing link between research and practice. *NIRN implementation brief, 1*.

Flaskas, C. (2007). Holding hope and hopelessness: therapeutic engagements with the balance of hope. *Journal of Family Therapy, 29*(3), 186-202.

Flaskus, McCarthy, & Sheehan (Eds.). (2007). *Hope and despair in narrative and family therapy*. N.Y.: Brunner Routledge.

Flaskus, C. (2007). The balance of hope and hopelessness. In C. Flaskus, I. McCarthy & J. Sheehan (Eds.), *Hope and despair in narrative and family therapy*. N.Y.: Brunner Routledge.

Flaskus, C., McCarthy, I., & Sheehan, J. (2007). Introduction: the territory of hope and despair. In C. Flaskus, I. McCarthy & J. Sheehan (Eds.), *Hope and despair in narrative and family therapy*. N.Y.: Brunner Routledge.

Fleischhacker, W. W., & Goodwin, G. M. (2009). Effectiveness as an outcome measure for treatment trials in psychiatry. *World Psychiatry, 8*(1), 23-27.

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination *Journal of Personality and Social Psychology., Vol 48*(1), 150-170

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry, 36*, 717-732.

Foussias, G., & Remington, G. (2010). Antipsychotics and schizophrenia: from efficacy and effectiveness to clinical decision-making. *Can J Psychiatry, 55*(3), 117-125.

Frank, J. (1968). The role of hope in psychotherapy. *Int J Psychiatry, 5*(5), 383-395.

Frank, J. D. (1968). The influence of patients' and therapists' expectations on the outcome of psychotherapy. *Br J Med Psychol, 41*(4), 349-356.

Frankl, V. (1963). *Man's Search for Meaning*. New York: Washington Square.

Frazier, P. A., Tix, A. P., & Barron, K. E. (2004). Testing moderator and mediator effects in counseling psychology research. *Journal of Counseling Psychology, 51*(1), 115.

Fredrickson, B. (2009). Why choose hope? *Positivity Insights from Science on the Art of Living* Retrieved March 2013, from http://www.psychologytoday.com/blog/positivity/200903/why-choose-hope

Fromm-Reichmann, F. (1948). Notes on the development of treatment of schizophrenics by psychoanalytic psychotherapy. *Psychiatry, 11*(3), 263-273.

Fusar-Poli, P., & Politi, P. (2008). Paul Eugen Bleuler and the birth of schizophrenia (1908). *American Journal of Psychiatry, 165*(11), 1407-1407.

Galletly, C. A., Foley, D. L., Waterreus, A., Watts, G. F., Castle, D. J., McGrath, J. J., et al. (2012). Cardiometabolic risk factors in people with psychotic disorders: The second Australian national survey of psychosis. *Australian and New Zealand Journal of Psychiatry, 46*(8), 753-761.

Ganju, V. (2003). Implementation of evidence-based practices in state mental health systems. *Schizophrenia Bulletin, 29*(1), 125-131.

Garety, P. A., Fowler, D., & Kuipers, E. (2000). Cognitive-behavioral therapy for medication-resistant symptoms. *Schizophrenia Bulletin, 26*(1), 73-86.

Garety, P. A., Fowler, D. G., Freeman, D., Bebbington, P., Dunn, G., & Kuipers, E. (2008). Cognitive--behavioural therapy and family intervention for relapse prevention and symptom reduction in psychosis: randomised controlled trial. *Br J Psychiatry, 192*(6), 412-423.

George, R., & Howell, C. (1996). Clients with schizophrenia and their caregivers perceptions of frequent psychiatric hospitalisation. *Issues in Mental Health Nursing, 17*, 573-588.

Gibb, J. (1990). *The Hope Scale Revisited: Further validation of a measure of individual differences in the hope motive.*, University of Ilinois at Urbana-Champaign.

Giffort, D., Schmook, A., Woody, C., Vollendorf, C., & Gervain, M. (1995). Recovery Assessment Scale. Chicago, IL: Illinois Department of Mental Health.

Girden, E. (2001). *Evaluating Research Articles*. Thousand Oaks: Sage Publications.

Girón, M., Fernández-Yañeza, A., Mañá-Alvarengaa, S., Molina-Habasa, A., Nolascoa, A., & Gómez-Beneytoa, M. (2009). Efficacy and effectiveness of individual family intervention on social and clinical functioning and family burden in severe schizophrenia: a 2-year randomized controlled study *Psychological Medicine*, 1 -12.

Gleeson, J. F., Cotton, S. M., Alvarez-Jimenez, M., Wade, D., Crisp, K., Newman, B., et al. (2010). Family outcomes from a randomized control trial of relapse prevention therapy in first-episode psychosis. *J Clin Psychiatry, 71*(4), 475-483.

Glynn, S. M., . , Cohen, A. N., & et al. (2007). New challenges in family interventions for schizophrenia. *Expert Rev Neurother, 7*(1), 33-43.

Goldberg, D. P., & Hillier, V. F. (1979). A scaled version of the General Health Questionnaire. *Psychological Medicine, 9*, 139-145.

Goldberg, D. P., & Williams, P. (1988). *A user's guide to the General Health Questionnaire: GHQ*. Windsor: NFER-Nelson.

Goldstein, M. J., Rodnick, E. H., Evans, J. R., May, P. R., & Steinberg, M. R. (1978). Drug and family therapy in the aftercare of acute schizophrenics. *Arch Gen Psychiatry, 35*(10), 1169-1177.

Goodwin, S. (1989). Community care for the mentally ill in England Wales: myths, assumptions and reality. *Journal of Social Policy, 18*(1), 27-52.

Gottschalk, L. A. (1985). Hope and Other Deterrents to Illness. *American Journal of Psychotherapy, 39*(4), 515.

Gower, B. (1997). *Scientific Method: An Historical and Philosphical Introduction*. London: Routledge.

Green, R. S., & Gracely, E. J. (1987). Selecting a rating scale for evaluating services to the chronically mentally ill. *Community Mental Health Journal, 23*(2), 91-102.

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: systematic review and recommendations. *Milbank Q, 82*(4), 581-629.

Groom, G., Hickie, I., & Davenport, T. (2003). *Out of hospital, out of mind. A report detailing Mental Health Services in Australia in 2002 and Community Priorities for National Mental Health Policy for 2003-2008*. Canberra: Mental Health Council of Australia.

Guerin, P. J. (1976). Family therapy - the first twenty five years. In P. J. Guerin (Ed.), *Family therapy: Theory and Practice*. New York: Gardner Press.

Gutierrez-Maldonado, J., Caqueo-Urizar, A., & Ferrer-Garcia, M. (2009). Effects of a psychoeducational intervention program on the attitudes and health perceptions of relatives of patients with schizophrenia. *Soc Psychiatry Psychiatr Epidemiol, 44*(5), 343-348.

Hale, W. D., Fiedler, L. R., & Cochran, C. D. (1992). The revised Generalized Expectancy for Success Scale: A validity and reliability study. *Journal of Clinical Psychology*.

Hambridge, J. A., & Rosen, A. (1994). Assertive community treatment for the seriously mentally ill in suburban Sydney: A programme description and evaluation. *Australian and New Zealand Journal of Psychiatry, 28*, 438-445.

Hamden, A., Newton, R., McCauley-Elsom, K., & Cross, W. (2011). Is deinstitutionalization working in our community? *International Journal of Mental Health Nursing, 20*(4), 274-283.

Harris, C. (1988). *Hope: Construct defintion and the development of an individual differences scale.* University of Kansas, Lawrence.

Harvey, C., H. Killaspy, Martino, S., & Johnson, S. (2011). Implementation of assertive community treatment in Australia: Model fidelity, patient characteristics and staff experiences. *Community and Mental Health Journal, November*(On line).

Harvey, C., O'Hanlon, B., & Leggat, M. (2004a). *NICS Report: Evidence uptake networks in Health Care, Final report Phase 1, Identifying Evidence Practice Gaps*. Melbourne: Psychosocial Research Centre.

Harvey, C., O'Hanlon, B., & Leggat, M. (2004b). *NICS Report: Evidence uptake networks in Health Care, Final report Phase 2, Closing Gaps*. Melbourne: Psychosocial Research Centre.

Harvey, C., & O'Hanlon, B. (2013). Family psycho-education for people with schizophrenia and other psychotic disorders and their families. *Australian and New Zealand Journal of Psychiatry, early on-line*.

Harvey, C., O'Hanlon, B., Leggat, M., Farhall, J., Juriansz, D., Burger, J., et al. (2007). *Building Family Skills Together: An implementation strategy for evidence-based family interventions in public mental health services.* Paper presented at the TheMHS Conference 2007: 2020 Vision - Looking towards excellence in mental health care in 2020, Melbourne, Australia.

Hatfield, A. B., & Lefley, H. P. (1993). Events leading to recovery *Surviving mental illness* (pp. 131-142). New York: Guilford Press.

Hatfield, A. B., & Lefley, H. P. (1993). *Surviving mental illness*. New York: Guilford Press.

Hatfield, A. B., Spaniol, L., & Zipple, A. M. (1997). Expressed Emotion: A family Perspective. *Schizophr Bull, 13*(2), 221-226.

Hawthorne, G. (2006). Measuring social isolation in older adults: development and initial validation of the friendship scale. *Social Indicators Research, 77*, 521-548.

Hawthorne, G. (2007). Chapter 3: Study Design in Evaluation Research *Public Health Evaluation*. Melbourne: University of Melbourne.

Hawthorne, G. (2008). Perceived social isolation in a community sample: its prevalance and correlates with aspects of people's lives. *Social Psychiatry and Psychiatric Epidemiology, 43*(2), 140-150.

Hawthorne, G., & Elliott, P. (2005). Imputing cross-sectional missing data: comparison of common techniques. *Australian & New Zealand Journal of Psychiatry, 39*(7), 583-590.

Hawthorne, G., Herrman, H., & Murphy, B. (2006). Interpreting the WHOQOL-Bref: preliminary population norms and effect sizes. *Social Indicators Research, 77*(1), 37-59.

Hayes, L., Harvey, C., & Farhall, J. (2013). Family psychoeducation for the treatment of psychosis. *InPsych, 35*(2), 16-17.

Hayes, L., Harvey, C., Hawthorne, G., & Perlesz, A. (2007). *Between a rock and a hard place - the care-giving experience of family members living with a relative having schizophrenia.* Paper presented at the TheMHS Conference 2007: 2020 Vision - Looking towards excellence in mental health care in 2020, Melbourne, Australia.

Hayes, L., Hawthorne, G., Farhall, J., O'Hanlon, B., & Harvey, C. (in submission). Quality of life and social isolation among caregivers of adults with schizophrenia: matched comparisons and historical contrasts. *Community Mental Health Journal*.

Hazel, N. A., McDonell, M. G., Short, R. A., Berry, C. M., Voss, W. D., Rodgers, M. L., et al. (2004). Impact of multiple-family groups for outpatients with schizophrenia on caregivers' distress and resources. *Psychiatr Serv, 55*(1), 35-41.

Headey, & Wearing, A. J. (1992). *Understanding Happiness*. Melbourne: Longman Chesire.

Hellman, C., Pittman, M., & Munoz, R. (2012). The First Twenty Years of the Will and the Ways: An Examination of Score Reliability Distribution on Snyder's Dispositional Hope Scale. *Journal of Happiness Studies*, 1-7.

Heppner, P. P., & Petersen, C. H. (1982). The development and implications of a personal problem-solving inventory. *Journal of Counseling Psychology, 29*(1), 66.

Herth, K. (1992). Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing, 17*(10), 1251-1259.

Hoenig, J., & Hamilton, M. W. (1966). The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry, 12*(3), 165-176.

Hoffmann, H., Kupper, Z., & Kunz, B. (2000). Hopelessness and its impact on rehabilitation outcome in schizophrenia -an exploratory study *Schizophrenia Research, 43* (2-3), 147-158.

Hogan, T. P., Awad, A. G., & Eastwood, R. (1983). A self-report scale predictive of drug compliance in schizophrenics: Reliability and discriminative validity. *Psychological Medicine, 13*, 177-183.

Hogarty, G. E., Anderson, C. M., Reiss, D. J., Kornblith, S. J., Greenwald, D. P., Javna, C. D., et al. (1986). Family psychoeducation, social skills training, and maintenance chemotherapy in the aftercare treatment of schizophrenia. I. One-year effects of a controlled study on relapse and expressed emotion. *Arch Gen Psychiatry, 43*(7), 633-642.

Holleran, S. A., & Snyder, C. R. (1990). *Discriminant and convergent validation of the Hope Scale*. Unpublished manuscript: University of Kansas, Lawrence.

Hooley, J. M., & Parker, H. A. (2006). Measuring expressed emotion: An evaluation of the shortcuts. *Journal of family psychology, 20*(3), 386-396.

Hornung, W. P., Feldmann, R., Klingberg, S., Buchkremer, G., & Reker, T. (1999). Long-term effects of a psychoeducational psychotherapeutic intervention for schizophrenic outpatients and their key-persons--results of a five-year follow-up. *Eur Arch Psychiatry Clin Neurosci, 249*(3), 162-167.

Horowitz, R. (2008). Hope and expectation in the psychotherapy of the long-term mentally ill. *Bulletin of the Menninger Clinic, 72*(4), 237-258.

Howard, L., de Salis, I., Tomlin, Z., Thornicroft, G., & Donovan, J. (2009). Why is recruitment to trials difficult? An investigation into recruitment difficulties in an RCT of supported employment in patients with severe mental illness. *Contemp Clin Trials, 30*(1), 40-46.

Howitt, D., & Cramer, D. (2008a). *Introduction to Research Methods in Psychology* (4th ed.). Harlow, UK: Pearson.

Howitt, D., & Cramer, D. (2008b). *Introduction to Statistics in Psychology* (4th ed.). Harlow, UK: Pearson.

Hubble, M. A., Duncan, B. L., & Miller, S. D. (1999a). Introduction. In M. A. Hubble, B. L. Duncan & S. D. Miller (Eds.), *The heart and soul of change: what works in therapy*. Washington: American Psychological Association.

Hubble, M. A., Duncan, B. L., & Miller, S. D. (Eds.). (1999b). *The heart and soul of change: what works in therapy*. Washington: American Psychological Association.

Irving, L. M., Snyder, C. R., Cheavens, J., Gravel, L., Hanke, J., Hilberg, P., et al. (2004). The Relationships Between Hope and Outcomes at the Pretreatment, Beginning, and Later Phases of Psychotherapy. *Journal of Psychotherapy Integration, 14*(4, Dec), 419-443

Jager, A. (1999). Patient v. client. *The British Journal of Psychiatry.*, 174: 180.

Kabacoff, R., Miller, I., Bishop, D., Epstein, N., & Keitner, G. (1990). A psychometric study of the McMaster Family Assessment Device in psychiatric, medical and nonclinical samples. *Journal of Family Psychology, 3*, 431-439.

Karanci, A. N. (1995). Caregivers of Turkish schizophrenic patients: causal attributions, burdens and attitudes to help from the health professionals. *Social Psychiatry and Psychiatric Epidemiology, 30*(6), 261-268.

Kavanagh, D. J., Piatkowska, O., Clark, D., O'Halloran, P., Manicavasagar, V., & Rosen, A. (1993). Application of cognitive-behavioural family intervention for schizophrenia in multidisciplinary teams: what can the matter be? *Australian Psychologist, 28*(3), 181-188.

Keller, S., & Hayes, R. (1998). The relationship between the Allen Cognitive Level Test and the Life Skills Profile. *American Journal of Occupational Therapy, 52*(10), 851-856.

Kellner, R., & Sheffield, B. F. (1971). The Relief of Distress following Attendance at a Clinic. *The British Journal of Psychiatry, 118*(543), 195-198.

Kendall, R. E., & Zealley, A. K. (Eds.). (1989). *Companion to Psychiatric Studies* (5 ed.). U.K.: Churchill Livingstone.

Knafl, G. J., Dixon, J. K., O'Malley, J. P., Grey, M., Deatrick, J. A., Gallo, A. M., et al. (2009). Analysis of cross-sectional univariate measurements for family dyads using linear mixed modeling. *Journal of family nursing, 15*(2), 130-151.

Kopelowicz, A., Liberman, R. P., Ventura, J., Zarate, R., & Mintz, J. (2005). Neurocognitive correlates of recovery from schizophrenia. *Psychological Medicine, 35*(8), 1165-1173.

Kopelowicz, A., Zarate, R., Wallace, C. J., Liberman, R. P., Lopez, S. R., & Mintz, J. (2012). The ability of multifamily groups to improve treatment adherence in Mexican Americans with schizophrenia. *Archives of General Psychiatry, 69*(3), 265-273.

Korner, I. N. (1970). Hope as a method of coping. *34*(2), 134-139.

Kreyenbuhl, J., Buchanan, R. W., Dickerson, F. B., & Dixon, L. B. (2010). The Schizophrenia Patient Outcomes Research Team (PORT): Updated treatment recommendations 2009. *Schizophrenia Bulletin, 36*(1), 94-103.

Kuhn, T. S. (1984). *The Structure of Scientific Revolutions*. Chicago: University of Chicago Press.

Kulhara, P., Chakrabarti, S., Avasthi, A., Sharma, A., & Sharma, S. (2009). Psychoeducational intervention for caregivers of Indian patients with schizophrenia: a randomised-controlled trial. *Acta Psychiatr Scand, 119*(6), 472-483.

Kwon, P. (2002). Hope, defense mechanisms, and adjustment: implications for false hope and defensive hopelessness. *J Pers, 70*(2), 207-231.

Kylma, J., Juvakka, T., Nikkonen, M., Korhonen, T., & Isohanni, M. (2006). Hope and schizophrenia: an integrative review *Journal of Psychiatric and Mental Health Nursing, 13*, 651-664.

Lammers, J., & Happell, B. (2004). Research involving mental health consumers and carers: a reference group approach. *Int J Ment Health Nurs, 13*(4), 262-266.

Landeen, J., Pawlick, J., Woodside, H., Kirkpatrick, H., & Byrne, C. (2000). Hope, quality of life, and symptom severity in individuals with schizophrenia. *Psychiatric Rehabilitation Journal, 23*(4), 364.

Lazarus, R. S. (1999). Hope: An Emotion and a Vital Coping Resource Against Despair. *Social Research*.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br J Psychiatry, 199*(6), 445-452.

Leff, J., Berkowitz, R., Shavit, N., Strachan, A., Glass, I., & Vaughn, C. (1990). A trial of family therapy versus a relatives' group for schizophrenia. Two-year follow-up. *British Journal of Psychiatry, 157*, 571-577.

Leff, J., Kuipers, L., Berkowitz, R., Eberlein-Vries, R., & Sturgeon, D. (1982). A controlled trial of social intervention in the families of schizophrenic patients. *Br J Psychiatry, 141*, 121-134.

Lefley, H. P. (1997). The consumer recovery vision: will it alleviate family burden? *Am J Orthopsychiatry, 67*(2), 210-219.

Leggatt, M. (2001). Carers and carer organizations. In G. Thornicroft & G. Szmukler (Eds.), *Textbook of Community Psychiatry* (pp. 476-486). New York: Oxford University Press.

Liberman, R. P. (1970). Behavioural approaches to family and couple therapy. *American Journal of Orthopsychiatry, 40*, 106-118.

Liberman, R. P. (2002). Future directions for research studies and clinical work on recovery from schizophrenia: Questions with some answers. *International Review of Psychiatry, 14*(4), 337-342.

Liberman, R. P., & Kopelowicz, A. (2005). Recovery From Schizophrenia: A Concept in Search of Research. *Psychiatr Serv, 56*(6), 735-742.

Liberman, R. P., Kopelowicz, A., Ventura, J., & Gutkind, D. (2002). Operational criteria and factors related to recovery from schizophrenia. *International Review of Psychiatry, 14*(4), 256 - 272.

Linszen, D., Dingemans, P., van der Does, J. W., Nugter, A., Scholte, P., Lenior, R., et al. (1996). Treatment, expressed emotion, and recent relapse in recent onset schizophrenic disorders. *Psychological Medicine, 26*, 333 - 342.

Littrell, K. H., & Herth, K. A. (1996). The experience of hope in adults with schizophrenia. *Psychiatric Rehabilitation Journal, 19*(4).

Lloyd, C., & Bassett, J. (1997). Life is for living: A pre-vocational programme for young people with psychosis. *Australian Occupational Therapy Journal, 44*(2), 82-87.

Lloyd, C., & King, R. (2003). Consumer and carer participation in mental health services. *Australasian Psychiatry, 11*(2), 180-184.

Lloyd, C., King, R., Bassett, H., Sandland, S., & Savige, G. (2001). Patient, client or consumer? A survey of preferred terms. . *Australasian Psychiatry., 9*(4), 321-324.

Loveland, D., Randall, K. W., & et al. (2005). Research methods for exploring and assessing recovery. In R. R. O. & P. W. Corrigan (Eds.), *Recovery in Mental Illness: Broadening our understanding of wellness*. Washington D.C: American Psychological Association.

Lysaker, P. H., Buck, K. D., Hammoud, K., Taylor, A. C., & Roe, D. (2006). Associations of symptoms, psychosocial function and hope with qualities of self-experience in schizophrenia: Comparisons of objective and subjective indicators of health. *Schizophrenia Research, 82*(2-3), 241-249.

Lysaker, P. H., Campbell, K., & Johannesen, J. K. (2005). Hope, Awareness of Illness, and Coping in Schizophrenia Spectrum Disorders: Evidence of an Interaction. *J Nerv Ment Dis, Volume . 193*((5).May), 287-292.

Lysaker, P. H., Davis, L. W., & Hunter, N. L. (2004). Neurocognitive, social and clinical correlates of two domains of hopelessness in schizophrenia. *Schizophrenia Research, 70*(2-3), 277-285.

Lysaker, P. H., Roe, D., & Yanos, P. T. (2007). Toward Understanding the Insight Paradox: Internalized Stigma Moderates the Association Between Insight and Social Functioning, Hope, and Self-esteem Among People with Schizophrenia Spectrum Disorders *Schizophrenia Bulletin, 33*(1), 192-199.

Lysaker, P. H., Salyers, M. P., Tsai, J., Spurner, L. Y., & Davis, L. W. (2008). Clinical and psychological correlates of two domains of hopelessness in schizophrenia. *Journal of Rehabilitation Research & Development, 45*(6), 911-919.

MacInnes, D. L., & Watson, J. P. (2002). The differences in perceived burdens between forensic and non-forensic caregivers of individuals suffering from schizophrenia. *Journal of Mental Health, 11*(4), 375-388.

MacKinnon, D. P. (1994). Analysis of mediating variables in prevention and intervention research. *NIDA research monograph, 139*, 127-127.

MacKinnon, D. P., & Dwyer, J. H. (1993). Estimating mediated effects in prevention studies. *Evaluation Review, 17*(2), 144-158.

Magaletta, P. R., & Oliver, J. M. (1999). The hope construct, will, and ways: Their relations with self-efficacy, optimism, and general well-being. *Journal of Clinical Psychology, 55*(5), 539-551.

Magliano, L., Fiorillo, A., Fadden, G., Gair, F., Economou, M., Kallert, T., et al. (2005). Effectiveness of a psychoeducational intervention for families of patients with schizophrenia: preliminary results of a study funded by the European Commission. *World Psychiatry, 4*(1), 45-49.

Magliano, L., Fiorillo, A., Malangone, C., De Rosa, C., & Maj, M. (2006a). Implementing psychoeducational interventions in Italy for patients with schizophrenia and their families. *Psychiatr Serv, 57*(2), 266-269.

Magliano, L., Fiorillo, A., Malangone, C., De Rosa, C., & Maj, M. (2006b). Patient functioning and family burden in a controlled, real-world trial of family psychoeducation for schizophrenia. *Psychiatr Serv, 57*(12), 1784-1791.

Magnabosco, J. L. (2006). Innovations in mental health services implementation: a report on state-level data from the US Evidence-Based Practices Project. *Implementation Science, 1*(13), 13.

Mak, K., Wong, M., Ma, L., & Fung, S. (1997). A cost effectiveness study of a community-based family management rehabilitation programme for schizophrenic outpatients in Hong Kong: A six month report. *Hong Kong Journal of Psychiatry, 7*(2), 26-35.

Marshall, M., Lockwood, A., Bradley, C., Adams, C., Joy, C., & Fenton, M. (2000). Unpublished rating scales: a major source of bias in randomised controlled trials of treatments for schizophrenia. *Br J Psychiatry, 176*, 249-252.

Marshall, S., Crowe, T., Oades, L., Deane, F., & Kavanagh, D. (2007). A review of consumer involvement in evaluations of case management: consistency with a recovery paradigm. *Psychiatric Services, 58*(3), 396-401.

McCreadie, R. G. (2001). Effects of schizophrenia on patients' relatives. *British Journal of Psychiatry, 178*, 575.

McCreadie, R. G., Phillips, K., Harvey, J. A., Waldron, G., Stewart, M., & Baird, D. (1991). The Nithsdale Schizophrenia Surveys. VIII: Do relatives want family interventions - and does it help? *British Journal of Psychiatry, 158*, 110-113.

McDonell, M. G., Short, R. A., Berry, C. M., & Dyck, D. G. (2003). Burden in schizophrenia caregivers: impact of family psychoeducation and awareness of patient suicidality. *Fam Process, 42*(1), 91-103.

McFarlane, W., Lynch, S., & Melton, R. (2012). Family psychoeducation in clinical high risk and first-episode psychosis. *Adolescent Psychiatry, 2*, 1-13.

McFarlane, W. R., Dushay, R. A., Deakins, S. M., Stastny, P., Lukens, E. P., Toran, J., et al. (2000). Employment outcomes in family-aided assertive community treatment. *American Journal of Orthopsychiatry, 70*(2), 203-214.

McFarlane, W. R., Dushay, R. A., Stastny, P., Deakins, S. M., & Link, B. (1996). A comparison of two levels of family-aided assertive community treatment. *Psychiatric Services, 47*(7), 744-750.

McFarlane, W. R., Link, B., Dushay, R., Marchal, J., & Crilly, J. (1995). Psychoeducational multiple family groups: Four-year relapse outcome in schizophrenia. *Family Process, 34*, 127-144.

McFarlane, W. R., Lukens, E., Link, B., Dushay, R., Deakins, S., Newmark, M., et al. (1995). Multiple-family groups and psychoeducation in the treatment of schizophrenia. *Archives of General Psychiatry, 52*(8), 679-687.

McGorry, P. (2005). Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of schizophrenia and related disorders. *Australian and New Zealand Journal of Psychiatry, 39*, 1-30.

McKenzie, P. (2006). The holding of hope: exploring the relevance of the recovery vision for carer/families. *New paradigm: The Australian Journal of Psychosocial Rehabilitation, September*, 22.

McKenzie, P. (2007). *The holding of hope and working towards family recovery.* Paper presented at the TheMHS Conference 2007: 2020 Vision - Looking towards excellence in mental health care in 2020, Melbourne, Australia.

McLaughlin, H. (2008). What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User'-What's Next? *British Journal of Social Work Advance Access, 0*(Published online on February 21, 2008), 1-17.

McNair, D. M., Lorr, M., & Droppleman, L. F. (1981). *Manual for the Profile of Mood States*. San Diego, California: Educational & Industrial Testing Service.

Mead, S., & Copeland, M. E. (2000). What Recovery Means to Us: Consumers' Perspectives. *Community Mental Health Journal, 36*(3), 315-328.

Meehl, P. E. (1990). Why summaries of research on psychological theories are often uninterpretable. *Psychological Reports, 66*(1), 195-244.

Menninger, K. (1959). The academic lecture on hope. *American Journal of Psychiatry, 116*(6), 481-491.

Merinder, L. B., Viuff, A. G., Laugesen, H. D., Clemmensen, K., Misfelt, S., & Espensen, B. (1999). Patient and relative education in community psychiatry: a randomized controlled trial regarding its effectiveness. *Social Psychiatry And Psychiatric Epidemiology, 34*(6), 287-294.

Miller, I., Bishop, D., Epstein, N. B., & Keitner, G. (1990). A Psychometric study of the McMaster FAmily Assessment Device in Psychiatric, Medical and Nonclinical samples. *JOURNAL OF FAMILY PSYCHOLOGY, 3*(4), 431-439.

Miller, I. V., Epstein, N. B., Bishop, D. S., & Keitner, G. I. (1985.). The McMaster Family Assessment Device: Reliability and validity. . *Journal of Marital and Family Therapy, 11*, 345-356.

Miller, J., & Powers, M. (1988). Development of an instrument to measure hope. *Nursing research, 37*, 6-10.

Moffatt, S., White, M., Mackintosh, J., & Howel, D. (2006). Using quantitative and qualitative data in health services research - what happens when mixed method findings conflict? . *BMC Health Services Research, 6*, 28.

Montero, I., Asencio, A., Hernandez, I., Masanet, M. J., Lacruz, M., & Bellver, F., et al. . (2001). Two strategies for family intervention in schizophrenia: a randomized trial in a Mediterranean environment. *Schizophr Bull,, 27*(4), 661-670.

Montero, I., Asencio, A., Ruiz, I., & Hernandez, I. (1999). Family interventions in schizophrenia: An analysis of non-adherence. *Acta Psychiatrica Scandinavica, 1000*, 136-141.

Moore, A. D., Stambrooke, M., Peters, L. C., & Lubusko, A. (1991). Family coping and marital adjustment after traumatic brain injury. *Journal of Head Trauma Rehabilitation, 6*(1), 83-89.

Moraitou, D., Kolovou, C., Papasozomenou, C., & Paschoula, C. (2006). Hope and Adaptation to Old Age: Their Relationship with Individual-Demographic Factors. *Social Indicators Research, 76*(1), 71-93.

Morgan, A., Waterreus, A., Jablensky, A., Mackinnon, A., McGrath, J., Carr, V., et al. (2012). People living with psychotic illness in 2010: The second Australian national survey of psychosis. *Australia and New Zealand Journal of Psychiatry, 46*(8), 735-752.

Morgan, V., Waterreus, A., Jablensky, A., Mackinnon, A., McGrath, J., Carr, V., et al. (2011). *People living with psychotic illness 2010: Report on the second Australian national survey*. Canberra: Commonwealth of Australia.

Morgan, V., Waterreus, A., Jablensky, A., Mackinnon, A., McGrath, J., Carr, V., et al. (2012). People living with psychotic illness in 2010. An overview of findings from the second Australian national survey of psychosis. *Australian and New Zealand Journal of Psychiatry, 46*(8), 735-752.

Morrison, D. (2004). Best Practices: Real-World Use of Evidence-Based Treatments in Community Behavioral Health Care. *Psychiatric Services, 55*(5), 485-487.

Mueser, K. T. (2012). Evidence-based practices and recovery-oriented services: Is there a relationship? Should there be one? *Psychiatric Rehabilitation Journal, 35*(4), 287-288.

Mueser, K. T., Deavers, F., Penn, D. L., & Cassisi, J. E. (2013). Psychosocial Treatments for Schizophrenia. *Clinical Psychology, 9*(1), 465.

Mueser, K. T., Webb, C., Pfeiffer, M., Gladis, M., & Levinson, D. F. (1996). Family burden of schizophrenia and bipolar disorder: Perceptions of relatives and professionals. *Psychiatric Services, 47*(5), 507-511.

Munoz-Dunbar, R. (1993). *Hope: A cross-cultural assessment of American college students.*, University of Kansas, Lawrence.

Nair, B. (1998). Patient, client or customer? *Medical Journal of Australia, 16*, 593.

National Collaborating Centre for Mental Health. (2002). *Schizophrenia: core interventions in the treatement and management of schizophrenia in primary and secondary care. Clinical Guideline1*. London: National Institute for Clinical Excellence.

National Institute for Health and Clinical Excellence. (2009). *Schizophrenia: Core interventions in the treatment and management of schizophrenia in adults in primary and secondary care.* London: National Collaborating Centre for Mental Health.

Nilsen, E., Myrhaug, H., Johansen, M., Oliver, S., & Oxman, A. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database Syst Rev, 3*.

Noh, C., Choe, K., & Yang, B. (2008). Hope From the Perspective of People with Schizophrenia (Korea). *Archives of Psychiatric Nursing, 22*(2), 69-77.

Noh, S., & Turner, R. J. (1987). Living with psychiatric patients: implications for the mental health of family members. *Social Sciences and Medicine, 25*(3), 263-271.

Noiseux, S., & Ricard, N. (2008). Recovery as perceived by people with schizophrenia, family members and health professionals: A grounded theory. *International Journal of Nursing Studies, 45*(8), 1148-1162.

Noordsy, D., Torrey, W., Mueser, K., Mead, S., O'Keefe, C., & Fox, L. (2002). Recovery from severe mental illness: an intrapersonal and functional outcome definition. *International Review of Psychiatry, 14*(4), 318-326.

Nordentoft, M., Thorup, A., Petersen, L., Ohlenschlaeger, J., Melau, M., Christensen, T. O., et al. (2006). Transition rates from schizotypal disorder to psychotic disorder for first-contact patients included in the OPUS trial. A randomized clinical trial of integrated treatment and standard treatment. *Schizophr Res, 83*(1), 29-40.

Nowotny, M. L. (1989). Assessment of hope in patients with cancer: development of an instrument. *Oncol Nurs Forum, 16*(1), 57-61.

Nunn, K. P., Lewin, T. J., Walton, J. M., & Carr, V. J. (1996). The construction and characteristics of an instrument to measure personal hopefulness. *Psychological medicine, 26*, 531-545.

O'Hanlon, B. (2008). BFT practitioner is more like a coach than expert. In L. Hayes (Ed.). Melbourne.

O'Hanlon, B. (2013). *PhD Thesis in preparation: Implementing Behavioural Family Therapy in a Continuing Care Team: A Process Evaluation of the Building Family Skills Together Initiative*. Melbourne: The Bouverie Centre, Latrobe University.

O'Hanlon, B., C. , Harvey, C., & et al. (2012). *Building Family Skills Together, Key learning from a project that aimed to implement an evidence -based family intervention in the Continuing Care Team of an Adult Mental Health Service.* Paper presented at the Australian Implementation Conference.

O'Hanlon, B., Perlesz, A., & et al. (2007). *This is fantastic but... ': Mental health staff experiences of using a family intervention in routine practice*. Paper presented at the World Psychiatric Association Congress.

Ohaeri, J. U. (2003). The burden of caregiving in families with a mental illness: a review of 2002. *Current Opinion in Psychiatry, 16*(4), 457 - 465.

Olesen, S. C., Butterworth, P., & Leach, L. (2010). Prevalence of self-management versus formal service use for common mental disorders in Australia: findings from the 2007 National Survey of Mental Health and Wellbeing. *Australian and New Zealand Journal of Psychiatry, 44*(9), 823-830.

Pai, S., & Kapur, R. L. (1981). The burden on the family of a psychiatric patient: Development of an Interview Schedule. *British Journal of Psychiatry, 138*, 332-335.

Pajonk, F.-G. (2005). Clinical trial design in schizophrenia: implications for clinical decisions. *Curr Opin Psychiatry, 18*(6), 692-699.

Parker, G., O'Donnell, M., Hadzi-Pavlovic, D., & Proberts, M. (2002). Assessing outcome in community mental health patients: A comparative analysis of measures. *International Journal of Social Psychiatry, 48*(1), 11-19.

Parker, G., Rosen, A., Emdur, N., & Hadzi-Pavlovic, D. (1991). The Life Skills Profile: psychometric properties of a measure assessing function and disability in schizophrenia. *Acta Psychiatrica Scandinavica, 83*(2), 145-152.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed ed.). Thousand Oaks, Calif: Sage Publications.

Pearsall, J. (Ed.). (1999). *The concise Oxford dictionary.* Oxford: Oxford University Press.

Pejlert, A. (2001). Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. *Health Soc Care Community, 9*(4), 194-204.

Perlesz, A. (1999). Complex responses to trauma: Challenges in bearing witness. *Australian and New Zealand Journal of Family Therapy, 20*(1), 11.

Perneger, T. V. (1998). What's wrong with Bonferroni adjustments. *British Medical Journal, 316*, 1236-1238.

Peterson, C., Semmel, A., von Baeyer, C., Abramson, L. Y., Metalsky, G. I., & Seligman, M. E. (1982). The attributional style questionnaire. *Cognitive therapy and research, 6*(3), 287-299.

Pharoah, F., Mari, J., Rathbone, J., & Wong, W. (2010). Family intervention for schizophrenia: 2010 update. *Cochrane Database of Systematic Reviews 2006*(4).

Pharoah, F. M., Mari, J. J., & Streiner, D. (2004). *Family intervention for schizophrenia (Cochrane Review)*. Chichester, UK: John Wiley & Sons Ltd.

Pilgrim, D. (2008). 'Recovery' and current mental health policy. *Chronic Illness, 4*(4), 295-304.

Pilling, S., Bebbington, P., Kuipers, E., Garety, P., Geddes, J., Orbach, G., et al. (2002). Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy. *Psychological Medicine, 32*(5), 763-782.

Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T., & Johnston, A. (2010). Who cares? A profile of people who care for relatives with a mental disorder. *Aust N Z J Psychiatry, 44*(10), 929-937.

Pitschel-Walz, G., Leucht, S., Bauml, J., Kissling, W., & Engel, R. R. (2001). The effect of family interventions on relapse and rehospitalization in schizophrenia - A meta-analysis. *Schizophrenia Bulletin, 27*(1), 73-92.

Plastow, M. (2010). The intrusion of the discourse of economics into the clinical space I: from patient to consumer. *Australas Psychiatry, 18*(4), 298-302.

Pols, H., & Oak, S. (2011). Mental Health in Australia: Current State and New Directions. *International Journal of Mental Health, 40*(2), 3-7.

Posner, C. M., Wilson, K. G., Kral, M. J., Lander, S., & McIlwraith, R. D. (1992). Family psychoeducational support groups in schizophrenia. *American Journal of Orthopsychiatry, 62*(2), 206-218.

Price, K., & Taylor, A. (2008). Qualitative and quantitative research – the ‘yin and yang’ of epidemiological research? *Social Science and Medicine., 40*(4), 459-468.

Priebe, S., Oliver, J. P. J., & Kaiser, W. (1999). *Quality of life and mental health care*: Wrightson Biomedical Pub.

Prochaska, J. O., & diClemente, C. (1982). Transtheoretical therapy: toward a more integrative model of change. *Psychotherapy: Theory, Research and Practice 19*, 276-278.

Psychosocial Research Centre. (2010). *Evaluation of the Building Family Skills Together Mind: An evaluation of program implementation and outcomes for families*. Melbourne: MIND.

Ralph, R. O., Kidder, K., Muskie, E., & Phillips, D. (2000). *Can we measure recovery? A compendium of recovery and recovery-related instruments*. Cambridge, MA: Evaluation Center.

Ramon, S., Healy, B., & Renouf, N. (2007). Recovery from mental illness as an emergent concept and practice in Australia and the UK. *International Journal of Social Psychiatry, 53*(2), 108-122.

Randolph, E., Eth, S., Glynn, S., Paz, G., Leong, G., Shaner, A., et al. (1994). Behavioural family management in schizophrenia outcome of a clinic-based intervention. *British Journal of Psychiatry, 164*, 501-506.

Reber, A. S. (1985). *Dictionary of psychology*. Harmondsworth: Penguin.

Resnick, S. G., Fontana, A., Lehman, A. F., & Rosenheck, R. A. (2005). An empirical conceptualization of the recovery orientation. *Schizophrenia Research, 75*(1), 119-128.

Resnick, S. G., Rosenheck, R. A., & Lehman, A. F. (2004). An exploratory analysis of correlates of recovery. *Psychiatr Serv, 55*(5), 540-547.

Riedel, M., Strassnig, M., Muller, N., Zwack, P., & Moller, H. J. (2005). How representative of everyday clinical populations are schizophrenia patients enrolled in clinical trials? *Eur Arch Psychiatry Clin Neurosci, 255*(2), 143-148.

Roberts, G., & Wolfson, P. (2004). The rediscovery of recovery: open to all. *Advances in Psychiatric Treatment, 10*(1), 37-48.

Roncone, R., Mazza, M., Ussorio, D., Pollice, R., Falloon, I., Morosini, P., et al. (2007). The questionnaire of family functioning: A preliminary validation of a standardized instrument to evaluate psychoeducational family treatments. *Community Mental Health Journal, 43*(6), 591-607.

Rosen, A., Hadzi-Pavlovic, D., & Parker, G. (1989). The Life Skills Profile: A measure assessing function and disability in schizophrenia. *Schizophrenia Bulletin, 15*(2), 325-337.

Rosenberg, S., Hickie, I. B., & Mendoza, J. (2009). National mental health reform: less talk, more action. *Medical Journal of Australia, 190*(4), 193-195.

Rossi, P. H., Lipsey, M. W., & Freeman, H. E. (2004). *Evaluation : a systematic approach*. Thousand Oaks, CA: Sage.

Rothman, K. J. (1990). No adjustments are needed for Multiple comparisons. *Epidemiology, 1*(1), 43-46.

Rothwell, P. M. (2005). External validity of randomised controlled trials: "to whom do the results of this trial apply?". *Lancet, 365*(9453), 82-93.

Rudnick, A. (2008). Recovery from Schizophrenia: A Philosophical Framework. *American Journal of Psychiatric Rehabilitation, 11*(3), 267 - 278.

Rund, B. R., Moe, L., Sollien, T., Fjell, A., Borchgrevink, T., Hallert, M., et al. (1994). The Psychosis Project: outcome and cost-effectiveness of a psychoeducational treatment programme for schizophrenic adolescents. *Acta Psychiatr Scand, 89*(3), 211-218.

Ruvelson, L. (1990). The tense tightrope: How patients and their therapists balance hope and hopelessness. *Clinical Social Work Journal, 18*(2), 145-154.

Salyers, M., & Macy, V. (2005). Recovery-Oriented Evidence-Based Practices: A Commentary. *Community Mental Health Journal, 41*(1), 101-103.

Scheier, M., & Carver, C. S. (1985). Optimism, coping and health: Assessment and implications of generalised outcome expectancies. *Health Psychology 4*, 219-247

Scheier, M., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A reevaluation of the Life Orientation Test. *Journal of Personality and Social Psychology 67*(6), 1063-1078

Schene, A. H. (1990). Objective and subjective dimensions of family burden. Towards an integrative framework for research. *Soc Psychiatry Psychiatr Epidemiol, 25*(6), 289-297.

Schene, A. H., Tessler, R. C., & Gamache, G. M. (1994). Instruments measuring family or caregiver burden in severe mental illness. *Soc Psychiatry Psychiatr Epidemiol, 29*(5), 228-240.

Schene, A. H., van Wijngaarden, B., & Koeter, M. W. (1998). Family caregiving in schizophrenia: domains and distress. *Schizophr Bull, 24*(4), 609-618.

Schooler, N. R., Keith, S. J., Severe, J. B., Matthews, S. M., Bellack, A. S., Glick, I. D., et al. (1997). Relapse and rehospitalization during maintenance treatment of schizophrenia. The effects of dose reduction and family treatment. *Archives of General Psychiatry, 54*, 453-463.

Schrank, B., Bird, V., Rudnick, A., & Slade, M. (2012). Determinants, self-management strategies and interventions for hope in people with mental disorders: Systematic search and narrative review. *Social Science & Medicine*.

Schrank, B., & Slade, M. (2007). Recovery in psychiatry. *Psychiatric Bulletin, 31*(9), 321-325.

Schrank, B., Stanghellini, G., & Slade, M. (2008). Hope in psychiatry: a review of the literature. *Acta Psychiatrica Scandinavica, 118*(6), 421-433.

Schrank, B., Woppmann, A., Hay Grant, A., Sibitz, I., Zehetmayer, S., & Lauber, C. (2012). Validation of the Integrative Hope Scale in people with psychosis. *Psychiatry Research*(0).

Scottish Intercollegiate Guidelines Network. (1998). *Psychosocial interventions in the management of schizophrenia. A national clinical guideline* (Vol. 30). Edinburgh.

Scull, A. (1986). The asylum as community or the community as asylum: Paradoxes and contradictions of mental health care. In P. Bean (Ed.), *Mental Illness: Changes and Trends.* England: John Wiley and Sons Ltd.

Sears, D. O. (1986). College sophomores in the laboratory: Influences of a narrow data base on social psychology's view of human nature. *Journal of Personality and Social Psychology, 51*(3), 515-530.

Secker, J., Membrey, H., Grove, B., & Seebohm, P. (2002). Recovering from illness or recovering your life? Implications of clinical versus social models of recovery from mental health problems for employment support services. *Disability & Society, 17*(4), 403-418.

Seligman, M. E., & Csikszentmihalyi, M. (2000). Positive psychology. An introduction. *Am Psychol, 55*(1), 5-14.

Seligman, M. E. P. (1998). *Learned Optimism*. New York: Pocket Books.

Sharkey, K., Savulescu, J., Aranda, S., & Schofield, P. (2010). Clinician gate-keeping in clinical research is not ethically defensible: an analysis. *J Med Ethics*.

Shawyer, F., Farhall, J., Mackinnon, A., Trauer, T., Sims, E., Ratcliff, K., et al. (2012). A randomised controlled trial of acceptance-based cognitive behavioural therapy for command hallucinations in psychotic disorders. *Behav Res Ther, 50*(2), 110-121.

Sherer, M., Maddux, J. E., & et al. (1982). The self-efficacy scale: Construction and validation. *Psychological Reports, 51*(2), 663 - 671.

Shorter, E. (1997). *A History of Psychiatry: From the era of the Asylum to the Age of Prozac.* U.S.A.: John Wiley and Sons, Inc.

Sieber, J. E. (1992). Voluntary informed consent and debriefing. In J. E. Sieber (Ed.), *Planning ethically responsible research. A guide for students and internal review boards* (Vol. 31, pp. 26-43). Newbury Park: Sage.

Sigmon, S. T., & Snyder, C. R. (1990). The independent contributions of positive and negative affect and hope in predicting psychological health. University of Kansas, Department of Psychology, Lawrence.

Silverstein, S. M., & Bellack, A. S. (2008). A scientific agenda for the concept of recovery as it applies to schizophrenia. *Clinical Psychology Review, 28*(7), 1108-1124.

Simmons, P., Hawley, C. J., Gale, T. M., & Sivakumaran, T. (2010). Service user, patient, client, user or survivor: describing recipients of mental health services. *The Psychiatrist, 34*(1), 20-23.

Singh, B. (2008). Reflections on 40 years of involvement in 'community and politics' in psychiatry. *Australasian Psychiatry, 17*(3), 185-188.

Skinner, E. A. (1996). A guide to constructs of control. *Journal of Personality and Social Psychology, 71*(3), 549-570.

Slade, M. (2009). 100 ways to support recovery: a guide for mental health professionals, *Rethink Recovery Series* (Vol. 1).

Slade, M. (2009). *Personal recovery and mental illness: a guide for mental health professionals* (Vol. 34): Cambridge University Press Cambridge.

Slade, M. (2010). Mental illness and well-being: the central importance of positive psychology and recovery approaches. *BMC Health Serv Res, 10*, 26.

Slade, M. (2012). Recovery research: the empirical evidence from England. *World Psychiatry, 11*(3), 162-163.

Slade, M. (2012). Recovery: past progress and future challenges. *International Review of Psychiatry, 24*, 1-4.

Slade, M., Bird, V., Le Boutillier, C., Williams, J., McCrone, P., & Leamy, M. (2012). REFOCUS Trial: protocol for a cluster randomised controlled trial of a pro-recovery intervention within community based mental health teams. *BMC Psychiatry, 11*, 185.

Slade, M., Leamy, M., Bacon, F., Janosik, M., Le Boutillier, C., Williams, J., et al. (2012). International differences in understanding recovery: systematic review. *Epidemiol Psychiatr Sci*, 1-12.

Smith, C., Haynes, K. N., Lazarus, R. S., & Pope, L. K. (1993). In search of the "hot" cognitions: Attributions, appraisals, and their relation to emotion. *Journal of Personality and Social Psychology 65*(5), 916-929.

Smith, T. W., Pope, M. K., Rhodewalt, F., & Poulton, J. L. (1989). Optimism, neuroticism, coping, and symptom reports: an alternative interpretation of the Life Orientation Test. *J Pers Soc Psychol, 56*(4), 640-648.

Snyder, C. R. (1995). Managing for High Hope. *R&D Innovator, 4*(6).

Snyder, C. R. (1999a). *Coping: The Psychology of What Works*. US Oxford University Press.

Snyder, C. R. (1999b). Hope, goal-blocking thoughts, and test-related anxieties. *Psychol Rep, 84*(1), 206-208.

Snyder, C. R. (2000a). Genesis: The birth and growth of hope. In C. R. Snyder (Ed.), *Handbook of hope : theory, measures & applications*. San Diego, Calif.: Academic Press.

Snyder, C. R. (2000b). Hypothesis: there is hope. In C. R. Snyder (Ed.), *Handbook of hope : theory, measures & applications*. San Diego, Calif.: Academic Press.

Snyder, C. R. (2002). Hope theory: Rainbows in the mind. *Psychological Inquiry, 13*(4), 249.

Snyder, C. R. (Ed.). (2000c). *Handbook of hope : theory, measures & applications*. San Diego, Calif.: Academic Press.

Snyder, C. R., Berg, C., Woodward, J. T., Gum, A., Rand, K. L., Wrobleski, K. K., et al. (2005). Hope against the cold: individual differences in trait hope and acute pain tolerance on the cold pressor task. *J Pers, 73*(2), 287-312.

Snyder, C. R., & Feldman, D. B. (2000). Hope for the many: an empowering social agenda. In C. R. Snyder (Ed.), *Handbook of hope : theory, measures & applications*. San Diego, Calif.: Academic Press.

Snyder, C. R., Hardi, S. S., Cheavens, J., Michael, S. T., Yamhure, L., & Sympson, S. (2000). The Role of Hope in Cognitive-Behavior Therapies. *Cognitive Therapy & Research, 24*(6), 747-762.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S., Irving, L. M., Sigmon, S. T., et al. (1991). The will and the ways: Development and validation of an Individual-differences Measure of Hope. *Journal of Personality and Social Psychology, 60*(4), 570-585.

Snyder, C. R., Hoza, B., Pelham, W. E., Rapoff, M., Ware, L., Danovsky, M., et al. (1997). The Development and Validation of the Children's Hope Scale. *Journal of Pediatric Psychology, 22*(3), 399-421.

Snyder, C. R., Lapointe, A. B., Crowson, J. J., & Early, S. (1998). Preferences of High- and Low-hope People for Self-referential Input. *Cognition & Emotion, 12*(6), 807-823.

Snyder, C. R., Lehman, A. F., B, K., & Monsson, Y. (2006). Hope for rehabilitation and vice versa. *Rehabilitation Psychology, 51*(2), 89-112.

Snyder, C. R., & Lopez, S. J. (Eds.). (2002). *Handbook of Positive Psychology*. New York: Oxford University Press.

Snyder, C. R., Michael, S. T., & Cheavens, J. (1999). Hope as a psychotherapeutic foundation of common factors, placebos and expectancies. In M. A. Hubble, B. L. Duncan & S. D. Miller (Eds.), *The heart and soul of change: what works in therapy*. Washington: American Psychological Association.

Snyder, C. R., Parenteau, S. C., Shorey, H. S., Kahle, K. E., & Berg, C. (2002). Hope as the underlying process in the psychotherapeutic change process. *International Gestalt Journal, 25*(2), 11-29.

Snyder, C. R., Rand, K., L., & Sigmon, D. R. (2002). Hope theory: A member of the positve psychology family. In C. R. Snyder & S. J. Lopez (Eds.), *Handbook of Positive Psychology*. New York: Oxford University Press.

Snyder, C. R., Sympson, S. C., Ybasco, F. C., Borders, T., F., Babyak, M. A., & Higgins, R. L. (1996). Development and validation of the State Hope Scale. *Journal of Personality and Social Psychology, 70*(2), 321-335.

Snyder, C. R., & Taylor, J. D. (2000). Hope as a common factor across psychotherapy approaches: A lesson from the Dodo's verdict. In C. R. Snyder (Ed.), *Handbook of hope : theory, measures & applications*. San Diego, Calif.: Academic Press.

Snyder, C. R., Wiklunds, C., & Cheavens, J. (1999). *Hope and success in college*. Paper presented at the American Psychological Association.

South London and Maudsley NHS Foundation Trust. (2010). *Social Inclusion and Recovery (SIR) Strategy 2010-2015*. London: SLAM.

Spaulding, W. D. (1992). Design prerequisites for research on cognitive therapy for schizophrenia. *Schizophr Bull, 18*(1), 39-42.

Spielberger, C. D., Gorsuch, R. L., & Luchene, R. E. (1970). *The State-Trait Anxiety Inventory.* Palo Alto, CA: Consulting Psychologists Press.

SPSS. (2007). SPSS Graduate Student Version for Mac (Version 16). Chicago: SPSS Inc.

Staats, S. (1989). Hope: A Comparison of Two Self-Report Measures for Adults. *Journal of Personality Assessment, 53*(2), 366 - 375.

State Government of Victoria, A., Department of Human Services. (2009). Adult Mental Health Services,. Retrieved 29 April, 2009, from http://www.health.vic.gov.au/mentalhealth/services/adult/map-mw.htm

Steckler, A., McLeroy, K. R., Goodman, R. M., Bird, S. T., & McCormick, L. (1992). Toward integrating qualitative and quantitative methods: an introduction. *Health Educ Q, 19*(1), 1-8.

Steed, L. G. (2002). A psychometric comparison of four measures of hope and optimism. . *Educational and Psychological Measurement, 62*(3, Jun), 466-482.

Stotland, E. (1969). *The psychology of hope*. San Francisco: Jossey-Bass.

Stuckey, J. C., Neundorfer, M. M., & Smyth, K. A. (1996). Burden and well-being: The same coin or related currency? *Gerontologist, 36*(5), 686-693.

Stull, D. E., Kosloski, K., & Kercher, K. (1994). Caregiver burden and generic well-being: opposite sides of the same coin? *Gerontologist, 34*(1), 88-94.

Substance Abuse and Mental Health Services Administration. (2005). *National Consensus Conference on Mental Health Recovery and Systems Transformation*. Rockville, Md: Department of Health and Human Services.

Summerfelt, W. T., & Meltzer, H. Y. (1998). Efficacy vs. effectiveness in psychiatric research. *Psychiatr Serv, 49*(6), 834-835.

Sun, Q., Ng, K.-M., & Wang, C. (2012). A Validation Study on a New Chinese Version of the Dispositional Hope Scale. *Measurement & Evaluation in Counseling & Development (Sage Publications Inc.), 45*(2), 133-148.

Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W., et al. (2003). An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis. *Social Psychiatry And Psychiatric Epidemiology, 38*(8), 411-418.

Szmukler, G. I., Burgess, P., Herrman, H., Benson, A., Cofusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: The development of the Experience of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemology, 31*, 137-148.

Tabachnick, B., & Fidell, L. (2001). *Using Multivariate Statistics*. United States: Allyn and Bacon.

Tarrier, N., Barrowclough, C., Vaughn, C., Bamrah, J. S., Porceddu, K., Watts, S., et al. (1988). The community management of schizophrenia. A controlled trial of a behavioural intervention with families to reduce relapse. *Br J Psychiatry, 153*, 532-542.

Tarrier, N., Barrowclough, C., Vaughn, C., Bamrah, J. S., Porceddu, K., Watts, S., et al. (1989). Community management of schizophrenia. A two-year follow-up of a behavioural intervention with families. *Br J Psychiatry, 154*, 625-628.

Taylor, J. A. (1953). A personality scale of manifest anxiety. *The Journal of Abnormal and Social Psychology, 48*(2), 285.

Telles, C., Karno, M., Mintz, J., Paz, G., Arias, M., Tucker, D., et al. (1995). Immigrant families coping with schizophrenia. Behavioral family intervention v. case management with a low-income Spanish-speaking population. *Br J Psychiatry, 167*(4), 473-479.

The WHOQOL Group. (1998a). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine, 28*, 551-558.

The WHOQOL Group. (1998b). The World Health Organization Quality of Life Assessement (WHOQOL): Development and general psychometric properties. *Social Sciences and Medicine, 46*(12), 1569-1585.

Tomaras, V., Mavreas, V., Economou, M., Ioannovich, E., Karydi, V., & Stefanis, C. (2000). The effect of family intervention on chronic schizophrenics under individual psychosocial treatment: a 3-year study. *Soc Psychiatry Psychiatr Epidemiol, 35*(11), 487-493.

Tong, E., Fredrickson, B. L., Chang, W., & Lim, Z. X. (2009). Re-examining hope: The roles of agency thinking and pathways thinking. *Cognition and emotion, 24*(7), 1207-1215.

Tooth, B., Kalyanasundaram, V., Glover, H., & Momenzadah, S. (2003). Factors consumers identify as important to recovery from schizophrenia. *Australasian Psychiatry, 11*(s1), S70-S77.

Torrey, E. F. (2011). Patients, Clients, Consumers, Survivors et al: What's in a Name? *Schizophrenia Bulletin, 37*(3), 466-468.

Torrey, W. C., Drake, R. E., Dixon, L., Burns, B. J., Flynn, L., Rush, A. J., et al. (2001). Implementing evidence-based practices for persons with severe mental illnesses. *Psychiatric Services, 52*(1), 45-50.

Trauer, T., Duckmanton, R. A., & Chiu, E. (1995). The Life Skills Profile: A study of its psychometric properties. *Australian & New Zealand Journal of Psychiatry, 29*, 492-499.

Trauer, T., Duckmanton, R. A., & Chiu, E. (1997). The assessment of clinically significant change using the Life Skills Profile. *Australian and New Zealand Journal of Psychiatry, 31*(2), 257-263.

Tuck, I., du Mont, P., Evans, G., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing, 11*(3), 118-125.

Turner-Crowson, J., & Wallcraft, J. (2002). The recovery vision for mental health services and research: a British perspective. *Psychiatric Rehabilitation Journal, 25*(3), 245-254.

Vaughn, C., & Leff, J. (1976). The influence of family and social factors on the course of psychiatric illness. *British Journal of Psychiatry, 129*, 125-137.

Venning, A. J., Eliott, J., Kettler, L., & Wilson, A. (2009). Normative data for the Hope Scale using Australian adolescents. *Australian Journal of Psychology, 61*(2), 100-106.

Victorian Auditor General's Office (Australia). (2002). *Carers and Families*.

Vinson, T. (2007). *Dropping off the Edge: The distribution of disadvantage in Australia*: Jesuit Social Services and Catholic Social Services Australia.

Walesa, L. (1987). *A Way of Hope: An Autobiography*. New York: Henry Holt.

Wallace, C. J., & Liberman, R. P. (1985). Social skills training for patients with schizophrenia: a controlled clinical trial. *Psychiatry Res, 15*(3), 239-247.

Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality and Social Psychology 54*(6), 1063-1070.

Watson, J. M., & Torgerson, D. J. (2006). Increasing recruitment to randomised trials: a review of randomised controlled trials. *BMC Med Res Methodol, 6*, 34.

Webb, C., Pfeiffer, M., Mueser, K. T., Gladis, M., Mensch, E., DeGirolamo, J., et al. (1998). Burden and well-being of caregivers for the severely mentally ill: the role of coping style and social support. *Schizophrenia Research, 34*, 169-180.

Wein, S. (2005). Hope: Concerning structure and function. *Palliative & Supportive Care, 2*(03), 229-230.

Weingarten, K. (2000). Witnessing, Wonder and Hope. *Family Process, 39*(4), 389-402.

Weingarten, K. (2007). Hope in a time of global despair. In C. Flaskus, I. McCarthy & J. Sheehan (Eds.), *Hope and despair in narrative and family therapy*. N.Y.: Brunner Routledge.

Wells, K. B. (1999). Treatment research at the crossroads: the scientific interface of clinical trials and effectiveness research. *Am J Psychiatry, 156*(1), 5-10.

West, C. (1999). *Restoring hope: Conversations on the future of black America*. USA: Beacon Press.

Wheeler, R. J. (1991). The theoretical and empirical structure of general well-being. *Social Indicators Research, 24*, 71-79.

White, R. G., McCleery, M., Gumley, A. I., & Mulholland, C. (2007). Hopelessness in Schizophrenia: The Impact of Symptoms and Beliefs About Illness. *Journal of Nervous & Mental Disease, 195*(12), 968-975.

WHOQoL-Group. (1998). Development of the World Health Organisation WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine*(28), 551-558.

Wilson, T. (2011). *Redirect: The surprising new science of psychological change*: Penguin UK.

Wolff, N. (2000). Using randomized controlled trials to evaluate socially complex services: problems, challenges and recommendations. *The journal of mental health policy and economics, 3*(2), 97-109.

Woltmann, E. M., Whitley, R., McHugo, G. J., Brunette, M., Torrey, W. C., Coots, L., et al. (2008). The role of staff turnover in the implementation of evidence-based practices in mental health care. *Psychiatr Serv, 59*(7), 732-737.

Woolf, S. H., & Johnson, R. E. (2005). The break-even point: when medical advances are less important than improving the fidelity with which they are delivered. *The Annals of Family Medicine, 3*(6), 545-552.

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

World Health Organization. (2008). *ICD-10, the ICD-10 classification of mental and behavioural disorders: diagnositc criteria for research*. Geneva: World Health Organisation.

World Medical Association. (2008). World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. 59th WMA General Assembly Seoul October 2008: World Medical Association.

Wykes, T., Steel, C., Everitt, B., & Tarrier, N. (2007). Cognitive Behaviour Therapy for Schizophrenia: Effect Sizes, Clinical Models, and Methodological Rigor. *Schizophr Bull, Advance Access October 2007*(Open Access), 1-15.

Xiang, M., Ran, M., & Li, S. (1994). A controlled evaluation of psychoeducational family intervention in a rural Chinese community. *Br J Psychiatry, 165*(4), 544-548.

Xiong, W., Phillips, M. R., Hu, X., Wang, R., Dai, Q., Kleinman, J., et al. (1994). Family-based intervention for schizophrenic patients in China. A randomised controlled trial. *Br J Psychiatry, 165*(2), 239-247.

Young, S. L., & Ensing, D. S. (1999). Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal, 22*(3), 219-231.

Zastowny, T. R., Lehman, A. F., Cole, R. E., & Kane, C. (1992). Family management of schizophrenia: a comparison of behavioral and supportive family treatment. *Psychiatr Q, 63*(2), 159-186.

Zhang, M., Heqin, Y., & Co-Authors. (1993). Effectiveness of psychoeducation of relatives of schizophrenic patients: A prospective cohort study in five cities of China. *International Journal of Mental Health 22*(1), 47-59.

Zhang, M., Wang, M., Li, J., & Phillips, M. R. (1994). Randomised-control trial of family intervention for 78 first-episode male schizophrenic patients. An 18-month study in Suzhou, Jiangsu. *Br J Psychiatry Suppl*(24), 96-102.

Zubin, J., & Spring, B. (1977). Vulnerability - a new view of schizophrenia. *Journal of Abnormal Psychology, 86*, 103-126.

Appendices

Appendices

Appendices Section 1: Questionnaires

Appendix 1.1 Consumer baseline questionnaire

Office use only		
Interviewer…… Venue H / O/ Oth	NW / MW/ N	ID Fam†
Date of interview……..	Interpreter Y / N	Match ID Con†

Baseline interview for consumer

This questionnaire asks you about some simple questions about yourself, your general well-being and your attitudes to medication use and how you are coping. It can be filled in by yourself independently, or with help from the researchers.

This questionnaire is 12 pages long. Please complete all sections 1 to 7 (pages 2 to 12) which will take you about 40 minutes to complete.

- Please read each question carefully
- Some answers are completed by writing the answer in the space provided eg. In which country were you born? .....
- Other answers are completed by ticking or filling in the circle for the answer which best describes you eg the circle like this ○ , becomes this ● or ✓.
- Remember, only select <u>one</u> circle for each question to fill in,
- If you make a mistake, just cross out your answer and select the answer that best describes you. There are no right or wrong answers.

Thank you for your help.

Dr Carol Harvey
Principal Researcher
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Ms Laura Hayes
Research Fellow
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Please return to:
Laura Hayes
Psychosocial Research Centre
130 Bell St
Coburg 3058
t: 9355 9827 e:lmhayes@unimelb.edu.au

Part 1: Some questions about yourself

1.1 You are
- Male
- Female

1.2 How old are you? …….years

1.3 In which country were you born? .....

1.4 What is your first language? .....

1.5 If you were not born in Australia, how many years have you lived in here? .....

1.6 What language do you speak at home? .....

1.7 What ethnic group do you consider yourself most strongly identified with?
- Australia
- NZ, Pacific Islands, PNG
- South East Asia
- Indian subcontinent and other Asia
- Middle East
- North Africa
- Central and Southern Africa
- UK and Ireland
- Europe
- North America
- Central and South America
- Other……..

1.8 You are
- Never married
- Married/de facto
- Divorced
- Separated
- Widowed

1.9 What are your living arrangements?
- Own home
- Rented home (private accommodation)
- Rented home (public accommodation)
- Rented room
- Family home (eg with your parents)
- Crisis/sheltered accommodation
- Group or supported accommodation
- Institution

1.10 What is the highest level of education you completed?

- Primary school
- High/Secondary school
- Trade certificate
- College certificate or degree
- University degree

1.11 What is your current working status?

- Working full time
- Working part time
- Unemployed, or looking for work
- Homemaker
- Student
- Retired receiving sickness benefits
- Receiving disability support or pension

1.12 What work do you do, or did the last time you worked? ……
(Eg, plumber, nurse, house worker, teacher, clerk)

1.13 If not working, when was the last time you worked (year)?…….

1.14 Best employment status in past year

- Working full time
- Working part time
- Unemployed, or looking for work
- Homemaker
- Student
- Retired receiving sickness benefits
- Receiving disability support or pension

1.15 Are you receiving any Social security, pension or sickness benefits payments?

- Yes, please list your benefit:…….
- No

Part 2: Some questions about your future

Read each item carefully. Please select (and circle) the number that best describes you over the <u>past 4 weeks.</u>

		Definitely false	***Mostly false***	***Mostly True***	***Definitely True***
2.1	I can think of many ways to get out of a jam.	○	○	○	○
2.2	I energetically pursue my goals.	○	○	○	○
2.3	I feel tired most of the time.	○	○	○	○
2.4	There are lots of ways around any problem.	○	○	○	○
2.5	I am easily downed in an argument	○	○	○	○
2.6	I can think of many ways to get the things in life that are most important to me.	○	○	○	○
2.7	I worry about my health.	○	○	○	○
2.8	Even when others get discouraged, I know I can find a way to solve the problem.	○	○	○	○
2.9	My past experiences have prepared me well for my future.	○	○	○	○
2.10	I have been pretty successful in life.	○	○	○	○
2.11	I usually find myself worrying about something.	○	○	○	○
2.12	I meet the goals that I set for myself.	○	○	○	○

Part 3: Some questions about how you feel about your family

Please respond to the items in terms of how you feel your family has been functioning in the past two months.

Complete the questions privately. Do not discuss your responses with other family members as we are interested in your personal view of your family.

Please read each statement carefully and decide how well it describes your family. You should answer according to how you see your family.

For each statement there is an answer space below. Try not to spend too much time thinking about each statement but respond as quickly and as honestly as you can. If you have trouble with one question, answer with your first reaction. Please be sure to answer <u>every</u> statement and mark all your answers in the space provided below each statement.

		Strongly agree	***Agree***	***Disagree***	***Strongly disagree***
3.1	Planning family activities is difficult because we misunderstand each other.	○	○	○	○
3.2	In times of crisis we can turn to each other for support.	○	○	○	○
3.3	We cannot talk to each other about the sadness we feel.	○	○	○	○
3.4	Individuals are accepted for what they are.	○	○	○	○
3.5	Making decisions is a problem for our family.	○	○	○	○
3.6	We can express feelings to each other.	○	○	○	○
3.7	There are lots of bad feelings in the family.	○	○	○	○
3.8	We feel accepted for what we are.	○	○	○	○
3.9	We avoid discussing our fears and concerns.	○	○	○	○
3.10	We are able to make decisions about how to solve problems.	○	○	○	○
3.11	We don't get along well together.	○	○	○	○
3.12	We confide in each other.	○	○	○	○

Part 4: Some questions on your attitudes to medication

Please indicate whether you find the following statements true or false.

		True	*False*
4.1	I don't need to take medications once I feel better.	○	○
4.2	For me, the good things about medication outweigh the bad.	○	○
4.3	I feel weird, like a 'zombie' on medication.	○	○
4.4	Even when I'm not in hospital I need medication regularly	○	○
4.5	If I take medication it's only because of pressure from other people	○	○
4.6	I am more aware of what I am doing, of what is going on around me, when I am on medication	○	○
4.7	Taking medications will do me no harm.	○	○
4.8	I take medications on my own free choice	○	○
4.9	Medications make me feel more relaxed.	○	○
4.10	I am no different on or off medication.	○	○
4.11	The unpleasant effects of medication are always present.	○	○
5.12	Medication makes me feel tired and sluggish.	○	○
4.13	I take medication only when I am sick.	○	○
4.14	Medication is slow-acting poison.	○	○
4.15	I get along better with people when I am on medication.	○	○
4.16	I can't concentrate on anything when I am taking medication.	○	○
4.17	I know better than the doctor when to go off medication.	○	○
4.18	I feel more normal on medication.	○	○
4.19	I would rather be sick than taking medication	○	○
4.20	It is natural for my mind and body to be controlled by medication.	○	○

Please indicate whether you find the following statements true or false.

		True	*False*
4.21	My thoughts are clearer on medication.	○	○
4.22	I should stay on medication even if I feel alright.	○	○
4.23	Taking medication will prevent me from having a breakdown.	○	○
4.24	It is up to the doctor when I go off medication.	○	○
4.25	Things that I could do easily are much more difficult when I am on medication.	○	○
4.26	I am happier, feel better, when taking medications.	○	○
4.27	I am given medication to control behaviour that other people (not myself) don't like.	○	○
4.28	I can't relax on medication	○	○
4.29	I am in better control of myself.	○	○
4.30	By staying on medication I can prevent getting sick.	○	○

These questions ask how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question **please choose the one** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life ***in the last two weeks.***

Please read each question, assess your feelings, and select the response that gives the best answer for you.

5.1	In general, would you say your health is:	*Excellent* ○	*Very good* ○	*Good* ○	*Fair* ○	*Poor* ○
5.2	How would you rate your quality of life?	*Very poor* ○	*Poor* ○	*Neither good nor poor* ○	*Good* ○	*Very good* ○
5.3	How satisfied are you with your health?	*Very dissatisfied* ○	*Dissatisfied* ○	*Neither satisfied nor dissatisfied* ○	*Satisfied* ○	*Very satisfied* ○
5.4	To what extent do you feel that physical pain prevents you from doing what you need to do?	*Not at all* ○	*A little* ○	*A moderate amount* ○	*Very much* ○	*An extreme amount* ○
5.5	How much do you need any medical treatment to function in your daily life?	○	○	○	○	○
5.6	How much do you enjoy life?	○	○	○	○	○
5.7	To what extent do you feel your life to be meaningful?	○	○	○	○	○
5.8	How well are you able to concentrate?	*Not at all* ○	*A little* ○	*A moderate amount* ○	*Very much* ○	*Extremely* ○
5.9	How safe do you feel in your daily life?	○	○	○	○	○
5.10	How healthy is your physical environment?	○	○	○	○	○
5.11	Do you have enough energy for everyday life?	*Not at all* ○	*A little* ○	*Moderately* ○	*Mostly* ○	*Completely* ○

5.12	Are you able to accept your bodily appearance?	*Not at all* ○	*A little* ○	*Moderately* ○	*Mostly* ○	*Completely* ○
5.13	Have you enough money to meet your needs?	○	○	○	○	○
5.14	How available to you is the information that you need in your day-to-day life?	○	○	○	○	○
5.15	To what extent do you have the opportunity for leisure activities?	○	○	○	○	○
5.16	How well are you able to get around?	*Very poor* ○	*Poor* ○	*Neither poor nor good* ○	*Good* ○	*Very good* ○
5.17	How satisfied are you with your sleep?	*Very dissatisfied* ○	*Dissatisfied* ○	*Neither satisfied nor dissatisfied* ○	*Satisfied* ○	*Very satisfied* ○
5.18	How satisfied are you with your ability to perform your daily living activities?	○	○	○	○	○
5.19	How satisfied are you with your capacity for work?	○	○	○	○	○
5.20	How satisfied are you with yourself?	○	○	○	○	○
5.21	How satisfied are you with your personal relationships?	○	○	○	○	○
5.22	How satisfied are you with your sex life?	○	○	○	○	○
5.23	How satisfied are you with the support you get from your friends?	○	○	○	○	○
5.24	How satisfied are you with the conditions of your living place?	○	○	○	○	○
5.25	How satisfied are you with your access to health services?	○	○	○	○	○
5.26	How satisfied are you with your transport?	○	○	○	○	○
5.27	How often do you have negative feelings such as blue mood, despair, anxiety, or depression?	*Never* ○	*Seldom* ○	*Quite often* ○	*Very often* ○	*Always* ○

We are interested in how YOU feel things have been for you ***during the past fortnight***.

It is important that you answer ALL the questions.

To what extent are you experiencing difficulty in the area of:

		No difficulty	*A little difficulty*	*Moderate difficulty*	*Quite a bit*	*Extreme difficulty*
6.1	Managing day-to-day life, eg getting to places on time, handling money	○	○	○	○	○
6.2	Household responsibilities, eg shopping, cleaning, cooking, laundry	○	○	○	○	○
6.3	Work, eg completing tasks, work level achieved	○	○	○	○	○
6.4	School, eg completing assignments, attendance	○	○	○	○	○
6.5	Leisure time or recreational activities	○	○	○	○	○
6.6	Adjusting to major stresses, eg separation, moving, a death, a new job	○	○	○	○	○
6.7	Relationships with family members	○	○	○	○	○
6.8	Getting along with people outside the family	○	○	○	○	○
6.9	Isolation or feelings of loneliness	○	○	○	○	○
6.10	Being able to be close to others	○	○	○	○	○
6.11	Being realistic about yourself and others	○	○	○	○	○
6.12	Recognising and expressing emotions appropriately	○	○	○	○	○
6.13	Developing independence, autonomy	○	○	○	○	○
6.14	Goals or direction in life	○	○	○	○	○
6.15	Lack of self-confidence, feeling bad about yourself	○	○	○	○	○
6.16	Apathy, lack of interest in things	○	○	○	○	○
6.17	Depression, hopelessness	○	○	○	○	○
6.18	Suicidal feeling or behaviour	○	○	○	○	○
6.19	Physical symptoms, eg head-aches, sleep disturbance, aches	○	○	○	○	○

During the past fortnight **to what extent are you experiencing difficulty in the area of:**

		No difficulty	*A little difficulty*	*Moderate difficulty*	*Quite a bit*	*Extreme difficulty*
6.20	Fear, anxiety or panic	○	○	○	○	○
6.21	Confusion, concentration, memory	○	○	○	○	○
6.22	Disturbing or unreal thoughts or beliefs	○	○	○	○	○
6.23	Hearing voices, seeing things	○	○	○	○	○
6.24	Manic, bizarre behaviour	○	○	○	○	○
6.25	Mood swings, unstable moods	○	○	○	○	○
6.26	Uncontrollable compulsive behaviour, eg eating disorder, hand-washing, self-harm	○	○	○	○	○
6.27	Sexual activity or preoccupation	○	○	○	○	○
6.28	Drinking alcoholic beverages	○	○	○	○	○
6.29	Taking illegal drugs, misusing drugs	○	○	○	○	○
6.30	Controlling temper, outbursts of anger, violence	○	○	○	○	○
6.31	Impulsive, illegal or reckless behaviour	○	○	○	○	○
6.32	Feeling satisfaction with your life	○	○	○	○	○

Please fill in the answer that best describes you.

During the past 4 weeks

		Almost Always	*Most of the time*	*About half the time*	*Occasionally*	*Not at all*
7.1	It has been easy to relate to others	○	○	○	○	○
7.2	I felt isolated from other people	○	○	○	○	○
7.3	I had someone to share my feelings with	○	○	○	○	○
7.4	I found it easy to get in touch with others when I needed to	○	○	○	○	○
7.5	When with other people, I felt separate from them	○	○	○	○	○
76	I felt alone and friendless	○	○	○	○	○

Thank you for completing this survey. There is another section which will be completed in a discussion with the researcher.

Part 8: some questions reviewing your future.

8.1.a What are you hoping to do for yourself next year?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:
  Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

8.1.b How much energy will you put towards these things?

Do you feel excited about these things?
How confident are you of reaching these things?

8.1.c Have you been thinking about any strategies to achieve these things?

How certain are you that the plan of X will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

8.2.a What are you hoping for your family/X and you ?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:

Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

8.2.b How much energy will you and the family put towards these things?

Do you and the family feel excited about these things?
How confident are you of yourself and the family reaching these things?

8.2.c Have you been thinking about any strategies to achieve these things ?
How certain are you that the plan of X will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

8.3. a Do you have any goals, hopes or expectations related to doing the BFST family sessions/working with your/X's case-manager?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:
  Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

8.3.b How much energy will you and the case-manager put towards these things?

Do you and the case-manager feel excited about these things?
How confident are you of you and Z [case-manager] reaching these things?

8.3.c Have you been thinking about any strategies to achieve these things
How certain are you that the plan of Y will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

Appendix 1.2 Consumer follow-up questionnaire

Office use only		
Interviewer…… Venue H / O / Oth	NW / MW/ N	ID Con†
Date of interview……..	Interpreter Y / N	Match ID Fam†

Follow-up interview for consumer

This questionnaire asks you about some simple questions about yourself, your general well-being and your attitudes to medication use and how you are coping. It can be filled in by yourself independently, or with help from the researchers.

This questionnaire is 11 pages long. Please complete all sections 1 to 7 (pages 2 to 11) which will take you about 40 minutes to complete.

- Please read each question carefully
- Some answers are completed by writing the answer in the space provided eg. In which country were you born? .....
- Other answers are completed by ticking or filling in the circle for the answer which best describes you eg the circle like this ○ , becomes this ● or ✓.
- Remember, only select <u>one</u> circle for each question to fill in,
- If you make a mistake, just cross out your answer and select the answer that best describes you. There are no right or wrong answers.

Thank you for your help.

Dr Carol Harvey
Principal Researcher
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Ms Laura Hayes
Research Fellow
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Please return to:
Laura Hayes
Psychosocial Research Centre
130 Bell St
Coburg 3058
t: 9355 9827 e:lmhayes@unimelb.edu.au

1.1 Have any of the following life events occurred in the last 10 months?

	Yes	*No*
Taken on loan or mortgage	○	○
Change in job/study	○	○
Started job/study	○	○
Change in residence/living arrangements	○	○
Death of close friend	○	○
Death of family member	○	○
Death of spouse/partner	○	○
Change in financial state	○	○
Change in health of family member	○	○
Pregnancy	○	○
Marriage/partnership	○	○
Personal injury or illness	○	○
Separation from spouse/partner	○	○
Divorce	○	○
Any other significant changes (1)……..	○	○
Any other significant changes (2)……..	○	○

1.2 Best employment status in past year

- ○ Working full time
- ○ Working part time
- ○ Unemployed, or looking for work
- ○ Homemaker
- ○ Student
- ○ Retired receiving sickness benefits
- ○ Receiving disability support or pension

1.3 Have you undertaken any treatment over the past 10 months? (tick as many as apply to you.

- ○ Usual case management with my case manager
- ○ Building Family Skills Together (BFST) program
- ○ Other family therapy
- ○ Seen a private therapist such as a psychiatrist, psychologist, or counsellor
- ○ Joined a group at my area mental health centre, specify……
- ○ Joined a group NOT at my area mental health centre, specify……

During the past 4 weeks
(Please fill in the answer that best describes you)

		Almost Always	***Most of the time***	***About half the time***	***Occasionally***	***Not at all***
2.1	It has been easy to relate to others	○	○	○	○	○
2.2	I felt isolated from other people	○	○	○	○	○
2.3	I had someone to share my feelings with	○	○	○	○	○
2.4	I found it easy to get in touch with others when I needed to	○	○	○	○	○
2.5	When with other people, I felt separate from them	○	○	○	○	○
2.6	I felt alone and friendless	○	○	○	○	○

We are interested in how YOU feel things have been for you ***during the past fortnight***.

It is important that you answer ALL the questions.

To what extent are you experiencing difficulty in the area of:

		No difficulty	*A little difficulty*	*Moderate difficulty*	*Quite a bit*	*Extreme difficulty*
3.1	Managing day-to-day life, eg getting to places on time, handling money	○	○	○	○	○
3.2	Household responsibilities, eg shopping, cleaning, cooking, laundry	○	○	○	○	○
3.3	Work, eg completing tasks, work level achieved	○	○	○	○	○
3.4	School, eg completing assignments, attendance	○	○	○	○	○
3.5	Leisure time or recreational activities	○	○	○	○	○
3.6	Adjusting to major stresses, eg separation, moving, a death, a new job	○	○	○	○	○
3.7	Relationships with family members	○	○	○	○	○
3.8	Getting along with people outside the family	○	○	○	○	○
3.9	Isolation or feelings of loneliness	○	○	○	○	○
3.10	Being able to be close to others	○	○	○	○	○
3.11	Being realistic about yourself and others	○	○	○	○	○
3.12	Recognising and expressing emotions appropriately	○	○	○	○	○
3.13	Developing independence, autonomy	○	○	○	○	○
3.14	Goals or direction in life	○	○	○	○	○
3.15	Lack of self-confidence, feeling bad about yourself	○	○	○	○	○
3.16	Apathy, lack of interest in things	○	○	○	○	○
3.17	Depression, hopelessness	○	○	○	○	○
3.18	Suicidal feeling of behaviour	○	○	○	○	○
3.19	Physical symptoms, eg head-aches, sleep disturbance, aches	○	○	○	○	○

During the past fortnight **to what extent are you experiencing difficulty in the area of:**

		No difficulty	*A little difficulty*	*Moderate difficulty*	*Quite a bit*	*Extreme difficulty*
3.20	Fear, anxiety or panic	○	○	○	○	○
3.21	Confusion, concentration, memory	○	○	○	○	○
3.22	Disturbing or unreal thoughts or beliefs	○	○	○	○	○
3.23	Hearing voices, seeing things	○	○	○	○	○
3.24	Manic, bizarre behaviour	○	○	○	○	○
3.25	Mood swings, unstable moods	○	○	○	○	○
3.26	Uncontrollable compulsive behaviour, eg eating disorder, hand-washing, self-harm	○	○	○	○	○
3.27	Sexual activity or preoccupation	○	○	○	○	○
3.28	Drinking alcoholic beverages	○	○	○	○	○
3.29	Taking illegal drugs, misusing drugs	○	○	○	○	○
3.30	Controlling temper, outbursts of anger, violence	○	○	○	○	○
3.31	Impulsive, illegal or reckless behaviour	○	○	○	○	○
3.32	Feeling satisfaction with your life	○	○	○	○	○

These questions ask how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life ***in the last two weeks.***

Please read each question, assess your feelings, and select the response that gives the best answer for you.

4.1	In general, would you say your health is:	*Excellent* ○	*Very good* ○	*Good* ○	*Fair* ○	*Poor* ○
4.2	How would you rate your quality of life?	*Very poor* ○	*Poor* ○	*Neither good nor poor* ○	*Good* ○	*Very good* ○
4.3	How satisfied are you with your health?	*Very dissatisfied* ○	*Dissatisfied* ○	*Neither satisfied nor dissatisfied* ○	*Satisfied* ○	*Very satisfied* ○
4.4	To what extent do you feel that physical pain prevents you from doing what you need to do?	*Not at all* ○	*A little* ○	*A moderate amount* ○	*Very much* ○	*An extreme amount* ○
4.5	How much do you need any medical treatment to function in your daily life?	○	○	○	○	○
4.6	How much do you enjoy life?	○	○	○	○	○
4.7	To what extent do you feel your life to be meaningful?	○	○	○	○	○
4.8	How well are you able to concentrate?	*Not at all* ○	*A little* ○	*A moderate amount* ○	*Very much* ○	*Extremely* ○
4.9	How safe do you feel in your daily life?	○	○	○	○	○
4.10	How healthy is your physical environment?	○	○	○	○	○
4.11	Do you have enough energy for everyday life?	*Not at all* ○	*A little* ○	*Moderately* ○	*Mostly* ○	*Completely* ○

4.12	Are you able to accept your bodily appearance?	*Not at all* ○	*A little* ○	*Moderately* ○	*Mostly* ○	*Completely* ○
4.13	Have you enough money to meet your needs?	○	○	○	○	○
4.14	How available to you is the information that you need in your day-to-day life?	○	○	○	○	○
4.15	To what extent do you have the opportunity for leisure activities?	○	○	○	○	○
4.16	How well are you able to get around?	*Very poor* ○	*Poor* ○	*Neither poor nor good* ○	*Good* ○	*Very good* ○
4.17	How satisfied are you with your sleep?	*Very dissatisfied* ○	*Dissatisfied* ○	*Neither satisfied nor dissatisfied* ○	*Satisfied* ○	*Very satisfied* ○
4.18	How satisfied are you with your ability to perform your daily living activities?	○	○	○	○	○
4.19	How satisfied are you with your capacity for work?	○	○	○	○	○
4.20	How satisfied are you with yourself?	○	○	○	○	○
4.21	How satisfied are you with your personal relationships?	○	○	○	○	○
4.22	How satisfied are you with your sex life?	○	○	○	○	○
4.23	How satisfied are you with the support you get from your friends?	○	○	○	○	○
4.24	How satisfied are you with the conditions of your living place?	○	○	○	○	○
4.25	How satisfied are you with your access to health services?	○	○	○	○	○
4.26	How satisfied are you with your transport?	○	○	○	○	○
4.27	How often do you have negative feelings such as blue mood, despair, anxiety, or depression?	*Never* ○	*Seldom* ○	*Quite often* ○	*Very often* ○	*Always* ○

[redacted]

Please indicate whether you find the following statements true or false.

		True	*False*
5.1	I don't need to take medications once I feel better.	○	○
5.2	For me, the good things about medication outweigh the bad.	○	○
5.3	I feel weird, like a 'zombie' on medication.	○	○
5.4	Even when I'm not in hospital I need medication regularly	○	○
5.5	If I take medication it's only because of pressure from other people	○	○
5.6	I am more aware of what I am doing, of what is going on around me, when I am on medication	○	○
5.7	Taking medications will do me no harm.	○	○
5.8	I take medications on my own free choice	○	○
5.9	Medications make me feel more relaxed.	○	○
5.10	I am no different on or off medication.	○	○
5.11	The unpleasant effects of medication are always present.	○	○
5.12	Medication makes me feel tired and sluggish.	○	○
5.13	I take medication only when I am sick.	○	○
5.14	Medication is slow-acting poison.	○	○
5.15	I get along better with people when I am on medication.	○	○
5.16	I can't concentrate on anything when I am taking medication.	○	○
5.17	I know better than the doctor when to go off medication.	○	○
5.18	I feel more normal on medication.	○	○
5.19	I would rather be sick than taking medication	○	○
5.20	It is natural for my mind and body to be controlled by medication.	○	○

Please indicate whether you find the following statements true or false.

		True	*False*
5.21	My thoughts are clearer on medication.	○	○
5.22	I should stay on medication even if I feel alright.	○	○
5.23	Taking medication will prevent me from having a breakdown.	○	○
5.24	It is up to the doctor when I go off medication.	○	○
5.25	Things that I could do easily are much more difficult when I am on medication.	○	○
5.26	I am happier, feel better, when taking medications.	○	○
5.27	I am given medication to control behaviour that other people (not myself) don't like.	○	○
5.28	I can't relax on medication	○	○
5.29	I am in better control of myself.	○	○
5.30	By staying on medication I can prevent getting sick.	○	○

Part 6: Some questions about goals in your life

Read each item carefully. Please select (and circle) the number that best describes you.

		Definitely false	*Mostly false*	*Mostly True*	*Definitely True*
6.1	I can think of many ways to get out of a jam.	○	○	○	○
6.2	I energetically pursue my goals.	○	○	○	○
6.3	I feel tired most of the time.	○	○	○	○
6.4	There are lots of ways around any problem.	○	○	○	○
6.5	I am easily downed in an argument	○	○	○	○
6.6	I can think of many ways to get the things in life that are most important to me.	○	○	○	○
6.7	I worry about my health.	○	○	○	○
6.8	Even when others get discouraged, I know I can find a way to solve the problem.	○	○	○	○
6.9	My past experiences have prepared me well for my future.	○	○	○	○
6.10	I have been pretty successful in life.	○	○	○	○
6.11	I usually find myself worrying about something.	○	○	○	○
6.12	I meet the goals that I set for myself.	○	○	○	○

Part 7: Some questions about how you feel about your family

Please respond to the items in terms of how you feel your family has been functioning in the past two months.

Complete the questions privately. Do not discuss your responses with other family members as we are interested in your personal view of your family.

Please read each statement carefully and decide how well it describes your family. You should answer according to how you see your family.

For each statement there is an answer space below. Try not to spend too much time thinking about each statement but respond as quickly and as honestly as you can. If you have trouble with one question, answer with your first reaction. Please be sure to answer every statement and mark all your answers in the space provided below each statement.

		Strongly agree	***Agree***	***Disagree***	***Strongly disagree***
7.1	Planning family activities is difficult because we misunderstand each other.	○	○	○	○
7.2	In times of crisis we can turn to each other for support.	○	○	○	○
7.3	We cannot talk to each other about the sadness we feel.	○	○	○	○
7.4	Individuals are accepted for what they are.	○	○	○	○
7.5	Making decisions is a problem for our family.	○	○	○	○
7.6	We can express feelings to each other.	○	○	○	○
7.7	There are lots of bad feelings in the family.	○	○	○	○
7.8	We feel accepted for what we are.	○	○	○	○
7.9	We avoid discussing our fears and concerns.	○	○	○	○
7.10	We are able to make decisions about how to solve problems.	○	○	○	○
7.11	We don't get along well together.	○	○	○	○
7.12	We confide in each other.	○	○	○	○

Thank you for completing this survey. There is another section which will be completed in a discussion with the researcher.

Part 8: some questions reviewing your treatment.

8.1.a What are you hoping to do for yourself next year?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:
  Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

8.1.b How much energy will you put towards these things?

Do you feel excited about these things?
How confident are you of reaching these things?

8.1.c Have you been thinking about any strategies to achieve these things?

How certain are you that the plan of X will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

8.2.a What are you hoping for your family/X and you ?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:

Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

8.2.b How much energy will you and the family put towards these things?

Do you and the family feel excited about these things?
How confident are you of yourself and the family reaching these things?

8.2.c Have you been thinking about any strategies to achieve these things ?
How certain are you that the plan of X will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

8.3. a Do you have any goals, hopes or expectations related to doing the BFST family sessions/working with your/X's case-manager?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:
  Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

8.3.b How much energy will you and the case-manager put towards these things?

Do you and the case-manager feel excited about these things?
How confident are you of you and Z [case-manager] reaching these things?

8.3.c Have you been thinking about any strategies to achieve these things
How certain are you that the plan of Y will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

TREATMENT ONLY

How did you get along with your helpers?

How were things like manners, punctuality and follow through (doing what they were said they would?)

What was it like working together (with your family) in sessions?

Do you think that you understand (your relative) better as a result of this BFST work? Do you think that they understand you better?

What's different about how the family talks together or deals with things together?

Some of the areas things may change might be:

- how openly people talk together
- how to solve differences and challenges
- how people talk about feelings
- how they respond when you are upset
- changes in roles, different understanding of who does what
- agreement about house rules

What has changed for you through this experience?

How have the hopes and goals we talked about before changed?

What were some key moments/ pivotal situations/ turning points/ most important revelations?

What have you learned from the BFST program?
Did you learn anything more about schizophrenia?
Some of the things that would have been covered were…….

- how to ask for things directly
- listening
- expressing unpleasant and positive feelings
- how to resolve issues and challenges and setting goals

And finally…..
If a friend or acquaintance asked you whether or not BFST was worth doing, what advice would you give them?

What advice would you like to give us about our BFST program?

Appendix 1.3 Carer baseline questionnaire

Office use only		
Interviewer…… Venue H / O/ Oth	NW / MW/ N	ID Fam†
Date of interview……..	Interpreter Y / N	Match ID Con†

Baseline interview for family

This questionnaire asks you some simple questions about yourself, your general well-being and your experience of caring for your relative. This first part can be filled in by yourself independently, or with help from the researchers. The researchers will also talk to you some more about your life with your family member.

This questionnaire is 21 pages long. Please complete sections 1 to 8 (pages 2 to 15) which will take you about 35 minutes to complete. Section 9 will be completed during a discussion with the researcher.

- Please read each question carefully
- Some answers are completed by writing the answer in the space provided eg. In which country were you born? .....
- Other answers are completed by ticking or filling in the circle for the answer which best describes you eg the circle like this ○ , becomes this ● or ✓.
- Remember, only select <u>one</u> circle for each question to fill in,
- If you make a mistake, just cross out your answer and select the answer that best describes you. There are no right or wrong answers.

Thank you for your help.

Dr Carol Harvey
Principal Researcher
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Ms Laura Hayes
Research Fellow
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Please return to:
Laura Hayes
Psychosocial Research Centre
130 Bell St
Coburg 3058
t: 9355 9827 e:lmhayes@unimelb.edu.au

1.1 You are
- Male
- Female

1.2 How old are you? …….years

1.3 In which country were you born? .....

1.4 What is your first language? .....

1.5 If you were not born in Australia, how many years have you lived in here? .....

1.6 What language do you speak at home? .....

1.7 What ethnic group do you consider yourself most strongly identified with?

- Australia
- NZ, Pacific Islands, PNG
- South East Asia
- Indian subcontinent and other Asia
- Middle East
- North Africa
- Central and Southern Africa
- UK and Ireland
- Europe
- North America
- Central and South America
- Other……..

1.8 You are
- Never married
- Married/de facto
- Divorced
- Separated
- Widowed

1.9 What are your living arrangements?
- Own home
- Rented home (private accommodation)
- Rented home (public accommodation)
- Rented room
- Family home (eg with your parents)
- Crisis/sheltered accommodation
- Group or supported accommodation
- Institution

1.10 What is the highest level of education you completed?

- Primary school
- High/Secondary school
- Trade certificate
- College certificate or degree
- University degree

1.11 What is your current working status?

- Working full time
- Working part time
- Unemployed, or looking for work
- Homemaker
- Student
- Retired receiving sickness benefits
- Receiving disability support or pension

1.12 What work do you do, or did the last time you worked? ……
(Eg, plumber, nurse, house worker, teacher, clerk)

1.13 If not working, when was the last time you worked (year)?…….

1.14 Best employment status in past year

- Working full time
- Working part time
- Unemployed, or looking for work
- Homemaker
- Student
- Retired receiving sickness benefits
- Receiving disability support or pension

1.15 Are you receiving any Social security, pension or sickness benefits payments?

- Yes, please list your benefit:…….
- No

<u>The following questions are about the relationship with your family member receiving treatment.</u>

1.16 What is your relationship with the family member getting treatment?

- Partner or spouse
- Daughter or son
- Father or mother
- Brother or sister
- Other family member. Please specify……

1.17 Do you live with them?

- Yes
- No

1.18 How often do you see them?

- More than once a day
- Once a day
- A few times a week
- Weekly
- About once a fortnight
- Less often

1.19 How often do you speak to them on the phone?

- More than once a day
- Once a day
- A few times a week
- Weekly
- About once a fortnight
- Less often

[redacted]

Please fill in the answer that best describes you.

During the past 4 weeks

		Almost Always	*Most of the time*	*About half the time*	*Occasionally*	*Not at all*
2.1	It has been easy to relate to others	○	○	○	○	○
2.2	I felt isolated from other people	○	○	○	○	○
2.3	I had someone to share my feelings with	○	○	○	○	○
2.4	I found it easy to get in touch with others when I needed to	○	○	○	○	○
2.5	When with other people, I felt separate from them	○	○	○	○	○
2.6	I felt alone and friendless	○	○	○	○	○

Part 3: Some questions about your future

Read each item carefully. Please select (and circle) the number that best describes you over the past 4 weeks.

		Definitely false	*Mostly false*	*Mostly True*	*Definitely True*
3.1	I can think of many ways to get out of a jam.	○	○	○	○
3.2	I energetically pursue my goals.	○	○	○	○
3.3	I feel tired most of the time.	○	○	○	○
3.4	There are lots of ways around any problem.	○	○	○	○
3.5	I am easily downed in an argument	○	○	○	○
3.6	I can think of many ways to get the things in life that are most important to me.	○	○	○	○
3.7	I worry about my health.	○	○	○	○
3.8	Even when others get discouraged, I know I can find a way to solve the problem.	○	○	○	○
3.9	My past experiences have prepared me well for my future.	○	○	○	○
3.10	I have been pretty successful in life.	○	○	○	○
3.11	I usually find myself worrying about something.	○	○	○	○
3.12	I meet the goals that I set for myself.	○	○	○	○

Part 4: Some questions about how you feel about your family

Please respond to the items in terms of how you feel your family has been functioning in the past two months.

Complete the questions privately. Do not discuss your responses with other family members as we are interested in your personal view of your family.

Please read each statement carefully and decide how well it describes your family. You should answer according to how you see your family.

For each statement there is an answer space below. Try not to spend too much time thinking about each statement but respond as quickly and as honestly as you can. If you have trouble with one question, answer with your first reaction. Please be sure to answer every statement and mark all your answers in the space provided below each statement.

		Strongly agree	***Agree***	***Disagree***	***Strongly disagree***
4.1	Planning family activities is difficult because we misunderstand each other.	○	○	○	○
4.2	In times of crisis we can turn to each other for support.	○	○	○	○
4.3	We cannot talk to each other about the sadness we feel.	○	○	○	○
4.4	Individuals are accepted for what they are.	○	○	○	○
4.5	Making decisions is a problem for our family.	○	○	○	○
4.6	We can express feelings to each other.	○	○	○	○
4.7	There are lots of bad feelings in the family.	○	○	○	○
4.8	We feel accepted for what we are.	○	○	○	○
4.9	We avoid discussing our fears and concerns.	○	○	○	○
4.10	We are able to make decisions about how to solve problems.	○	○	○	○
4.11	We don't get along well together.	○	○	○	○
4.12	We confide in each other.	○	○	○	○

The following questionnaire contains a number of statements that commonly apply to persons who care for relatives or friends with a serious mental illness.

We would like you to read each one and decide how often it is applied to you ***over the past one month***.

If is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While there seems to be a lot of statements, you will find that it will not take more than a moment or so to answer each one.

During the past month how often have you thought that/about:

		Never	*Rarely*	*Sometimes*	*Often*	*Nearly always*
5.1	Your covering up his/her illness	○	○	○	○	○
5.2	Feeling unable to tell anyone of the illness	○	○	○	○	○
5.3	His/her difficulty looking after the money	○	○	○	○	○
5.4	Having to support him/her	○	○	○	○	○
5.5	What sort of life he/she might have had	○	○	○	○	○
5.6	His/her risk of committing suicide	○	○	○	○	○
5.7	I have learnt more about myself	○	○	○	○	○
5.8	I have contributed to others understanding of the illness	○	○	○	○	○
5.9	Being unable to do the things that you want to do	○	○	○	○	○
5.10	How health professionals do not take you seriously	○	○	○	○	○
5.11	His/her dependence on you	○	○	○	○	○
5.12	Helping him/her to fill in the day	○	○	○	○	○
5.13	I have contributed to his wellbeing	○	○	○	○	○
5.14	That he/she makes a valuable contribution to the household	○	○	○	○	○
5.15	The effect on your finances if he/she becomes more seriously ill	○	○	○	○	○

During the past month how often have you thought that/about:

		Never	*Rarely*	*Sometimes*	*Often*	*Nearly always*
5.16	Dealing with psychiatrists	○	○	○	○	○
5.17	Him/her always being at the back of your mind	○	○	○	○	○
5.18	Whether you have done something to make him/her ill	○	○	○	○	○
5.19	That he/she has shown some strengths in coping with his illness	○	○	○	○	○
5.20	I have become more confident in dealing with others	○	○	○	○	○
5.21	How family members do not understand your situation	○	○	○	○	○
5.22	That he/she is good company	○	○	○	○	○
5.23	I have become more under-standing of others with problems	○	○	○	○	○
5.24	How he/she thinks a lot about death	○	○	○	○	○
5.25	His/her lost opportunities	○	○	○	○	○
5.26	How to deal with mental health professionals	○	○	○	○	○
5.27	Feeling unable to have visitors at home	○	○	○	○	○
5.28	How he/she gets on with other family members	○	○	○	○	○
5.29	Backing him/her up when he/she runs out of money	○	○	○	○	○
5.30	How family members do not understand his/her illness	○	○	○	○	○
5.31	How he/she deliberately tries to harm him/her self	○	○	○	○	○
5.32	I have become closer to some of my family	○	○	○	○	○
5.33	I have become closer to friends	○	○	○	○	○
5.34	I share some of his/her interests	○	○	○	○	○
5.35	I feel useful in my relationships with him/her	○	○	○	○	○
5.36	How health professionals do not understand your situation	○	○	○	○	○
5.37	Whether he/she will ever get well	○	○	○	○	○
5.38	Feeling the stigma of having a mentally ill relative	○	○	○	○	○
5.39	How to explain his/her illness to others	○	○	○	○	○
5.40	Others leaving home because of the effect of the illness	○	○	○	○	○

During the past month how often have you thought that/about:

		Never	*Rarely*	*Sometimes*	*Often*	*Nearly always*
5.41	Setting him/her up in accomm-odation	○	○	○	○	○
5.42	How to make complaints about his/her care	○	○	○	○	○
5.43	I have met helpful people	○	○	○	○	○
5.44	I have discovered strengths in myself	○	○	○	○	○
5.45	Feeling unable to leave him/her home alone	○	○	○	○	○
5.46	The effect of the illness on children in the family	○	○	○	○	○
5.47	The illness causing a family break-up	○	○	○	○	○
5.48	Him/her keeping bad company	○	○	○	○	○
5.49	How his/her illness affects special family events	○	○	○	○	○
5.50	Finding out how hospitals or mental health services work	○	○	○	○	○
5.51	Doctors knowledge of the services available to families	○	○	○	○	○
5.52	The difficulty getting information about his/her illness	○	○	○	○	○

During the past month how often have you thought about him/her being:

		Never	*Rarely*	*Sometimes*	*Often*	*Nearly always*
5.53	Moody	○	○	○	○	○
5.54	Unpredictable	○	○	○	○	○
5.55	Withdrawn	○	○	○	○	○
5.56	Uncommunicative	○	○	○	○	○
5.57	Not interested	○	○	○	○	○
5.58	Slow at doing things	○	○	○	○	○
5.59	Unreliable about doing things	○	○	○	○	○
5.60	Indecisive	○	○	○	○	○
5.61	Irritable	○	○	○	○	○
5.62	Inconsiderate	○	○	○	○	○
5.63	Behaving in a reckless way	○	○	○	○	○
5.64	Suspicious	○	○	○	○	○
5.65	Embarrassing in appearance	○	○	○	○	○
5.66	Behaving in a strange way	○	○	○	○	○

[redacted]

Below is a list of words that describe feelings people have. Please read each one carefully. Then fill in one circle under the answer to the right which best describes how you have been feeling **during the past week including today.**

		Not at all	*A little*	*Moderately*	*Quite a bit*	*Extremely*
6.1	Friendly	○	○	○	○	○
6.2	Tense	○	○	○	○	○
6.3	Angry	○	○	○	○	○
6.4	Worn out	○	○	○	○	○
6.5	Unhappy	○	○	○	○	○
6.6	Clear headed	○	○	○	○	○
6.7	Lively	○	○	○	○	○
6.8	Confused	○	○	○	○	○
6.9	Sorry for things done	○	○	○	○	○
6.10	Shaky	○	○	○	○	○
6.11	Listless	○	○	○	○	○
6.12	Peeved	○	○	○	○	○
6.13	Considerate	○	○	○	○	○
6.14	Sad	○	○	○	○	○
6.15	Active	○	○	○	○	○
6.16	On edge	○	○	○	○	○
6.17	Grouchy	○	○	○	○	○
6.18	Blue	○	○	○	○	○
6.19	Energetic	○	○	○	○	○
6.20	Panicky	○	○	○	○	○
6.21	Hopeless	○	○	○	○	○
6.22	Relaxed	○	○	○	○	○
6.23	Unworthy	○	○	○	○	○
6.24	Spiteful	○	○	○	○	○
6.25	Sympathetic	○	○	○	○	○
6.26	Uneasy	○	○	○	○	○
6.27	Restless	○	○	○	○	○
6.28	Unable to concentrate	○	○	○	○	○
6.29	Fatigued	○	○	○	○	○
6.30	Helpful	○	○	○	○	○
6.31	Annoyed	○	○	○	○	○
6.32	Discouraged	○	○	○	○	○
6.33	Resentful	○	○	○	○	○
6.34	Nervous	○	○	○	○	○
6.35	Lonely	○	○	○	○	○
6.36	Miserable	○	○	○	○	○
6.37	Muddled	○	○	○	○	○
6.38	Cheerful	○	○	○	○	○
6.39	Bitter	○	○	○	○	○
6.40	Exhausted	○	○	○	○	○

Fill in one circle under the answer to the right which best describes how you have been feeling **during the past week including today.**

		Not at all	*A little*	*Moderately*	*Quite a bit*	*Extremely*
6.41	Anxious	○	○	○	○	○
6.42	Ready to fight	○	○	○	○	○
6.43	Good natured	○	○	○	○	○
6.44	Gloomy	○	○	○	○	○
6.45	Desperate	○	○	○	○	○
6.46	Bushed	○	○	○	○	○
6.47	Sluggish	○	○	○	○	○
6.48	Rebellious	○	○	○	○	○
6.49	Helpless	○	○	○	○	○
6.50	Weary	○	○	○	○	○
6.51	Bewildered	○	○	○	○	○
6.52	Alert	○	○	○	○	○
6.53	Deceived	○	○	○	○	○
6.54	Furious	○	○	○	○	○
6.55	Efficient	○	○	○	○	○
6.56	Trusting	○	○	○	○	○
6.57	Full of pep	○	○	○	○	○
6.58	Bad-tempered	○	○	○	○	○
6.59	Worthless	○	○	○	○	○
6.60	Forgetful	○	○	○	○	○
6.61	Carefree	○	○	○	○	○
6.62	Terrified	○	○	○	○	○
6.63	Guilty	○	○	○	○	○
6.64	Vigorous	○	○	○	○	○
6.65	Uncertain about things	○	○	○	○	○

These questions ask how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question **please choose the one** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life ***in the last two weeks.***

Please read each question, assess your feelings, and select the response that gives the best answer for you.

7.1	In general, would you say your health is:	*Excellent* ○	*Very good* ○	*Good* ○	*Fair* ○	*Poor* ○
7.2	How would you rate your quality of life?	*Very poor* ○	*Poor* ○	*Neither good nor poor* ○	*Good* ○	*Very good* ○
7.3	How satisfied are you with your health?	*Very dissatisfied* ○	*Dissatisfied* ○	*Neither satisfied nor dissatisfied* ○	*Satisfied* ○	*Very satisfied* ○
7.4	To what extent do you feel that physical pain prevents you from doing what you need to do?	*Not at all* ○	*A little* ○	*A moderate amount* ○	*Very much* ○	*An extreme amount* ○
7.5	How much do you need any medical treatment to function in your daily life?	○	○	○	○	○
7.6	How much do you enjoy life?	○	○	○	○	○
7.7	To what extent do you feel your life to be meaningful?	○	○	○	○	○
7.8	How well are you able to concentrate?	*Not at all* ○	*A little* ○	*A moderate amount* ○	*Very much* ○	*Extremely* ○
7.9	How safe do you feel in your daily life?	○	○	○	○	○
7.10	How healthy is your physical environment?	○	○	○	○	○
7.11	Do you have enough energy for everyday life?	*Not at all* ○	*A little* ○	*Moderately* ○	*Mostly* ○	*Completely* ○

7.12	Are you able to accept your bodily appearance?	*Not at all* ○	*A little* ○	*Moderately* ○	*Mostly* ○	*Completely* ○
7.13	Have you enough money to meet your needs?	○	○	○	○	○
7.14	How available to you is the information that you need in your day-to-day life?	○	○	○	○	○
7.15	To what extent do you have the opportunity for leisure activities?	○	○	○	○	○
7.16	How well are you able to get around?	*Very poor* ○	*Poor* ○	*Neither poor nor good* ○	*Good* ○	*Very good* ○
7.17	How satisfied are you with your sleep?	*Very dissatisfied* ○	*Dissatisfied* ○	*Neither satisfied nor dissatisfied* ○	*Satisfied* ○	*Very satisfied* ○
7.18	How satisfied are you with your ability to perform your daily living activities?	○	○	○	○	○
7.19	How satisfied are you with your capacity for work?	○	○	○	○	○
7.20	How satisfied are you with yourself?	○	○	○	○	○
7.21	How satisfied are you with your personal relationships?	○	○	○	○	○
7.22	How satisfied are you with your sex life?	○	○	○	○	○
7.23	How satisfied are you with the support you get from your friends?	○	○	○	○	○
7.24	How satisfied are you with the conditions of your living place?	○	○	○	○	○
7.25	How satisfied are you with your access to health services?	○	○	○	○	○
7.26	How satisfied are you with your transport?	○	○	○	○	○
7.27	How often do you have negative feelings such as blue mood, despair, anxiety, or depression?	*Never* ○	*Seldom* ○	*Quite often* ○	*Very often* ○	*Always* ○

We should like to know if you have had any medical complaints and how your health has been in general, ***over the past few weeks***. Please answer **ALL** the questions by ticking or crossing the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.
It is important that you answer **ALL** the questions.

Have you recently….

8.1	Been feeling perfectly well and in good health?	*Better than usual* ○	*Same as usual* ○	*Worse than usual* ○	*Much worse than usual* ○
8.2	Been feeling in need of a good tonic?	*Not at all* ○	*No more than usual* ○	*Rather more than usual* ○	*Much more than usual* ○
8.3	Been feeling run down and out of sorts?	○	○	○	○
8.4	Felt that you are ill?	○	○	○	○
8.5	Been getting any pains in your head?	○	○	○	○
8.6	Been getting a feeling of tightness or pressure in your head?	○	○	○	○
8.7	Having hot or cold spells?	○	○	○	○
8.8	Lost much sleep over worry?	○	○	○	○
8.9	Had difficulty in staying asleep once you are asleep?	○	○	○	○
8.10	Felt constantly under strain?	○	○	○	○
8.11	Been getting edgy and bad-tempered?	○	○	○	○
8.12	Been getting scared or panicky for no good reason?	○	○	○	○
8.13	Found everything getting on top of you?	○	○	○	○
8.14	Been feeling nervous and strung up all the time?	○	○	○	○
8.15	Been managing to keep yourself busy and occupied?	*More so than usual* ○	*Same as usual* ○	*Rather less than usual* ○	*Much less than usual* ○
8.16	Been taking longer over the things that you do?	*Quicker than usual* ○	*Same as usual* ○	*Longer than usual* ○	*Much longer than usual* ○

Over the past few weeks have you recently….

8.17	Felt on the whole you were doing things well?	*Better than usual* ○	*About the same* ○	*Less well than usual* ○	*Much less well* ○
8.18	Been satisfied with the way you've carried out your tasks?	*More satisfied* ○	*About the same as usual* ○	*Less satisfied than usual* ○	*Much less satisfied* ○
8.19	Felt that you are playing a useful part in things?	*More so than usual* ○	*Same as usual* ○	*Rather less than usual* ○	*Much less than usual* ○
8.20	Felt capable of making decisions about things?	○	○	○	○
8.21	Been able to enjoy your normal day-to-day activities?	○	○	○	○
8.22	Been thinking of yourself as a worthless person?	*Not at all* ○	*No more than usual* ○	*Rather more than usual* ○	*Much more than usual* ○
8.23	Felt that life is entirely hopeless?	○	○	○	○
8.24	Felt that life isn't worth living?	○	○	○	○
8.25	Thought of the possibility that you might do away with yourself?	*Definitely not* ○	*I don't think so* ○	*Has crossed my mind* ○	*Definitely has* ○
8.26	Found at times you couldn't do anything because your nerves were too bad?	*Not at all* ○	*No more than usual* ○	*Rather more than usual* ○	*Much more than usual* ○
8.27	Found yourself wishing you were dead and away from it all?	○	○	○	○
8.28	Found the idea of taking your own life kept coming into your mind?	*Definitely not* ○	*I don't think so* ○	*Has crossed my mind* ○	*Definitely has* ○

Thank you for completing this survey. There is another section which will be completed in a discussion with the researcher.

ID f_ _ _

[redacted]

We are trying to assess the various difficulties felt by the families and carers, and will ask you a few questions about these. Please do not hesitate to express your true feelings.

9.1: Financial Burden

9.1a Loss of patient income: Has he/she lost a job? Stopped doing the work which he/she was doing before? To what extent does it affect the family income?	
9.1b Loss of income of any other member of the family due to the patient's illness: Has anyone stopped work in order to stay at home, lost pay, lost a job? To what extent are the family finances affected	
9.1c Expenditure incurred due to patient's illness and treatment: Has he/she spent or lost money irrationally due to illness? How much has this affected the family finances? How much has been spent on treatment, medicines, transport, accommodation away from home etc? How much has been spent on other treatments such as temples and native healers? How much has this affected family finances?	
9.1d Expenditure incurred due to extra arrangements: Other relatives coming to stay with patient, appointing a nurse or servant, boarding out children. How have these affected the family finances?	
9.1e Loans taken or savings spent: How large a loan? How do they plan to pay it back? How much does it affect the family? Did they spend from savings? Were these used up? How much is the family affected?	
9.1f Any other planned activity put off because of financial pressure of the patient's illness: Like postponing a marriage, a journey or a religious rite. How much is the family affected?	

9.2: Disruption of routine family activities

9.2a Patient not going to work, school, college etc: How inconvenient is this for the family?	

9.2b Patient not helping in the household work: How much does this affect the family?	
9.2c Disruption of activities of other members of the family: Has someone had to abandon other routine activities to look after the patient? How inconvenient is this?	
9.2d Patient's behaviour disrupting activities: Patient's insisting on someone being with him/her, not allowing that person to go out, etc? Patient becoming violent, breaking things, not sleeping or allowing others to sleep? How much does this affect the family?	
9.2e Neglect of the rest of the family due to patient's illness: Is any member missing school, meals etc? How serious is this?	

9.3: Disruption of family leisure

9.3a Stopping of normal recreational activities: Completely, partially, not at all? How do the family members react?	
9.3b Patient's illness using up another person's holiday and leisure time: How is this person affected by it?	
9.3c Patient's lack of attention to other members of the family: Such as children and its affects on them.	
9.3d Has any other leisure activity had to be abandoned owing to the patient's illness or incapacity, eg a holiday or family gathering? How do the family members feel about it?	

9.4 : Disruption of family interaction

9.4a Any ill effect on the general atmosphere in the house: Has it become dull, quiet? Are there a lot of misunderstandings etc? How do the family members view this?	
9.4b Do the other members get into arguments over this? Like how the patient should be treated, who should do the work, who is to blame etc. How are they affected?	
9.4c Have relatives and neighbours stopped visiting the family or reduced the frequency of their visits because of the patient's behaviour or the stigma attached to his illness? How does the family feel about this?	
9.4d Has the family become secluded? Does it avoid mixing with others because of shame or fear of being misunderstood? How do the members feel about this?	
9.4e Has the patient's illness had any other effect on relationships within the family or between the family and neighbours or relatives? ie: separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members etc. How does the family feel about it?	

9.5 : Effect on physical health of others

9.5a Have any other members of the family suffered physical ill health, injuries etc due to the patient's behaviour? How has this affected them?	
9.5b Has there been any other adverse effect on health, like someone loosing weight or an existing illness being exacerbated? How severe is it?	

9.6 : Effect on mental health of others

9.6a Has any other family member sought help for psychological illness brought on by the patient's behaviour? For instance by a patient's suicide bid, or his/her disobedience, or worry about his/her future. How severe is this?	
9.6b Has any other member of the family lost sleep, become depressed, or weepy, expressed suicidal wishes, become excessively irritable etc? How severely?	

9.7 Finally:

9.7a Is there any other burden on the family about which we have not asked you? If so, what is it? How badly does it affect you?	

Subjective burden on the family:

9.7b How much would you say **you have suffered** owing to the patient's illness, severely, a little, or not at all? (Circle on response only).

Severely **A little** **Not at all**

10: Hopes and expectations

10.1.a What are you hoping to do for yourself next year?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:
  Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

10.1.b How much energy will you put towards these things?

Do you feel excited about these things?
How confident are you of reaching these things?

10.1.c Have you been thinking about any strategies to achieve these things?

How certain are you that the plan of X will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

10.2.a What are you hoping for your family/X and you ?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:

Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

10.2.b How much energy will you and the family put towards these things?

Do you and the family feel excited about these things?
How confident are you of yourself and the family reaching these things?

10.2.c Have you been thinking about any strategies to achieve these things ?
How certain are you that the plan of X will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

10.3. a Do you have any goals, hopes or expectations related to doing the BFST family sessions/working with your/X's case-manager?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:
  Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

10.3.b How much energy will you and the case-manager put towards these things?

Do you and the case-manager feel excited about these things?
How confident are you of you and Z [case-manager] reaching these things?

10.3.c Have you been thinking about any strategies to achieve these things
How certain are you that the plan of Y will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

Appendix 1.4 Carer follow-up questionnaire

V2

Office use only		
Interviewer…… Venue H / O / Oth	NW / MW/ N	ID Con†
Date of interview……..	Interpreter Y / N	Match ID Fam†

Follow-up interview for family

This questionnaire asks you some simple questions about yourself, your general well-being and your experience of caring for your relative. This first part can be filled in by yourself independently, or with help from the researchers. The researchers will also talk to you some more about your life with your family member.

This questionnaire is 22 pages long. Please complete sections 1 to 8 (pages 2 to 15) which will take you about 35 minutes to complete. Section 9 will be completed during a discussion with the researcher.

- Please read each question carefully
- Some answers are completed by writing the answer in the space provided eg. In which country were you born? .....
- Other answers are completed by ticking or filling in the circle for the answer which best describes you eg the circle like this ○ , becomes this ● or ✓.
- Remember, only select <u>one</u> circle for each question to fill in,
- If you make a mistake, just cross out your answer and select the answer that best describes you. There are no right or wrong answers.

Thank you for your help.

Dr Carol Harvey
Principal Researcher
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Ms Laura Hayes
Research Fellow
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Please return to:
Laura Hayes
Psychosocial Research Centre
130 Bell St
Coburg 3058
t: 9355 9827 e:lmhayes@unimelb.edu.au

[redacted]

1.1 What are your living arrangements?

- Own home
- Rented home (private accommodation)
- Rented home (public accommodation)
- Rented room
- Family home (eg with your parents)
- Crisis/sheltered accommodation
- Group or supported accommodation
- Institution

1.2 What is your current working status?

- Working full time
- Working part time
- Unemployed, or looking for work
- Homemaker
- Student
- Retired receiving sickness benefits
- Receiving disability support or pension

1.3 Best employment status in past year

- Working full time
- Working part time
- Unemployed, or looking for work
- Homemaker
- Student
- Retired receiving sickness benefits
- Receiving disability support or pension

1.4 Are you receiving any Social security, pension or sickness benefits payments?

- Yes, please list your benefit:…….
- No

1.5 Have any of the following life events occurred in the last 10 months?

	Yes	*No*
Taken on loan or mortgage	○	○
Change in job/study	○	○
Started job/study	○	○
Change in residence/living arrangements	○	○
Death of close friend	○	○
Death of family member	○	○
Death of spouse/partner	○	○
Change in financial state	○	○
Change in health of family member	○	○
Pregnancy	○	○
Marriage	○	○
Personal injury or illness	○	○
Separation from spouse or partner	○	○
Divorce	○	○
Any other significant changes (1)……	○	○
Any other significant changes (2)……	○	○

1.6 Have you undertaken any treatment over the past 10 months? (tick as many as apply to you.

- ○ Building Family Skills Together (BFST) program
- ○ Other family therapy
- ○ Seen a private therapist such as a psychiatrist, psychologist, or counsellor
- ○ Joined a group at the area mental health centre, specify……
- ○ Joined a group NOT at the area mental health centre, specify……

The following questions are about the relationship with your family member receiving treatment.

1.7 Do you live with them?

- ○ Yes
- ○ No

1.8 How often do you see them?

- ○ More than once a day
- ○ Once a day
- ○ A few times a week
- ○ Weekly
- ○ About once a fortnight
- ○ Less often

1.9 How often do you speak to them on the phone?

- ○ More than once a day
- ○ Once a day
- ○ A few times a week
- ○ Weekly
- ○ About once a fortnight
- ○ Less often

During the past 4 weeks
(Please fill in the answer that best describes you)

		Almost Always	*Most of the time*	*About half the time*	*Occasionally*	*Not at all*
2.1	It has been easy to relate to others	○	○	○	○	○
2.2	I felt isolated from other people	○	○	○	○	○
2.3	I had someone to share my feelings with	○	○	○	○	○
2.4	I found it easy to get in touch with others when I needed to	○	○	○	○	○
2.5	When with other people, I felt separate from them	○	○	○	○	○
2.6	I felt alone and friendless	○	○	○	○	○

We should like to know if you have had any medical complaints and how your health has been in general, ***over the past few weeks***. Please answer **ALL** the questions by ticking or crossing the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you answer **ALL** the questions.

Have you recently….

3.1	Been feeling perfectly well and in good health?	*Better than usual* ○	*Same as usual* ○	*Worse than usual* ○	*Much worse than usual* ○
3.2	Been feeling in need of a good tonic?	*Not at all* ○	*No more than usual* ○	*Rather more than usual* ○	*Much more than usual* ○
3.3	Been feeling run down and out of sorts?	○	○	○	○
3.4	Felt that you are ill?	○	○	○	○
3.5	Been getting any pains in your head?	○	○	○	○
3.6	Been getting a feeling of tightness or pressure in your head?	○	○	○	○
3.7	Having hot or cold spells?	○	○	○	○
3.8	Lost much sleep over worry?	○	○	○	○
3.9	Had difficulty in staying asleep once you are asleep?	○	○	○	○
3.10	Felt constantly under strain?	○	○	○	○
3.11	Been getting edgy and bad-tempered?	○	○	○	○
3.12	Been getting scared or panicky for no good reason?	○	○	○	○
3.13	Found everything getting on top of you?	○	○	○	○
3.14	Been feeling nervous and strung up all the time?	○	○	○	○
3.15	Been managing to keep yourself busy and occupied?	*More so than usual* ○	*Same as usual* ○	*Rather less than usual* ○	*Much less than usual* ○
3.16	Been taking longer over the things that you do?	*Quicker than usual* ○	*Same as usual* ○	*Longer than usual* ○	*Much longer than usual* ○

Over the past few weeks have you recently….

3.17	Felt on the whole you were doing things well?	*Better than usual* ○	*About the same* ○	*Less well than usual* ○	*Much less well* ○
3.18	Been satisfied with the way you've carried out your tasks?	*More satisfied* ○	*About the same as usual* ○	*Less satisfied than usual* ○	*Much less satisfied* ○
3.19	Felt that you are playing a useful part in things?	*More so than usual* ○	*Same as usual* ○	*Rather less than usual* ○	*Much less than usual* ○
3.20	Felt capable of making decisions about things?	○	○	○	○
3.21	Been able to enjoy your normal day-to-day activities?	○	○	○	○
3.22	Been thinking of yourself as a worthless person?	*Not at all* ○	*No more than usual* ○	*Rather more than usual* ○	*Much more than usual* ○
3.23	Felt that life is entirely hopeless?	○	○	○	○
3.24	Felt that life isn't worth living?	○	○	○	○
3.25	Thought of the possibility that you might do away with yourself?	*Definitely not* ○	*I don't think so* ○	*Has crossed my mind* ○	*Definitely has* ○
3.26	Found at times you couldn't do anything because your nerves were too bad?	*Not at all* ○	*No more than usual* ○	*Rather more than usual* ○	*Much more than usual* ○
3.27	Found yourself wishing you were dead and away from it all?	○	○	○	○
3.28	Found the idea of taking your own life kept coming into your mind?	*Definitely not* ○	*I don't think so* ○	*Has crossed my mind* ○	*Definitely has* ○

[redacted]

These questions ask how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life ***in the last two weeks.***

Please read each question, assess your feelings, and select the response that gives the best answer for you.

4.1	In general, would you say your health is:	*Excellent* ○	*Very good* ○	*Good* ○	*Fair* ○	*Poor* ○
4.2	How would you rate your quality of life?	*Very poor* ○	*Poor* ○	*Neither good nor poor* ○	*Good* ○	*Very good* ○
4.3	How satisfied are you with your health?	*Very dissatisfied* ○	*Dissatisfied* ○	*Neither satisfied nor dissatisfied* ○	*Satisfied* ○	*Very satisfied* ○
4.4	To what extent do you feel that physical pain prevents you from doing what you need to do?	*Not at all* ○	*A little* ○	*A moderate amount* ○	*Very much* ○	*An extreme amount* ○
4.5	How much do you need any medical treatment to function in your daily life?	○	○	○	○	○
4.6	How much do you enjoy life?	○	○	○	○	○
4.7	To what extent do you feel your life to be meaningful?	○	○	○	○	○
4.8	How well are you able to concentrate?	*Not at all* ○	*A little* ○	*A moderate amount* ○	*Very much* ○	*Extremely* ○
4.9	How safe do you feel in your daily life?	○	○	○	○	○
4.10	How healthy is your physical environment?	○	○	○	○	○
4.11	Do you have enough energy for everyday life?	*Not at all* ○	*A little* ○	*Moderately* ○	*Mostly* ○	*Completely* ○

4.12	Are you able to accept your bodily appearance?	*Not at all* ○	*A little* ○	*Moderately* ○	*Mostly* ○	*Completely* ○
4.13	Have you enough money to meet your needs?	○	○	○	○	○
4.14	How available to you is the information that you need in your day-to-day life?	○	○	○	○	○
4.15	To what extent do you have the opportunity for leisure activities?	○	○	○	○	○
4.16	How well are you able to get around?	*Very poor* ○	*Poor* ○	*Neither poor nor good* ○	*Good* ○	*Very good* ○
4.17	How satisfied are you with your sleep?	*Very dissatisfied* ○	*Dissatisfied* ○	*Neither satisfied nor dissatisfied* ○	*Satisfied* ○	*Very satisfied* ○
4.18	How satisfied are you with your ability to perform your daily living activities?	○	○	○	○	○
4.19	How satisfied are you with your capacity for work?	○	○	○	○	○
4.20	How satisfied are you with yourself?	○	○	○	○	○
4.21	How satisfied are you with your personal relationships?	○	○	○	○	○
4.22	How satisfied are you with your sex life?	○	○	○	○	○
4.23	How satisfied are you with the support you get from your friends?	○	○	○	○	○
4.24	How satisfied are you with the conditions of your living place?	○	○	○	○	○
4.25	How satisfied are you with your access to health services?	○	○	○	○	○
4.26	How satisfied are you with your transport?	○	○	○	○	○
4.27	How often do you have negative feelings such as blue mood, despair, anxiety, or depression?	*Never* ○	*Seldom* ○	*Quite often* ○	*Very often* ○	*Always* ○

The following questionnaire contains a number of statements that commonly apply to persons who care for relatives or friends with a serious mental illness.

We would like you to read each one and decide how often it is applied to you ***over the past one month***.

If is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While there seems to be a lot of statements, you will find that it will not take more than a moment or so to answer each one.

During the past month how often have you thought that/about:

		Never	*Rarely*	*Sometimes*	*Often*	*Nearly always*
5.1	Your covering up his/her illness	○	○	○	○	○
5.2	Feeling unable to tell anyone of the illness	○	○	○	○	○
5.3	His/her difficulty looking after the money	○	○	○	○	○
5.4	Having to support him/her	○	○	○	○	○
5.5	What sort of life he/she might have had	○	○	○	○	○
5.6	His/her risk of committing suicide	○	○	○	○	○
5.7	I have learnt more about myself	○	○	○	○	○
5.8	I have contributed to others understanding of the illness	○	○	○	○	○
5.9	Being unable to do the things that you want to do	○	○	○	○	○
5.10	How health professionals do not take you seriously	○	○	○	○	○
5.11	His/her dependence on you	○	○	○	○	○
5.12	Helping him/her to fill in the day	○	○	○	○	○
5.13	I have contributed to his wellbeing	○	○	○	○	○
5.14	That he/she makes a valuable contribution to the household	○	○	○	○	○
5.15	The effect on your finances if he/she becomes more seriously ill	○	○	○	○	○

During the past month how often have you thought that/about:

		Never	*Rarely*	*Sometimes*	*Often*	*Nearly always*
5.16	Dealing with psychiatrists	○	○	○	○	○
5.17	Him/her always being at the back of your mind	○	○	○	○	○
5.18	Whether you have done something to make him/her ill	○	○	○	○	○
5.19	That he/she has shown some strengths in coping with his illness	○	○	○	○	○
5.20	I have become more confident in dealing with others	○	○	○	○	○
5.21	How family members do not understand your situation	○	○	○	○	○
5.22	That he/she is good company	○	○	○	○	○
5.23	I have become more under-standing of others with problems	○	○	○	○	○
5.24	How he/she thinks a lot about death	○	○	○	○	○
5.25	His/her lost opportunities	○	○	○	○	○
5.26	How to deal with mental health professionals	○	○	○	○	○
5.27	Feeling unable to have visitors at home	○	○	○	○	○
5.28	How he/she gets on with other family members	○	○	○	○	○
5.29	Backing him/her up when he/she runs out of money	○	○	○	○	○
5.30	How family members do not understand his/her illness	○	○	○	○	○
5.31	How he/she deliberately tries to harm him/her self	○	○	○	○	○
5.32	I have become closer to some of my family	○	○	○	○	○
5.33	I have become closer to friends	○	○	○	○	○
5.34	I share some of his/her interests	○	○	○	○	○
5.35	I feel useful in my relationships with him/her	○	○	○	○	○
5.36	How health professionals do not understand your situation	○	○	○	○	○
5.37	Whether he/she will ever get well	○	○	○	○	○
5.38	Feeling the stigma of having a mentally ill relative	○	○	○	○	○
5.39	How to explain his/her illness to others	○	○	○	○	○
5.40	Others leaving home because of the effect of the illness	○	○	○	○	○

During the past month how often have you thought that/about:

		Never	*Rarely*	*Sometimes*	*Often*	*Nearly always*
5.41	Setting him/her up in accomm-odation	○	○	○	○	○
5.42	How to make complaints about his/her care	○	○	○	○	○
5.43	I have met helpful people	○	○	○	○	○
5.44	I have discovered strengths in myself	○	○	○	○	○
5.45	Feeling unable to leave him/her home alone	○	○	○	○	○
5.46	The effect of the illness on children in the family	○	○	○	○	○
5.47	The illness causing a family break-up	○	○	○	○	○
5.48	Him/her keeping bad company	○	○	○	○	○
5.49	How his/her illness affects special family events	○	○	○	○	○
5.50	Finding out how hospitals or mental health services work	○	○	○	○	○
5.51	Doctors knowledge of the services available to families	○	○	○	○	○
5.52	The difficulty getting information about his/her illness	○	○	○	○	○

During the past month how often have you thought about him/her being:

		Never	*Rarely*	*Sometimes*	*Often*	*Nearly always*
5.53	Moody	○	○	○	○	○
5.54	Unpredictable	○	○	○	○	○
5.55	Withdrawn	○	○	○	○	○
5.56	Uncommunicative	○	○	○	○	○
5.57	Not interested	○	○	○	○	○
5.58	Slow at doing things	○	○	○	○	○
5.59	Unreliable about doing things	○	○	○	○	○
5.60	Indecisive	○	○	○	○	○
5.61	Irritable	○	○	○	○	○
5.62	Inconsiderate	○	○	○	○	○
5.63	Behaving in a reckless way	○	○	○	○	○
5.64	Suspicious	○	○	○	○	○
5.65	Embarrassing in appearance	○	○	○	○	○
5.66	Behaving in a strange way	○	○	○	○	○

[redacted]

Below is a list of words that describe feelings people have. Please read each one carefully. Then fill in one circle under the answer to the right which best describes how you have been feeling **during the past week including today.**

		Not at all	*A little*	*Moderately*	*Quite a bit*	*Extremely*
6.1	Friendly	○	○	○	○	○
6.2	Tense	○	○	○	○	○
6.3	Angry	○	○	○	○	○
6.4	Worn out	○	○	○	○	○
6.5	Unhappy	○	○	○	○	○
6.6	Clear headed	○	○	○	○	○
6.7	Lively	○	○	○	○	○
6.8	Confused	○	○	○	○	○
6.9	Sorry for things done	○	○	○	○	○
6.10	Shaky	○	○	○	○	○
6.11	Listless	○	○	○	○	○
6.12	Peeved	○	○	○	○	○
6.13	Considerate	○	○	○	○	○
6.14	Sad	○	○	○	○	○
6.15	Active	○	○	○	○	○
6.16	On edge	○	○	○	○	○
6.17	Grouchy	○	○	○	○	○
6.18	Blue	○	○	○	○	○
6.19	Energetic	○	○	○	○	○
6.20	Panicky	○	○	○	○	○
6.21	Hopeless	○	○	○	○	○
6.22	Relaxed	○	○	○	○	○
6.23	Unworthy	○	○	○	○	○
6.24	Spiteful	○	○	○	○	○
6.25	Sympathetic	○	○	○	○	○
6.26	Uneasy	○	○	○	○	○
6.27	Restless	○	○	○	○	○
6.28	Unable to concentrate	○	○	○	○	○
6.29	Fatigued	○	○	○	○	○
6.30	Helpful	○	○	○	○	○
6.31	Annoyed	○	○	○	○	○
6.32	Discouraged	○	○	○	○	○
6.33	Resentful	○	○	○	○	○
6.34	Nervous	○	○	○	○	○
6.35	Lonely	○	○	○	○	○
6.36	Miserable	○	○	○	○	○
6.37	Muddled	○	○	○	○	○
6.38	Cheerful	○	○	○	○	○
6.39	Bitter	○	○	○	○	○
6.40	Exhausted	○	○	○	○	○

Fill in one circle under the answer to the right which best describes how you have been feeling **during the past week including today.**

		Not at all	*A little*	*Moderately*	*Quite a bit*	*Extremely*
6.41	Anxious	○	○	○	○	○
6.42	Ready to fight	○	○	○	○	○
6.43	Good natured	○	○	○	○	○
6.44	Gloomy	○	○	○	○	○
6.45	Desperate	○	○	○	○	○
6.46	Bushed	○	○	○	○	○
6.47	Sluggish	○	○	○	○	○
6.48	Rebellious	○	○	○	○	○
6.49	Helpless	○	○	○	○	○
6.50	Weary	○	○	○	○	○
6.51	Bewildered	○	○	○	○	○
6.52	Alert	○	○	○	○	○
6.53	Deceived	○	○	○	○	○
6.54	Furious	○	○	○	○	○
6.55	Efficient	○	○	○	○	○
6.56	Trusting	○	○	○	○	○
6.57	Full of pep	○	○	○	○	○
6.58	Bad-tempered	○	○	○	○	○
6.59	Worthless	○	○	○	○	○
6.60	Forgetful	○	○	○	○	○
6.61	Carefree	○	○	○	○	○
6.62	Terrified	○	○	○	○	○
6.63	Guilty	○	○	○	○	○
6.64	Vigorous	○	○	○	○	○
6.65	Uncertain about things	○	○	○	○	○

Part 7: Some questions about goals in your life

Read each item carefully. Please select (and circle) the number that best describes you.

		Definitely false	***Mostly false***	***Mostly True***	***Definitely True***
7.1	I can think of many ways to get out of a jam.	○	○	○	○
7.2	I energetically pursue my goals.	○	○	○	○
7.3	I feel tired most of the time.	○	○	○	○
7.4	There are lots of ways around any problem.	○	○	○	○
7.5	I am easily downed in an argument	○	○	○	○
7.6	I can think of many ways to get the things in life that are most important to me.	○	○	○	○
7.7	I worry about my health.	○	○	○	○
7.8	Even when others get discouraged, I know I can find a way to solve the problem.	○	○	○	○
7.9	My past experiences have prepared me well for my future.	○	○	○	○
7.10	I have been pretty successful in life.	○	○	○	○
7.11	I usually find myself worrying about something.	○	○	○	○
7.12	I meet the goals that I set for myself.	○	○	○	○

Part 8: Some questions about how you feel about your family

Please respond to the items in terms of how you feel your family has been functioning in the past two months.

Complete the questions privately. Do not discuss your responses with other family members as we are interested in your personal view of your family.

Please read each statement carefully and decide how well it describes your family. You should answer according to how you see your family.

For each statement there is an answer space below. Try not to spend too much time thinking about each statement but respond as quickly and as honestly as you can. If you have trouble with one question, answer with your first reaction. Please be sure to answer every statement and mark all your answers in the space provided below each statement.

		Strongly agree	***Agree***	***Disagree***	***Strongly disagree***
8.1	Planning family activities is difficult because we misunderstand each other.	○	○	○	○
8.2	In times of crisis we can turn to each other for support.	○	○	○	○
8.3	We cannot talk to each other about the sadness we feel.	○	○	○	○
8.4	Individuals are accepted for what they are.	○	○	○	○
8.5	Making decisions is a problem for our family.	○	○	○	○
8.6	We can express feelings to each other.	○	○	○	○
8.7	There are lots of bad feelings in the family.	○	○	○	○
8.8	We feel accepted for what we are.	○	○	○	○
8.9	We avoid discussing our fears and concerns.	○	○	○	○
8.10	We are able to make decisions about how to solve problems.	○	○	○	○
8.11	We don't get along well together.	○	○	○	○
8.12	We confide in each other.	○	○	○	○

Thank you for completing this survey. There is another section which will be completed in a discussion with the researcher.

We are trying to assess the various difficulties felt by the family of a psychiatric patient, and will ask you a few questions about these. Please do not hesitate to express your true feelings.

9.1: Financial Burden

9.1a Loss of patient income: Has he/she lost a job? Stopped doing the work which he/she was doing before? To what extent does it affect the family income?	
9.1b Loss of income of any other member of the family due to the patient's illness: Has anyone stopped work in order to stay at home, lost pay, lost a job? To what extent are the family finances affected	
9.1c Expenditure incurred due to patient's illness and treatment: Has he/she spent or lost money irrationally due to illness? How much has this affected the family finances? How much has been spent on treatment, medicines, transport, accommodation away from home etc? How much has been spent on other treatments such as temples and native healers? How much has this affected family finances?	
9.1d Expenditure incurred due to extra arrangements: Other relatives coming to stay with patient, appointing a nurse or servant, boarding out children. How have these affected the family finances?	
9.1e Loans taken or savings spent: How large a loan? How do they plan to pay it back? How much does it affect the family? Did they spend from savings? Were these used up? How much is the family affected?	
9.1f Any other planned activity put off because of financial pressure of the patient's illness: Like postponing a marriage, a journey or a religious rite. How much is the family affected?	

9.2: Disruption of routine family activities

9.2a Patient not going to work, school, college etc: How inconvenient is this for the family?	

9.2b Patient not helping in the household work: How much does this affect the family?	
9.2c Disruption of activities of other members of the family: Has someone had to abandon other routine activities to look after the patient? How inconvenient is this?	
9.2d Patient's behaviour disrupting activities: Patient's insisting on someone being with him/her, not allowing that person to go out, etc? Patient becoming violent, breaking things, not sleeping or allowing others to sleep? How much does this affect the family?	
9.2e Neglect of the rest of the family due to patient's illness: Is any member missing school, meals etc? How serious is this?	

9.3: Disruption of family leisure

9.3a Stopping of normal recreational activities: Completely, partially, not at all? How do the family members react?	
9.3b Patient's illness using up another person's holiday and leisure time: How is this person affected by it?	
9.3c Patient's lack of attention to other members of the family: Such as children and its affects on them.	
9.3d Has any other leisure activity had to be abandoned owing to the patient's illness or incapacity, eg a holiday or family gathering? How do the family members feel about it?	

9.4 : Disruption of family interaction

9.4a Any ill effect on the general atmosphere in the house: Has it become dull, quiet? Are there a lot of misunderstandings etc? How do the family members view this?	
9.4b Do the other members get into arguments over this? Like how the patient should be treated, who should do the work, who is to blame etc. How are they affected?	
9.4c Have relatives and neighbours stopped visiting the family or reduced the frequency of their visits because of the patient's behaviour or the stigma attached to his illness? How does the family feel about this?	
9.4d Has the family become secluded? Does it avoid mixing with others because of shame or fear of being misunderstood? How do the members feel about this?	
9.4e Has the patient's illness had any other effect on relationships within the family or between the family and neighbours or relatives? ie: separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members etc. How does the family feel about it?	

9.5 : Effect on physical health of others

9.5a Have any other members of the family suffered physical ill health, injuries etc due to the patient's behaviour? How has this affected them?	
9.5b Has there been any other adverse effect on health, like someone loosing weight or an existing illness being exacerbated? How severe is it?	

9.6 : Effect on mental health of others

9.6a Has any other family member sought help for psychological illness brought on by the patient's behaviour? For instance by a patient's suicide bid, or his/her disobedience, or worry about his/her future. How severe is this?	
9.6b Has any other member of the family lost sleep, become depressed, or weepy, expressed suicidal wishes, become excessively irritable etc? How severely?	

9.7 Finally:

9.7a Is there any other burden on the family about which we have not asked you? If so, what is it? How badly does it affect you?	

Subjective burden on the family:

9.7b How much would you say **you have suffered** owing to the patient's illness, severely, a little, or not at all? (Circle on response only).

Severely **A little** **Not at all**

Part 10: some questions reviewing your treatment.

10.1.a What are you hoping to do for yourself next year?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:
  Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

10.1.b How much energy will you put towards these things?

Do you feel excited about these things?
How confident are you of reaching these things?

10.1.c Have you been thinking about any strategies to achieve these things?

How certain are you that the plan of X will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

10.2.a What are you hoping for your family/X and you ?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:

Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

10.2.b How much energy will you and the family put towards these things?

Do you and the family feel excited about these things?
How confident are you of yourself and the family reaching these things?

10.2.c Have you been thinking about any strategies to achieve these things ?
How certain are you that the plan of X will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

10.3. a Do you have any goals, hopes or expectations related to doing the BFST family sessions/working with your/X's case-manager?

- Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty?
- Maybe they are about sustaining or improving in an area that you are already working on?
- Some of the areas that people have goals in are:
  Work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?

10.3.b How much energy will you and the case-manager put towards these things?

Do you and the case-manager feel excited about these things?
How confident are you of you and Z [case-manager] reaching these things?

10.3.c Have you been thinking about any strategies to achieve these things
How certain are you that the plan of Y will work?
What would you do if there was a set back or problems occurring as you go along?
What might prevent you from achieving them?

TREATMENT ONLY

10. 4a How did you get along with your helpers?

10.4b How were things like manners, punctuality and follow through (doing what they were said they would?)

10.5a What was it like working together (with your family) in sessions?

10.5b Do you think that you understand (your relative) better as a result of this BFST work? Do you think that they understand you better?

10.6a What's different about how the family talks together or deals with things together?

Some of the areas things may change might be:

- how openly people talk together
- how to solve differences and challenges
- how people talk about feelings
- how they respond when you are upset
- changes in roles, different understanding of who does what
- agreement about house rules

10.7 What has changed for you through this experience?

10.8 How have the hopes and goals we talked about before changed?

10.9 What were some key moments/ pivotal situations/ turning points/ most important revelations?

10.10 What have you learned from the BFST program?

Did you learn anything more about schizophrenia?

Some of the things that would have been covered were…….

- how to ask for things directly
- listening
- expressing unpleasant and positive feelings
- how to resolve issues and challenges and setting goals

10.11aAnd finally…..

If a friend or acquaintance asked you whether or not BFST was worth doing, what advice would you give them?

10.11b What advice would you like to give us about our BFST program?

Appendix 1.5 Case manager baseline questionnaire

Date of baseline interview……

ID Cons ____ ____ ____

Baseline questionnaire for case manager

This questionnaire asks you about some simple questions about the client you case-manage.

This questionnaire is 4 pages long. Please complete sections 8 to 10 (pages 2 to 4) which will take you about 10 minutes to complete.

- Please read each question carefully.
- Part 8 is completed by ticking or filling in the circle for the answer which best describes the client eg the circle like this ○ , becomes this ● or ✓.
- Part 9 is completed by circling a number eg the number like this, 2, becomes ②.
- Part 10 is completed by writing the answer in the space provided eg. Number of admissions .....
- Remember, only select <u>one</u> circle for each question to fill in,
- If you make a mistake, just cross out your answer and select the answer that best describes your client. There are no right or wrong answers.

Thank you for your help.

Dr Carol Harvey
Principal Researcher
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Ms Laura Hayes
Research Fellow
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Please return to:
Laura Hayes
Psychosocial Research Centre
130 Bell St
Coburg 3058

Tel: 9355 9827
Fax: 9355 9855
Email: lmhayes@unimelb.edu.au

Please rate the average functioning over the last 3 months

8.1	Does this person generally have any difficulty with initiating and responding to conversation?	*No difficulty* ○	*Slight difficulty* ○	*Moderate* ○	*Extreme* ○
8.2	Does this person generally withdraw from social contact?	*Does not withdraw at all* ○	*Withdraws slightly* ○	*Withdraws moderately* ○	*Withdraws (near) total* ○
8.3	Does this person generally show warmth to others?	*Considerable warmth* ○	*Moderate warmth* ○	*Slight warmth* ○	*No warmth at all* ○
8.4	Is this person generally well groomed (eg neatly dressed, hair combed?)	*Well groomed* ○	*Moderate well groomed* ○	*Poorly groomed* ○	*Extremely poorly groomed* ○
8.5	Does this person wear clean clothes generally, or ensure they are cleaned if dirty?	*Maintains cleanliness* ○	*Moderate cleanliness* ○	*Poor cleanliness* ○	*Very poor cleanliness* ○
8.6	Does this person generally neglect his/her physical health?	*No neglect* ○	*Slight neglect* ○	*Moderate neglect* ○	*Extreme neglect* ○
8.7	Is this person violent to others?	*Not at all* ○	*Rarely* ○	*Occasionally* ○	*Often* ○
8.8	Does this person generally make and/or keep up friendships?	*Friendships made/kept well* ○	*Friendships made/kept with slight difficulty* ○	*Friendships made/kept with considerable difficulty* ○	*No friendships made/kept* ○
8.9	Does this person generally maintain an adequate diet?	*No problem* ○	*Slight problem* ○	*Moderate problem* ○	*Extreme problem* ○
8.10	Does this person generally look after and take her/his prescribed medications (or attend for prescribed injections on time) without reminding?	*Reliable* ○	*Slightly unreliable* ○	*Moderately unreliable* ○	*Extremely unreliable* ○
8.11	Is this person willing to take psychiatric medication when prescribed by a doctor?	*Always* ○	*Usually* ○	*Rarely* ○	*Never* ○
8.12	Does this person co-operate with health services (eg doctors and/or other health workers)?	○	○	○	○
8.13	Does this person generally have problems (eg friction, avoidance) living with others in the household)?	*No obvious problems* ○	*Slight problems* ○	*Moderate problems* ○	*Extreme problems* ○
8.14	Does this person behave offensively (includes sexual)?	*Not at all* ○	*Rarely* ○	*Occasionally* ○	*Often* ○
8.15	Does this person behave irresponsibly?	○	○	○	○
8.16	What sort of work is this person capable of (even if unemployed, retired or doing unpaid domestic duties)?	*Capable of full-time work* ○	*Capable of part-time work* ○	*Capable of sheltered work* ○	*Totally incapable of work* ○

	Domain	Score	
9.1	**Working productivity** *Rate the client in the most expected role (ie. home-maker, student, wage earner)*	1	Productivity severely limited, often unable to work or adapt to school or home-making: virtually no skills or attempt to be productive
		2	Occasional attempts at productivity are unsuccessful, productive only with constant supervision in sheltered work, home or special classes
		3	Limited productivity: often with restricted skills/ abilities for home-making, school, independent employment (eg requires highly structured routine)
		4	Marginal productivity (eg productive in sheltered work or minimally productive in independent work: fluctuates at home, in school; frequent job changes
		5	Moderately functional in independent employment, at home or in school. (Consider very spotty work history or fluctuations in home, in school with extended periods of success).
		6	Adequate functioning in independent employment home or school; often not applying all available skills/ abilities
		7	Optimally performs homemaking, school tasks or employment-related functions with ease and efficiency.
9.2	**Independent Living, Self Care** *Management of household, eating, sleeping, hygiene care*	1	Lacking self-care skills approaching life endangering threat, often involves multiple and lengthy hospital services, not physically able to participate in running a household
		2	Marked limitations in self-care/ independent living: often involving constant supervision in or out of protective environment (eg frequent utilisation of crisis services)
		3	Limited self-care/ independent living skills; often relying on mental/ physical health care; limited participation in running household
		4	Marginally self sufficient often uses REGULAR assistance to maintain self care/ independent functioning, minimally participates in running household
		5	Moderately self-sufficient, ie living independently with ROUTINE assistance (eg home visits by nurses, other helping persons)
		6	Adequate independent living and self care with MINIMAL support (eg some transportation, shopping, assistance with neighbours)
		7	Optimal care of health/ hygiene; independently manages to meet personal needs and household tasks
9.3	**Immediate social network relationships** *Close friends, spouse, family*	1	Severely deviant behaviours within immediate social networks (ie often with imminent physical aggression or abuse to others or severely withdrawn from close friends spouse, family, often rejected by immediate social network)
		2	Marked limitations in immediate interpersonal relationships (eg excessive dependency or destructive communication or behaviours)
		3	Limited interpersonally; often no significant participation/communication with immediate social network
		4	Marginal functioning with immediate social network (ie relationships are often minimal and fluctuate in quality)
		5	Moderate affective continuing and close relationship with at least one other person
		6	Adequate personal relationship with one or more immediate member of social network (eg friend or family)
		7	Positive relationships with spouse or family and friends assertively contributes to these relationships
9.4	**Extended social network relationships** *Neighbourhood, community, church, clubs, agencies, recreational activities*	1	Severely deviant behaviour within extended social networks (ie overtly disruptive, often leading to rejection by extended social networks)
		2	Often totally isolated from extended social networks refusing community involvement or belligerent to helpers, neighbours etc
		3	Limited range of successful and appropriate interaction in extended social networks (ie often restricts community involvement to minimal survival interactions)
		4	Marginally effective interactions, often in a structured environment, may receive multiple public system support in accord with multiple needs.
		5	Moderately affective and independent in community interactions; may receive some public support in accord with need
		6	Adequately interacts in neighbourhood or with at least one community or other organisation or recreational activity.
		7	Positively interacts in community, church or clubs, recreational activities, hobbies or personal interests often with other participants

Part 10: CMI-RAPID and case-note review baseline

During the previous year:

10.1 Antipsychotic medication prescribed

- ○ None
- ○ Oral anti-psychotics
- ○ Depot anti-psychotics
- ○ Combination of oral and depot anti-psychotics. Specify

10.2 Other medications prescribed

- ○ None
- ○ Anticholinergics
- ○ Lithium
- ○ Antidepressants
- ○ Sedatives or hypnotics
- ○ Other, specify……..…
- ○ Combination, specify……..

10.3 Numbers of admissions during past year…….

10.4 Total length of stay (days) during past year…….

10.5 Number of CATT referrals during past year……..

10.6 Other episodes of relapse documented during past year……

10.7 Number of service contacts during past year…….

10.8 Total length of illness……..

10.09 Diagnosis……

10.10 Comorbidities:

- ○ None
- ○ Alcohol abuse / dependence
- ○ Substance abuse / dependence
- ○ Depression
- ○ OCD
- ○ Intellectual disability
- ○ Other, specify……..

Research only

10.11 Antipsychotic medication in mg chlorpromazine equivalents per day …….

Appendix 1.6 Case manager follow-up questionnaire

Date of follow up interview……

ID Cons ____ ____ ____

Follow up questionnaire for consumer

This questionnaire asks you about some simple questions about the client you case-manage.

This questionnaire is 4 pages long. Please complete sections 8 to 10 (pages 2 to 4) which will take you about 10 minutes to complete.

- Please read each question carefully.
- Part 8 is completed by ticking or filling in the circle for the answer which best describes the client eg the circle like this ○ , becomes this ● or ✓.
- Part 9 is completed by circling a number eg the number like this, 2, becomes ②.
- Part 10 are completed by writing the answer in the space provided eg. Number of admissions .....
- Remember, only select <u>one</u> circle for each question to fill in,
- If you make a mistake, just cross out your answer and select the answer that best describes your client. There are no right or wrong answers.

Thank you for your help.

Dr Carol Harvey
Principal Researcher
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Ms Laura Hayes
Research Fellow
Psychosocial Research Centre
Department of Psychiatry
University of Melbourne

Please return to:
Laura Hayes
Psychosocial Research Centre
130 Bell St
Coburg 3058

Tel: 9355 9827
Fax: 9355 9855
Email: lmhayes@unimelb.edu.au

Please rate the average functioning over the last 3 months

8.1	Does this person generally have any difficulty with initiating and responding to conversation?	*No difficulty* ○	*Slight difficulty* ○	*Moderate* ○	*Extreme* ○
8.2	Does this person generally withdraw from social contact?	*Does not withdraw at all* ○	*Withdraws slightly* ○	*Withdraws moderately* ○	*Withdraws (near) total* ○
8.3	Does this person generally show warmth to others?	*Considerable warmth* ○	*Moderate warmth* ○	*Slight warmth* ○	*No warmth at all* ○
8.4	Is this person generally well groomed (eg neatly dressed, hair combed?)	*Well groomed* ○	*Moderate well groomed* ○	*Poorly groomed* ○	*Extremely poorly groomed* ○
8.5	Does this person wear clean clothes generally, or ensure they are cleaned if dirty?	*Maintains cleanliness* ○	*Moderate cleanliness* ○	*Poor cleanliness* ○	*Very poor cleanliness* ○
8.6	Does this person generally neglect his/her physical health?	*No neglect* ○	*Slight neglect* ○	*Moderate neglect* ○	*Extreme neglect* ○
8.7	Is this person violent to others?	*Not at all* ○	*Rarely* ○	*Occasionally* ○	*Often* ○
8.8	Does this person generally make and/or keep up friendships?	*Friendships made/kept well* ○	*Friendships made/kept with slight difficulty* ○	*Friendships made/kept with considerable difficulty* ○	*No friendships made/kept* ○
8.9	Does this person generally maintain an adequate diet?	*No problem* ○	*Slight problem* ○	*Moderate problem* ○	*Extreme problem* ○
8.10	Does this person generally look after and take her/his prescribed medications (or attend for prescribed injections on time) without reminding?	*Reliable* ○	*Slightly unreliable* ○	*Moderately unreliable* ○	*Extremely unreliable* ○
8.11	Is this person willing to take psychiatric medication when prescribed by a doctor?	*Always* ○	*Usually* ○	*Rarely* ○	*Never* ○
8.12	Does this person co-operate with health services (eg doctors and/or other health workers)?	○	○	○	○
8.13	Does this person generally have problems (eg friction, avoidance) living with others in the household)?	*No obvious problems* ○	*Slight problems* ○	*Moderate problems* ○	*Extreme problems* ○
8.14	Does this person behave offensively (includes sexual)?	*Not at all* ○	*Rarely* ○	*Occasionally* ○	*Often* ○
8.15	Does this person behave irresponsibly?	○	○	○	○
8.16	What sort of work is this person capable of (even if unemployed, retired or doing unpaid domestic duties)?	*Capable of full-time work* ○	*Capable of part-time work* ○	*Capable of sheltered work* ○	*Totally incapable of work* ○

	Domain	Score	
9.1	**Working productivity** *Rate the client in the most expected role (ie. home-maker, student, wage earner)*	1	Productivity severely limited, often unable to work or adapt to school or home-making: virtually no skills or attempt to be productive
		2	Occasional attempts at productivity are unsuccessful, productive only with constant supervision in sheltered work, home or special classes
		3	Limited productivity: often with restricted skills/ abilities for home-making, school, independent employment (eg requires highly structured routine)
		4	Marginal productivity (eg productive in sheltered work or minimally productive in independent work: fluctuates at home, in school; frequent job changes
		5	Moderately functional in independent employment, at home or in school. (Consider very spotty work history or fluctuations in home, in school with extended periods of success).
		6	Adequate functioning in independent employment home or school; often not applying all available skills/ abilities
		7	Optimally performs homemaking, school tasks or employment-related functions with ease and efficiency.
9.2	**Independent Living, Self Care** *Management of household, eating, sleeping, hygiene care*	1	Lacking self-care skills approaching life endangering threat, often involves multiple and lengthy hospital services, not physically able to participate in running a household
		2	Marked limitations in self-care/ independent living: often involving constant supervision in or out of protective environment (eg frequent utilisation of crisis services)
		3	Limited self-care/ independent living skills; often relying on mental/ physical health care; limited participation in running household
		4	Marginally self sufficient often uses REGULAR assistance to maintain self care/ independent functioning, minimally participates in running household
		5	Moderately self-sufficient, ie living independently with ROUTINE assistance (eg home visits by nurses, other helping persons)
		6	Adequate independent living and self care with MINIMAL support (eg some transportation, shopping, assistance with neighbours)
		7	Optimal care of health/ hygiene; independently manages to meet personal needs and household tasks
9.3	**Immediate social network relationships** *Close friends, spouse, family*	1	Severely deviant behaviours within immediate social networks (ie often with imminent physical aggression or abuse to others or severely withdrawn from close friends spouse, family, often rejected by immediate social network)
		2	Marked limitations in immediate interpersonal relationships (eg excessive dependency or destructive communication or behaviours)
		3	Limited interpersonally; often no significant participation/communication with immediate social network
		4	Marginal functioning with immediate social network (ie relationships are often minimal and fluctuate in quality)
		5	Moderate affective continuing and close relationship with at least one other person
		6	Adequate personal relationship with one or more immediate member of social network (eg friend or family)
		7	Positive relationships with spouse or family and friends assertively contributes to these relationships
9.4	**Extended social network relationships** *Neighbourhood, community, church, clubs, agencies, recreational activities*	1	Severely deviant behaviour within extended social networks (ie overtly disruptive, often leading to rejection by extended social networks)
		2	Often totally isolated from extended social networks refusing community involvement or belligerent to helpers, neighbours etc
		3	Limited range of successful and appropriate interaction in extended social networks (ie often restricts community involvement to minimal survival interactions)
		4	Marginally effective interactions, often in a structured environment, may receive multiple public system support in accord with multiple needs.
		5	Moderately affective and independent in community interactions; may receive some public support in accord with need
		6	Adequately interacts in neighbourhood or with at least one community or other organisation or recreational activity.
		7	Positively interacts in community, church or clubs, recreational activities, hobbies or personal interests often with other participants

Part 10: CMI-RAPID and case-note review baseline

During the previous 10 months:

10.1 Antipsychotic medication prescribed

- ○ None
- ○ Oral anti-psychotics
- ○ Depot anti-psychotics
- ○ Combination of oral and depot anti-psychotics. Specify

10.2 Antipsychotic medication in mg chlorpromazine equivalents per day …….

10.3 Other medications prescribed

- ○ None
- ○ Anticholinergics
- ○ Lithium
- ○ Antidepressants
- ○ Sedatives or hypnotics
- ○ Other, specify……..…
- ○ Combination, specify……..

10.4 Numbers of admissions during past 10 months…….

10.5 Total length of stay (days) during past 10 months …….

10.6 Number of CATT referrals during past 10 months ……..

10.7 Other episodes of relapse documented during past 10 months ……

10. 8 Number of service contacts during past 10 months …….

Appendix 2: Telephone recruitment script

Telephone protocol for Building Family Skills Together Study Recruitment phone call contact

Laura Hayes

Version Wednesday, 8 September 2006

Telephone protocol

Q1 [Dial the number]

- If **answered**:
  - GOTO **Q2**
- If **no answer/engaged**:
  - Re-dial this number later. Enter Recontact on database
  - If no response after 3 calls, then check with case-manager for correct number
- If **not connected/fax line**: Note on database then check with case-manager for correct number
- If **answering machine** leave the following message:
  - Hello. My name is Laura Hayes and I am calling from the Building Family Skills Together research project. I am calling to see if you are interested in joining a study we are doing. If you could phone me back on 03 9355 9827 it would be much appreciated.
  - Note on database and re-dial number later, do not leave more than one message.
  - If no response after 3 calls, then check with case-manager for correct number

Q2 Good *[morning/afternoon]*. My name is Laura Hayes and I am calling from the Building Family Skills Together research project.

I'd like to speak with…….

- If not available
  - — leave message as above and also find out good time to recontact. **See Q8**.
- [**YES**, speaking]
  - — GO TO Q3

Q3 How are you today?

[Reply]

That's [*good/no good] (as appropriate).*

You might remember that you said to [case manager] it would be OK for me to contact you regarding some research. They passed on your phone number to me. Is it OK to talk briefly now?

- [**NO** I'm not interested in the study at all.]
  - — GOTO **Q9**
- [**NO** I haven't time now.]
  - — GOTO **Q8**
- **[YES**, Tell me more]
  - — GOTO **Q4**.

Q4 There is a pilot program for a family support program called the Building family skills together program [which you are part of/which is running in Coburg and Broadmeadows]. It is very important that we demonstrate the program is effective so we can keep it funded and get the program into other areas of Melbourne. So we are asking you to be part of our study to do that. It would involve and interview of about an hour now, and then a repeat interview in 10 months.

- [**NO** I'm not interested in the study at all.]
  - — Go to **Q9** [to finish call]

- [**I'M NOT SURE**.]
  - — Do you have any questions you would like me to clarify for you at the moment?
  - — [YES]
  - — Answer questions.
    - **YES** I will join the study,
      - GO TO **Q5,**
    - **NO**
      - go to **Q9**.
- **[YES**, I will do the interviews]
  - — Well that's great GO TO **Q5**.

Q5

Q5.1 When would be a good time to catch up? I am available Mon, Tuesday and Wednesday.

- Arrange time

Q5.2 Would you like to meet at the clinic? Otherwise I could meet you at your home.

- Arrange venue

Q6 What we will do at the interview is firstly look at more details about the study so you know all about it, then if that's all OK we'll do the interview.

Q7 If you have any further problems please call us and we will be happy to help you. If you need to contact me I am on 9355 9827. I'll see you on [date, time] at [venue].

Thank you for your help and have a good day. Good bye.

— [End call]
— Enter "recruited" into database.

Q8 [Make a time to ring back when the person will be at home]

[Probe to make another time that is convenient for the them]:

8.1 When would be convenient for *[name]]*?

- [TIME]

8.2 Thank you very much, and I will be in touch on [TIME]. Thank you for your time. Goodbye.

[End call]

- Ring back at the agreed time. GOTO **Q1**.

Q9 Well thank you for your time anyway.

— [End call]
— Enter "declined" into database.

Appendices Section 3: Participant information and consent

Appendix 3.1 Participant information and consent for carers in treatment Area Mental Health Service

FOR CARERS - [redacted]

[redacted] Mental Health

[redacted] Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Participant Information and Consent Form – Carer - [redacted]AMHS
Version: #3 Dated: 20 April 2009

Site: [redacted] Mental Health

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

Principal Researcher: Dr Carol Harvey

Associate Researcher(s): Dr John Farhall, David Juriansz, Brendan O'Hanlon, Dr Amaryll Perlesz, Dr Noel Renouf

---

This Participant Information and Consent Form is **6** pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

The purpose of this project is to evaluate Building Family Skills Together - a training program providing families with practical strategies to cope with difficulties experienced when caring for a person with schizophrenia. In this program a worker from the mental health service will provide training in problem solving and communication skills to families in their homes on a weekly basis for approximately 9 months.

This research is about families. We would like to include the consumer and one of their carers. We hope to include 160 consumers and 160 carers in this project

It is important to gain a better understanding of the experiences of caring for persons with schizophrenia. In particular, we would like to know if the training provided in *Building Family Skills Together* helps relatives to cope better with their caring role and if there is any improvement in their own health and quality of life as a result. Also, we would like to know if the training leads to improvement in consumers' own health and daily lives.

You are invited to take part in this research project so that you can contribute to an increased understanding of these issues that may help us to work out how to better help and support people with schizophrenia and their carers.

The results of this research will tell us whether this training can help families and individuals cope with the difficulties associated with this illness and may help to make this sort of training more available to other consumers and their families.

3. Procedures

Participation in this project will involve a number of questionnaires about you and your general health, your experience of caring for your relative and the effects of this on you, your social support and your views about your quality of life. We will ask you to complete these questionnaires at the beginning of the training provided in *Building Family Skills Together* and again about 10 months later.

- Some of these questionnaires will be completed during an interview with a researcher and some of them can be completed during this same time by you.
- The interview may be taped, but only with your consent.
- We can arrange an appointment to do this at the clinic at a time that will suit you or we can come to your home to help you complete the questionnaires.
- We estimate that in total all the questionnaires will take about an hour to complete.

4. Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project. However, you may benefit from discussing your experience of being a carer with the researcher. Hopefully, your participation in the study will also improve our understanding of caring for someone with schizophrenia which may help us to work out how to better help and support carers. If this research is successful it may make it more possible that other families receive this training in future.

5. Possible Risks

There are unlikely to be risks or discomfort to you as a result of taking part in the study. However, if you become distressed in any way during the interview – the interview can be suspended or if necessary your participation in the project ended. Also, the Principal Researcher (Dr Harvey) can arrange for you to speak with one of the carer consultants in the service and we will provide you details of what they can offer. Alternatively, we can arrange for you to speak with the treating clinician (i.e. case manager or psychiatrist) of your relative who is receiving treatment in the clinic.

6. Privacy, Confidentiality and Disclosure of Information

All information obtained during this study will remain confidential and will not be made available to anyone apart from the Principal and Associate researchers. You have a right to access your information if you choose.

Research records and tapes of your information will remain anonymous and are kept in a locked filing cabinet for a period of 7 years. The information will only be disclosed with your permission, except as required by law. Your identity will not be revealed in any written research report or publications related to this study.

7. Results of Project

Following the completion of the study, the findings from the study may be made available to you if you wish. This will take the form of written feedback of the anonymised findings for the entire group of participants.

8. Further Information or Any Problems

If you require further information or have any problems concerning the project in which you are involved you should contact the Principal Investigator. The Principal Investigator responsible for this project is Dr Carol Harvey of the Psychosocial Research Centre, 130 Bell Street, Coburg 3058. Telephone: 9355-9826. Laura Hayes (researcher) can also help you on 9355 9827.

9. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: Ms Michelle Clemson

Position: Secretary Mental Health Research and Ethics Committee

Research Directorate

6 East Main Block

Royal Melbourne Hospital

Grattan Street

Parkville 3050

Telephone: 9342 – 7215

You will need to tell her the name of one of the researchers given in section 8 above.

Alternatively, you can contact the Executive Officer, Human Research Ethics, University of Melbourne, VIC 3010. Tel: (03) 8344 2073.

10. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect the treatment of your relative or your own relationship with North Western Mental Health. Specifically your involvement in the training will not be affected.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

11. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of this Institution (North Western Mental Health) and The University of Melbourne.

12. Reimbursement for your costs

Unfortunately, you will not be paid for your participation in this project.

Thank you for giving your consideration to taking part in this study. Please feel free to take this information away with you and discuss it with family and friends, before agreeing to participate. We would be happy to discuss any questions you may have about it

Dr Carol Harvey

Principal Researcher

•

CONSENT FORM – CARER - [redacted]AMHS

[redacted] Mental Health

North Western Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Consent Form – Carer - [redacted]AMHS
Version: #3 20 April 2009
Site: [redacted] Mental Health

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

I have read, and I understand the Participant Information version #3 dated ***20 April 2009***.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I consent to my interview being tape-recorded for data collection purposes

- YES
- NO

I would like to receive written feedback on this study

- YES
- NO

Participant's Name (printed) ……

Signature ……. Date

Name of Witness to Participant's Signature (printed) ……

Signature …… Date

Researcher's Name (printed) ……

Signature …… Date

Note: All parties signing the Consent Form must date their own signature.

REVOCATION OF CONSENT FORM – CARER - [redacted]AMHS

•

[redacted] Mental Health

North Western Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Revocation of Consent Form – Carer - [redacted]AMHS

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment of my relative or their relationship or my own relationship with [redacted] ***Mental Health***.

Participant's Name (printed) …….

Signature Date

Appendix 3.2 Participant information and consent for consumers in the treatment Area Mental Health Service

FOR CONSUMERS - [redacted]AMHS

[redacted] Mental Health

[redacted]n Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Participant Information and Consent Form – Consumer - [redacted]AMHS
Version: #4 Dated: 20 April 2009

Site: [redacted] **Mental Health**

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

Principal Researcher: Dr Carol Harvey

Associate Researcher(s): Dr John Farhall, David Juriansz, Brendan O'Hanlon, Dr Amaryll Perlesz, Dr Noel Renouf

---

This Participant Information and Consent Form is **7** pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

We also ask for your consent, for your relative or carer to be invited to take part in this research project. If you agree, a researcher will contact your relative / carer to take part in it. By signing the Consent Form, you indicate that you understand the information and that you give your consent for your relative / carer to participate in the research project, should they want to.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

The purpose of this project is to evaluate Building Family Skills Together - a training program providing families with practical strategies to cope with difficulties experienced when caring for a person with schizophrenia. In this program a worker from the mental health service will provide training in problem solving and communication skills to families in their homes on a weekly basis for approximately 9 months.

This research is about families. We would like to include the consumer and one of their carers. We hope to include 160 consumers and 160 carers in this project.

It is important to gain a better understanding of the experiences of caring for persons with schizophrenia. In particular, we would like to know if the training provided in *Building Family Skills Together* helps relatives to cope better with their caring role and if there is any improvement in their own health and quality of life as a result. Also, we would like to know if the training leads to improvement in consumers' own health and daily lives.

You are invited to take part in this research project so that you can contribute to an increased understanding of these issues that may help us to work out how to better help and support people with schizophrenia and their carers.

The results of this research will tell us whether this training can help families and individuals cope with the difficulties associated with this illness and may help to make this sort of training more available to other consumers and their families.

3. Procedures

Participation in this project will involve a number of questionnaires and an interview about you and your health, your attitude to your treatment, your day to day functioning and your quality of life. We will ask you to complete questionnaires at the beginning of the training provided in *Building Family Skills Together* and follow-up questionnaires and an interview about 10 months later.

- Some of these questionnaires will be completed during an interview with a researcher and some of them can be completed during this same time by you. If you wish, the researcher can guide you through the completion of all the questionnaires.
- The interview at follow-up is for the purposes of talking about your experiences of the *Building Family Skills Together* training. It may be taped, but only with your consent
- We can arrange an appointment to do this at the clinic at a time that will suit you or come to your home.
- We estimate that in total all the questionnaires will take about 45 minutes to complete.

- The interview at the final meeting will take about ten minutes.

In addition, the researcher will ask your case manager to answer some brief questionnaires on your relationships and your life roles. The researcher will also obtain some information on your use of services from your casenotes and the service database.

Two of the questionnaires in this research (the BASIS-32 and the Life Skills Profile) are also regularly completed by this service to help with the planning of your care. If you wish, the researcher can give your case manager copies of these questionnaires to help with your care planning.

4. Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project. However, you may benefit from discussing your experience with the researcher. Hopefully, your participation in the study will also improve our understanding of how to help and support people with schizophrenia and their families. If this research is successful it may make it more possible that other families receive this training in future.

5. Possible Risks

There are unlikely to be risks or discomfort to you as a result of taking part in the study. However, if you become distressed in any way during the interview – the interview can be suspended or if necessary your participation in the project ended. Also, the Principal Researcher (Dr Harvey) can arrange for you to speak with one of the consumer consultants in the service and we will provide you details of what they can offer. Alternatively, we can arrange for you to speak with your treating clinician (i.e. case manager or psychiatrist).

6. Privacy, Confidentiality and Disclosure of Information

All information obtained during this study will remain confidential and will not be made available to anyone apart from the Principal and Associate researchers. You have a right to access your information if you choose.

Research records of your information will remain anonymous and are kept in a locked filing cabinet for a period of 7 years. The information will only be disclosed with your permission, except as required by law. Your identity will not be revealed in any written research report or publications related to this study.

7. Results of the project

Following the completion of the study, the findings from the study may be made available to you if you wish. This will take the form of written feedback of the anonymised findings for the entire group of participants.

8. Further Information or Any Problems

If you require further information or have any problems concerning the project you should contact the Principal Investigator. The Principal Investigator responsible for this project is Dr Carol Harvey of the Psychosocial Research Centre, 130 Bell Street, Coburg 3058. Telephone: 9355-9826. Laura Hayes (researcher) can also help you on 9355 9827.

9. Other Issues

If you have any complaints about any aspect of the project or the way it is being conducted, then you may contact

Name: Ms Michelle Clemson
Position: Manager, Mental Health Research and Ethics Committee
Research Directorate
6 East Main Block
Royal Melbourne Hospital
Grattan Street
Parkville 3050
Telephone: 9342 – 7098

You will need to tell her the name of one of the researchers given in section 8 above.

Alternatively, you can contact the Executive Officer, Human Research Ethics, University of Melbourne, VIC 3010. Tel: (03) 8344 2073.

10. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your treatment or the relationship you and your relative have with North Western Mental Health. Specifically the involvement of you and your carers in the training will not be affected.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

11. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of this Institution (North Western Mental Health) and The University of Melbourne.

12. Reimbursement for your costs

Unfortunately, you will not be paid for your participation in this project.

Thank you for giving your consideration to taking part in this study. Please feel free to take this information away with you and discuss it with family and friends, before agreeing to participate. We would be happy to discuss any questions you may have about it.

Dr Carol Harvey

Principal Researcher

CONSENT FORM – CONSUMER - [redacted]AMHS

[redacted] Mental Health

[redacted] Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Consent Form – Consumer - [redacted]AMHS
Version: #4 Dated: 20 April 2009
Site: [redacted] Mental Health

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

I have read, and I understand the Participant Information version #4 dated ***20/04/2009***.

I freely agree to participate in this project according to the conditions in the Participant Information.

I give my permission for the research team to access my clinical files.

- YES
- NO

I give my permission for the research team to access my clinical data in the mental health service's computerised database.

- YES
- NO

I freely agree to allow the researcher to contact my carer about participating in this project according to the conditions in the Participant Information.

- YES
- NO

I consent to my interview being tape-recorded for data collection purposes

- YES
- NO

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I would like copies of the BASIS-32 and LSP-16 to be given to my case manager for the purpose of helping with planning my care

- YES
- NO

I would like to receive written feedback on this study

- YES
- NO

Name of consumer (printed) ……

Signature Date

Name of Witness to consumer's Signature (printed) ……

Signature Date

Researcher's Name (printed) ……

Signature Date

Note: All parties signing the Consent Form must date their own signature.

REVOCATION OF CONSENT FORM - CONSUMER - [redacted]AMHS

•

[redacted] Mental Health

North Western Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Revocation of Consent Form – Consumer - [redacted]AMHS

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

I hereby wish to WITHDRAW my consent to participate in the research proposal and to allow the researcher to contact my carer for participation in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or relationship I or my carer has with [redacted] ***Mental Health***.

Consumer's Name (printed) …….

Signature Date

Appendix 3.3 Participant information and consent for carers in comparison Area Mental Health Service

FOR CARERS - [redacted]AMHS

North Western Mental Health

North Western Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Participant Information and Consent Form – Carer - [redacted]AMHS
Version: #2 **Dated: 1st November 2007**

Site: **North Western Mental Health**

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

Principal Researcher: Dr Carol Harvey

Associate Researcher(s): Dr John Farhall, David Juriansz, Brendan O'Hanlon, Dr Amaryll Perlesz, Dr Noel Renouf

---

This Participant Information and Consent Form is **6** pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

The purpose of this project is to evaluate the benefits of work done by mental health services with families of people with schizophrenia. To do this, we are comparing the usual work done in this area ([redacted]) with a different approach (the Building Family Skills Together training program) being taken in a neighbouring area ([redacted]).

This research is about families. We hope to include 160 consumers and 160 carers in this project to gain a better understanding of the experiences of caring for persons with schizophrenia. In particular, we would like to know whether the different services offered to families in the two areas lead to differences in coping with their caring role, or in their own health and quality of life as a result.

You are invited to take part in this research project so that you can contribute to an increased understanding of these issues that may help us to work out how to better help and support people with schizophrenia and their carers.

3. Procedures

Participation in this project will involve a number of questionnaires about you and your general health, your experience of caring for your relative and the effects of this on you, your social support and your views about your quality of life. We will ask you to complete these questionnaires on two occasions, 10 months apart.

- Some of these questionnaires will be completed during an interview with a researcher and some of them can be completed during this same time by you.
- The interview may be taped, but only with your consent.
- We can arrange an appointment to do this at the clinic at a time that will suit you or we can come to your home to help you complete the questionnaires.
- We estimate that in total all the questionnaires will take about an hour to complete.

4. Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project. However, you may benefit from discussing your experience of being a carer with the researcher. Hopefully, your participation in the study will also improve our understanding of caring for someone with schizophrenia which may help us to work out how to better help and support carers.

5. Possible Risks

There are unlikely to be risks or discomfort to you as a result of taking part in the study. However, if you become distressed in any way during the interview – the interview can be suspended or if necessary your participation in the project ended. Also, the Principal Researcher (Dr Harvey) can arrange for you to speak with one of the carer consultants in the service and we will provide you details of what they can offer. Alternatively, we can arrange for you to speak with the treating clinician (i.e. case manager or psychiatrist) of your relative who is receiving treatment in the clinic.

6. Privacy, Confidentiality and Disclosure of Information

All information obtained during this study will remain confidential and will not be made available to anyone apart from the Principal and Associate researchers. You have a right to access your information if you choose.

Research records and tapes of your information will remain anonymous and are kept in a locked filing cabinet for a period of 7 years. The information will only be disclosed with your permission, except as required by law. Your identity will not be revealed in any written research report or publications related to this study.

7. Results of Project

Following the completion of the study, the findings from the study may be made available to you if you wish. This will take the form of written feedback of the anonymised findings for the entire group of participants.

8. Further Information or Any Problems

If you require further information or have any problems concerning the project in which you are involved you should contact the Principal Investigator. The Principal Investigator responsible for this project is Dr Carol Harvey of the Psychosocial Research Centre, 130 Bell Street, Coburg 3058. Telephone: 9355-9826. The researcher on this project is Laura Hayes, telephone 9355 9827.

9. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: Ms Michelle Clemson

Position: Secretary Mental Health Research and Ethics Committee

Research Directorate

6 East Main Block

Royal Melbourne Hospital

Grattan Street

Parkville 3050

Telephone: 9342 – 7215

You will need to tell her the name of one of the researchers given in section 8 above.

10. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect the treatment of your relative or your own relationship with North Western Mental Health.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

11. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of this Institution (North Western Mental Health).

12. Reimbursement for your costs

- Unfortunately, you will not be paid for your participation in this project.

Thank you for giving your consideration to taking part in this study. Please feel free to take this information away with you and discuss it with family and friends, before agreeing to participate. We would be happy to discuss any questions you may have about it.

Dr Carol Harvey

Principal Researcher

-

CONSENT FORM – CARER - [redacted]AMHS

North Western Mental Health

North Western Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Consent Form – Carer - [redacted]AMHS
Version: #2 1 November 2007
Site: [redacted] Mental Health

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

I have read, and I understand the Participant Information version #2 dated ***01/11/2007***.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I consent to my interview being tape-recorded for data collection purposes

- YES
- NO

I would like to receive written feedback on this study

- YES
- NO

Participant's Name (printed) ……

Signature …… Date

Name of Witness to Participant's Signature (printed) ……

Signature …… Date

Researcher’s Name (printed) ……

Signature …… Date

Note: All parties signing the Consent Form must date their own signature.

REVOCATION OF CONSENT FORM – CARER - [redacted]AMHS

•

[redacted] Mental Health

North Western Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 – 8548

Revocation of Consent Form – Carer - [redacted]AMHS

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment of my relative or their relationship or my own relationship with ***North Western Mental Health***.

Participant's Name (printed) …….

Signature Date

Appendix 3.4 Participant information and consent for consumers in comparison Area Mental Services

FOR CONSUMERS - [redacted]AMHS

[redacted] Mental Health

NorthWestern Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Participant Information and Consent Form – Consumer - [redacted]AMHS
Version: #1 **Dated: 26th July 2006**

Site: **[redacted] Mental Health**

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

Principal Researcher: Dr Carol Harvey

Associate Researcher(s): Dr John Farhall, David Juriansz, Brendan O'Hanlon, Dr Amaryll Perlesz, Dr Noel Renouf

---

This Participant Information and Consent Form is **7** pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

We also ask for your consent, for your relative or carer to be invited to take part in this research project. If you agree, a researcher will contact your relative / carer to take part in it. By signing the Consent Form, you indicate that you understand the information and that you give your consent for your relative / carer to participate in the research project, should they want to.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

The purpose of this project is to evaluate the benefits of work done by mental health services with families of people with schizophrenia. To do this, we are comparing the usual work done in this area ([redacted]) with a different approach (the Building Family Skills Together training program) being taken in a neighbouring area ([redacted] Area).

This research is about families. We hope to include 160 consumers and 160 carers in this project to gain a better understanding of the experiences of caring for persons with schizophrenia. In particular, we would like to know whether the different services offered to families in the two areas lead to differences in coping with their caring role, or in their own health and quality of life as a result.

You are invited to take part in this research project so that you can contribute to an increased understanding of these issues that may help us to work out how to better help and support people with schizophrenia and their carers.

3. Procedures

Participation in this project will involve a number of questionnaires about you and your health, your attitude to your treatment, your day to day functioning and your quality of life. We will ask you to complete these questionnaires on two occasions, 10 months later.

- Some of these questionnaires will be completed during an interview with a researcher and some of them can be completed during this same time by you. If you wish, the researcher can guide you through the completion of all the questionnaires.
- We can arrange an appointment to do this at the clinic at a time that will suit you or come to your home.
- We estimate that in total all the questionnaires will take about 45 minutes to complete.

In addition, the researcher will ask your case manager to answer some brief questionnaires on your relationships and your life roles. The researcher will also obtain some information on your use of services from your casenotes and the service database.

Two of the questionnaires in this research (the BASIS-32 and the Life Skills Profile) are also regularly completed by this service to help with the planning of your care. If you wish, the researcher can give your case manager copies of these questionnaires to help with your care planning.

4. Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project. However, you may benefit from discussing your experience with the researcher. Hopefully, your participation in the study will also improve our understanding of how to help and support people with schizophrenia and their families.

5. Possible Risks

There are unlikely to be risks or discomfort to you as a result of taking part in the study. However, if you become distressed in any way during the interview – the interview can be suspended or if necessary your participation in the project ended. Also, the Principal Researcher (Dr Harvey) can arrange for you to speak with one of the consumer consultants in the service and we will provide you details of what they can offer. Alternatively, we can arrange for you to speak with your treating clinician (i.e. case manager or psychiatrist).

6. Privacy, Confidentiality and Disclosure of Information

All information obtained during this study will remain confidential and will not be made available to anyone apart from the Principal and Associate researchers. You have a right to access your information if you choose.

Research records of your information will remain anonymous and are kept in a locked filing cabinet for a period of 7 years. The information will only be disclosed with your permission, except as required by law. Your identity will not be revealed in any written research report or publications related to this study.

11. Results of the project

Following the completion of the study, the findings from the study may be made available to you if you wish. This will take the form of written feedback of the anonymised findings for the entire group of participants.

12. Further Information or Any Problems

If you require further information or have any problems concerning the project you should contact the Principal Investigator. The Principal Investigator responsible for this project is Dr Carol Harvey of the Psychosocial Research Centre, 130 Bell Street, Coburg 3058. Telephone: 9355-9826. The researcher on this project is Laura Hayes, telephone 9355 9827.

13. Other Issues

If you have any complaints about any aspect of the project or the way it is being conducted, then you may contact

Name: Dr Stacey Gabriel

Position: Secretary Mental Health Research and Ethics Committee

Research Directorate

6 East Main Block

Royal Melbourne Hospital

Grattan Street

Parkville 3050

Telephone: 9342 – 7098

You will need to tell her the name of one of the researchers given in section 8 above.

14. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your treatment or the relationship you and your relative have with North Western Mental Health.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

11. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of this Institution (North Western Mental Health).

12. Reimbursement for your costs

- Unfortunately, you will not be paid for your participation in this project.

Thank you for giving your consideration to taking part in this study. Please feel free to take this information away with you and discuss it with family and friends, before agreeing to participate. We would be happy to discuss any questions you may have about it.

Dr Carol Harvey

Principal Researcher

-

CONSENT FORM – CONSUMER - [redacted]AMHS

[redacted] Mental Health

North Western Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Consent Form – Consumer - [redacted]AMHS
Version: #1 Dated: 26th July 2006
Site: [redacted] Mental Health

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

I have read, and I understand the Participant Information version # 1 dated ***26/07/2006***.

I freely agree to participate in this project according to the conditions in the Participant Information.

I give my permission for the research team to access my clinical files.

- YES
- NO

I give my permission for the research team to access my clinical data in the mental health service's computerised database.

- YES
- NO

I freely agree to allow the researcher to contact my carer about participating in this project according to the conditions in the Participant Information.

- YES
- NO

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I would like copies of the BASIS-32 and LSP-16 to be given to my case manager for the purpose of helping with planning my care

- YES
- NO

I would like to receive written feedback on this study

- YES
- NO

Name of consumer (printed) ……

Signature Date

Name of Witness to consumer's Signature (printed) ……

Signature Date

Researcher's Name (printed) ……

Signature Date

Note: All parties signing the Consent Form must date their own signature.

REVOCATION OF CONSENT FORM - CONSUMER - MWAMHS

•

[redacted] **Mental Health**

North Western Mental Health Research and Ethics Committee, Research Directorate, 6 East Main Block, Royal Melbourne Hospital, Grattan Street, Parkville 3050.

Telephone: 9342 – 7098 Fax: 9342 - 8548

Revocation of Consent Form – Consumer - [redacted]AMHS

Full Project Title: ***Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy***

I hereby wish to WITHDRAW my consent to participate in the research proposal and to allow the researcher to contact my carer for participation in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or relationship I or my carer has with [redacted] ***Mental Health***.

Consumer's Name (printed) …….

Signature Date

Appendices Section 4: Invitation to research

Appendix 4.1 Flyer for comparison group consumer and families

NorthWestern Mental Health

An invitation to **Families…**

psychosocial RESEARCH CENTRE

…who would like to participate in a Research Project

What is the research about?

We are evaluating the benefits of help provided by mental health services to families of people experiencing schizophrenia. To do this, we are comparing the usual work done in both [redacted] Area Mental Health Services with a different approach (the *Building Family Skills Together* program) in a neighbouring area ([redacted]).

Why do the research?

We want to learn more about the experience of families where a member is suffering from schizophrenia. In particular, we would like to know to what extent the different types of help provided to families enables them to cope better with their caring role and if there is any improvement in their own health and quality of life. Also, we would like to know how much improvement there is in the health and daily lives of the family member suffering from schizophrenia.

Who is taking part?

Families who use mental health services in Northern and Western Melbourne. We plan to include 160 consumers and 160 carers in this project.

What does it involve?

Participation in the research will involve answering some questionnaires about you, your health, your day to day activities and your quality of life. We will ask you to complete these questionnaires at two times, about 10 months apart.

How long will it take?

The questionnaires will take about 45-60 minutes to complete. We can arrange an appointment for you to do this at the clinic at a time that will suit you, or one of the researchers can come to your home.

Why is it important?

We believe it is important to include families in the care of people with schizophrenia. If this research shows that Building Family Skills Together is helpful to families it may make it more possible that other families receive this program in future.

If you would like to participate or you just to want to find out more about the research please contact Laura Hayes at the Psychosocial Research Centre, 130 Bell Street on 9355 9826

Appendix 4.2 Flyer for staff at comparison sites

INFORMATION FLIER FOR STAFF – NAMHS AND MWAMHS

Project title: *Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers & of the service change strategy*

Principal Researcher: Dr Carol Harvey

Associate Researchers: Dr John Farhall, Mr David Juriansz, Mr Brendan O'Hanlon, A/Prof. Amaryll Perlesz, Dr Noel Renouf.

Background

There is much evidence that effective family involvement will result in measurable improvements in both the health and well-being of people living with schizophrenia and their families. However, previous attempts to implement effective family involvement internationally and in Australia have been largely unsuccessful. Therefore, there is an urgent need to provide the mental health sector with evidence of an effective way to implement the research evidence (and associated best practice clinical guidelines) for family involvement in schizophrenia.

What is this project about?

The purpose of this project is to evaluate the benefits of work done by mental health services with families of people with schizophrenia. To do this, we are comparing the usual work done in [redacted]) with a different and more intensive approach (the *Building Family Skills Together* training program) being taken in a neighbouring area [redacted] AMHS).

This evaluation has two parts: a) an evaluation of whether consumers and families benefit from the service they receive, with respect to their health and quality of life, and how families cope with their caring role, and b) an evaluation of the effect on family work services of the level of intensity of implementation of family work programs.

How can staff assist?

- **Recruitment and involvement of consumers and carers**

We would like to invite up to 80 families to participate in the evaluation (80 consumers together with a nominated relative). You can assist in identifying possible families for this project, as per the following inclusion criteria:

- Consumers with a diagnosis of schizophrenia (schizophrenia, schizoaffective disorder and other psychotic conditions excluding psychoses associated with affective disorders) and a nominated carer
- Minimum of weekly face to face contact between the consumer and family
- Families most likely to benefit from evidence-based family interventions that are recommended in clinical guidelines (such as Behavioural Family Therapy – see description in box below)
- English speaking or able to participate in a research interview with the assistance of an interpreter

Evidence-based Family Interventions:

- Involve available family members together with the person experiencing schizophrenia
- Contact is planned, face to face and takes place over at least nine months
- Includes
  - Engagement and assessment of each family member
  - Education of family members about the nature of the illness
  - Communication Skills Training for family members

Consumers and carers will be invited to take part in two interviews, 10 months apart. You can assist with letting suitable families know about the project and asking them if they would talk with the Senior Research Officer about participation. With their consent, the researcher will complete self report questionnaires and semi-structured interviews with the consumer (interview time about 45 minutes) and a nominated relative (interview time about 60 minutes).

There will also be 2 brief questionnaires on the consumer's functioning and roles that the researcher would seek to complete with your assistance (5-10 minutes on each occasion).

- **Staff involvement**

All CMHC and CCT staff will be invited to participate in the evaluation on 3 occasions in the period 2006-2008 by completing the brief Family Work Session Record for each family contact over a 2-4 week period nominated in discussions with your service.

Are there any likely benefits for staff arising from this project?

This research will tell us more about the most effective ways for services to work with families and individuals to help them cope with the difficulties associated with schizophrenia. The results may inform the sorts of programs that are made available to consumers and their families in future. In addition, some of the questionnaires (the BASIS-32 and the LSP-16) are part of the outcome measures that clinicians routinely collect. With the consumer's permission, these can be made available to you to help with your treatment planning.

This study will be considered for approval at the Mental Health Research and Ethics Committee on Wednesday 7th June 2006.

If you require further information please contact: Dr Carol Harvey (Psychosocial Research Centre, 130 Bell Street) on 9355 9826 (via Catherine Bressanuti) or via e-mail: c.harvey@unimelb.edu.au. Or Dr John Farhall (Whittlesea Clinic) on 9409 8779 or via e-mail: John.Farhall@mh.org.au

Appendix 4.3 Flyer for treatment group consumer and carers

An invitation to Families…

…who would like to participate in a Research Project

What is the research about & why take part?

Some of our case managers and mental health staff have trained in a way of working that is more responsive to family members' needs and that has also been found to be helpful for the mental health of the person with schizophrenia. This way of working has had good outcomes for families overseas and we'd like to know if it works in Australia as well. Its called *Building Family Skills Together* and this program will give you an opportunity to be listened to more regularly, be more directly supported in your care giving role by case managers, and to work on problems and communication at home. It's like having your own, in-home skills training program. You'll be working with mental health workers in your homes on a weekly basis for around 9 months.

Why do the research?

We want to learn more about the experience of families where a member is suffering from schizophrenia. In particular, we would like to know if the *Building Family Skills Together* Program helps relatives to cope better with their caring role and if there is any improvement in their own health and quality of life. Also, we would like to know if the training leads to any improvement in consumers' own health and daily lives.

Who is taking part?

Families who use mental health services in Northern, North West and Western Melbourne. We hope to include 160 consumers and 160 carers in this project.

What does it involve?

Participation in the research will involve answering some questionnaires about you, your health, your day to day activities and your quality of life. We will ask you to complete these questionnaires at the beginning of the training provided in *Building Family Skills Together* and again about 10 months later.

How long will it take?

The questionnaires will take about 45 minutes to complete. We can arrange an appointment for you to do this at the clinic at a time that will suit you or one of the researchers can come to your home.

Why is it important?

We believe it is important to include families in the care of people with schizophrenia. If this research shows that Building Family Skills Together is successful it may make it more possible that other families receive this program in future.

If you would like to participate please contact Laura Hayes at the Psychosocial Research Centre, 130 Bell Street) on 9355 9826

Appendix 4.4 Flyer for treatment group case managers

Building family skills together research

Comparative Evaluation of the Building Family Skills Together Program: Evaluation of outcomes for consumers and carers

Background

There is much evidence that effective family involvement will result in measurable improvements in both the health and well-being of people living with schizophrenia and their families. However, previous attempts to implement effective family involvement internationally and in Australia have been largely unsuccessful. Therefore, there is an urgent need to provide the mental health sector with evidence of an effective way to implement the research evidence (and associated best practice clinical guidelines) for family involvement in schizophrenia.

What is this project about?

The purpose of this project is to evaluate the benefits of work done by mental health services with families of people with schizophrenia. To do this, we are comparing the usual work done in [redacted]) with a different and more intensive approach (the *Building Family Skills Together* training program) being taken in a neighbouring area ([redacted] AMHS).

How can staff assist?

Staff can assist by asking all families who receive Behavioural Family Therapy (BFT) if a researcher can contact them about some research that NorthWest AMHS is conducting to demonstrate the effectiveness of

the Building Family Skills Together Program. You can reassure families that the phone call is just to explain the research to them and will not obligate them at all. Also, the decision to join the research is confidential and will not affect treatment in any way.

Who do I ask to participate?

- All families receiving BFT as part of the Building Family Skills Together program.

What does it involve for participants?

Consumers and carers will be invited to take part in two interviews. The first interviews will be at the start of their treatment, and the second interview will be 10 months later. With their consent, the researcher will complete self report questionnaires and semi-structured interviews with the consumer (interview time about 45 minutes) and a nominated relative (interview time about 60 minutes).

There will also be 2 brief questionnaires on the consumer's functioning and roles that the researcher would seek to complete with your assistance (5-10 minutes on each occasion).

We can arrange to do the research at their regular clinic or at their home. We can also arrange for translators to be available.

Why is it important?

This research will tell us more about the most effective ways for services to work with families and individuals to help them cope with the difficulties associated with schizophrenia. The results may inform the sorts of programs that are made available to consumers and their families in future. In addition, some of the questionnaires (the BASIS-32 and the LSP-16) are part of the outcome measures that clinicians routinely collect. With the consumer's permission, these can be made available to you to help with your treatment planning.

Contact details

If a family agrees to a phone call from researchers please contact:

LAURA HAYES at the Psychosocial Research Centre on

9355 9826 or lmhayes@unimelb.edu.au

with names and phone numbers of the potential participants

Alternative contacts are:

Dr Carol Harvey (Principal Researcher), Psychosocial Research Centre, 130 Bell Street on 9355 9826 (via Catherine Bressanuti) or via e-mail: c.harvey@unimelb.edu.au. Or

Dr John Farhall (Whittlesea Clinic) on 9409 8779 or via e-mail: John.Farhall@mh.org.au

Appendix 5: Script for Case managers

Script for Case managers

> “There is some research at the moment about different treatments for mental illness, and it involves a researcher dropping by your house and doing an interview. Is it OK if the researcher gives you a call? She can explain more about it to you, then you can decide if you want to go ahead”

Any questions about the research by the consumer or family member could be referred to the researcher:

> “I’m not sure about that, the researcher can explain that to you.”

Appendix 6: Supplementary table to Chapter 5

Table A.49: Principal components analysis of the WHOQOL for consumers

Component Matrix[a]							
ITEM NUMBER	Component						
	1	2	3	4	5	6	7
1	.736						
2	.606		.495				
3	-.441		-.316	.426	.508		
4	-.409		.345	.432			
5	.510	-.414		.474			
6	.357	-.563		.353			
7	.721						
8	.691			.346			
9	.513	.358		.406	.311		
10	.641		.297			.361	
11	.706				-.347		
12	.635						
13	.585						
14	.471	.496	-.545				
15	.430	.373	-.373			.309	-.463
16	.446		-.398	-.303	.329		.336
17	.663			-.468			
18	.738						
19	.819						
20	.747						
21	.595	-.360		.358			
22	.581					-.388	
23	.283*	.468	.433		.318	-.303	
24	.392	.564			-.409		.341
25	.358	.469		.341			-.387
26	-.772		.323				

Principal components Analysis, No rotation. Where factor loading is under 0.300 it is not reported except for *.
Total Eigenvalues for Component 1 = 9.14, % Variance explained = 34.7%
Total Eigenvalues for Component 2 = 2.3, % Additional variance explained = 9.0%
Total Eigenvalues for Component 3 = 1.8, % Additional variance explained = 7.0%
Total Eigenvalues for Component 4 = 1.8, % Variance explained = 6.7%
Total Eigenvalues for Component 5 = 1.3, % Additional variance explained = 4.9%
Total Eigenvalues for Component 6 = 1.1, % Additional variance explained = 4.2%
Total Eigenvalues for Component 7 = 1.1, % Variance explained = 4.1%
Total variance explained= 70.7%
Kaiser-Meyer-Olkin = 0.75
Bartlett's test Approx Chi-Square = 77.21, df = 325, Sig <0.001

Appendix 7: Supplementary table to Chapter 6

Table A.50 Principal components analysis of the WHOQOL for carers

Component Matrix							
ITEM NUMBER	Component						
	1	2	3	4	5	6	7
1	0.603						-0.430
2	0.627				-0.322		
3	-0.523	0.768					
4	-0.472	0.636					
5	0.460		-0.394	-0.444	-0.358		
6	0.555				-0.378		
7	0.677						
8	0.638		-0.317		0.408		
9	0.619					-0.394	-0.418
10	0.791					-	
11	0.535			0.442	-0.452		
12	0.623		-0.323	0.397			
13	0.587		-0.352	0.493			
14	0.564			0.400			
15	0.647						0.410
16	0.622						0.413
17	0.745			-			
18	0.598	-0.400					
19	0.737						
20	0.636		0.606				
21	0.451		0.674				
22	0.621				0	0.363	
23	0.555	0.380					0.328
24	0.690					0.337	
25	0.663				0.379	0.385	
26	-0.676						

Extraction Method: Principal Component Analysis. 7 components extracted. .Where factor loading is under 0.300 it is not reported.
Factor 1 = 37.8 % of variance explained, Eigenvalue = 10.19
Factor 2 = 9.1 % of variance explained, Eigenvalue = 2.47
Factor 3 = 7.3 % of variance explained, Eigenvalue = 1.97
Factor 4 = 5.7 % of variance explained, Eigenvalue = 1.55
Factor 5 = 4.7 % of variance explained, Eigenvalue = 1.26
Factor 6 = 4.5 % of variance explained, Eigenvalue = 1.21
Factor 7 = 4.1 % of variance explained, Eigenvalue = 1.11
Total variance explained= 73%
Kaiser-Meyer-Olkin = 0.73
Bartlett's test Approx Chi-Square = 854.65, df = 325, Sig <0.001

Appendix 8: Semi-structured interview on hope

Table A.51: Questions for consumer and carer on goals in the hope interview, summarised from the questionnaires in Appendix 1.

Goal type	Questions for carer and consumer at baseline and follow-up	Optional prompts
Personal goals	Do you have any goals/hopes for yourself in the next year?	· Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty? · Maybe they are about sustaining or improving in an area that you are already working on? · Some of the areas that people have goals in are: work, family, friends, hobbies, health, money etc. Do you have any hopes or goals in these areas?
	How motivated do you feel about this/these goal(s)?	Do you think you will achieve them?
	Do you have any plans as to how you will work towards them?	How would you cope with a set back or problems occurring as you go along?
Family goals	Do you have any goals/hopes for your family/your consumer relative in the next year?	· Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty? · Maybe they are about sustaining or improving in an area that you are already working on?
	How motivated do you feel about this/these goal(s)?	Do you think you and your family/your relative will achieve them?
	Do you have any plans as to how you will work towards them?	How would you cope with a set back or problems occurring as you go along?
Treatment goals	Do you have any goals, hopes or expectations related to doing the BFST family sessions/working with your case-manager?	· Maybe you have some hopes /goals about keeping some things the same, or lessening a difficulty? · Maybe they are about sustaining or improving in an area that you are already working on?
	How motivated do you feel about this/these goal(s)?	Do you think you/ X will achieve them?
	Do you have any plans as to how you will work towards them?	How would you cope with a set back or problems occurring as you go along?

Appendix 9: Exit interview with consumers and carers

Table A.52: Questions for consumer and carer in treatment group only, on treatment satisfaction, summarised from the questionnaires in Appendix 1.

Evaluation of BFST **When: Follow-up** **Who: Consumer** **Group: BFST only**	
Lead question	**Follow up questions**
How did you get along with your helpers?	
How were things like manners, punctuality and follow through (doing what they were said they would?)	
What was it like working together (with your family) in sessions?	Do you think that you understand (your relative) better as a result of this BFST work? Do you think that they understand you better?
What's different about how the family talks together? Deals with things together?	Some of the areas things may change might be: • more open talking • better at solving differences and challenges • more open about feelings • responding more to when you are upset • changes in roles, more understanding of who does what • better agreement about house rules
What has changed for you through this experience?	What were some key moments/ pivotal situations/ turning points/ most important revelations?
What have you learned from the BFST program?	Did you learn anything more about schizophrenia? Did you learn anything more about how to talk together with the family? Some of the things that would have been

Evaluation of BFST **When: Follow-up** **Who: Consumer** **Group: BFST only**	
Lead question	**Follow up questions**
	covered were……. • how to ask for things directly • listening • expressing unpleasant and positive feelings • how to resolve issues and challenges and setting goals
And finally….. If a friend or acquaintance asked you whether or not BFST was worth doing, what advice would you give them?	What advice would you like to give us about our BFST program?

Glossary

Agency Hope	Snyder's theory on hope suggests that hope has two components that work together, the first is agency hope, which is the motivational energy to work towards a goal (see also pathways hope).
Analysis of co-variance (ANCOVA)	Analysis of co-variance, a statistical procedure.
Area Mental Health Service	The community-based services offering treatment for mental health problems for people living in the designated catchment area.
Behaviour and Symptom Identification Scale (BASIS-32)	A 32-item self-report instrument covering a wide range of typical psychiatric symptoms, behaviours and daily functioning.
Behavioural Family Therapy	A type of family psycho-educational intervention for serious mental illnesses such as schizophrenia. In this study, it was the intervention the treatment cohort received.
Bipolar disorder	A psychotic disorder which features significant mood disturbance
Bloated specifics	A bloated specific is a trivial factor that emerges in a factor analysis due solely to repeated/narrow item content (Cattell, 1978).
Building family skills together (BFST)	A Behavioural Family Therapy program, evaluated in this research.
Caregiving	Caregiving is taken to mean the totality of care-giving tasks, the positive and negative aspects, and the objective (i.e. observable) aspects and the subjective (i.e. the personal emotional reactions) aspects of care-giving (G. I. Szmukler, et al., 1996).

Caregiving burden	Caregiving burden refers to the negative or difficult aspects of care-giving, both objective (i.e. observable) and subjective (i.e. the personal emotional reactions) (Schene, et al., 1998; G. I. Szmukler, et al., 1996).
Carer or caregiver	Family member or person with a close relationship, who takes on the role of supervising and caring for a person with a significant illness or disability.
Case manager	A person who is assigned the task of co-ordinating the care and treatment of a person with a severe mental illness attending an Area Mental Health Service. In this study the case manager also conducted the family psychoeducation sessions with the consumer and their family.
Consumer	A term referring to people who receive treatment for mental illness. The term is applicable across the health field, but has particular currency in the mental health field in Australia (Chris Lloyd, et al., 2001; McLaughlin, 2008).
Continuing care team	The mental health care program providing ongoing out-patient care for consumers with significant mental health problems, where most participants for this study attended.
Coping	The use of initiative and skill that an organism brings to bear in formulating strategies to master life situations: orthogonal to vulnerability (Zubin & Spring, 1977)
Cronbach's alpha	Cronbach's alpha is a measurement of an aspect of the internal reliability of an instrument. It calculates how consistently the items in a measure assess the same construct. A general guideline is that a Cronbach's Alpha of 0.8 or more is acceptable for an instrument (R. J. Cohen, Swerdik, & Smith, 1992; Howitt & Cramer, 2008b).
Delusional disorder	A psychotic illness featuring delusions, which are

	impossible or false beliefs that are not amenable to logic or contradictory evidence.
Drug Attitude Inventory	30 questions with a true/false response. Explores attitudes to medication including side-effects, use between relapse episodes, attitudes to prescribing authority (doctor**)** (Hogan, et al., 1983).
Experience of Care-giving Inventory	This a 66 question instrument, exploring all aspects of care-giving, both positive and negative. (G. I. Szmukler, et al., 1996)
Expressed Emotion	A construct which reflects the extent that close family members express critical, hostile of emotionally overinvolved attitudes to a consumer. It is measured using the Camberwell Family Interview, which operationalises the construct through counting the number of comments that reflect the number of critical, hostile of emotionally overinvolved attitudes, that occur in a semi-structured interview (Hooley & Parker, 2006).
External validity	External validity is concerned with how valid are the conclusions made in generalising from one study to the rest of the population under consideration or other groups in time, space or place. The factors that may influence external validity are issues such as sample selection (D. T. Campbell & Stanley, 1966; Howitt & Cramer, 2008b).
Family Assessment Device General Functioning Scale	A 12 item scale that measures increases in healthy family functioning via improvement in joint problem sharing, sharing of positive and negative emotions, acceptance of family members and mutual support.
Family intervention for severe mental illness	Empirically-based therapy aimed at working with families, with benefits for consumer and family members
Family Management approaches for severe	Family treatment based on acceptance of biological basis for mental illness and empirically-based

mental illness	manualised approach, including family psychoeducation (Burbach, 1996).
Family Therapy	Therapeutic engagement of family to assist treatment of mentally ill family member, tend to focus on non-biological explanations for mental illness (Burbach, 1996).
Friendship Scale	Measures social isolation with a brief 6-item measure. (116)
General Health Questionnaire	A widely used measure for assessing non-specific psychological distress over the previous few weeks, consisting of 28 questions.
High prevalence disorders	Mental illnesses that are more frequently diagnosed, and generally less severe, such as depression and anxiety.
Implementation Study	Research program undertaken to study the process of implementation for the Building Family Skills Together intervention, Author Brendan O'Hanlon
Internal validity	Internal validity is concerned with how valid are the conclusions made within a study. There are many factors that influence internal validity, including, the proficiency of the methodology employed (D. T. Campbell & Stanley, 1966; Howitt & Cramer, 2008a, 2008b)
Kuder- Richardson measure	The Kuder-Richardson is a special case reliability measure. It is appropriate for scales with dichotomous items,(ie where the response set is two items such as "yes/no" or "true/false"). In the case of the instruments in the present study, it would be appropriate for the DAI instrument. (R. J. Cohen, et al., 1992; Howitt & Cramer, 2008b).
Level of Family work study	Research program undertaken to study the level of family work across all three Area Mental Health Services involved in the Building Family Skills Together

	research, Author John Farhall
Life Orientation Test	A scale to measure optimism and pessimism, by Scheier, Carver and Bridges (Scheier, Carver, & Bridges, 1994).
Life Skills Profile	16-item version, which is routinely used with outpatients in Victoria, which allows for benchmarking. (Rosen, et al., 1989)
Low prevalence disorders	Mental illnesses that are less frequently diagnosed, and tend to be more severe, such as
Multi-family group	a small number of families attending a group together for family psychoeducation.
Operant conditioning	A method of learning or behavioural change that occurs due to punishment or rewards being applied such that an association arises between the behaviour and the punishment or reward.
Outcomes study	Research program undertaken to study the outcomes for the Building Family Skills Together intervention, with Chief Investigator: Carol Harvey
Pai and Kapur Family Burden Scale	**The:** Objective and subjective caregiving burden assessed via semi-structured interview **(Pai & Kapur, 1981)**
Pathways Hope	Snyder's theory of hope suggests that hope has two components that work together, the second is pathways hope, which is the capacity to generate steps or ways towards a goal (see also agency hope).
PhD study	Research program undertaken in conjunction with the outcomes study for the Building Family Skills Together intervention, focussing on hope and recovery, by student Laura Hayes
Profile of Mood States	An instrument using 65 single words to describe mood over the previous week.
Psychosis	A mental state or set of symptoms which include hallucinations, delusions, and thought disorder.

Recovery	Two main approaches to the concept of recovery exist, one from the scientific literature, and the other from the consumer literature (Bellack 2006; Silverstein and Bellack 2008). In the scientific approach to recovery, set criteria in areas such as remission, stabilisation of symptoms, psychosocial rehabilitation, improved vocational activities, additional social connections and independent living are defined (Liberman, Kopelowicz et al. 2002; Kopelowicz, Liberman et al. 2005; Bellack 2006). The second approach to recovery is derived from the consumer-oriented literature, case studies and qualitative surveys (Bellack 2006). This typifies recovery as a process (Liberman and Kopelowicz 2005), rather than a fixed end point, and delineates a number of important characteristics that contribute to recovery. Recovery is not about symptom remission, or "cure", but the capacity to have a meaningful, purposeful life with hope for the future (Hatfield and Lefley 1993; Hatfield and Lefley 1993; Lefley 1997). . This thesis focuses on the second approach to recovery.
Reliability	Reliability is an estimate of the consistency of an instrument. Internal reliability measures how consistently all items in an instrument measure the same construct. Measures of internal consistency are procedures such as split-half reliability - comparing answers on one half of the test with answers on the other half of the test). Other approaches to reliability measure consistency across time (test-retest reliability), or consistency between rates or observers (inter-rater reliability -

	consistent assessments by different raters for a test) (Girden, 2001; Howitt & Cramer, 2008b).
Role Functioning Scale	The Role Functioning Scale is a 4-item scale that summarises a consumer's productive work, independent living, close and extended social network relationships.
Schizoaffective disorder	A mental illness that combines symptoms of schizophrenia, with mood disturbance.
Schizophrenia	A mental illness, with symptoms including hallucinations, delusions, thought disorder and loss of motivation, planning and social interaction (American Psychiatric Association, 1994)
Sensitivity	Sensitivity is the proportion of cases from a group that return positive results (ie are over the threshold score) that are truly positive cases (Goldberg & Williams, 1988).
Snyder Hope Scale	The Snyder Hope Scale measures the clarity and force with which a person pursues goals (agency), and the ability to find ways to achieve these goals (pathways).
Socio-Economic Index For Areas	The Socio-Economic Index for Areas (SEIFA) comprises four measures, one of which is the Index of Relative Socio-economic Disadvantage, that indicates disadvantage for a geographic area. The higher the index, the lesser is the disadvantage, where the Australian average is 1000. The factors that are included in the scale are income, educational attainment, unemployment and occupation.
Specificity	The specificity of a test is the proportion of true normals identified by a test. This is the percentage of test results below threshold or cut-off score, that are correctly identified as actual "normals" (Goldberg & Williams, 1988)
Stress-Diathesis model	Model of causation of mental illness that proposes that

	symptoms are occur as stressors in the environment interact with an underlying predisposition (diathesis) in a person (Zubin & Spring, 1977).
Test-retest reliability	Test-retest reliablilty Using the same instrument at two points in time, an estimate is obtained that correlates the two results from the same person. It is suitable for instruments that purport to measure stable traits and not characteristics that are expected to fluctuate over time (R. J. Cohen, et al., 1992) (ie it is appropriate for the hope scale, but not the POMS or the GHQ-28).
Total negative affect	Totality of feelings such as depression or anxiety. The opposite of negative affect is calmness or relaxation (Headey & Wearing, 1992)
Total positive affect	Total positive feelings such as joy, elation or happiness. The opposite of positive affect is not negative affect, but dullness or sluggishness (Headey & Wearing, 1992).
Validity of test instruments	Validity, in reference to a test instrument, refers to how well it measures what it purports to measure. In the present research, it would refer to how well the SHS actually measured hope, or the DAI measured attitudes to medication use. It has 3 main components: *Content validity* – refers to how adequately a test covers the realm of behaviours or "things" that a test is designed to sample. For instance, does the ECI cover the areas of burden for a carer? *Criterion-related validity* – refers to how well a score on a test is related to a score on a criterion measure. Concurrent validity will refer to a criterion measure taken at the same time (ie concurrently). It is often used in development of a new test, by using a well validated instrument as the criterion measure. Predictive validity refers to how well a test score will

	predict scores on the criterion measure. An obvious example is the use of admission tests at an educational facility, where the criterion measure would be performance at the end of first year, or drop-out rates for instance. A test of high predictive validity would accurately predict later academic achievement, and low rates of course drop-out. In the instance of the present research, the predictive validity of the FADGH for carer outcomes will be very important. The quantified measure for criterion validity is a correlation co-efficient. Construct validity is a judgement as to how the test results give us insight into a particular construct the instrument purports to measure. Construct validity is investigated in various ways such as: • Reviewing the homogeneity of an instrument's subscales since homogeneity will indicate all items are referring to the same construct. • Correlation with other validated measures of the same construct (convergent evidence) and no correlation with validated measures that theoretically have no relation with the correlation (discriminant evidence). • Scores change as theory predicts. • Test scores vary with membership to distinct groups as expected. Construct validity judgements will include reference to other reliability and validity measurement tools such as Cronbach's alpha used for reliability, or a correlation co-efficient used for predictive validity (R. J. Cohen, et al., 1992).

Vulnerability	The empirical probability that an individual will experience an episode of psychiatric disorder: an enduring trait (Zubin & Spring, 1977)
World Health Organisation Quality of Life Brèf Version (WHOQOL-Brèf)	**T**he World Health Organisation Quality of Life Brèf Version, is a quality of life instrument which emphasizes life satisfaction. 26 items measuring physical, psychological, social and environment domains.