Enduring anorexia:

A multi-storied counter document of living and coping with anorexia over time

Kristina Lainson

ORCID: 0000-0002-5208-810X

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Department of Social Work, Melbourne School of Health Sciences

Faculty of Medicine, Dentistry and Health Sciences

University of Melbourne

Abstract

It has been well-documented that anorexia (nervosa) often endures in people's lives, yet very limited research attention has been given to the perspectives of adults who have lived with its influence and effects over time. What studies do exist have engaged participation through specialist services, potentially skewing representation, and participants' experiences, knowledge and capabilities have tended to either go unrecorded or else are dominated by bleak narratives and/or deficit-based portrayals written from clinical perspectives. The Enduring anorexia project addresses these issues by inviting more inclusive participation via social media and by employing the theoretical lens of narrative practice. This hopeful lens centres lived experience perspectives, acknowledges personal agency and seeks entry points into alternative storylines of preferred identity that can lead to new possibilities and understandings.

Since social workers Michael White and David Epston first co-created narrative practice as a respectful and non-blaming approach to counselling and community work that recognises people as separate to problems and intentional in responding to difficulties, the field has been characterised by innovation and diverse application. The Enduring anorexia project extends this application, innovation and practice stance into conducting academic research in the realms of longer-term experience of living and coping with anorexia, demonstrating what opportunities arise as a consequence.

A two-step format of online survey and optional interview gathered stories of experience, response, and ideas about ways forward from 96 participants across 13 countries. Their generous and insightful contributions were thematically analysed congruently with narrative practice's theoretical bases of poststructuralist, feminist and critical thought. This reflexive process generated 12 themes describing complex and multi-storied experiences of living with anorexia over time. Some themes highlighted the capacity for anorexia's ongoing influence to create profound and extensive difficulties in people's lives; accumulating consequences for physical, psychological and social wellbeing were compounded by multiple psychiatric and societal discourses that created obstacles and confounded

attempts at seeking support or creating change. Other themes illuminated the meaningful ways participants engaged with their circumstances to purposively manage both their lives and anorexia's influence in it in order to overcome barriers, to reclaim all or part of their lives, and to live meaningfully and consistently with their values, beliefs and hopes.

In a realm where there is considerable professional uncertainty about how best to proceed or help, the Enduring anorexia project points to a need for

- professional attitudes that view people as separate from problems and privilege 'insider' over 'expert' perspectives;

- therapeutic approaches that attend to the politics of experience, and double-listen for skills, knowledges and entry points into alternative storylines;

- support services that are available, accessible and intentionally inclusive;

- research lenses and directions that focus on response, inclusion, opening space for possibility, and reporting respectfully;

- a re-conceptualisation of what has been considered a problem of the individual, to invite wider societal responses.

Throughout, narrative practice is shown to be an effective lens/tool for conducting inclusive, non-blaming, hopeful and generative research.

The Enduring anorexia project incorporates reflections on academic research processes, written from the perspective of an insider-practitioner-researcher.

Declaration

I certify that:

1. this thesis comprises of my original work towards the Doctor of Philosophy;
2. due acknowledgement has been made to all other materials used; and
3. the thesis is fewer than 100,000 words in length exclusive of tables, bibliography and appendices.

Kristina Janet Lainson

This thesis is dedicated to the participants

who so generously and insightfully

and often courageously

shared their experiences, stories and knowledge.

They have made this project

and everything that may come from it

possible.

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CHAPTER 1. INTRODUCTION

1.1 Identifying beginnings

This chapter outlines the Enduring anorexia project and thesis structure. It describes the beginnings of the project by briefly setting out its history, context, aims, and justification, and by identifying what further beginnings I hope it may contribute to. Provision of a personal, professional and academic rationale for the research locates me, as researcher, in multiple domains. This is not to centre me in the research but to be transparent from the outset about the influences that have inspired and shaped the project. This is followed by a description of the project as one response to pressing issues in the field of long-term experience of anorexia, explaining how the project's inception, purpose and significance fit into wider fields of academic research and therapeutic practice, and identifying what possibilities flow from that. The chapter concludes with a summary of the thesis structure.

1.2 Becoming an insider-practitioner-researcher

It was early (UK) summer 1981 when, in response to circumstances that had me feeling I wasn't doing so well at certain aspects of life I placed value on, I embarked on an extensive regime of what I hoped would be self-improvement. I wasn't convinced by my efforts but did inadvertently discover that going without food helped me feel better about things. Eventually, eating anything much at all became very difficult. Two years on, told I was no longer welcome to attend school as I was a source of distraction for the other girls, a formidable psychiatrist turned up at my home and told me I *had* something called Anorexia Nervosa. This required admission to an adult psychiatric hospital where I was to be cured. Once admitted, the focus of professional attention quickly switched from *what I had* to *who I was*, and to discovering what flaws and failings led me to behave in such a way. The imperative to self-improvement, now fully sanctioned, became intensified. Anorexia Nervosa was less spoken of then, at least in my context, and was new to my vocabulary. Yet

those two words, and the complexity of meanings they carry, went on to shape much of the rest of my life and, for a very long time, to define my sense of who I was.

The rationale for the Enduring anorexia project came from what I learned in the intervening years. I don't have answers for how, why or where anorexia begins and ends in a person's life, but I do have knowledge of living and coping with its presence and influence, and others' responses to it, for many years. Over decades, I have moved between the domains of my own lived experience, volunteering in peer support and advocacy, training and working in the field as a narrative practitioner, participating in other people's research, and now conducting my own. It would be neither possible nor desirable to entirely separate what I learned in each domain, and it has been their interactions that have shaped and formed the range of concerns, beliefs and hopes that led to this project's formulation, its implementation, and my conviction that it was necessary.

1.3 Locating the project as a hopeful response

The Enduring anorexia project is a community-based study that utilises the theoretical lens and practices of narrative therapy[1] to explore what it is like for adults who live with the influence and effects of anorexia for many years, and to enquire about how they respond to their circumstances. The project seeks to provide inclusive and respectful representation in a realm where these experiences have often been ignored and/or pathologised. It also seeks to contribute useful understandings in a context where support services often find mainstream approaches thwart their attempts to help. The Enduring anorexia project is one response to a recent editorial call in the *Journal of Eating Disorders* for a 'new paradigm' (Touyz & Hay, 2015, p. 26) for understandings in the context of long-term experience of anorexia 'not only by the medical profession but by the world at large,' (p. 26), and their invitation to consider approaches that can offer hope of 'a better tomorrow' (p. 26).

[1] The terms narrative therapy and narrative practice are used interchangeably throughout this thesis. There is more about this in the methodology chapter.

Concerns about limited and limiting attention

"'You're an adult now, you're supposed to have grown out of that!' And I haven't, and I don't know what to do with it … I went to my doctor to talk about it and she didn't know what to do with me, because that's something you have when you're younger." (Participant)

It has been well-documented that anorexia usually turns up in people's lives when they are fairly young (Treasure & Russell, 2011), but has a tendency to maintain its influence and effects in people's lives for many years, if not whole lifetimes (Bamford et al., 2015; Broomfield, Stedal, Touyz, & Rhodes, 2017; Dawson, Rhodes, & Touyz, 2014; P. J. Hay, Touyz, & Sud, 2012; Knatz, Wierenga, Murray, Hill, & Kaye, 2015; Robinson, 2009; Stockford, Kroese, Beesley, & Leung, 2018; Touyz et al., 2013; Wonderlich et al., 2012). Yet there has been a paucity of attention given to adult or longer-term experience, particularly from a lived experience perspective (Dawson, Rhodes, & Touyz, 2014; Stockford et al., 2018; Touyz & Hay, 2015; Wonderlich et al., 2012), despite evidence that the detrimental effects for a person's life over time have the capacity to be profound (Arkell & Robinson, 2008; Bamford et al., 2015; Robinson, Kukucska, Guidetti, & Leavey, 2015). Clinical understandings and therapeutic approaches that have offered very little by way of hope or possibility of change continue to dominate the field (Bamford et al., 2015; Stockford et al., 2018; Touyz & Hay, 2015), and common representations in this realm are reductive, stereotyped, and limiting (Gremillion, 2008; Saukko, 2008b; Warin, 2004), contributing to hope-less outlooks (Robinson et al., 2015) that ultimately have unhelpful effects for people living with anorexia over time, and those who seek to be of help to them (Button & Warren, 2001; Strober, 2010).

Beliefs and hopes that lead to seeing the alternatives

"I don't think the treatment I received kind of contextualised my experience … and I think feminism, or the feminism I have surrounded myself with, acknowledges that a lot more and can understand it a lot more … it's made me feel that my experiences are less unusual … It was me doing my best with what I had available … I think it makes me feel less to blame. I can understand it more." (Participant)

Working as a narrative practitioner in Aotearoa New Zealand I found I heard different stories to those represented in the academic and clinical literature relating to this realm. As I listened to the stories people told me about their experiences of living and coping with anorexia's influence and effects over time, through ears that were 'tuned in' (Hibel & Polanco, 2010, pp. 51-66) to 'double-listen' for skills, knowledge and alternative storylines (Freedman & Combs, 1996; Morgan, 2000; M. White, 2003, 2007; M. White & Epston, 1990), I witnessed what possibilities narrative therapy had to offer for understanding people respectfully and for supporting them in creating wished-for change (see Lainson, 2016, 2019). I also began to be curious about applying the stance, practices and lens of narrative therapy, with its underpinnings of poststructuralism (Thomas, 2002; M. White, 1991) and feminist thought (C. White, 2016) in the context of research as a means of offering improved representation of people by viewing them as separate from problems; paying attention to the roles of broader social context, discourse, story and the politics of experience; privileging insider knowledges and perspectives and making visible complex and multi-storied experience; and illuminating acts of personal agency that point to intentions, beliefs, values and hopes (Epston, 1999; Morgan, 2000; Russell & Carey, 2004; M. White, 1991, 1995, 2000, 2007; M. White & Epston, 1990).

Possibilities for narrative practice in research

> The narrative mode leads, not to certainties, but to varying perspectives … [it] locates a person as a protagonist or particular participant in his/her world. This is a world of interpretative acts, a world in which every retelling of a story is a new telling, a world in which persons participate with others in "re-authoring," and thus in the shaping, of their lives and relationships. (M. White & Epston, 1990, pp. 78-82)

The Enduring anorexia project differs from existing research in this realm by privileging the voices of people with lived experience of the influence and effects of anorexia over time rather than clinical perspectives, and by drawing on narrative practice principles that take an interest in how people respond to, or cope with, hardships and difficult circumstances. Uniquely, this study invites diverse contributions from international, community-based participation (see Robinson et al., 2015) via a narratively informed qualitative online survey

and optional semi-structured interview, circulated on social and news media. Reflexive thematic analysis (Braun & Clarke, 2006, 2019; Lainson, Braun, & Clarke, 2019) is utilised to generate twelve themes constructed from participants' own words that richly describe multi-storied experience, highlight agentive response, and bring into focus the contexts and discourses that make these experiences and responses possible, and which give them meaning (Braun, Clarke, & Hayfield, 2019; Jankowski, Braun, & Clarke, 2017). Narratively informed, double-storied research is presented as a form of counter documentation (M. White & Epston, 1990) that can respectfully and helpfully improve representation in medical and wider social contexts; provide insights that have implications for service provision, therapeutic practice and social action; and honour skills, knowledge and agentive response in ways that seek to avoid diminishing what actions people are already engaging in, whilst simultaneously making new possibilities more available.

1.4 Outline of thesis structure

i. The literature review provides a critical overview of the existing landscape of mainstream literature relating to anorexia, setting out how, over time, theories and models of understanding have both changed and remained the same to create a problematic picture more likely to keep people stuck than enhance possibilities for change. Glimpses of a few sparkling exceptions infer other possibilities but, in response to the discouraging landscape, the literature review begins with an insider-researcher critique of academic requirements that privilege engagement with unhelpful ideas as an assumed part of the research process. The bleak scenario is then juxtaposed against more hopeful possibilities by introducing readers to the history, literature, principles and practices of narrative therapy.

ii. The methodology defines the research aims, establishes the research questions, and sets out the steps taken to conduct the project, providing the theoretical and practical rationale for decisions, making rigorous attempts to be visible about intentions, assumptions, and other influential factors along the way. The selection of a narrative therapy lens is explained and justified, drawing links between the

methods utilised and the ontological and epistemological understandings that supported choices made, steps taken, and conclusions drawn.

iii. The results of the online survey and optional interviews are reported as a three-part chapter: Part 1 provides participant demographic and background information along with a summary of the responses to closed survey questions, Part 2 provides a profile of interview participants, and Part 3 constitutes rich descriptions of twelve themes constructed from the combined survey and interview responses through a narratively congruent, iterative process of reflexive thematic analysis (Braun & Clarke, 2006; Lainson et al., 2019).

iv. The discussion chapter critically considers the results from the survey and thematic analysis through the theoretical lens of narrative practice and identifies what can be offered by way of understandings, representation and future therapeutic and research practices. Implications of this research are proposed, and recommendations made for how the findings of this project can guide therapeutic practice and service provision to ensure more inclusive, respectful and hopeful futures. The use of a narrative therapy lens in research is put under scrutiny, establishing what possibilities are generated for future research. Limitations of the study are also considered.

v. The conclusion sets out what has been achieved by the Enduring anorexia project; its contribution to the field of research, and what it makes possible for future practice in the context of long-term experience of anorexia.

CHAPTER 2. LITERATURE REVIEW

2.1 Outline of literature review structure

This literature review is comprised of the following four sections:

i. An introduction to writing an academic literature review from an insider-researcher perspective, reflecting on the challenges and politics of meeting this requirement.
ii. A critical analysis of several decades of literature on anorexia, its conceptualisation, and dominant approaches, with particular reference to long-term experience.
iii. An overview of narrative therapy heritages, practices and principles as they relate to the design and intentions of this research, and to the theme of anorexia.
iv. Concluding comments that establish how embracing narrative practice ideas in research can contribute to a new, alternative evidence base.

2.2 An insider-researcher reflection on the literature review process

> We can't remain captive to what is contained in existing literature. When you do your review, are you challenging the prejudices that arise from the literature that you read?
> (Chilisa & Denborough, 2019, p. 14)

This literature review requires a special introduction because there's a story that wouldn't typically be included in academic writing, but that is crucial to understanding the background to this thesis. It's a personal story of the potential for effects when engaging with academic literature on particular topics. A feature of this research is that it is insider research in so far as I have personal experience of the central theme, i.e. I have long-term lived experience of anorexia. This is relevant to the research in several ways that are discussed at greater length in the methodology chapter, but it is also important in relation to the literature review.

As I will show, there is no shortage of literature on the topic of anorexia, but next-to-nothing on how people manage their experience over time. This is a significant omission because, as this chapter illustrates, much of the literature on anorexia and in particular long-term experience makes neither encouraging nor flattering reading. It is all-too-often written from the perspective of personal deficit, through a lens that assumes that people living with anorexia lack life skills and coping capacities, have problematic personality traits or flawed neurobiology, or are suffering as a consequence of some personal or inter-personal psychopathology. It was my own early engagement with these sorts of depictions that ultimately inspired me to embark on this research project. A project that seeks to contribute to something different.

A personal history of engaging with academic literature on anorexia

Many years ago, after a decade of failed and sometimes traumatic treatments, I opted out of the medical system, choosing to attempt to deal with things myself. Part of my strategy of self-help was to learn about anorexia by reading whatever was available to me. In those days this meant visiting the local library for details of a small organisation known as Anorexia Aid, applying for a recommended booklist, sending a cheque through the post, and waiting up to several weeks for the book to arrive. I waited with something between eager anticipation and sheer desperation, hoping dearly that my money had not been wasted and that this would finally be the book that changed everything. Time and time again, I was worse than disappointed. Academic theories that pathologised my identity, disturbingly florid accounts of lived experience, and self-help regimes designed by people who had never lived a day with anorexia, served to overturn what gains and reclamations I had made myself. These descriptions of my personhood seared, my own means of getting by were rendered worthless or symptomatic, and I was framed as problematic, errant and worse. Many of the theories, perhaps worst were those that also captured the attention of newspapers, would quite literally crush me. Try as I might to repudiate the deprecating portrayals, I could only ever believe myself to be in denial of the facts. These truths were, after all, told by experts and so provided proof of who and what I was. Most often this resulted in me literally curled up unable to move or speak, and sometimes it was much worse. I was fortunate in having an incredibly supportive friend who would sit with me

during those times, in the silence and the darkness. It was always his kindness, patience, humour and uncanny ability to present an alternative perspective that eventually got me on my feet again, helping me transcend the awfulness. It took a while for this pattern to become visible to me, but eventually I learned the skills that became a literal means of survival; to ignore distant expert opinions of me, and instead to listen to those who knew me better and thought well of me, and to allow myself to do the things I knew were helpful to me. I don't claim some miraculous recovery as a consequence, but some of my biggest reclamations of life were during years I didn't read a single thing about anorexia. Ironically, I did miss out on one or two new developments that might have been useful to me, but for the most part avoiding academic theories of my personhood was the best thing I could do to help myself.

Putting myself 'back in there' and coming up with strategies

So, now finding myself re-engaging with that same, and still further extended, body of literature has not been without challenge or effect. In the interim years I have been exposed to more helpful ideas than in those earlier theories. I have grown to see things in a different light, but it wouldn't be true to say that I am not, at times significantly, affected in very unhelpful ways when reading deficit-based literature. It's somehow still difficult not to wonder if they might be true and whether I might really be that inherently problematic, or to become frustrated that problematic ideas are being re-circulated in revised forms. I have read for this literature review with trepidation and exasperation. I have been annoyed, saddened and at times quite crushed by what I have read; by what is still being written.

An extensive review of the literature, however, is an expected component of academic research and I couldn't be considered credible without proving I had read, understood and critically analysed what I didn't really want to read at all because I found it so personally undermining, invalidating and depleting. I had to find some means of coping. This led to the development of my *Strategies for surviving a literature review as an insider-researcher* project. I began this practice one afternoon when I felt moved to hypothetically write back to the anthropologist whose article I was reading. It was tongue in cheek, but I sent it to one of my supervisors, David Denborough, suspecting he would appreciate it. He did! In fact, he suggested I keep up this practice of recording the strategies I was using. Some of these are

listed in Appendix 1, and a hope I hold is that they might be of use or inspiration to future insider-researchers in any realm who become faced with deficit-based literature about themselves and their communities as they attempt to offer something more hopeful and just.

Politics and principles of writing this literature review

For these reasons, I have had to think very carefully about what I include in my literature review, which avenues to explore and how I write or present what has been written. Being thorough and rigorous was essential, but additional principles I tried to follow were:

- *Asking myself through what lens I was reading, and whether I was providing unnecessary or unhelpful detail when reflecting on deficit-based theories and representation*s: This review aims to acknowledge the existence and effects of deficit-based literature; not to give it credibility but to honour what insiders have had to put up with. It seeks to demonstrate how these representations can contribute to negative self-understandings and adverse treatment from others, but to do so without re-telling deficit stories about people or replicating unhelpful effects.

- *As an overarching principle, research reporting should be accessible and welcoming for insiders to read*: I know that some participants intend to read this thesis and I hope that other people with insider experience do too, and that they might recognise themselves in the representations herein. I won't get it entirely right, and not everyone with lived experience will hold the same viewpoint. I respect readers' self-knowledge and their choices about what is appropriate for them. I uphold their right to move forward cautiously and to decide for themselves whether engaging with aspects of this research will be helpful or unhelpful to them. My hope is that for those who do choose to read on, they may find themselves in a helpful and respectful domain.

- *Referencing areas of professional confusion or uncertainty is important, but refusing to accept them as barriers to hope creates space for new possibilities:* Recognising gaps in professional knowledge as spaces where insider knowledges can make contributions was a political act I embraced throughout this review.

- *Recognising there is room for hope even when someone has lived with anorexia's influence for many years, and that both hope and change can take multiple forms:* This review does not accept the limitations of prescriptive ideas about hope and change, and seeks to evade imposing the normative expectations on people's lives that can lead to significant oversights, and obscure meaningful possibilities.

- *Re-viewing earlier research, paying attention to evidence of insider knowledge, alternative storylines, and other possibilities that may have been overlooked by the original researchers:* This review highlights how taking a new lens to existing literature can sometimes illuminate previously neglected storylines, such as steps being taken by participants to reclaim or retain certain aspects of their life even when things seemed overwhelmingly bleak.

- *Resisting the language of illness that pervades even non-medical writing:* Traditions of terminology that have been derived from pathologising contexts can shape our understandings of people and problems in unhelpful ways that this thesis seeks to escape. This review privileges non-pathologising language and practices of deconstructing pathologising ideas.

- *Bringing to the forefront practices, philosophical understandings and possibilities that have previously been under-explored and under-represented within mainstream clinical and academic literature*: Given overwhelming evidence that dominant approaches have not solved the problem of people's lives being negatively affected by anorexia, this review has actively sought out writers with alternative lenses, approaches and viewpoints.

2.3 The literature on anorexia

Anorexia has been a source of research, study, fascination and confoundedness to clinicians and academics from a wide range of disciplines for many years, resulting in an extensive body of literature. Although medicalised understandings of anorexia are not universally accepted they clearly dominate. Literature relating to anorexia across multiple fields of study typically has a deep biomedical hue and the language of *illness, treatment and recovery* imbues much of what has been written.

The historical construction of anorexia

What is currently commonly known as anorexia was first recorded in the clinical literature in the 1870s. The name was bestowed by two physicians around the same time. British physician William Gull coined the term anorexia nervosa and Charles Lasègue designated l'anorexie hystérique to describe the practices and attitudes of certain women towards eating and exercise that they identified as sharing commonalities and considered problematic (Hepworth, 1999). This naming and classification established anorexia as a condition that fell under the umbrella of psychiatry, heralding the beginning of the dominance of medicalised understandings, and it is not uncommon to read that Anorexia Nervosa (initial letter capitalisation is variable) is one of the oldest psychiatric diagnoses (Touyz & Hay, 2015). It is unclear whether what is now commonly called anorexia actually has a much longer history. Scholars Bynum (1988) and Bell (2014) have debated whether the fasting rituals of young Catholic nuns in Europe in the Middle Ages, known as anorexia mirabilis, were in fact historical examples of the same practices and attitudes that would later become diagnosed as anorexia nervosa, or whether these young medieval women were engaged in some spiritual quest or form of self-expression that is distinguishable from the concerns of the women described by Gull and Lasègue, and those who become diagnosed today.

Alongside naming anorexia nervosa and adopting it into a family of psychiatric conditions, Gull and Lasègue made a number of recommendations for therapeutic interventions that involved encouraging the women to eat more and move less in order to increase their

bodyweight. Both physicians advised that, should initial encouragements prove unsuccessful, then moral treatment was called for whereby the young women were separated from their usual social networks, with non-familial attendants taking on the task of ensuring their eating and bodyweight were restored (Hepworth, 1999). This prescription conflated medical with moral practice in a way that 'not only elevated medical treatment as implicitly good but also denigrated women's practices of food refusal as implicitly bad' (Conti, 2013, p. 17). While in the present day one is more likely to find family members being called upon to take up the responsibility of ensuring the person's eating and bodyweight are restored, the recommendation for another person to take decision-making control remains common (see Conti et al., 2017; Le Grange, 2005; J. Lock & Le Grange, 2015; Rhodes, Gosbee, Madden, & Brown, 2005; Wierenga et al., 2018).

Assumed demographics

In order to better appreciate how anorexia and the people who live with it have come to be understood, there is a need to recognise how particular beliefs about where anorexia resides in our communities have shaped ideas about its nature, effects, and the usefulness of therapeutic approaches. These ongoing assumptions about incidence have potentially distorted the true picture, stifling opportunities for improved understandings (Gremillion, 2008). Anorexia has traditionally been considered the preserve of White middle-class girls and young women living in Western culture (McClelland & Crisp, 2001), in contexts where high academic achievement and particular forms of social conformity are valued (Bould et al., 2016; Bruch, 1978; Evans, Rich, & Holroyd, 2004; Halse, Honey, & Boughtwood, 2007; Rich & Evans, 2008) and who have shared personality traits (Bastiani, Rao, Weltzin, & Kaye, 1995; Bruch, 1978; Kaye, 2008; Klump et al., 2000). This has led to homogenised beliefs about, and representations of, people and experiences (Kaye, Fudge, & Paulus, 2009; Saukko, 2008a) sometimes implicating these factors as contributory or causative. A problematic consequence of these assumptions and conclusions remaining unchallenged is an ongoing pattern of circular logic, whereby only those people who fit the original demographic assumptions have become diagnosed. Diagnosis thus reinforces the stereotype that, in turn, informs the potential for future diagnoses.

> Privileging of diagnostic 'expertise' in defining anorexia here conceals from view, and therefore also perpetuates, the race and class particularities of the problem as we currently understand it'. (Gremillion, 2008, p. 219)

This presents a multitude of difficulties for people living with anorexia, and for those seeking to help and understand. Whilst receiving a diagnosis may not always be considered desirable, in practical terms it is usually a pre-requisite for access to public support services. As Gremillion (2008) also points out, diagnosis is more often than not a pre-requisite for participation in research. Hence, only people who fit the original assumed demographic are included in studies, contribute to research findings, and are fully considered in the development of therapeutic approaches and service design and provision. The cycle continues.

In recent years this limited picture has been increasingly contested as inaccurate; slowly unsettling many long held professional and societal beliefs. Increased recognition of male experience (Baum, 2006; Botha, 2010; Gremillion, 2008), of anorexia existing across multiple cultures and ethnicities (Abraham & Birmingham, 2008; Eli, 2014; Gremillion, 2008; Lee, Ho, & Hsu, 1993), and of its impact on older age-groups (Bulik, Reba, Siega-Riz, & Reichborn-Kjennerud, 2005; Mitchison et al., 2013; Robinson et al., 2015; Touyz & Hay, 2015; Wonderlich et al., 2012) challenges what was once thought of as known, as incomplete. However, changes to understandings move slowly and, despite The Royal Australian and New Zealand College Of Psychiatrists (2009) stating in their Clinical Practice Guidelines that 'Anorexia Nervosa crosses diverse cultural boundaries' (p. 619), in Australia the Butterfly Foundation (2012) reported that people who do not fit into what has been considered the typical demographic often still find it much harder to gain access to appropriate supports and services, or to have their difficulties recognised. There is no reason to assume that this situation is unique to Australia, and the contradictions therein exemplify how incomplete demographic understandings have material and detrimental effects in people's lives.

Reported incidence

Evidence of reported incidence must, of course, be read in the light of the limitations created by this assumed demographic. The Butterfly Foundation (2012) report lifetime prevalence of anorexia nervosa in Australia as 0.3% - 1.5% for females and 0.1% - 0.5% for males (p. 21), with a point prevalence average across Australia, New Zealand and Switzerland of 0.15% for females and 0.07% for males, between the years of 1995 and 2005 (p. 22). Incidence of anorexia is considered to have risen significantly between 1960 and 1980 (Brumberg, 2000; Hoek, 2006), during which time the concept of anorexia was becoming more known, particularly to the public, making it possible that this recognition led to the growth in reporting and demand for care rather than an actual rise in incidence (Hoek & van Hoeken, 2003). This apparent increase is reported to have stabilised since the 1980s (Bulik et al., 2005; Hoek, 2006) in contrast to other eating practices that have also become named as disorders, that are reported as appearing to be on the rise (Gordon, 2000; P. Hay, Mond, Buttner, & Darby, 2008; Nasser, Katzman, & Gordon, 2003). Hoek (2006) points out that eating problems are often very private concerns that never reach the attention of professional services and gaining a true picture of the extent to which people are living with these challenges is difficult to achieve. An additional complexity in coming to an appreciation of how prevalent anorexia is in our communities, is that a common feature of literature and advocacy is a tendency to identify anorexia as having one of the highest mortality rates of any psychiatric illness (see Keski-Rahkonen et al., 2014) and then quickly conflate it with other eating disorders to emphasise prevalence in the population at large.

Unsettling these early understandings illuminates a need for research that creates space for inclusive participation, that seeks a rich appreciation of diverse experience, and can offer complex and accurate representations in order to better inform our responses, shape our therapeutic approaches, and improve the design, provision and accessibility of services.

Severe and enduring anorexia: New categories and language

A new conversation about anorexia has emerged during the last decade. To give some background, a notably common feature in the literature is to describe anorexia as a serious and tenacious problem with the potential to become long term or recurrent, that responds

poorly to treatment (Halmi et al., 2005; Kaye, Bailer, Klabune, & Brown, 2014; Keski-Rahkonen et al., 2014; Steinhausen, 2002). However, consideration of this longevity generally ceases at the article's introduction. Specific attention to the implications of long-term experience of anorexia, and the potential for unique effects or support needs, has been surprisingly overlooked until very recently (Touyz & Hay, 2015; Touyz et al., 2013; Wonderlich et al., 2012).

What little attention has been given to the longer-term picture has tended to focus on clinical management of the problem (Robinson, 2009; Strober, 2004; Sullivan, 2003; Wonderlich et al., 2012) with nominal attention to subjective accounts of long-term experience, representing a significant gap in professional knowledge (Dawson, Rhodes, & Touyz, 2014; Touyz & Hay, 2015). Very recently, debates have arisen around the usefulness or otherwise of creating a separate diagnostic category for long-term anorexia, and what should constitute such a category if the idea was to be embraced (Broomfield et al., 2017; P. Hay & Touyz, 2018; Tierney & Fox, 2009). These debates have brought with them a new language. Whilst the term chronic was typically used to describe anorexia's longer-term influence in a person's life (Dawson, Rhodes, & Touyz, 2014; Fox & Diab, 2015; Knatz et al., 2015; Mander, Teufel, Keifenheim, Zipfel, & Giel, 2013; Strober, 2004; Sullivan, 2003; Wonderlich et al., 2012), it is increasingly common to see severe-and-enduring used to describe longer-term experience of anorexia (Arkell & Robinson, 2008; Bamford et al., 2015; Broomfield et al., 2017; Conti et al., 2016; P. Hay & Touyz, 2018; Le Grange et al., 2014; Raykos, Erceg-Hurn, McEvoy, Fursland, & Waller, 2018; Robinson, 2009; Robinson et al., 2015; Stockford et al., 2018; Touyz & Hay, 2015; Touyz et al., 2013). This aligns with the language of other long-term and serious mental health concerns, called for by Arkell and Robinson (2008) as part of seeking better appreciation for the profound effects of long-term anorexia on a person's life and their ability to function. In part, this was to secure parity of rights and benefits within the British health and social services as those living with schizophrenia and severe depression. However, this altered language also appears to herald a shift in thinking about longer-term experience; a move away from attitudes of immediacy and of anorexia as a problem to be remediated through rigorous intervention with a focus on weight gain, towards consideration of approaches that might involve drawing from a less robustly linear trajectory of illness-treatment-recovery.

This new interest in considering the long-term picture has resulted in a (very) small number of studies relating to quality of life, all of which have indicated that for someone living with anorexia over time the effects on their wellbeing can be profound across multiple life domains, and that chances of what might be thought of as recovery reduce over time (Arkell & Robinson, 2008; Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014; Robinson et al., 2015; Strober, 2004; Touyz et al., 2013). The literature in these realms describes a rocky terrain, depicting desolate lives dominated by multiple forms of suffering, largely devoid of hope (Mitchison et al., 2013; Robinson et al., 2015), supported by considerable professional pessimism (Touyz et al., 2013). People living with anorexia over time are characterised as difficult to engage and ambivalent about change (Wonderlich et al., 2012). Said to be unmotivated, high treatment drop-out rates are explained away by clinical claims of attachment to ego-syntonic symptoms, and treatment failures explicated by the patient's lack of engagement with recovery attempts (Arkell & Robinson, 2008; Fox & Diab, 2015; Higbed & Fox, 2010; Stockford et al., 2018; Touyz et al., 2013; Wonderlich et al., 2012).

The serious effects of anorexia

> How does one assess the seriousness …? Its prevalence, mortality, chronicity, effect on the sufferer's life, on the family, and on society in general, must all be considered. On each of these measures, anorexia nervosa is very severe. (Beumont & Touyz, 2003, p. 20)

In whatever way one understands anorexia, there is no doubt that it can be a highly disruptive intrusion in the lives of individuals and their families. Although commonly making its first appearance in the lives of adolescents or even children (Cottee-Lane, Pistrang, & Bryant-Waugh, 2004; Treasure & Russell, 2011), anorexia is well-known for its tendency to remain or recur in people's lives for many years, or even whole lifetimes (Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014; Le Grange et al., 2014; Stockford et al., 2018; Touyz & Hay, 2015), giving rise to calls to prioritise early intervention (Treasure & Russell, 2011) in the hope of warding off what may otherwise become a long-term physically, socially and psychologically debilitating problem with potential for profound effects on people's lives, especially over time (Arkell & Robinson, 2008; Bamford et al., 2015; Button & Warren, 2001;

Dawson, Rhodes, & Touyz, 2014; Fox & Diab, 2015; Ross & Green, 2011). Medical complications and suicide combine to account for its high mortality rate and accompanying practices of intentional self-injury are common (Arcelus, Mitchell, Wales, & Nielsen, 2011; Birmingham, Su, Hlynsky, Goldner, & Gao, 2005; Paul, Schroeter, Dahme, & Nutzinger, 2002; Sansone & Levitt, 2002). In an attempt to address a recognised lack of research into long-term experience of anorexia, Robinson et al. (2015) undertook what was arguably the most in-depth qualitative study of the effects of anorexia over time, conducting a series of interviews with people who had lived with anorexia for more than 20 years and evidencing how participants endured a precarious health status, alongside multiple other difficulties. Long-term physical effects of anorexia were cited as including osteoporosis, hypokalaemia, Reynaud's syndrome, dental problems, Grave's disease, bouts of pneumonia, and cardiac arrest amongst others. Psychological difficulties were reported to include feelings of unworthiness, self-loathing, depression, hopelessness, and thoughts of suicide, with additional effects including lack of paid employment, financial struggles, unwanted social isolation and the potential for difficult family relationships. This, albeit sensitive and thoughtful, study painted a picture of people living with anorexia over time as destined to bleak and barren lives with little opportunity for hope of improvement, a perspective that has been supported elsewhere (Arkell & Robinson, 2008; Bamford et al., 2015).

In whose estimation? Barren lives and flat representations, or recognition of agency

A limitation of much of the literature on quality of life in this context is the emphasis on clinician assessment of wellbeing and clinical decisions about where attention should be focussed, with little space for the views and perspectives of people actually living with anorexia. The very small handful of articles centred on long-term experiences of anorexia that give voice to insider knowledge have tended to focus on deficits or what is missing in participants' lives. Perhaps rightly so, as these efforts were aimed at identifying the problem's severity, but this has been at the expense of other aspects of participants' lives which stood in contrast to the story of deficit.

Robinson et al. (2015) did note expressions of positivity alongside participants' experiences of profound sadness and bleak horizons.

> A striking finding was the fact that the participants we interviewed were not all crushed by their long illnesses, but showed signs of resilience and pride at their achievements. (Robinson et al., 2015, p. 324)

However, they did not go on to make this a focus for further enquiry which may be a significant oversight. Careful reading of the study gave glimpses of another storyline. Some participants had married and had children despite a wider theme of social isolation and difficulties with intimate relationships, some maintained voluntary work in the absence of paid employment. These events likely paled into insignificance in relation to the dominant, problematic story but, as will be discussed in greater depth later in this chapter, through a lens of narrative practice they also reveal potential entry points into alternative stories (M. White, 2007; M. White & Epston, 1990) that might be helpful to those who seek change. Similarly, this dominant story of hopelessness is somewhat challenged by Dawson, Rhodes, and Touyz (2014) whose interviews with 8 participants identified as recovered after long-term experiences of anorexia, detailed how active, intentional and engaged they were in the process of what they defined as recovery.

The study by Robinson et al. (2015) also revealed that anorexia provided participants with a sense of purpose and gave structure to their lives. Unpleasant experiences such as guilt tended to be assuaged by the practices of anorexia, including exercise and eating rituals. Some participants even reported gaining a sense of pride from continuing with certain aspects of life despite these rigours. While physical problems were described as 'legion' (p. 320), the authors also commented that participants tended to minimise these effects and remarked on a 'sense of brinkmanship' (p. 320) that they perceived participants had towards their own health status, and a belief that they could manage the physical risks of anorexia with medical support. Complex attitudes towards health status in relation to anorexia have been written about elsewhere. Rebecca Lester (2014) argued that poor physical health was actively sought after by participants in her study, who considered practices supportive of good health as a moral failing that evidenced undue self-care. Musolino, Warin, Wade, and Gilchrist (2015), on the other hand, made the case that the restrictive eating practices of anorexia became justifiable to their participants if they

concurred with discourses of healthy eating, and where practices towards maintaining good physical health are considered a moral category (see Crawford, 2006) despite the ultimately unhealthy consequences. These conflicting interpretations of the health consequences of anorexia, as either unwanted negative effects or potentially meaningful outcomes, give rise to questions about how researchers draw conclusions about the lives of others. Privileging clinical measures of quality of life assumes a great deal that leaves little space for alternative understandings that might otherwise illuminate how intentions, beliefs and values give shape to choices and action that appear irrational to the uninformed onlooker.

The search for a cause

> Despite increased attention and awareness of both the severity and chronicity of Anorexia Nervosa, significant gaps in our knowledge limit our ability to effectively treat this disorder. (Federici & Kaplan, 2008, p. 2)

There is no doubt about the seriousness of anorexia and poor understandings of its aetiology have been said to underlie a consequent lack of adequate models for intervention, resulting in sobering predictions for long-term outcomes (Arkell & Robinson, 2008; Bulik et al., 2005; Halmi et al., 2005; Touyz & Hay, 2015; Wonderlich et al., 2012). The quest to find some identifiable cause for anorexia has contributed to considerable clinical research and ongoing academic debate, with psychological and psychiatric thinking shifting over time. Despite a plethora of theories emerging over the past half-century, from multiple disciplines, anorexia is still generally considered to be an insufficiently understood problem (Dalle Grave, Calugi, Conti, Doll, & Fairburn, 2013; Eli & Warin, 2018; Kaye, Wierenga, Bailer, Simmons, & Bischoff-Grethe, 2013; Munro, Randell, & Lawrie, 2017; Touyz & Hay, 2015). Yet this attention from a wide range of disciplines and paradigms, framing of anorexia as being multiply and complexly caused, has led to an unfortunate consequence that becomes visible by retracing some of the steps taken and conclusions drawn.

One of the earliest and foremost theorists on anorexia was psychiatrist Hilde Bruch, whose influential work *The Golden Cage* (Bruch, 1978) characterised the young women living with anorexia with whom she met as lacking in autonomous character development, rendering

them unreasonably and unusually vulnerable to external pressures and influences. In addition, Bruch claimed that these girls were situated in, usually middle-class, over-involved and over-controlling family structures, thus problematising parents (especially mothers) alongside their daughters. Despite her theories being rigorously contested by later writers and advocates, Bruch's work has guided understandings of anorexia and many of her ideas continue to be pervasive, whether in their original or altered form (Saukko, 2008a).

Anorexia has remained firmly entrenched in clinical thinking as a disorder with a cause (Garrett, 1998) for which there must inevitably be a solution, and the evolution of a pattern of putting the personality, character and mental capabilities of the person affected under the spotlight has been continually augmented over the years (see Bastiani et al., 1995; Crisp, 1980; Dalle Grave et al., 2013; Holmes, 2017; Kaye, 2008; Klump et al., 2000; Merwin et al., 2010; Moorey, 1991; Treasure & Schmidt, 2013). More recently, neuroscience has made its mark by building theories of anorexia as a brain based disorder (Kaye, 2008; Kaye et al., 2014; Knatz et al., 2015), the consequence of faulty neural pathways that create 'deviant attitudes and perceptions' (Kaye, 2008, p. 121), determine temperament and character traits (Klump et al., 2000), and establish 'aberrant reward processing systems' (Park, Godier, & Cowdrey, 2014, p. 47), compounded by a high density of oxytocin receptors in the insula that make decisions difficult due to 'moral hypersensitivity' (Munro et al., 2017, p. 10). In this frame anorexia is considered virtually meaningless, perhaps triggered or supported by environmental factors, but largely an unwarranted interruption to normal physiological and psychological development by virtue of genetic predisposition (Bulik et al., 2005; see Lainson, 2019 for a critique).

How complex attentions from multiple perspectives resulted in an unfortunate consequence

Wider interest in the phenomenon of some people (usually women) engaging in extreme eating restriction has come from multiple realms, including anthropology (Eli, 2018; see also Eli & Warin, 2018; Gremillion, 2003, 2008; Lavis, 2011, 2018; Lester, 2014; Musolino et al., 2015; Warin, 2003, 2004, 2006). 'Anthropological theories have been deployed in the past three decades to explain eating disorders (and, particularly, anorexia nervosa) as cultural

phenomena' (Eli & Warin, 2018, p. 444). Critical feminist thinking has also made significant contributions (see Bordo, 2008; Holmes, 2014; Malson & Burns, 2009; Orbach, 2005; Riley, Burns, Frith, Wiggins, & Markula, 2008; Saukko, 2008a) 'from a stance that regards issues of weight and its management not as immutable facts, but as thoroughly social and political concerns' (Riley et al., 2008, p. 3). Overlapping interests, and a shared emphasis on matters of personal meaning-making within influences from broader social and political contexts, has paid attention to the politics of experience through complex discussions of the interrelationships between bodily thinness as a culturally designated optimum, female resistances to constraining prescriptions of feminine roles and identity, compliance with neoliberal imperatives to individualistic ideals of selfhood, and culturally shaped meanings derived from embodied experience; all contributing to an alternative and multi-faceted picture, implicating societal structures and patriarchal regimes that exist well beyond individual psychologies or immediate family contexts.

These broader, multi-disciplinary explorations have contributed to psychiatry by widening its focus to consider the potential for complex causes, and to embrace notions of combined biological and environmental factors (Garner & Garfinkel, 1980), though even contemporary developments in bio-psycho-social models that argue for recognition of a multiplicity of contributing factors still have a tendency to emphasise notions of personal and psychological deficit, and lean heavily on concepts of problematic neurobiology as being at the core (see Munro et al., 2017). Early theories that implicate personality and cognitive traits (Bastiani et al., 1995; Bruch, 1978; Crisp, 1980; Klump et al., 2000) have been augmented by claims of a brain-based disorder (Kaye, 2008; Kaye et al., 2013; Knatz et al., 2015; Park et al., 2014). Assertions of genetic predisposition (Bulik et al., 2007; Thornton et al., 2018) and ongoing concepts of family dysfunction (Minuchin, Rosman, & Baker, 2009) have become infused by notions of over-compliance with cultural imperatives to beauty and conformity (Saukko, 2008b), and the personal struggle to find one's way within socio-political contexts and embodied experience (Bordo, 2008; Eli & Warin, 2018; Orbach, 2005; Warin, 2006). The combined result of this multiplicity of approaches is a vast body of literature on anorexia that has the search for a cause, and thereby signposts to its corresponding solution, at its centre.

Ultimately, however, an unfortunate consequence of these converging interests is that much of the body of literature on anorexia coalesces with the effect of characterising people living with anorexia as deficient, inadequate, aberrant and/or dysfunctional in terms of their personal agency, their biology, their cognitions, their family, and their capacity to manage their lives, thus problematising them in just about every way possible. Media representation has tended to align with these understandings, spectacularising anorexia as a 'disease of thinness' (Warin, 2004) and ensuring that public discourses of anorexia fit professional notions of personal deficit, with multiple unhelpful effects for people being represented thus, such as experiences of stigma, of feeling misunderstood, of being negatively treated by health professionals and others, and/or of coming to understand themselves through these representations leading to poor self-belief and even hopelessness (Button & Warren, 2001; Saukko, 2008b; Stockford et al., 2018).

Therapeutic trends

Despite the efforts put into searching for causes and solutions, Steinhausen (2002) stated that there was 'no convincing evidence that the outcome of anorexia nervosa has improved over the second half of the last century' (p. 1284), a finding that has been echoed over a decade later in relation to long-term experience (Eli & Warin, 2018; Munro et al., 2017; Touyz & Hay, 2015; Wonderlich et al., 2012). Changing ideas and understandings have resulted in shifting treatment approaches over time. Ranging from family-based therapies (Le Grange, 2005; J. Lock & Le Grange, 2015; Minuchin et al., 2009) and cognitive behavioural approaches (Fairburn, Shafran, & Cooper, 1999) to behaviour modification regimes (Eckert, Goldberg, Halmi, Casper, & Davis, 1979; Touyz, Beumont, Glaun, Phillips, & Cowie, 1984), narrative therapy (Epston, Morris, & Maisel, 1995; Maisel et al., 2004; M. White, 2011; M. White & Epston, 1990), pharmacology (Flament, Bissada, & Spettigue, 2012; McKnight & Park, 2010) and many others. Some progress has been said to have been made in terms of early intervention with adolescents (Treasure & Russell, 2011), notably Maudsley and family-based therapy models (Le Grange, 2005; J. Lock & Le Grange, 2015), but these claims are increasingly contested (Conti et al., 2017). Conti et al. (2016) and Conti et al. (2017) draw on practice experience with families and individuals who are struggling under current treatment protocols, to create a strong case for reconsidering mainstream

approaches to therapeutic endeavour and linear concepts of recovery in the context of anorexia. Treatment models emerging from neuroscientific understandings of anorexia (Kaye, 2008; Kaye et al., 2013; Kaye et al., 2015; Knatz et al., 2015; Weir, 2016; Wierenga et al., 2018), with their attendant focus on heritability via genetic predisposition (Bulik et al., 2007; Bulik et al., 2005), have garnered considerable attention, not only compounding the notion that anorexia is a discrete biological condition, but also promoting the use of brain-directed interventions (Schmidt & Campbell, 2013). These interventions include punishment-based learning to be imposed by family members, who are incited to take authority over their loved ones (Kaye et al., 2015; Knatz et al., 2015; Schmidt & Campbell, 2013; UCSD, 2019; Wierenga et al., 2018), and the potential for brain-invasive remediation (Oudijn, Storosum, Nelis, & Denys, 2013). I have written elsewhere about my considerable concerns about these developments that obscure much of anorexia's complexity, position those living with it in particularly unhelpful ways and that, as well as being cruel and risky, are likely to ultimately be antithetical to their therapeutic aims (Lainson, 2019).

For longer-term experience, complex staged treatment approaches involving ongoing engagement with multi-disciplinary teams are increasingly favoured by researchers (Munro et al., 2017; Robinson, 2009; Touyz & Hay, 2015; Wonderlich et al., 2012). A review of clinical approaches by Wonderlich et al. (2012) stressed therapeutic alliance as central to making any meaningful progress, although progress as meaningful to who isn't fully articulated. Wonderlich et al. go on to recommend a fully integrated multi-disciplinary team approach in an outpatient setting, with an expectation for long-term engagement with services, warning that the 'risks of unnecessary or ineffective hospital treatments are substantial' (p. 474) and asserting that living long-term with anorexia brings with it a set of 'unique needs' (p. 474).

A general consensus is clearly visible in the clinical literature that if anorexia remains in a person's life for more than a year or two, and hasn't been remediated by family-based therapies that require early recognition and intervention (Treasure & Russell, 2011) and intense parental involvement (Le Grange, 2005; J. Lock & Le Grange, 2015), then there is a lack of professional knowledge about how best to assist (Dawson, Rhodes, & Touyz, 2014; Stockford et al., 2018; Touyz & Hay, 2015; Wonderlich et al., 2012). Though a randomised

controlled trial of treatment approaches in relation to long-term experience of anorexia conducted by Touyz et al. (2013) did report that

> individuals with SE-AN [severe and enduring anorexia nervosa] can make significant strides in terms of achieving a higher quality of life along with a reduction in ED [eating disorder] pathology. By widening the treatment goals, focusing on quality of life and lessening the pressure to achieve weight gain, we were able to engage individuals with SE-AN in treatment, circumvent the 'customary' high drop-out rates, and bring about significant progress and achieve meaningful positive change in their lives. For individuals with SE-AN, we argue that it is more constructive to address eating and weight pathology with this patient group by setting minimum weight thresholds for treatment participation rather than setting weight gain or weight normalization as the treatment priority. (Touyz et al., 2013, p. 2509)

This represents a significant change in approach, where bodyweight and eating has so often been considered the primary, if not the only, focus of therapeutic concern from the perspective of the clinician (Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014; Stockford et al., 2018).

Subjective evaluations of treatment experiences

The very small number of studies that have enquired about subjective experience of therapeutic intervention after long-term experience of anorexia (Button & Warren, 2001; Fox & Diab, 2015; Robinson et al., 2015; Ross & Green, 2011) highlight diverse and conflicting responses about the interventions engaged with, leaving an overall impression that there is considerable dissatisfaction with what is currently available, and that staff attitudes and therapeutic emphasis have a significant role to play in the likelihood of ongoing engagement. Contrasting views were expressed by participants, across and within studies, about whether control over eating being handed across to medical staff in treatment settings was welcome or unwelcome. Ross and Green (2011) interviewed two women about inpatient treatment, one of whom spoke of feeling trapped by the setting,

the other of it providing a sense of security, while both articulated a number of challenges after discharge and of feeling they were facing their difficulties alone. This complexity was reiterated by Fox and Diab (2015), whose participants described their responses to the effects of nasogastric feeding. For some, distress combined with relief at handing over control to others was complicated by a sense of increased vulnerability at the loss of this control, while others spoke of engaging with ongoing resistance to such re-feeding practices. In these studies, no single approach or practice was identified as especially helpful and many current approaches were considered unhelpful and unpleasant.

Robinson et al. (2015) and Ross and Green (2011) did conclude that approaches which place a strong emphasis on the therapeutic relationship should be favoured, citing that their participants placed particular value on matters of interpersonal trust, feelings of being understood, and clinician belief in possibilities for recovery. These findings have been supplemented by Fox and Diab (2015) who interviewed 6 people in an inpatient setting, and found that practitioner competence was of pivotal importance to participants' evaluations of available treatments, although therapies engaged with were frequently viewed as counterproductive, and staff pessimism about recovery possibilities was singled out as having particularly unhelpful consequences. An earlier study by Button and Warren (2001) concurred, stating staff attitudes had a significant effect on participant perceptions of the value of hospital treatment. In each case, therapeutic over-emphasis on bodyweight was identified by participants as unhelpful, while being treated with compassion and understanding and building a good therapeutic relationship were regarded by study participants as helpful. Similar findings by Stockford et al. (2018) identified negative staff attitudes and being treated as 'group of patients … (and) … not being recognised as an individual was extremely unhelpful, in particular with regard to an individual's self-worth' (p. 135). An overemphasis on weight restoration at the expense of psychological understanding was said to render therapies ineffective, and 'the focus on weight within services was experienced by some participants as indicating that their weight was not low enough to be deserving of treatment and served as a motivator to lose more weight' (p. 135). While an alternative frame of reference might consider that these collective findings point not to ambivalence, but rather to agentive response and active engagement with personal wellbeing, the naming by Robinson et al. of a sense of 'brinkmanship' (p. 320) in managing

precarious health emphasised the importance of hospital services being readily available to anyone managing their physical condition through strategic engagement with medical support.

A limitation of the studies of subjective experience is that findings should be evaluated in relation to the small number of participants involved, between 2 and 11, with the exception of Button and Warren (2001) who interviewed 36 participants. A further feature of these studies, that is common to what little research has been done on subjective experience of living with anorexia over time, is that participation was invited via specialist eating disorder services, thus ensuring that current or prior medical diagnosis and engagement with services is a pre-requisite to being included in research. As Robinson et al. (2015) suggest, research 'with a community sample may well have led to different results and conclusions' (p. 325).

Recovery debates in anorexia: Contested meanings and competing clinical attention

Recovery in relation to anorexia has recently become a contested term (Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014). Recovery models of mental health exist in many realms due to the considerable efforts and successes of consumer, anti-psychiatry, service user and survivor movements (Coleman, n.d.; Faulkner & Tallis, 2009; Slade, Adams, & O'Hagan, 2012). These models rest in a particular politic that recovery from mental illness is possible for everyone, and in collective recognition of hardship, insider accounts of experience and 'subjective and self-evaluated accounts' of wellbeing (Roberts & Wolfson, 2004, p. 37). Recovery models of mental health have the benefit of emphasising the skills and knowledges of the person affected in managing their own wellbeing, that are said to offer increased opportunities for hope and autonomy (Dawson, Rhodes, & Touyz, 2014). However, until very recently almost no attention has been given to the possibility of adopting recovery models of mental health in the context of anorexia (Butterfly Foundation, 2016) where the term recovery almost exclusively continues its traditional emphasis on restoration of a bodyweight-to-height ratio that is considered clinically normal and evidence of an absence of symptomology according to clinically defined measures (Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014). Weight targets are set

by clinicians and are expected to be complied with by patients (see Stockford et al., 2018), with weight restoration as the ultimate goal. As debates emerge about the appropriateness of recovery models in the context of long-term experience of anorexia (Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014; Lavis, 2018), the traditional weight-gain approach is increasingly becoming known as full-recovery, almost as if recovery models are somehow compromised or incomplete. Yet, escaping clinically defined measures of wellness, adoption of recovery models could resist the current sick-well binary that dominates clinical thinking, and frequently advocacy, in the field of anorexia (Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014; Touyz & Hay, 2015).

Professional debate about whether recovery models should be embraced by clinicians in the context of long-term experiences of anorexia, somewhat ironically given the consumer origins of the movement, centres around whether weight restoration brings sufficient life quality benefits to justify its focus as the primary goal of treatment. Bamford et al. (2015) examined the relationship between quality of life (QoL) and symptoms of severe-and-enduring anorexia nervosa using QoL questionnaires alongside clinical assessment of participants' physical condition, and concluded improvements to quality of life are directly related to increases to body mass index (BMI), justifying retention of clinical focus on weight restoration. Robinson et al. (2015), on the other hand, argued that participants' life quality after 20+ years of living with anorexia is so impaired that improvements should take precedence over continued efforts for weight gain, particularly as these had repeatedly failed in the past, citing low motivation for creating change as an additional reason for this proposed shift in clinical focus after a number of years' duration.

Dawson, Rhodes, and Touyz (2014), on the other hand, took a both/and position by suggesting the two approaches 'may not necessarily be mutually exclusive' (p. 503). Interviewing participants who identified as recovered from what their study named chronic anorexia, they establish an insider-informed account of four stages of recovery: an initial unreadiness for change; a tipping point at which recovery became the preferable option; an engagement with active pursuit of recovery; and arrival at a period of reflection and rehabilitation. Change was reported as gradual, complex and multidimensional, with the means by which individuals passed through each stage, or how an initial tipping point was

reached, remaining intangible. However, motivation alone was considered unlikely to be enough to propel recovery as it required ongoing pro-active effort, rather than being a static state. Dawson et al. argued that their findings indicate that 'full recovery from chronic anorexia nervosa is possible' (p. 494) and that significant factors in achieving it are 'hope, motivation, self-efficacy, and support from others' (p. 494). Their study deserves considerable merit for paying careful attention to the detailed experiences and expressions of knowledge gleaned from lived experience, and for offering a more nuanced discussion of recovery in stark contrast to reliance on numerical measures and hierarchical authoritarian structures that continue to proliferate in the field (see Kaye et al., 2015; Weir, 2016; Wierenga et al., 2018) and that have been argued to be so problematic in their capacity to replicate the very conditions that have supported the evolution of anorexia in the first place (Gremillion, 2003). Their discussion states that recovery models benefit from promoting 'many factors that were found to be important for participants, such as hope, autonomy, and empowerment' (p. 503). However, they go on to caution that focussing on improvements to quality of life might appear to suggest that full recovery from chronic anorexia is an unachievable goal which could have unhelpful effects where a sense of 'hopelessness was a major obstacle to change' (p. 502). Their caution is confusing as it appears to rest in a belief that so-called full recovery is a superior form, perhaps consigning recovery models to the realms of palliative care or accommodating of so-called ego-syntonic symptoms, representing how difficult it is to escape entrenched beliefs about attachment to problems and hierarchies of recovery.

A move to seek meanings not causes

There has been a small amount of research attention given to what personal meanings people living with anorexia long-term have made of their experience, offering an alternative focus to that of cause. These studies have sought to gain understandings as a more generative way forward, and pay attention to the relationships participants report having with anorexia, what value they give to it, and what meanings or purposes it holds for them. Fox and Diab (2015) noted participants' complex love-hate relationship with anorexia, an observation supported Arkell and Robinson (2008) and Button and Warren (2001) whose participants reported both advantages and disadvantages of living with anorexia. Positive

consequences were said to be of a sense of control, feelings of achievement or purpose, and avoidance of some of the more difficult aspects of life. Robinson et al. (2015) presented participants' pride in their achievements as a way to understand how anorexia is meaningful to people, with resilience supporting their long-term survival. However meaningful, the positives were consistently outweighed by negatives of damaging consequences to physical health and the loss of interpersonal relationships, with participants articulating that they had no choice in the matter and were trapped in any case.

Fox and Diab (2015), in their interpretative phenomenological analysis of in-patient experiences of participants living long term with anorexia, established how participants had taken some time to 'realise' (p. 30) anorexia was a problem in their life, concluding that it was as participants gradually recognised the validity of other peoples' concerns that they themselves came to understand how anorexia was serving as a solution to life's difficulties. There are, however, a number of potentially erroneous assumptions made. Concepts of realising or arriving at circumscribed understandings go unchallenged and are presented as essential truths. The possibility of anorexia as purposive action goes unconsidered, with the authors stressing that anorexia's usefulness to participants does not mean it is a choice, but a product of feeling overwhelmed and fearful. This re-imposes an ongoing story of people living with anorexia as lacking in agency or insight into their own actions and troubles, positioning them as in deficit or unable to cope, rather than acting agentively as a response to their circumstances.

A more recent interpretative phenomenological analysis by Stockford et al. (2018) identified specific stressors, perfectionism, and low sense of personal worth as contributing factors to anorexia's initial appearance in the lives of a small group of women, with anorexia being forwarded as a means to manage difficult experiences, emotions and an ongoing lack of sense of self, by providing distraction, comfort and predictability. Stockford et al. thus concluded that long-term experiences were a symptom of 'deeper underlying issues' (p. 136). This is a somewhat disappointing conclusion replicating notions of deficit, unlike an alternative ethnographic account of participants living with anorexia over time, by Anna Lavis (2018), which spoke of meaning as suggesting 'the illness may thereby offer a way to be in the world that both responds to and ameliorates distress; some individuals describe

the ambivalent 'safety' of living through their anorexia' (p.454). The difference may be subtle, but the latter perspective affords much greater recognition of personal agency, intentional living and therefore possibilities for change if desired.

Whilst each of these studies is commendable in their exposing many of the difficulties of living with anorexia over time, and for their sensitive engagement with participants' expressions of lived reality, to a greater or lesser extent there is a continued trend of centring ideas of personal deficit and lacking focus on how certain meanings become available to people. As Paula Saukko (2008b) points out, the meanings that people give to their own experiences are often as shaped by discourse as anyone else's. People living with anorexia do not exist in a bubble which protects them from public and professional discourses and gives them access to pure truths. This is not to minimise the importance of understanding how people make sense of what happens in their lives and the effects of that, but to recognise that when people use terminology laden with deficit discourses, potentially giving rise to trope explanations for experience, it is pertinent to recognise how psychiatric discourses, representations and imagery can inform meaning-making and shape a person's sense of themselves. The social contexts that give rise to such understandings are worthy of deconstruction and scrutiny. Narrative therapist, Michael White was known to refer to such 'insights as propaganda' and there is challenge for both the practitioner and researcher in navigating this complexity (D. Newman, personal communication 16 June 2019).

The call for a new paradigm in anorexia research and therapeutic approach

Whilst structuralist ontologies and medical models have underpinned much of what has been said and written on anorexia, even that which has been written from constructionist perspectives has frequently contributed to homogenised and problematic representations of anorexia (Saukko, 2008a, 2008b) and the people whose lives are affected by it. As such, these theories that have dominated the field are documented here not to give them validity, or as a basis on which to build, but as a backdrop for understanding how people living with anorexia may come to experience themselves and their predicament, and how others may have come to understand them. What has been demonstrated is a dominant,

often problematic, storyline ripe for interrogation and unsettling. It provides plenty of opportunity to do research differently, and to explore alternative, more hopeful possibilities. This is important because the difficulty of a continuing focus on ideas of personal deficit and professional pessimism is that they have the capacity to be constraining. After interviewing people who identified as recovered from anorexia after many years Dawson, Rhodes, and Touyz (2014) identified that 'hopelessness was a major obstacle to change' and that 'Hope and self-efficacy might be promoted by circulating stories of recovery' (p.502). When considered in conjunction with the lack of community-based study that was acknowledged by Robinson et al. (2015), a space appears for a study that recruits participation more widely, focusses differently than on deficit understandings, that recognises agency and privileges insider perspectives.

Increased recognition of how significant long-term experience of anorexia can be, and the unhelpfulness, and often undesirability, of dominant treatment approaches (Robinson et al., 2015; Touyz et al., 2013; Wonderlich et al., 2012) led Phillipa Hay and Stephen Touyz (2015) to make their call for 'a new paradigm' (p. 26) that offers greater possibilities for hope. A call that I seek to respond to by now considering a different lens through which to approach research in this realm.

2.4 Narrative practice: Heritages, principles and key practices

In order to propose narrative practice as a new paradigm for respectful and hopeful research in relation to anorexia, it is significant to give a brief overview of some of its heritage, principles, and key practices and outline the existing relationship with the theme of anorexia.

Some background to narrative ideas

Narrative therapy was developed in the 1980s by social workers Michael White and David Epston, who worked and resided in Australia and New Zealand respectively, as a development of family therapy, in response to dominant psychiatric and psychological

thinking of the day (Madigan, 2010; C. White, 2016) and as a reflection of changing social and philosophical contexts (C. White, 2011; M. White, 2011). Drawing on philosophies of Foucault, Derrida, Bateson, Geertz and Bruner amongst others they developed an approach that understood people's lives as multi-storied (Morgan, 2000; M. White, 2007; M. White & Epston, 1990), their sense of identity as relational (Combs & Freedman, 2016) and discursively constructed, and problems as contextualised. This stood in contrast to prevailing structuralist notions of what is or isn't normal, good or healthy within concepts of an essential self or human nature (Thomas, 2002; M. White, 1997). As such, a narrative therapy approach to the problems people face escapes pathologising concepts that characterise many dominant understandings of mental and psychological wellbeing. The first narrative therapy book *Literate Means to Therapeutic Ends*[2]*,* co-authored by Michael White and David Epston, was published in 1989, and this pioneering text established philosophical and practice principles that Michael White later described in the following terms

> Is this work better defined as a world-view? Perhaps, but even this is not enough. Perhaps it's an epistemology, a philosophy, a personal commitment a politics, an ethics, a practice, a life, and so on. And, because whatever it is happens to be on intimate terms with recent developments in social theory that are generally referred to as "non-foundationalist" or perhaps "postmodern", then whatever it is also happens to be a theory. (M. White, 1995, p. 37)

It is this conceptualisation of narrative as a theory that goes beyond a set of therapeutic practices that supports its role as part of a research methodology.

A poststructuralist therapeutic approach

Narrative therapy is located within the realms of postmodern and poststructuralist thought (Thomas, 2002; M. White, 1991, 1997; M. White & Epston, 1990) and as such ideas of neutrality and objectivity in our endeavours to understand ourselves and others are

[2] The book was subsequently republished with an additional chapter in 1990, by Dulwich Centre Publications, Adelaide, under the title *Narrative Means to Therapeutic Ends.*

contested; taken-for-granted assumptions are made available for scrutiny; and notions of a singular fixed reality or global truth are challenged. Instead, local meaning-making and the socially located lens that influences how we approach our enquiries and shape our conclusions is acknowledged, thereby moving away from pathologising notions about individuals, or indeed families, and bringing into focus possibilities for social movement as part of healing (Denborough, 2008).

Michael White reported being open to a range of explanations for what are known as 'psychiatric disorders', and that his practice was more concerned with people's relationships to problems.

> Michael: To answer your question, I have always resisted taking a position on the aetiology of the so-called psychiatric disorders. In fact, I have consistently refused the incitement that I have experienced to step into a position on this, and to enter into debates and other activities that depend upon such positions. I am willing to consider most notions of aetiology, but, quite frankly, these considerations are as irrelevant to what I do in this work as they are for others.
>
> Ken: Does this mean that you are even willing to entertain some of the current biological notions of aetiology for what is referred to as schizophrenia?
>
> Michael: Of course! Of course! But this is not relevant to what I do.
>
> Ken: So, what do you do? In taking the position that you do on psychiatric discourses, isn't there a risk that you wind up excluding yourself from participation in this field? Isn't it possible that, in this way, you will cancel out your own contribution? Doesn't this leave you with nothing to say?
>
> Michael: Certainly not, I am simply talking about standing outside of the territory as it is defined by psychiatric knowledge, and as it is structured by pathologising discourses. I am not talking about standing apart from people and their experiences, including those experiences that are so often taken up into

> pathologising discourses. (M. White, 1995, p. 121)

However, alongside this non-expert stance on so-called causes of problems, a narrative perspective takes account of the social and discursive contexts which enable problems to exist in people's lives. M. White (1995) spoke of anorexia in relation to the politics of experience, as a 'pinnacle of achievement' (p. 45) of self-government, self-surveillance and subjugation within systems of modern power that operate in the realms of gender politics. In what has arguably become the best known narrative therapy text on the subject of anorexia *Biting the Hand that Starves You* Maisel et al. (2004) characterise anorexia as a 'disempowering cultural force' (p. 10), and in an interview that became the influential book chapter *On Anorexia* (M. White, 2011, pp. 87-97), Michael White outlines a line of enquiry that promotes the externalisation, naming and characterisation of problems by inviting people to 'orient themselves to their problems as "investigative reporters"' (p. 88). He explains how, in this way

> people are encouraged to develop an exposé of the contexts of life that sponsor anorexia nervosa. This would be an exposé of the discourses of life and identity that foster anorexia nervosa, including the practices of the self and practices of relationship that are associated with these discourses and the complicity of social institutions in this. Externalizing conversations of this sort are well-suited to bring forth the politics of people's experience of these forces, and I regard this also to be a priority in therapeutic practice. (M. White, 2011, p. 89)

Escaping pathologising understandings

A narrative stance also takes a position on practices which are often associated with medical or traditional psychotherapeutic approaches, i.e. those which pathologise individuals or locate anorexia (or any problem) within a person in any totalising way that prevents them from creating a sense of themselves outside of the problem, but rather conceptualise the self as fluid and relational (Combs & Freedman, 2016). Similarly Maisel et al. (2004) bring into focus the circumstances, meaning-making and societal influences that 'open the door for a/b [anorexia/bulimia]' (p. 24).

Thus, taking a non-essentialist approach to persons and a discursive approach to problems, narrative engagement with someone experiencing anorexia's influence and effects will speak less of origins and aetiology, and certainly not of pathology or personal deficit, and more about the effects and influence it has on the person's life; what sort of relationship they have with/to anorexia; what consequences anorexia has on their life; how anorexia fits with their other commitments, hopes, beliefs and values, and so on. Such investigations that result in a richly described externalised perspective on anorexia and its activities support people in thinking of themselves in less totalising and problematic ways. This practice of externalising problems 'Frees persons to take a lighter, more effective, and less stressed approach to "deadly serious" problems' (White & Epston, 1990, p. 40). In moving away from beliefs of 'being anorexic', or anorexia being intrinsic to their nature, towards anorexia as a problem with which they can alter their relationship, space is created for new possibilities for action. That said, narrative practice, importantly, does not ignore the histories and contexts of how a problem has gained a hold in a person's life (Morgan, 2000), but tracing this through collaborative enquiry places emphasis on deconstructing the discourses and making visible and available for interrogation the social contexts that sponsor and sustain problems (Epston, 1999; M. White, 2011).

Heavily influenced by feminist thought (C. White, 2016), narrative approaches emphasise the power and gender dynamics that give rise to particular prescriptions for identity and pay attention to the politics of experience. A narrative practice stance seeks to expose operations of power or dominant discourses that support problems like anorexia (Gremillion, 2003; M. White, 1991; M. White & Epston, 1990). This is significant as it creates opportunities to unveil and counter taken-for-granted ideas about people and problems. Ideas that often work *for* problems.

> a/b [anorexia/bulimia] exploits psychological theories that claim to explain problems in terms of the personal and pathological … turns them away from addressing the injustices they may have experienced. Instead of taking steps to remake their world, a/b convinces them that security and control will only be theirs when they themselves are refashioned. (Maisel et al., 2004).

By inviting an unsettling or problematisation of these operations and discourses as a means of lessening their effects, narrative practices create space for acts of resistance and possibilities for change in individual lives, and at societal level (see Grieves, 1997) .

What's in a name? Recognising uniqueness

Narrative approaches acknowledge that anorexia is a diagnostic label that has generally been given to the problem by someone else, usually a clinician, or perhaps the person consulting has come to identify with practices and ideas that are frequently called anorexia in contemporary Western society (Maisel et al., 2004; M. White & Epston, 1990). However, while there may be notable similarities between people's experiences of anorexia, conversations that pay close attention to the details of people's lives and their expressions reveal that, despite the reputation for homogeneity (Kaye et al., 2009; Saukko, 2008a), living with the influence and effects of anorexia is rarely exactly the same experience for two people (M. White, 2011). Using terminology which fits unique individual experience is considered a more helpful practice than applying a diagnostic label which may be quite meaningless to the person, or at least distanced from their own near experience, and runs a high risk of allowing the problem to gain gravitas from having a medicalised label or title (Maisel et al., 2004; M. White, 2007; M. White & Epston, 1990).

Narrative approaches are highly individualised, in the sense of not trafficking in 'global and unitary truth claims' (M. White & Epston, 1990, p. 28), but seek to work with the experiences, skills, knowledges and resiliencies of the person, as well as their own meaning-making. They position the person as expert in their own life and as knowledgeable about the problem, rather than the practitioner as expert. These knowledges that have been gleaned as a consequence of first-hand experience are considered a valuable resource in seeking new possibilities (Morgan, 2000; M. White, 2007; M. White & Epston, 1990). Narrative practice resists one-size-fits-all prescriptions for therapy, applied in manualised ways. Recent writings that support ideas of the diagnostic category of anorexia as a social construction, and that call for new therapeutic approaches in the face of a fifty year history of poor outcomes and general dissatisfaction from those affected, have identified narrative

practices as an appropriate and hopeful way forward (Botha, 2009, 2015; Gelo, Vilei, Maddux, & Gennaro, 2015).

Recognising agency and response: Double-listening, unique outcomes and re-authoring conversations

A significant feature of narrative practice and theory is that it assumes people respond to the conditions of their lives, and in particular they respond to oppressive events and circumstances in ways that seek to improve their circumstances or reduce the negative effects in their lives (Wade, 1997; Weingarten, 1998; M. White, 1991; Yuen, 2009). These actions may be so small, or even intentionally disguised, as to be barely visible unless one is specifically looking for them. These responses have often become re-specified within mainstream psychological approaches as the effects of what happened to the person, or the symptoms of a so-called condition, considered to have arisen as a consequence of being exposed to oppressive or traumatic events. In fact, when people respond to oppression through actions and practices that become named as symptoms or effects they frequently become framed as contributing to their own suffering (Wade, 2007). The honouring of response as action based on knowledge derived from experience is, therefore, a distinctly different understanding of people and behaviour when difficult things happen, with two particular implications

1. It understands people as intentional and purposeful in their actions: that is, they act agentively (M. White, 2007).

2. It invites us, whether as therapists or researchers, to double-listen (M. White, 2000, 2003) for knowledge, skill and agency when receiving peoples' stories.

Double-listening is the practice of witnessing the stories that people tell us, particularly stories of hardship, by listening not just for the events and effects of events but simultaneously for the small actions that speak to their resistances, which give clues about their values, commitments and intentions that the person holds for their life (Freedman & Combs, 1996; Hibel & Polanco, 2010; M. White, 2000). Action thus becomes understood as reflective of the values a person holds, rather than as symptomatic of some pathology. This

double-listening is made more possible by how questions are asked. In therapeutic practice, stories are enabled and invited in particular ways.

Research in the realms of anorexia has, as explained above, all too often sought out only one story, a problem story that represents people living with anorexia as lacking in agency. By employing double-listening in a research context, I propose that it becomes possible to recognise response and acts of agency that have otherwise been overlooked in the rush to find problems, causes and externally imposable solutions.

In therapy, people often arrive with 'problem-saturated' descriptions of their lives (M. White & Epston, 1990, p. 16). That is, they understand themselves and their lives to be overwhelmingly dominated by the problem. Re-authoring conversations of narrative practice (M. White, 2007) seek exceptions to this by gently inviting the telling of alternative stories of people's lives, stories that are not entirely dominated by the problem.

> Re-authoring conversations invite people to continue to develop and tell stories about their lives, but they also help people to include some of the more neglected but potentially significant events and experiences that are "out of phase" with their dominant storylines. These events and experiences can be considered "unique outcomes" or "exceptions." (M. White, 2007, p. 61)

What this makes possible in therapy is for people to see themselves and their lives as other than entirely dominated by the problem, and therefore more able to imagine new possibilities that enable further reclamations of life from the problem. What this makes possible in research is an illumination of the skills and knowledges that people use as they navigate their lives in the presence of problems, and recognition that they are in fact doing that. The sort of questions this requires are ones which recognise the person's first-hand knowledge of living with problems, using externalising language that enables the person to speak of the problem separately from themselves and that enquires about the unique outcomes Michael White refers to in his above quote.

In re-authoring conversations, the therapist and researcher both actively enquire about and double-listen for unique outcomes that suggest an alternative storyline. In order to create an entry point into an alternative story, a narrative therapist or researcher might ask

- 'Are there times when the problem is not as bad as usual?' or
- 'Is there a story you could tell me about a time when you resisted the problem and did what you wanted to do instead?'

(Morgan, 2000, pp. 57-58)

Or, they may listen for 'anything that the problem would not like; anything that does not 'fit' with the dominant story' (Morgan, 2000, p. 52) such as a plan, action, feeling, statement, desire, thought, belief (p. 53) and so on, that gives a glimpse of some aspect of the person's life that has not been entirely dominated by the problem. In order to invite such conversation therapists/researchers have to take up a particular stance, which Michael White called being de-centred and influential (M. White, 2005). Being de-centred means staying close to the experience, meanings, hopes and intentions of the person whose life is under discussion rather than the therapist taking up an expert position on the person's life or on what is healthy or normal. Being influential means asking questions that cast new light on circumstances and invite consideration of new possibilities.

> Conversations that highlight unique outcomes support a decentred therapist participation, which privileges the authorship of the people seeking consultation. These conversations assist people in rendering specific out-of-phase aspects of their experience significant; they support people in the characterization of, and in reflecting on, these aspects of their experience. This is often novel for people who consult therapists, as these people often have been simply subject to the meanings given and the position taken by others on the developments of their lives. Among other things, conversations that highlight unique outcomes provide people with the opportunity to give voice to intentions for their own lives and to develop a stronger familiarity with what they accord value to in life. This provides them with a springboard for action in addressing their problems, predicaments and dilemmas. (M. White, 2007, p. 220)

What re-authoring conversations can do, alongside creating transformation in lives, is to produce a different type of understanding and representation of people living with problems than that of a passive victim, or active producer, of the problem (M. White, 2007). They are thus respectful, acknowledging of context, agency and intentional state ways of being, and enable new understandings and possibilities, making them an ideal basis for a research conversation, particularly one that seeks to step outside the dominant pathologising discourses that surround anorexia.

Co-research and counter documents

A principle of narrative therapy is the privileging of first-hand knowledge, otherwise known as insider knowledge, that comes from lived experience rather than expert knowledge which comes from professional training, academic study and clinical research. Co-research was a term devised by David Epston (1999) as a means of illustrating the co-construction of alternative knowledge in conversations between practitioner and client, through lines of investigative enquiry that centred on the knowledge that came from lived experience. This was in direct response to practices and attitudes of family and patient blaming that dominated the hospital settings Epston found himself working in during the 1970s. It was a commitment of being 'determined to find an alternative frame of reference so I might meet these people with compassion rather than suspicion' (Epston, 1999, p. 140).

David Epston explains this development as follows

> I chose to orient myself around the co-research metaphor both because of its beguiling familiarity and because it radically departed from conventional clinical practice. It brought together the very respectable notion of research with the rather odd idea of the co-production of knowledge by sufferers and therapist. What made this possible, in the first instance, was a fairly thorough-going externalising conversation, one in which the problem was a problem for everyone - and here I included myself. Here's where I parted company from the disinterested ethnographer. This has led, and continually leads, to practices to discover a 'knowing' in such a fashion that all parties to it could make good use of it. Such knowledges are fiercely and unashamedly pragmatic. (Epston, 1999, p. 142)

Co-research is key to narrative practice as a therapeutic approach and as a research methodology, because it makes available alternative knowledge to that so often produced by clinical assessment tools and so-called unbiased, objective research methods. The knowledges produced through co-research are recognised as a shared construction that privilege insider experience, that is practical and directly relevant to the lives of the people who are central to its construction.

Similarly, alternative documentation as part of therapeutic practice is an important part of narrative therapy is it stands in contrast to, and defiance of, dominant psychiatric practices that have too often centred clinician assessment of people's lives, minimised or erased peoples' own experiences and intentions of their life, and represented people in unhelpful and problematic ways. Michael White and David Epston (1990) write about documentation in general terms as follows

> The proliferation and elevated status of the modern document are reflected by the fact that it is increasingly relied upon for a variety of decisions about the worth of persons. For example, in job applications it is standard practice for the documents that are available on the person to be reviewed before the person is interviewed, and there exist circumstances in which decisions are wholly made about the applicant's worth, not through a meeting of persons, but through a meeting of documents. Thus, documents have become influential in the lives of persons to the extent that they precede and preclude persons in a great number of situations. (M. White & Epston, 1990, p. 188)

They go on to note how 'these documents have an existence independent of their authorship and their subject' (p. 188), and to explain their thinking that

> The life of the file proceeds through the process of "re-transcription," and in this process the patient's experience is appropriated and transferred into the domain of expert knowledge. The language of the patient is transcribed into "official language," everyday descriptions of problems into correct diagnoses – from "feeling miserable" to "displays low affect." Eventually, the patient's experience is not recognizable within the terms of its original presentation. (M. White & Epston, 1990, p. 189)

Documents precede people, represent people and contribute significantly to understandings of, and developments in, people's lives even to the extent that their experience becomes distorted and unrecognisable as a consequence of expert analysis and translation. Drawing on Foucault, M. White & Epston (1990) go on to argue that 'the rise and spectacular success of all the disciplines have been entirely facilitated by those practices of evaluation (normalising judgment) and documentation that enable the subjugation of persons' (p. 190) that result in 'rituals of exclusion' (p. 190). White and Epston were writing predominantly with respect to individual psychiatric files, but their reference to how 'Psychiatry is by no means the only discipline that employs the file for the redescription of persons and for the presentation of the moral worth of the author' (p. 190) leaves the door wide open for the inclusion of research in the field of so-called psychiatric illness, including anorexia. In the introduction to this literature review I reflected on how representations and understandings contained within academic literature that informed professional discourse shaped my experience of myself and others' impressions of me, largely to my detriment. Just as White and Epston conceptualise psychiatric files as de-grading (in the sense that they are objectifying of and humiliating for persons, while concurrently re-assigning them and their knowledge to a lower social ranking or grade of personhood) documents that precede and represent people, often in a distorted and detached way, certain forms of academic literature may at times be conceptualised as a collection of publicly de-grading documents that precede and represent groups of people, often in distorted and detached ways; including people whose lives have had no part whatsoever to play in the creation of the document.

As a counter practice to the de-grading ritual of creating psychiatric files, M. White and Epston (1990) began to create alternative forms of documentation, or counter documents. Documentation that was more honouring of the people it represented and that would 'emphasize [the person's] special knowledges and competencies, as well as their place in the larger community of persons' (p. 190). Whilst White and Epston were predominantly referring to practices of bestowing awards and certificates to people in order to mark and make more widely known significant developments in their lives, and for the therapeutic purpose of leading to 'a sense of possessing the capacity to intervene in the shaping of one's

life and relationships' (p. 191), they also spoke of these counter documents as standing in contrast to marginalising practices of presenting images of a spoiled identity, and of the significance of the audience in contributing to how the person at the centre understands themselves. If clinicians are the intended audience of academic literature on anorexia, and people living with anorexia become an additional audience that was perhaps not originally intended but nonetheless real and significant, then deficit-based or hope-less representations contribute to marginalising practices, whereas research that speaks to agency and response has increased capacity to present images of people who are capable of contributing to developments in their own lives.

Working with anorexia using narrative therapy practices and principles

Although working with anorexia was a context in which many narrative therapy practices and ideas were developed (Epston et al., 1995; M. White & Epston, 1990) and anorexia has a clear presence in the writings about narrative practices, relatively little space has been given to it as a discrete 'theme' within the published narrative literature, and references to working with anorexia have commonly been incorporated as transcripts or stories of practice within broader discussions of narrative ideas. In some measure this paucity of publications may be reflective of a reluctance on behalf of narrative writers to take up an expert position on any particular problem in preference for emphasising how practice principles combined with local knowledge can support the co-production of unique solutions.

There is a small handful of notable exceptions, illustrative of the possibilities, including a systematically described model for working with anorexia using narrative therapy, written by Rudi Kronbichler (2004). Kronbichler documents the series of steps he has taken when working therapeutically with men experiencing anorexia, demonstrating his use of narrative practices of deconstruction, re-authoring, externalisation, statement of position maps (M. White, 2005) and therapeutic documentation. Illustrating how he scaffolds the re-storying of persons' lives and relationship with anorexia in order to create new possibilities for action and welcome change, by pathologising neither individuals nor families, Kronbichler

compares male experience of anorexia to female experience to find some similarities and differences. He clearly situates anorexia firmly within the realms of discourse

> Anorexia seems to be one of the characteristic problems of western post-capitalist culture as it invades the lives of a growing number of girls/women and boys/men … Cultural discourses which stress the importance of appearance and body shape, including specifications for clothing and even the corresponding body posture, currently significantly influence the lives of girls and this is becoming increasingly true also for boys … Broader popular discourses which emphasize individualism set up a culture of ruthless competition and comparison on the basis of physical attractiveness. These discourses can be particularly destructive during times of rapid bodily changes, when the gaze of peers, with respect to body shape, becomes increasingly powerful … At the same time, discursive pressures emerge in teenage subcultures on the basis of ideas and specifications about what it means to be 'cool' and desirable. (Kronbichler, 2004, p. 56)

He goes on to provide a strong critique of structuralist ideas and practices that have dominated the field, which he also argues limit therapeutic engagement by marginalising the voices of people who live with anorexia and their families, with the consequent effect of alienating them from the therapist and the encounter.

> In-patient treatment programs are often organized around surveillance based on mistrust, following from ideas about the allegedly 'manipulative personality structure' of persons diagnosed as anorexic. The interactions between nurses and doctors and the so-called patients intensify around positions of surveillance, reward and punishment on the part of the helpers; and resignation, rebellion, secrecy and feelings of not being understood on the part of the 'patients'. (Kronbichler, 2004, p. 58).

Other narrative practitioner-authors have written more broadly about working in the context of eating difficulties, and there is an extent to which diagnostic terminology being a poor fit for many who work in the narrative field has created political, philosophical, ethical

and practical resistances to the delineation and language of anorexia. However, these writings do illustrate how utilising narrative therapy practices and understandings has supported them in their work with, usually women, who have expressed a wish to create change in relation to concerns about eating and its effects on their bodies (Borden, 2007; Lainson, 2016, 2019; Pederson, 2015; Robbins & Pehrsson, 2009; Weber, 2007; Weber, Davis, & McPhie, 2006; Zucker & Borden, 2013).

Anti-anorexia

The work of David Epston is the most visible, prolific and arguably influential work with anorexia in the realms of narrative practice (see for example Epston et al., 1995; A. Lock, Epston, & Maisel, 2004; A. Lock, Epston, Maisel, & Faria, 2005; Madigan & Epston, 1995; Maisel et al., 2004), culminating in the renowned book *Biting the Hand that Starves You: Inspiring resistance to anorexia/bulimia* by Maisel, Epston and Borden (2004). Over a series of articles, David Epston and numerous colleagues have documented the development of an understanding and approach to working with anorexia. Perhaps Epston et al. (1995) exemplifies this with most clarity for the newcomer to these concepts, as it sets out an understanding of anorexia as a tyrannical and oppressive, culturally derived force that can become further co-produced by psychiatry's preference for practices of weighing and measuring people who are already in anorexia's grip. In this article, the authors set out a series of steps by which the second author, Fran Morris, became able to free herself from a 23-year relationship with anorexia/bulimia through a collaboration with David Epston by way of their mutual correspondence. David Epston introduced Fran Morris to a set of practices that he collectively names anti-anorexia.

The practices of anti-anorexia involve

i. externalisation and personification of anorexia;
ii. linking the person with others with similar circumstances by way of shared writing;
iii. establishing a repertoire of actions that the person takes in defiance of anorexia;
iv. making visible a characterisation of anorexia as a tyrant, torturer and oppressor;

v. enthusiastically embracing acts of resistance to the demands or imperatives of anorexia, thus making reclamations of life from anorexia;
vi. followed by proposals for ritual celebration of the person's changed relationship and this life progression (Epston et al., 1995).

These documented practices of anti-anorexia were supplemented by establishment and maintenance of the *Archive of Resistance: anti-anorexia/anti-bulimia*[3] which contain an extensive collection of documentation produced or co-produced by persons living with, and taking up resistance against, anorexia. This was/is a means of sharing insider knowledge and building supportive networks known as anti-anorexia leagues, perhaps the most well-known being the Vancouver Anti-Anorexia/Bulimia League whose political activism included letter writing campaigns, candlelight vigils, slogan t-shirt production and educational events (Grieves, 1997; Madigan, 2010), illustrating just some of the innovation, creativity and enthusiasm that David Epston generated and inspired in these realms. Much of what is contained in the *Archive of Resistance* is publicly available online, and ongoing submissions are invited. In *Biting the Hand that Starves You* Maisel et al. (2004) provide further detail about the principles and practices of anti-anorexia/bulimia, and establish the process of taking up an anti-anorexia stance through a series of practice stories in which as therapists they have collaborated with people who have re-negotiated their relationship with anorexia by taking up a resolute and moral position against anorexia's ongoing influence and presence in their life.

Critiques of anti-anorexia

Though many have found this anti-anorexia approach compelling, the forms of externalising practices engaged with in anti-anorexia work are not without critique. Anti-anorexia relies on a totalised, personified, vilification of anorexia which might be unhelpful, especially if this characterisation is disconnected from the person's actual experience of anorexia. Complex relationships with anorexia have been documented quite widely, and anorexia is often considered as much a friend, or a means to live, as it is a foe or negative force to be

[3] *The Archive of Resistance: anti-anorexia/anti-bulimia* can be found at http://www.narrativeapproaches.com/resources/anorexia-bulimia-archives-of-resistance/

repudiated (Conti, 2013; Lavis, 2018; Tierney & Fox, 2010). The potential for reification of anorexia has been argued, and practices of detailed personification claimed as problematic in their capacity to become overwhelming (Vitousek, 2005). Recognition of personal agency is potentially diminished by characterising anorexia as an overwhelming and controlling force, which would be contrary to narrative therapy's broader aims (Saukko, 2008a), and drawing on limited, therapist-imposed metaphors, particularly those which incur combat and embattlement positions, have been argued as constraining, with the potential to intensify a person's relationship with the problem (Conti et al., 2016; M. White, 2011). Paula Saukko (2008a) offers a rigorous and convincing feminist argument that anti-anorexia approaches replicate ideas that people (predominantly women) living with anorexia are weak-minded in having become duped by an anorexia that is founded in discourses of beauty and femininity in ways that other people have managed to evade. Unfortunately, Paula Saukko falls into a common trap of conflating practices of anti-anorexia with the entire repertoire of narrative approaches to anorexia and, in doing so, her critique concludes that narrative therapy is not useful in the context of anorexia, sadly missing out on the more nuanced opportunities within the broader realms of narrative practice and on the subtleties of discourse transmission that go beyond peer pressure and media images.

Inviting experience-near metaphors

Interestingly, two related teams writing from a largely psychological paradigm, Conti et al. (2016) and later Conti et al. (2017) , draw extensively on narrative writings to challenge what have become dominant mainstream practices in the realms of anorexia, such as Maudsley or family-based models of therapy, whereby the person and their family are expected to take up a position against an externalised anorexia, similar to that of anti-anorexia. Drawing heavily on wider narrative writings, Conti and her colleagues argue against the use of both the linear and combative metaphors that are embraced by an anti-anorexia stance. They have been influenced in particular by M. White (2007) and M. White (2011), illustrating how such metaphors risk intensifying the person's relationship with the problem, how this can be isolating for the individual, and how it creates potential to replicate notions of success and failure when faced with the task of beating or overcoming difficult problems. As Conti et al. (2016) point out, M. White (2011) recommended 'avoiding

the imposition of metaphors' (p. 89) whilst taking 'significant responsibility in terms of the metaphors that we choose to join with' (p. 90), a responsibility Conti et al. argue therapists need to pay greater attention to.

> Whether or not we are aware as a profession, we are powerful in selecting the stories and metaphors that become encoded in research and enacted in therapy sessions. The metaphors that we draw upon in our work are not merely descriptive, but also shape our understandings, the ways our clients engage with their life, and the processes of their identity formation. (Conti, Rhodes & Adams, 2016, p. 6)

2.5 Creating an alternative evidence base

A challenge for narrative therapy being embraced in the realms of anorexia is that there is an ever-increasing imperative in much of the world for public eating disorder services to utilise so-called evidence-based practice (EBP), a concept which draws on evidence-based medicine (EBM), the latter being defined by Sackett, Rosenberg, Gray, Haynes, and Richardson (1996) in the following terms

> EBM is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. (Sackett et al., 1996, p. 71)

And subsequently

> Evidence-Based Practice (EBP) requires that decisions about health care are based on the best available, current, valid and relevant evidence. These decisions should be made by those receiving care, informed by the tacit and explicit knowledge of those providing care, within the context of available resources. (Dawes et al., 2005, p. 1)

Of course, it makes good sense for practitioners to utilise practices that have a sound and verified base of evidence to support them. However, an evidence base in these terms often relies on research methodologies such as randomised controlled trials (RCTs) and

manualised approaches that are at odds with a poststructuralist epistemology and with the ethical commitments of centring the voices of people with lived experience, privileging them over clinical measures and observations that characterise narrative practice. Conti et al. (2017) point out that this thinking has led to Maudsley Family Therapy, an approach best-suited to adolescents (J. Lock & Le Grange, 2015; J. Lock et al., 2010), being positioned as the only evidence-based approach for anorexia, with one effect being a tendency to defer the wishes and intentions of those receiving care in favour of recommendations from clinical expertise.

What I propose, however, is that it is possible to establish a different type of evidence base. By employing the practices and principles of narrative therapy in an academic research context it is possible to engage in double-storied research that privileges insider perspectives and has the potential to contribute to very different conclusions to the pathologising understandings of the past, the unproductive quests for causes and clinical solutions, and the production of bleak horizons. Employing narrative practice in research methodology engages participants in co-research that constructs and documents alternative knowledges, based in lived experience, that have the capacity to alter representation and be of practical use to participants and other insiders.

By following lines of enquiry that

- honour difficult experience and acknowledge the effects of living with anorexia over time;
- utilise narratively informed questioning to highlight unique outcomes;
- create openings into double-story development;
- double-listen for response;
- illuminate previously overlooked skills and knowledge; and
- honour agentive actions based in intentions, beliefs, hopes and values,

we can expose and shape more respectful and honouring storylines to co-create an alternative, insider-informed, multi-storied and preferred evidence base.

CHAPTER 3. METHODOLOGY

The Enduring anorexia project is unique in bringing a narrative practice lens to research in the context of adults' long-term experiences of living with anorexia. The literature review has set the context for this research by outlining historical and contemporary issues in the field of research and clinical considerations that relate to anorexia, and in particular its duration in people's lives over the longer-term. This chapter now establishes the detail of this study's rationale and aims. It then sets out the research questions, before going on to describe how decisions were made, and what steps were taken, in order to answer these questions congruently with the research intentions and philosophical position.

3.1 Establishing the research aims

The overarching aim of this research was to respectfully explore the experiences of adults who have lived with the influence and effects of anorexia over several or many years, whilst concurrently acknowledging of their acts of agency in responding to those circumstances, as means of illuminating poorly attended to experience and contributing to better understandings and improved representation. It makes a number of unique contributions by addressing significant gaps in the existing literature, and by highlighting multiple benefits of bringing a new theoretical lens to research in this realm.

Making experience and response visible by using a fresh approach

First-hand accounts of adults who have experience of living with anorexia over the long term are scant. To briefly summarise, until very recently what attention there has been to the longer-term picture has largely been limited to specialist service-based studies of perceived deficits and losses in the lives of people affected through the lens of a medical model (Arkell & Robinson, 2008; Bamford et al., 2015; Button & Warren, 2001; Robinson et al., 2015; Wonderlich et al., 2012), debates about approaches to clinical management (Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014; Robinson, 2009; Wonderlich et al.,

2012), and establishing stages of illness and recovery (Broomfield et al., 2017; Dawson, Rhodes, & Touyz, 2014), with just a few writers also turning their focus to exploring the meanings people give to anorexia over time (Eli & Warin, 2018; Fox & Diab, 2015; Lavis, 2018; Ross & Green, 2011; Shohet, 2018; Stockford et al., 2018),

What is notably missing is a community-based study that takes an interest in adults' experiences of living with anorexia over time to establish first-hand accounts that creates space to either concur with, or differ from, what has been written as a consequence of service-based studies (Robinson et al., 2015). What is also missing is a study that pays attention not just to the effects of anorexia's influence on participants' lives, but to how they respond to their circumstances, as a form of counter reporting to the bleak outlooks and deficit-based understandings outlined in the literature review. Such an endeavour calls for a very particular approach to research as there are a number of dilemmas. Inviting community-based participation is not without challenge as living with anorexia is considered to be an under-reported, often private, concern (Hoek, 2006), and engaging people living with anorexia long-term has been recognised as complex (Robinson, 2009; Wonderlich et al., 2012). Well-utilised research lenses and methods of the past may simply serve to replicate what has been claimed before. Consequently, of particular significance in this research project is not just *what* was being researched, but *how* it was being researched.

Throughout this chapter the multi-faceted rationale for this emphasis on *how* will become increasingly apparent, but there was a clear need for a fresh approach to research; one that was capable of inclusive and respectful enquiry about first-hand experience, in non-assuming ways that can attend to complexity, incongruence and recognise agency and intention.

Alice Morgan (2000) describes narrative therapy/practice in the following way

> Narrative therapy seeks to be a respectful, non-blaming approach to counselling and community work, which centres people as the experts in their own lives. It views problems as separate from people and assumes people have many skills,

> competencies, beliefs, values, commitments and abilities that will assist them to reduce the influence of problems in their own lives. (Morgan, 2000, p. 2)

The engaging practices, respectful principles and curious stance of narrative practice were considered well-suited to meeting each of the requirements and aims of this research, providing an ideal theoretical lens for the study.

Unique contributions of the research design

This research is thus designed to make a number of unique contributions, by

- Inviting community-based participation to establish first-hand accounts of the effects of anorexia's influence on adult participants' lives over the long term.

- Focussing on what skills and knowledges participants draw upon, and the values and intentions that guide them, as they get on with their lives alongside anorexia's effects and influence.

- Utilising the poststructuralist, feminist informed lens of narrative practice to design the research questions, select the methods, inform the analysis and interpretation, and shape the reporting.

Narrative practice commitments embedded into the research design

In line with a narrative practice stance, central commitments embedded in this project design are

- To centre the voices of people with first-hand experience of living with anorexia.

- To create space for recognition of the ways in which people living with anorexia draw upon their own skills, knowledge and commitments to respond to their circumstances.

- To utilise research methods that illuminate both congruence and diversity, thereby escaping homogenisation of experience.

- To invite contributions from people who may have previously been excluded from research on anorexia.

- To recognise that knowledge derived from first-hand experience can make valuable contributions to the lives of others and guide improved understandings and professional approaches.

3.2 An alternative research lens: What a narrative practice paradigm brings into focus

Before anything further is said, it is important to provide some greater detail about aspects of the very particular lens through which this research has been conducted; a lens that sets this project apart from other studies on long-term experience of anorexia, and that is inextricably woven into each step, concurrently supporting and shaping the research aims and commitments.

A distinctive worldview

Bringing a narrative practice paradigm to research is distinct from using narrative inquiry or narrative analysis. In this study the term narrative practice refers to the model of therapeutic practice originated by Michael White and David Epston (1990), as described in the literature review. This thesis embraces the notion that narrative practice extends far beyond being a set of therapeutic tools, or even a therapeutic modality, but encompasses a poststructuralist worldview from which its therapeutic or restorative operations flow (Thomas, 2002; M. White, 1995). This worldview enables an understanding of people and problems that is both respectful and hopeful (Morgan, 2000).

Key features of a narrative practice perspective essential to this research

- Narrative practice is informed by 'the tradition of poststructuralist thought' (M. White, 1997, p. 217), and recognises social realities as multiple, fragmented, partial, shifting, and socially constructed. Identity is claimed as a 'social and public achievement' (M. White, 2000, p. 62) with people making meaning and arriving at a sense of themselves and others through the milieu of interactions that occur within wider political, social, historical and cultural contexts.

- Poststructuralist thought thus posits that 'understandings are never objective, neutral, or value-free' (Thomas, 2002, p. 88), and a defining feature that distinguishes narrative practice as poststructuralist (M. White, 1991, 1997, 2000), from under the broader umbrella of social constructionism (Burr, 2015), is its especial attention, and response, to Foucault's analysis of modern power (Monk, Winslade, & Sinclair, 2007; M. White, 1997).

- Narrative practice critiques the dominant structuralist understandings of human behaviour in Western psychological thought that have rendered us 'oblivious to the extent to which persons are active in shaping their lives as they live their lives' (M. White, 1997, p. 226). Through a narrative practice lens, people's actions are guided by values, beliefs and commitments that have meaningful histories in their lives, and people are cast as living intentionally (M. White, 2007).

- The development of narrative ideas and practice has been heavily influenced by feminist thought (Russell & Carey, 2004; C. White, 2016), contributing substantially to decisions, assumptions and conclusions made throughout this research.

3.3 The research questions: Fitting words for a given paradigm

This section lists two sets of research questions. The original research questions that were posed at the outset were later considered in need of re-wording to more accurately fit the

approach that was being taken. Both the original and the re-worded questions are included in the reporting in alignment with feminist research ethics of transparency and critique (Kitzinger & Wilkinson, 1997), and by the qualitative research tradition of credibility through visibility (Creswell & Miller, 2000).

The original research questions

The original wording of the research questions was as follows:

1. What is the experience of living with anorexia over the long term? *(Perceived costs/benefit, impacts across multiple areas of life)*

2. How do adults living with anorexia over the long term get on with life to a greater or lesser extent? (*How, and under what circumstances do people make change to recover elements of their lives from the effects of anorexia? What thoughts and actions support or challenge such changes?)*

3. What responses from others (at a societal, local or service level) have proved beneficial or problematic over time?

4. What, if any, recommendations or suggestions do participants have for ways forward in thinking about and responding to this issue?

It became apparent that this wording framed the questions in a realist paradigm by implying a singular, truthful account, that could be captured and naively reported upon by an objective researcher. This did not accurately reflect how decisions were being made, or fit the poststructuralist research lens utilised, that understands realities as multiple, fluid and context dependent (Thomas, 2002). The questions were therefore reviewed and re-worded to better reflect the research lens used, steps taken, and claims made.

Final research questions

The questions that more accurately reflect the research design and lens, and which are ultimately those answered by this study, are:

1. How do adults who have lived with anorexia over several years describe the experience, the effects, and the challenges?

2. In what ways do adults who have lived with anorexia over the long term go about coping and getting on with their lives?

3. What have other people's responses contributed to the experience of adults who live with anorexia's influence and effects over the long term?

4. What possibilities for improving public attitudes and professional approaches become visible when we draw from first-hand reports of living and coping with anorexia in adulthood?

3.4 Using language intentionally

As with all schools of thought, narrative practice uses language that reflects its theoretical underpinnings. Narrative practice takes a clear position on language, arguing that its use is dynamic and constitutive rather than merely reflective of realities.

> The language that we use constitutes our world and beliefs. It is in language that societies construct their views of reality … Speaking isn't neutral or passive. Every time we speak, we bring forth a reality. Each time we share words we give legitimacy to the distinctions that those words bring forth. (Freedman & Combs, 1996, pp. 28-29)

This understanding brings with it a particular ethic around careful use of language, in recognition of the embedded and socially agreed meanings that words and phrases carry, and which have effects on people's lives. But it isn't only about the spoken word, it also relates to the written word.

> The professional disciplines have been successful in the development of language practices and techniques that determine that it is those disciplines that have access to the "truth" of the world. These techniques encourage persons in the belief that the members of these disciplines have access to an objective and unbiased account of reality, and of human nature. (M. White, 1997, p. 36)

Consequently, this thesis both uses and resists particular forms of written language intentionally as part of ethical commitments, and in support of theoretical consistency. It also attempts to be transparent about the ways in which language is used. Just as terminology influences how we tend to think of the world, and shapes our realities, what is often thought of as everyday language reflects and replicates the hegemony of particular viewpoints that derive from realist assumptions and maintain status-quo conclusions. Typically, research about anorexia is strongly infused with the language, assumptions and inferences of biomedical models of mental health or structuralist understandings of personality and the development of the self. This thesis attempts to escape that dominance, especially where it makes a difference to how people are represented and how problems and contexts are understood.

How some special terms are used in this thesis

The authorial intention has been to make this thesis as accessible as possible to multiple readerships, without significant knowledge or understanding of narrative ideas, or familiarity with its terminology. However, some special terms are used throughout as part of the aforementioned intentional use and resistance of particular forms of language, and because of their significance in a narrative practice paradigm.

The following list seeks to expound upon terminology that was not fully explained by the literature review, but without repeating what has been said already:

Narrative practice is used throughout this thesis as an alternative to the original term, narrative therapy. This follows *Maps of Narrative Practice* (M. White, 2007) and reflects the growing diversity of contexts in which narrative ideas are being effectively utilised, of which academic research is one example. However, older writings and many contemporary authors in these realms use the original term, narrative therapy. For the purposes of reading this study the two terms can largely be considered interchangeable, though narrative practice is predominantly favoured with narrative therapy appearing only where other authors are being cited or, from time to time, where it seems necessary for clarity or flow.

Anorexia is not a narrative term per se, but it is used in alignment with narrative practice principles as an abbreviated alternative to the medical and diagnostic term, Anorexia Nervosa. This serves a dual purpose. It goes some way to escaping dominant medical understandings, or arguably ownership, of anorexia whilst simultaneously following narrative practice's tradition of privileging people's own words and understandings (Morgan, 2000). It is more common to hear someone speak casually of anorexia, than of Anorexia Nervosa.

The way the term anorexia in used and written in this thesis follows the influential writing of Maisel et al. (2004) who, as part of their narrative practice stance, use lower case typography as part of re-grading (i.e. diminishing) anorexia's importance in people's lives, and who emphasise that their use of the word anorexia does not imply alignment with medical models, or define the problem in specified ways:

> Although we typically use the terms anorexia and bulimia as ways of referring to the problem (and not as a means to capture it), we do not intend for them to be diagnostically precise. Rather, in this text the terms are employed very loosely (Maisel et al., 2004, p. 13)

Of course, anorexia is not a word all people use to describe their experiences, and acknowledgement of this involved a degree of reflexivity in the research process. Participants were asked in the online survey whether or not they used the word to describe their experience, and several said that they didn't. However, the study did need some means of establishing a common understanding of what problem or phenomenon was under discussion. Eating disorder or disordered eating, both commonly used terms, were considered too generic in their capacity to encompass a wide range of difficulties including those that are often called bulimia and binge eating disorder, which were beyond the scope of this particular study. Anorexia was settled on as a commonly recognisable term for the purposes of invitations to participate and for the online survey questions, with increased flexibility around language use during interviews.

Rescued words is a commonly used phrase in narrative practice that describes the art of staying close to a person's experience or meanings in conversation by noting and using their own words, phrases and descriptions. Paraphrasing the writings of anthropologist Clifford Geertz, Michael White called this practice of capturing people's meanings, rather than allowing their initiatives to 'fly by' in their words without acknowledgement, 'rescuing the said from the saying of it' (Newman, 2008, pp. 25-26). Similarly, thematic analysis (the mode of data analysis used in this study, and described below) has its own term, data extract, that refers to research participants' own words noted as meaningful and which are captured for the purpose of sense-making through the construction of themes (Braun & Clarke, 2006). It seems incongruent that narratively informed research should entirely abandon narrative practice's careful terminology, yet in qualitative research the term data extract is more familiar and expected. Consequently, the terms data extract and rescued words are used interchangeably at times in this study, the movement between these two languages bringing together practices and principles of thematic analysis and narrative therapy.

Insider and insider knowledge are also used in this thesis in alignment with narrative practice traditions (see Epston, 2014; Maisel et al., 2004). Insider is used in narrative practice to refer to a person who has first-hand experience of a problem or situation, i.e.

from the inside and, as such, insider knowledge is the unique knowledge that derives from the perspective of lived experience.

> Thus it was from the very outset that we conceived of therapy as a reciprocal exchange that honoured the 'local' knowledges of the person consulting a therapist. We later dubbed these 'insider knowledges' to distinguish them as a very different order than professional knowledges. Such 'knowledges' had something of the sacrosanct about them and as such should be given unusual respect as they were particular, local, non-identical and usually emerged out of the very vicissitudes of life in which 'necessity was the mother of their invention'. (Epston, 2014, p. 66)

Insider knowledge of problems is recognised has having often been subjugated in clinical settings and research, in favour of what is considered expert knowledge (M. White & Epston, 1990). Yet narrative practice's alternative conceptualisation enables the privileging of knowledge that comes from first-hand experience, inviting people into the position of experts in their own lives, rather than a clinician or researcher taking up that position in their life. It should be noted that the term insider has also been used by researchers not connected to narrative practice, several of whom have been a source of inspiration and guidance when conducting this research (Acker, 2000; Chavez, 2008; Costley, Elliott, & Gibbs, 2010; Dwyer & Buckle, 2009; Ganga & Scott, 2006; Humphrey, 2007; Kanuha, 2000; LaSala, 2003; Teusner, 2016; Wilkinson & Kitzinger, 2013). However, the terms insider and insider knowledge are used here in alignment with their understandings and use in narrative practice and, in this thesis, predominantly to refer to people who have lived with anorexia and the knowledge that has come from that experience.

Deconstruction of discourse is, again, not exclusive to narrative practice but it is a key part of the therapeutic repertoire. It refers to a style of questioning that is based in understandings of the social world as constructed through a process of spoken and unspoken agreements (discourses) about what is normal, healthy, acceptable and so on (M. White & Epston, 1990). Problems exist in, and are often sustained by, discourse-laden contexts (Morgan, 2000). Deconstruction of discourse is the conversational practice of asking questions that make these discourses more visible and therefore more available for

scrutiny, and potentially dissent (Freedman & Combs, 1996). This conversational practice can be helpful for illuminating how social pressures and commonly assumed norms and expectations can constrain lives, limiting action and choice. It highlights how these discourses are not fixed realities, but are contestable and reviewable ideas, thus opening up new avenues and possibilities in therapeutic practice (M. White, 1991).

Absent but implicit. Michael White (2000, pp. 35-58) drew on the work of Jacques Derrida and Gregory Bateman to establish how, in conversation, what is spoken of is not merely a reflection of what the speaker knows to *be*, but also a reflection of the speaker's knowledge about what else *could be.* It is the speaker's knowledge of difference that makes what *is* discernible. In narrative therapeutic practice, the concept that knowledge can be both absent (in not being directly attended to) and yet implicit (in being essential for sense-making sense of what is) in conversation, invites practitioners into double-listening for what is otherwise known to the speaker that may be of use or preferred and valued by them, and as an entry point into an alternative storyline (Carey, Walther, & Russell, 2009; Freedman, 2012). At times, this thesis draws on the concept of absent but implicit as a means of sense-making during the research process, and as an implication for therapeutic practice.

Considering the effects of terminology. As a concluding petition, where language use deviates from what is familiar in an academic context towards that which is familiar in the context of narrative practice, the reader is invited to reflect on the effects of terminology, on how people become thought of, or positioned, in research; on how their stories are held and represented; and on what understandings, knowledge and meanings are maintained or created through particular forms of language use.

3.5 Embracing subjectivity in the research: Matters of visibility and accountability

Due to its poststructuralist underpinnings, narratively informed research cannot subscribe to the positivist notion of an objective, impartial researcher reporting expertly on essential truths about problems, or even naively acting as a conduit for people's stories (see Lainson

et al., 2019). In line with qualitative research traditions this subjectivity is embraced as a strength in this study, rather than viewed as a limitation, in so far as it is made visible as part of research credibility (Creswell, 2007; Fine, 1992; Jankowski et al., 2017; Kidder & Fine, 1987). Embracing subjectivity has a number of implications. Research methods should be selected that allow diverse participant voices to be centred and respected and this has been a key aspect of the design, as detailed later in this chapter. In addition, visibility practices of situating the researcher in the research, being transparent about the myriad decisions taken and assumptions made at every stage of the research, and naming conclusions as a commentary from a specific location and perspective are all part of researcher accountability (Braun & Clarke, 2006, 2019; Fine, 1992; Lainson et al., 2019).

Attending to one's own social location in recognition of the operations of power and privilege that flow from that is consistent with qualitative research and feminist and narrative practice frameworks (Braun & Clarke, 2019; Creswell & Miller, 2000; M. White, 1997; Wilkinson & Kitzinger, 2013). These habits augment the credibility, and potential for transferability of qualitative research. As a start, far-reaching claims about the generalisability of conclusions arrived at in this study should be resisted. In the chosen paradigm, it is recognised that knowledge cannot be detached from the context in which it was produced (Braun & Clarke, 2013; Creswell, 2007; Kidder & Fine, 1987; see Lainson et al., 2019). Rather, interested readers are invited to consider the applicability of the findings to their own particular context. Thus, visibility about the researcher's social location, decisions and assumptions is intrinsic to supporting the reader in establishing the transferability, or otherwise, of findings and conclusions arrived at to their own context. The following sections attend to matters of researcher visibility and accountability.

Making myself visible: Situating the researcher in the research

Locating myself in relation to this project thus becomes an obligation, and Mauthner and Doucet (2003) argue that qualitative researchers should go beyond simply naming their social location, but call upon them to acknowledge their emotional and intellectual involvement in the research process. I attempt at several points throughout this thesis to make available the aspects of my social location that are particularly relevant to how this

research may be understood, in particular my own long-term experience of anorexia, and to transparently reflect on how my very personal connection has influenced this study. I have, at times, been extremely reluctant to say much about me, and making my own experience visible has not been an easy choice. However, a dilemma I face is that whenever I limit myself to brief passing references to personal experience the effect is to make seem casual the very serious concerns I hold. Concerns that mobilised me into doing research in the first place.

I am a white British New Zealander, Pākehā, woman. The middle of three sisters, I grew up in a northern English port in the 1970s and 1980s. Inhabiting both working and middle-class worlds without entirely belonging to either, I by and large benefitted from the advantages afforded by the latter. For the most part I have occupied privileged and non-marginalised spaces, though this has been complicated by my having been given the medical diagnosis of Anorexia Nervosa in my teens, which had profound consequences for my life. Excluded from school and propelled into a medicalised system that had no specialist eating disorder services, I was treated within general adult psychiatric hospitals. The psychiatric discourses of the day were that the problem lay within my character, my personality, my family and my cognitions, all of which were said to be deeply flawed. As such, my every thought and action could be interpreted as an expression of my now pathologised identity. I prefer not to recall my ensuing treatment, and it took several years before someone who thought differently encouraged me to extricate myself from a hospital system that clearly wasn't helping, and to find my own solutions. This, with varying degrees of success, was what I did. Getting on with life as best I could alongside what I had come to know as anorexia, I did slowly make incremental change. What was notable during that time was that as anorexia became more widely spoken of, and written about, my progress would stall substantially whenever some new deficit-based theory was circulated, until I eventually learned not to read or attend to them.

My later training as a narrative therapist in Aotearoa New Zealand helped me make new sense of how these events had unfolded. I found a great many benefits in witnessing my story through the lens of narrative practice. Perhaps most striking to me was a renewed sense of dignity, and with that came new possibilities. It became apparent to me how

theories of anorexia that focussed on what was wrong with me, and which diverted attention from what was helpful to me and from what I did to help myself, had proved to be extraordinarily unhelpful. I also noticed in the counselling work I undertook with adults who were living with similar difficulties, that whenever their own knowledge about what did and didn't help them was overlooked in favour of professional knowledge that also seemed to have unhelpful effects for them. Consequently, this project is borne out of a commitment to conduct research that recognises the efforts people make in order to get on with their lives alongside anorexia, centres insider knowledge, acknowledges skills and commitments, highlights personal agency, and fosters respectful representation. I sincerely hope this research achieves those aims.

Doing insider research

Insider research is not presented here as the only way, or even as a superior way, to conduct respectful research in the context of marginalised experience, but as a uniquely useful lens (see also Lainson, 2019). Conducting insider research has many significant complexities with as many challenges as there are benefits (Acker, 2000; Breen, 2007; Chavez, 2008; Dwyer & Buckle, 2009; Ganga & Scott, 2006; Humphrey, 2007; Kanuha, 2000; LaSala, 2003; Wilkinson & Kitzinger, 2013) but it does offer a particular opportunity to reflect on the effects of representation in research.

Wilkinson and Kitzinger (2013) describe how mainstream psychology has characterised insider subjectivity as contamination in knowledge production yet, they argue, escaping insider status is not the goal, but to use it ethically and reflexively in transformative ways. In alignment with writings by Acker (2000), Breen (2007), Chavez (2008), Dwyer and Buckle (2009) and Kanuha (2000), they challenge the dichotomous positioning of insider or outsider status by pointing out that 'similarity and difference are neither unitary nor fixed categories; they can be partial, and they can shift across the course of a research project' (p. 251). This was certainly my experience. At times, participants' words resonated strongly with my own stories but even in the same conversation there would be times when the story of experience I was witnessing was entirely unfamiliar to me. LaSala (2003) points to the risks of shared understandings being assumed between researcher and interviewee,

but balances this with recognition that the researcher's insider knowledge of the subtle ways in which oppressions can be replicated can allow the creation of safer spaces for sharing. As one means of engaging in responsible reflexivity when conducting insider research Teusner (2016) suggests ensuring the inclusion of multiple diverse voices in the analysis and reporting, which is a key feature of this study.

Holding myself accountable: Researcher assumptions that shaped design decisions

Methods utilised in research need to be selected to elicit data in ways that can answer the research questions, which involves giving thought to who will be invited to participate, how they will be invited, and what they will be asked to do. Transparency about decisions taken and assumptions made is key, as normative thinking is notoriously difficult to evade or notice in oneself (Hare-Mustin, 1994; Heath, 2012). Special efforts were made to ensure inclusive research practices, invite diverse participation, allow complex responses, and resist reproduction of reductionist or homogenised accounts of experiences, as has been a critique of both medical and feminist research on anorexia in the past (Saukko, 2008b; Warin, 2004). Some of those efforts are more explicitly described in the research design sections, but the unique range of influential factors and assumptions that contributed to the design of this project were as follows:

- Potential research participants were considered likely to be what is often called 'hard to reach'. It was expected that some may be accessing specialist services, but that some would not. Understandings about experience derived from relevant literature, and both personal and practitioner experience suggested some people may find it difficult to take part in research activities due to complexities of their lifestyle, or that maintenance of the often private nature of living with anorexia in adulthood might influence decisions about whether to participate (Hoek, 2006; Robinson et al., 2015). Consequently, it was decided that an online survey format, using social media for the dissemination of invitations to participate, would remove geographic limitations (although not language barriers), reach beyond specialist services, and allow participants to contribute with complete anonymity, at a time and location that suited them.

- It was also anticipated that people interested in participating would have different ideas what they wanted to say and so there was an imperative for the design to allow participants to contribute as much or as little as they wished. Many people living with anorexia are highly skilled in meeting the expectations of others, and it was assumed that participants might find it difficult to withdraw from the study, despite being assured it was their right to do so. It was also assumed this might discourage them from participating in the first place. Consequently, the online format addressed this ethical concern and made tentative participation more inviting by enabling anonymous withdrawal.

- Anorexia has predominantly been considered to be a problem of White, middle class, teenage girls immersed in Western culture (Brumberg, 2000; Darmon, 2009; McClelland & Crisp, 2001). This limited demographic is being increasingly challenged (Gremillion, 2008; Royal Australian and New Zealand College Of Psychiatrists, 2009) and a consideration of this research was that potential participants may not belong to this demographic. Attempts were made to invite inclusive participation by utilising social media and contacting potential circulation sources that would appeal to a broad demographic. However, most participants were ultimately female and identified as White or Caucasian with only a small number of participants who fitted a wider demographic, most of whom discovered the study via mainstream media coverage. Consequently, an assumption of the research is that this was probably an underrepresentation and that heavy reliance on social media might have excluded many older potential participants.

- There are many reasons why people may never have received a medical diagnosis for their concerns: older generations, for whom anorexia may have entered their life before the exponential rise in diagnoses during the 1970s and 1980s (Brumberg, 2000; Hoek, 2006), people belonging to a wider demographic who are reported to have difficulty accessing services, and many others might never have interacted with services or had trouble accessing services. They, and others, may use different words to explain their experience. In addition, narrative practice does not subscribe to the

use of medical diagnoses. For these reasons, diagnosis at any time in a person's life was not required for participation. Inclusion criteria simply asked that participants state they identified with what they thought of as common understandings of anorexia.

- The study was interested in adult experience of living with anorexia in the long term. Long-term has different meanings for different people, and so the invitation was for participants to have lived with anorexia 'for a number of years' beyond the age of 18, rather than specifying a particular number of years.

A two-stage approach to gathering stories

In response to the above considerations, this research invited global participation from adults who self-identified as having lived with anorexia for a number of years over the age of 18 to engage in (their choice of) a one or two-step research process for gathering stories of experience, as follows:

Step one: Anonymous online survey, circulated via social and mainstream media.
Step two: Optional semi-structured interviews, following on from the survey.

Further detail about each step is described and explained later in this chapter, but first it is significant to also name some of the ethical considerations that contributed to how the research unfolded.

3.6 Ethics: Obtaining approval and attending to broader considerations

Research ethics is dynamic and an evolving consideration that includes, but extends beyond, meeting the requirements for formal committee approvals. Both are discussed in this section. Working from a narrative practice framework, the influences of poststructuralist and feminist thought invite particular ethical considerations in relation to the operations of power and privilege, and the hegemony of Western realist practices and perspectives.

Wider ethical considerations relating to this research are discussed here in relation to relevant literature. Some issues have been satisfactorily addressed in the research process, some have not, and some dilemmas may never entirely be resolved.

Obtaining ethics approval

Ethics approval for this study was sought and obtained from The University of Melbourne Psychology, Health and Applied Sciences Human Ethics Sub-Committee with only a few minor amendments around accessibility of language. Two amendments were later approved as developments to enhance survey circulation and engagement. These are discussed at greater length in the survey design and circulation sections. Considerations that were identified by the approval process as being especially important when researching in a mental health realm were that potential participants would not be approached directly, and that I was able to respond to any distress which arose. My membership of the New Zealand Association of Counsellors contributed to recognition of my skills in speaking with people experiencing distress. A copy of ethics approval 1748564 is attached as Appendix 2.

Researching marginalised experience

Bagele Chilisa (2011) draws our attention to the colonising histories of Western research methodologies and challenges us to reflect on whose knowledge, and which worldviews, we are legitimising in the process of academic research. Chilisa was writing about Indigenous research, but her critical outlook and social justice emphasis can be extended into other realms. This focus is consistent with both the commitments of narrative practice, and the principles of the psychiatric survivor movement (Coleman, n.d.; Findlay, 2016; Slade et al., 2012), that research in the context of mental health should have a transformative element and 'should attempt to counter the stigma and discrimination experienced by survivors in society' (Faulkner & Tallis, 2009, p. 55).

When researching in the context of people whose experiences have been marginalised it is important to consider how accountability might be envisioned, how marginalised experiences can be brought to the centre, and how practices that replicate oppressions can

be avoided (Kitzinger & Willmott, 2002). Of particular importance was reflecting on how participants became positioned in and by the research. Within communities and groups of people whose experiences have been marginalised, such as people who have lived with mental health diagnoses and concerns, research has all too often sought to gather knowledge about the perceived deficits of people living with these concerns and difficulties or focus on how clinical intervention might assist them in returning to 'normal' (Sweeney, Beresford, Faulkner, Nettle, & Rose, 2009). In alignment with a narrative practice of re/de-grading the importance of problems in relation to people's lives (Maisel et al., 2004), and recognising that people respond agentively to their circumstances (Weingarten, 1998; M. White, 1997), this project sought to depart from a tradition of deficit seeking, by specifically enquiring about people's skills and knowledge in living with concerns.

Creating safer spaces to receive stories

Drawing on narrative practice contributions to ethical ways of receiving stories from people who have experienced hard times (Denborough, 2005), care was taken to design the survey and interview questions to create space to balance honouring the difficulties people faced with illuminating the responses they make, and knowledges they hold, that assist them in getting on with their lives. This is a similar approach to the double story testimony framework employed by Marlowe (2010) when interviewing Sudanese men resettled in Australia as a means to 'create safer spaces to engage people's lived experiences' (p. 41). Although some participants in this study did contribute descriptions of how anorexia operated in their life, this did not form part of the line of questioning. This approach had the dual benefit of reducing the likelihood of distress, and create opportunities for people to give preferred accounts of their lives, or tell 'strong stories' about themselves (Wingard & Lester, 2001). These were not counselling conversations, but several participants commented on the helpful and therapeutic effects of being interviewed in this way.

Considerations of inclusivity

Inclusion of diverse contributions is an important ethical commitment in mental health and feminist research as part of disrupting stereotypical representation and breaking down barriers to support, inclusion and understanding (Gremillion, 2008). This project focussed on

adults who have lived with anorexia for many years because of a lack of literature specifically relating to this age group. As such, it goes some way to extending representations and bringing marginalised experience to the centre. Attempts were made to invite even greater diversity of participation, including contacting agencies which specifically advocate for men, and addressing the matter of diversity in a mainstream media interview, but for the greater part participants in this study fitted a familiar demographic in every aspect other than age and duration of experience.

Utilising open ended questions in the survey, including in the demographic component, was part of an ethical commitment to recognising the right to self-identification. There was no requirement for medical diagnosis of anorexia in order to participate, only personal identification with common ideas of anorexia over a number of years beyond the age of 18 was requested. Space was created for participants to acknowledge that they used other words than anorexia to describe their experience, and check boxes were deliberately avoided in the demographic component so that ethnicity and gender could be described in personalised ways. This opportunity was taken up by some participants.

Acknowledging researcher privilege

Although every attempt has been made to be respectful of participants and their stories, including staying close to participant stories and meanings by incorporating their own (rescued) words in the reporting, this can in no way be claimed as co-produced research. Participants were not consulted about research aims, design, or even dissemination in all but a couple of cases where participant interviews took this turn. Nor were participants remunerated or compensated in any way for their time and generosity. Acknowledgement of their contribution to the research is anonymised. All participants were offered the opportunity to receive a copy of the themes if they wished, and one participant has asked to be sent a copy of the entire thesis when completed, but this was the extent of any recognisable benefit. A pleasing coincidence was participant's comments that the interview and/or sense of contribution had been helpful or therapeutic, but this still falls far short of the ethical commitments of survivor research (Ormerod et al., 2018; Sweeney et al., 2009)

However, it is hoped that this research will contribute to improved representation, better understanding and, where wanted, increased access to more appropriate ways forward.

The relationship between researcher and participant is not an equal one (Chilisa, 2011; Faulkner & Tallis, 2009), and my privileged position must be acknowledged in my ability to shape the conversation. A semi-structured format for the interview did impose some direction for line of enquiry, but there was also plenty of capacity to adapt and stay close to the interests of the person being interviewed. This not only met the requirements of exploratory research, but also attempted to centre participants' hopes for the research by checking in from time to time about the direction of the conversation, and as a reminder that there was no obligation to answer questions that didn't appeal. Participants were invited to select whether the interview was conducted via audio or video link and were provided with a copy of the interview transcript with an invitation to edit if they wished. Again, this was in part to meet the requirements of research rigour but had the advantage of providing participants with an opportunity to review or retract their contribution.

An un-resolved dilemma

A decision I regularly revisit is that, as interviewer, my own experience of anorexia was not acknowledged to participants. A number of considerations contributed to this:

- Writings on insider research that identify the complex insider/outsider position we occupy, and how naming oneself as an insider risks inviting erroneous assumptions of shared understandings, leading to participants omitting rich descriptions or explanations (Wilkinson & Kitzinger, 2013).

- Wanting to centre the voices of participants, I was committed to ensuring the conversations did not somehow become about me or my experience.

- A conversation I was aware of within eating disorder advocacy communities about whether therapists with lived experience of anorexia should be transparent about

that led me to wonder whether some participants might feel obliged to adjust their stories out of concern for how they may affect me.

- I have past experience of speaking with adults who have despaired at a sense of their own 'failure' when they learn that I have managed changes they struggle to make, and I was keen not to invite this.

- I was concerned about assumptions being made in relation to my own recovery status that might interact with my privileged position as researcher. I wondered if I could become positioned as an 'expert in recovery' and wasn't confident that I could effectively respond to requests for advice or guidance based on my own experiences of change, so thought it better not to put myself in a position with that potential.

- In a very personal sense, the real or imagined ramifications of making my own history and diagnosis visible on a social media platform preyed heavily on my mind.

Only one participant asked whether I had personal experience, and I was truthful in my response. But if I am to be entirely honest, my decision was in many ways an in-decision. Saying nothing was easier to overturn than saying something. I cannot be certain how participants might think of this in-decision, but ultimately not making my relevant experience known to participants falls short of feminist ethics of transparency, and of bringing marginalised experience to the centre in the way that was so respectfully modelled by Celia Kitzinger in her interviews with women living with polycystic ovarian syndrome (Kitzinger & Willmott, 2002). However, perhaps public disclosure of a mental health diagnosis by a new researcher on a social media platform is riskier, and I remain unconvinced by recent calls for people with lived experience of eating disorders to shoulder the burden of stigma reduction by telling their stories publicly. So maybe there is scope for my in-decision to be justified by way of a responsibility to 'Do Thyself No Harm' in the research process (Chatham-Carpenter, 2010). I am still un-decided.

3.7 Gathering stories stage 1: The online survey

A survey of 20 largely open-ended questions was circulated via social media. Participants were welcome to contribute as much, or as little, as they wished and so there were no compulsory questions. Apart from the brief demographic enquiry at the start of the survey, questions were originally designed to be entirely open-ended, and were informed and shaped by the practices and principles of narrative therapy. Some concerns about whether participants would be willing to complete so many open-ended questions led to several being adapted to a checkbox format. However, in uploading the survey onto Survey Monkey, the online platform, some technical problems occurred, and the questions had to be reverted to their original open-ended format. Ultimately, this was considered beneficial in providing greater scope for participants to provide rich and nuanced descriptions of their experiences and remained consistent with an entirely qualitative approach to analysis. It may however, account for a number of participants only partially completing the survey. Survey questions and invitations to participate are attached as Appendices 3 and 4 respectively, with Appendix 5 being the social media invitation slide. A plain language statement, consent form and wellbeing statement/distress protocol were all embedded in the survey and are attached as Appendices 6, 7 and 8 respectively.

Establishing avenues for enquiry

The following sources contributed to establishing avenues for enquiry in the online survey:

- Existing literature that indicates a range of impacts on the lives of adults who live for a long time with anorexia (Robinson et al., 2015).

- Reporting of difficulties in accessing services, particularly for people who don't fit the expected demographic (Butterfly Foundation, 2012).

- Matters highlighted by a number of international eating disorder advocacy agencies, largely via social media.

- Practitioner experience of counselling and peer support conversations with people living with anorexia over a number of years.

- Narrative practice commitments that lines of enquiry should both honour hard times and invite stories of response and personal agency (Denborough, 2005; Marlowe, 2010).

- The research commitment to centre participant voices and concerns.

Four domains of enquiry

Four domains of enquiry were identified as being most relevant to answering the research questions and maintaining alignment with narrative practice research commitments. These domains were:

1. The effects and experience of living with anorexia long term, in adulthood.

2. How participants have responded to anorexia's ongoing influence and effects in their life; how they cope and get on with or reclaim aspects of their life.

3. How responses from others have contributed to participants' experience of living with anorexia over time.

4. What ideas participants have about preferred responses from others, including what recommendations for future professional approaches and service provision.

A final question provided participants with the opportunity to bring any other matter they thought relevant to the attention of the researcher.

Pre-testing

A pre-test of the online survey was attempted in collaboration with a busy counselling service. However, there were no contributors to the pre-test and so a practitioner consultation process was undertaken instead. Three experienced narrative practitioners, with varying experience of working with people living with anorexia, were asked to provide feedback. Their suggestions led to the addition of a 'warmer welcome' at the start of the survey, through a brief researcher biography and photograph on the introductory page, for which an ethics amendment was obtained.

The survey welcome page is attached as Appendix 9.

Survey circulation and invitations to participate

The survey circulation strategy was both pragmatic and informed by ethical commitments of inclusion. Social media was considered a means of reaching a people who may not otherwise hear about the research, and requests for the survey to be circulated were sent to a wide range of individuals and organisations. News outlets were contacted, eating disorder and mental health advocacy agencies, gyms and sports organisations, celebrities and well-known people with large followings, as well as personal and professional networks of the researcher. Several hundred circulation requests were sent out, mostly via a dedicated Twitter account @Enduringa and a small number via my personal Facebook account. In reality, only a handful of Twitter users took up the option to re-tweet and those that did largely had some connection to eating disorder advocacy and research, with just a few exceptions. Social media campaigns are difficult to keep track of, however, and re-tweets occurred within networks unfamiliar to the researcher. A widely distributed press release (Appendix 10) caught the attention of Radio New Zealand and its partner The Wireless, both mainstream media outlets in Aotearoa New Zealand, and interviews with the researcher were aired and published on their respective social media accounts[4].

[4] The Wireless article is retrievable at: https://www.rnz.co.nz/news/the-wireless/374991/meet-a-researcher-who-s-breaking-down-misconceptions-about-anorexia
and the Radio New Zealand article is retrievable at: https://www.rnz.co.nz/news/national/347140/treatment-options-limited-for-anorexic-adults-study

That most of the re-tweets occurred via eating disorder interested groups did suggest that participation would likely come from a more typically expected demographic, except for adult age which was part of the inclusion/exclusion criteria. Nonetheless, the interview in The Wireless did attract a small number of significant contributions by male, transgender and Māori participants. The reliance on social media use may have limited potential participation from older people, but an additional form of promotion was an invitation to write a contribution for a recovery blog[5] aimed at older women living with eating difficulties. A further ethics amendment was obtained, and a contribution made to the blog towards the end of the recruitment process, but it did not appear to generate any additional participation.

The online survey remained open for 6 months, during which time 96 responses were received. There were noticeable flurries of activity which normally occurred within a few hours of a re-tweet. Activity would then die down. Twitter invitations were sent out in batches, timed to both keep the campaign alive, and to ensure that an overwhelming number of responses wasn't received at any one time, enabling contact to be made with anyone who volunteered for interview. Although a small amount of snowball sampling did occur due to some interview participants circulating the survey via their own support networks, this was not an active strategy of the recruitment process. Snowball sampling has been noted as advantageous for reaching 'hidden populations', but carries an inherent limitation of amplifying the voices of a specific demographic (Sadler, Lee, Lim, & Fullerton, 2010). As the mode of analysis in this study was not tied to notions of prevalence as an indicator of significance (as discussed further in the section on thematic analysis), and the study does not claim to be descriptive of an entire population, the effect of this small amount of casual snowball sampling was not considered problematic. The circulation campaign continued until there were no more obvious avenues, and responses and re-tweets had dwindled to nil. By this stage it was assumed that the most prolific communities of interest on Twitter had seen the invitation and decided whether or not they would

[5] The Diary Healer blog post, hosted by Dr June Alexander is retrievable at: https://www.thediaryhealer.com/2017/12/12/our-lives-have-many-storieswhich-can-give-hope/

participate. There was also a practical element to the timing as a decision had to be made about whether or not to renew the Survey Monkey fees, and this was considered unlikely to be worthwhile. The survey was closed, and a message left thanking potential participants for their interest.

3.8 Gathering stories stage 2: Optional semi-structured interviews

Everyone who participated in the online survey was invited to volunteer for a follow up interview via phone, Skype, or similar online app of their choice. The interview process was conducted concurrent with the survey circulation, and participants were contacted within a few days of completing the survey. Everyone who volunteered was contacted by email, and those who responded were interviewed at a time nominated by them. Written consent to record the interviews was obtained and the plain language statement and distress protocols that had been embedded within the online survey were resent via email.

Interview design

Interviews followed a similar format to the survey and sought to elicit richer descriptions of participants' written responses and to create space for the discussion of matters that were raised by participants, or of particular interest to them. Although a number of topics that aligned with the domains of the survey were established to guide the interviews (Appendix 11), every attempt was made to stay close to the stories and topics that each participant brought. Consequently, the focus of interviews varied quite considerably, as becomes more visible in the results and discussion chapters. For instance, some participants were understandably very focussed on their ongoing struggle in living with anorexia, detailing its effects as they related to their particular circumstances and/or the difficulties of navigating access to supports; others spoke extensively about daily acts of reclaiming their lives from its influence, or the process of what they considered to be recovery; others of frustrations relating to public representation and professional understandings or approaches, and more. Questions were carefully worded to reflect the stated intention of the research, i.e. to

highlight insider knowledge and skills in coping alongside the challenges faced, by drawing on the co-research interview principles of narrative practice.

Conducting the interviews

Respecting the individual understandings and beliefs of participants about anorexia and its nature involved moderating my typical use of language. Not wanting to impose certain understandings or assume particular beliefs about or attitudes towards anorexia involved a delicate balancing act, in which I attempted to maintain an 'agnostic' position on anorexia and its nature. I cannot be sure how well I achieved this, and certainly used externalising, as opposed to internalising, language in that I spoke of 'living with anorexia' rather than 'being anorexic'. However, this is increasingly common practice within eating disorder services, well beyond the narrative practice realms in which it was originated. A small number of interviewees commented that they did not subscribe to externalised understandings of anorexia and found them unhelpful despite being routinely exposed to the concept in treatment settings, but they continued to use externalising language nonetheless.

There were 23 interviews, all between 45 and 90 minutes long. All were audio-recorded and transcribed verbatim by the researcher, as part of the process of rich engagement and familiarisation with the content. I kept a reflective journal during this time as a means of capturing some of my thoughts, and of recognising them as mine rather integrating them into my recollections of the stories themselves. A copy of each participant's transcript was returned to them, with an invitation to alter or edit it to better reflect their recollections or intentions, if they wished. Two participants chose to alter their grammar and some of their expressions, and one participant chose to take out stories she had shared that she thought might identify her. She suggested that I include in the research a comment about the extent to which shame and fear of exposure had contributed to this, but her strongly held views on the importance of this research were sufficient for her to participate nonetheless.

3.9 Telling stories about stories: Using reflexive thematic analysis (TA)

Selecting an analytical approach that was theoretically consistent with narrative ideas and flexible enough to accommodate the multiple commitments and constraints of the research was fraught with challenge and dilemmas. Multiple options were considered and discarded due to practical or theoretical problems (Lainson et al., 2019). Ultimately, Braun and Clarke's (2006) model of thematic analysis (TA), which the creator/authors have come to call reflexive TA (Braun & Clarke, 2019), was selected due to its theoretical independence, practical flexibility and capacity to generate a richly described story of the interview and survey data that highlighted patterns of meaning whilst allowing divergence to be considered an equally important part of the overall picture.

> Since the publication of what became a landmark paper, TA as a 'named and claimed' method has gained hugely in popularity and has entered the qualitative canon as a recognisable and reputable method of analysis. (Terry, Hayfield, Clarke, & Braun, 2017, p. 18)

For clarity, in this thesis TA is used to refer to Braun and Clarke's approach while thematic analysis will be used when discussing generic concepts that apply to multiple models. In recognition of the later decision to describe their model as reflexive TA (Braun & Clarke, 2019), the prefix of reflexive will be used unless making specific reference to works written prior to this change.

Establishing theoretical consistency

As Braun and Clarke's (2006) rigorous exploration of a wide range of models makes very clear, not all thematic analysis is the same. They identify two distinct 'camps' (p. 78). One camp comprises models of thematic analysis that are attached to a particular epistemology, and the other camp is made up of models that are theoretically independent. The model set out by Braun and Clarke sits firmly in the second, theoretically independent, camp. As such, it should be thought of as a method to be embedded into a wider methodological framework rather than as an entire methodology in its own right (Terry et al., 2017). The

advantage of this theoretical independence is that it allows reflexive TA to be used consistently within both essentialist and constructionist paradigms, so long as the wider methodological framework is consistent with the ontological basis of the research project in question (Braun & Clarke, 2006). In the case of this research, reflexive TA was selected because this theoretical flexibility allows it to be used consistently with the poststructuralist foundations of narrative practice.

Pivotal to research integrity is maintenance of theoretical consistency at every stage. Braun and Clarke (2006) argue that reflexive TA allows qualitative research to be done within its own paradigm, a significant point for research undertaken through the lens of narrative practice, by calling on Kidder and Fine's (1987) differentiation between:

1. small q research that is conducted according to realist assumptions by relying on quantitative practices such as triangulation, saturation, inter-coder reliability and prevalence as equivalent to significance as part of its claims to validity, and researcher neutrality. These concepts have no place in a constructionist paradigms as they depend upon the realist assumption of a singular or essential truth that can be objectively sought, identified and delineated (Braun & Clarke, 2018; Clarke & Braun, 2018); and

2. Big Q qualitative research that is conducted within its own paradigm by escaping the quantitative concepts and essentialist assumptions of small q research and embracing constructionist understandings, such as the inevitability of researcher subjectivity, as part of a wider recognition of multiple realities constructed within particular social contexts.

The conceptualisation of themes

Clarke and Braun (2018) state that by this definition reflexive TA is, when undertaken within a constructionist framework, Big Q research. Arguing against the legitimacy of saturation, triangulation, prevalence as equivalent to significance, and inter-coder reliability in

constructionist research, a fundamental point on which Clarke and Braun's case rests is their conceptualisation of themes (Braun & Clarke, 2016). In an essentialist paradigm themes are conceptualised as pre-existing entities which emerge from the data through meticulous and objective searching that, once found, will illuminate the true state of things (Braun & Clarke, 2016). When working within a non-essentialist paradigm, on the other hand, Braun and Clarke follow DeSantis and Ugarriza (2000) in conceptualising themes as constructions that are generated through rich engagement with the data by the researcher. The researcher is recognised as neither objective nor detached from the process, and acknowledgement of their inevitably active role is viewed as part of research accountability. This does not mean themes are arbitrary or unsubstantiated as they must tell a compelling story of the data (Clarke & Braun, 2018), and quality assurance strategies are embedded within the researcher's detailed familiarity and deeply reflective and recursive engagement with the data (Terry et al., 2017).

Two forms of theme generation and two types of theme

Braun and Clarke (2006) identify two forms of theme generation. Inductive themes build up from the data content and theoretical themes draw upon existing ideas and theories as a means of understanding and interpreting the data. As an exploratory study, this research used inductive reasoning to generate themes from what was contributed by participants, rather than using established theories as a starting point. However, we cannot entirely rid ourselves of our existing theoretical understandings and researcher exposure to a wide range of literature, ideas, practice understandings and lived experience will inevitably have contributed to what stood out, and how conclusions were arrived at.

Braun and Clarke (2006) also identify two types of theme. Semantic themes are descriptive and establish the terrain whereas latent themes illuminate discourses and contribute to an understanding of the structures and ideas that support and give shape to semantic themes. Latent themes speak to how experience becomes possible, theorising how it might be understood. This study generated both semantic themes (e.g. Theme 1: *Every single area of my life has been negatively affected by my anorexia*) and latent themes (e.g. Theme 3: *It's difficult to still be struggling with what's viewed as a teenage disease*) as a means of

describing participants' experience of living with anorexia in adulthood and theorising how that experience may be understood in relation to the systems, structures and discourses that shape our social world.

Practicalities of design

Alongside its theoretical independence and applicability for constructionist research, an additional advantage of reflexive TA is its practical flexibility (Braun & Clarke, 2006). In order to meet particular commitments of this research, i.e. the scope for diverse participation, and for the survey and interview questions to be informed by narrative practice ideas, it was necessary to utilise a research method that did not come as a prescriptive methodological 'package' with ready-made design choices. Unlike locked-in models like interpretative phenomenological analysis or narrative analysis, TA's flexibility provides enough practical latitude for pragmatic and context-specific decisions about data collection, sample size, homogeneity of participant, types of questions asked and methods of data collection, and so long as each decision remains theoretically consistent, researchers are free to shape and innovate their methodology according to the unique context of their research (Braun & Clarke, 2013). As such, reflexive TA was ideally suited to ensuring that the commitments of this research were not constrained by the analytic model.

Particular congruences of narrative practice and reflexive TA

The congruence of reflexive TA (Braun & Clarke, 2019) with the ideas, principles and practices of narrative therapy, and reflexive TA's suitability for research undertaken through a narrative practice lens, is further detailed and confirmed in a published interview with Prof Virginia Braun and Assoc. Prof Victoria Clarke, about the practical intentions, theoretical understandings, ethical commitments, and feminist heritages that underpinned the development of reflexive TA (Lainson et al., 2019). This paper identifies the following congruences of reflexive TA with narrative ideas

- Consistent with narrative practices of co-research by calling on subjective accounts and valuing insider knowledge.

- Invites researcher reflexivity and awareness of our own role in shaping the research.
- Escapes analysing individuals, highlights common experience, and illuminates wider contexts that make experience and meaning-making available.
- Remains close to participant accounts through integration of participants' own words in the reporting, keeping some context around those words.
- Requires close listening, lingering in the detail of conversations, and an awareness of what is 'absent but implicit' that makes the story knowable.
- Inclusion of rich, nuanced and complex descriptions, using rescued words.

(Lainson et al., 2019, p. 96)

Areas for ongoing researcher attention when utilising reflexive TA

Lainson et al. (2019) also identifies how using reflexive TA does not exempt narrative researchers from paying continued attention to key issues, including

- TA is a central part of the wider methodology but does not constitute its entirety. The researcher must make a range of decisions to ensure theoretical consistency at each stage, retain accountability for each decision made, and ensure the overall usefulness of the design for the intended goals.
- The six phases[6] alone don't address issues of power and privilege or bring marginalised experiences to the centre. The researcher needs to consider elsewhere in their design how this will be done.
- TA makes more sense of commonalities than of idiosyncrasies, so care is needed to ensure fair representation of diversity, without tokenism. It is important to consider how, given the researcher's theorising role, themes will be generated to accommodate diversity and represent a variety of perspectives.

(Lainson et al., 2019, p. 96)

[6] These phases are described later in this chapter.

Throughout this methodology chapter there has been detailed description of steps were taken to ensure alignment with narrative practice principles, how previously marginalised voices have been centred and what efforts have been made to accommodate and reflect diversity.

Conducting the reflexive TA

Reflexive TA follows a 6-phase process (Braun & Clarke, 2006, 2013)

1. Familiarisation with, and immersion in, the data
2. Generation of initial codes
3. Searching for themes - Clarke and Braun (2018) switches to generation of themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the final report

These phases, however, are neither rigid nor linear (Braun & Clarke, 2019; Braun et al., 2019; Lainson et al., 2019) and the process of coding of data and generation of themes has no inevitable outcome as a consequence of procedural correctness (Terry et al., 2017). This is an iterative, reflective and creative process in which the researcher plays an active and meaningful part (Braun & Clarke, 2006, 2016, 2019).

> Coding and theme development are assumed to be subjective and interpretative processes. This means the outcomes of these processes can be stronger or weaker, but they cannot be right or wrong in any objective sense. (Terry et al., 2017, p. 20).

The recursive, reflective and dynamic process of refinement continues until the researcher is eventually satisfied that the themes they have generated tell a convincing and well organised story of the data in relation to the research question (Clarke & Braun, 2013). Arguably, within a constructionist paradigm, theme generation could go on ad infinitum and it would not be possible to capture every potential meaning. Therefore 'the subjectivity of the researcher is seen as integral to the process of analysis' (Terry et al., 2017, p. 20) with

researcher analytic skills and engagement being key. Credibility is supported through the rigour that comes from rich engagement with the data, researcher visibility, transparency of approach, and theoretical consistency (Braun & Clarke, 2006). It is important to recognise that analysis begins the moment you begin to engage with the data (Braun & Clarke, 2013) and, in this study, my multiple careful readings of each survey response, conducting and accurately transcribing, re-reading and re-listening to interviews ensured my thorough familiarity with both the survey and interview data sets. As mentioned earlier, throughout the interviewing and reading of survey responses I kept a record of what I was noticing, as during the entire process of coding and theme generation.

The process of generating twelve richly described themes

The interview transcripts and survey responses were coded on a line-by-line basis. This was completed manually, without the use of dedicated software. Initially, highly detailed and idiosyncratic codes were applied, as a means of capturing nuance and specificity. Codes were then gradually and progressively reviewed, sorted and gathered within increasingly inclusive groupings in a recursive and reflexive fashion, as patterns were established within and across data items. Candidate themes were generated and reviewed for internal homogeneity and external heterogeneity until ultimately 12 final themes were established, each constructed around a central organising concept, that together told a compelling story of the data as it related to the research questions (Braun & Clarke, 2006; Clarke & Braun, 2018).

This process of coding to theme generation was tracked using tables so the data extracts that contributed to each theme could be easily traced to the original source, ensuring nuance, meaning and context were not lost. Examples of transcript coding (Appendix 12a) and the progressively inclusive grouping of codes are attached as Appendices 12b and 12c. Code groups that ultimately contributed to the generation of each theme are attached as Appendix 12d.

In line with narrative practice commitments to centring insider voices, privileging their knowledges, demonstrating multi-storied experience and evading standardisation, data

extracts were incorporated more numerously into the reporting than is commonly seen. This reflected the complexity of participant experience, highlighted nuance in their diverse responses, and aligned with an essential quality of reflexive TA, where participant words are not considered to be simply illustrative of themes, as in some forms of thematic analysis, but rather as constitutive of them (see Lainson et al., 2019).

An important aspect of research conducted within a narrative practice paradigm is that it does not discard contributions that misalign with the dominant story, or with common themes, but allows space for even the most marginalised voice. Consequently, although inclusive groupings were formed as a means of highlighting congruence and patterns of meaning, the following actions were taken to escape reductionism or homogenisation

- Prevalence was not equated with significance and themes were identified according to their apparent key-ness and significance in relation to the research question, rather than their frequency or dominance (Braun & Clarke, 2006).

- In the reporting, themes were richly described to retain nuance, incorporate incongruence, and accommodate complexities within them (Braun, Clarke, & Weate, 2016).

- Care was taken to ensure that multiple diverse voices were incorporated into the reporting (Teusner, 2016).

Themes were then named in alignment with Braun and Clarke's (2006) recommendation that data extracts should be used as a means of capturing some of the theme's essence, and also following the feminist precedent utilised by Wilkinson and Kitzinger (2013) in using participants' own words to name themes. This was also consistent with the narrative practice of rescuing words and centring the voices, and meanings, of the people we interview.

CHAPTER 4. RESULTS

4.1 Structure of the results

Having established the rationale and theoretical lens of the Enduring anorexia project and described and explained the steps taken to conduct the research, this chapter now sets out the results of the online survey and interview. It does so in three parts:

i. The survey. Completion rates, participant demographics, and a summary of responses are detailed.
ii. The interviews. A profile of the interview participants is described.
iii. The themes. The 12 themes are initially summarised and tabled, with their key points identified. Each theme is then richly described, foregrounding participant rescued words from which they were constructed.

4.2 The survey

In this section, a descriptive account of participant demographics and engagement with the survey questions is provided alongside illustrative figures. No statistical analysis has been undertaken nor is any claim made that participants' responses encapsulate the entirety of the experience for them, or others. Numbers are used only to paint an overall picture of the participant cohort, the experiences they reported, and their engagement with the study, not as a means of quantifying them.

Question completion rates

There was a total of 96 survey respondents but, as the survey contained no compulsory questions, response rates for individual questions varied considerably. The open-ended and later questions had lower response rates than the earlier, demographic and closed questions. All primary questions were answered by over half, and more often closer to two-

thirds or three-quarters, of participants. Those with a lower than fifty percent response rate were supplementary questions that invited optional, additional details. Responses to the open-ended questions varied considerably in length and style. Some participants wrote briefly, just a few words or a line or two, some succinctly listed their main points, while others wrote extensively.

Survey participant demographics

Participant age

There was participation from all specified age groups, tailing off toward the upper age range, possibly due to reduced likelihood of social media use, less personal identification with the topic, or not having survived into old age.

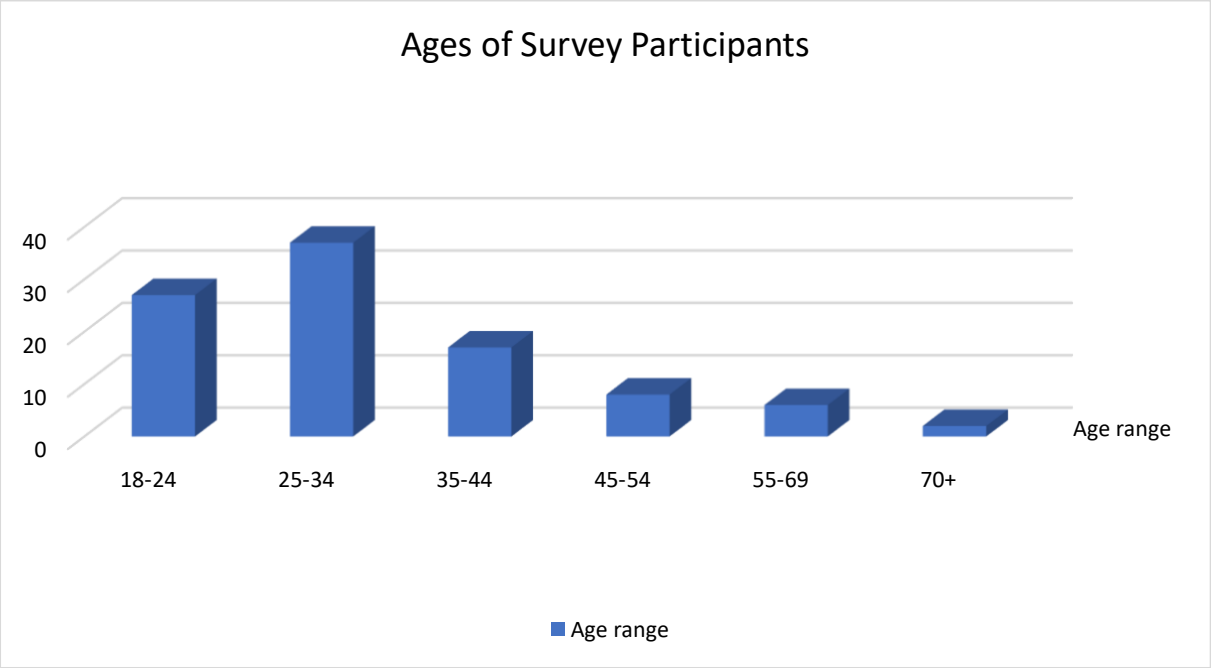


Figure 1 Age of survey participants

Participant gender

Participants were invited to identify their gender using their own words. Ninety-two identified as female, two as male, one as *'male (but in a queer way)'* and one as Takatāpui[7]/transmasculine. There are many potential reasons for predominance of female

[7] Takatāpui is a New Zealand Māori word which originally referred to close same sex friendships. Although going out of general use for some time it has recently been reclaimed by Māori LGBTIQ+ communities.

participation, including the possibility of higher rates of experience, greater likelihood of personal identification with the topic, a consequence of the circulation strategy, but none can be assumed from the information made available through this study.

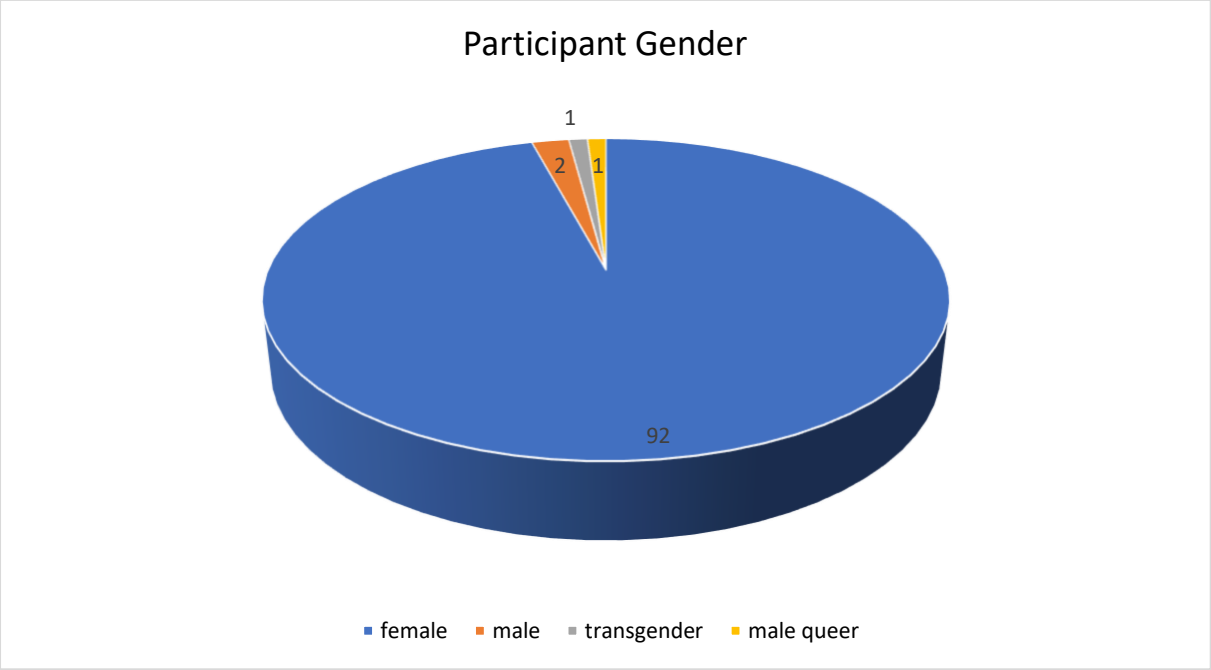


Figure 2 Gender of survey participants

Participant ethnicity and country of residence

Again, participants were invited to use their own words to describe their ethnicity. This was described in a variety of ways, but only 8 participants did not mention being White, Caucasian and/or of European extraction as at least part of their ethnicity. Three Australians and 3 New Zealanders used their country as an identifier with no reference to Indigeneity or otherwise, and 4 New Zealanders identified as Māori. Three Māori participants identified dual ethnicity, being also European or Pākehā. One participant identified as NZ Māori. Other ethnicities that combined with European included South African, Kuwaiti, Sri Lankan and Eurasian. Two participants identified as Greek, which is understood by many people as European, but by others as Middle Eastern. Participants resided across 12 countries with contributions from Europe, the Middle East, South America, North America and Australasia.

Ethnicity		Ethnicity	
Australian	3	Māori & European/Pākehā	3
Australian Caucasian	2	NZ Māori	1
British	3	New Zealander	3
British White	11	NZ European/Pākehā	16
Eurasian	1	None	1
European White	7	Scottish White	1
German	2	South African & European	1
Greek	2	Sri Lankan & Caucasian	1
Irish	1	White/Caucasian	34
Kuwaiti & British	1	Skipped question	2

Figure 3 Ethnicity of survey participants

Country of residence		Country of residence	
Australia	8	Ireland	1
Belgium	1	Kuwait	1
Chile	1	Scotland	2
England	8	New Zealand	34
France	2	UK	12
Germany	2	USA	22
Greece	2		

Figure 4 Country of residence of survey participants

Because some participants spent time living in more than one country, the one most associated with their ethnicity *and* their current residence are shown in Figure 5, illustrating the combined extensive global influence on the results of this study. The Eurasian contribution could not be depicted as only counties were included, not global regions.

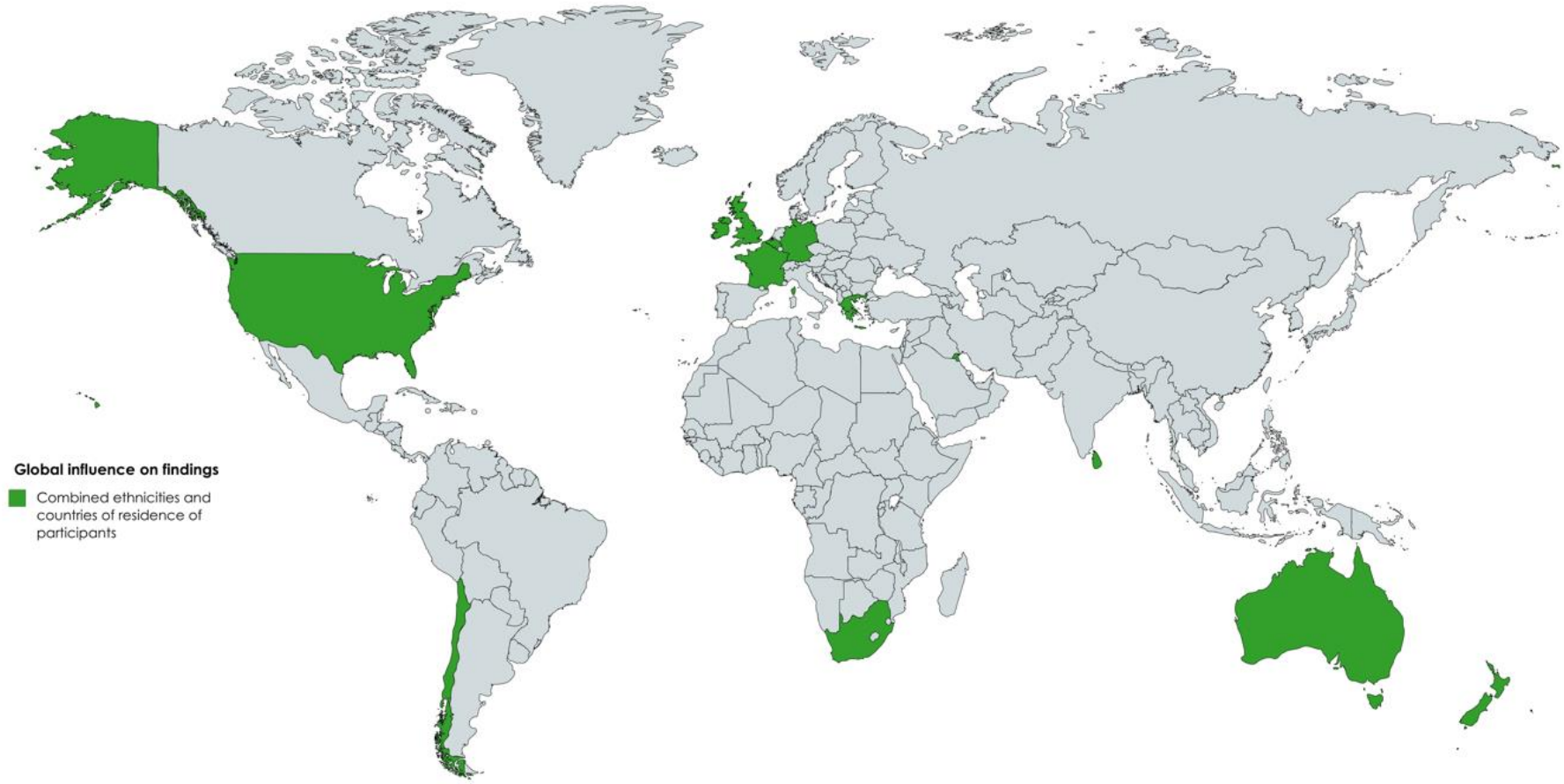


Figure 5 World map of international influence

Presence and influence of anorexia

Anorexia's duration in participants' lives was stated as ranging from less than 5 to over 20 years. Whilst having no statistical meaning, it was nonetheless sobering to notice that participants' combined contributions represented 1,291 years' experience of anorexia. Marginally less than half experienced anorexia as a consistent presence in their lives, with slightly over half naming anorexia's fluctuating influence throughout their lives. Twice as many participants reported anorexia as currently influential in their life as those who reported its influence as being in their past. All but 16 participants had received a diagnosis at some point in their life, although it became apparent during the interviews that this may have been when they were much younger. Roughly two thirds used the word anorexia to describe their experience, with just over a third using different words, but still relating to common understandings of anorexia.

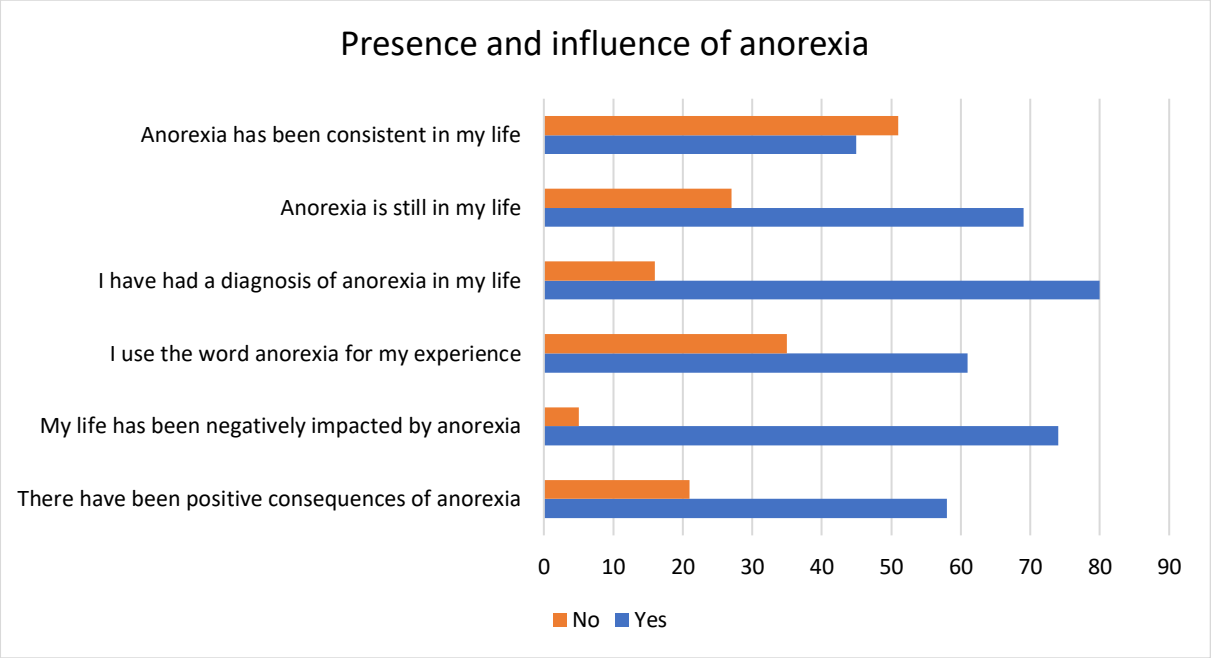


Figure 6 Presence and influence of anorexia

Anorexia's effects on participants' lives

The vast majority of participants who responded to questions about the impacts and consequences of anorexia identified negative effects, whereas only 5 stated there were

none. On the other hand, 58 reported positive consequences with 21 reporting no positive consequences of living with anorexia over time.

Stigma, prejudice and/or disadvantage

Experiences of stigma, prejudice and/or disadvantage as a consequence of anorexia's effects or others' attitudes were reported by between a third and just over a half of participants. Details of these experiences become apparent in the richly described themes

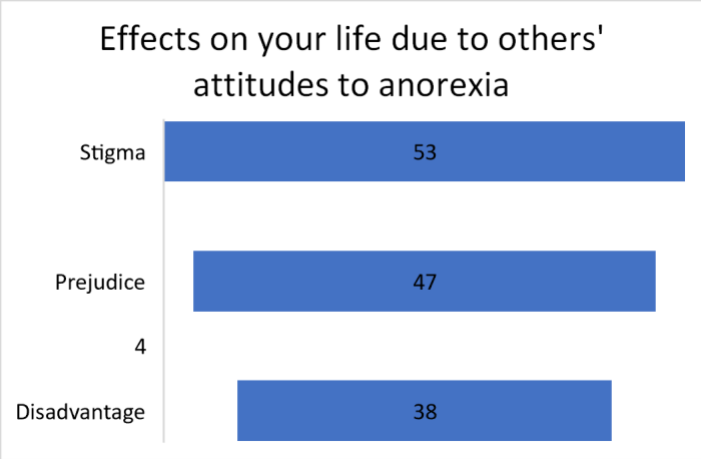


Figure 7 Reported stigma, prejudice and disadvantage

Responses of others

A more detailed enquiry about others' attitudes and responses suggested categories generated from practitioner/peer support conversations I have had with people experiencing a wide range of responses from others, and an additional space for alternatives. Participants painted a complex picture of receiving support from family, friends, employers/educators and health professionals, as well as anger or interference, and there were several reports of people in each category 'walking away'.

How others have responded to the anorexia's presence in your life							
	Parents	*Brothers & sisters*	*Own children*	*Romantic or intimate partners*	*Employers or education providers*	*Friends*	*Health professionals*
By being supportive	49	31	6	37	28	55	48
By expressing worry	62	39	5	34	24	56	49
By getting angry	45	25	2	25	5	23	11
By giving unwanted advice and interference	40	15	2	21	17	26	26
Walking away	16	12	2	13	10	38	12

Figure 8 Responses from others

Accessing help and/or support

When asked if they would like help or support, not everyone responded but roughly two thirds of participants reported having sought support at some time, with only 8 having never done so. Sixteen stated they did not want help or support, whilst 50 said they would like support and offered suggestions for what would be useful to them.

Participant suggestions for support

These included

- a choice of specific therapeutic approaches
- a preference for the therapeutic approach to be non-judgemental
- services that are accessible and practical to attend
- opportunities for social connections
- financial support
- respite care, support groups

- occupational therapy
- understanding from others
- nutritional and cooking advice
- opportunities for re-integration into social, educational and work activities
- services specifically designed to suit adults
- improved transitions from in-patient treatment to home.

Participant recommendations for preferred therapeutic approaches and service provision are addressed further in the richly described themes and in chapter 5, the discussion.

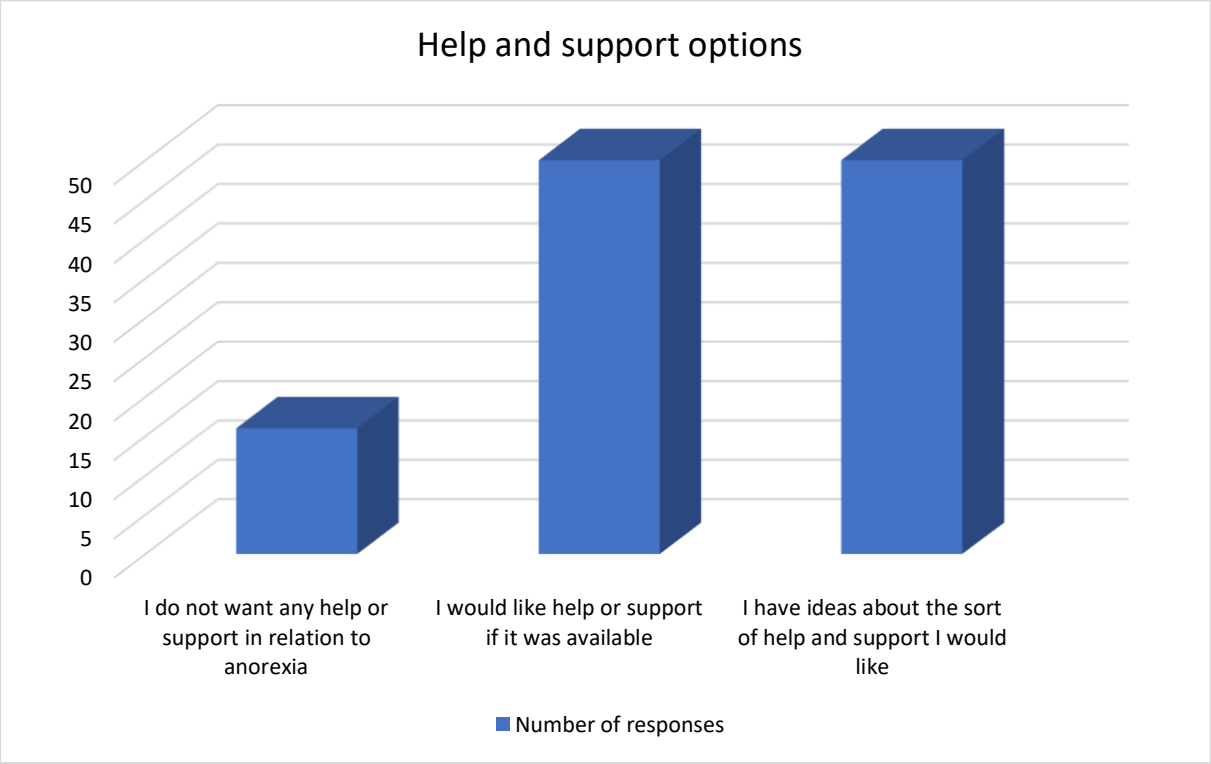


Figure 9 Help and support options

Barriers to accessing support

Despite many participants wishing for support or help of some kind, a myriad of barriers to doing so were identified. Only 9 participants stated they had experienced no barriers, and later responses introduced the possibility that for some participants this barrier-free route had been imposed upon them as compulsory treatment against their will, sometimes earlier in life. However, a few did speak of easily gaining access to sought-after support.

The vast majority who responded to this question had experienced at least one, and more often several, barriers. Categories of barrier enquired about in the survey were selected based on my practitioner and peer support conversations, and participants identified many additional barriers.

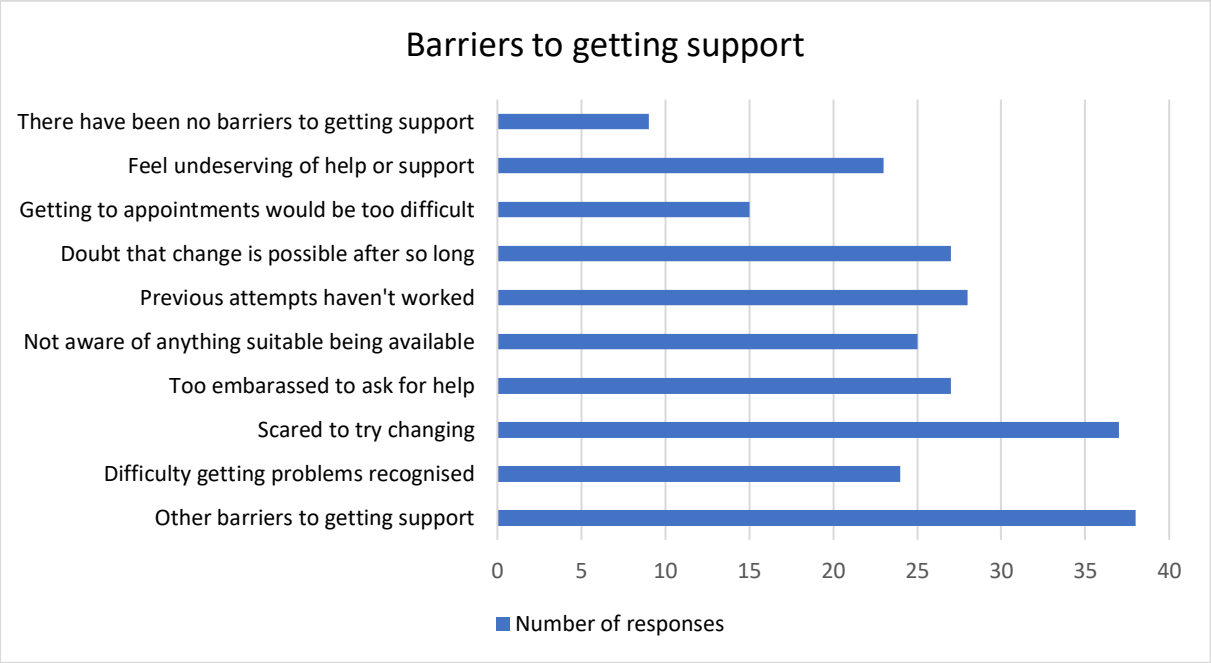


Figure 10 Barriers to getting support

Participant-named additional barriers to accessing help or support

As well being invited to select from researcher-identified suggestions about barriers to gaining support, participants were provided with the additional option of identifying other barriers they had experienced. There were many additional barriers that became apparent this way, including

- lack of choice in therapeutic approaches provided
- lack of family support in engaging with treatments
- the potential for negative effects for their career or professional standing
- fear of being involuntarily admitted again
- multiple diagnoses creating problems for service providers
- myths and misconceptions that others held about anorexia and whose lives it affects

- not enough hospital beds and long waiting lists
- long travel distances to services
- lack of understanding of complexities of transgender health
- difficulties getting time off work
- personal decision to reject the world
- having exceeded the allocated number of counselling sessions
- services only accepting the most extreme cases
- cost of private therapy
- older service users and those labelled 'chronic' being considered less favourably by services
- lack of time and energy to engage in exhausting and fallible treatments
- insurance policies that provide insufficient cover
- not being considered ill or thin enough for treatment by service providers.

The open-ended questions

The above sections summarise participant responses to the closed survey questions. In addition, 12 open-ended questions (Figure 11) allowed participants to write their responses freely in a comments box. Responses to the open-ended questions contributed to the development of themes, and the table below shows response rates for each question.

Participant response rates to open-ended questions	
Q12 If you answered 'yes' to question 11, what are the positive consequences (of living with anorexia)?	57
Q13b (*Whether or not they know about the anorexia, how have other people reacted to anorexia and/or its effects on your life?*) If you would like to include other responses, please write about them here.	21
Q14b Details of experiences of stigma, disadvantage or prejudice.	31
Q15 What would you say are the biggest, or most important, challenges or negative effects of living with anorexia for a long time?	75

Q17 What was it that you did (to reduce the effects of anorexia)? If you can think of several things, please feel free to write about as many as you wish.	56
Q18 What supported you in doing this?	55
Q19 When you took this action, what was more important to you than anorexia?	55
Q20 Is there anything you do, or have done, that helps you get through difficult times as a result of anorexia?	59
Q22b (*Are there any barriers to getting support?*) Other (please specify).	38
Q23b Please provide details of what sort of support would be useful to you.	50
Q24 Has anyone ever done or said anything especially helpful with regard to your experience of anorexia? If so, please can you give details.	54
Q25 Is there anything else you would like the researcher to know?	41

Figure 11 Survey response rates to open-ended questions

4.3 The interview participants

Following completion of the survey all participants were invited to supply contact details should they wish to take part in a follow-up interview. All participants who provided contact details were interviewed, and the table below provides demographic information about each of them. One person has been included in the demographic data but not in the construction of themes, although their story was the focus of an interview. This was Faye, who was recently deceased, and whose daughter requested an opportunity to speak about Faye's experiences on her behalf. A summary of the interview about Faye is provided in the discussion chapter, as Box 1. Despite not meeting inclusion criteria for thematic analysis, due to it not being a first-hand account, the interview about Faye's life did align with other aims of this study. It made an important contribution to thinking about diversity, as well as raising questions about how we might recognise and respond to lifelong experiences of anorexia in elderly populations and aged care settings.

Profile of Interview Participants							
	Age	**Gender**		**Ethnicity**	**Years lived with anorexia**	**Current or past experience**	**Past or current diagnosis**
Isobel	25-34	female	France	White	16	current	yes
Amelia	18-24	female	England	White British	6	current	yes
Marian	35-44	female	New Zealand	White European	32	current	yes
Diana	35-44	female	UK	White British	11	current	yes
Adrian	25-34	male (but in a queer way)	New Zealand	Pākehā/Māori	11	current	no
Hayley	25-34	female	Australia	Caucasian Australian	5	past	yes
Emma	25-34	female	Australia	Caucasian	14	current	yes
Najida	35-44	female	Kuwait	British/Kuwaiti	27	current	yes
Ruth	45-54	female	New Zealand	New Zealander	38	current	yes
Jules	25-34	female	Scotland	White Scottish	15	past	yes
Candice	25-34	female	New Zealand	NZ European	5	past	yes

Elspeth	35-44	female	UK	White British	20	current	yes
Zinnia	18-24	female	New Zealand	South African European	3	current	no
Allie	35-44	female	USA	Caucasian	17	past	yes
Steph	35-44	female	New Zealand	NZ European and Māori	26	current	yes
Sophie	18-24	female	New Zealand	NZ Pākehā	12	past	yes
Ryder	25-34	female	USA	White	9	past	yes
Lin on behalf of Faye	70+ now deceased	female	Australia	Caucasian	lifelong	from youth to end of life	no
Danielle	18-24	female	New Zealand	NZ European	4	past	yes
Bethany	25-34	female	New Zealand	NZ European	10	current	yes
Rose	35-44	female	New Zealand	Pākehā	20	past	yes
River	18-24	Takatāpui/transmasculine	New Zealand	NZ Māori	7	past	yes
Moira	25-34	female	New Zealand	NZ European	16	current	yes

Figure 12 Profile of interview participants

4.4 The themes

Twelve themes were constructed from a combination of survey responses and participant interviews. Without claiming to capture the entirety of experience for all persons living with anorexia over time, the 12 themes bring into focus key features that link participants' descriptions of life, as they relate to the research questions. Following the precedent of Kitzinger and Willmott (2002), and aligning with narrative practice principles of staying experience-near and using rescued words, themes were named using participants' own words either by rescuing a direct quote or, in some cases where no single quote entirely captured the richness of the central organising concept, a composite of rescued words from several participants.

For ease of reference, a summary of the 12 themes and their key points is tabled in Figure 13. This is followed by rich descriptions of each theme. In line with constructionist thematic analysis and narrative practice and feminist commitments, participants' words and accounts centred with my researcher voice minimally narrating, creating links, highlighting patterns and weaving together the words and expressions of participants. Where two or more participant quotes are included it is neither to denote prevalence nor emphasis, but to richly describe nuanced and multi-faceted experience. There were many, many more data extracts that contributed to the construction of themes than could possibly be included in one thesis as participants were so generous and insightful in their contributions, so significant effort went into ensuring that rescued words in the themes drew widely to allow diverse participant voices to be heard. In a few instances, rescued words have been re-cited elsewhere in the thesis, such as the discussion chapter. This is where they capture an essence or demonstrate an aspect of a theme particularly well, and cogence and relevance have been privileged over novelty.

Participants' rescued words are incorporated not just as being illustrative of each theme, but as constitutive of them (see Lainson et al., 2019). Great care was used to ensure that participant interviews were transcribed accurately, and careful attention given to the contextual stories that gave meaning to the extracted phrases. However, it is important to recognise that there is no way to simply 'give voice' to participants' meanings and as

researcher I played an active role in making selections and interpretations (see Fine, 1992; Lainson et al., 2019). Survey responses are included as they were written, with typographical inconsistencies neither 'ironed out,' nor emphasised by the repeated use of *(sic).* Data extracts have not been ascribed to individual participants in the reporting but are presented collectively. This is not to homogenise; incongruences are clearly visible within themes, but in alignment with principles and practices of narrative and collective narrative practice that seek to connect lives around shared knowledge as part of overcoming the isolation of hardships endured, and link experience in ways that de-individualise/de-privatise pain, making more visible how broader social contexts contribute to the lives of problems, and what future action might be taken as a consequence (see Denborough, 2008; Lainson, 2016; Madigan & Epston, 1995). At the end of each richly described theme there is a corresponding figure showing how groups of coded data extracts contributed to the construction of the theme. Code groups were named to capture essences and patterns within and across participant contributions as a means of supporting me in constructing cohesive themes and consistent with a reflexive process of establishing a compelling story of the data (Braun & Clarke, 2006, 2019; Lainson et al., 2019)

Summary of the themes

Theme 1: *Every single area of my life has been negatively affected by my anorexia*

Theme 2: *It's a very lonely singular experience*

Theme 3: *It's difficult to still be struggling with what's viewed as a teenage disease*

Theme 4: *The road to actually getting treatment for anorexia is difficult … there are a lot of barriers along the way*

Theme 5: *I don't paint it in a fully negative light*

Theme 6: *What you learn if you get out the other side is amazing*

Theme 7: *It's what you do to get around it*

Theme 8: *Finding distractions, escapes and therapeutic practices*

Theme 9: *Seeking connection and taking up activism*

Theme 10: *Doing research, exploring feminism, and embracing the 'new and different'*

Theme 11: *Recovery is more nuanced than currently portrayed*

Theme 12: *Connection, community and 'being got' matter*

Theme	Key Points
Theme 1: *Every single area of my life has been negatively affected by anorexia*	• Any and every aspect of life can be disrupted by anorexia • Some, many, none or all aspects of life can be disrupted • Disruptions can have profound consequences over time • Disruptions are often complex, nuanced and interwoven • 15 domains of life were spoken about • Individual differences and commonalities
Theme 2: *It's a very lonely singular experience*	• Socially and emotionally isolating • Adult experience of anorexia often misunderstood, invisible or erased • Anorexia itself benefits from isolation
Theme 3: *It's difficult to still be struggling with what's viewed as a teenage disease*	• Anorexia spoken of as commonly perceived to be only a teenage girls' problem • Such limited representation impacts unhelpfully on others and own perceptions and responses to the experience • This leads to difficulties with services
Theme 4: *The road to actually getting treatment for anorexia is difficult … there are a lot of barriers along the way*	• There are many practical and personal challenges to accessing services • Lack of appropriate service provision • Strong personal advocacy skills are frequently required, but may not be possible
Theme 5: *I don't paint it in a fully negative light*	• Some aspects of anorexia may be valued or appreciated • Valued or appreciated aspects provide some amelioration and possibly some justification for anorexia's continued presence
Theme 6: *What you learn if you get out the other side is amazing*	• The experience of anorexia followed by recovery is viewed by some as beneficial to personal development • Recovery spoken of as an active process of personal transformation and shifting priorities

Theme 7: *It's what you do to get around it*	• Participants were knowledgeable about the operations of anorexia in their lives • Participants strategise to live as they would prefer • Participants use skills in managing life around anorexia • Participants use skills in managing anorexia
Theme 8: *Finding distractions, escapes and therapeutic practices*	• Participants engage in a wide range of practices and activities to transcend anorexia and its effects • The simple things in life are often the most helpful
Theme 9: *Seeking connection and taking up activism*	• Despite the isolating impetus of anorexia, participants actively sought connections with people, values and issues of importance to them • Connections with others had to be made discerningly • Activism and social contribution were important to many participants
Theme 10: *Doing research, exploring feminism, and embracing the 'new and different'*	• Participants were active in learning and researching about anorexia and recovery options • Several participants found usefulness in exploring feminism and body positivity movements • Several participants found engaging with alternative philosophies and lifestyle practices helpful
Theme 11: *Recovery is more nuanced than currently portrayed*	• Recovery was thought of in many different ways • Recovery was a focus for some, but not for others • Difficult messages about long-term experience can invite loss of hope for recovery • Limited representations of recovery were found constraining and problematic
Theme 12: *Connection, community and 'being got' matter*	• Many participants found usefulness and sustenance in connections with people, communities and important values and ideas • Being properly understood was important and helpful, but rare • Varied forms of connection with people with similar experience were considered valuable and supportive • Discourses of people living with anorexia being harmful to one another were constraining

Figure 13 Summary of key points for the 12 themes

Theme 1: *Every single area of my life has been negatively affected by my anorexia*

The theme of anorexia causing disruption to multiple domains of life is by far the most extensive in this thesis. Accounts of disruption permeated both the survey responses and interview conversations, which described how the effects of anorexia had become entwined with participants' lives. Much consideration was given to whether the extent and varied foci of these accounts of disruption allowed them to constitute a single theme at all; the risk being that it was actually a collection of smaller, separate-but-related themes, or what Braun and Clarke (2016) call a 'domain summary,' (p. 740), i.e. a disparate collection of responses describing a terrain but lacking a 'central organising concept' that provides coherence (Braun & Clarke, 2006, p. 94). Attendant to this concern was Braun and Clarke's case for the division of larger themes into sub-themes to be used sparingly, and only where sufficiently clear distinctions exist between the sub-themes to justify their separate categorisation, whilst simultaneously retaining close enough ties for them to be gathered together under a single umbrella (Braun, Clarke, & Rance, 2014).

After numerous attempts to either arrange the different accounts of disruption to varied domains of life under separate thematic headings, or else morph the entire concept of disruption into one richly described category, it became apparent that the most effective way of illuminating the experience of anorexia shared by participants was to highlight its extensive and dominant presence. This was best done by naming a single theme of disruption to life, though to speak of disruption in general terms would have been a significant injustice, given the distinct descriptions of how anorexia could become so completely entwined with multiple aspects of a person's life that it altered its course and dictated the minutiae of daily living. Thus, an expansive, intricate and complex theme more fully reflective of the potential for anorexia to influence or affect a person's life was called for. Consequently, Theme 1: *Every single area of my life has been negatively affected by my anorexia* is long, complex and divided into sub-themes.

The sub-themes identify fifteen different domains of life identified by participants, and it is difficult to think of anything that would not fit into one of these domains. Some participants spoke of every area of life being affected by anorexia's influence, while others listed specific

areas of life. No conclusions are drawn about the entirety of any individual's experience, but what became evident was anorexia's potential to disrupt and dominate life sufficiently to alter it in far-reaching ways over time.

Before describing the domains, it is pertinent to address that an appreciation for multiple realities based in poststructuralism holds every personal account as important, and an ethic of attending to marginalised voices is a commitment to ensuring participants' stories that diverge from the dominant theme are not erased (Lainson et al., 2019). No theme is ubiquitous, but the extent and dominance of this particular theme is such that disruption to life could easily be assumed as a common, or even defining, feature of a life influenced by anorexia. To risk such an assumption would be to misalign with the epistemological stance and ethical commitments of this research. In fact, a small minority of participants did state that anorexia had no negative effects on their life. There is challenge in providing equitable time, space and attention for this small number of expressions of absence, insufficient to construct a richly described separate theme on their own, against a tide of expressions of strong presence. This challenge is accentuated by the brevity of these contributions which amounted to written survey responses of *'No', 'nothing'* and *'there are no disadvantages.'* Nor did these participants opt to be interviewed. These brief responses were almost invisible and could easily be missed, or it might be tempting to skip over them considering them such a rarity as to be inconsequential, or too briefly described to make any meaningful contribution. But, prevalence does not equate to significance in a constructionist paradigm, and in research informed by narrative practice it is essential to appreciate multiple realities and acknowledge rich diversity of experience and perspective (Braun & Clarke, 2006; Braun et al., 2019; Lainson et al., 2019).

There is also the chance that, supported by the overwhelming evidence that anorexia does disrupt many people's lives extensively and longstanding discourses of people living with anorexia lacking awareness of their plight (Bruch, 1978; Konstantakopoulos, Tchanturia, Surguladze, & David, 2011), one might even be drawn to the idea that these few participants are so enraptured by anorexia that they are blind to its disruptive influence or are minimising their own negative experience as part of the problem itself. While acknowledging that perspectives can be fluid, and sometimes change over time, this would

be a problematic act of subjugating insider knowledge (see M. White & Epston, 1990), and the simple clarity of these participants' statements *must* be respected as truthful, cognisant accounts of personal experience. The decision to bring these accounts into focus up front at the beginning of the theme, rather than as a cursory addendum, was meant as a way of attending to their relevance in portraying a complex picture of what it is like to live with anorexia over time.

The dominant theme of disruption to life should be read in the light of knowing that this is not the only story.

The majority of participants expressed that anorexia had multiple significant, often profound, disruptive impacts on many areas of life.

> *"I no longer can live a normal life as my body weight is so low I have energy for nothing. I stay at home all day."*

> *"It has controlled the majority of my lifetime and I am unable to do many things I dreamed of and would have liked to do"*

> *"The feeling of living a 'limited capacity' life"*

> *"But, yeah, my life with anorexia there's nothing in it. It destroys everything. It's an existence, it isn't a life and I think I probably… I wanted more from me than that… yeah."*

Several spoke of anorexia's centrality to how they lived their lives that was restrictive and resented.

> **"***My life is controlled by anorexia. I follow a strict, mundane routine, existing but not really living. I have limited energy to do all the things I want to. I am unable to have a career. I am a recluse except for visiting family and a trip to town once a month. I've given up hope of ever getting better."*

"Overall, anorexia rules your life, making you a shell of who you were and a virtual hermit."

"It becomes the navigator of all life decisions"

"I don't think people really understand the constant voice in your head situation that is like having someone telling you what to do all the time. I know it's your head, but it doesn't feel like it. It feels like having someone sitting on your shoulder saying, 'You've got to do this, you've got to do that.' And you've got to please them all the time."

Anorexia was noted to affect multiple aspects of life, often seeping pervasively and disruptively throughout the entirety of a person's world, with some participants reporting that no area of life remained untouched.

"Anorexia wrecks your body, mind and life"

"All areas of my life, I had a cardiac arrest, spent years in and out of treatment, lost friends, exhausted my family's patience and financial resources"

"My relationship with my husband is much more difficult due to my anorexia. My children worry about me and I hate that. I am a 2nd grade teacher and I don't socialise with the other teachers because it always involves food, so I'm terrified. My friendships and parent relationships have been affected. Every single area of my life has been negatively affected by my anorexia"

"You've got the mental and the physical and you know, my mental state is pretty terrible. But having the physical, wanting to do things and not being strong enough or feeling dizzy... When keeping going you've got different problems, it's coming at you at all levels."

These broad-ranging effects were spoken of in terms of their mounting costs and increased significance over time.

> *"I've had a very hard time and I think it's destroyed my life over the years. You don't notice it until it's too late, but when I look back now I've changed so much as a person. It just changes you, you don't feel like yourself anymore and you don't know how to get yourself back."*

Losses of relationships, opportunities, the physical and financial costs were all lamented, and stakes were spoken of as increasing over time.

> *"When I relapsed it did put my marriage at risk and obviously that wasn't around when I was a teenager. The stakes felt a bit higher in some ways because it wasn't just my life I was destroying, it was my husband's as well. I think being an adult you're probably held more accountable for that than when you're a 13-year old."*

> *"I've got so many more stakes now with education and income."*

> *"Definitely as I've got older I realise this doesn't come for free and I notice my energy levels. I just can't manage them if I'm going through a harder period and I think that comes down to what we were talking about before. Without knowing it you reduced your activity and responsibility when you were starving but when you need to do the same amount of things every day you just have to get really tired. Because you can't just choose to go, 'Oh, I'm going to back off and expend a bit less energy in life'. And it's things like teeth, that you thought were always going to be ok and now they're not."*

The sub-themes: Fifteen domains of life

By way of creating sub-themes, I identified[8] fifteen separate domains of life spoken of by participants as significantly disrupted by anorexia:

i. social connections
ii. intimate relationships
iii. family
iv. physical wellbeing
v. mental health
vi. education
vii. career
viii. finances
ix. practicalities of daily living
x. time and attention
xi. life experiences and opportunities
xii. hopes for the future
xiii. sense of self and identity
xiv. cultural engagement
xv. religious faith.

[8] It is not claimed that these domains were natural or pre-existing entities. Rather, as with themes, these sub-themes are reflexively produced constructions of the researcher.

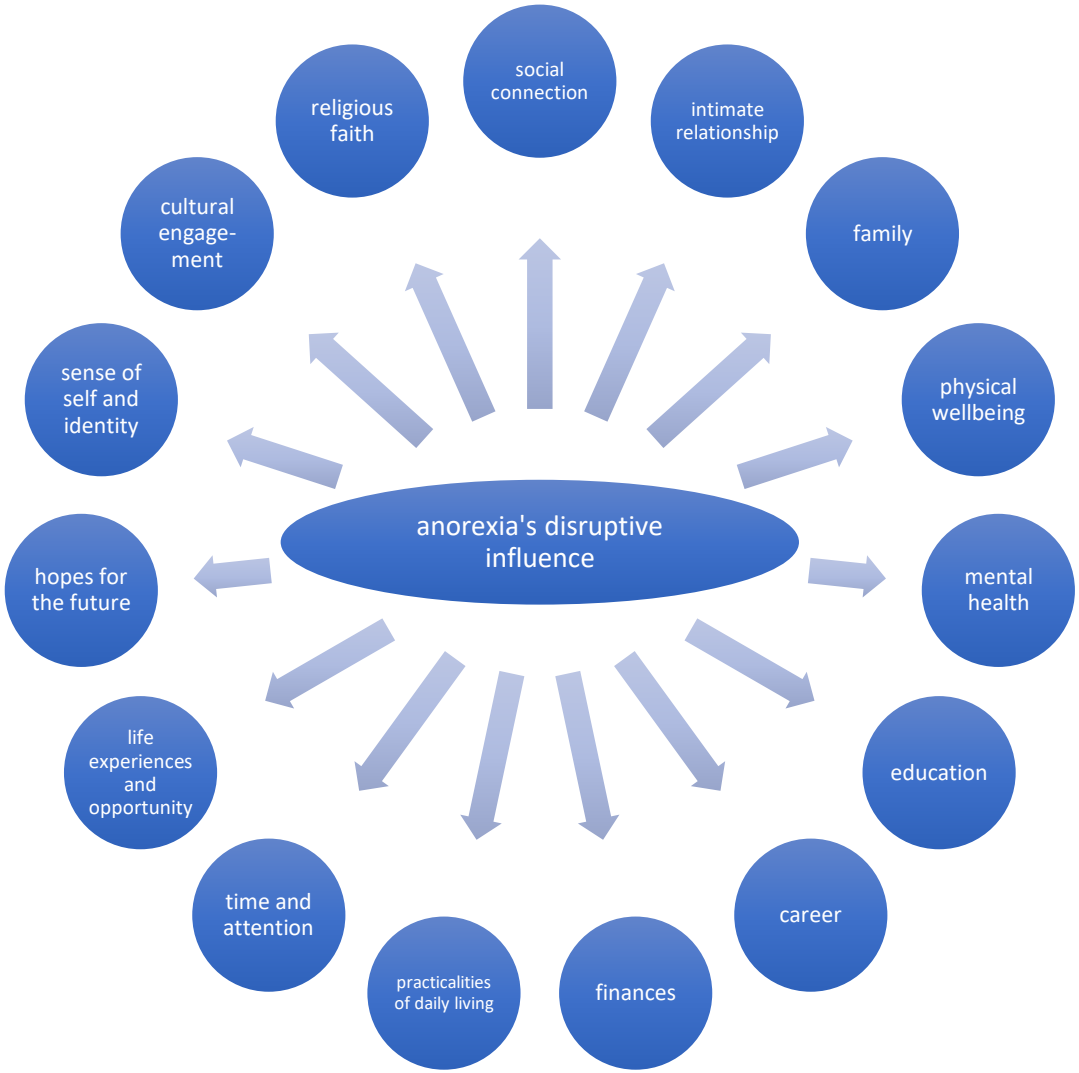


Figure 14 Illustrating anorexia's disruptive influence

i. Social connections were frequently regarded as eroded or completely absent due to anorexia. Even casual friendships, association with work colleagues or participation in group or social activities were often spoken of as difficult, if not impossible. Taking part in activities required substantial planning, involved distress, or created embarrassment; all sufficient to prevent repeat participation. The practicalities of managing expectations to eat in public, the need to adhere to strict routines, physical exhaustion and offence taken by others due to the very private nature of the experience of anorexia necessitating excuse making, all contributed to the disruption.

> *"Loss of friendships-lack of energy to go out and upkeep a social life."*

> *"became completely withdrawn from social events involving food, still experience significant distress and I have to plan in advance what I'm going to eat that's socially acceptable and minimally distressing"*

> *"You want to isolate yourself because you want to be able to do what you need to do around food and that means not socialising and going out with your friends, or if you do you have the consequences of having to purge whatever you've done, so it makes you not want to be with anyone."*

> *"My friends came to my door and I had to tell them to go away and I felt awful about it, because they were hurt and confused. There's one friend who lives in another state, so we can maintain that connection that way, but I do find myself cutting people out because of my routine, but also there's nothing to say. I don't have anything in my life. I work and sit with this disorder."*

Younger adults told how interruptions to school and university for treatment led to discontinuity of friendships and difficulty creating connections. Several also felt their disrupted lives resulted in them being different to, or at a different life-stage than, their peers.

"It also felt like I wasn't really an adult when I was living with it. Because I was unwell when I was 16 and I was still unwell into my early to mid-twenties, I think for that period I felt very childlike and I didn't feel like an adult."

Some of this sense of difference was said to have preceded anorexia, but many also spoke of it as a consequence of anorexia's presence or of being due to the unusual experiences they endured, such as spending time in psychiatric hospitals or being held under mental health laws against their will. These experiences were spoken of as a trauma that altered their sense of themselves and their sameness with others over the long term.

"My earliest memory of any kind of irregularity or thing that was different about me was that I didn't feel like I had a personality. All the other kids at primary school were like, Chloe or Sam, they had who they were. But I was a really messy concept, and that's continued throughout my whole life."

"I still struggle with that having, you know, friendships and relationships and other guys and things like that so, you know, that's a huge missing piece."

"I still struggle to connect with people socially and figure out appropriate emotional boundaries with those that do not know my history. This has led to a lot of isolation and made it difficult for me to interact with "normal" people at school or in the workplace."

There was mention of being treated differently by others who knew they were living with anorexia and who 'spoke to the eating disorder' rather than to the person, creating a further sense of disconnection.

"I think the disorder is very isolating both due to my own actions, my inability to partake in social activities outside of my disordered routines/rituals. I have also found it to be incredibly isolating in that over time people start to interact not with me the subjective individual, but with my disorder."

ii. Intimate relationships have been categorised somewhat broadly here, to mean strong or special friendships, as well as romantic, marital or sexual partners. This is intended to embrace a nuanced appreciation of what intimacy can mean to different people and escape dominant ideas about what distinguishes some relationships as closer or more important than others. Intimate relationships are considered those which go beyond acquaintanceship, casual friendship and social inclusion.

Some participants did speak of important people in their lives and of relationships that had developed during, or had readily withstood the challenges of, anorexia's influence, but many also spoke of difficulty. Stories of close friendships, marriage, supportive partners and relationships considered worth saving were often recounted within a framework of anorexia having created considerable challenges, or of having strained those relationships.

> *"My relationship with my long-term partner has suffered and we are no longer intimate"*

> *"Relationship struggles-unstable blood sugars as a result meaning I often get frustrated and grumpy if I haven't eaten."*

> *"For me, the conflict it causes in relationships and the worry that you will eventually drive people away"*

> *"It changed our relationship from one where we were husband and wife to he, at times, was carer/ more of a parental figure. That was something that definitely wasn't around when I had anorexia as a teenager and as a younger person. And that was something that was very difficult to navigate and could very easily have destroyed our relationship, definitely."*

Some important relationships were even put at risk.

"Yeah, even if I'm having bad days now they understand it's not me not wanting to talk to them … At first, they didn't get it at all and we had quite a bit of friction."

"Even my husband is, 'Well if you can't get better…… out you go.' So, yes definitely understanding is much lower … and that in turn makes you worse. Because where there's little support from those around you in …. I spent about 6 weeks in [specialist residential treatment centre], and there were a couple of girls in their 20s. Everyone else's family were very supportive, whereas my husband just didn't get it."

There were also those who spoke of anorexia as the reason for significant relationships and marriages ending.

"Relationships (husband left me over it); marriage breakdown; lost job friends partner"

"One of my friends said 'Well, you're doing this to yourself.' That was so… you start to feel very alone. I'm not doing this to myself, but that's how it looks to other people. She said, 'Well you're doing it to yourself.' And I felt very alone when she said that, and it ruined our friendship."

Several participants identified anorexia's presence or influence in their life as the main reason they could not embark upon, develop, or sustain, relationships that they might otherwise choose to have.

"I didn't feel like I could have the relationships I wanted to"

"Recently I was trying to get out more and start dating, but by 3 or 4 o'clock I'm done. My thinking's not clear. I'm just tired. Also, I have breakfast and then my evening meal at a specific time, so I don't want to go out because I won't get my evening meal and I won't have that time, so it's tiring. It's like I could go out and push

that back, but I'll be hungry and tired and grumpy, and I don't want to put anyone else through that."

"In relationships that social pressure to be like, 'Come out, come and do this,' but you don't want to. And so, a couple of intimate relationships really have passed by, and the body image side of it. Of, 'I don't want to be seen.' That side of it can be really, really destructive."

One male participant also spoke of his conviction that the effects of anorexia on his physical appearance was off-putting to others.

I am pretty sure one reason guys aren't interested in me is I am too thin … I literally had only seen that on photos of people from concentration camps and then all of a sudden there it was in the mirror. So that made me realise, I look like shit. So, getting undressed is not, with someone else, is not particularly good.

iii. Family life was another relational area of life disrupted by anorexia over time. Family relationships were said to be put under strain, some seemingly irreparably.

"Disrupted family relations+++; exhausted my family's patience and financial resources;"

"I don't live with my family anymore because that came with its challenges so they kicked me out."

This was by no means the only story as families were also frequently named as incredible supports, but a theme of disruption over time threaded its way through many stories of family relationships.

"Because I couldn't live on campus during the holidays I came home. They started to notice and that put a strain on the relationship between my parents and my sister. It became really difficult to maintain my eating habits, or lack thereof, and maintain a

healthy relationship with my parents and my sister because they associate food and eating together as a family, with family. Yeah"

"My parents are offended by it and want me to eat normal, they want me to eat whatever they're eating. I mean I'd eat and I'd eat more than enough…."

"It's put a strain on the relationship with my sister and it's also put a strain on the relationship between my parents. It's not like they're blaming each other, but they want the other partner to get a solution and it's not happening. They're really trying, and I don't want them to sort of take it out on each other."

Anorexia problematically interfered with participants' engagement with family life, occasions and events.

"I've been doing it for so many years my parents have an understanding, and they don't mention food. I eat with them on Christmas day and no one else comes over. I just have a salad with no dressing and Diet Coke. They know what I'm comfortable with. They leave me to it and I've expressed that if they show concern and bring weight into it, I maybe haven't articulated that clearly enough to them but if they just mention something about my personality and I'm not as engaged – and not needing to harp on about it"

"I think what really hit home was my nephew is getting married and it's one thing I would really, really have loved to have gone to. But it's up in [city] and it would mean a few days away from home. There's a reception in the evening. It broke my heart, but I just had to say, 'no' because I wouldn't be able to do it".

Difficulties crept into the realms of becoming and being a parent, including problems conceiving and infertility caused by anorexia delaying and preventing much-wanted families. Pregnancy could be particularly stressful due to concerns about body changes, and the effects of maternal diet and health on the baby's wellbeing. Hurdles had to be overcome in

relation to breastfeeding and becoming run-down was identified as contributing to poor postnatal health and wellbeing.

> *"I got scared and I would oscillate between what it would be like if I put too much weight on, what it would be like post-baby? What was my body going to be like after having a child?"*

> *"This pregnancy was tricky because I was carrying a previous experience over and went into it feeling defensive. The obstetrician had noted my revelation about my eating disorder in my notes, and again they said anorexia and that made me take a step back. It felt dramatic. I also didn't want that on my notes, I didn't want any written record of that being part of my baby's experience"*

> *"This is my second lot of breastfeeding. It's a repeated experience. My first experience I was completely run down, I got every bug that was going around, I got pneumonia. I was just completely run down. And because of all those problems, or they were contributing factors to postnatal depression."*

The physical and emotional work and responsibility of caring for children was magnified by living with anorexia, and several participants spoke of worries about the influence anorexia's existence in their life might have on their children, and of thinking of themselves as a poor role model. There was nuance, however, as these challenges and concerns were spoken of as a reason for maintaining hope.

> *"You've got children to look after. So, they obviously get very concerned about what you're like, or if you pass out, or whatever. I guess, I can't …it's the same with any illness when you've got children. You can't just go to bed, can you? You've got to carry on, you've got to get them to school, you've got to carry on as normal. But that's a good challenge in a way I think. It stops you giving in to the illness, it certainly gives you impetus to fight."*

"But I also think as far as being a parent, managing my eating disorder on my own is a lot harder because I feel it's having an influence on the kids as well."

iv. Physical wellbeing was a matter of considerable concern and disruption for many participants. The increasing demands of what was spoken of as a normal adult life served to highlight some participants' physically compromised state. Extreme exhaustion was a regular feature of daily life, at times seriously limiting activities and choices, although at times this simply had to be pushed through.

"It's tiring, it's exhausting, and I think also that you need some sense of hope that improvement is possible."

"I would only go to town once a month. But that's part of my routine. I probably couldn't do it more. I'd panic at going every week. I wouldn't be able to physically go every week because I find it a very tiring effort. They expect you to be able to do these normal things, or work or what have you … People think you've got a small garden, you should be able to dig out all the weeds and just the thought of it … I can't do it."

"Last year, I didn't have enough energy to go out of the house, so I had to cancel and postpone things. And it affects your concentration and I do tutoring, so that has to stop".

Impacts on many participants' physical health had become increasingly visible to them over time.

"I think physically it's harder as well. Because obviously the damage that you've done to yourself becomes a lot more obvious. As a teenager, you kind of think you've got this all for free. And what the doctors were telling you potentially could happen was just like, 'Ah yeah, they're just saying that to scare me'. Definitely as I've got older I realise this doesn't come for free"

Medical complications were listed freely and multiply.

> *" weak heart; osteomalcia, a bowel prolapse and have other more serious complications; stomach ulcers, insomnia, vaginismus; amenorrhea, slow pulse, low blood pressure, elevated liver enzymes; infertility issues; liver failure and heart arrhythmia; stress fracture from over-exercising and under-eating; frequent collapsing, stunted growth/development, bradycardia, hypothermia, losing most of my hair, etc; endocrine, osteopaenia and dental."*
>
> *(Multiple participants, with individual responses separated by semi-colon.)*

Some participants spoke of requiring regular hospitalisation, and of holding very real fears that they might simply drop dead one day.

> *"I am at a dangerous BMI right now and being threatened to be sent back to the hospital again by my therapist"*

> *"Sometimes I get scared that I'm going to drop dead and that terrifies me too."*

> *"For a person in my situation, because of malnutrition and low energy I need to know what's going to happen next. Because I could die."*

Others noted that the existence of identifiable physical complications offered them a complex interplay of anxiousness and reassurance.

> *"I have found that when I develop worrisome physical symptoms, I feel anxious about it but at the same time I also feel relieved or proud, because it's a clear sign I'm still sick enough to matter"*

v. Mental health was identified by many participants as compromised. Speaking of it by using medicalised terminology such as depression, OCD or anxiety disorders that may or may not have been diagnosed by a medical professional, or using lay terms such as '*having trouble sleeping*, *distressed*, *anxious*, *extremely emotionally vulnerable*, *chronic inability to*

do enjoyable things,' the picture portrayed was one of complex concerns that interfered with participants' capacity to engage with, and enjoy, life. Some were unconvinced that they deserved or could expect better.

> *"Added to that you're severely depressed. Major anxiety. I remember completely being isolated, not spending time with friends because I remember thinking I wasn't good enough for them, or they're better off without me. So, I remember for like a year I just stayed in my room and stayed in my bed. Because I had no energy and I didn't want to participate in life."*

> *"I think so, it just makes me realise how long it's gone on for. It's the majority of my life and I think, 'What a hell of a life it's been.' I suppose it's feeling sorry for myself."*

The relationship between participants' mental health and anorexia was identified as intricately interwoven, mutually impacting one-another and contributing to the overall experience.

> *"Trauma caused by suffering for a long time and having the condition evolve to encompass many more disturbing behaviours (Co-morbid OCD, Anxiety, depression ect)"*

> *"I have been diagnosed with OCD as well, so I think that plays."*

Enjoyment of life was significantly disrupted for several participants due to the practicalities and consequences of living with anorexia preventing pleasurable activity, inviting a sense of hopelessness and a loss of enjoyment or pleasure due to the physical and mental effects.

> *"It blurs the connections with loved ones and squeezes any hope or joy out of day to day life."*

> *"Chronic inability to do enjoyable things as I'm either too tired or too distressed. I'd like to devote more mental energy to thinking about other things"*

vi. Education. Given the effects of anorexia on physical wellbeing and mental health, it is perhaps no wonder that numerous participants identified that the course of their education had been disrupted by anorexia. Whilst several participants stated they had been able to maintain their grades and academic achievements throughout, and this was perhaps the one aspect of their life that continued to flourish, many spoke of difficulties in concentrating and being physically unable to keep going as well as requiring time out for treatments. Several spoke of multiple interruptions to their course of study, having to repeat years or eventually dropping out of university entirely despite being excellence students when physically well.

> *"It was hard for me to even read a book. I found it very hard to concentrate when I was restricting."*

> *"In terms of study, it's so hard to study when you're not nourished, and you'd think I would know that and just eat, but it's not that simple. I get pretty decent grades, but I can see where they slip in patches where I'm not eating properly."*

vii. Career was similarly affected. Whilst some participants maintained senior-level roles in educational, medical, and creative settings, for others anorexia was highly disruptive or even preventative of them obtaining, maintaining and progressing the jobs and careers they both wanted and felt that they were otherwise capable of. Taking time out for treatment, sometimes involuntarily, led to some feeling their careers and their employers' and colleagues' views of them being negatively affected.

> *"Career! Not moving forward. Being held back missing opportunities"*

> *"I was sacked from job because of my anorexia"*

> *"I took six weeks off work and my employer's/colleagues' opinions of me have been impacted"*

"I have since completed my undergraduate, honours and masters degree in Clinical Psychology and have commenced work in this area, however anorexia has made this difficult and both my professors and employers have voiced their concerns regarding my health and wellbeing"

"I was threatened with losing/being suspended from my job due to my low weight and poor health"

For some participants, career choices and paid employment were simply no longer an option.

"Mostly regarding career. I don't have one any more"

"I have left my vocation"

"I am unable to have a career. I am a recluse"

For those in work there were further complexities as highly demanding schedules exacerbated the difficulties.

"I was working all day and I didn't have time to eat. What happens to you in life makes it worse and affects it. I was working all day and couldn't eat. Not because I wanted to lose weight at that time but because I just didn't have time. But the fact that I was working all day and didn't have time, I lost weight and then sort of I suppose you start to notice your bones and you get used to it and you don't want to lose that. And it does affect my work because I'm not like I used to be. I can't think. I can't focus."

Concentration and physical health were not the only contributors to career challenges. The simple acts of taking lunch to work, eating communally and having to socialise around food could cause significant distress and disruption, as could fears of colleagues discovering their difficulties.

"Even having lunch with the rest of the team I was like, 'Oh no! I can't let them know that I have an eating disorder, or I won't be seen as a credible support worker anymore!' I just don't like people seeing me eat, or the thought of people hearing me eat and stuff."

viii. Finances. Unsurprisingly, with such disruption to education and career, over time finances had become strained for many participants. Family legacies of the financial drain of private treatments preyed upon participants' minds.

"Financial less so on me when anorexic as a child however some strain on family paying for appointments etc; exhausted my family's patience and financial resources"

For those needing to pay for private treatments and therapy alongside living with the consequences of educational and career disruptions, financial concerns remained and debts of several tens of thousands of dollars were mounting, with health insurance policies rarely covering the extensive and long-term treatment private programmes available.

"Financially, therapy is expensive but necessary - I fall off a cliff with my weight without weekly therapy"

"I'm only just starting to see a time when I might start earning money and I'm almost 30. So, I do feel like that has put things back a lot."

"My insurance only covered 7 days of residential treatment."

Medical costs, the expense of therapy, and income loss were not the only financial costs identified, as anorexia itself can incur significant expense.

"Nowadays some impact on me as very irrational about food- will buy things then decide they are not "right", have to throw them away buy new ones.. there is also the aspect of buying extensive amounts of food for binge purges (AN BP type/bulimia)"

Purchasing the amount of food required for weight restoration became co-opted into the practices of anorexia.

"I'm too poor to actually recover and that validates it too, because if you don't have money to buy food then, well for starters do you have an eating disorder or are you just living in poverty? I know it's an eating disorder because I'll still refuse help from the food banks, or still not really accept help from other people trying to give me food."

It has been documented elsewhere that some people living with anorexia have complex thoughts about money, finding it very difficult to spend, particularly on themselves (Robinson et al., 2015). This caution that went beyond financial prudence was expressed by only a small number of participants, but could become so stringent that it presented problems with having access to basic necessities, such as one physically frail participant being unable to use heating in the winter or pay for help with a garden getting out of hand.

"I have the same attitude to money as food. I find it very hard to spend, even on things I need. I have denied myself other things as well as food."

ix. Practicalities of daily living were disrupted in multiple ways, from finding appropriate living circumstances, to the sheer physical and mental effort of having to decide, buy and prepare food several times a day. These challenges turned day-to-day activities into a full-time, stressful job of merely trying to cope with simple acts of everyday living.

"I can't flat with other people. I couldn't live at home because of contamination of food and stuff like that, and there were times when that was too distressing for the family. I couldn't live with a flatmate for the same reason, so then I had to live… I

now live with another person who has an eating disorder, which is terribly challenging."

"It's like having the actual energy to walk through the supermarket and make all those decisions yourself and basically do everything on your own."

"Shopping's one major difficulty … for food … it was all consuming. I'd spend hours and hours deliberating what to buy, what not to buy and food became my whole world really. And I couldn't make myself eat much of it. I'd buy things and then end up not wanting them, or if I did have them I'd end up bingeing on them and then purging."

A later theme will cover the efforts participants engaged in to keep going and maintain daily life, but attempts to eat, change or work towards recovery could easily tip their delicately balanced means of coping into disarray.

"I'm just in a really destructive phase. I used to be such a neat freak but even my bed is half covered with clothes at the moment. And it's like my brain at the moment. I look at my bed and it's such a mess and I hate it, but I can't do anything with it. And it's like I'm punishing myself making myself sit in this mess and I sit and look at it and hate it, but I can't be at peace and yet I do nothing about it."

x. Time and attention were recognised as taken up in vast chunks over extensive periods of time, seriously diminishing opportunities to do or think about anything other than the requirements and effects of anorexia. Complex and detailed decision making, particularly around food, was simultaneously virtually impossible and absolutely imperative. Exercise could be sufficiently excessive to fill the day, as could purging, and attempts to resist anorexia required constant monitoring, negotiation and self-reassurance.

"It should be a twenty-minute dog walk and it turns into half an hour or forty-minutes …"

"I experience significant distress when I am not able to exercise at least once a day"

"It would take me 2 or 3 hours to feel that I'd actually emptied my stomach. So, I just sat over the toilet for hours and hours. And then that became more difficult when I started doing it at work as well."

"It takes up so much space in my head. I'm so terrified of gaining weight, there's never been a day in more than 10 years I haven't tbought of it. And it's never going to get better."

"There's so many decisions, it's constant. You have to make so many decisions. You have to constantly choose not to go along with the urges because they're there 24/7, because the eating disorder worms its way into everything."

xi. Life experiences and opportunities. Alongside disruptions to educational and career opportunities and possibilities for relationships, participants identified a wide range of other life experiences and opportunities that were disrupted or lost due to anorexia. Beloved activities had to be abandoned due to the physical strain and the concerns of others.

"I used to really enjoy playing rugby but now I'm at a weight where I can't safely play. I referee now, but that's less involved as a team. Whereas I'd have liked to continue being part of the team I've had to shuffle out of that."

"I had to drop out of ballet, which I loved."

"I'm one of Jehova's Witnesses, so when I'd go out witnessing, I don't know if you've ever seen any of the witnessing carts … But I had to come off it because basically you're a bad Witness because you look so ill."

"Stopping me from looking after grandchildren (no longer seen as responsible because anorexia is a mental illness)"

Special events were spoiled by the effects of managing anorexia, or simply made impossible.

> *"Many sad memories of trips and holidays where food has been a main priority and/or issue for me"*

> *"I'd love to be able to travel and see the world. I think that's always been a big dream. I think it would be lovely to sit on a plane and go and see or do that. Or go to Italy, or go to Vienna, or go to England to see my cousin. I'd love to be able to do that, but I can't because of eating, I just can't and having to face food and meals. I can't it's just impossible."*

Several of the younger adults spoke of a strong sense of loss at missing out on the experiences they associated with youth, in which their peers had participated.

> *"The feeling of living a 'limited capacity' life, being sick while not looking outstandingly ill, missing out on my youth (no dating, drinking, parties, close friendships)"*

xii. Hopes for the future. For some, hope for improvement, hope for recovery, and hope for the future were all spoken of as significantly diminished, if not entirely missing.

> *"I've given up hope of ever getting better."*

> *"Terrible mental impact obviously ... have no hope for the future."*

This absence of hope was, in itself, disruptive of wellbeing.

> *"It's difficult to kind of spend so much time thinking about this stuff and to think also that I'm never going to get better. This is my life."*

Loss of hope appeared to be linked to the desire for change, frustration from unsuccessful attempts at change, the perceptions of others, and information received from health

professionals and personal research, and a belief that adult anorexia is not considered a health priority.

> *"I have been inpatient 4 times and outpatient for many years. I am beginning to feel hopeless in this disease."*

> *"Health risk and lost of hope, with out hope nothing else matters, if health professionals loose hope for you then what are you left with. When family begin to accept you will always be this way there is no hope for recovery because after a while you loose it your self"*

> *"All of the studies that suggest having an eating disorder for more than 5 years renders you incurable. And there's nothing I can think of that would fix the problem."*

> *"I'd like to be able to say that it's possible to get better, but I just don't believe it. Especially when all the treatment is focussed on younger people."*

Rather than abandoning the concept of recovery entirely, for at least one participant improvements to life had become more of a focus.

> *"As I say, I've given up hope of ever getting better. I suppose I wish I was physically and mentally a bit more able to cope."*

xiii. Sense of self and identity were spoken of by several participants. In some cases, there was a clear statement that sense of self had been impacted and altered by the experience of anorexia, and in some ways sense of self had become entangled with, or appropriated by, anorexia.

> *"It becomes intertwined with your identity and you forget what it is like to feel "normal" and happy. You begin to lose hope that you can ever feel that again"*

"It becomes such a part of you that you don't see anything wrong with it—it's been my normal since childhood and I didn't know anything differently."

"Loss of sexual and gender identity"

Some of this sense of self was spoken of as related to how they felt they were perceived through the eyes of others.

"I think that the more people focus on the Anorexia, the more I personally felt lost and unseen."

Other expressions were that the sense of oneself wasn't necessarily altered so much as diminished by anorexia and the experiences associated with it, including self-belief and sense of self-worth.

"My worth as a person was also diminished and had been hard to rebuild through being placed unjustifiably under the mental health act and having all rights including that to contact my family, friends, support people taken off me alongside and right to my privacy"

"I hate that this 'thing' that I cannot quite control is making me hate myself more due to me not feeling in control of my life."

"A feeling of a lack of freedom from your self and subsequent frustration, anger and self-loathing"

A third type of expression from some participants was the belief that anorexia existed, or at least remained, in their life because of their own personal deficits.

"It makes me realise how limited I am, how hopeless I am, how pathetic I am. Not just being able to do something like that."

xiv. Cultural engagement was only spoken of directly by one participant but key-ness to experience is privileged over prevalence in reflexive TA. As cultural engagement may be considered a central aspect of life and identity, and certainly was for this participant, its inclusion as a sub-theme was deemed justifiable. The following statement was made by one of the two participants who identified as Māori, unsettling assumptions that Māori are not affected by anorexia. Like many cultures, and especially those with collective traditions, partaking in food and the sharing of food is central to many Māori protocols and gatherings. Difficulties with food can result in difficulties with taking part in one's own culture.

> *"So much of our culture is centred around food, and I'm Māori as well and so much of my own culture is intensely around food. If there's not a kai [food] after we've had the Hui [meeting/gathering] then is it really a Hui?"*

xv. Religious faith was also only spoken of as being disrupted by one participant, although several referred to prayer and other spiritual practices as sustaining. Disruption and challenge to faith may be experienced as a loss in itself, and loss of the very thing that has been sustaining up to that point has potential for significant ramifications.

> *"Because I think with a faith you think that your faith should be able to carry you through. I guess when you listen to what others say, you begin to judge yourself. That it's not an illness, so even I myself will be like, 'Why can't I just do it? Why am I staying in this rut? And surely my faith should be enough to pull me out.' … you know you follow this faith and it's a happy lifestyle… but I'm not really looking the part. So, it definitely impacted my spirituality in that way.*

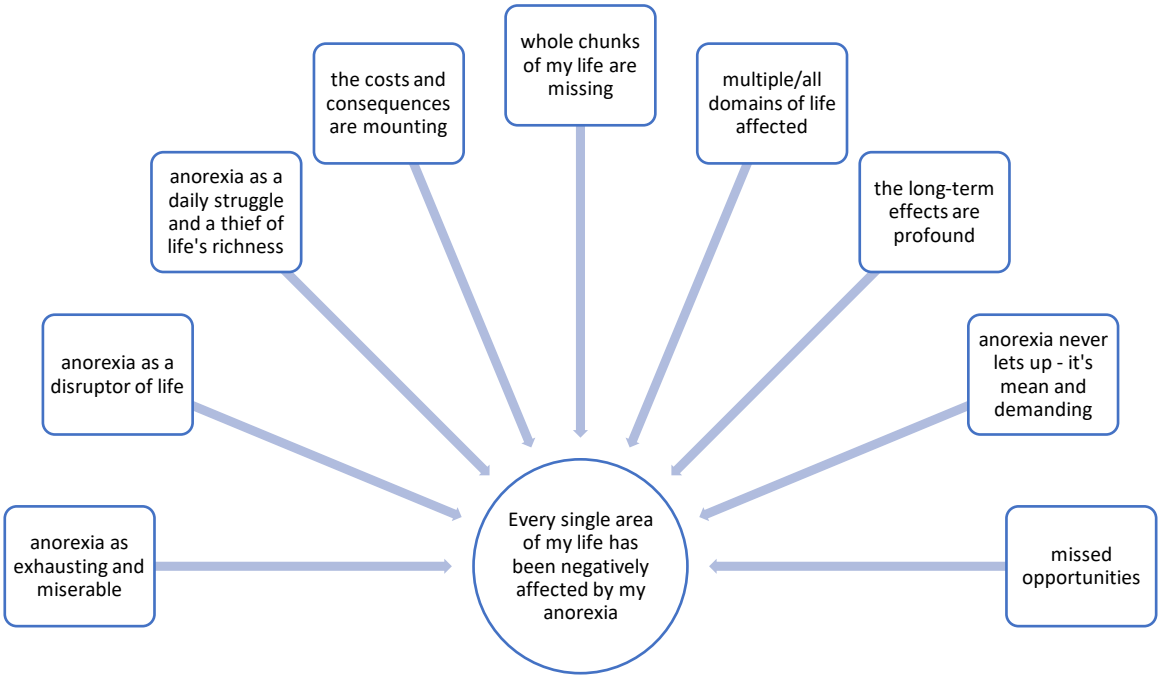


Figure 15 Code groups that contributed to Theme 1

Theme 2: It's a very lonely singular experience

The theme of aloneness was also very dominant, especially during the interviews. Most interviewees spoke of isolation in some form and *'lonely'* was a frequent response to the question 'How would you describe the experience of living with anorexia as an adult?'

> *"It's a very lonely experience. A very lonely experience. You feel that you can't talk about it with anyone. I would just say a very lonely experience."*

> *"It's a very lonely, singular experience."*

Aloneness appeared to come in many forms and from a variety of sources. There was the social isolation that has already been outlined in theme 1, i.e. the consequences of disrupted social activities and involvement.

> *"It makes you isolate yourself, so you find you inadvertently push people away. So, it's very isolating, especially if you've had it for a few years."*

There was a sense of isolation stemming from feeling different or cut off from others.

> *"You're alone in your head. Your brain is like 24/7."*

> *"There are all these little pockets of silent, suffering women that aren't connected, and that feel like their experience is a very alone and unique one, when actually it's not unique. It feels almost like you're put in a different bracket. Suffering from the condition when you are in your teens feels like a different bracket to my experience and other people my age."*

There were experiences of difficulty with speaking to others about what was happening.

> *"But, the reason for not telling my peers was because my anorexia felt/feels like a closely guarded secret. The shame element is most likely the reasoning behind keeping quiet."*

Sometimes this was due to not wanting to bother or worry others.

> *"I think that's what a lot of people don't realise. Out with people like my family I try to put on a bright side but unless I'm feeling really, really terrible and I say something, they don't realise it's a struggle even to keep going physically, doing what I'm doing … But I've got to the stage where I don't like letting my family know because they would worry."*

Sometimes it was due to earlier experiences of being misunderstood, judged, or having the problem minimised by others, leading caution about the wisdom or usefulness of being honest or open about anorexia.

> *"I hate that I cannot speak to anyone and just have them listen without judgement or trying to fix me, so I guess, feeling alone with the 'problem'"*

"Feeling so alone and like no one understands or cares and as though if I die it doesn't matter. After all, they think I did this to myself"

"I think the people around you really want to minimise it because it's so weird and hard to deal with and conceptualise. They're constantly trying to bring it down into terms that they understand and usually that means treating it as something that, 'It'll be a phase, but you'll get over it. We don't need to worry about this too much'."

Some participants had found others who had been supportive or sympathetic in the early years of their experiences of anorexia had lost patience or interest over time, or tended to think that the problem was, or should be, a transient one.

"It's actually interesting because I think people think that because you've done these things like have children and survived for this long that you just must be a lot better than you were. So, when you're really struggling it's harder to get understanding a space for that because they're like, 'Oh you've done that you'll be fine … it'll just be temporary again', you know. Expect your resilience to be always there."

"I think people's tolerance of it decreased over time. When I was… I suffered from anorexia the purging type … when I was younger it was seen as a teenage disease or a young person's disease, and certainly … I wasn't old but at 25/26 I think it was viewed as, 'Have you not got over that now … surely … oh, we've been here before, you've done this before.' A sense of I should just be able to snap out of it because I'm old. I got a lot of, 'You're an intelligent girl why are you doing this?'"

There was also a sense that lack of representation rendered their experience invisible, reducing the opportunities to articulate the experience or relate to others about it.

"I think that's indicative of the whole thing, that there isn't that awareness and everything is quite taboo especially when you're older, so the fact that I saw [the invitation to participate] on Facebook and was immediately drawn to it shows that I was desperate to speak about it … what was most important for me to share was

that I saw your study and I felt this big relief that someone is talking about this! The thing about adulthood … it's the thing that's always missing in conversations about anorexia"

"I've never seen anyone like me portrayed in anything about eating disorders. I've seen occasionally older women portrayed, and I've seen younger boys, but I've never seen an adult man."

Several participants spoke of there being a lack of understanding of adult experience of anorexia or of how to help, even within health professions.

"It was very much if you don't have family support you're not going to recover because we know that Maudsley family-based therapy has a good success rate and you don't fit into that. Your family aren't supporting you. You're living out of home at 19 by yourself. This therapist just said your weight is dropping again there's not a lot we can actually do any more."

"I think this research is really important because I'm sorry to say that adult services do get it wrong a lot of the time."

An especial difficulty that arose, in part due to the aloneness and in part created by it, was the feeling that any steps they might take towards recovery were a solo endeavour.

"Challenges included things like the fact I was an adult , unlike children where you use madusley family therapy , mine was all individually done and i lived by myself , it was up to me to do the groceries , make food , force myself to eat and then be left alone afterwards and deal with the eating disorder thoughts and this was so hard and it required a lot of my own responsibility as well as intrinsic motivation"

"Unlike ED patients under 18 most adult ED patients don't have a designated support person so they are trying to recover while their brain is screaming loudly not to"

Having to constantly advocate for themselves was experienced as a challenge, especially as support was not easily accessible (as is covered in a later theme) and the very act of seeking help in the first place could be incredibly difficult, let alone having to push for it.

> *"You've got to fight for it, and they make you feel like you're making a fuss. Like that person who said, 'Oh you don't look half as bad as I thought you would.' And so, again it's that not being taken seriously. You know your own mind, don't you?"*

> *"There's probably a lot more shame attached in going to the doctor and asking for help rather than your parent going and advocating that for you."*

> *"Another reason for not telling many people was that I felt a bit of a fraud, and I might not really have it because I wasn't fitting popular culture's image of dramatic weight loss seen amongst anorexics in the media. Scary pictures you see of people and thinking that I don't look like that. It felt melodramatic to use that term for my experience."*

Problematically, the sense of isolation was spoken of as a source of strength for anorexia and easily lead to a downward spiral in which seeking help was avoided, and anorexia made increasing gains in dominating the person's life.

> *"But, you're living alone. You can get away with missing a meal or not having things in the cupboard that other people might take for granted having in the cupboard."*

> *"I think that's where a lot of adult people fall through the cracks because, 'We can avoid going to the doctor, we've got no-one who's going to make us get on the scales.'"*

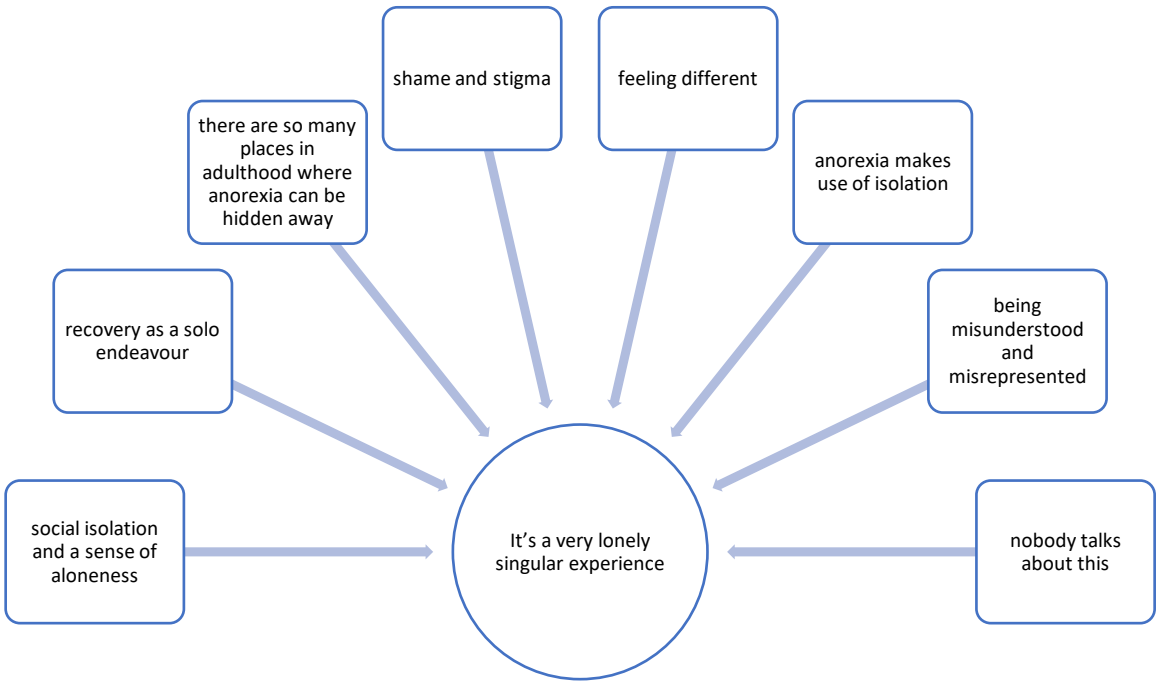


Figure 16 Code groups that contributed to Theme 2

Theme 3: It's difficult to still be struggling with what's viewed as a teenage disease

Several participants spoke of confusion and frustration associated with anorexia being still present at their stage of life. This was linked to perceptions of anorexia as a teenage girls' disorder, and some associated this discrepancy with a sense of shame.

> *"The stigma is that there's a stereotype of it as a teen disorder. As an adult, it's difficult to admit something that is identified with adolescence. You're instantly infantilising yourself in front of everyone. You're saying, 'Well I've got this condition that 14-year-old girls have.'"*

> *"So, when it came back you get the extra shame that I got over this when I was eleven, but now it's coming back to me."*

Frustration came from a belief that anorexia should be a transient problem associated with teenage angst.

"Because when they're a teenager you expect them to have problems. And young people have problems. But the older you get they think, 'Well you're an adult, you should be able to cope with everything. You should be able to do adult things'"

"I got older and going through University and jobs for example it's difficult to still be struggling with what's viewed as a teenage disease."

Participants spoke of lack of public awareness of adult experience.

"People don't realise the diversity of eating disorders and I think it's a big problem for people's understanding of it. Because if you understand it properly it can happen to anyone."

"The disorder is defaulted by mainstream media to be an adolescent experience and as a result, older women who are suffering end up feeling alienated even further."

"I've never seen anyone like me portrayed in anything about eating disorders. I've seen occasionally older women portrayed, and I've seen younger boys, but I've never seen an adult man."

This led to participant concerns about how others perceived them.

"That's the outside view of people who don't know much about it, but there's a lot of shame involved in that. I'm a grown woman, I should know better! And this is me judging what everyone else thinks, and I've never asked them what they think. But that was my preconceived idea."

Participants also spoke of frustration with services that also appeared to categorise anorexia as a teenage girls' problem, tailoring services to that demographic and rendering them unsuited to adults.

"If you're a teenager with supportive parents there are a whole heap of recovery methods that rely on teenagers still living with their parents, and the teenager not having any control over their food and the parents doing that work. I'm an adult and live in my own flat and it's just not feasible for anyone else to make those decisions. I don't have anyone whose responsibility is to make those decisions. It's not fair on others to have to be responsible for me. We definitely need other methods of helping people recover that are not that."

"Unlike ED patients under 18 most adult ED patients don't have a designated support person so they are trying to recover while their brain is screaming loudly not to."

Some found GPs seemed to lack adequate training and information about anorexia.

"Because he'd just been to a course. About a month or so before he'd been to a course on dealing with people with anorexia, and it only covered teenagers. So that was interesting."

This created difficulties in gaining referrals to services.

"On the plus side, no-one will ever accuse you of having any sort of eating disorder because I'm a 30-something year old man and 30-something year old men don't have eating disorders. Even when I've experienced extreme weight loss it's never brought up. Not even by my doctors, not by anybody … for treatment providers and this just goes down to GPs and other health providers who aren't in any way associated with eating disorders, but who see people ... When a grown arsed man shows up in their surgery and has lost a significant amount of weight in a short time it's worth asking if he's having trouble eating."

In some cases, participants disqualified themselves for not fitting an expected profile.

"Yes, having anorexia as a thing that is portrayed. And I think in part it's because I don't fit into the stereotypes, I just don't feel like I can in any way relate to the word 'anorexia'. I know my eating is disordered but I don't feel like 'an anorexic' or someone who 'has anorexia.'"

"It felt like they were all much younger than me, and all much skinnier than me … these things that made me think, 'Well maybe I'm not, maybe I'm in the wrong place.'"

Associated shame could make the experience of using services uncomfortable.

"There's not much out there, its taboo, there's stigma. People have their preconceived ideas of what it's about, but it's actually multi-layered and very unique to every person and there just isn't the … there's not conversations going on about it because there's shame and embarrassment. It's a very lonely disorder. Teens, I could sense at (the ED service) they got dragged along by their Mom who desperately wanted to help them but at least they have that person. I would go alone bringing along my own feelings of shame and embarrassment."

The issue of services not knowing how to help adults arose a number of times.

"So, it was quite yea, it was very difficult when the treatment is so hard because when you're an adult they don't know what to do with you."

"Inpatient programs are set up for adolescents. Older patients have a lower priority because 'outcomes are poor for long-term anorexics' and 'younger patients get sicker quicker'. If you are lucky enough to get inpatient help older anorexics can only have two weeks. Their is no support for older anorexics basically we are just left to sink or swim."

The concept of an adult struggling with a teenage girls' disorder appeared to invite not so much surprise or concern, as stigma and judgement from professionals.

"A friend in her late 20s now, a woman I know, she's been hospitalised as an adult woman and she said the treatment she's received has been abysmal because she's expected to know better."

Participants often applied the same judgement to themselves.

"*Yeah, well when you're 52 ... a 52-year-old not being able to eat properly. Not being able to look after myself so I'm fit and healthy. It's … I don't know, it's pathetic. It's unbelievable in a way"*

These issues supported a belief that recovery was no longer possible for them.

"I don't fit any of the stereotypes and am too old for help."

Consequently, research into adult experience was welcomed by participants.

"Adults deserve help too. It may be too late for me. But please try to make a change for the future generations. Doctors need to have more compassion for adults. We are not vain or narcissistic. We are in tremendous emotional pain"

"Very important that the research includes more than the teenage girl demographic, because there are so many more of us. And I definitely don't fit that box"

"I think that information or knowing that anorexia affects adults is so important. I was really excited when I heard about this research."

Similarly, forms of confirmation that they were not the only adult experiencing these difficulties were spoken of as appreciated.

"One thing that helped me was a conversation with my therapist. I said I felt like a fraud because it's a disorder that teen girls have, but she said without breaking

confidentiality that she could say there were older women, and that made me feel like I wasn't the only one out there."

Figure 17 Code groups that contributed to Theme 3

Theme 4: The road to actually getting treatment for anorexia is difficult … there are a lot of barriers along the way

When it came to accessing supports or services, or aiming for recovery in whatever form that might be meaningful to participants, the notion of reaching out for help was an issue fraught with complexity.

"So the road to actually getting treatment for anorexia is difficult , people dont have a lot of knowledge and there are a lot of barriers along the way that you need to overcome, you have to get good at advocating for yourself and actually pushing for help , otherwise it doesn't happen. Which with anorexia it can be really hard to advocate for recovery , when recovery is terrifying"

In a very practical sense, many participants spoke of considerable difficulty gaining access to appropriate supports and services. Those who had found helpful therapies and programmes expressed considerable gratitude for them, even if change still took time, suggesting they were unusually fortunate and acknowledging a belief that such access was not the norm, that others remained stuck due to inadequate access, and that was not a good place to be.

> *"I feel very privileged and lucky in the way I was able to get help. Medicare covered a great deal of my treatment, my illness was first recognised about 7 months in, and although my family wasn't perfect they DID care about me and want me to get better. I had some good friends who supported me and I was able to completely recover. Not all people have had these advantages, and it makes me very sad to think that such a horrible struggle could be made even worse by not having support and financial resources."*

Poor access was put down to myriad factors, including those described in earlier themes; the lack of recognition of the problem for adults preventing referrals, services being tailored for a teenage demographic, and a shortfall in insurance policies or lack of finances available for private therapy.

Participants from several countries bemoaned limited or poorly resourced services with unreasonably long waiting lists.

> *"I live in a country – [identifying detail removed by request] - where anorexia is not understood at all not even by doctors and there is no help available for anorexics. We are just abandoned".*

> *"The mental health NHS system in the UK is very poor and you wait months and even years to be seen by professionals."*

Some participants found that referral to specialist eating disorder services depended upon being critically physically unwell and had to lose weight to gain a referral. This was spoken of by several participants as a particular frustration because they said it reinforced '*anorexic*

thinking,' and by the time they gained access to services the problem had become much worse and harder to deal with. The requirement to lose further weight gave veracity to their pre-existing concerns that they were, in fact, undeserving of help. A sense of undeserving had been an obstacle to seeking help in the first place, leading to a resignation to their fate. In addition, services often only focussed on regaining sufficient weight to get out of the critical state before discharging them without further support, resulting in a revolving door effect.

> *"I have had help in the past. I also had some help fairly recently and reached partial recovery, but help is obviously limited to severe cases, so I'm not eligible for any more"*

Several participants spoke of frustration at inaccessibility. Limited services resulted in long travel distances, and changing appointment times created difficulties getting time off work, making it challenging to attend, especially if already physically exhausted by everyday activity. To make matters worse, dual mental health diagnoses sometimes resulted in participants being required to attend separate services for each problem, in separate locations. On occasion, both services refused to accept the referral until the other difficulty had been attended to, leaving them with no help for either.

> *"barriers here were location as it was a 6 hour trip via bus"*

> *"I think sometimes people have sort of, they try and treat them as two separate … I know they are separate issues … but what I've experienced before is that I've been sent to one establishment for anorexia, and then a completely different establishment for the OCD … And trying to talk to two completely different people, and talk about… d'you know what I mean? Trying to talk to two completely different people about different issues which sort of come hand in hand."*

Labels of chronicity and professional attitudes of hopelessness were also stated as reasons why services were sometimes reluctant engage with some participants.

"When I was in hospital they were like we don't know if you're going to go through and make this because your family's not supporting. You're showing so much resistance to any therapies, you're not gaining weight, you're on the feeding tubes. At that point, I didn't know if I was going to recover I was told pretty much to expect lifelong complications or that I would be in and out of hospital."

"Well, because I have the chronic label, or treatment resistant. The services want to invest in people they can fix."

Lack of training for, or support from, GPs was a matter of great disappointment for some, yet a knowledgeable and supportive GP was said to play a pivotal role in creating a gateway to speaking of the problem, gaining specialist referrals, and providing on-going support.

"My GP keeps recommending restrictive diets to help my autoimmune disease."

"But, it would be nice to know, I suppose, that the doctor was more understanding. I go to the doctor and they don't … I went to a new GP and he didn't even ask me how my eating was, he didn't weigh me. He didn't ask how I was feeling mentally or physically. It's just sometimes you need someone you can talk to, to say, 'Hey how are you really, truly feeling?"

"There needs to be a lot more education given to doctors (GPs) about the signs and symptoms of eating disorders and that often people are very unwell before they even become underweight in appearance"

"I went to the doctors and told her I was getting colds and feeling run down, general postnatal health. She asked, 'How's your eating?' She didn't even look at me and for some reason I said, 'Not great.' That was the first time I admitted it to anybody … the GP didn't go into much, but I think the way she spoke and asked, 'What if you spoke to somebody at (Public ED service) … I remember she wasn't looking at me. She just asked about my eating and threw out (the ED service) as an option, and I said it might be helpful which was a big relief."

The very act of asking for help in relation to anorexia was noted as incredibly challenging, and the discomfort, sense of undeserving and fear of what might come next were all spoken of as sufficient to discourage or prevent doing so.

> *"I feel really uncomfortable talking about it, so I would need a really good reason to contact someone. A helpline might be helpful for other people, I know talking about it helps me, but just taking that step of dialling the number takes guts. And you need to really know that you have it, because honestly 6 months ago I thought I was on top of the world. I think realisation might come too late for an eating disorder"*

Attempts to ask for help were not necessarily productive anyway.

> *"I have once asked a doctor. It was kind of my round-about way of saying that I was having issues, because I was regularly weighed for when I was seeing an endocrinologist and I said, 'I keep losing weight and I don't know if that's okay.' He worked mostly with type 2 diabetes, so he looked at me and said, 'You're the healthiest person I've seen all day.' And I was just like, 'Well that kind of shuts the door on it."*

Worries about having their request for help rejected, or their concerns dismissed, aroused a sense of vulnerability that prevented many participants from speaking of the problem to another person at all.

> *"Researcher: So, [you mean that raising the topic of anorexia is an] even more intimate conversation than having a smear test?*
> *Participant: More vulnerable. I could have had something thrown back at me. I could have been rejected or something could have gone wrong. Once it's said, it's out there and how they respond to you is make or break."*

At least one participant feared that re-engagement with services might take her backwards.

> *"I could go through (the ED service) again but she also does private practice. So that's always a possibility as a first point of call. But I also want to take a step away from that, because would that put me back into an environment where I wasn't doing well, and it would be like jumping back into the darkness? … When I say that I actually refer to the physical clinical space itself. I'm a 2 out of 10 but was a 7 out of 10 in terms of severity and returning to a place of previous treatment, might push me further down."*

Another feared her needs were so demanding and overwhelming appropriate support was an impossibility.

> *"I need help. But the only thing that would work is if someone constantly babysits me."*

Others articulated that just someone to speak with on a regular basis, or some support and advice with food and cooking would be beneficial, though neither option appeared to be available. There was a strong sense for many of not being understood by service providers, and a lack of respect for the meanings the person gave to their experience, and what their beliefs were about which approaches would be useful to them.

> *"I think more about coping mechanisms and anxiety management. Exposure response therapy, that sort of thing, rather than whereas I've been in in-patients there's been some form of therapy a lot of the time it's been digging right back into my childhood or talking about what type of people my parents were, or grandparents were and things like that. I had a very happy, healthy childhood. My parents were entirely normal. I was a completely healthy, happy child. I didn't develop this until I was 27, this is completely irrelevant."*

Several participants who had engaged with services over the years spoke of prior treatments being so inappropriate, unhelpful, and even traumatic, that they were keen to avoid re-engagement.

"When in the past I've had treatment, it's been refeeding and involuntary and not a nice experience."

"The thing is with treatment I can still smell the hospital , or here the other girls scream as they got their feeds put up , and i can still feel the tube in my nose."

Efforts towards recovery or change were spoken of as exhausting, and off-putting due to the disruptive and potentially futile process. For some, making the best of the situation had become the preferred option, or at least considered the most realistic.

"Most of the time now I'd rather just try and get on with what I can do, and not focus on how I'm really, truly feeling and focussing on the food and weight and so on. You know, get on with life, but then I can't do what I want because it takes such an effort. I don't want to put all my energy into trying to understand myself and everything else again. Having got therapy and psychological therapy and all that."

"I mean, I know how much work it would be and what kind of intensive therapy and that kind of thing that it would take. I'm not dying yet so I might as well keep going."

"I cannot keep my job, and do my work, if my head is full of this battle of trying to get rid of anorexia … when I was trying to get better, I felt like I was gaining just a little bit of weight or maybe I was imagining it. My brain was not focussed on the work. My brain was completely focussed on how my weight felt, and worrying about it, and what I'm going to eat next … For me it was one or the other. I cannot do them in parallel, I cannot multi-task both of them. I have to just do… obviously I have to survive, I need my job. So, my job is a priority. If I don't have my job I don't have an income."

Others expressed uncertainty and confusion about whether anorexia was a problem or if their experiences were just part of normal life.

"And then this battle that was going on in my head, 'Am I anorexic, am I not, am I anorexic, am I not?'"

"Part of me is still in denial, thinking it's not that bad, it's not that big of a problem."

"I am terrified of supermarkets. I never know what I'm doing. I've kind of got a routine set up that I will buy the same things each week. But that's quite restrictive and I don't know if it's an eating disorder."

Or were pretty sure asking for help would be a pointless exercise anyway.

"I don't see what someone else is going to be able to do to help. You can tell me that I'm beautiful or whatever, and I think you're lying. I don't understand how many times I'd need you to say that, and I don't understand how a counsellor is going to coach that out of me."

Figure 18 Code groups that contributed to Theme 4

Theme 5: I don't paint it in a fully negative light

Alongside the many disadvantages and problems of living with anorexia, several participants also spoke of other consequences of anorexia being in their lives. Not all participants spoke of these other consequences as positive, or even stated that they did not want to frame them as positive, but they still considered them other than negative or neutral. For the most part these consequences didn't appear to simply be incidental effects or consequences, such as those caustically joked about by two the male participants.

> *"cheaper!!!"*

> *"I've gotten two roles as an extra playing an inmate in a concentration camp. I fit into children's clothing"*

Rather, they seemed to form an integral part of the experience.

> *"So, I don't paint [anorexia] fully in a negative light, and I think people would like to see it as, 'Oh, you know, it's this terrible thing,' but it's more complex than that".*

Participants indicated that these helpful effects may be part of why they had mixed feelings about ideas of recovery.

> *"There's a fear of full recovery too because it's safe and comfortable, and it becomes a part of who you are so it's not comfortable to let that go."*

That's not to say that participants saw anorexia as a choice, and several were adamant it was anything but a choice.

> *"Living with anorexia is hell - it is not a life choice. Just because a person has an ED for a long time does not mean we are stupid or do not know what we need. Nobody wants to live with an eating disorder no matter how long they have been sick or what they say."*

However, for some participants what they perceived as recovery held limited appeal due to the potential loss of the more useful or helpful effects of anorexia.

> *"I want to be ill, I want to disappear which is why recovery seems so very impossible. I have gained weight and now at a healthy normal weight I hate myself and just want to disappear even more! The pain of feeling emotions in recovery I think is the hardest thing of all, I now understand why anorexia has the highest mortality rate of any mental illness, you feel left with the choice of killing yourself slowly through restriction or taking your own life to stop the pain of emotions during recovery."*

For some, anorexia was credited with having provided solutions as much as it did difficulties stating that anorexia served a function, and as a means of coping with some of life's challenges, or a buffer from particularly difficult experiences.

> *" [anorexia] is one of the reasons I'm still alive. Which I know is a bit paradoxical because it also nearly killed me, but it also is part of the reason why I am still here. So, I have quite a mixed relationship with it I guess. It's an unusual one, it's complex."*

> *"I also think it does serve a function. I don't want to say it's necessarily a positive thing, but there are positive elements to it … for me it's a coping mechanism, perhaps a maladaptive one but a coping mechanism."*

> *"You feel protected somehow from all the pain."*

These experiences, it seemed, would otherwise have been felt intensely.

> *"helped me cope with the abuse and trauma I suffered"*

> *"Coping with the underlying anxiety, inadequacy, unworthiness, fear and shame"*

This buffering effect, it was said, may have developed along the way rather than being present at the outset.

> *"It almost becomes your way of dealing with stress or difficult emotions, whether or not it started like that."*

Several participants spoke of anorexia as a reliable friend, and an antidote to being alone or misunderstood.

> *"For me at least, it served as a friend in a way. It served as something that was always there for me."*

> *"It was my best friend for a long time and it's still my 'go to' when I'm stressed."*

> *"It kind of feels like a special relationship which sounds stupid. You feel like anorexia understands, but nobody else does. That's silly because it's you anyway."*

Some pointed to a sense of safety or calm.

> *"It provides a sense of control, safety, security"*

> *"There is for me a sense of safety and calm that are associated with the illness."*

In turn, this led to a feeling of wellbeing, greater resilience and increased capacity to get on with life.

> *"I think I was able to cope better with life and achieve more when my weight was very low mentally I felt more stable"*

> *"I feel I am more resilient to other stressors and have a higher tolerance to hard work, which makes me better at my job and my sport."*

For others, being able to 'opt out' of interactions was experienced as a benefit.

> *"Anorexia is your own little bubble. You don't talk to the world, and they don't talk to you."*

Several participants spoke of feeling more comfortable living in a thin body, and a belief that this made them more acceptable to others.

> *"I felt lean and good about my minimal approach to food."*

> *"feel more accepted by others"*

> *"And in a world where being thin is valued over being fat, I am at least thin."*

> *"I feel more comfortable in my body. I feel less self-conscious."*

For one participant thinness seemed to help with the discomfort of their mis-gendered body.

> *"Reduced gender dysphoria associated with being transgender. (Am presently transitioning and hoping this works to reduce my reliance on my eating disorder)."*

A small number spoke of pleasurable altered states being derived from the effects of starvation.

> *"I enjoy food more during bouts of restricting than when I'm not restricting. I savor what I eat, and it is a sensual, euphoric experience."*

> *"you do sometimes feel a light europhoria from being light headed."*

More common expressions were those of anorexia having become such a familiar, or constant, feature of their life over time that it was difficult to separate themselves from it.

"I also think it became a very strong part of my identity … It's just so interwoven throughout my life and that is very difficult to disentangle that."

Participants did not state having anticipated or aimed for these effects prior to restricting their eating, other than perhaps wanting a slimmer body, or that they had been actively seeking some solution to problems. However, once found, these consequences were considered to have sufficient appeal to at least ameliorate some of the sense of struggle, or go some way to justifying continuing along the same path.

Figure 19 Code groups that contributed to Theme 5

Theme 6: What you learn if you get out the other side is amazing

Although the question of recovery was not a focus for this study, several participants did speak of their experiences, and if we are to attempt to gain a sense of the experience of living with anorexia over time, it follows that recovery, reclamation of life, and change would form a part of that conversation. For participants who identified as recovered or who said that anorexia was more in their past than their present, many spoke of the overall

experience of having lived with anorexia and leaving it in their past as being a process of beneficial personal change that they did not regret or resent. Several referred to an appreciation of the experience of anorexia and recovery.

> *"Living with anorexia has changed me so much as a person. It sounds weird and I know this is a odd sentiment , but I am so thankful I developed anorexia. Don't get me wrong living with it was hell , it was terrifying , i can close my eyes and still remember things like the pain of physically walking , how cold i was , the feeling of being tubed , the complications of being tubed, the daily blood tests, and the anguish of each meal and the voice that would follow the moment i ate. However at some points in my life now I miss the voice , i don't miss the eating disorder , but my life was so different prior to the eating disorder."*

> *"In terms of symptomology I would say it's something that's completely left and would never come back. I'd be strong enough to say that. But I don't think the experience ever leaves you. If that makes sense, so the residual nature of what you learn if you come out of the other side is amazing"*

There was talk of gaining a better understanding of how to attend to their own wellbeing.

> *"I'm more aware of my physical health, something that was of no consequence to me before."*

> *"I think that when 'in recovery' you learn to be a lot more self-aware about what's going on for you, and what your body needs."*

> *"I learnt how to be appropriately assertive and to prioritise my own wellbeing. I learnt hard lessons about friendship and connectedness but as a result the people I surround myself with in my life now are my closest, most valued people. Recovery gave me the gift of freedom- freedom to be unapologetically who I truly want to be which was something I had struggled with log before I was ever diagnosed."*

Some spoke of developing new skills for living their life.

> *"It's hard to put into the right words, but some of my darkest moments with my eating disorder have - with the right attitude and reflection - helped me develop a stronger character (after recovery)."*

> *"Learning more about my resilience to cope and find strengths to become a happier and more confident/ self assured person."*

> *"I worked really hard on having no self-confidence in my ability to deal with things, and I've spent a long time learning that actually I can cope, and I can manage and there are things I can do that help with that".*

> *"[The process of going through anorexia and recovery] allowing me to actually see I had more power and control in my life than I perceived me to have. Or that I had growing up that I actually could do this and wasn't what I was told I was."*

Some spoke of family relationships which had improved as a consequence of therapy and having lived through the difficult experience together.

> *"- my family and I are more emotionally-aware through some family therapy, and I think we connect more on a deeper level than we would have had we not gone through this experience together - as ultimately hurtful as it has been for everyone."*

New and meaningful relationships that developed as a consequence of being in treatment centres.

> *"I've met some of my closest friends"*

> *"I made some very good friends who I still keep in contact with."*

Others believed the experience had increased their capacity for empathy and compassion.

"- It's increased my capacity for empathy, particularly for marginalized populations and/or those who struggle with oppression or disability. It's made me more passionate about learning more about the struggles others face and how I can contribute to both raising awareness and taking action to create satisfactory opportunities for equality and justice."

"It has made me a more understanding person towards others"

They said it taught them skills in caring for others.

"I can often identify adult anorexics in my yoga community and work with them with an understanding of the thoughts and processes that might go on. I think they would easily fall through the cracks otherwise. I've created a yoga space that is fiercely body positive in response to my own experiences and other people benefit from that."

"I now work in the field of eating disorders, and I'm not sure if I would have done this if I hadn't had a lived experience! I really love my work, and I also feel like I now have a good understanding of the problems with diet culture, fat phobia, etc., and feel equipped to fight against these things."

"now work as a holistic health practitioner helping others with eating difficulties. This for me is the best outcome I could have asked for. The experience taught me lots about myself and others and gave me life skills I would otherwise never have attained."

There was a sense for many that recovery was not a question of beating or getting over anorexia, or returning to a prior way of being, but one of transformation and change.

"You're never going to be the person you were before, but you can be a new person. Who you are, able to go even further than you ever thought you could. You're a new chapter."

"Realising that you can't go back to how it was before because that was one of the huge things that realising my expectations of recovery are different than what I was told they were going to, because recovery was always. 'You're going to gain weight and you'll recover, and you'll go back to your normal life'. I gained weight, but I couldn't go back to my normal life because my normal life is no longer my life. So, it's yea, making a new life and actually having to be ok with that."

This transformation wasn't necessarily predicted or predictable.

"If you had asked me at 18 when I was struggling with anorexia what recovery looked like, compared to if you asked me now what it looks like having recovered, or being as recovered as you can get with an eating disorder, they would be two very different answers. So, the original goal, although something I still strived for it wasn't the end goal in the end."

Choice, agency and decision making formed important components of the transformation.

"Being able to live with anorexia in itself is a very difficult thing. It's tiring, it's exhausting, and I think also that you need some sense of hope that improvement is possible. I think I want to say improvement rather than recovery. It's not linear, but also there are different versions of that and you can choose what that looks like, and that you can… I think that's what I didn't know. That it's not passive. You can have a choice and you can… I think it can often feel like you have no choice and no control over what happens, and I think maybe that there are different possibilities and there are different people that have learned to navigate it in different ways."

The process of change was spoken of as being gradual and progressive.

"I can see this picture in my head of what I mean…. There's like these building blocks of what I need and when I've got the basis of what I need I can go to the next step, once I was able to start working full time then I thought, 'Well I can study now' because I can do the higher-level thinking, and once I did that it was, 'Okay now I have the opportunity to do well' and I've got even more motivation to eat properly again and that kind of thing".

Preferred aspects of life were said to slowly take up the space that had previously been occupied by anorexia.

"When you start to get these little pieces of happiness, pieces of happiness in your life that fill in, it starts to push out that anorexia. And once you get this full life it's like, 'Why would I go back to that, when I have all this good stuff here?' It starts to push out the bad … I think [friendship] definitely didn't replace [anorexia] right away because even after she and I became friends I had another stay in residential. So, it didn't necessarily replace it but it led to the pushing it out, if that makes sense."

At the start, there did seem to be some meaningful impetus for change.

"I saw them doing interesting things and realising that I was really exhausted with not being able to work very well or enjoy anything or have a bigger purpose, I realised something had to change."

"I thought I might wake up and she would be dead in the bed next to me. She was Catholic and she had told me that right before she got there she was blessed to die. Even though I had encountered people who were sick before, I had never encountered someone who had been blessed to die. And there was this lady who had celebrated her 16th birthday in a treatment centre, and now she was celebrating her 40th birthday in a treatment centre and I thought, 'I don't want this to be my life'."

"The GP, not my regular GP, asked if I'd looked at my nutrition. The 101 on fertility health really, and I stopped exercising, so I put on a bit of weight for me. I was just wanting to get pregnant before I hit 40, so that was quite a motivating factor."

The timing of this impetus was spoken of as important.

"I also think it was a combination of me being ready for that. So, if I had kind of been engaging with that sort of stuff [body positivity] when I was more unwell I would probably have disregarded it. I was at a stage when, maybe it was a question of me wanting something else. Wanting an alternative to the world I'd grown up in."

The process of change was neither linear, nor easy to maintain.

"I haven't gone backwards but feel I'm at the top of a slippery slope at the moment and fighting really hard to stay there. I'm trying desperately to move away from that slippery slope."

For at least one participant change in other areas of life may have been gradual, but change in comfort around eating was sudden and unexpected.

"I've read a lot about the normal recovery. My recovery seems very different. People always talk about 'You'll notice the little steps,' but it wasn't until one day I was making dinner for myself and I realised I was looking forward to the meal and there was no eating disorder voice. It didn't … it kind of hit me out of nowhere I was making progress, whereas for a long time … So, I don't think I consciously noticed if I was increasing my engagement with the coping skills … It was a very weird moment, I remember it because I was standing in my kitchen going 'There's no eating disorder voice. I can't remember the last time there was no voice.' It was just me quietly making a meal. It was 'Oh, this is a weird experience.'"

Importantly, engagement with change was spoken of as active and purposeful. Whether through therapy or via personal research, new ideas were actively sought out and engaged with.

> *"Definitely something that I had to stick at to get used to. I think when I first started it I thought [therapy] was a load of codswallop and it was absolutely no help, I was very resistant in the start to engage in things like mindfulness or sensory modulation because I was like, it seems silly."*

> *"I will always try and do things however scared I am, and being able to acknowledge that I was terrified, but I was willing to give it ago I think was probably the thing that pushed me forward and also knowing that I'd done it before, in some way, that I could do it again."*

> *"I think the work in therapy had a lot to do with it. It helped me see that I could achieve these goals where I think before I couldn't."*

> *"It almost seemed like a natural course of getting better for me. And towards the end some of the healthier ways of dealing with stuff, things like engaging with lots of feminism and body positivity, and I think probably studying was a really big one for me as well. So, keeping my brain busy and having something bigger to work towards."*

> *[In yoga] You have to rely on a measure that's not physical to get relief and comfort. Which is kind of alien to me with anorexia. Because that used to be the only thing that gave me any kind of relief was feeling lighter, so that's it. I can't think of anything else. It's been really important in that way for me."*

This was supported by hopes for a preferred future, for themselves and for others too.

"[Speaking of the body positivity movement] I was at a stage when, maybe it was a question of me wanting something else. Wanting an alternative to the world I'd grown up in."

"It's funny, it's a conscious thing. I built my whole business on it not being about weight loss. I was almost vicious with anyone who talked about weight loss in my classes. We don't have the classic yoga attire, which is yoga tights and not a lot for the teacher. No, it's baggy yoga trousers and tops, so it's been a really conscious decision for my students not to be facing that … It kind of turned me into an activist in a funny way. Uhm, because we're constantly treated … you know, the magazines, the constant focus on the epidemic of obesity and you know, for an anorexic it's, 'Oh, that's a good reason to diet. That's a good reason to control my food.' And I'm like, 'Rah, rah.' I almost went the other way and said, 'Hey, I don't want any of that in my life.'"

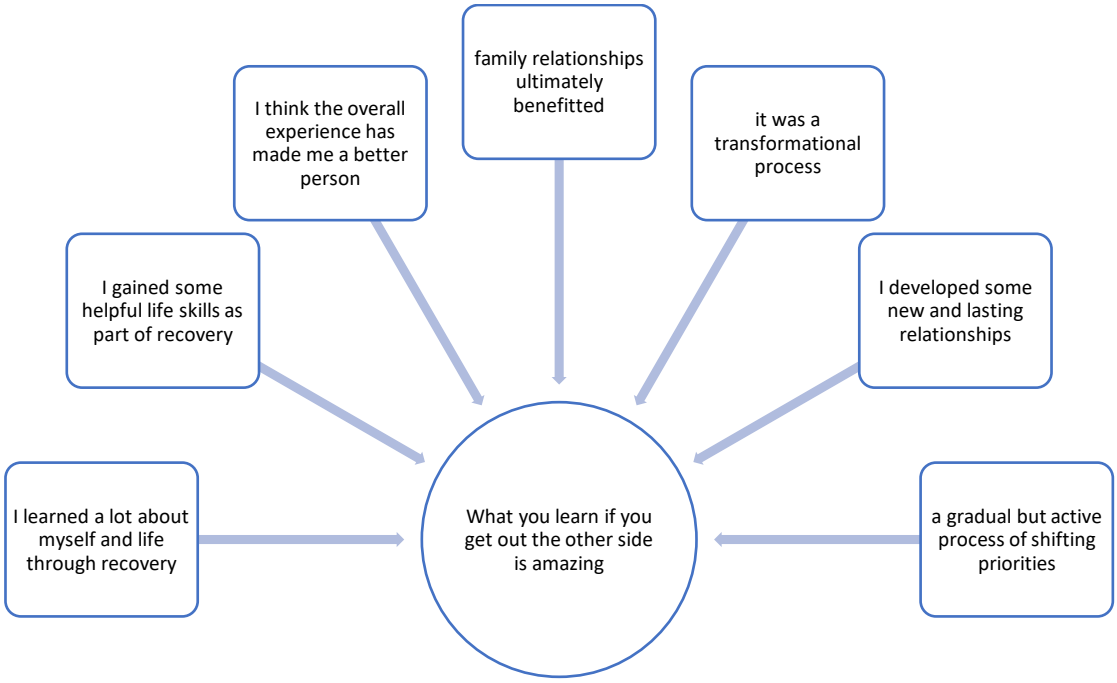


Figure 20 Code groups that contributed to Theme 6

Theme 7: It's what you do to get around it

Participants spoke of a variety of ways in which they coped with, or managed, their life alongside the ongoing presence of anorexia. Whilst some of the actions taken led towards life improvements that could be thought of as reclamation of life in line with a preferred future, others appeared to be a prevention of the situation deteriorating, or a means of getting by. The thread that connected these actions was one of managing the situation, either adjusting their activities and daily practices of living to accommodate anorexia alongside their commitments and intentions, or by navigating their way around anorexia in order to incorporate favoured activities. They seemed to be getting around anorexia in order to get along with life.

Some ways participants spoke of this included finding a means to get around anorexia in order to eat.

> *"I'm growing my food. But in a way, it's allowing me to eat food because I know it hasn't been sprayed and it's not fattening."*

At times this required what might be considered mental gymnastics.

> *"It was humiliating to stand there in my 30s and I am literally the size of a 12-year old boy. So, I picked the weight, because I like odd numbers when it comes to my weight, I made sure all the numbers of this weight were odd. And I made sure that my BMI was still underweight, and I said, 'Okay, you can get up to that particular weight. You don't have to take any special precautions so long as you are under that weight'. And I've managed to gain quite a bit by doing that."*

Skills in bargaining, negotiation or, at the very least, making things equivalent were utilised.

> *"I've got to say, 'Well it's ok if I don't do that, it's ok if I do this instead'"*

"I would say, 'Find what's safe. What's safe for you physically and what's safe in your head and try and match those two things together.' That way you're much less likely to die from it."

These actions could be seen as symptomatic or problematic in one frame of reference but were viewed by participants as what was necessary to sidestep or get around anorexia.

"Yeah, so say we were going out for a birthday meal. For the lead-up to that day it will be a sequence of following routines, only eating certain things. So, say I know we're going out for an Italian meal I'd just eat fruit and veg that day. No carbs or anything like that. And it would all be in even numbers … But it's what you do to get around it."

Having a preferred goal or focus was one strategy used.

"To have an important life goal. For me I focus on my [work]. Have something important to focus on, and you have to have food to survive. You just have to survive. You just have to do your best. But I wouldn't wish for anyone to be where I am right now."

Finding different ways of thinking about food was another.

"You have to relearn to enjoy food and enjoy life. When I spent time around children it helped me to eat again, because they just enjoy eating a cookie and you have to learn how to do that again."

"Not necessarily looking at food that could potentially harm me or make me fat. But that it's something that can be fun and can be creative. One aspect of it that I've really been enjoying is making it look really pretty. That has been helpful."

Using logic and reasoning.

"While I'm occasionally one of those people who gets into the whole, 'eating less is more virtuous than eating more,' I look at my friends and family who are into fitness and try to gain weight. They look really good and I think, well eating less is not making me into a better person, so I just kind of try to make it a little less virtue related. I try to get the bits in my head to shut up long enough to get the food in my face and then deal with the problem later."

Focussing on the concern or distress anorexia caused for others in their life was sometimes more possible than eating for oneself.

"Focusing on the distress it caused loved ones, and not wanting to be the cause of this pain. Thinking of this sometimes helps me to eat even when I really want to reatruct [understood to mean restrict]"

It wasn't always about getting the better of anorexia. In fact, on occasion, coping was about knowing when not to take a stand.

"And being able to just stop sometimes comes in different forms. Sometimes it's like, fear of being stuck in hospital and having no control over your food. And sometimes it's someone deciding you need to eat properly and feeding you for a couple of days. And sometimes it's just knowing I'm just going to let the eating disorder win for a few days because I'm too tired to fight."

Learning about how anorexia operated in their life and being able to predict and recognise how anorexia worked was one strategy utilised.

"It's helped because I feel more in control of it now. Because I can see it, I can see when it's stronger and go, 'I've got your number!'"

For some, this involved looking at the wider context of their circumstances and what else might be contributing to anorexia's influence gaining or losing traction.

"The first thing I will go to is, 'Oh, I could lose a bit of weight,' but I've learned to say, 'Okay, what's happening here? Something's going on in my life.'"

Assigning some of their thoughts to anorexia, and managing those thoughts by focussing on their hopes and intentions for life was sometimes helpful.

"You have to get on with life and keep down a job and relationships but having to control the anorexic thoughts, as you would. Keep them in control as well as wanting to hold down other things as well as a relationship and a stable job … you're wanting to sort of keep control of them thoughts as well as wanting to seem… I don't like using the word but to seem 'normal."

A non-combative approach to resisting anorexia was spoken of.

"People say, 'that is ED who is telling you lies and trying to destroy you and you should be fighting back' … It's not true, you have the thought and the more you fight against the anorexic thoughts the worse it makes you feel. You think they should go away but they get stronger no ..."

"Now I do remind myself. That's how I keep myself going now. It's for my health. Not that I fancy food or have an appetite. I'm eating now for the sake of my health."

Some participants devised practical tactics that left less space for anorexia to have a voice.

"Not weighing myself is a good one, not looking the mirror or examining my body."

"Having a meal plan is good. Not complex like in hospital, but just have a plan so it's there and it's okay to buy food if you have to."

This included utilising routines and structure that removed the need for continual and stressful decision making.

"If I go on autopilot it's easier. If I'm following that structure I don't have to think as much because I know that's safe, what I'm doing."

For some, making substantial life changes was helpful, such as changing jobs or living circumstances.

"I moved away from uni and in with my boyfriend, he did all the cooking so i would eat regularly"

Sometimes small but strategic practices, such as taking short holidays so that the temporary change in routine felt more manageable, was key. For others, considerable planning, organisation and/or recruiting the support of others was a means by which they were able to continue with valued aspects of life that might otherwise have gone by the wayside.

"I was able to attend some social events and I managed by bringing my own "safe foods", those around my were aware of my disorder and knew that I was going somewhere private (my car or in the tent when at a camping festival) to eat my food. I let them know and directed those around me on how to best help me … In an odd way, preparing foods and organising to go home and have that before going to an event has been helpful. I would often not engage in any new or different activities as my life often revolves around food/eating/routines. But having the reassurance that I can dash home and have my dinner, gives me piece of mind and enables me to rejoin colleagues out at events etc afterwards. I think also engaging in "structured" social events has been helpful, I joined a dance group which was primarily a job, for which we were paid, but whilst doing that I was able to also feel part of something bigger and feel like I had friends again."

Making a concerted effort to do things that they knew would be beneficial, even when they don't feel like it, helped some participants limit the influence of anorexia in their lives.

"Going to yoga classes frequently even when I felt to disgusted to look at or feel my body. They always feel worth it afterward. Went to a social gathering I really didn't

want to go to (nearly every one). Went back to uni at 27 (now in honours year) still hard to go on my bad 'head days' which might be 4 times a week."

Some strategies, such as self harm (which was only referred to briefly in writing) or some compensatory actions in response to eating were of more concern.

"In-between patients I'd be bingeing and drinking loads of water, and then making myself sick. So, it was really quite difficult"

What was notable was that these were identified by participants as a means of coping with, or managing, anorexia and not as part of the problem itself. One participant wrote about

'throwing things at walls'

as helpful, despite its potential for being interpreted negatively by others.

The need for practices of managing anorexia did not seem to disappear when participants arrived at what they considered to be recovery, and several spoke of ongoing efforts to manage life and anorexia so that it did not gain the hold it previously had on their lives.

"When I have big achievements now I choose to reflect on how I wouldn't have made them possible for myself if I'd not embarked on recovery."

Even participants who had lost hope of making significant change in their life still spoke of taking steps to make it more tolerable.

"I learnt to recognise when I needed help and would try to get it. My GP prescribes me a high calorie, total nutrition food supplement which I allow myself to have as "medicine" on top of a limited diet. I'm sure it helps me survive. I've now learnt to live with my anorexia stabilising so I can exist at a low level. Recently I have come to accept I will never get better and will never do many things I had hoped. I also know I can not do anything to hasten my death so try to make my life as bearable as

possible. I've resigned myself to this existence. I force myself to follow a routine and try to set goals to achieve no matter how I feel."

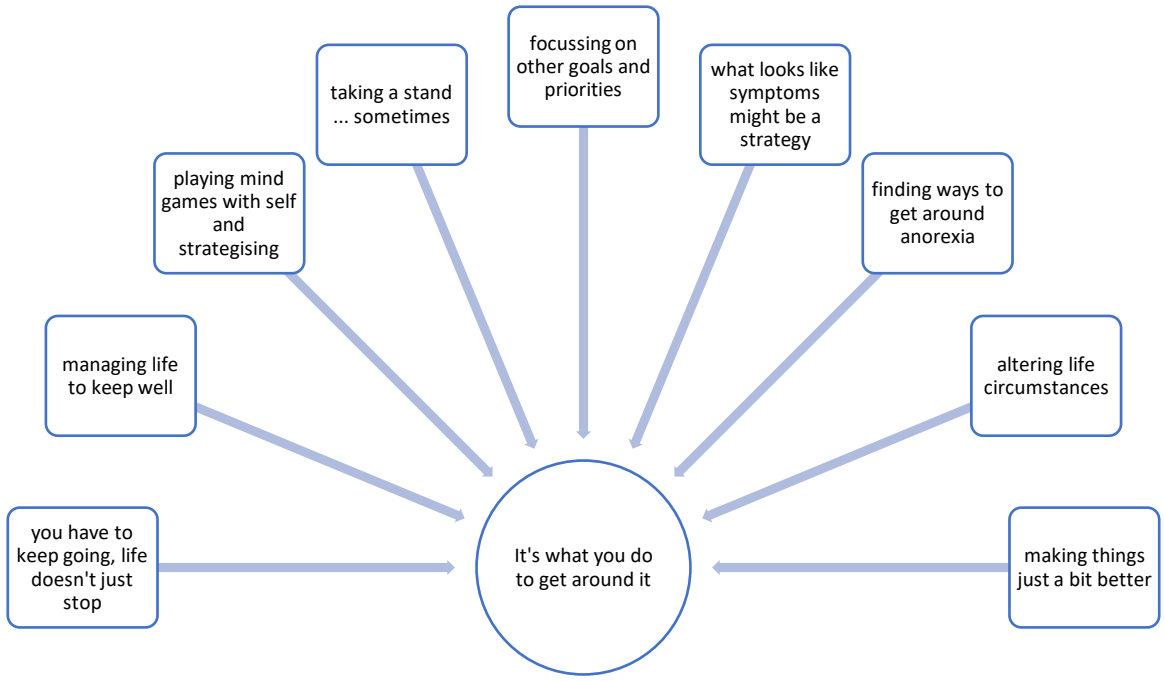


Figure 21 Code groups that contributed to Theme 7

Theme 8: Finding distraction, escape and therapeutic practices

Alongside managing life and anorexia, many participants spoke of the usefulness of escapes and distractions. These were activities and practices they took part in, that had a distancing, transcendent or therapeutic purpose for them.

"Things like putting on make-up that was, I think it's always just been like a therapeutic thing I can do to keep my hands busy. It's impermanent, so you can just wash it off if you do a bad job. You can experiment with lots of different colours. I think it was just the therapeutic nature of doing something with my hands. Keeping them busy."

"Kind of like a happy transcendence I suppose. Kind of like, even for a little while, to kind of get away from all of the horrible anorexia stuff. It's tricky because I'm sure it's not something I could have done all of the time, but at times, yes just transcend above all of the horrible things that were going on."

"I guess it's like going into a tunnel but it's a nice warm, peaceful tunnel. You're totally absorbed. Encapsulated in something. I can't think of the right word, but I guess it'll come. Like getting into a tin or something like that. Your safe space."

These activities were generally relatively everyday ones, accessible to anyone. Reading for pleasure, writing poetry or blogs, and journaling were amongst literary interests.

"reading books (whatever can keep my attention as it is good for distracting me from stressful thoughts as well as reminding me that there is more to life than food/weight/etc)"

"Journaling, that's really useful. Some of my journaling is theocratic, obviously I read Scriptures every day and that's what we do as Witnesses. There might be pages in my journal where I'm writing about Scriptures that talk about looking after and nurturing yourself."

Some participants told of listening to and playing music, creating artworks or taking up crafts. A creative element was spoken of as integral to many activities, and engagement was active whether sought out or making the best of serendipity.

"Sometimes playing music. I have what I call my recovery playlist now, just to… either to lift you up, or sometimes very sad songs."

"Listening to Einaudi always helps!"

"Music (practicing my instruments) helps by giving me something pleasant to focus on"

"I would say it's mainly when I'm unwell then I'm a lot more creative because that's where I find my safe space."

"I make the effort of looking on the internet for music I might like that I can download. I make the effort to look for CDs when I go to town. And I usually make the effort to play my piano. So, some things are my efforts, and some things just drop down from heaven."

"I love drawing and lately I've been doing lots of artwork and stuff to try and help when I've been feeling low. I've done a logo for a couple of friends from the forum who've started their own website, and I'm designing the front cover for the woman who runs the forum… she's writing a book on recovery from anorexia and she's asked me to draw a front cover for her book. So, I can kind of do it for other people and I enjoy it."

Other practices were considered comforting, particularly during eating or other stressful times.

"I'd use a hot water bottle on my stomach when I eat. I don't any more, sometimes I do. But that kind of felt like I was allowing myself to be hugged and wearing the fluffy pants made me feel like I was comfortable."

Some were distracting and absorbing.

"I'm also artistic. That's another of my outlets is getting totally absorbed in that. I guess it's all those recreational things isn't it."

Many spoke of the helpfulness of keeping busy.

"I keep busy and distracted. You can't sit with that all day, you'd go insane you just have to find ways of distracting yourself sometimes. I'm about to start my dissertation for my masters"

Busyness could be important, whereas being otherwise unoccupied could be risky in relation to anorexia's influence.

"It sort of made things worse, because I didn't have a job, so I ended up … in my spare time, I went to the gym. Because I didn't have anything to occupy my day, that's literally what occupied my thoughts."

"I think it's about me shutting out the bad stuff and knowing I have to find some ways of not harming myself."

Activities such as work and study served an important purpose in staying connected to a bigger life than themselves and anorexia.

"At times it's felt like the only thing that I can do or can still do. I can't go out socially anymore because it's too frightening for me. It's hard to maintain friendships. I see my parents every now and then, but only usually for a coffee or something not for very long. So, it's almost like work can be the limited social contact that you have, and that sense of purpose that you have outside the eating disorder."

"You try and live life as normal as possible but it's kind of like, it's essential to be able to eat and take care of yourself to sustain life. So sometimes it's easier just to make, have [people and activities] in your life. A lot of people just isolate but I need to keep busy, I need to be doing things."

Also, finding fun was identified as being the antithesis of anorexia.

"I think that was a word I haven't used. I wanted to have fun again, and anorexia was a classic not fun thing to have. And it was boring me, and I was boring myself … I

was not having fun, and life was way too short to not have fun. And that was the big part … and the sacred part of it … but that was a big part of it."

Fun was an important means of coping with difficult times. Simple acts such as watching comedies and cartoons were a great way of forgetting the challenges for a while.

"I think that, I don't know it just makes me forget things for a little while and reminds me that there are things that you can laugh at in life. I think cartoons are along that vein as well. I would watch a whole bunch of The Simpsons with friends, and it's something that's kind of nice, and familiar, and simple and funny."

Viewing television and videos were named as practices of coping, both for pleasure and, for some participants who enjoyed repeats, for providing a familiarity and certainty that was calming.

"Distraction when eating is huge for me. Having TV or YouTube on while eating is a great distraction."

"watching tv shows I know off by heart to soothe me"

One way these acts were spoken of was of taking a break or finding escapes from demanding thoughts.

"And I think I use [music] as an escape too, more so than just thinking about food. I follow my usual routine food, the same every day so I don't think too much about it"

"Anything that gets me outside of my head with my raging thoughts"

Activities that took them outside, being in nature, and engaging in non-extreme exercise were recounted by many participants.

"get fresh air and a walk in every day, exercise to feel good about myself and not to punish"

"being out in nature with the dog only times have moments of hope"

"I like having the garden too ... that's where I get a lot of my veggies. It's an aim, it gives me something to do, it gets me outside."

Similarly, being with or connected to animals and children was valued.

"snuggling with my best friend who is my cat"

"Taking walks with my dog - it clears my mind as I can focus on what is happening there & then"

"Going out with my children"

"I would look at pictures on my phone especially ones of my grandchildren"

Spiritual practices, including prayer, yoga and meditation were important for maintaining wellbeing for some, and yoga and meditation were spoken of as helpful.

"Meditation is a huge part of my recovery. connecting with the earth through spiritual practise. yoga, not just asana but all the aspects including the philosophy."

It seemed that simplicity and accessibility was an integral and consistent feature of what was helpful, as beautifully articulated by one participant.

"There's a lot of suggestions about doing like DBT, CBT, ACT, but they're not … It's sometimes really hard to apply that to life. You learn all these tools, and the most difficult part is when you leave and how you apply those things in real life. And so, I think using simple things … like if you go to the beach and you put your toes in the

sand, that's tangible. You're feeling the earth, or looking at the butterflies outside, or sitting in nature and hearing the birds. I remember when I was sick I would watch this girl on You Tube, she's from Canada and it's called 'The Little Things', like a gratitude journal. Connecting back to the little things in life, a warm shower being really comforting or, you know, smelling a flower. And it's like if you can connect to maybe one little thing, it turns into a bunch of little things, and eventually into big things. You can connect back to life and that's probably the best thing to know."

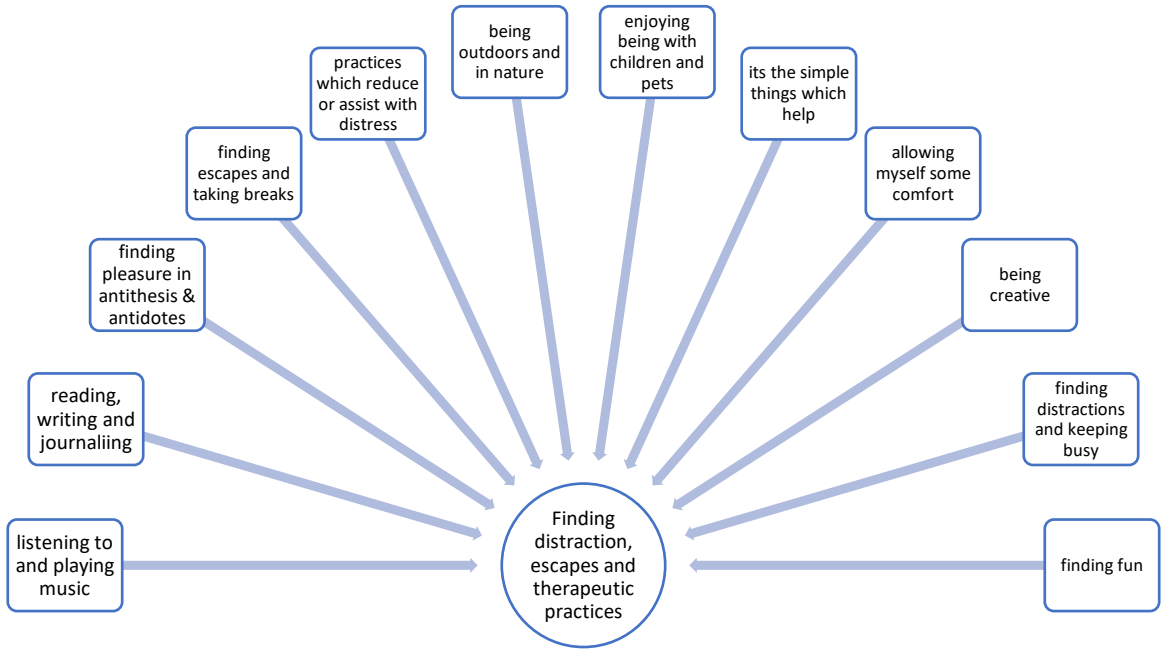


Figure 22 Code groups that contributed to Theme 8

Theme 9: Seeking connection and taking up activism

Despite, or perhaps because of, living with anorexia being identified as incredibly isolating many participants also spoke of actively seeking connections and of the efforts they made to do so. The significance and usefulness of connection is explored in greater detail in a separate theme, but this theme addresses the intentional steps participants spoke of in seeking connection to others, either through relationships and social inclusion or through engagement with what they felt were important social issues.

Connections were spoken of as a counter to anorexia.

> *"When I met my husband, now husband, I think that made a huge difference. I think having someone I can share that with, and be honest with and say, 'I'm having these thoughts.' And he's very supportive and understanding."*

> *"I've a good network of friends as well who know. Like my closest friends know what's happened before and they're… obviously they come around and see me, and we go out shopping and things like that."*

> *"Was open with my husband and made myself accountable for my actions"*

> *"When those things are happening, those are the days I fight harder because I want to stay connected to my communities and cultures, so I'll usually try pretty hard to not let my eating disorder win on those days".*

Connection was a means of recognising that they were not alone in their struggle.

> *"And, when you start talking to others and you start doing advocacy you realise like 'Wow, I'm not alone!' So many people go through it, and it's giving a voice to those who are still suffering in silence."*

> *"I really like the yoga community and so I felt good about myself again. People in the yoga community often have recovered some difficulties like addictions."*

> *"looking at eating disorder recovery blogs as it makes me feel less alone in my struggles"*

Connection was also, for gaining support.

"The community that's around me they're very body conscious, very body aware in a healthy way. When I lost weight when I was in India and I came back. They weren't sort of, 'Ooh, ooh, you've lost weight!' They were the sort of community who were like, 'Come for dinner. This is not good.' A lot of women like that … A lot of them are women that kind of notice and, 'Hang on… are you okay?' A classic one at the moment I got invited out … I know I'm in the right space when the other day I got invited out for dinner and I declined, and my friend gave me this look. And it was that look of, 'Are you okay?' Because, of course, going out for dinner is quite stressful as an anorexic. And she picked that I was having a hard time."

"Keeping in contact with other inpatients that I had found supportive on the ward. We remind each other of the need to move forward and celebrate the small steps. Have sent photo evidence of a particular meal or snack we are having trouble eating eg lunch or supper. Send positive affirmations to keep ourselves on track with recovery."

Crucially, the benefits of connection were recognised by participants and their efforts to spend more time with others were actively constructed in order to make engagement possible.

"Being at University I was aware that I needed to meet more people and found a job that involved that. So, the friends I recently had were part of a [performance art] group and we had rehearsals and were around together but in quite a structured way".

A sense of inclusion was valued.

"Researcher: What was the essence of those activities?
Participant: Probably the sense of social inclusion, which could have been anything for me. Having fun, watching a tv programme, a hug. Something really simple, but social inclusion."

Telling other people about their experience was a strategy some participants used to overcome the privacy invited by anorexia. This strategy also served as a means to ensure that people understood why socialising wasn't easy, so as to avoid offence.

> *"And it's important that they know… not the whole kinda story, but I have been open with friends that I've struggled with this, and that I need to be careful."*

> *"Being honest and sharing with others so that the secret life of anorexia would be more difficult to maintain."*

Creating and maintaining connections often took persistence, as sometimes it was a struggle to interact with others.

> *"And the third thing is people interaction. I hated it at first, but you get used to it and start to see the value in it. It's the value of distraction and the elicitation of a different emotion through an interaction with someone else is probably the best way I can describe it."*

> *"Went to a social gathering I really didn't want to go to (nearly every one)."*

> *"I've really struggled to work. I just started doing an hour a day at home for a friend's company."*

There was a need to overcome some limiting discourses about risks associated with people living with anorexia being potentially harmful to one another if engaging in unsupervised communication (see Lavis, 2011; Tierney, 2006 for discussion).

> *"Even as I was writing that I was a bit concerned about how that might be taken [that I engage in an online eating disorder forum] because I know they can be very disruptive and unhelpful, and I think it's more because there are certain areas where there are more adults and reassurances that I can see what's going on in their lives, and feel a sense of connection I don't get anywhere else."*

"We weren't really allowed to talk to the other people and we were told we couldn't exchange numbers. They didn't want us meeting up with each other afterwards because they thought we would be a bad influence on each other (laughs) which I think was a shame because we're all adults."

Making these efforts was not necessary done lightly and some spoke of the importance of finding the right people with whom to connect or build a relationship.

"Of course, she was in the right mindset and she was ready for recovery as well, and she was very instrumental in helping me to feel like I had another person"

"Speaking to them directly about it. Especially friends and loved ones who I knew were not the type to be dramatic."

These relationships were actively sought, and some participants found going online was the most effective way to connect with people who understood their situation.

"I then went online and found an eating disorders forum, a worldwide forum with lots of people in recovery from anorexia. And so, I think that was the most useful thing because I think they actually did understand, because the professionals although they know what they're supposed to do to help, actually living it is a completely different thing."

Persistence and discernment were named as important to finding appropriate online connections. Care was taken, and some participants alluded to not wanting to inadvertently end up on pro-ana[9] sites. There was a slight air of defensiveness in these statements, possibly reflecting awareness that engaging in online eating disorder communities might be represented as problematic.

[9] Pro-ana sites are websites and internet forums where (often young) people living with anorexia connect and promote or encourage practices associated with anorexia (see Lavis, 2011 for a discussion).

"I mean it's finding them. It's taken me a while to find them. You know, because obviously online forums for anorexia you don't want to stumble on the wrong ones and you don't want to find anything that's triggering or anything like that but there are places out there to find one another."

"I don't feel I am talking to people who want to die. I started an Instagram account to recover but they weren't truthful, they posted just to get more likes. It's not sincere. On the forum, we're not trying to get more likes or followers we are just being ourselves. We are on there for the support, not to compare."

Sometimes the connections participants sought out were vicarious, rather than making direct contact, such as hearing stories of others' experiences.

"I very selectively read some people's success stories and how they coped, what helped them. And that was really good."

One participant spoke of the decision to take part in this study as an active intention to connect with the experiences of others. Part of what she spoke of was the importance of being able to make a contribution to others, as much as to hear of their experiences.

"In saying I was desperate to speak to you about all of my experiences because I wanted to help other people, I also wanted to hear about other people's experience … I'm seeing an image in my head now of a line drawn between me and the Facebook post and me thinking, 'Yes, I'm jumping to that because that connects me to the experience. There's some other experience there that I can latch onto.'"

At times, difficult steps to overcome or get around anorexia were given impetus because relationships and people were viewed as an important priority.

"When my significant other said they would probably leave me if I didn't stop my behaviors, I increased my food intake and stopped tracking calories. I am also trying to reduce time spent exercising"

"My parents volunteered to bring up my 5 young nieces and nephews after my sister and her husband were killed in a car accident. I vowed to help them as much as possible so have needed to maintain my health so I could do so. After 16 years, last year all the children had left home to work or study.. My parents are elderly I still help when I can and visit them each day."

Connection to the wider community/society was practiced through participation in political matters, activism and making social contribution.

"I taught myself to use a computer and the internet which has opened up the world to me and something I can do at home. I have got interested in local government and central government affairs and often make submissions to help make it a better country. It makes me think a lot about other things and feel as if I'm trying to do some good … I don't go to hearings or anything, I just do it via the internet. You wouldn't see me. There's something I've been really fighting against or fighting for that's become an important part of my life. It takes a lot of thinking and waking at night just thinking about it … it's a few issues that really affect me. The first one is they were going to build a dam and destroy a whole load of native bush and I was totally against that and saw that a lot of other people were. So, I've spent the last three or four years trying to stop that happening through submissions, letters to the Council and all that."

"Getting more involved with politics and social justice (podcasts, Twitter, speaking with others who share similar views/experiences"

"Yeah, cos you can't march down the street if you haven't eaten first. Because then you faint and that's not a great form of protest … I've been to a lot of rallies which has… there's this photo of me at my lowest weight at a rally and I don't know how I

got through that day other than adrenalin. Because I look so incredibly sick, and I keep the photo around as a reminder that I don't want to go back to that. Since then I've definitely come to the realisation that it's not sustainable. It's great to have that activism around, because I'm not doing it for myself. I'm doing it for other people who probably need some change, and often I fit into those demographics too. But it's never been about me, it's always been about other people. So, forcing myself to eat something so I can go march down the street, was quite helpful".

As well as through engagement with culture and heritage

"I've been able to learn about the links with my own whakapapa[10] and what that means for myself as a Māori person. It's been really good for, not forming because I already had the identity, but solidifying my identity. And there's a lot of research into how cultural identity is really important, and for a lot of people with mental illness it gives us a place in the world where it's ok for us to be us."

"I'd done a few years' research, genealogy, and it was a chance to go over and see where my family roots were from and all that. So that was, as I said in my thing, I put a lot of effort into getting to a certain weight, so I could go."

Some stories evidenced efforts being made to maintain other forms of connection to aspects of life and cultures that mattered to them, such as beloved sporting cultures.

"I used to really enjoy playing rugby but now I'm at a weight where I can't safely play [so] I referee now."

[10] Māori geneology.

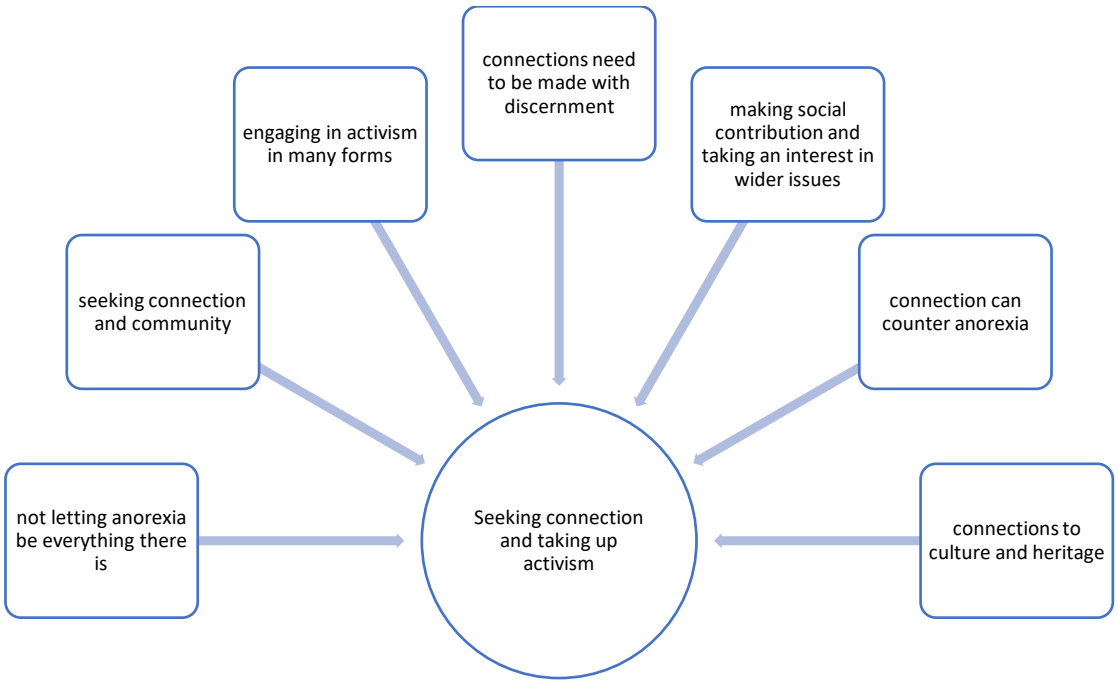


Figure 23 Code groups that contributed to Theme 9

Theme 10: Doing research, embracing feminism and exploring the 'new and different'

Several participants spoke of active attempts to both make sense of their experience and move beyond it through seeking understandings, knowledge and exploring alternative possibilities for thinking and living. Research was done on the internet, using blogs, websites and following activists on social media and recovery forums, as well as watching related movies and documentaries. Others engaged in more formal forms of education.

> *"Reading online resources"*

> *"looking at eating disorder recovery blogs as it makes me feel less alone in my struggles"*

> *"I actually sought [To the Bone[11]] out because I saw the trailer and thought that doesn't look like my kind of thing. Because normally I like action movies, and fantasy,*

[11] 'To the Bone' is a semi-autobiographical Netflix movie released in 2017, documenting a young woman's experiences of anorexia, which caused consternation amongst the international eating disorder advocacy community due to claims that it glamorised anorexia.

*supernatural and that sort of thing. So, I don't really go for the sad soppy stuff. But I sought it out and I watched it, and the obsessive stuff… oh, and the different types of eating disorders. And just having a combination of the symptoms and signs of eating disorders. I definitely related, and it helped me realise I've got a problem, and if I don't stop now it's going to become irreversible***."**

There were a variety of interests and approaches to research such as seeking information about anorexia from a range of perspectives, including exploring therapeutic modalities.

"I do research and bits and pieces whether that's why psychodynamic is so helpful, and that narrative therapy stuff. Highlighting the subjective. Rather than CBT which focuses on the behaviours."

This included taking an interest in social and political understandings, such as feminism, the body positivity movement[12] and critical media literacy.

"I've spent a lot of time reading feminist literature and I think broadening… for instance on Instagram I don't follow the eating disorder community any more, I follow certain body positivity [sites]."

"I was using to seeing very thin women represented in the media. So, seeing people with larger bodies being really happy and feeling good made me feel good as well. And learning about a lot of the tricks that the media uses, and generally learning about double standards with men and women in terms of attractiveness. I think that was helpful for me. I think it kind of allowed me to see some stuff a lot clearer."

"Learning about politics, feminism, and social justice have been incredibly important to me and understanding my illness. Although eating disorders are not entirely

[12] There are currently two common forms of 'body positivity'. The original movement promotes body acceptance and is connected to the Health at Every Size movement. There has been a more recent co-option of the term by online fitness gurus to promote diet and exercise regimes. In this thesis the term is used to mean the original movement, as indicated by participants.

caused by social or cultural triggers, they obviously impact so much of what we experience in our day-to-day lives, and understanding how they affect both ourselves and others - how they spread messages that fuel disordered thinking/behavior- can be empowering; being aware of implicit and explicit messages that harm us is just one step in learning how to combat ED thoughts - in my case anyway, and I think it has helped others, too."

Several spoke of this search as one of trying to discover how to make sense of their experience.

"It took me a long time to convince myself that I'm truly anorexic. That was my own hard work to understand it by my own research"

"I tried to find stuff online and trying to diagnose myself when I first realised, 'Hey, I've got a problem.' And you find a lot of stuff on puking and laxatives, and having a restricted diet? But how restricted is restricted? And how bad is it? Because BMI isn't that accurate, and the waist measurement thing that doesn't really help. I guess if you don't do it properly. There are a lot of things that can help you get on a diet, but not a lot of things that can tell you that your diet has gone too far."

"I think kind of understanding my experiences … Anorexia exists in a social context, as do all our experiences and as a young girl and as a young woman I was exposed to a lot of things. And I don't know that it fully represented my experience and the experience of a lot of women growing up. I think it was devoid of that, and I think feminism, or the feminism I have surrounded myself with, acknowledges that a lot more and can understand it a lot more. … it's made me feel that my experiences are less unusual. But actually, they're sadly quite common but other women might not have taken the rather extreme path that I took. But I think being able to understand it as a coping mechanism and a response to a very difficult situation, and me doing my best with what I had available to me at that time and for me anorexia fell under that. It was me doing my best with what I had available. And I think viewing it as

that, rather than this terrible disease. Which it is but, I don't know, I think it makes me feel less to blame. I can understand it more."

Some sought out self-help strategies that might be helpful to them.

"Read books about other people's experiences & how they have helped themselves."

A couple of participants spoke of how they researched approaches to health and nutrition and incorporated new eating practices into their lives as an alternative to anorexia.

"I don't think I'd be where I am today in terms of recovery if I hadn't have done those qualifications. It was almost the recovery I needed to do, post my eating disorder to ensure I never got skinny again. So, I could fully understand what happened to me … So, for me understanding psychology was how I could see why I did things, and with personal training I could see that exercise was for human body function, not just for calorie counting. Learning about nutrition helped me understand how nutrients are something that helps you function, not just something you manipulate to change your body shape. It opened my eyes to seeing nutrition as something different. Once I studied it I realised it was what you need it for."

Some went on to explore and adopt new philosophies or lifestyle approaches which stood out as being alternative ways of thinking and being to that of anorexia.

"Yoga is no judgement and no comparison, and I like that mindset. I've been practising mindfulness meditation for quite some time and that helped me the most to recover. I really connected and started to practice it more and that has really helped, and to be around people who really understand the concept."

"I was really lucky at the right time to fall into sacred food practices and that was through yoga, and when that happened it felt like there was a real shift of being able to hear myself think … It started with thinking of food as sacred. Not in a religious way but a more earthy way. I began to consciously connect food with my spiritual

path. Then I couldn't limit my intake so much because it was part of the work of celebrating that connection to the earth. It took a long time to feel my body as sacred. I knew the theory, but I had to get to the feeling. That's really recent and I struggled a lot before then. When I would feel the urge to control and to limit and to push my body I learned to stop and come back to this idea."

"There's often an element of, 'Oh this is a bit new and different, and maybe I can just be happy now. I can be into meditation and make a new identity that way. But the cool thing about yoga and meditation is that they kind of don't let you do that. They keep drawing you back to why you're there … modern life is so set out to make it easy to have things like eating disorders, because we're so distracted all the time. You know, we hardly ever have a moment when we are just doing nothing … And I think that's what's so unusual about it for me … So, yes definitely offering something new."

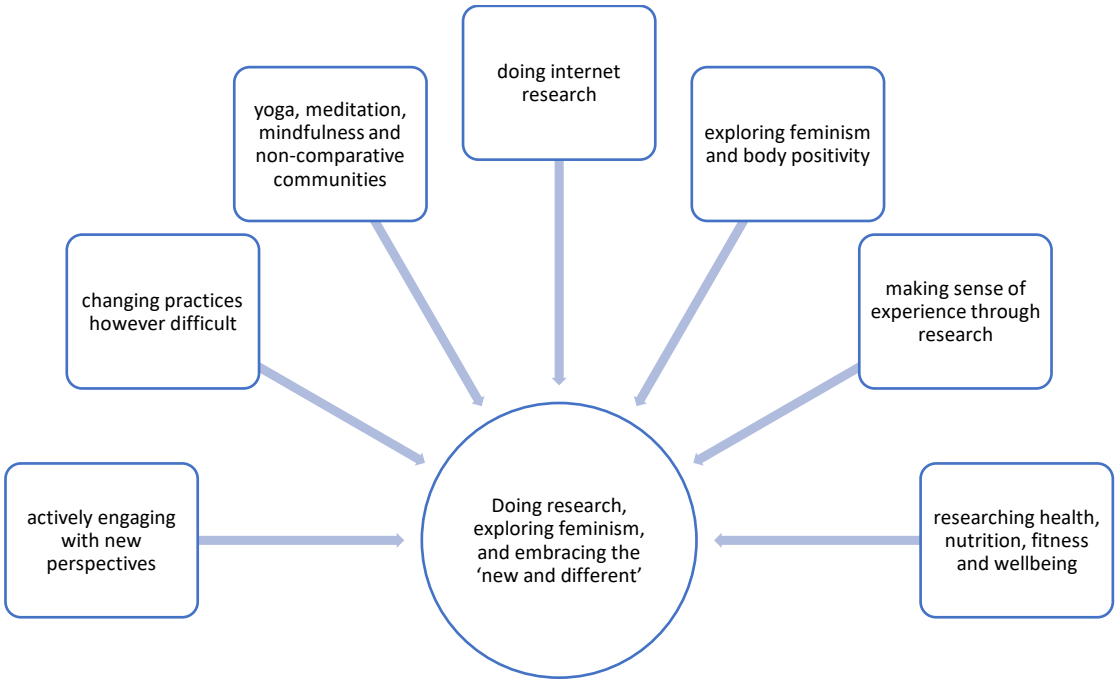


Figure 24 Code groups that contributed to Theme 10

Theme 11: Recovery is more nuanced than currently portrayed

When spoken of by participants, recovery was considered to be complex, and the concept was not uniformly defined. Some spoke of recovery as being an absence of anorexia.

> *"Not being compelled to move, but just being able to move my body in the way I want to move my body, when I want to move my body. And a day lying on the sofa, then being able to do that and not feeling totally anxiety ridden. Being able to socialise again, spending time with friends and family. Being able to have a family Christmas meal … just living a very normal life that most people take for granted. Probably the life I took for granted before anorexia hit. In terms of being very normal, having relationships, being able to socialise, being able to work but work not being the only thing in my life. Being able to travel and go on holidays."*

Others told of their experience of recovery being a reprioritisation of matters of importance in their life.

> *"That shift in priorities from the thinness and weight loss and food restriction being right at the top. To having relationships and career and that sort of thing being more at the top. And yeah, I guess just knowing that that is the sort of thing that can happen, and you can end up being comfortable with."*

For some the word recovery felt too rigid for them to identify with it, arguing the term was unreasonably used to both define their experience as an illness and prescribe what their goals and hopes should be. This was found to be constraining with the potential to set them up for failure.

> *"Over the years I haven't identified with the term because it implies that you had it, and you can just take the right drugs and get better … I think my own definition of that now is just actually unwinding and working through the things rather than just allowing them to be there but filling yourself up with enough stuff so that you can ignore it for a little while."*

"That recovery is not returning to your old life, but creating a new one for yourself"

"I think also perhaps an acknowledgement of the things we discussed around recovery, that it's more nuanced than I think is currently portrayed and it would make life a lot easier for people if there was an understanding of … I'm just thinking of the slogans that you get of 'recovery is possible', and I've been part of that as well. Until I started to think about it more critically, and maybe for some people recovery isn't possible. Or full recovery isn't possible, but if they find a way to have a meaningful life and that's okay for them, and that's perfectly acceptable. And perhaps that needs to be portrayed in services a bit more, I think."

For some recovery was not necessarily thought of as an absolute position, or final destination.

"You can have two ideas that can co-exist at the same time, and that was one of those lightbulb moments where, you know, I can live and have a good life and still have some of these thoughts at the same time."

"I think that we need to view it more on a scale and that fluctuate throughout someone's life."

"There will always be remains of it. There are still fears I have now, that are from the eating disorder even though I don't have the eating disorder voice. It is going to be a part of you, but it is not all of you, I think that's a really big thing."

"I have filled this out as I do not feel people ever recover from an Eating disorder. It is always with you - you either learn to live with it or live with it in the background"

Although others did speak of anorexia as having completely left their lives.

"I consider myself fully recovered, seven years now where I don't have body image distortion or the eating disorder voice."

Nor was recovery considered to be a separate endeavour that was divorced from the rest of life, but was embedded within wider beliefs and approaches taken up by participants.

"It's funny, it's a conscious thing. I built my whole business on it not being about weight loss. I was almost vicious with anyone who talked about weight loss in my classes. We don't have the classic yoga attire, which is yoga tights and not a lot for the teacher. No, it's baggy yoga trousers and tops, so it's been a really conscious decision for my students not to be facing that, but also for me to take that … again to dial that down. So, confronting that every day on the yoga mat and dial that down."

However, a common theme was that several of the services engaged with had been experienced by participants as having rigid and limited perceptions of what recovery meant. Service-led definitions of recover that didn't meet the experience of participants at times left them frustrated, lacking in sufficient support, feeling misunderstood, and inviting a sense of personal failure and hopelessness.

"I actually find it more useful with people who have a similar history to me. Because it's not just as straightforward as eating. Because that's what some people say, 'Just eat, your brain will be fine.' Well actually, I've eaten I've put the weight on and my brain is not fine. It's far from fine"

"It's been there for a long, long time so it's not a failure if I never fully get rid of it from my head."

A focus on body mass index (BMI) as being the main determinant of recovery was perceived by many as problematic in that it was discouraging and dehumanising.

"On the F.E.A.S.T[13]. website they talk a lot about 'state not weight' which is a concept that Janet Treasure and people like that talk about. Take that focus in treatment services away from our weight. I understand they do need to weigh us, but let's take that focus away from our consultations. I'm not just a number on a scale, let's talk about what's going on in our brains and not just what's going on, on the dial."

"Things like graphs, if you're having to sit there in front of a piece of paper for your whole therapy session, with your weight on a graph it's just, it's really confronting, and it's not conductive of therapy or telling you that you have a life above the eating disorder. It's going, 'You're just a graph.'"

This focus, they argued, drew attention away from working towards change that was more meaningful.

"I think in talking to the individual person and having them engaged. Yes, monitoring weight and intake is important but it's not helpful to fall into sessions where they are just talking about symptoms. So, asking what a meaningful life would look like, more collaborative, that stuff."

"Yes, it's about finding what's your normal, and what you're happy to call normal."

"Measuring recovery would be measuring how your life has improved, the quality of your life. Is it better, are you still restricting by not eating this or that? Because I could be at a normal weight and eating what seems like a normal diet, but deep inside my life would still be a living hell. The appearance would be ... When I was in (overseas city) I was eating a healthy vegan diet and people thought I looked great, and I was well, but inside I feel like crap and I wouldn't be healthy in that situation."

The emphasis on BMI was also considered unrealistic as it did not address their concerns, so much as the concerns of those around them.

[13] Eating disorder advocacy website http://www.feast-ed.org

"First, you're in all these services and people are paying attention but then you get to what's considered a healthy weight and people think you're recovered but your brain is a complete mess. Nobody can see that because it's not physical."

"Not being treated like another number, and not so much focus on your weight. Because even my parents they are going to measure recovery with how much you eat, and how much you weigh. And I don't think that's a good way to measure recovery."

There was a sense that the focus on BMI also blinded health professionals to what was happening in a person's life when they no longer fitted into definitions of severely underweight, with unhelpful results.

"I think that there's still not enough understanding of what people go through when they're not severely underweight with anorexia and I think that from what I can tell, when I was going through the first lot of treatment I felt like the people who were treating me didn't know how to help someone who was not severely underweight but was still really unwell, if that makes sense"

"When I was being told I was just fine I was really miserable and really distressed that I had gained so much weight on medication and using quite extreme methods of trying to make my weight drop again."

A personal sense of recovery and weight being misaligned could result in an ongoing, if not exacerbated, struggle that wasn't necessarily recognised by services providers, leaving participants distressed and without adequate supports, often eventually leading to a return to a low bodyweight and restrictive eating anyway.

"I'm a healthy weight and from the perspective of most people I'm recovered. But my brain is really struggling with being this weight. I do not want to be this weight. I hate my body. I struggle with getting dressed in the mornings. I end up putting on

four or five outfits and still feel very uncomfortable. I just don't feel like me. And then I've got all the emotions as well"

"They take you so far, and then if things aren't quite right, it's easy to go back to what you were doing before"

Sometimes, attempts to move towards a preferred life became co-opted by forms of absolute thinking that were associated by many with anorexia.

"I went from my perfectionistic, 'I'm going to be the best anorexic I can be, so I'm going to be the best recovered person I can be. I'm never going to slip up and I'm going to count all the different ways that I've not engaged in behaviour. I'm going to be perfect"

"It's just learning how to manage that rather than labelling myself 'better' or 'suffering'. That's what a lot of the therapy helped with."

"And, don't get me wrong, those still creep in. You know they will creep in and they'll start talking, 'You're not ok' and I have to tell myself, 'No, it is ok' and it's hard but I've done enough work."

There was also some frustration that messages such as 'love your body' type campaigns left participants feeling that they had not achieved enough just by making improvements. Loving their body felt an unreasonable expectation, and a much more realistic and desirable hope was to at least not hate or loathe one's body.

"I'm not going to claim that I love the way I look. I've got to a place at the moment where I can tolerate it. I can tolerate my body, I don't weigh myself. I enjoy food … I follow certain body positivity. But even within that I think there's a certain ideal that, you know, 'My body doesn't look like that and I'm not vegan and I'm not a clean eater, or whatever that bullshit is.' You know, that's not how I want to be. I just think that there's a certain portrayal of recovery that doesn't match my experience outside

of severe and enduring anorexia … I think for me that's where I've reached. It's a tolerance rather than a complete self-loathing and hatred."

There was also mention that limited and prescriptive representations of what a recovered body looked like was problematic, and arguably part of the wider story of body perfectionism that led to eating difficulties in the first place, leading to people being unclear about whether the concept of recovery was a good fit for them or not.

"I think also there can be a lot of pressure to be recovered and do all these things that are recovered. Or that if you recover you fit a certain mould, so that if you recover from anorexia your bodyweight must be at the bottom of a BMI scale for instance, that you will be very slim or that you'll have a certain relationship with food, or that you'll act in a certain way … I also kind of acknowledge that as a privileged, White female I don't identify with the recovered bodies, so it must be very difficult for people of different ethnicities or people who identify as overweight to identify with that ideal of recovery, whatever it is. Because I certainly don't."

Having individualised understandings of, and hopes for, recovery was spoken of as being much more desirable and helpful.

"I think also that you need some sense of hope that improvement is possible. I think I want to say improvement rather than recovery. It's not linear, but also there are different versions of that and you can choose what that looks like, and that you can… I think that's what I didn't know. That it's not passive. You can have a choice and you can… I think it can often feel like you have no choice and no control over what happens, and I think maybe that there are different possibilities and there are different people that have learned to navigate it in different ways."

For some this meant not wanting to be limited by labels of chronic, and limited options for understanding recovery.

"And, you often hear that the relapse rates are really high, so you think, 'Oh cool, so I've got this for life!"

"When the patient is having that battle in their brain they are really trying to understand and are trying to maybe have some hope of getting out of it. If they don't get support at that time it's like pushing them back into it and they're just going to give up."

They maintained hope through a belief that recovery, as they understood it, was still possible for them. They neither wanted to be trapped in what they thought of as a half-illness for the remainder of their life, nor told that this was the expected outcome for them.

"They say get you up to so far and see what you can deal with and that's just a BMI of 17/18 and keeping yourself well and that's fine. No, I don't want to be told that. I want to be told that recovery is possible because I have to know that recovery is possible, and if you knew what it was like to live with a BMI of 16/17/18 and keep yourself there… that would leave me suicidal if I knew that was what it was going to be for the rest of my life …"

"This is what makes me so angry as well. It seems like… you see it so often in the adult eating disorder services, and even in that Louis Theroux documentary, the thing that makes me most angry and upset…. I think because the treatment services believe it, that we don't want to get better or we want to live with it… we've lived with it so long and this is our normal and the best that we can hope for … I believe that every person wants to overcome it. And as much despair and soullessness, and lifelessness as you see in people, and as long as they've been ill, that's they want that. I have friends who have been ill for 30/40 years and now they are fighting services because the services are telling them, 'This is as good as it's going to be for you.' And yet, they're just expected to be revolving door patients. And it's like, 'Please don't, don't put that on us.'"

"I was first told I was a chronic and enduring anorexia case when it had only been going on for five years, and you get that…. You almost feel like you've been given up on by services."

For others, making the best of things and aiming for a few small improvements was a preferred option, as notions of pushing for full recovery, as they understood the term to mean, were seen as disruptive, exhausting, pointless and ultimately off-putting.

"I think before it was very much about 'recovery' whereas for me this is more about 'improvement' and improvement as defined by the person rather than a number. So, improvement might be that you gain more function, or it might be that you are able to eat out, for example. And it might be that you restrict your calories, or control them, maybe. But there's some shift from the rigidity that is life with anorexia. Yeah, I think that is more important than an arbitrary number, that when you reach your BMI of 18.5 or whatever that that's it, that's the pinnacle."

"It is depressing when I think of it like that. I suppose having had an eating disorder for, well now going on 12 years, getting better isn't really something I know if I'd want … I mean, I know how much work it would be and what kind of intensive therapy and that kind of thing that it would take. I'm not dying yet so I might as well keep going … So, I'm not sure I've got the energy to deal with that and at least the early stages of recovery."

Greater accommodation of personal wishes was experienced as positive in terms of engaging with therapy.

"Finally, having a psychiatrist work with me to improve my quality of life, maintain a reasonable physical condition, but not focusing on weight or full recovery- increasing other areas of my life to make it more fulfilling, rather than trying to simply remove the anorexia without any substitution"

For others, recognition of recovery being complex would include not removing supports too early once bodyweight had been restored yet anorexia remained prominent in their thoughts, leaving them vulnerable to it regaining ground.

> *"I came home from treatment it's not that you come home from treatment and you're fine … [treatment] doesn't really prepare you for 'Oh I wonder what happens if I end up having to skip a meal because I end up doing x or y? Is that normal? Should I worry about recovering that meal?' So, there's that kind of negotiation period, where you're trying to work out if you're eating disordered or not. It's like, 'Do I still have anorexia? Or not? If I do that is that normal?"*

> *"But, it is still in my head, I still have to battle it. Some times are worse than others."*

> *"If we think that we've cured it, it can come along and trip you over … 'Oh I'm over, I'm all good!' and it can slip back in insidiously almost, and I've realised that."*

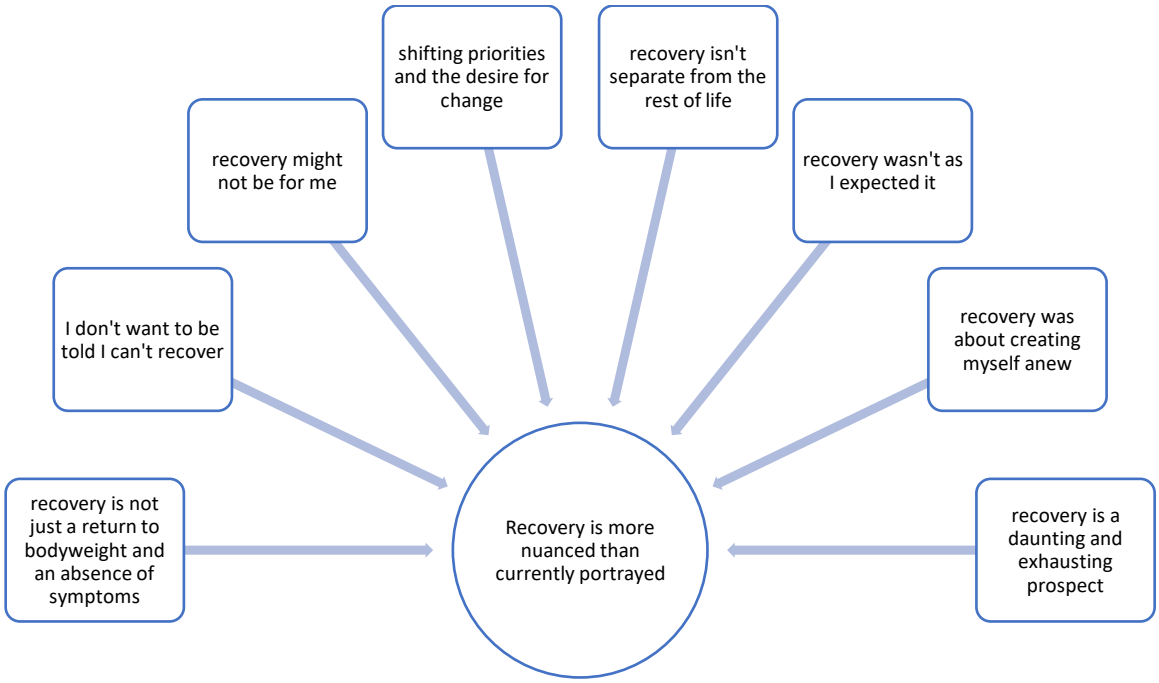


Figure 25 Code groups that contributed to Theme 11

Theme 12: Connection, community and 'being got' matter

The isolating consequences of anorexia, and that many participants actively sought to counter that by creating and maintaining connections, have been addressed in earlier themes but, alongside these, the actual significance and beneficial aspects of connection and understanding was a strong theme on its own. Connection and understanding were highly valued by many participants, and their missingness was frequently lamented.

Having a good connection with therapists, and a sense that they truly understood, was spoken of as central to participants' wish to continue speaking with someone about the difficulties they were facing.

> *"When I ended up getting a therapist who was absolutely fantastic"*

> *"I think really the whole non-judgmental thing. I could tell her anything, and she was not going to judge me for it"*

> *"Because we had, there was me and about four other girls went to a group counselling session with her, on a Monday night. And I could tell that all of us were very, we trusted her. All of us could open up and speak to her. In front of each other, as well as counselling us on a one to one basis as well".*

There was no one therapeutic style that was predictably favoured, as different participants appreciated different approaches, but a good fit and sense of connection was highly valued and considered to be an important component of therapy.

> *"I almost feel like it would be like Carl Rogers, unconditional positive regard. She was there for me no matter what. I wasn't afraid that if I did something she would leave".*

> *"I think for me what gave me hope was someone who… it was my therapist at the time… someone who had confidence that I could achieve it, and who always believed that I had it in me to achieve movement from where I was at that time regardless of*

all the years that I'd spent being anorexic. So, there was a sense of someone else having hope or of being able to see it was possible."

Poor fit connections seemed to result in therapy being less useful and engagement less likely to be maintained.

"With the counsellor I saw before, she was very honest and very to the point, whereas the one I saw after was very, quite… asked lots of… the only way I can explain it was she was quite floaty."

"I think that kindness was really missing from him. I don't do well with…. he was very paternalistic I don't do well with that."

For some participants, finding a strong connection with special friends or partners was pivotal, and these people were spoken of as playing a highly valued role in the participant's life, giving them an increased sense of their ability to manage anorexia.

"Luckily my closest friends are very, very understanding. They 'get it' if that's the right phrase to use. They understand what happened. They understand it's not me not wanting to talk to them, or anything to do with them. It was an illness. They understand that."

"But, with my husband he's someone who didn't know my past, who I told very early on under the impression that that would definitely scare him off. He would definitely run, and he didn't. And I think that was probably the single most important thing for me, that someone could see that I had a very, very colourful past, shall we say. But still be interested in the person that they saw, and I think that was probably… that was important for me, and kind of, yeah, changed things for me a lot."

Perhaps some of the most significant connections spoken of were those with other people who also had experience of living with anorexia for a long time.

"Of course, she was in the right mindset and she was ready for recovery as well, and she was very instrumental in helping me to feel like I had another person … She made me test the water like, 'Let's eat this meal together. If you can't do it by yourself, let's do it together.'"

Group support/therapy, and particularly online forums, were spoken of as lifelines and places where participants felt understood or less alone in realising that they were not the only person struggling with these difficulties.

"The best thing I liked about treatment was group therapy because there's this, people who have eating disorders, there's like this forever unexplainable connection that you don't have to explain what you're going through…people just get you."

"It made you feel a bit less weird. A lot of the other girls, it was all girls, that went to the group therapy. When they mentioned something that sort of related to the OCD as well, you though, 'Ohh, I'm not the only one.'"

"I then went online and found an eating disorders forum, a worldwide forum with lots of people in recovery from anorexia. And so, I think that was the most useful thing."

This stood in contrast to some of the isolating experiences they had when engaging with treatment services and programmes.

"As an experience, other than in the waiting room of (the ED service) and assessing one another (making assumptions in your own mind) and wondering why they're there and what their experience is, you don't have any other connection with anybody else at all. It's a very lonely, singular experience."

"I've become very involved in the eating disorder communities online and things like that, where we share a lot of information. I've got more support from those sort of communities than from treatment services."

Shared experiences didn't need to be exactly similar.

> *"You know that they truly understand. And although our experiences are all slightly different and we see things differently, it's just that kind of understanding that as a group of people we seem to have***."**

However, age and life stage mattered.

> *"I'd probably say one of the most useful people is someone I met on the forum who I know speak to daily, we just message each other on Facebook, and we just get each other. We're a similar age, we've both been through similar background history of trauma and stuff ... So, I feel like I can just be open and honest and talk about how I'm actually feeling. But I'm not good at doing that with other people… you know the professionals."*

> *"It would be more relevant for me to speak to someone of my age to talk about what they're going through. The thoughts in our heads might be the same about what not to eat, and the external way of coping with it. But the very internal things about how we feel around our age, that's the bit there's no connection with anyone about. Women suffering from anorexia share the common ground that we are all starving ourselves, but our experiences are undoubtedly closer to those of our own peer group."*

Online forums were sought out with discernment.

> *"It feels safe there because it's a community and you have to be invited"*

> *"Even as I was writing that I was a bit concerned about how that might be taken because I know they can be very disruptive and unhelpful, and I think it's more because there are certain areas where there are more adults and reassurances that I*

can see what's going on in their lives, and feel a sense of connection I don't get anywhere else."

In doing so, care had to be taken to ensure that the forum did not dominate their lives, or that the participant did not entirely adopt a carer/support role for others, as this practice was considered to have the potential to become overwhelming.

"Because its (online forum) 24/7 you can almost become too embroiled in it because it's too widely available, and there's that risk that it becomes a bit too absorbing and it becomes too much of your identity, and ideally you still want to have that non-eating disorder identity."

"It's definitely not always helpful, I can end up helping my friends in a very intense way that can be a strain on me."

Not everyone wanted to do much talking on a forum, but still valued knowing they weren't the only one and hearing from others.

"I quite like forums and I can look at what other people are saying. I don't think, a support group would be a bit unnecessary, but just to talk to another girl for half an hour would make a big difference … just wanting to know if other people are going through the same thing or similar."

"The girls on there, guys and girls, are very kind. Not judgemental or comparing each other. They are at different stages of the recovery process and having different problems, maybe binge eating or something else, but you can gain insights from what they share."

However, a sense of contribution to others and mutual support was said to be helpful.

"I ask her to come to our yoga community dinners and I said, 'Come and sit next to me,' because she can't eat in public she just can't do it. I said, 'Come and sit next to me and be in that community environment.'"

"And then we became really good friends just by hanging out and then she would really help challenge my eating disorder, like I would with hers."

"We are supporting each other. I am thinking about what would help her, and by thinking about what would help her I'm thinking about what would help myself as well. Because I might be facing the same situation three weeks from today, or maybe I notice I am also struggling the same but not noticing it. Maybe I'm not thinking it's a problem to think that way but obviously it is. Then you think maybe I should try that too."

Similarly appreciated was a feeling of being 'got' or understood, without the need to explain oneself to an outsider with no inside experience of anorexia.

"You have to explain to people who've never had an eating disorder, how your mind works. Like how could you possibly explain that you feel like you look overweight in the mirror, and how you could starve yourself, or not feel good enough? And it's like, if you've had an eating disorder you've got that connection."

"Somebody I could just talk to and say, 'Man it's been a rough day'…. Somebody who just 'got it'. That was hugely important."

"But, certainly it's very supportive (online forum) and having that support of people who understand and that insider knowledge. People who just get what's inside your head without you having to explain too much."

The sense of being judgement free was experienced as relieving.

"You sometimes feel that you can't say what's going on inside your head because people will think your absolutely doolally and completely mad, whereas people who are in recovery from anorexia they just get it, so you can say these things it's okay they understand."

"A bit of relief almost. The people I have told haven't judged, I felt comfortable not to feel judged by them."

Some participants spoke of discourses within professional circles that prevented adults living with anorexia from communicating with one another, based on the notion of risk and problematic sharing. This was found by some to be patronising and insulting, and the opportunities missed were spoken of as a loss.

"We weren't really allowed to talk to the other people and we were told we couldn't exchange numbers. They didn't want us meeting up with each other afterwards because they thought we would be a bad influence on each other (laughs) which I think was a shame because we're all adults … I'd joined forums on [eating disorder advocacy website] which was ok but they were quite restricted, you weren't allowed to say certain things around food which I understand because of the triggering nature, but when all you want to talk about are your fears around food that can make it more difficult … part of me feels like they still treat people with anorexia like children … there's so many things out there that you can be triggered by that actually avoiding it is not going to help you in the long run anyway … somebody posted an article about a woman who went back to marathon running and her relapse into anorexia after 20 years. And I found that really triggering, because I was struggling with not being able to run and so I said that, and everyone was really supportive. It was okay to say, 'What you just posted was a bit triggering for me.' And that felt like an adult forum, you know!"

In fact, even vicarious and hypothetical connections with others with similar experience was also valued as reducing the sense of aloneness.

"One thing that helped me was a conversation with my therapist. I said I felt like a fraud because it's a disorder that teen girls have, but she said without breaking confidentiality that she could say there were older women, and that made me feel like I wasn't the only one out there … she told me enough to help me feel rest assured or less alone, and less of an anomaly. It helped validate the disorder in my mind too. Knowing others my age also suffer brought some peace to the immense loneliness inherent in the disorder."

Not every significant group was connected around experiences of anorexia, but the sense of community appeared to be key.

"When I think back to the time when I was in the [performing arts] school being around people who were very content with themselves, and very unique and with performance being involved I found that very uplifting, or heartwarming. It was nice to have people come together and perform. After a long week training we would gather in someone's house and some would be cooking, other would be playing a game, or we would be taking turns massaging sore, knotted muscles. And it was just really lovely, a lovely sense of community. Having that again would be nice, and there was a sense of security of comfort."

Some participants spoke of communities that they created around themselves, or engaged with, who actively supported lifestyles which were alternative to the type promoted by anorexia. Shared concerns, mutual support and encouragement around collective interests were both valued, and valuable.

"And, when you start talking to others and you start doing advocacy you realise like 'Wow, I'm not alone!' So many people go through it, and it's giving a voice to those who are still suffering in silence."

"When those things are happening, those are the days I fight harder because I want to stay connected to my communities and cultures, so I'll usually try pretty hard to not let my eating disorder win on those days."

Some of these support systems were maintained by participants beyond what was identified as recovery

> *"I think because we're all, like a few of my friends are also, I guess activists … not out there but challenging of people when they say things. That's really helped."*

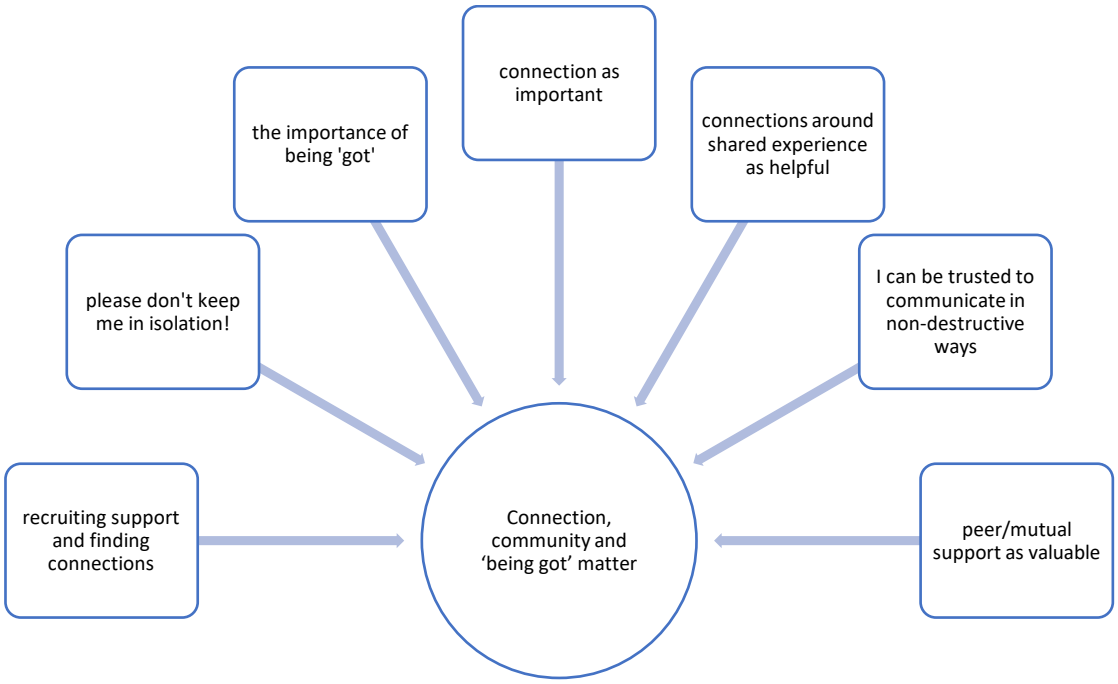


Figure 26 Code groups that contributed to Theme 12

CHAPTER 5. DISCUSSION

5.1 Unique contributions and hopeful perspectives

This study set out to extend knowledge by bringing into focus experiences that have gone under-explored and under-reported in academic research. It also set out to do this in very particular ways. The following chapter reflects on the results of this study and its methodological approach in order to establish an overview of what has been learned about the experience of living and coping with anorexia's influence over time, and about what a narrative practice lens has to offer when conducting academic research. It will set out a range of unique contributions that have been made and the means by which more hopeful perspectives have been created.

In order to set the scene for this chapter, it is pertinent to reflect on the *Enduring anorexia* project title that encapsulates significant commitments that have shaped the project and underpin the following discussion.

A double-storied title

Enduring anorexia is a double-storied title reflective of the narrative practice paradigm it sits within. Its first meaning refers to the long-term and ongoing nature of anorexia's influence, and consequent hardships in some people's lives. This might be thought of as the problem story. In addition, the title also names a counter story by referencing the acts of endurance people engage in as they navigate anorexia's ongoing influence and effects in their lives. Both of these storylines are significant and establishing an appreciation for their co-existence is a guiding principle in this discussion. It is important to make proper acknowledgement of hardships people are enduring in order to incite the sort of action that supports social change. It is also significant for contextualising response and gaining a more insightful appreciation for the acts of personal agency in which people engage. In bringing double-story development together with academic research this study reaches beyond an established academic lineage that has paid insufficient attention to long-term experience of

anorexia and almost none to personal agency in that context, in order to generate a more respectful and hopeful story of people's lives.

The *Enduring anorexia* title sets the tone for a research project that seeks to evade the marginalising practices of occluding context and overlooking evidence of personal agency. By privileging insider knowledge over 'expert' opinion it illuminates a wide range of other possibilities and documents counter stories of people's lives that constitute and create a range of unique contributions to knowledge.

Making unique contributions to knowledge

This chapter demonstrates how the *Enduring anorexia* project has made a number of unique contributions to the field of research relating to anorexia by embracing the above-mentioned attitude and approaches. In order to answer the research questions in alignment with its stated aims, the results and the themes generated by this study are now considered through the theoretical lens of narrative practice. This is inevitably influenced by my own insider knowledge and experience (Lainson et al., 2019) that I have sought to neither escape nor privilege, thus offering a narratively informed insider-practitioner-researcher interpretation. The research questions are not addressed as discreet lines of enquiry, as such endeavour would likely fail to capture the nuance, complexity and interrelatedness of effects, experience, response, understandings and possibilities. Instead, an interweaving of a critical analysis of the reported results flows into naming implications for future therapeutic practice and service provision, and discussion of how these alternative understandings, and evidence of new possibilities, have come to light as a consequence of the methodological approach utilised. This chapter will demonstrate how the *Enduring anorexia* project extends our knowledge in this field by:

- Developing an appreciation of whose lives may be affected by anorexia and how, illuminating an array of serious effects that are particularly associated with long-term and adult experience, thus highlighting an urgent need for recognition of diversity and the significance of longer-term experience.

- Richly describing what it can be like to live with anorexia's influence over time and recognising diverse and multi-storied experiences that contribute to our broader understanding of anorexia's potential for effects in people's lives.

- Acknowledging that people respond to anorexia's influence and effects in their life and detailing the ways in which participants engaged in agentive action and purposive decision-making in order to navigate their difficult circumstances and live their lives in ways that are meaningful to them.

- Unsettling a number of unhelpful discourses about anorexia and the people who live with its influence and effects, especially over the long term, and by offering alternative interpretations and understandings that become available through a narrative lens.

By establishing the above points and in line with the stated research aims, this study makes the additional unique contributions of:

- Providing an alternative, respectful and inclusive representation of people whose lives are affected by the influence and effects of anorexia as a form of counter documentation.

- Circulating and making more widely known a wealth of insider knowledge that is likely to be of interest and use to other people experiencing similar circumstances, as well as to those who seek to be in support of them.

- Making visible an array of implications for therapeutic practice and service design and provision, derived from insider knowledge of long-term experience.

- Illustrating an imperative to conduct research in these realms that engages inclusive practices, and that is based in respectful and hopeful understandings of people and theories of change.

- Creating and demonstrating one possible pathway for future research that extends inclusive practices, provides respectful representation, offers hopeful perspectives, and illuminates new possibilities, by employing a narrative practice lens.

5.2 There is no single story: Illuminating multi-storied experience

Perhaps one of the most immediately visible and compelling findings of this study is that it illuminates anorexia's potential for creating profound unwelcome and deleterious effects in a person's life over time. Yet, despite providing clear evidence of anorexia's capacity to negatively affect and shape a person's life in extensive and detrimental ways, what also became clear from this study was that this was by no means the only story available, of living with anorexia over time. The following discussion does not take a light-hearted approach to the serious problem of anorexia, but it does contribute to balance amongst myriad forms of less hopeful reporting by highlighting gaps in what has previously been presented as hope-less outlooks (Touyz & Hay, 2015), in order to consider where there may be other possibilities.

Changing the focus by re-searching through a narrative practice lens

The principles of narrative practice invite us into listening out for multi-storied experience, complexity, incongruence and incompleteness. Inconsistencies where events and anecdotes diverge from the dominant storyline are not viewed as outliers or anomalies but entry points into alternative storylines that speak of other knowledges and new possibilities (see Morgan, 2000; M. White, 1995, 2007; M. White & Epston, 1990). It is significant to demonstrate how it was this lens that enabled this study to unsettle a wide range of limiting discourses and assumptions about anorexia and the people whose lives it affects.

Traditionally, much of the literature about anorexia has tended to produce a single story of anorexia and a tendency to write and think about the experience of anorexia as a homogenised one (Kaye et al., 2009; Saukko, 2008a) whether based in biological, psychological or social and environmental paradigms. It is seemingly assumed that anorexia

enters different people's lives for a common reason and operates in relatively routine ways. Emphasis has been placed on similarities and consistencies between the practices, attitudes, concerns and beliefs of people, and of their belonging to a particular demographic that has often been treated as supporting evidence for claims that anorexia is produced by certain social locations (Halse et al., 2007; Rich & Evans, 2008), belonging to a particular 'type' of family (Bruch, 1978) - a rather historic notion with lingering effects (Saukko, 2008a) - or having specific personality traits, thinking styles or genetic make-up (Bastiani et al., 1995; Bulik et al., 2005; Kaye et al., 2013; Klump et al., 2000; Merwin et al., 2010; Wonderlich, Lilenfeld, Riso, Engel, & Mitchell, 2005). Similarly, the small amount of literature that has attended to experiences of living with anorexia over a long period of time has focussed solely on life's losses (Arkell & Robinson, 2008; Bamford et al., 2015; Robinson et al., 2015), has assumed a wide range of personal deficits and incapabilities (Gregertsen, Mandy, & Serpell, 2017; Stockford et al., 2018; Wierenga et al., 2018; Wonderlich et al., 2012), and demonstrated an absence of knowledge in mainstream professional conversations about how to best to help (Touyz & Hay, 2015).

By utilising the lens of narrative practice to bring into focus complexity and double-listen for entry points into alternative storylines, the *Enduring anorexia* project establishes how this traditional single-storied account of people and experience is not only incomplete and inaccurate but limiting and highly problematic. It does so by providing evidence of other experiences and knowledges and illuminating previously overlooked opportunities and new possibilities.

Complicating existing ideas by naming alternative storylines

When behaviour and beliefs are viewed as symptoms that infer a definable disease of the mind that can be delineated from what is a normal or healthy way of engaging with the world, any shared features across lives all too easily become motifs for anorexia. Yet, this study has achieved an unsettling of the notion of uniformity in two ways:

- Inclusion of contributions from a diverse cohort by virtue of age, gender, ethnicity, sexuality, global location, spiritual beliefs, family context, educational attainment,

life circumstances and so on illuminated a wide variety of experiences of living with anorexia. While some aspects of participants' experiences overlapped or carried resonances of one another, other aspects were so very different as to almost be at odds.

- Richly described themes illustrated how the experience of anorexia can be complex, contradictory, multi-storied and change over time, even in the life of just one person.

Working with theories of change that are based on assumptions of personal deficit and the necessity of often elusive expert assistance can invite a sense of hopelessness. This study complicates the bleak outlook created by previous reporting in three ways:

- Identifying stories of recovery (as defined by participants), even after many years of living with anorexia.

- Recognising acts of agency and acknowledging reclamations of life that may not fit clinically defined expectations of recovery, but neither fit a story of hopelessness.

- Documenting the means by which participants cope and manage their difficult circumstances in order to live meaningful and satisfying lives, despite significant hardships.

These features of this study provide a significant challenge to the idea of anorexia as an overwhelming disease located in the minds of a fixed population. They also invite us into considering how people and problems have been represented and understood as a consequence of a particular research lens and what possibilities have been obscured as a result. This in turn provides an imperative for improvements to methodological approaches and assumptions in this realm.

Connecting marginalised voices and including subjugated knowledges

Highlighting and richly describing experiences that have previously gone under-explored and under-reported in academic research is significant, and several effects of being effectively invisible in mainstream conversations about anorexia became apparent throughout this study. The social isolation that many participants named as a consequence of living with anorexia was echoed in their reported sense of being erased from professional consideration, that left them feeling silenced, isolated, overlooked and stigmatised in their difficulties. There was a thread of thankfulness that the matters of long-term and adult experiences of anorexia were finally being highlighted, as illustrated by one participant's story of being drawn the moment she spotted the invitation to participate on social media and which, she went on to explain, made it possible to link her own experience to that of others and feel connected in that way for the first time.

> *"I think that's indicative of the whole thing, that there isn't that awareness, and everything is quite taboo, especially when you're older. So, the fact that I saw that on Facebook and was immediately drawn to [this study] shows that I was desperate to speak about it … what was most important for me to share was that I saw your study and I felt this big relief that someone is talking about this! The thing about adulthood … it's the thing that's always missing in conversations about anorexia"*

These sentiments were reinforced by another participant who conveyed serious concerns about maintaining anonymity for fear of consequence; concerns which were ultimately outweighed by her conviction that this topic needed to be highlighted, and her wish to contribute to the lives of others in similar circumstances by taking part.

> *"Mention that I initially responded more but then deleted it because I was scared of potential identification (it will also show how stigmatised patients actually feel!)"*

The themes generated by this study richly describe a wide variety of experiences of living with anorexia, its influence and its effects. These results concur with, extend and diverge from what has been formally documented in this realm in the past. In part, the complex

reporting in this study was likely due to invitations to participate being made directly to the wider community on social media rather than via specialist services, supporting the inclusion of more diverse contributions. However, it was the lens of narrative practice that shaped the methods and lines of enquiry, that informed the analysis, that made visible alternative storylines of people's lives and generated counter stories. These alternative storylines in no way minimise people's struggles but do contribute to a complex and nuanced picture that creates space for hope by acknowledging personal agency, recognising response and enabling double-story development in research, as in therapeutic practice.

5.3 Shaping life: Evidencing anorexia's potential for profound and extensive effects over time

The majority of participants in this study did take the view that living with anorexia for many years brought multiple challenges and hardships. For most participants the experience of living with anorexia over time was a struggle that was predominantly unwelcome. They reported extensive and severe disruption to, and throughout, their lives that was often constraining and deeply distressing. Many described it as exhausting, lonely, miserable and even frightening due to awareness of their physical frailty. Several expressed regret and sadness, lamenting that their hopes for life had been dashed, and that their future seemed unavoidably bleak.

> *"It's an existence, it isn't a life and I think I probably… I wanted more from me than that…"*

Many of the themes generated in this study do provide a basis for concurring with much of what has been reported previously about potential for profound deleterious effects over time, and supporting some of the arguments that call for greater recognition of the problem (Arkell & Robinson, 2008; Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014; Robinson et al., 2015). This study also expands what has previously been reported by extending recognition of these effects beyond service-based populations and into the community. If additional confirmation was ever needed of anorexia's potential for profound effects in

order to provide an imperative to take long-term experience of anorexia very seriously and to re-think our understandings and approaches, then there is no doubt that the majority of participants' stories in this study provide exactly that.

However, as well as richly describing effects, several themes provide additional insights into the contexts and discourses that support and create these challenges. By escaping some of the more pathologising interpretations of previous reporting the rich descriptions of experience, when interpreted through a narrative practice lens, made visible a number of influential factors that combined to ensnare people just as they sought change:

- Theme 1: *Every single area of my life has been affected negatively by anorexia* details the potential for anorexia's influence to complexly and intricately weave its way throughout just about every aspect of a person's life including physical and mental health, financial security, relationships and life's opportunities. The severity and extent of the difficulties went some way to explaining

- Theme 2: *It's a very lonely singular experience,* which richly describes the multiple ways in which living with anorexia's influence and effects over time can serve to isolate people physically, emotionally and relationally to the extent that some feel they neither fully engage with the world, nor is their experience acknowledged by it. This sense of exclusion was, in some measure, expounded by

- Theme 3: *It's difficult to still be struggling with what's viewed as a teenage disease,* which demonstrates how powerful discourses of anorexia being a problem that affects only White, Western, teenage girls (Steinhausen, 2002) contribute to self-understandings and influence the responses of others, including many health professionals and loved ones. Some of the effects of these discourses created the context for

- Theme 4: *The road to actually getting treatment for anorexia is difficult … there are a lot of barriers along the way,* which illuminates myriad complexities of seeking

support and the challenges that lie therein, contextualising the struggle. The barriers of having one's difficulties dismissed, of being judged or of finding support services are unavailable, inaccessible, and unsuitable were compounded by lack of recognition of

- Theme 11: *Recovery is more nuanced than is currently portrayed*, which provides insights into how limited representation of the possible versions of recovery, and a strong emphasis on clinical assessment or externally imposed goal-setting, can serve to keep people stuck in their difficulties.

The themes generated in this study problematise a range of dominant and pathologising discourses that exist in professional and social domains that characterise people who have lived with anorexia for many years as becoming so stuck because they lack insight into their difficulties, have poor motivation for change, or have some form of desired attachment to their so-called symptoms (Gregertsen et al., 2017; Knatz et al., 2015; Stockford et al., 2018; Touyz & Hay, 2015; Wonderlich et al., 2012). The findings of this study do not in any way serve to support those ideas, but instead demonstrate participants' acute awareness of their predicament, their strong desire for something different, and their significant efforts towards creating change that are frequently confounded through no fault of their own and disregarded by professional expertise. Their efforts become especially apparent when viewed in the light of the multiple ways participants coped with and responded to their difficult circumstances, as detailed in Theme 7: *It's what you do to get around it*, Theme 8: *Finding distractions, escapes and therapeutic practices*, Theme 9: *Seeking connection and taking up activism* and Theme 10: *Doing research, exploring feminism, and embracing the 'new and different'*. The significance of these four themes is discussed at greater length later in this chapter.

Implication for therapeutic practice/service provision:

- *There is a pressing need to ensure sufficient and appropriate service provision in support of this population.*

Appreciating *how* effects shape life, not just *that* they do

There is much more to understanding difficult experience than recognition of its existence. One of the achievements of this study has been that by widening the scope of inclusion and using open-ended survey questions and semi-structured interviewing influenced by narrative practice, rather than relying on the clinical measures and quality of life rating scales (e.g. see Bamford et al., 2015) and interviews shaped by positivist understandings of so-called mental illness within service settings, it enabled rich descriptions of experience and a complex appreciation for *how* anorexia's effects and influence can shape a person's life over time, not just *that* it does. This is significant. Better understandings of some of the details of people's lives and struggles as a consequence of living with anorexia over time provide services with scope to adapt and become more useful. This is good news, but better understandings of how those experiences have come about and how it is that people's lives have taken those turns enables more appropriate attribution of responsibility for certain outcomes. Rather than risk becoming tangled up in the pathologising discourses and internalised understandings that led many participants to feelings of personal inadequacy, and the health professionals they had engaged with to expressions of negativity, we can begin to see how the circumstances that people find themselves in, or are dealing with, are not indicative of their intrinsic ways of being as has so often been argued, but the result of a complex interplay of circumstances and effects of discourses that participants were navigating on a day to day, if not minute to minute, basis.

Working in tandem: Combined effects of anorexia's centrality and reach

Anorexia was frequently spoken of by participants as being a central, or dominant, influence over their life. For many participants, life often had to be fitted around anorexia's influence and effects. Considerations relating to anorexia frequently informed major life decisions such as whether to take up educational opportunities, make certain career choices, have children and so on, as well as myriad smaller daily decisions; when and how they could socialise, the schedule by which their day must run, whether they could engage in a pleasant activity for a while, make a small purchase, or turn the heating up on a winter's day. These were spoken of as being far from unnecessary accommodations but an essential means of getting by.

"I don't think people really understand the constant voice in your head situation that is like having someone telling you what to do all the time. I know it's your head, but it doesn't feel like it. It feels like having someone sitting on your shoulder saying, 'You've got to do this, you've got to do that.' And you've got to please them all the time."

Sometimes decisions were made in alignment with what seemed required by anorexia's influence, and at other times decisions were made as part of responding to, or coping with, its effects or potential for effects. Some decisions about life's direction were largely taken out of the person's hands such as disruptive hospital admissions, other people's assessment of their mental fitness, or the physical consequences of anorexia. Many participants also referred to a process of making everyday decisions by first contemplating what possible outcomes there may be in relation to anorexia or what level of discomfort that might create for them, and then navigating around that.

"There's so many decisions, it's constant. You have to make so many decisions."

Sometimes these decisions were made quickly and easily, perhaps even routinely, being familiar with the likely outcome of any given choice. At other times, making even the smallest decision could take up inordinate amounts of time due to the complexity of the considerations and uncertainty of the outcome. On these occasions daily life became almost impossible.

Closely connected to the centrality of anorexia's influence was the capacity for its reach. Although not uniformly, and to different degrees for different people, when viewed collectively participants' stories illuminated how anorexia seemed able to affect, shape and disrupt just about any and every aspect of life. Whilst there was considerable variation in how this was felt, and in the extent to which anorexia's effects altered their lives, most participants did speak of anorexia as infiltrating several or multiple domains in complex ways, and some of it negatively affecting every aspect of their life in some way or other. It seemed that no part of life was entirely invulnerable to anorexia's potential for effects. Nor

were these disruptions to participants' lives necessarily discreet instances that could be spoken of or addressed separately from the rest of the persons' life. These experiences were complex, nuanced and intertwined, the effects of anorexia's influence weaving its way intricately and seemingly inescapably through every part of their lives.

> *"It's complicated. Things go into each other like a spider web, and everything sort of … it's complicated, it's very difficult to get out of."*

Centrality and reach interacted to shape participants' lives in profound and complex ways. Theme 1: *Every single area of my life has been negatively affected by anorexia* illuminated 15 domains of life, each of which may be considered relevant in their own right, but that must also be considered in relation to how they might interact with other domains. Physical health was a common topic of discussion, with undernutrition leading to exhaustion and a wide range of physical ailments, some of which were due to permanent and irreversible health effects. Poor physical health sometimes combined with psychological concerns such as feelings of overwhelming sadness or all-consuming thoughts that couldn't be ignored. Reading and listening to the stories it becomes easy to appreciate how such a combination resulted in difficulties for a person trying to maintain or progress their studies or career.

> *"It does affect my work because I'm not like I used to be. I can't think. I can't focus. When I talk about how my brain is now, my brain is very foggy. I can't focus, I can't concentrate and when I come to write I'm not ... (trails off*) … the depression and anxiety is unbelievable."

As the effects of anorexia limited some participants' options, at times losing the opportunity to work at all, the resultant financial hardship, social isolation, and loss of structure to their day created possibilities for anorexia's influence to increase.

> *"It sort-of made things worse because I didn't have a job, so I ended up in my spare time I went to the gym. Because I didn't have anything to occupy my day, that's literally what occupied my thoughts."*

An internalised sense of failure or hopelessness seemed to allow anorexia to have a greater voice, exemplifying how anorexia's influence and effects can combine to create and exacerbate the challenges and even change the direction of a person's life.

> *"You don't notice it until it's too late, but when I look back now I've changed so much as a person. It just changes you, you don't feel like yourself anymore and you don't know how to get yourself back."*

When someone has lived with the influence and effects of anorexia for a long time, and their life and understanding of themselves has been thus shaped, we cannot assume the conversations will be similar to those with someone who has shorter-term experience, and there is a need to engage in therapeutic practices that recognise these complex effects and differences. It is probable that they are putting up with a lot, and very possible that their concerns extend beyond what is immediately apparent. What is visible to others may not accurately or adequately reflect what it is that most concerns them, or what they hope for in life or in a therapeutic conversation. This provides a challenge for manualised approaches that delay 'talk therapy' until after weight restoration (Le Grange, 2005) currently being considered transferrable from adolescent to adult contexts (see Conti et al., 2017 for a critique). Opportunities arise, however, from the careful collaborative work of therapeutic models that require us to listen carefully (Conti et al., 2016) to double-listen for the skills and knowledge that can support change (M. White, 2004), to recognise complexity and attend to the politics of experience.

Implication for therapeutic practice/service provision:

- *There is a need to utilise approaches and provide services that recognise the diverse effects anorexia has on life over time, and the complex ways in which it has become interwoven throughout people's lives*

5.4 Sparkling moments that interrupt bleak narratives

"I think people would like to see it as, 'Oh, you know, it's this terrible thing,' but it's more complex than that." (Participant)

So far, the picture being painted by this discussion of the results is a challenging one. It is important to note however that it is not the only one available and later sections will pay greater attention to how participants' ways of living and responses to anorexia's influence, even for those most struggling to maintain a connection to hope in circumstances they would not have chosen, were not entirely detached from their intentions, values, beliefs and choices. Similarly for some participants, anorexia's influence in giving shape to their life was not considered entirely problematic and a small number made very clear statements that living with anorexia did not affect them in adverse ways at all. These were largely short, written responses to survey questions about anorexia's negative effects that didn't allow for further exploration (e.g. *"None"*), but they nonetheless form part of the diverse picture. Adding an additional layer of complexity, while for some interviewees the negative effects on their lives were a central focus for conversation, for others it was naming what they had learned through the experience of living with and reclaiming their lives from anorexia's influence that gave shape to the conversation. Even participants who found living with anorexia difficult or even miserable in many ways also spoke of anorexia as contributing positively to their lives in others, as part of their multi-storied experience.

Honouring welcomed experiences

It is significant for gaining fuller appreciation of anorexia's effects in people's lives to acknowledge that some aspects of its influence were appreciated by participants. It provided a helpful structure for some and gave purpose to their daily life, others spoke of its constant and familiar companionship. Recognition of these welcomed effects help make sense of why steps towards externally imposed definitions of recovery were often experienced as extremely unpleasant and disruptive.

"I think I was able to cope better with life and achieve more when my weight was very low mentally I felt more stable."

Other welcomed effects that were reported included a sense of achievement, social acceptability and pride, desired opportunities to feel invisible, calm or numb in times of difficult emotions or challenging circumstances. Some even spoke of anorexia as having provided them with a crucial means for survival, indicating how anorexia's influence and effects can be experienced in ways that ameliorate other forms of suffering.

"[anorexia] is one of the reasons I'm still alive. Which I know is a bit paradoxical because it also nearly killed me, but it also is part of the reason why I am still here. So, I have quite a mixed relationship with it I guess. It's an unusual one, it's complex."

While this study has purposively not sought to establish the meanings that people give to anorexia's existence in their lives, participants' stories do highlight the importance of honouring multi-storied experience if we hope to better understand or be of assistance. What is also of interest is how these complex stories were often referred to in ways that suggested the speaker assumed such contradictions might be unexpected, perhaps pointing to a taboo or discourse that disallows or places judgement on these experiences.

"Living with anorexia has changed me so much as a person. It sounds weird and I know this is a odd sentiment, but I am so thankful I developed anorexia".

Appreciated aspects of anorexia's effects have been documented before, but often in frameworks that serve to pathologise identity, which might go some way to explaining why participants showed caution when speaking this way. A notable exception is the recent work of Anna Lavis (2018) who invites acknowledgement of welcome aspects of the experience as suggestive that therapy should focus not on eliminating anorexia's influence in a person's life, but on attending to the contexts that support it. This is an idea that fits well for narrative therapy and which is also transferrable to research practices.

In Theme 6: *What you learn if you get out the other side is amazing* participants spoke of their experiences of anorexia combined with a story of what they named recovery, some reporting that the overall experience had supported them in gaining special knowledges, skills and directions that they found meaningful and life enhancing. There were also those who went on to use their experiences in order to assist others in similar circumstances through advocacy, training in psychological, nutritional or alternative therapies, in research and more. These were hopeful stories that provided evidence of the possibility for change even after many years of struggle.

These stories make sense through the lens of collective narrative practice; a lens that brings into focus how many people do manage to find meaning in difficult experience and find ways to utilise the knowledges and skills gained during hardship to ultimately contribute to their own life, as well as those of others (Denborough, 2008). This idea should not be treated carelessly, as unsolicited impositions of meaning or inferences of personal growth can risk being dismissive of the very real struggle and consequent losses. However, it does offer much needed opportunities for hope; it illuminates how creating awareness of others having gone through similar hardships and gradually finding ways to transform their experience and connect to what is meaningful to them in life enhancing ways may offer a sense of possibility to anyone currently in the depths of despair; and suggests that finding opportunities to contribute to the lives of others as a consequence of one's own personal hardships in this context could be very meaningful and healing.

Implications for therapeutic practice/service provision:

- *Practice approaches should honour complex, and often contradictory, experiences of living with anorexia that neither require nor expect that clients take a totalising stance against its existence in their life.*
- *Practice approaches should recognise and respond to the contexts that support or promote the influence of problems in people's lives.*
- *There is scope for therapeutic practices and community projects that enable sharing of knowledge derived from experience of living with anorexia over time, and of making contributions to the lives of others*

Viewing change as possible: Double-listening and finding the exceptions

Stories of what was spoken of as recovery, even after many years of living with anorexia's influence, importantly leave the door open for hope and serve to destabilise some of the less hopeful reporting. This study is not the first to document stories of recovery and change after many years, but it is a rare exception amidst a dominant terrain of unhelpful portrayals that, as I will later demonstrate, can contribute to experiences of despair. One exception has been Dawson, Rhodes, and Touyz (2014) who interviewed eight women "assessed as having fully recovered from chronic AN [Anorexia Nervosa]" (p. 494). This study supports and builds on their case that hope of change should not be abandoned after a certain number of years, by including significant stories of what participants' named recovery after many years, and by expanding understandings of what recovery might be. A later section in this chapter argues for more nuanced understandings of recovery that would, in part, create opportunities for more hopeful and helpful reporting. Alongside this, many participants spoke of times when they had acted in ways that did not align with the dominant story of recovery as a state to be arrived at, but nor did they align with a notion of their life being entirely subsumed by anorexia.

> *"I was told that I couldn't go to Outward Bound[14] due to low BMI which had been a dream of mine for years. I forced myself to put on weight so that I could go, which was very mentally challenging."*

Some of these seemingly small or 'one-off' instances might easily be overlooked in many paradigms or dismissed and considered insignificant in the face of a seemingly overwhelming problem story of someone's life. Through the lens of narrative practice, however, these exceptions to the dominant/problem story are unique outcomes, or sparkling moments, that point to agency, resistance, alternative knowledges and skills that may be useful to a person and invite new possibilities for future action (M. White, 2007). They offer potential entry points into double-story development that can support further reclamations of life and create welcome change. In therapy, a narrative practice perspective

[14] Outward Bound is a not-for-profit organisation that runs outdoor challenge, adventure and education programmes designed for achievement of personal potential. https://www.outwardbound.co.nz

invites us not to overlook these instances but revisit them for consideration. If appropriate, they may be lingered around, richly described, linked to the person's values, hopes and heritages, documented appropriately and made more widely known (M. White, 1995, 2007; M. White & Epston, 1990).

Close listening that has been informed by therapeutic practice has already been indicated as helpful in research in these realms by Janet Conti (2013) who wrote about some of the benefits of asking narratively informed questions in research, and listening for metaphors introduced by participants (Conti, 2018). This study supports her claims that by drawing from narrative therapy's practices of staying close to participant experience and listening for otherwise subjugated knowledges, they can be named and therefore useful. Similarly, in a research context, through engaging in forms of data analysis such as reflexive thematic analysis that can honour incongruences and exceptions to the dominant problem story, space is created to arrive at new and more helpful, hopeful and respectful understandings. It becomes possible to focus not on the problem or dominant storyline, but on response and exceptions that allow double-story development, and recognition of the means people use to create change in their lives.

Getting on with life despite the difficulties

Other unique outcomes were the stories shared in this study of people getting along with complex and rewarding lives alongside the experience of anorexia. The struggle of living with anorexia can be a significant burden and disadvantage that makes their efforts and achievements all the more noteworthy. As such, the difficulties should not be minimised but recognised as failing to entirely prevent them from living their lives in ways that are meaningful to them. Unlike Robinson et al. (2015) who noted participants' lack of paid employment, whilst omitting to highlight several achievements that stood out from the dominant storyline, several participants in this study had highly successful careers and rewarding roles in academia, journalism, administration, as health professionals, business owners and others. They spoke of the additional challenges of working around anorexia whilst meeting the demands of their careers, but also about how important their work was to them, and to keeping them going.

"Over the years I started working as an auxiliary nurse and then I did NVQs and then I went back and did my training, and I'm now a clinical nurse specialist, so it hasn't really interfered with my progression as far as my career's concerned."

Career was just one aspect of life spoken of in ways that differed considerably from earlier studies. Several participants spoke about maintaining meaningful relationships, social lives, having children and so on, contrary to what might be expected from reading less hopeful reporting.

I in no way want to suggest that some people 'do better' than others in relation to living with their experiences of anorexia, or privilege certain lifestyles over others. Seeking evidence of people's lives complying with social norms is not the aim here. Comparisons based on normative expectations for peoples' lives not only invite an unnecessary and unhelpful sense of personal failure but can impose prescriptions for living that simply do not fit for them. This is important, and reflections such as

"It makes me realise how limited I am, how hopeless I am, how pathetic I am."

illustrate how internalised ideas of 'being hopeless' were sadly prevalent amongst many participants. I have seen in my own role as a narrative practitioner how acknowledgement of my own reclamations of life can quickly invite despair and self-acrimony into a conversation with someone who is struggling with daily living. There are many, many factors that can contribute to how a person's life turns out, what opportunities become available to them and, indeed, what is desirable for them. It is, however, significant to note that the considerable hardship and difficulties of living with anorexia did not automatically preclude better things as well, and these instances gave reasons to believe in possibilities for a good life, whatever that may mean for someone.

A further significance of recognising that the picture is not entirely bleak is that escaping this binary helps ensure that just because someone is living a busy and meaningful life, we don't miss the fact that they may still be struggling with significant difficulties. Several

participants spoke of the very private nature of a life lived with anorexia, which meant even those close to them may not realise their struggle.

> *"He didn't know about my anorexia. I lived in London and didn't tell anyone, I just went out to work and … London can be quite a lonely experience, and everyone is getting on with their own thing. I was living with my husband and I'd come home from work and eat dinner with him, and that's all he'd see. I was able to keep the anorexia a secret from him and others."*

Some were in jobs that invited good salaries, but a significant portion of that salary went on expensive private therapy sessions (and were concerned that these were not available to everyone). Many spoke of the need to keep going regardless of the challenges, particularly where they had children or elderly parents who needed to be cared for.

> *"you've got children to look after. So, they obviously get very concerned about what you're like, or if you pass out, or whatever. I guess, I can't … it's the same with any illness when you've got children. You can't just go to bed, can you? You've got to carry on, you've got to get them to school, you've got to carry on as normal. But that's a good challenge in a way I think. It stops you giving in to the illness, it certainly gives you impetus to fight."*

Managing the effects of living with anorexia on relationships, finances, work and social commitments was often time-consuming, tiring, stressful and there was a sense of a precarious balancing act. Participants spoke of concerns that they might lose their jobs or be overlooked for promotions if their difficulties were found out at work. Some had already experienced workplace discrimination due to what was considered their poor mental health status.

> *"I was sacked from job because of my anorexia"*

Others were worried that if friends or colleagues may discover their difficulties they might face stigma and judgement as a consequence.

> *"even having lunch with the rest of the team I was like, 'Oh no! I can't let them know that I have an eating disorder or I won't be seen as a credible support worker anymore!'"*

An additional worry was that of well-meaning folk trying to interfere with how they managed their life, or act with good intentions, but unhelpfully so, and a further consideration was concern for how participants' difficult experience might affect others. Steps taken to protect loved ones from worry were described throughout the interviews.

> *"I think that's what a lot of people don't realise. Out with people like my family I try to put on a bright side but unless I'm feeling really, really terrible and I say something, they don't realise it's a struggle even to keep going physically, doing what I'm doing … But I've got to the stage where I don't like letting my family know because they would worry."*

These considerations led to considerable efforts being made to hide the difficulties, and to daily concerns about commonplace events such as expectations to eat lunch with their colleagues in the staffroom or handle special occasions such as weddings, or religious and cultural traditions.

The contributions participants made to this study support ideas that many people do get on with living rich and meaningful lives that make significant contributions whilst coping with very difficult problems (Kitzinger & Perkins, 1993), and evidence how these ideas translate to the context of long-term experience of anorexia. It was also apparent how, given the right conditions, significant reclamations and improvements to life can be made even after many years and meaning and that purpose can be found in many places, as will be further expanded upon in chapter 6. Anorexia is a matter of considerable concern, and people living with these difficult experiences deserve better, but this study demonstrates that long-term experience of anorexia should not necessarily be assumed a cause for despair or hopelessness.

Implication for therapeutic practice/service provision:

- *Practices should recognise the complexity of people's lives and attend to the meaning and value people give to multiple aspects of their lives.*

The significance of hopeful storylines

In summary, this section has demonstrated that complicating bleak storylines by instead giving emphasis to complex and multi-storied experience has its own significance. It provides much-needed and well-deserved improvements to representation, creates new opportunities to find the sort of hope that is often wished for by insiders and is beneficial to those who seek to be in support of them, and acknowledges that struggle and a meaningful life are not mutually exclusive. Recognising the complex circumstances that people find themselves in, and the factors that combine to confound them as they seek solutions, enables recognition of intentions, beliefs and values in ways that enable consideration of new possibilities for action.

5.5 Specific challenges associated with longer-term experience

Inviting participation exclusively from adults who had lived with anorexia for several years and extending that invitation into the community via social media made it possible to privilege experience that has typically been made invisible and has therefore been less well attended to. Many aspects of life with anorexia's influence that were spoken of by participants aligned with what has already been reported in relation to shorter-term experience, such as descriptions of living with a constant harsh and intrusive critical commentary (Tierney & Fox, 2010) or providing a sense of safety or calm (Lavis, 2018). Others that have been less documented relate to duration of experience and life stage, creating specific challenges for those affected and additional considerations for those seeking to be helpful. This study illuminates some of those challenges.

Navigating transitions: Experiences of young adults

Several younger participants spoke of how transitioning from being a teenager at home to a university student and/or independent adult whilst managing anorexia brought its own difficulties as they navigated their new environments, roles and circumstances.

> *"I was also flatting and cooking on my own. I didn't have that much money and I couldn't be bothered cooking nutritious meals so that was tied into it too … There was a time in my life where I wasn't talking to my flatmates much as well, so yes definitely very conducive to an eating disorder."*

One participant spoke of how house-sharing was very stressful as she found herself unable to eat food that had been in the same fridge as that of her housemates, or if she discovered one of her housemates had borrowed food she had intended to use for her next, carefully planned, meal. What might otherwise be considered the minor irritations of shared living spaces created significant difficulties for her, contributing to a sense of herself as an intolerant and intolerable person.

Decisions previously made by parents were now their own and a continual tension existed between the demands of maintaining wellbeing, the influence or anorexia, the challenges of living on a small budget, and fitting in with friends. Planning meals and shopping for food became matters of immense proportion and the supermarket became dreaded site - something that was not necessarily limited to younger experience - and some days it was just easier to neither shop nor eat, starting a downward spiral.

> *"I didn't have enough energy to go out of the house so I had to cancel and postpone things. And it affects your concentration, and I do tutoring, so that has to stop. And the student allowance, it's so minimal you can't pay your rent and food so that had a really big impact, because food is the first place you'll start cutting costs."*

Others identified the ease with which anorexia could suddenly begin to gain more ground in their life as having left the family home as nobody was watching what they ate anymore. No

longer being with one group of friends all day, as they had been at school, meant there were fewer external factors or influences in support of any resolution to eat. All too often anorexia's opportunistic influence in a more flexible environment resulted in hard-won routines of eating becoming unravelled. These experiences offer an important reminder that as life changes are encountered over time, and routines and expectations alter, finding oneself in previously uncharted waters sometimes create renewed opportunities for anorexia's influence to increase or return. As addressed in more detail later in this chapter, many participants spoke of recovery as other than being a fixed state. As such, even a young person who has made significant reclamations from anorexia may still benefit from additional support and encouragement when they leave the family home. Through the lens of narrative practice, co-researching (Epston, 1999) existing skills and knowledge in managing or coping with anorexia may be a particularly useful means of finding their feet, and their way.

> *"I got really into making art and playing my music which I think was really good for me … so it was a distraction and I connected to a few people through that. I gave away some of my art and sold it."*

Implication for therapeutic practice/service provision:

- *The practice of co-researching in narrative therapy could offer additional support when navigating life changes.*

Meeting demands and keeping on going: Experiences of everyday adult life

Participants spoke of numerous practical problems and challenges that anorexia's effects created or exacerbated at different stages during adulthood. Many articulated concerns about difficulties with meeting the demands of everyday life such as holding down a job, paying bills as a consequence of their reduced employment opportunities, protecting relationships, raising and influencing their children in hoped-for ways, caring for elderly

parents, participating in social commitments, and maintaining their homes whilst living with what at times felt like overwhelming effects and influence of anorexia.

> *"You have to get on with life and keep down a job and relationships but having to control the anorexic thoughts, as you would. Keep them in control as well as wanting to hold down other things as well as a relationship and a stable job."*

Taking time out of daily demands, either for themselves or to focus on recovery which is an increasingly common suggestion in some advocacy circles, simply wasn't an option for most participants in this study. There was talk of having to keep going regardless of the difficulties, regardless of how they were feeling, regardless of how physically unwell or exhausted they were, regardless of their distress.

> *"But it's harder just to take time out when you need it, to either go in and do an in-patient or to clear enough space to do a regular out-patient visit or something. I mean, the logistics are harder. You've got to take time off, and you've committed yourself to various things."*

Keeping going was a multi-storied experience. In fact, the need to keep going was helpful in some instances as it provided a sense of purpose, and ready justification for prioritising something or someone else that was valued over and above anorexia. This gave some participants the strength or reason they needed to get along with life in ways that might have been less possible if they only had themselves to consider.

> *"Because I enjoy the work that I'm doing, and I feel like it's in line with my values, it gives me a reason to get up and eat, and do all those things."*

At other times, having to keep going when in need of a break was recognised as draining, miserable and extremely difficult to maintain and several participants commented that they realised they were not living, parenting, attending to relationships, or being in their workplaces in their preferred ways which added to their distress.

"It's not just my life I'm ruining. It's my husband's too."

"My friends came to my door and I had to tell them to go away and I felt awful about it, because they were hurt and confused."

"I'm one of Jehova's Witnesses … But I had to come off it because basically you're a bad Witness because you look so ill."

This distress can be understood through the concept of the absent but implicit (M. White, 2000) as indicating that anorexia's influence is taking them in a different direction to something else that is known and valued or treasured in life. Through the lens of narrative practice these moments also suggest that anorexia's influence is not so entirely convincing that they are oblivious to its effects. In a narratively informed therapeutic conversation these experiences of distress can provide an entry point into a re-authoring conversation.

Implication for therapeutic practice/service provision:

- *Narrative therapy considerations of the absent but implicit could recognise alternative knowledges and commitments that support preferred ways of living.*

Taking extra care: Experiences of motherhood

Being a parent was a role that was spoken of by several participants as bringing joy and providing an alternative purpose to anorexia, and as a matter of considerable concern due to anorexia's influence and effects. All participants who identified themselves as parents in the interviews were mothers, and those with daughters spoke of fears they might in some way pass their troubles on to them, either via genetics or by influencing their attitudes.

"I don't know about your research but quite often in runs in families. I certainly worry for my middle child that it's something she might struggle with…. which adds to the guilt."

This is perhaps unsurprising given that dominant theories have for decades implicated families, particularly mothers (Bruch, 1978), and more recently genetic heritability in anorexia appearing in a young person's life (Bulik et al., 2005). It was almost as though traditional practices of mother-blaming that have officially been refuted as unfounded, but whose effects still linger in professional and public discourses (Saukko, 2008a), continue to find additional avenues for their expression; adding to the pressure for women who become mothers whilst living with anorexia over time. These ideas seemed to invite a sense that they were somehow inherently problematic, a risk to their own children or letting them down by not being able to 'recover *for* them'.

> *"People are less understanding of particularly a mother of young children. You know, people judge very much more quickly. They kind of ask, 'Why can't you get better for your children?'"*

> *"They think it's something you can just get over, and put your children first, you know be a responsible adult. Which I think is missing the point with what it feels like I guess."*

This is one example of how discourses around anorexia, that have traditionally been steeped in misogyny (see Lainson, 2019), can lead to significant injustices. These critiques the participant mothers had received from others about their capacity to prioritise their children were not raised as a complaint but, rather, spoken of as a source of great concern that inspired feelings of guilt and worry. What was also visible was how the participant mothers responded to those concerns, through their significant acts and attitudes of additional care-taking in relation to their role in their children's lives. They spoke of working strenuously to either hide their difficulties with eating from their children, or else of actively and openly discussing these realms in the hope of promoting their daughters' wellbeing. In each case they were actively seeking to spare their children from a life lived similarly to theirs.

> *"And I think [my daughter] was starting to come into that early womanhood and thinking, 'Hell no! I don't want to be that role model.' … she went through a stage*

around 14/15 and she went through some of the markers for anorexia. And I told her my story, and she credits that with being aware that there was the risk of it … she now says she's really conscious when working with women."

On a practical note, they also reported challenges of preparing food for their family when they really didn't want to have to deal with food at all, and mothers of younger children spoke of the difficulties they encountered in frequently being physically exhausted both due to the effects of anorexia and the role of parent. One mother spoke of worrying she might not maintain the ability to breastfeed her new baby, and of fearing that anorexia's influence in her life may have somehow altered her pregnancies or her babies' development, requesting that her midwife not mention anorexia on her maternity file in case her children ever thought of anorexia as somehow part of their start in life.

"I don't want my children looking back at my pregnancy notes and anorexia being part of their start in life or wondering if Mum did everything she could have done for their health … there was some defensiveness about this pregnancy and wanting it to be different [than my first pregnancy]. Even the growth scans, the idea is that you're supposed to make this baby bigger, and I was eating really well. When she was born she was smaller than the scans said, and there was no pre-eclampsia so that's obviously what I do, I just make small babies."

This is just one example of the complexity of concerns mothers were living with, the degree of responsibility that is added to parenting, and potential for guilt as a consequence of powerful discourses. From a narrative practice perspective there is a case for introducing conversations that invite deconstruction of some of these discourses (M. White, 1991), to make them visible and therefore available for interrogation. Bringing into question the validity of expected norms or problematising their limiting influences might be found helpful or welcome.

Implication for therapeutic practice/service provision:

- *Deconstruction of discourses could contribute to mothers' resisting invitations to guilt or understanding themselves as problematic in their children's lives.*

Becoming invisible and wrong: Experiences of exclusion and judgement

Despite the gravity of their circumstances, taking part in this research was either the first time some participants had spoken to anyone about what they were going through, or else was acknowledged as a rare opportunity to speak openly about their difficulties and have them recognised as legitimate. Many had experienced a lack of recognition that the problem of anorexia could exist in the life of an adult, perhaps particularly so for men. They spoke of their being invited to contribute to research as a feeling of finally being recognised as they often felt excluded from broader conversations about anorexia which, they thought, focussed on younger people.

> *"I've never seen anyone like me portrayed in anything about eating disorders. I've seen occasionally older women portrayed, and I've seen younger boys, but I've never seen an adult man."*

This helps to explain how several participants were led to doubting themselves and questioning their own reality.

> *"I felt a bit of a fraud, and I might not really have it because I wasn't fitting popular culture's image … one thing that helped me was a conversation with my therapist. I said I felt like a fraud because it's a disorder that teen girls have, but she said without breaking confidentiality that she could say there were older women, and that made me feel like I wasn't the only one out there."*

This erasure from representation made it more difficult for participants to access support, and ensured services were not designed for them and that services they did attend were often ill-equipped to help.

> *"So it was quite, yeah it was very difficult when the treatment is so hard because when you're an adult they don't know what to do with you."*

Services that did not address their concerns or recognise their age, and in which they felt markedly different to other attendees, were found to be unhelpful and led to disinclination to maintain engagement.

> *"As an experience, other than in the waiting room and assessing one another and wondering why they're there and what their experience is, you don't have any other connection with anybody else at all. It's a very lonely, singular experience. And being in the waiting room, in terms of your study being about adults instead of adolescents, I was always sitting there with girls in school uniforms. The people of my age and above were parents … If I was completely honest, I would say I was a little bit embarrassed. I would second guess they would presume I was there because I had a daughter there."*

For many, these stated effects of dominant discourses of anorexia being a problem of teenage girls were further compounded by experiences of stigma and discrimination, and attendant feelings of embarrassment or shame.

> *"Because everything around the idea of adult anorexia is surrounded by shame … The stigma is that there's a stereotype of it as a teen disorder … I'm a grown woman, I should know better!"*

This statement illuminates several discourses that contribute to experience, including that anorexia is a problem that is naturally limited to teenage years and that it is somehow possible to escape anorexia's influence simply by gaining maturity and 'knowing better'. Both discourses are highly problematic and understanding these experiences can help us escape readily available assumptions that privacy or secrecy around experience is solely for the purpose of protecting the problem from external intervention, as has been proposed (Hoek, 2006). In fact, experiences of being misunderstood, judged or discriminated against severely limited many participants' opportunities to confide, and this diminished likelihood of support or sympathetic approaches from others was viewed by several participants as necessitating strenuous attempts at hiding their difficulties. Consequently, there was talk of having to 'go it alone' when seeking help or attempting to create change. Unlike when they

were younger, when there had often been an adult (usually a parent), telling them there was a problem, insisting they sought treatment, taking them to appointments and encouraging them to eat, several spoke about how doing these things for themselves now was challenging for a number of reasons.

Some who were engaged with services found they were treated as hopeless cases, that the health professionals they worked with weren't interested in them, didn't believe they could recover, or doubted they even wanted to. Participants believed that others thought of them as too difficult and a drain on resources.

> *"You've got to fight for it, and they make you feel like you're making a fuss."*

Even accepting help when offered is known to be difficult in the context of anorexia, so independently deciding they might benefit from or deserve support, then having to seek out services that barely recognised adult experience and advocate for themselves became significant barriers to reaching out or to receiving help. In the light of this it is perhaps all the more remarkable that some participants spoke of their continued and determined efforts to advocate for themselves.

> *"I wanted to try and put on weight. I wanted to have one last bash at getting better, because for years and years I just accepted it and that. And I thought, 'Maybe now it's just habit'. It took me a year or so to talk [my GP] into letting me have the food supplement, which I said, 'You know if I could just get that down me. It's medicine, it's easy to swallow and put on weight, and that would prove my anorexia had just become a habit.' And it took me years before he would allow me and get me to see a psychiatrist and have therapy as well."*

Though the dominant story of anorexia being a problem exclusive to White, Western, teenage girls (Steinhausen, 2002) may have been officially challenged (Gremillion, 2008; Royal Australian and New Zealand College Of Psychiatrists, 2009) it was clear from participants' stories that this discourse remains strong in wider society and many health service settings with serious consequences. Concurring with an Australian study that

suggested the further removed a person's social location is from fitting the anticipated demographic the more they are likely to find their struggles minimised, ignored, dismissed or repudiated (Butterfly Foundation, 2014), this study evidences a dire need for more accurate representation in research, advocacy and professional training, and how longstanding factors of exclusion and misrepresentation in research continue to contribute to discourses that inform responses from others and powerfully shape experience.

Implication for therapeutic practice/service provision:

- *There is a significant need for service providers to recognise and accommodate adult experience by enabling referral pathways, providing appropriately designed, welcoming services and ensuring workers maintain a supportive attitude.*

Gathering effects: Experience over time

For several participants there was a growing recognition of the cumulative consequences of living with anorexia's influence over time. It was notable that many older participants who had lived with anorexia for a longer period of time showed a stronger sense of conviction about anorexia's detrimental effects in their life than younger participants, some of whom expressed a degree of conflict about whether they might actually be able to manage anorexia's negative effects sufficiently that they could maintain its more welcome effects. Several older participants spoke of how in their younger years, when anorexia had not been in their life for so long, they had a sense of there being little or no consequence, but that feeling of being invulnerable became depleted as living long term with inadequate nourishment and other intrusive effects took their toll.

> *"So, I've got a far greater awareness of it. When I was younger I felt like it was in control, but now I'm going, 'Hmm.'"*

Deteriorating physical health was one area of concern that became more significant and apparent to participants after many years. Some spoke of their growing weariness with anorexia's influence and effects alongside a decreasing conviction that anorexia had anything much that was helpful or positive to offer by way of compensation for the costs of its presence. This recognition, combined with the increased conspicuousness of the effects of anorexia on a person's life did not, however, make change any easier or more available. In fact, participants' increased resolve to make change being repeatedly thwarted often resulted in frustration and a growing sense of failure and despair.

> *"You do actually get to a point of acceptance where you realise that you just have to manage and make the most of the times when you're feeling better. But there are times where that's just not enough."*

Several reported a sense they were running out of chances to repeat or reclaim missed opportunities, or to ever live life free from anorexia's influence. These experiences were reported in relation to career, relationships and other life opportunities that were spoken of as being important. Some participants shared concerns about what had been put off or not worried about in younger years later was now becoming visible to them as lost opportunities that could never be reclaimed. Due to extended hospital stays or having been isolated by the practices and effects of anorexia, some participants spoke of their sense of grief at missing out on romantic relationships, explorations of identity, having adventures, or transitioning to adulthood alongside their peers. Several felt that what they understood as losses or gaps had a continued effect in their life, negatively impacting their ability to engage in social interaction, further their education or career, or take up other opportunities. Others spoke of detrimental effects for their sense of themselves in the world, of feeling they were different to their peers and believing they lacked significant life skills and knowledges to fit in.

> *"And where I'm up to as well. Yeah, I guess when I look at my peers and people around me who are similar age. I get the sense I'm not where I should be in terms of relationships and I guess general comfort in your own skin, so just being able to go out and join in things. I'm not sure how others do it."*

There was evidence that participants believed themselves to have personal deficits that negatively affected their lives in ways that could never be remedied due to anorexia's effect on their life course. For instance, feeling they had been excluded from 'normal life' growing up had left some participants with a sense that they could never be 'normal'.

> *"There was all these 'should've'. I wasn't following the right timeline for getting married, having kids, whatever society was telling me was the deal, so it was very difficult for me that I wasn't following that."*

There is no doubt that participants will have witnessed differences between their own life and those of many of their peers. There were certainly missed opportunities that could not be reclaimed. However, there is also space to consider the effects of discourse on people's understandings of themselves and their lives, and to question normative assumptions about what experiences or opportunities people 'should' have. Questioning the perception and desirability of a 'normal life' in favour of a 'preferred life' might be a worthy conversation to hold. Through a narrative practice lens, change is best supported when people are enabled to tell counter stories that unsettle the dominant problem story (M. White, 1995, 2007; M. White & Epston, 1990) . Re-authoring conversations of narrative practice (see M. White, 2007) that create space to speak of alternative knowledges (M. White & Epston, 1990) and make connections to the hopes a person holds for their life can assist in moving away from such ideas of personal deficit as a consequence of early experience, towards a preferred storyline. It is significant to highlight that the co-creation of new storylines does not only relate to visible change in a person's life, but also invites a re-evaluation of normative expectations and a re-consideration of what sort of life they might prefer for themselves.

Implication for therapeutic practice/service provision:

- *Re-authoring conversations that provide space for deconstruction of normative assumptions and privilege alternative knowledge could unsettle beliefs about personal deficit.*

Interview with Lin, about Faye

After seeing the call to participation on social media, Lin contacted me asking if she could complete the survey and participate in an interview on behalf of her mother, Faye. Faye had recently passed away, aged in her 80s, and Lin believed there was an important story to be told of Faye's lifelong experience of anorexia. We established a time to for the interview and Lin completed the demographic components of the survey on Faye's behalf. Faye's story was not included in the thematic analysis because it was told through the eyes of her daughter and was therefore inconsistent with privileging insider knowledge and personal accounts. However, the interview was considered relevant to the study because it raises some important considerations. Lin was fairly sure her mother had never been given a diagnosis of anorexia and that this might have been due to the times she lived in, as a rural Australian woman whose adult life was mostly during the middle and second half of last century. Lin spoke of how Faye's limited eating had caused significant family tensions for as long as she could remember, although Faye and Lin's father remained devoted to one another nonetheless. The family doctor had frequently implored Faye to eat and drink more due to the impacts of under-nutrition on her physical health. Yet Faye led a busy life, typical of a woman of her era and context and was a significant contributor to local community life. In late life, Faye and her family faced new challenges when Faye was given a diagnosis of dementia. Lin and her siblings noticed that regardless of the many changes to Faye's ways of being at this time, the muddles she got into about who people were and her growing confusion over everyday tasks and activities, Faye never lost her skills in avoiding eating. The tensions over food and eating that had affected their family life over decades re-asserted themselves in Faye's residential aged care setting as staff became increasingly alarmed at her malnourished state and adeptness at missing meals. Lin and her siblings believed that, whether or not she would have used the word anorexia to describe her experience, whatever it was that prevented Faye from eating throughout their own lives remained with Faye right up to the end of her own. Restraint should be exercised when drawing conclusions. If Faye could speak for herself, she may say that her story does not belong in a study about experiences of anorexia. The influence of dementia complicates what we may or may not assume. However, what Lin's contribution to this study does is it invites us to consider the following question: If anorexia's influence can persist for an entire lifetime, what implications might this have for late life wellbeing, arrangements for care, and family concerns?

Box 1 Interview with Lin, about Faye

Acknowledging response and recognising agency

A key question posed in this study was how people respond to living with anorexia over time, and in what ways they cope and manage their lives. This line of enquiry was based in the understanding that people always respond to their circumstances (Wade, 1997, 2007; Yuen, 2009) in order to improve their lives in ways that seek to reconnect with what they value (M. White, 2007). There was certainly a good deal of evidence throughout participants' stories of living lives alongside anorexia in meaningful ways. Similar stories of response have been less well attended to in previous studies, and certainly haven't been a focus for enquiry. What glimpses of response have been visible in the reporting that seem to connect to a hope, belief or value, have gone unremarked upon. In this study, participants' meaningful responses to their circumstances ware made visible through the lens of narrative practice, by employment of:

- Curiosity about, and double-listening for, participants' skills and knowledges in managing their circumstances.
- Intentional state understandings of identity that recognise people as responding meaningfully and purposively to difficult circumstances, linking action to hopes, beliefs and values.
- Recognition of how broader social contexts and prevailing discourses contribute to experience and choice.

As a consequence, this study was able to recognise domains of life beyond anticipated achievements and socially sanctioned norms, to pay attention to what participants gave value to in life, and how they maintained connection to their values, beliefs and hopes. In doing so, acts of personal agency that challenged anorexia's influence in participants lives were brought into focus.

Beyond expectations: Seeing what is of value to people

Participants certainly spoke of working hard to protect and maintain a range of important and valued aspects of their lives, including employment and education.

"Even though I was still sick as an adult I still had all the expectations of paying bills and getting by and, you know, things that adults do"

"I got my degree on time, I was able to manage to get a job. Trying to focus on the things that are normal life events in spite of still suffering from anorexia."

They also spoke of protecting and maintaining connection to social lives, relationships, health, interests and passions.

"I have a twin sister who is much more social than I am and she likes to go out, and so I try to let myself be a bit more forgiving with food/drink."

"I make the effort of looking on the internet for music I might like that I can download. I make the effort to look for CDs when I go to town. And I usually make the effort to play my piano. So, some things are my efforts, and some things just drop down from heaven."

Sometimes, these were multi-storied experiences that involved a complex mix of compromise, effort to maintain connection, and possibility.

"I used to really enjoy playing rugby but now I'm at a weight where I can't safely play. I referee now, but that's less involved as a team. Whereas I'd have liked to continue being part of the team … [when] I'm refereeing I don't feel anywhere near the amount of guilt. It's like the thing that stops me from eating shuts up for a little bit."

There were also stories of maintaining and protecting a sense of duty or responsibility and of caring for others. One participant who had dedicated much of her life to bringing up her sister's children after they tragically lost both their parents, and then later caring for her elderly parents, spoke of there being no alternative in her mind regardless of the difficulties of managing the inevitable demands alongside profound effects of anorexia.

"*I mean we literally had our lives turned upside down. The trauma of it, and the kids, and family problems. And a totally different routine … I just had to do it because I wouldn't want it to be any other way. You know, it's my obligation, and even now it's my obligation. With Mum and Dad, I want to give them something back because they've given me so much."*

It was notable throughout the conversations that participants spoke not only of concerns for their own wellbeing, but significantly for that of others. Some spoke of how anorexia's influence in their life affected those around them - family, friends, colleagues - led to them taking action that they hoped would minimise others' distress, often hiding their own struggles or making things more difficult for themselves in order to do so.

"Some of [making myself eat] was making my Mum happier, because she was really concerned about me … I've had a struggle with depression and things, and she's gone through enough hell with that, that I wanted her to not worry about things quite so much."

"But I've got to the stage where I don't like letting my family know because they would worry … they've had so much trauma in their own life. Or, have in the last sixteen years or so, apart from just me … most of the time now I'd rather just try and get on with what I can do."

"Focusing on the distress it caused loved ones, and not wanting to be the cause of this pain. Thinking of this sometimes helps me to eat even when I really want to reatruct [assumed to mean restrict]"

Several spoke of the significance of living in ways that were consistent with their beliefs despite the difficulty of doing so, and of becoming involved in eating disorder advocacy, education and body positivity movements, or similar, which were said to be integral to their experiences of change.

"It kind of turned me into an activist in a funny way. Uhm, because we're constantly treated… you know, the magazines … 'Oh, that's a good reason to diet. That's a good reason to control my food.' And I'm like, 'Rah, rah.' I almost went the other way and said, 'Hey, I don't want any of that in my life.' … I've built a network around myself of people, and ideas and writing and yeah."

Whilst several spoke of these actions as being personally beneficial and supportive of them escaping some of the less welcome effects of anorexia, their immediate focus was that of concern for others, and not wanting anyone else to go through what they have experienced.

"I feel very privileged and lucky in the way I was able to get help … I had some good friends who supported me and I was able to completely recover. Not all people have had these advantages, and it makes me very sad to think that such a horrible struggle could be made even worse."

Some had gone on to dedicate their careers to helping people living with similar difficulties to those they had gone through.

One realm of life that was protected that may not necessarily have been anticipated was that of wider social contribution. Several spoke of contributing to this research as something they did not believe they would benefit from personally, but they hoped their stories and insights might contribute in some way to the lives of others whether in the short or long term.

"It may be too late for me. But please try to make a change for the future generations. Doctors need to have more compassion for adults."

"I think my hopes would be that [this research] goes beyond the stereotype of the White, privileged female, and I know I represent that. I think that those views are important, but we hear that a lot in the media and that is the representation of anorexia. So, I think it's important to challenge that, I guess."

"I wanted to help other people because I don't think that there's that much help or awareness out there."

"So many people go through it, and its giving a voice to those who are still suffering in silence."

A few also spoke of their social activism, of the meaning it had for them to make a social contribution. They spoke of overcoming difficulties or finding creative means to participate.

"I've been to a lot of rallies which has… there's this photo of me at my lowest weight at a rally and I don't know how I got through that day other than adrenalin because I look so incredibly sick, and I keep the photo around as a reminder that I don't want to go back to that. Since then I've definitely come to the realisation that it's not sustainable. It's great to have that activism around, because I'm not doing it for myself. I'm doing it for other people who probably need some change, and often I fit into those demographics too. But it's never been about me, it's always been about other people. So, forcing myself to eat something so I can go march down the street, was quite helpful."

One of the older participants who described herself as almost entirely reclusive as a consequence of anorexia had taught herself how to use a computer in order to take part in important local issues, despite being unable to attend meetings.

"I just do it via the internet. You wouldn't see me. There's something I've been really fighting against or fighting for that's become an important part of my life. It takes a lot of thinking and waking at night just thinking about it. … The first one is they were going to build a dam and destroy a whole load of native bush and I was totally against that and saw that a lot of other people were. So, I've spent the last three or four years trying to stop that happening through submissions, letters to the Council and all that … I would never go to a meeting or a hearing. And just being able to sit down at my computer and do it at home is possible for me."

These stories of care, effort and contribution, of agentive action being taken despite the challenges in order to maintain connection to values and beliefs, and to continue to participate and contribute in the world have too frequently been overlooked in research that focusses on the problem and its negative effects. These are the alternative stories of people's lives, that offer more counter representation and that, through practices such as re-authoring conversations and outsider witness ceremonies, have the capacity to support change. Narrative practice has a heritage of social activism in these realms. Communities of concern (Madigan & Epston, 1995), such as the insider-led Vancouver anti-anorexia/bulimia league that ran a campaign of overt political activism and awareness raising through a dedicated magazine, letter writing campaigns, t-shirt slogans and more over several years (Grieves, 1997; Madigan, 2010; Maisel et al., 2004), can offer meaningful connection whilst contributing to social movement. Flat portrayals of people's lives limit our understandings, misrepresent identities and inevitably miss opportunities which is why the unusual step of illuminating themes of response is such a significant component of this research.

Themes that illuminate response

The four themes that probably best illuminate response were:

Theme 7: *It's what you do to get around it*
Theme 8: *Finding distractions escapes and therapeutic practices*
Theme 9: *Seeking connection and taking up activism*
Theme 10: *Doing research, exploring feminism and embracing the 'new and different'*

These themes are described in more detail in chapter 5 and a close look at them unsettles some ongoing notions of people being either controlled by anorexia, or else choosing and creating it. There are two threads which seem to weave throughout the four themes under consideration, which are 'coping with what is' and 'preparing for an alternative'. Themes of managing anorexia and life or finding in-the-moment distractions and strategies could be framed as shorter-term coping; the essentials for managing day to day life. Seeking alternatives and connections that counter anorexia's influence, on the other hand, might be thought of as representative of looking ahead and making steps towards active change.

Such steps suggest that participants may be resourcing and informing themselves in ways that counter anorexia, as a means of creating an alternative future for themselves. It is vitally important that we do not get drawn into evaluating types of strategy against one another or the creation of rigid categories of strategy. But recognition of the potential for such actions as being evidence of people managing their life circumstances in the short term whilst resourcing themselves for a preferred life may be illustrative of agency, intention, knowledge and insight that are often overlooked in other frameworks.

This is a nuanced picture, in which participants can be viewed managing their circumstances as they navigate anorexia's centrality and reach in their lives by moving between these response positions. Just as they seem sandwiched between the constraints of anorexia's influence and effects, and the external pressures from barriers to support, isolation, limited representation of experience and recovery, and myriad unhelpful discourses, these four response positions appear to create spaces where participants were able to make significant reclamations of life (see figure 27). By taking up these agentive and purposive positions they became more able to cope with daily life, engage in preferred ways of being and creatively plan and create change.

Coping with daily life: Managing life and managing anorexia

Theme 7: *It's what you do to get around it* involved both managing anorexia and managing life, at times interchangeably, in order to live in ways that were important to the person. In some situations, going along with anorexia's influence was considered the best option under the circumstances.

> *"Sometimes it's just knowing I'm just going to let the eating disorder win for a few days because I'm too tired to fight."*

Elements of life were adjusted to accommodate anorexia, though not necessarily given up.

> *"I was able to attend some social events and I managed by bringing my own "safe foods", those around my were aware of my disorder and knew that I was going*

somewhere private (my car or in the tent when at a camping festival) to eat my food. I let them know and directed those around me on how to best help me."

For instance, growing organic vegetables supported one participant in eating nutritious food whilst also having an outdoor interest that she felt was good for her; another engaged in 'mental gymnastics' to solve dilemmas; and others established goals that made it more possible for anorexia to be navigated around.

"I picked the weight, because I like odd numbers when it comes to my weight, I made sure all the numbers of this weight were odd. And I made sure that my BMI was still underweight, and I said, 'Okay, you can get up to that particular weight. You don't have to take any special precautions so long as you are under that weight'. And I've managed to gain quite a bit by doing that."

In other situations, anorexia was managed. This wasn't a simple decision of not going along with the influence of anorexia, but was often a process of creating logical argument, restructuring practical aspects of life, or finding new ways to think about food that differed to those associated with anorexia.

"I think sometimes step back and look at the bigger picture. Because one of the big thoughts is that when I've not ate enough I feel quite faint. And the anorexic voice says to me, 'It's good to feel like that.' And then when I look back and think to myself, 'Why would you want to feel like that? Why would you not want to feel strong enough to tackle the day?' Does that make sense?"

"Even though it's a 20-minute drive to university … I'll be coming home every single day and making sure I eat breakfast and dinner."

"I've tried to start making food fun again. I've started baking and cooking … not necessarily looking at food that could potentially harm me or make me fat, but that it's something that can be fun and can be creative. One aspect of it that I've really been enjoying is making it look really pretty. That has been helpful."

In a narrative practice paradigm, it is possible to consider whether these are acts of resistance, of finding ways around anorexia, that provide an entry point into an alternative storyline of steps being taken towards something different, or of recognition of some beliefs about life that do not fully align with the influence of anorexia. These possibilities are worthy of exploration as they could lead to generative re-authoring conversations that support welcome change. For instance, one participant spoke of how eating was more possible when they had exercised. A 'symptom' focussed approach invites a framing of such exercise as 'compensatory' and therefore problematic, but a carefully scaffolded conversation may illuminate absent but implicit knowledges and beliefs that, again, are supportive of change.

At this point I feel an ethical responsibility to briefly draw on my own insider knowledge in a more explicit way than in some other areas of this thesis. Once these acts of resistance, or alternative practices that circumvent anorexia, become a focus for conversation it can be tempting for practitioners to become quite influential in relation to these new discoveries. Michael M. White (2007) advises us not to get ahead of the people with whom we are speaking, and under these circumstances I would emphasise his attitude of caution. There can be acts of resistance and insider knowledge about managing anorexia that are better not spoken of, at least not right away. There have been times when I personally relied on using 'loopholes' or 'blindspots' to evade anorexia's influence, but premature acknowledgement of their existence would close them off. 'Not looking too closely' at one's own practices of evading anorexia's influence can be an act of resistance in itself. Tentative enquiry, being prepared to move ahead slowly, and careful scaffolding that thickens storylines of commitment to resistance can precede making such actions the focus of conversation, and assist with maintaining what might be lifesaving strategies.

Theme 8: *Finding distractions escapes and therapeutic practices* illustrated how participants spoke of making their life alongside anorexia more tolerable, and manageable. Music, art and writing featured highly in the list as did being outside, enjoying nature, watching TV or being with friends or pets. These are ordinary, everyday activities that participants spoke of as being in active support of their wellbeing.

"Sometimes playing music. I have what I call my recovery playlist now, just to … either to lift you up, or sometimes very sad songs … I also do find that if I give myself space to be, space in my life, and make myself just stop and stay at home and stop, or whatever it is."

"Things like putting on make-up that was, I think it's always just been like a therapeutic thing I can do to keep my hands busy. It's impermanent, so you can just wash it off if you do a bad job."

"I would watch a whole bunch of The Simpsons with friends, and it's something that's kind of nice, and familiar, and simple and funny."

It is possibly their ordinariness that has tended to make them invisible in research, as they stand in contrast to a dominant storyline in existing literature of people living with anorexia as being dominated by punitive practices of self-denial. This isn't in any way to deny or diminish the frequently spoken of acts of self-denial or beliefs of being undeserving of comfort that participants shared. However, it does highlight how there are multiple stories available when we ask differently, and the need to listen carefully and actively for alternative storylines in research, just as in therapy.

Seeking difference: Exploring possibilities and resourcing for change

A third theme that particularly relates to response was Theme 9: *Seeking connection and taking up activism*. The two components that stand out in the title of this theme may not at first glance appear to be directly related, but what became apparent was that concepts of connection rippled throughout ideas of activism, and in many cases vice versa. The two ideas were frequently inseparable in the stories articulated by participants.

"When you start talking to others and you start doing advocacy you realise like 'Wow, I'm not alone!'"

Connection was often spoken of as an antidote or act of resistance to the isolating practices associated with maintaining anorexia or going along with its influence.

> *"I think because we're all, like a few of my friends are also I guess activists… not out there but challenging of people when they say things. That's really helped."*

That participants actively sought out connection with others, and with ideas and ideals that stood in contrast to those that often seem to be an inevitable consequence (or potential creator) of anorexia.

> *"[I started] to look around for recovered people who were ill for a long time and have recovered … I mean it's finding them. It's taken me a while to find them."*

> *"You have to find that hope, and look around for other people and other places."*

> *"I'm seeing an image in my head now of a line drawn between me and the [Enduring anorexia] Facebook post and me thinking, 'Yes, I'm jumping to that because that connects me to the experience. There's some other experience there that I can latch onto.'"*

Again, this is a topic where complexity and nuance are relevant as it doesn't serve to contradict or diminish very real experiences of isolation or acts of separation from others. But recognition of the significant steps taken by participants to overcome isolation despite socialising being a daunting concept at times does make visible agency, intention and perhaps some creativity and courage in working around the difficulties.

> *"I was aware that I needed to meet more people … the friends I recently had were part of a [performance art] group and we had rehearsals and were around together but in quite a structured way."*

> *"She just seemed like a nice person who had the same sense of humour and things. And then it was about hanging out, which was very scary for me … [but] it got easier.*

And then we became really good friends just by hanging out and then she would really help challenge my eating disorder, like I would with hers."

Significantly, this story of connection and mutual support stands outside totalising descriptions and unsettles prevalent notions of people living with anorexia only ever being a negative influence on one another's experiences.

This leads us to the fourth of these themes, Theme 10: *Doing research, exploring feminism and embracing the 'new and different*.' This theme was constructed from stories of participants' active engagement with, and exploration of, ideas, practices, politics and philosophies which they spoke of as being alternatives to ideas which supported anorexia in their life. The topic of doing research is covered in a little more depth later in this chapter but it is fair to say that many participants were very active in seeking knowledge, solutions and alternative possibilities or outlooks that might assist them in understanding and changing their current circumstances. Many found that discovering new ways of interpreting their lives and their experiences had a great deal to offer them.

"Learning about politics, feminism, and social justice have been incredibly important to me and understanding my illness."

"I really like the yoga community and so I felt good about myself again … Yoga is no judgement and no comparison, and I like that mindset."

These ideas often escaped internalising or individualising discourses of anorexia and located it outside the person, and rather in social contexts that supported normative ideas, promoted by problematic operations of power.

"I think feminism, or the feminism I have surrounded myself with, acknowledges that a lot more and can understand it a lot more. I can understand my experiences but also, it's made me feel that my experiences are less unusual … I've spent a lot of time reading feminist literature and I think broadening … for instance on Instagram I don't follow the eating disorder community any more, I follow certain body positivity."

Such perspectives appeared to offer some participants a sense of relief that they were not solely responsible for their predicament and suggested more hopeful horizons.

> *"learning about a lot of the tricks that the media uses, and generally learning about double standards with men and women in terms of attractiveness. I think that was helpful for me. I think it kind of allowed me to see some stuff a lot clearer."*

Participants spoke of searching widely for understandings, both about anorexia and about philosophies of life, from sources such as books, other people, journal articles, media representations, and the internet including blogs and discussion forums.

Through a lens of personal agency and understanding people acting in intentional ways that connect them to treasured values (M. White, 2007) this research and these explorations are perhaps a form of self-resourcing, and a refusal to simply accept the status quo for their lives. In some instances, this search was spoken of as being directly related to a desire for change in relation to anorexia and for others their relationship to anorexia's influence flowed from their interest. Nonetheless, it seemed that the two were inextricably linked. Those who spoke of change flowing from the discovery of new ideas also spoke of this as being welcomed and subsequently actively pursued.

Illumination of these four themes through the lens of narrative practice, that understands people as active decision makers about life, illustrates how people do take active steps to improve their lives in relation to anorexia's influence. It resists ideas of passive or deluded victims of anorexia and tells a more respectful and hopeful story of people as being skilled and knowledgeable about in-the-moment coping with their daily lives, and forward-looking in their actively seeking ideas that will support wished for change. It also invites consideration of what interested participants in what they thought of as alternative ideas, which seemed to be connection, community, social justice and deconstruction of dominant discourses, recognition of the operations of power and the politics of experience. In this light, therapeutic practices that also take an interest in these matters seem worthy of consideration.

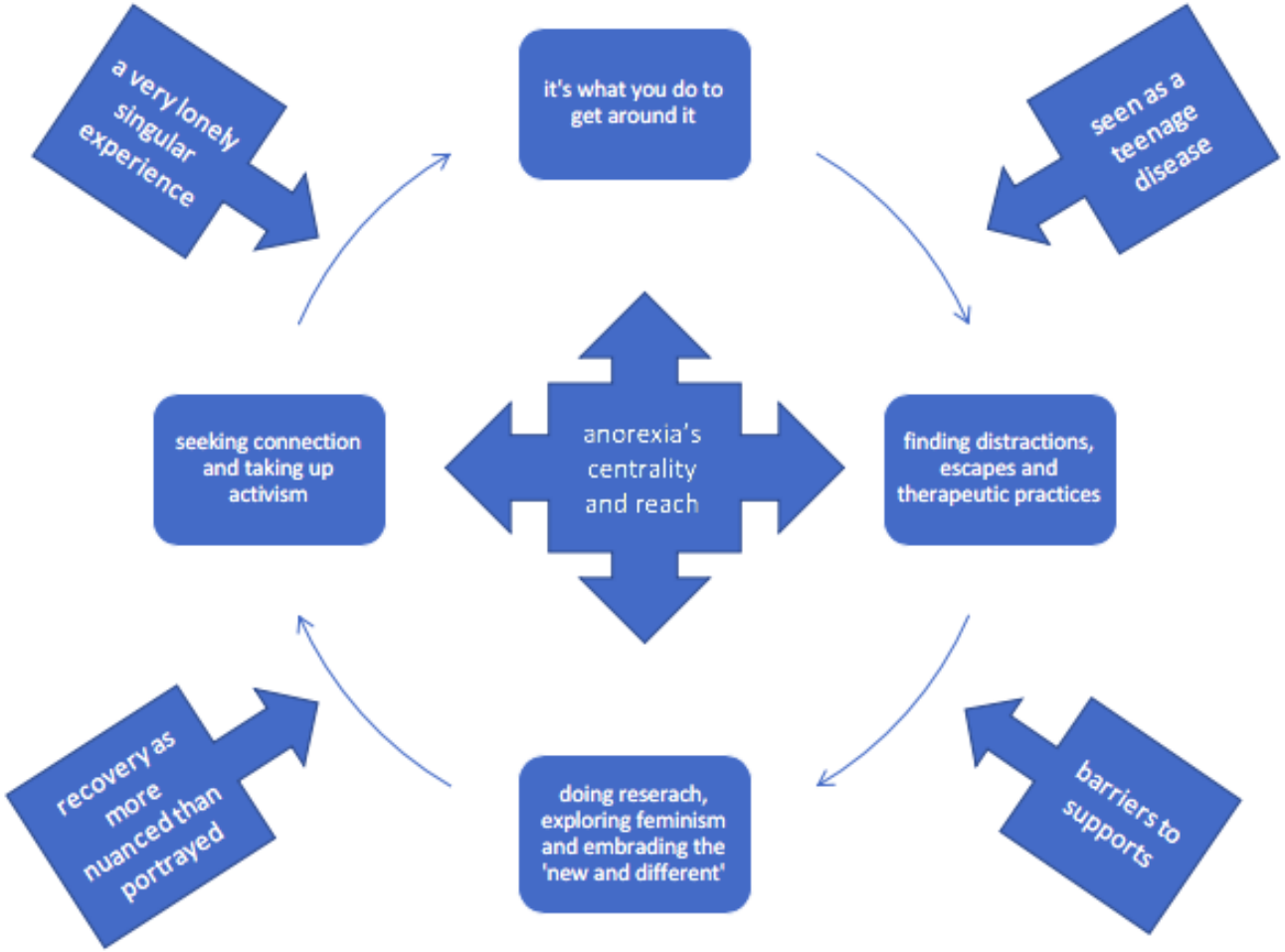


Figure 27 Moving around response positions

Implications for therapeutic practice/service provision:

- *Therapeutic approaches should attend to what people give value to in life and recognise their agentive responses to their circumstances, such as landscape of identity and action questions of narrative practice.*
- *Therapeutic approaches that embrace ideas of the problem being outside the person, of collective responsibility, and of resisting societal invitations to comparison may be of interest to anyone who finds these concepts meaningful.*
- *Practices that connect people around concerns could provide welcome opportunities for social contribution that support change.*

Research recommendation:

- *Methods of enquiry and analysis should be curious about the values, beliefs and hopes that guide participants' choices and actions, as well as the contexts that contribute to them.*

5.6 Welcoming community participation: Crossing boundaries of age, identity and diagnosis

"It's very important that the research includes more than the teenage girl demographic, because there are so many more of us. And I definitely don't fit that box." (Participant)

Just as there is no single story of the experience of anorexia, its influence, or its effects on peoples' lives, neither is there a single story of the people whose lives anorexia enters. From a methodological point of view, this study has demonstrated many benefits of broadening the scope of research invitations beyond specialist services to gather stories and contributions from people who have typically been excluded from research. Helen Gremillion (2008) has argued that social class, race and gender have served as informal

exclusion criteria in much of the research on anorexia. What little research there has been that has centred on long-term experience of anorexia has tended towards clinical assessment tools (see Bamford et al., 2015) and, even where interview processes have been utilised, participation has been recruited via specialist eating disorder services leaving gaps in knowledge about community-based experiences (Robinson et al., 2015). Though recruitment processes in this study were not ideal (see later section entitled *Limitations of this study and recommendations for future research* for a discussion), removing any requirement for participants to have ever received a diagnosis or engaged with specialist services, by circulating invitations internationally via social media and by offering flexible ways of contributing, relatively diverse participation was made possible. As such, this study has gone a small way towards more inclusive representation and community-based participation, thus contributing new knowledge by making visible people and experiences that have all too often been marginalised or erased.

How excluding practices in research have real effects in peoples' lives

A significant consequence of excluding practices in research that quickly became apparent in this study was that the absence of a diagnosis or lack of engagement with services did not indicate any less hardship being endured as a consequence of anorexia's influence or effects, highlighting how severity of experience does not necessarily result in a person becoming engaged with services. Nor can we assume that what has already been documented in these realms is anything near a complete picture. Gender appeared to play a part in experience for some participants in this study.

> *"I'm a 32 year old man and 32 year old men don't have eating disorders. Even when I've experienced extreme weight loss it's never brought up. Not even by my doctors, not by anybody. It's difficult to kind of spend so much time thinking about this stuff and to think also that I'm never going to get better. This is my life."*

Because only a very small number of participants identified as other than female, making generalisations should be strongly resisted. However, one male interviewee did speak of his belief that gender blinded others to the possibility that anorexia might be an influence in his

life. Extreme practices often associated with eating concerns went uncommented on by significant others in his life, and his emaciation and restricted eating were treated as a source of humour and teasing by friends. His attempts to gain recognition of the problem from his doctor were repeatedly rebuffed.

> *"For treatment providers and this just goes down to GPs and other health providers who aren't in any way associated with eating disorders, but who see people … when a grown arse man shows up in their surgery and has lost a significant amount of weight in a short time it's worth asking if he's having trouble eating."*

Similarly, the one interviewee who identified as takātapui/transmasculine found their difficulties attributed by health professionals to other factors, such as poverty, despite their being quite open that eating had become extremely challenging. Whilst it is true to say that older female participants in the study also spoke of their concerns being minimised by health professionals, both of these participants were relatively young and had made significant unsuccessful attempts to be heard. This lack of recognition also had the effect of not only excluding them from services, but in supporting the problem.

> *"[It was] really hard to access treatment, really hard to access any sort of support because it's hard to be believed if you don't fit that demographic. … For a while I was thinking, 'Well I was diagnosed with this in [elsewhere] and treated for this in [elsewhere] but obviously I must be fine now and what I'm doing must be fine. So, it validated for me the behaviours that I was using."*

Although only a very small number of participants identified as male, trans, queer, Asian, Māori, Kuwaiti and African, their stories make a significant contribution to understandings of anorexia's influence as crossing the assumed boundaries of gender, race and identity. They align with earlier claims that people who do not fit into a young, White, middle class, female demographic find it more difficult to have their struggles recognised or attended to (Butterfly Foundation, 2012; Gremillion, 2008), add to a rich description of the potential effects of anorexia's prolonged duration in some people's lives, and illuminate the need for greater recognition of adult and long-term experience.

Implication for therapeutic practice/service provision:

- *Practice approaches and services, including referral pathways, need to be inclusive and appropriate for diverse populations.*

Respectful conversations that enrich storylines without diverting them

Conversations that expand our understandings of anorexia beyond the commonly assumed demographic are vitally important, and we need to cast our attention more widely than has often been done in order to expand our knowledge of the difficulties, our understanding of the problem, and to ensure that people are not excluded from support by a limited representation of age, gender, race and class. We must also find ways to engage in conversations about anorexia extending across these boundaries that do not diminish the seriousness or significance of the struggles of White, middle class, teenage girls living with anorexia, nor inadvertently risk suggesting that it takes evidence of diverse experience to validate their difficulties as serious. It is also worth stating clearly that whilst this study certainly adds to the unsettling a story of anorexia affecting only a fixed demographic, it does not support claims made by some advocacy circles that anorexia doesn't discriminate. Evidence that anorexia *can* affect the lives of people from just about any demographic group does not equate to a lack of discrimination.

Virginia Braun and Victoria Clarke argue for researchers giving deep thought to inclusion criteria as part of a commitment to equity and rigour in methodological approaches (Lainson et al., 2019). If research doesn't actively create space for diverse and unanticipated voices, then it cannot expect to hear from them. It was clear from this study that many people are enduring considerable struggles alone, their voices and stories excluded from academic or public knowledge and clinical considerations. It is nobody's obligation to contribute to research, but there is an imperative for researchers to extend invitations more widely and more inclusively, and for service providers and others to be alert to broader understandings of who may be affected by difficulties, and how.

5.7 How reputations are made: Effects of representation in research

This study has illuminated some of the potential effects of research, and how it becomes documented, in the lives of people it claims to represent. It was very apparent from participants' stories how their experience was shaped in a number of ways by the effects of research that informs public and professional discourses, therapeutic practice, advocacy and policy. Research reports served to inform participants about themselves, their circumstances and the possibilities for their lives with a number of effects, and the consequences of the reputations that preceded them (see M. White & Epston, 1990).

Not the only researcher in the conversation

During the participant interviews I quickly discovered that I was not the only researcher in these conversations. Some participants were academics, students, scientists and journalists, with extensive skills in research and easy access to university libraries and medical or academic journals. Others conducted research in other ways, often via the internet, accessing health-related and eating disorder advocacy websites and social media pages, blogs and discussion forums, as well as mainstream media and open access academic journal articles. Several participants spoke of actively seeking information about recovery, long-term experience and prognosis. Many were well read, and most were well-informed regarding dominant models, approaches and ideas surrounding anorexia. The sense of hopelessness some participants spoke of about their situation had been supported by research they had done themselves. Their explorations of clinical literature and other sources of relevant information had offered them little by way of hope. If anything, it had just contributed to their conviction that change was no longer possible for them.

> *"it's not very encouraging when a lot of the research is saying that if you've had anorexia for 'x' amount of years then you're probably not going to get better. So, you hear that research and you're like, you kind of get dismayed"*

It is crucially important to fully acknowledge disappointing statistics and name areas of professional confoundedness in relation to a problem with such serious effects as anorexia

has, but nor should we be surprised to discover that people reading gloom-filled projections or hearing there is little or no hope for them or their situation adds to their experiences of distress.

> *"All of the studies that suggest having an eating disorder for more than 5 years renders you incurable. And there's nothing I can think of that would fix the problem … It is depressing when I think of it like that."*

This serves as a stark reminder to those of us who conduct research, and who write, that we cannot assume that it will only be clinicians and academics (some of whom will have their own lived experience) who read or are influenced by reports of research.

Research recommendation:

- *Researchers should consider the potential effects of their reporting on a diverse audience that includes health professionals, insiders, their loved ones, and others.*

Preferring hopeful stories

As an alternative to discouraging reporting, several participants spoke of their desire to hear or know something more hopeful and said that hearing stories of recovery and change was significant for them, and some actively sought out such stories as part of their practices of getting by. A few spoke of seeking out stories of recovery that either related directly to experiences of anorexia or someone that was more like them, who seemed somehow more connected to their own experience, and had overcome hardships or obstacles in life. These stories were thought of as more helpful, in contrast to several participants' difficulties in finding hope in existing clinical literature, as they provided encouragement and hope.

> *"I very selectively read some people's success stories and how they coped, what helped them. And that was really good."*

However, discernment needs to be exercised in relation to messages of hope as alongside the difficulties of engaging with pessimistic prognoses offered in academic literature and the desire for alternatives, there was also mention of well-intentioned ideas about recovery being "hard work but worth it" having unintended effects for some participants who expressed that they were struggling to manage life as it was. Ideas that recovery was achievable with a combination of commitment and effort not only risks diminishing their struggle and contributing to a sense of personal failure, but for some brought with it images of unmanageable disruption that made any thoughts of change daunting and out of reach. For someone who feels in a highly precarious position and that they are barely getting by, perhaps already having made many previous attempts at change without the outcomes they hoped for, this message can be experienced in a less-than-positive way. The promise of putting up with worse before things get better, for at least one (male) participant in this study, added to his sense of discouragement.

> *"I mean, I know how much work it would be and what kind of intensive therapy and that kind of thing that it would take. I'm not dying yet so I might as well keep going … So, I'm not sure I've got the energy to deal with that and at least the early stages of recovery."*

A very small amount of research has been conducted in relation to the usefulness of 'recovery stories', producing inconclusive results (Dawson, Rhodes, Mullan, Miskovic, & Touyz, 2014). However, the results of this study suggest there is a case for greater consideration of what gathering and sharing double-storied accounts might contribute to people whose experiences make them relatable. It also suggests there is a strong case for considering very carefully who is represented in those stories, and how.

Unhelpful effects of internalised understandings

Poor representation, feeling misunderstood and dominant discourses of hopelessness combined with the unhelpful responses they elicited from others unsurprisingly had effects for participants' self-understanding. Several spoke of repeated attempts at making wished

for changes or at achieving a state thought of as recovery, that were deemed unsuccessful, leaving them with a sense of personal failure and hopelessness.

> *"I feel in my situation it's impossible. I've tried therapy, I've tried medication. I've had a great family supporting me all along, and I can understand what's going on but I still just can't do it … For about 7 years I was in and out of hospital. I had hospital support, I had therapy, counseling, I had drugs. And then I came home and I saw a psychiatrist for a while. But then I more or less just accepted it and just lived with it."*

In some instances, this became translated into believing it was they who were a hopeless person, rather than a person in a situation where hope was difficult to find, or that treatment programmes or therapies had failed to serve them well.

> *"I say sadness too because sometimes if we want to recover but we see that we have been struggling for so long, we feel like a failure. We feel unable to recover or that we are wasting people's time who are trying to help us. We feel bad about ourselves. Sad and shame."*

It is acknowledged in professional circles that prevalent therapeutic programmes are not always helpful for people living with anorexia, particularly over the long term (Touyz & Hay, 2015), yet it is people living with long-term experience of anorexia who have frequently been positioned within clinical and academic literature as being ambivalent about recovery, lacking motivation for change, or attached to what have unflatteringly been described as 'ego-syntonic symptoms' (Gregertsen et al., 2017; Stockford et al., 2018; Williams & Reid, 2010; Wonderlich et al., 2012). The clear efforts and disappointments that participants in this study describe demonstrates why these are unjustifiable suppositions. It is also worth drawing attention to how the ready availability of these interpretations can create totalising descriptions of people which have, in themselves, the potential to limit possibilities (M. White, 2007; M. White & Epston, 1990). Internalised understandings of anorexia allow little space for change, they occlude the multiple contextual factors that can contribute to the generation and perpetuation of problems, and allow established beliefs about people,

problems and therapeutic approaches to go uninterrogated and therefore unaccountable (Lainson, 2019; M. White, 2011).

Implication for therapeutic practice/service provision:

- *There is a need to employ approaches that do not locate the problem in the person.*

Effects of misrepresentation and the need for improved understandings

Many participants reflected on problematic experiences of engaging with support services. Some had received treatment or therapy in their younger years, others had done so more recently, as adults. These engagements inevitably contribute to the overall experience of living with anorexia. For several participants, past experiences of harsh or inappropriate regimes of treatment had put them off re-engaging with services, and family and other personal relationships had become strained due to the difficulties of living with, and arguing about, anorexia. Responses participants had received from other people, who may have been experiencing their own sense of frustration at the situation or a sense of helplessness in the face of someone they cared about being tangled up with such a tenacious problem, served to exacerbate participants' feelings of isolation and poor self-belief. Being thought of negatively by others, feeling misunderstood or being misinterpreted, and having people pull away over time were all spoken of by many participants as having added to their distress, even allowing anorexia to somehow gain an even stronger hold in their life.

> *"It's actually interesting because I think people think that because you've done these things like have children and survived for this long that you just must be a lot better than you were. So, when you're really struggling it's harder to get understanding a space for that because they're like, 'Oh you've done that you'll be fine ... it'll just be temporary again', you know. Expect your resilience to be always there."*

It is perfectly understandable that supportive others would become discouraged over time by having their attempts to assist someone struggling with anorexia repeatedly thwarted, or

that may they have been educated into believing anorexia was the consequence of a person's own actions or choices.

These are compelling reasons for dominant discourses to be challenged within services, within advocacy, within academia, within media representation and beyond. All too often people living with anorexia are represented in the public eye in stereotyped, reductive and unhelpful ways (Lavis, 2018; Saukko, 2008b; Warin, 2004) and there is an obvious need for improved and genuinely inclusive forms of representation in these realms. Whilst some advocacy agencies and services are making moves in this direction, it is clear that there is much room for improvement.

Implication for therapeutic practice/service provision:

- *An invitation is extended to all who have influence in these realms to reflect on who is being included in representations, how people are being portrayed, how welcoming and inclusive their services are, and whether they truly accommodate the needs of those who seek them. To continue to build on what they are already doing well, to share ideas that are proving effective, and to review areas for improvement.*

Research recommendation:

- *Careful consideration should be given to who is being included in the research, and to what avenues are being utilised for ensuring invitations to participate are made widely available and welcoming.*

Honouring agency in facing of barriers and deciding to (re-)engage with services

"There are things that happen in treatment that have a lasting effect … very traumatic." (Participant)

A wide range of challenges that many participants faced when attempting to gain access to support are detailed in Theme 4: *The road to actually getting treatment for anorexia is*

difficult … there are a lot of barriers along the way and Theme 3: *It's difficult to still be struggling with what's viewed as a teenage disease* combined with Theme 11: *Recovery is more nuanced that currently portrayed*. Obstacles ranged from dismissal of their concerns and inaccessibility or inappropriateness of services that were made available to them to unwelcoming contexts, unhelpful and even traumatic treatments and negative professional attitudes towards them.

Several participants spoke of quite dreadful experiences of engaging with services.

> *"You feel like you're a cattle cow. I always thought it was really weird. We'd be woken up at 5.30 in the morning, made to go to the bathroom and then we would all line up one by one, and made to go into a room, be stripped down, be weighed. And for the rest of the day you would basically be waiting for that next weigh-in."*

> *"When in the past I've had treatment, it's been refeeding and involuntary and not a nice experience. There are not a great deal of psychologists in my area who have a good understanding because they tend to focus on the physical, they focus on the symptoms as opposed to the person."*

Others relayed stories of feeling misunderstood or being judged negatively by the very people from whom they might otherwise have anticipated help or support.

> *"the first thing I would say is not to generalise and to stop thinking or accusing anorexics of being attentions seekers. I've heard a lot about that, and I've seen it on the news. And I notice that this is how even professionals see it."*

> *"when they see an adult with anorexia their preconceptions are much more judgemental."*

These knowledges must be incorporated into our understandings of the overall experience of living with anorexia over time. It would be almost inconceivable to think these recollections would not contribute to future deliberations about re-engagement with

services, even years or decades later, or to how a person might imagine or approach services. Some participants dealt with these complex experiences by eventually distancing themselves from services that were only making things worse for them (if they were not already being excluded), while others continued to advocate for themselves and struggle on within systems that often served them very poorly.

These decisions about whether or not to engage with services are acts of personal agency that illustrate what Michael White referred to as 'intentional states of identity' (Carey & Russell, 2003) and reflect effective utilisation of insider knowledge to engage in purposive action. As they navigate the operations of power and privilege that constrain choice (M. White & Epston, 1990), and systems and institutions that shape what sort of help is available, it is possible to see how decisions that suggest an interest in care for self and for others might include opting out of services. These agentive acts can be understood as potential entry points into alternative storylines in therapeutic practice and research interpretations that point to possible ways forward that are likely to support sustainable change because they work with the person's own knowledges, hopes, beliefs, intentions and values (M. White, 1995, 2007, 2011; M. White & Epston, 1990).

It is important to recognise that by the time a practitioner or service provider meets with someone who has lived with anorexia for years, who may have gone through many previous treatment programmes, they are likely to be meeting with someone who is not only exhausted, exasperated and even despairing, but very possibly someone who has very good reason to be highly sceptical, if not fearful, about what is likely to be on offer, the capacity of the practitioner to understand, or their own chances of achieving sustainable and welcome change. In these circumstances a person's willingness to even consider the possibility of re-engagement needs to be honoured. Through the lens of narrative practice re-engagement might be understood as evidence of, perhaps, courage, determination or hope. These potential interpretations should not be imposed on people, but an early conversation about what brought them back to engage despite their earlier difficult experiences with services, or about what knowledge they have that makes them believe in other possibilities for their life, and what steps they have already taken in order towards making that happen, or hopes (however germinal or fragile) they hold, could illuminate

entry points necessary to maintain ongoing and more hopeful engagement, and the beginning of an alternative story. Through carefully scaffolded questions (M. White, 2007) drawing on concepts of the absent but implicit (M. White, 2000) it may become possible to speak to knowledge they do have about a preferred life that could support them in creating change.

Implication for therapeutic practice/service provision:

- *Approaches that recognise agency and intention, illuminate absent but implicit knowledges, and honour the initiatives people take are well-suited to working in the context of long-term adult experience of anorexia.*

A case for further research as counter documentation

Part of responsible writing is considering the potential effects for our readership. We won't always get it right, but there are steps we can take. Inclusive methods that create space for diverse participation and centre insider experience and perspectives; forms of analysis that seek out agency, recognise response and name resistances; illuminating missed opportunities in previous research; and a refusal to engage with internalised understandings of problems or pejorative or totalising representations of people are all part of more balanced reporting that is likely to create ripples. Following these principles can assist our work in contributing to hoped-for change. Research that illuminates possibilities and offers diverse and more respectful representation can be viewed through the lens of narrative practice as a form of counter documentation, as it provides an alternative to limiting and pathologising reporting of the past. This is significant. Several participants spoke of the difficulties of negative attitudes towards them by the health professionals they encountered.

> *"The thing that makes me most angry and upset ... I think because the treatment services believe it, that we don't want to get better or we want to live with it."*

It has previously been shown that these negative attitudes can have detrimental effects for service users in the context of long-term experiences of anorexia (Button & Warren, 2001; Fox & Diab, 2015), a conclusion supported by this study. Yet one can hardly blame health professionals who are experiencing the frustration of working with therapeutic approaches that are not serving people well for feeling pessimistic about the possibilities if the research and clinical literature only emphasises hopelessness and characterises the people they are working with through a narrow lens of understanding. Counter documentation in therapeutic practice provides scope to alter the reputations that precede people and illuminates and invites consideration of other, preferred, possibilities (M. White & Epston, 1990). Research as counter documentation has similar scope, just on a wider scale.

5.8 Introducing insider perspectives on recovery

Despite not being an intentional focus of this study, it was perhaps inevitable that some interviews involved conversations about recovery. This often translated to participants identifying themselves as being recovered or not, although some felt that the word recovery wasn't a good fit for their experience of making changes to their life to the extent that anorexia no longer had the place or influence that it had in the past. Many of the stories and experiences spoken of invite us into complex understandings of the concept of recovery that extend beyond the debates outlined in the literature review, that centre on whether or not recovery models of mental health have a part to play in therapeutic approaches to long-term experience of anorexia (Bamford et al., 2015; Dawson, Rhodes, & Touyz, 2014; Robinson et al., 2015; Touyz & Hay, 2015; Touyz et al., 2013). Debates that have notably omitted insider views.

An active process not a destination

The concept of recovery was spoken of by participants in multiple ways that are described in detail in the *Theme 11: Recovery is more nuanced that currently portrayed*. While some participants shared a conviction that anorexia had left and could never re-gain its place, others described recovery not as an absolute position or fixed state, but in relation to periods when they had more or less influence over their life relative to that of anorexia. It is

also notable that recovery was frequently spoken of something as something people *did*, not something that happened to them or a destination.

> *"I can see this picture in my head of what I mean…. There's like these building blocks of what I need and when I've got the basis of what I need I can go to the next step."*

Most of those who identified themselves as recovered spoke of recovery as a process of learning or transformation that had significantly improved their lives.

> *"You start to get these little pieces of happiness, pieces of happiness in your life that fill in, it starts to push out that anorexia. And once you get this full life it's like, 'Why would I go back to that, when I have all this good stuff here?' It starts to push out the bad."*

This was not simply a matter of escaping or eradicating anorexia, but an improvement on how their life had been prior to anorexia's appearance.

Unhelpful impositions: Time to stop weighing

Many participants who identified as recovered did speak of how health professionals and counsellors had been part of that process but, aligning with a recurring theme throughout this thesis, there was no single story. Some spoke of preferring to remain in control of decisions about food and eating, whilst others found considerable advantage in being able to 'hand over control' of decisions about food and eating to someone else. Several reported the significance of finding a therapist who took time to listen and understand without judgement. One emphasised the value of being supported in connecting to aspects of herself and her life that she valued beyond anorexia and that she found meaningful, whilst concurrently increasing her own sense of contribution through activism. Being expected to take giant steps and meet unrealistic goals were not generally appreciated by the participants and being asked to 'love your body,' was found by some to be oppressive and problematic, commenting that the idea of tolerating your body is more achievable and less likely to evoke feelings of failure than measuring oneself against ideals of recovery and

being judged not 'better enough'. Binaries of wellness and illness and absolute notions of recovery were equally problematic. What was perceived to be more useful than all-or-nothing positions was allowing space for recognising improvements to life, whilst acknowledging the complexity of experience around reclaiming particular aspects of life. For these, and other, reasons many participants objected strongly to what they felt was an emphasis on weight as a defining feature of recovery. Being weighed and centring weight as a measure of wellness was experienced by several as replicating ideas of success or failure that were associated with anorexia, and the practice was thought of as dehumanising and unhelpful.

> *"There are so many other ways it feels like the treatment services collude with the anorexia. And they don't do it deliberately, but they really do reinforce that anorexic mindset, and it's almost like they're on anorexia's side in some ways ... even if you try to talk to them about it they're so set in their ways. They're so rigid. I've always been weighed … actually, I have stopped weighing myself and I think that has helped me."*

In her ethnographic study of young women's experiences of in-patient treatment for anorexia Gremillion (2008) found that common treatment approaches to anorexia replicate paternalistic and patriarchal discourses that may contribute to anorexia's existence in some people's lives. The findings of this study suggest that similar effects can be experienced in both in and out-patient settings, by people of all ages.

A further difficulty of a focus on weight in therapy was how it affected participants' positioning within services. If their weight was not considered sufficiently low, support was refused or withdrawn despite participants being aware they desperately needed and wanted support.

> *"If someone is going to the doctor to say, 'I am struggling with eating,' or the thoughts around that. Rather than saying, 'Oh well we'll weigh you and come back in two months and we'll see how you are.' It's amazing how much weight you can lose in two months, and so start that ball rolling earlier … It was like you've got to get to*

crisis stage before anything happens. So, you've got to get to the point where it's costing the health service a bomb to take you in."

Some had been discharged from services whilst feeling very unsteady and in the incredibly distressing circumstance of living in a body they found intolerable.

"I do not want to be this weight. I hate my body. I struggle with getting dressed in the mornings."

Yet it was considered a measure of success and wellbeing to services and others, even though they felt far more wretched than they had previously. Some spoke of this experience being sufficiently painful for them to actively seek a return to a low bodyweight. Others spoke of it as contributing to considerations of whether to end their life.

Weight has too long been used as a measure of wellbeing in relation to anorexia, and this is becoming increasingly recognised. So much so that DSM-5[15] no longer includes the weight component as part of diagnostic criteria with consequent implications for diagnosis, prognosis and understandings (Mustelin et al., 2016). This is a step in the right direction, but what was clear from participants' stories was that not only is weight a poor indicator of personal experience of wellbeing it is still being utilised by many services as a reason for referral, treatment approach and discharge. This is too limited and limiting an understanding of wellbeing and recovery if we are to consider people's experience of anorexia beyond the perceived risk to their physical health, and if we are to understand anorexia as more than a body weight. Though even on those terms, that some people are considering whether or not to end their own lives due to the effects of what has been required of them or how they have been treated by services, there is much that is gravely wrong with how some services are being conceptualised and structured. It is vital that more

[15] American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013). Arlington, VA, or DSM-5, is a publication intended for use by clinicans and other interested parties, e.g. researchers and insurance companies, to define and classify mental health concerns using standardised criteria and language. Not without critique, it is commonly relied upon in many Western health and psychological contexts.

collaborative approaches to decision making are adopted and for therapeutic approaches to involve something other than a focus on numbers, bodies and weight restoration. Although one or two participants named assistance with eating and weight gain as their preferred approach without any requirement that they engage in 'talk therapy', the most common preference was to be given the opportunity to talk about broader concerns.

An invitation to create personally meaningful concepts of recovery and approaches that fit

What became abundantly clear was the potential for limited ideas of recovery to keep people stuck by exacerbating difficulties, excluding people from much needed and wanted support, and by failing to recognise and build upon what people were already doing in order to manage their lives and create change that was meaningful to them. There is a need for complex and nuanced understandings of recovery alongside honouring of the steps people take to protect their wellbeing in complex circumstances, and consideration of what is meaningful and currently imaginable or possible for them. Rather than relying on measuring bodies, imposing externally derived goals that diminish personal experience in favour of clinical measures, considerations of recovery should be individually negotiated and collaboratively decided upon. The concept of recovery also needs to be represented in ways that do not leave people considering seeking support discouraged by seemingly impossible aims, nor in ways that ensure those who prefer to create change without professional support are not left feeling their experiences of improvement and wellbeing are somehow lesser or inadequate. Wonderlich et al. (2012) pointed out that one of the difficulties with therapeutic approaches to long-term experience of anorexia is maintaining engagement, as many service users withdraw before significant progress has been made. Perhaps one consideration for services in the light of this study would be to offer flexible approaches that have capacity to accommodate personal preference.

Implication for therapeutic practice/service provision:

- *Consideration needs to be given to diverse understandings of recovery. Individual's own desired reclamations of life should be honoured rather than placing the focus on weight and externally derived goal-setting.*

5.9 Implications for therapeutic practice and recommendations for services

Some of the findings of this study do support emerging ideas in the field about the need for more attention to long-term experience (Dawson, Rhodes, & Touyz, 2014; Stockford et al., 2018), greater recognition of the unique challenges and consideration of new paradigms (Touyz & Hay, 2015); this study illuminates participants' experiences of substantial gaps in current service provision and therapeutic understandings. There is a clear need for services to reflect and consider how available and accessible they are, whether they are truly inclusive and welcoming of a diverse range of people, whether they give value to a variety of experiences and hopes, whether the therapeutic approaches they are utilising are oriented towards honouring multi-storied experience, acts of personal agency, and privileging insider knowledge of living with, and moving beyond, anorexia's influence and longer-term effects, as well as how effective they are at attending to the powerful operations of psychiatric and societal discourses and the politics of experience (as discussed more fully below).

Insider perspectives on service provision: The need for inclusivity, accessibility and availability

The themes which most readily identify problems with service provision are Theme 4: *The road to actually getting treatment for anorexia is difficult … there are a lot of barriers along the way* and Theme 3: *It's difficult to still be struggling with what's viewed as a teenage disease.* These themes not only highlight a wide range of obstacles and misconceptions that mean making the decision to reach out for help is neither simple, nor necessarily generative, but also provide some insight into how services provision has commonly been shaped; to meet the needs of an assumed teenage demographic. There was a clear need for services across many geographic locations to be more available, more accessible, and intentionally designed to welcome and accommodate a wide range of people and their circumstances. Robinson et al. (2015) make a case for hospital admissions to be readily accessible for people who manage their difficulties without regular engagement with therapeutic services, but who still require medical assistance from time to time. This research supports that proposition by recognising the agency in these decisions, but augments it by recommending that non-imposed invitations are made available for further engagement in-between critical

admissions to ensure people who have become familiar with 'revolving door admissions' do not feel they have no other option than to live from one medical crisis to another, as was the case for some participants in this study.

> *"I said, 'I can't do this anymore.' So, they took me into the hospital and gave me the N-G[16] and from then onwards I got help. But there was nothing in-between … I was in the hospital about a week, and then in the psych ward for 4, 5 weeks waiting a place in [specialist unit] so there was nothing in-between. Nothing at all."*

Consideration needs to be given to why people may not be engaging with services, including practicalities of childcare, work commitments and so on. Social work or community support may, in some instances, be at least as helpful as attending a clinic or therapy. Similarly, finances should not be forgotten in relation a person's ability to find, attend or comply with therapy. This is particularly relevant if public services are unavailable or unsuitable, if a person's employment is affected or if the service expects compliance with costly and time-consuming eating plans. Wonderlich et al. (2012) argued for engagement with multi-disciplinary teams, allowing space for longer-term engagement and, once more, this research both supports and expands on that case. A variety of understandings and contributions from a range of disciplines would certainly support richer appreciation of possibilities for support, but it must also be recognised that attending multiple appointments or needing to access a range of disjointed services can be detrimental to engagement, and it is crucial that people do not fall between the gaps.

Participants spoke of different hopes from services. Ross and Green (2011) suggest that therapeutic relationship is pivotal to the success of the approach in this context, and whilst this study certainly suggests a good relationship between the person and their counsellor is supportive of continued engagement, and therefore possibly of change, what was much more visible was the need for the therapeutic approach to be suited to the person's hopes and intentions, to be treated as a "whole person" not a number on a scale, for agency to be recognised, and for social context and discourse to be placed under scrutiny.

[16] Nasogastric feeding tube.

Recognising the politics of experience: What narrative practice can offer

Collectively, these various factors point to the need for recognition of the politics of experience in therapeutic endeavours. Approaches that recognise the person in context and take into account the powerful effects of dominant discourses that affect their lives, that create space to listen in non-assuming ways, that recognise people as active and intentional in their choices, and that view people as striving to improve their circumstances and live consistently with their hopes, beliefs and values have a great deal to offer. In this study, narrative practice has proven itself as a valuable research lens, or approach; one that has pointed to the importance of working in this context with therapeutic approaches that view people as separate to problems, recognise agency, deconstruct discourses and unsettle normative assumptions, and engage in double story enquiry. In the light of this, and of the accumulating evidence for narrative therapy's usefulness in relation to anorexia (Borden, 2007; Kronbichler, 2004; Lainson, 2016; Maisel et al., 2004; Pederson, 2015; Robbins & Pehrsson, 2009; Weber, 2007; Weber et al., 2006; M. White, 2011; Zucker & Borden, 2013), narrative practice must be considered a worthy therapeutic approach in the context of long-term experience. In particular, for its non-assuming and collaborative stance that is suited to working with a wide range of people with different hopes or experiences; its careful and multiple listening; its appreciation for agentive response and intentional ways of being; its respectful and non-blaming positioning of people; and its orientation towards new possibilities and preferred storylines.

Because there is still only fairly limited literature about narrative practice that specifically relates to anorexia, it is strongly advised that practitioners who do seek to utilise narrative ideas in this context gain a robust appreciation for the full range of narrative ideas and practices available. Externalising practices create space for practitioner and client to speak of anorexia in ways that enable alternations to the influence anorexia has in a person's life but, as discussed earlier, there are different means to engage with these ideas. As a narrative practitioner, I found myself reflecting on how I bring externalisation into my own practices (see Box 2 below).

Practice Reflection: Engaging with externalising practices

Using externalising practices in relation to anorexia has become common practice in therapeutic and advocacy contexts, and all interviewed participants used externalising language to some extent. It is difficult to be clear whether this was influenced by the wording of the online survey and by my own speech, though I made active attempts throughout to avoid imposing any particular understanding of anorexia, and earnestly resisted its personification. However, I did have to speak in one way or another, so chose externalising over internalising language. When the concept of externalisation came up in conversation, there was a tendency for participants to conflate externalisation with personification; perhaps unsurprisingly, given how the ideas have been taken up in many advocacy and therapeutic contexts where anorexia is often assigned a character, identity and rationale almost entirely separate to the person living with it. A common metaphor is that of anorexia as a puppeteer with nefarious intentions. Experience of externalisation amongst participants was multi-storied. Some found it helped in creating distance and perspective, and in revising their relationship with anorexia.

> *"[externalisation] helped because I feel more in control of it now. Because I can see it, I can see when it's stronger and go, 'I've got your number!'"*

Others thought it the "*worst possible thing,*" experiencing it as a denial of their reality and personal agency; a diminishment of their capacity for change; a feeling of being out of control due to analogies of possession; or had found that those around them believed they had been given licence to be angry at anorexia, or critical in ways that were felt keenly by participants as personal accusations.

> *"I've been told all these years that my perception is wrong, or 'That's just the eating disorder' or 'You're only saying that because you have an eating disorder.' So, what of my thoughts are mine, and which are the eating disorder. It's really hard to know which are mine, and if I say that someone is hurting me … 'No that's the eating disorder'. So, people are allowed to do and say whatever they like, it's just my perception that's wrong!"*

As a narrative practitioner, I was left curious. Were internalised understandings preferred? Or, was it personification that was unhelpful because of a potential for reification, and a tendency towards dichotomous thinking and totalisation (Vitousek, 2005)? Morgan (2000) reminds us externalising practices are an 'orientation' not a 'technique' (p. 17). Yet there is a case to be made that they have been co-opted in some contexts as a tool or metaphor to serve prescriptive purposes, without their originating theoretical underpinnings, rendering them potentially problematic and apt to replicate practices of oppression and coercion. Conti, Rhodes, and Adams (2016) emphasise practitioners' privileged positions in influencing metaphors used in therapy. The influential stance of anti-anorexia proposed by Maisel, Epston, and Borden (2004) is highly valued by some, while M. White (2011) wrote that metaphors that invite ideas of contest or embattlement have potential to be the least helpful. As a narrative practitioner, I feel invited to proceed tentatively, to listen carefully to what is experience-near (M. White, 2007), and to be reflexive in my use of metaphor and externalising practices.

Box 2 Practice reflection: Engaging with externalising practices

Creating opportunities for connection to counter experiences of isolation

A particular thread which ran through several themes was that of connection. A sense of isolation was frequently spoken of, as described in Theme 2: *It's a very lonely singular experience* and Theme 3: *It's difficult to still be struggling with what's viewed as a teenage disease.* In Theme 9: *Seeking connection and taking up activism* participants spoke of making connection as a significant part of change and Theme 12: *Connection, community and 'being got' matter* illuminated how countering isolation was a key component of both improvements to life and creating potential for change. This is significant, as common practice in services is to mistrust or monitor connections made between people living with anorexia, suspecting that they subversively share secret knowledges in order to defy treatment teams, or compete with one another in ways that strengthen anorexia's influence and effects, with in-patient settings and internet forums being proposed as particular sites for these activities (see Lavis, 2011; Warin, 2005). Yet themes in this study illustrate how connection and communication with people of shared experience can be extremely helpful, encouraging and supportive whilst reducing the problematic effects and strong sense of isolation. As with most aspects of life spoken about in this study, participants were active in seeking contexts that were beneficial to them and discerning about their engagement. Highly valued experiences that came from connections with others in similar circumstances, often achieved via internet forums, included realising that they were not unique or alone in their struggle, feeling able to contribute to others who were also struggling, and speaking with others who understood them and their circumstances without feeling the need to continually explain themselves. One participant's frustrated cry of *"Please don't keep me in isolation!"* in response to her experience of services that disallowed private conversations with other service users, was followed with a cogent deconstruction of what she spoke of as infantilising assumptions that she was neither capable of communicating safely with others, nor managing her own experience and assessing for herself what degree of engagement was useful to her.

Experiences such as this, and the aforementioned evidence of participants seeking out and benefitting from hearing how others have made welcome changes to their lives, point to the value of service providers recognising that connection with others in, or who have

experienced, similar circumstances. Age appropriate support groups, peer support programmes and dedicated internet forums are all potential ways for services to create spaces where connections can be made. Flexible means of engagement are worth considering in recognition that some participants spoke of the need to be careful they didn't become overwhelmed by caring for others, and that some people prefer flexibility, privacy and an easy, non-confrontational means of withdrawal when required.

Being self-directed: Casual engagement, as needed

Similarly, a key factor visible from many participants' responses was how they largely managed their circumstances themselves. In addition, given the long-term nature of their difficulties and, in some instances, their conviction that attempts at recovery, however defined, would be beyond their reach they felt disinclined to embark on a treatment programme even if one was available to them. Yet this did not necessarily mean that they had no interest in improving their circumstances, or in finding support in relation to specific aspects of their difficulties, or having an opportunity to speak about them once in a while.

As one participant explained

> *"I don't want to put all my energy into trying to understand myself and everything else again. Having got therapy and psychological therapy and all that. Just sometimes if there was someone who could just listen for ten minutes or what have you."*

Many participants spoke of the challenges of attending regular appointments with services for different reasons, either because leaving the house was difficult, because of work and other scheduling commitments, because of travel distances, or because they were concerned about externally imposed goal-setting. It seemed likely that opportunities for more casual engagement, perhaps via internet or phone, on an as-needed basis might have something to offer in these instances. This could provide an accessible and flexible means to be heard and understood without judgement at times that were particularly frustrating or when feeling despondent, to talk through or resolve a specific challenge or difficulty, to dip

in and out of support conversations as part of managing their own circumstances and making reclamations of life in their own way and at their own pace, or to keep in touch with services in-between (and perhaps hopefully preventing the need for) intermittent hospital admissions. Some participants spoke of a desire to have in-the-moment help when they were experiencing unexpected or intensely felt difficulties that would not be well-met by services with appointment times and waiting lists. Such services would, of course, need to fit with other recommendations for engaging with therapeutic practices that are able to recognise diversity and work with the politics of experience, respect insider knowledge and acknowledge personal agency, and are worthy of consideration for their potential to fill much-needed gaps in service provision that were identified by participants.

Summary of Practice Implications and Recommendations
Implications for therapeutic practice/service provision
1. *There is a pressing need to ensure sufficient and appropriate service provision in support of this population.* 2. *There is a need to utilise approaches and provide services that recognise the diverse effects anorexia has on life over time, and the complex ways in which it has become interwoven throughout people's lives.* 3. *Practice approaches should honour complex, and often contradictory, experiences of living with anorexia that neither require nor expect that clients take a totalising stance against its existence in their life.* 4. *Practice approaches should recognise and respond to the contexts that support or promote the influence of problems in people's lives.* 5. *There is scope for therapeutic practices and community projects that enable sharing of knowledge derived from experience of living with anorexia over time, and of making contributions to the lives of others.* 6. *Practices should recognise the complexity of people's lives and attend to the meaning and value people give to multiple aspects of their lives.* 7. *The practice of co-researching in narrative therapy could offer additional support when navigating life changes.* 8. *Narrative therapy considerations of the absent but implicit could recognise alternative knowledges and commitments that support preferred ways of living.* 9. *Deconstruction of discourses could contribute to mothers' resisting invitations to guilt or understanding themselves as problematic in their children's lives.*

10. *There is a significant need for service providers to recognise and accommodate adult experience by enabling referral pathways, providing appropriately designed, welcoming services and ensuring workers maintain a supportive attitude.*

11. *Re-authoring conversations that provide space for deconstruction of normative assumptions and privilege alternative knowledge could unsettle beliefs about personal deficit.*

12. *Therapeutic approaches should attend to what people give value to in life and recognise their agentive responses to their circumstances, such as landscape of identity and action questions of narrative practice.*

13. *Therapeutic approaches that embrace ideas of the problem being outside the person, of collective responsibility, and of resisting societal invitations to comparison may be of interest to anyone who finds these concepts meaningful.*

14. *Practices that connect people around concerns could provide welcome opportunities for social contribution that support change.*

15. *Practice approaches and services, including referral pathways, need to be inclusive and appropriate for diverse populations.*

16. *There is a need to employ approaches that do not locate the problem in the person.*

17. *An invitation is extended to all who have influence in these realms to reflect on who is being included in representations, how people are being portrayed, how welcoming and inclusive their services are, and whether they truly accommodate the needs of those who seek them. To continue to build on what they are already doing well, to share ideas that are proving effective, and to review areas for improvement.*

18. *Approaches that recognise agency and intention, illuminate absent but implicit knowledges, and honour the initiatives people take are well-suited to working in the context of long-term adult experience of anorexia.*

19. *Consideration needs to be given to diverse understandings of recovery. Individual's own desired reclamations of life should be honoured rather than placing the focus on weight and externally derived goal-setting.*

Research recommendations

- *Methods of enquiry and analysis should be curious about the values, beliefs and hopes that guide participants' choices and actions, as well as the contexts that contribute to them.*

- *Researchers should consider the potential effects of their reporting on a diverse audience that includes health professionals, insiders, their loved ones, and others.*

- *Careful consideration should be given to who is being included in the research, and to what avenues are being utilised for ensuring invitations to participate are made widely available and welcoming.*

Figure 28 Summary of Practice Implications and Recommendations

5.10 Limitations of this study and recommendations for future research

There are a number of limitations that need to be considered in relation to the study's applicability to a range of contexts, and to guide directions for future research.

One aspect of this study that was both a strength and a limitation was its international reach. Using social media as a source of invitation dissemination meant that participation was enabled from multiple geographic and cultural locations. This allowed diversity of contribution, but it also meant that only a very small number of participants contributed from most locations. For this reason, generalisations cannot be made about service provision in specific locations. Circulation largely occurred in Aotearoa New Zealand, North America and Britain, shaping participation and the results accordingly.

Some attempt was made to make invitations to participate inclusive, but this was challenging to achieve. Several factors likely contributed:

- In order to identify the topic of conversation the word anorexia was used with the effect that participants had to have some sense of connection to that word, even if they didn't use it themselves.

- Although strenuous efforts were made to interest a wide range of potential circulation sources, it was mostly eating disorder advocacy groups and others with a special interest in this topic that promoted the invitation.

- It was difficult to gain support from potential circulation sources that might have attracted increased male participation. Consequently, the invitation did not travel as widely and would be ideal.

- Promotion of the invitation to participate was almost entirely via social media, largely excluding anyone without access to, or interest in, Twitter or Facebook.

- Language was a barrier to inclusion, as participation was only possible in English.

In the light of this study, future research might

- Take an interest in exploring some of the issues that arose in relation to service provision in specific localities. Such research could inform local policy.

- Engage in rigorous practices of research inclusion or target specific populations to enable richer understandings of how particular groups of people's lives are affected by anorexia over time.

- Explore the effects of engaging with possibilities highlighted in the suggested implications for therapeutic practice and service provision.

5.11 In summary

This study has illuminated multi-storied experiences of a diverse population that has been under-represented, misrepresented and frequently excluded from academic research and clinical considerations in relation to anorexia. By providing extensive and detailed evidence of the potential for profound effects and complex experiences of adults who live, or who have lived, with anorexia for many years it has established a compelling case for their difficulties and circumstances to be taken very seriously, and a pressing need for improved and more appropriate service provision for those who wish to engage. It has highlighted how people living with anorexia over time use their own accumulated skills, knowledge and resources to navigate and manage their circumstances on a day to day basis and to seek longer-term change, escaping dominant notions of victimhood and in doing so unsettle assumptions of the need for clinical intervention and the imposition of expert knowledge, instead pointing to alternative ways of understanding people, problems and possibilities.

The study has also demonstrated a variety of benefits of utilising narrative practices in research and as a therapeutic approach in this realm. Significant practices that have

contributed to this research and which are indicated as helpful in therapeutic practice include double-listening, privileging insider knowledge, understanding people as separate to their problems and as intentional and purposive in their acts of personal agency, recognition of the role of context and discourse in shaping experience, and assuming people respond in order to improve their circumstances and live in ways that connect to what they believe and value in life. In particular, these practices and understandings made available a more respectful, accurate and helpful representation of people who live with anorexia over time. These practices enabled rich descriptions of diverse experiences and problematised several existing discourses that limit options and constrain understandings of the possibilities for change. Employing the theoretical lens of narrative practice and utilising several of its methods in research has interrupted dominant narratives in this field that have emphasised bleakness and supported a sense of hopelessness, instead illuminating a wide range of unique outcomes and identifying myriad potential entry points into alternative, hopeful and helpful storylines of people's lives. Storylines that have all too often been overlooked in research and by many of the therapeutic approaches that dominate the field, and yet are likely to be vitally useful in creating wished for change in the lives of individuals and in a field that desperately needs, and is actively seeking, a new paradigm for understanding people, problems and ways forward.

This study has provided significant evidence of the need for change and improvement in relation to

- prevalent understandings and representation of people living with anorexia over time;
- recognition of the difficulties people experience;
- availability and accessibility of appropriately designed services;
- therapeutic approaches in this field in order to embrace flexible, collaborative practices that privilege insider knowledge, recognise personal agency, illuminate hopeful possibilities, and attend to context, storylines, the effects of discourse and the politics of experience.

The results of this study support the proposition that by changing how we look (and listen) in research, as in therapy, by reviewing how we interpret and understand the actions and lives of people whose profoundly difficult experiences have all-too-often been overlooked, demeaned or regarded as hopeless, there is in fact a great deal to honour, and much to hope for.

CHAPTER 6. CONCLUSION

The Enduring anorexia project set out to address a significant gap in the literature on anorexia by contributing to better understandings of adults' experiences of living with anorexia over time. It also sought to illuminate what steps they take in order to cope with their circumstances and get on with their lives; to learn how responses from others contributed to the experience of living with anorexia; and to discover what ideas for future approaches become visible when we privilege insider accounts and escape some of the limitations of clinical definitions of problems and deficit-based theories about people and change.

Uniquely, the Enduring anorexia project utilised a narrative practice lens to establish how double-story development in research in the context of long-term experience of anorexia could offer alternative understandings and improved representation of those whose lives are so-affected.

6.1 Achievements of the project: Multi-storied accounts and agentive representation

The project has achieved its aims in a number of ways. Contrary to commentaries that have assumed a largely homogeneous experience of anorexia, it became apparent that adults enduring its effects and influence over time are a diverse group, living multi-storied lives. The study did not seek to quantify the prevalence of long-term experience of anorexia in our communities, but it did serve to highlight the plight of adults who, by virtue of age, gender and/or ethnicity, have found their experiences either made invisible due to professional inattention, or marginalised through negative representation resulting in exclusion or poor treatment from services. Denial of access to services, or being misunderstood within them, was shown to be highly problematic as difficulties endured by people living with anorexia over many years were demonstrated to be profound, often resulting in cumulative effects of

compromised health, limited life opportunities, and significant social isolation. Evidence of anorexia's capacity to shape lives over time by dominating and infiltrating the minutiae of participants' daily experience left no doubt that enduring anorexia can make a person's life quite miserable and extraordinarily difficult, and that those doing so deserve appropriately tailored and adequate support and understanding that is all too often missing.

However, this was not the only story. The lens of narrative practice made visible complexity, incongruence, and acts of personal agency that illuminated other storylines alongside those of losses and hardships. Asking non-assuming questions that privileged insider accounts brought forth accounts of experience that varied considerably between participants, and over time for some individual participants. While some found employment and personal relationships difficult or impossible, others were juggling demanding careers or academic study, being a parent, social lives and community commitments as they navigated anorexia's effects and influence. Many were living lives that gave no clue to others, even those close to them, about the struggles they were managing on a daily basis, sometimes adding to their sense of being misunderstood and isolated and highlighting the complexity and incongruity of experience.

Not everything about living with anorexia was thought of negatively. Some elements of its presence were valued and appreciated by many participants, such as providing a source of comfort or enabling them to get on with aspects of life in ways they thought they might not otherwise be able to achieve, although they reported having no choice over whether or not it remained in their lives anyway.

Utilising a narrative practice lens that understands people as intentional, agentive, and responsive to hardships in order to remain connected to beliefs, hopes and values, demanded a line of enquiry that attended to participants' means of coping with their difficult situation. Re-authoring questions and practices of double-listening throughout the gathering of stories and thematic analysis enabled hitherto rarely told storylines of people living with anorexia over time as knowledgeable, skilled, and purposive in managing their circumstances in a multitude of ways. Participants responded to their situation by using knowledge gleaned from first-hand experience to manage their lives around anorexia and,

at times, manage anorexia's influence. They also spoke of their multiple means of finding much-needed respite, solace and sustenance, of exploring alternative philosophies for living, and of seeking knowledge and connections that supported them in both coping with their ongoing circumstances and creating change in order to reclaim valued aspects of their lives from anorexia's ongoing influence and potential for effects.

Highlighting these stories in research, which is presented in this study as a form of counter documentation, dramatically unsettles common discourses and alters the oft-held reputations of people living with anorexia over time as lacking in insight or having poor motivation for change. Instead, this response-focussed line of enquiry meant participants could be more fairly and accurately represented as a diverse population who are knowledgeable, capable and active in coping with and improving their circumstances; thus, illuminating gaps in a panorama of professional confoundedness, where hope of wished for change can enter.

6.2 Implications for future research and therapeutic practice

There are several of significant implications for research and therapeutic practices as a consequence of this study that can shape our future aims and guide our endeavours.

- A number of features of the study design contributed to diverse participation and enabled an emphasis on personal experience that was not shaped by service procedures. Using social media meant this community-based study could bypass any need for participants to be engaged with services; the initial step of taking part in a confidential online survey ensured anyone interested could 'test the water' before committing; open-ended survey questions with the option of an interview created opportunities for greater inclusion and choice; and extending invitations beyond the limitations of diagnosis meant previously excluded voices and marginalised experiences could be brought into focus.

- Narrative practice has been strongly implicated throughout this study as an appropriate therapeutic approach in the context of long-term experience of anorexia due to its non-assuming practices of co-research that can respond to diverse and complex experience; its respectful and non-blaming understanding of people as separate from the problems that enter their lives and that are recognised as context dependant; its practices of inclusion and attention to the operations of power and privilege, and the politics of experience; and its re-authoring of lives in ways that acknowledge agency, link action to intention, and illuminate possibility.

- The practices and lens of a narrative approach have been demonstrated by this study as powerfully effective and respectful research tools. By embracing a stance and utilising practices that bring to the centre who and what has previously been overlooked or marginalised, a narrative practice lens in research has proven itself capable of making unique contributions to rich, diverse and complex knowledge; of improving understandings and representation; and of illuminating therapeutic possibilities and much-needed opportunities for hope, whilst simultaneously being inviting, engaging, and possibly even helpful, for participants.

- Being an insider researcher brought its own lens to this study, creating opportunities to reflect on research approaches and their influence; on participation and engagement; on the analysis of data and interpretation of findings; and on the effects of reporting. Being an insider meant I sometimes 'felt' the potential for effects even before I was able to articulate my concerns, leading me to explore new ways of doing and thinking about things. Conducting research as an insider afforded me a unique vantage point from which to appreciate certain significances, such as honouring response, agency and multi-storied experience, and remain deeply committed to inclusive and respectful understandings and reporting.

6.3 Narrative practice research as one paradigm for a more hopeful tomorrow

The Enduring anorexia project began as a hopeful response to the call for a 'new paradigm' (Touyz & Hay, 2015, p. 26) for research and therapeutic approach in the context of long-term experience of anorexia, that will improve understandings 'not only by the medical profession but by the world at large,' (p. 26), in the hope of providing 'a better tomorrow' (p. 26). Narrative practices of double-story development in therapeutic approach and research, with research reporting being conceptualised as a form of counter documentation, have been demonstrated as an effective response to this call.

The conceptualisation that has been threaded throughout this project is that

- people are knowledgeable and capable in relation to their own experiences;
- they find ways to respond that are meaningful and purposive in order to live life more as they would wish, even in the most challenging circumstances;
- experience is diverse, complex and multi-storied;
- when we multiply-listen for skills, knowledges, unique outcomes and entry points into alternative storylines new possibilities appear;
- it is important to remain open to less prescriptive ideas of what recovery or change might be.

Key advantages of this conceptualisation are the multiple and far-reaching applications of being able to guide professional and service settings, but also transcend them. These ideas can inform anyone in any context, whether engaging with a person living with the effects and influence of anorexia in a formal therapeutic way, or as a family member, friend, colleague, researcher, advocate or any other concerned person. This understanding has the capacity to shape more accessible services, telephone or online support, group forums, peer work and more. Significantly, this conceptualisation can also contribute to insiders' self-understanding, self-advocacy and self-determination.

A narrative practice approach is therefore proposed as one appropriate, useful, and socially just paradigm to shape future research in the context of long-term adult experience of enduring anorexia; to inform professional and societal understandings; to guide therapeutic practice and service provision; and as a means of offering a much better, brighter, and more hopeful tomorrow.

6.4 Final reflections

As I draw to a close there is one feature of this thesis that I would like to return to momentarily, and that is to reflect on my own experience of being an insider-practitioner-researcher.

Like other PhD candidates, I have had moments of wondering whether my thesis would ever be completed, or if I could truly write something that would make any sort of contribution. Well, it has been completed. I have every confidence in the contributions made by participants, and I dearly hope that what my work has added also proves to be of value. What I can say with absolute certainty is that this research has made a significant contribution to my own life. I have been engaged in an intellectual and deeply personal process of deconstructing problematic histories, ideas and practices and exploring new and more hopeful ones that has been richly rewarding and invigorating. The whole endeavour has felt like an important journey of activism; a commitment that has kept me going when things got difficult and inspired celebrations at each new development.

My favourite aspect of this research, what I have most appreciated and what has meant the most to me, has been the sense of connection and collaboration with others who have insider experience (even though I didn't make this connection known to them at the outset). Not only could this project not have happened without the generosity and thoughtful insights of all 96 participants, but I am forever changed by reading and listening to their stories and perspectives. Witnessing the collective willingness to contribute makes me feel braver about speaking up, and hearing of the diversity of experiences reminds me to reflect carefully when doing so. Learning of participants' concern for others in similar

circumstances has strengthened my resolve to advocate for change, and knowing I am not the only person to have lived with these struggles ensures I no longer feel alone in my knowledge, concerns and commitments.

In his book *Collective Narrative Practice*, David Denborough (2008) writes about ways narrative practices can link people's lives enabling 'those who are struggling with the effects of hardship to make meaningful contributions to the lives of others who are struggling' and how 'this experience of making a contribution to others can lead to an increased sense of personal/collective agency' (p. 199). He also writes that when people's 'local initiatives, skills and values are acknowledged and documented, we can seek out a relevant audience to whom these will be resonant' (p. 198). The next step for this research will be to seek out these and other audiences, in part to highlight connection and enable contributions in the lives of individuals, but also in the hope that making insider 'initiatives, skills and values' more widely known will contribute to improved professional understandings and conditions that encourage societal change.

APPENDICES

Appendix 1 Strategies for surviving a literature review as an insider-researcher

Strategies for surviving a literature review as an insider-researcher[17]

This document lists some of the strategies I used when, during the preparation of my PhD literature review as an insider-researcher, I felt overwhelmed by the array of deficit-based writings I was exposed to. Too often, they contained limited and unflattering descriptions of me, and put forward theories that positioned me in ways that felt unkind, and which were unhelpful to me. Immersing myself in this literature as a requirement of my study had some pretty profound effects, so I needed to come up with some strategies for survival!

Reading an exciting and engaging interview with Prof Bagele Chilisa about strategies for decolonising research (Chilisa & Denborough, 2019) reminded me that I am not alone in facing this dilemma, and there are long heritages of particular worldviews dominating in research with unhelpful ways. I hope my list of strategies can offer other insider-researchers exposed to problematic literature a sense of companionship. Importantly, this is not intended as an exclusive list, but a living and inclusive one. Hopefully other insider-researchers might feel inspired to make their own lists. Perhaps together we could draw on the principles of collective narrative practice (Denborough, 2008) and create a collective list, as a reminder of the ways we stay strong, remain connected to our own knowledge, and get through difficult times, whilst simultaneously making a contribution to the lives of others! Perhaps our list(s) will capture the attention of other academics, also interested in making academia a bit more of an inviting space for researchers whose experiences have typically been marginalised.

Wouldn't that be a great outcome!

1. Turning the spotlight back on the normalising gaze[18]: If someone, perhaps an anthropologist or clinician, was studying me and wondering why I do what I do, I would often feel inclined to be curious about them and wonder what drew them to this field, what their intentions were, and what beliefs underpinned their

[17] This list of strategies is also to be published in, L. Joubert and I. Epstein (Eds.) *The Routledge Handbook of Social Work Practice Research* (in press). Chapter 27.
[18] From: Hutton, J. (2008). Turning the spotlight back on the normalising gaze. *International Journal of Narrative Therapy & Community Work*, *1*, 3-16.

observation and research practices. Sometimes I would write about them in the style they wrote about me.

2. Remembering my research questions: Sometimes when I became a bit overwhelmed by pathologising and gloomy literature I realised it was because I had been drawn 'off track' and was reading about 'the problem' instead of 'the person'. My research questions were never about anorexia, but about people responding to hardship in the context of anorexia, and to showing how different questions lead us to different conclusions. When I remembered that, I could go back to reading helpful and interesting literature.

3. Writing my literature review for insiders: Having extensive experience of the problematic effects of pathologising theories I was determined to neither give these ideas credibility nor subject readers with their own experiences of anorexia to them. I wrote carefully with insiders in mind, referring to problematic ideas only to illuminate the injustice and highlight the effects, then juxtaposing this with more hopeful and helpful ideas.

4. Writing a rebuttal: I wrote robust and knowledgeable accounts that exposed limitations in problematic theories, augmenting my case with alternative knowledge, and the extensive insider experience I have at my fingertips.

5. Finding companionship: Often, I lost interest in constantly arguing it out with 'detractors.' So, I read articles by writers with similar experiences or whose views are affirming and calming instead. I would spend time in the actual, virtual or hypothetical company of like-minded folk whose company was much more engaging.

6. Having fun with it: Being immersed in pathologising literature meant that unhelpful ideas were often at the forefront of my mind. When I noticed myself doing something that totally contradicted what had been written about me or aligned with the theory, but in a clearly unrelated way, I turned it into a bit of a parody, realising how hilariously funny it was.

7. Taking the Citation Practices Challenge[19]: I would try and actively seek out authors whose work hadn't been taken up by the mainstream, but whose thinking I respected. In doing so, I felt connected in solidarity with a community of academics who refuse to be limited by/to dominant ideas (Tuck, Yang, & Gaztambide-Fernández, 2015).

[19] For more on the Citation Practices Challenge please visit: http://www.criticalethnicstudiesjournal.org/citation-practices/

8. Remembering the many people who want me to write, for multiple reasons: There were many people who wanted me to write and remembering them provided me with considerable encouragement in the moments when I began to think nobody would be interested in what an insider's alternative perspective was. These encouragers who 'kept me company' were the people who had participated in my research, people who found existing theories weren't helping them or the people they wanted to help, people who were on my cheer-team (or who would be if they knew), and the people who had enabled me to take up this opportunity in the first place and who supported me throughout.

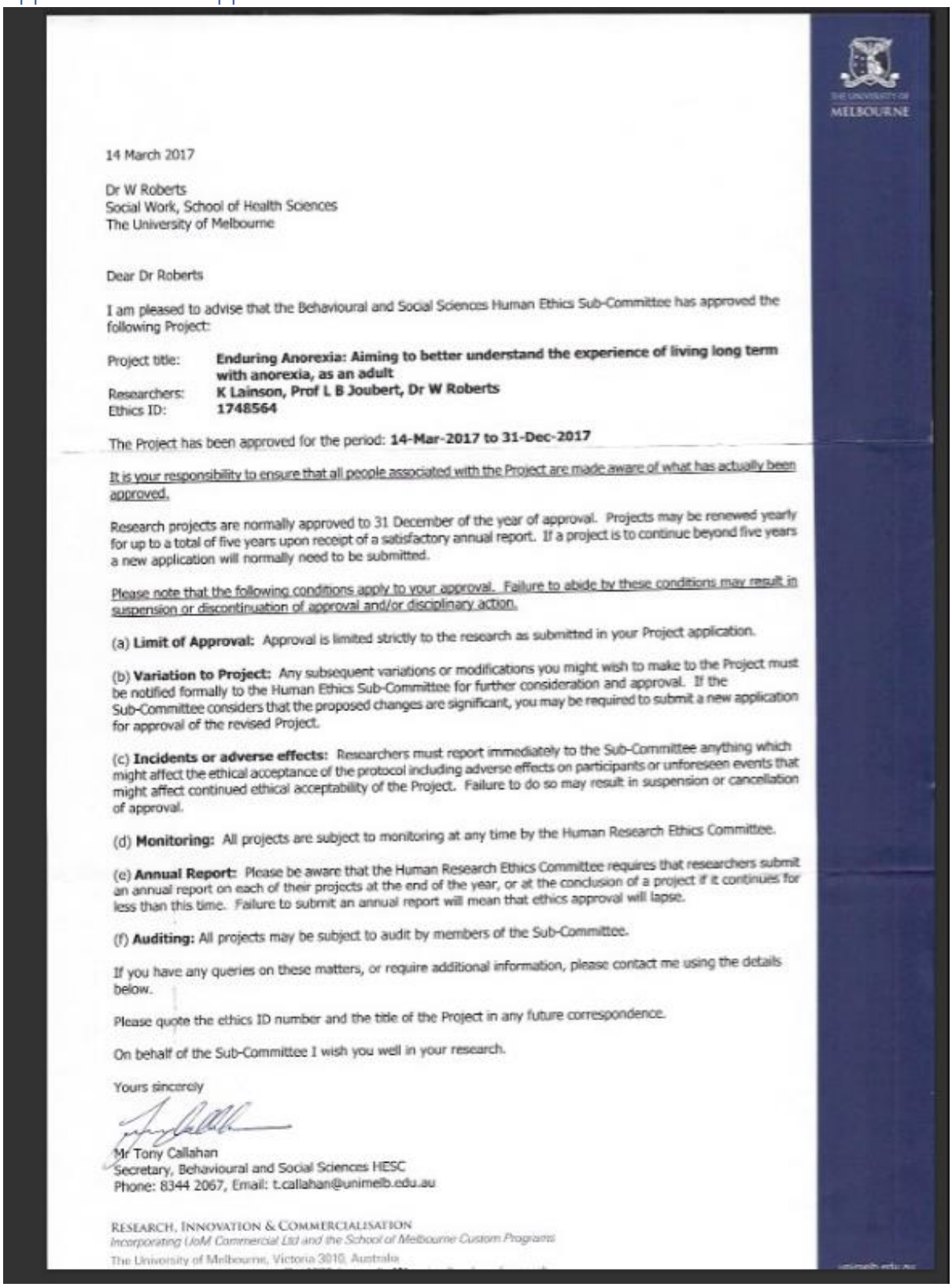
References

Chilisa, B., & Denborough, D. (2019). Decolonising research: An interview with Bagele Chilisa. *International Journal of Narrative Therapy & Community Work, 1*, 12-18.

Denborough, D. (2008). *Collective narrative practice: Responding to individuals, groups, and communities who have experienced trauma*. Adelaide: Dulwich Centre Publications.

Tuck, E., Yang, K. W., & Gaztambide-Fernández, R. (2015). Critical Ethnic Studies. Retrieved from http://www.criticalethnicstudiesjournal.org/citation-practices/

Appendix 2 Ethics approval



THE UNIVERSITY OF MELBOURNE

14 March 2017

Dr W Roberts
Social Work, School of Health Sciences
The University of Melbourne

Dear Dr Roberts

I am pleased to advise that the Behavioural and Social Sciences Human Ethics Sub-Committee has approved the following Project:

Project title: **Enduring Anorexia: Aiming to better understand the experience of living long term with anorexia, as an adult**
Researchers: **K Lainson, Prof L B Joubert, Dr W Roberts**
Ethics ID: **1748564**

The Project has been approved for the period: **14-Mar-2017 to 31-Dec-2017**

It is your responsibility to ensure that all people associated with the Project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

(a) **Limit of Approval:** Approval is limited strictly to the research as submitted in your Project application.

(b) **Variation to Project:** Any subsequent variations or modifications you might wish to make to the Project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised Project.

(c) **Incidents or adverse effects:** Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the Project. Failure to do so may result in suspension or cancellation of approval.

(d) **Monitoring:** All projects are subject to monitoring at any time by the Human Research Ethics Committee.

(e) **Annual Report:** Please be aware that the Human Research Ethics Committee requires that researchers submit an annual report on each of their projects at the end of the year, or at the conclusion of a project if it continues for less than this time. Failure to submit an annual report will mean that ethics approval will lapse.

(f) **Auditing:** All projects may be subject to audit by members of the Sub-Committee.

If you have any queries on these matters, or require additional information, please contact me using the details below.

Please quote the ethics ID number and the title of the Project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Yours sincerely

Mr Tony Callahan
Secretary, Behavioural and Social Sciences HESC
Phone: 8344 2067, Email: t.callahan@unimelb.edu.au

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The University of Melbourne, Victoria 3010, Australia

Appendix 3 Online survey questions

N.B. These questions were preceded by the introductory welcome, plain language statement, invitation to participate (inclusion criteria), consent form and wellbeing statement (distress protocol).

A little about you

1. What is your age? 18-24 25-39 40-54 55-69 70 or older
2. What is your gender?
3. What is your ethnicity?
4. What is your country of residence?
5. Approximate number of years impacted by anorexia (sliding scale)
6. Which of these statements best describes your experience of anorexia?

   Anorexia is/was there all the time
   Anorexia has come and gone at various times in my life

7. Which statement is more true?

   Anorexia is still in my life
   Anorexia is in my past

8. Please select the statement which is most true for you:

   I was given a diagnosis of anorexia by a doctor or therapist
   I have never had a diagnosis, but relate to common ideas or descriptions of anorexia

9. There are common ideas about what gets called anorexia, but some people use different words to describe that experience. Please select the statement which is most true for you:

   I use the word anorexia to describe my experience
   I use different words to describe my experience

Effects of living with anorexia

10. What aspects of your life have been affected negatively by living with anorexia for a long time? *E.g. financial, relationships, physical health, hopes, study or career options etc)*

    My life has not been negatively impacted by anorexia
    My life has been negatively impacted by anorexia *(Please provide some detail)*

11. Are there any positive consequences of living with anorexia for a long time?

Yes/No

12. If you answered 'yes' to question 11, what are the positive consequences?

13. Whether or not they know about the anorexia, how have other people reacted to anorexia and/or its effects on your life? *Please select all that apply.*

	Parents	**Brothers & sisters**	**Own children**	**Romantic or intimate partners**	**Employers or education providers**	**Friends**	**Health professionals**
By being supportive							
By expressing worry							
By getting angry							
By giving unwanted interference							
Walking away							

If you would like to include other responses, please write about them here.

14. Have you ever experienced any of the following as a result of other people's attitudes to anorexia or its effects?

Stigma *(being thought less of or devalued)*
Prejudice *(unfair negative judgement about you)*
Disadvantage *(having less chance of success at something, or fewer opportunities)*

Please feel free to include any details if you wish.

15. What would you say are the biggest, or most important, challenges or negative effects of living with anorexia for a long time?

How you respond to anorexia

This section asks some questions about things you have done in order to get on with life despite anorexia. It may not be easy to think of examples at first, but please take some time to consider carefully. Examples do not need to be big. Even tiny actions or decisions you

have made will be very useful to this research. If you think writing about them will make it less possible for you to do them in future, you may want to skip this section.

16. Can you think of a time when you did something to reduce the impact of anorexia in your life, or cope with some of its effects, so that you could live life more as you would prefer? For example, maybe anorexia could easily have got in the way of you taking up an opportunity or attending an important event, but you didn't let it. Perhaps anorexia could have spoiled a relationship you value, but you found a way to maintain it. Or anorexia could have got worse or taken up even more of your life, but you prevented that from happening.

    Yes - *Questions 17, 18 & 19 ask for more detail about this*
    No - *Please skip questions 17, 18 & 19 and continue from question 20*

17. What was it that you did? If you can think of several things, please feel free to write about as many as you wish.

18. What supported you in doing this? Perhaps some thoughts, ideas or special circumstances, or another person helped.

19. When you took this action, what was more important to you than anorexia?

20. Is there anything you do, or have done, that helps you get through difficult times as a result of anorexia? *For example, listening to music or watching favourite TV shows, spending time in nature, focussing on hopes and dreams, or taking part in spiritual practices such as prayer or meditation*

    Yes – *please provide details in the comment box below*
    No – *please go to question 21*
    If you answered 'yes' please write about what it is you do, and how it helps

Seeking help or support

21. Have you ever tried to get help or support with regard to anorexia?

    Yes/No

22. Are there any barriers to getting help or support? *Please tick all that apply*

    Doctors don't know anorexia affects people like me, so it's hard to get my difficulties recognised
    I am scared to try changing
    I am too embarrassed to ask for help
    There is nothing available that is suitable for me
    I have tried getting help but it didn't work
    This has been going on so long I doubt change is possible

Getting to appointments would be too difficult
I don't think I deserve help
I have not experienced barriers to getting help
Other *(please specify)*

23. What sort of help or support, if any, would you like if it was available? *Eg. counselling support, financial assistance, childcare, respite, social connections, workplace support etc.*

    I do not want any help or support
    I would like support. *Please provide details of what sort of support would be useful to you.*

24. Has anyone ever done or said anything especially helpful with regard to your experience of anorexia? If so, please can you give details.

Additional reflections

Please use this opportunity to write about anything that you think may be relevant to better understanding the experience or effects of living with anorexia for a long time. Perhaps there are things you have discovered about anorexia that are not well known, or factors which have reduced or increased its influence at different times in your life. Maybe your beliefs about anorexia have changed over time, or possibly you would like to reflect on your experience of completing this survey. These are just some suggestions. Please feel free to write as much or as little as you wish.

25. Is there anything else you would like the researcher to know?

Survey results

This survey is confidential, and you do not have to provide contact details unless you want to. If you would like to receive a summary of the results of this research, please provide an email address where they can be sent.

26. Email address for the results to be sent:

Follow-up interviews

You are invited to volunteer for a confidential follow-up interview which will most likely be held by Skype, unless you request an alternative means that we can make work. There is no obligation to take part in the interview stage, it is entirely up to you. Interview questions will follow similar themes to the survey to enhance understanding of the written responses. You will be given the opportunity to discuss any concerns or questions before deciding to

participate, and you do not have to answer any questions that you don't want to answer. You will be free to withdraw at any time and your answers will only be included in the research if you want them to. Interviews will be in English and you are welcome to invite a support person to accompany you if you wish.

If you are willing to be contacted by the researcher about a confidential follow-up interview, please provide a name (It doesn't need to be your real name, but please use one that you will remember) and an email address where you can be contacted.

27. Contact details:

Name:
Email address:

Thank you for your time and effort

Your contribution to this research is greatly appreciated.

By submitting your responses you will be consenting for them to be included in this research project.

Appendix 4 Invitation to participate in research

Invitation to participate in research

Do you have long-term experience of living with anorexia?

You are invited to participate in this University of Melbourne research via an **anonymous online survey, and optional confidential interview** if:

- you are over 18
- have personal experience of living with anorexia (nervosa) for a period of years as an adult (now or in the past)
- whether or not you have ever been given a diagnosis

Including diversity of experience

People of all ages, genders, ethnicities and social groups can be affected by anorexia. For some people, it remains in their life for many years, either constantly or coming and going intermittently. Some people, particularly older generations, may never have sought help or may use different words to describe the difficulties that are commonly named 'anorexia'. All stories are important to this research.

Why is this research important?

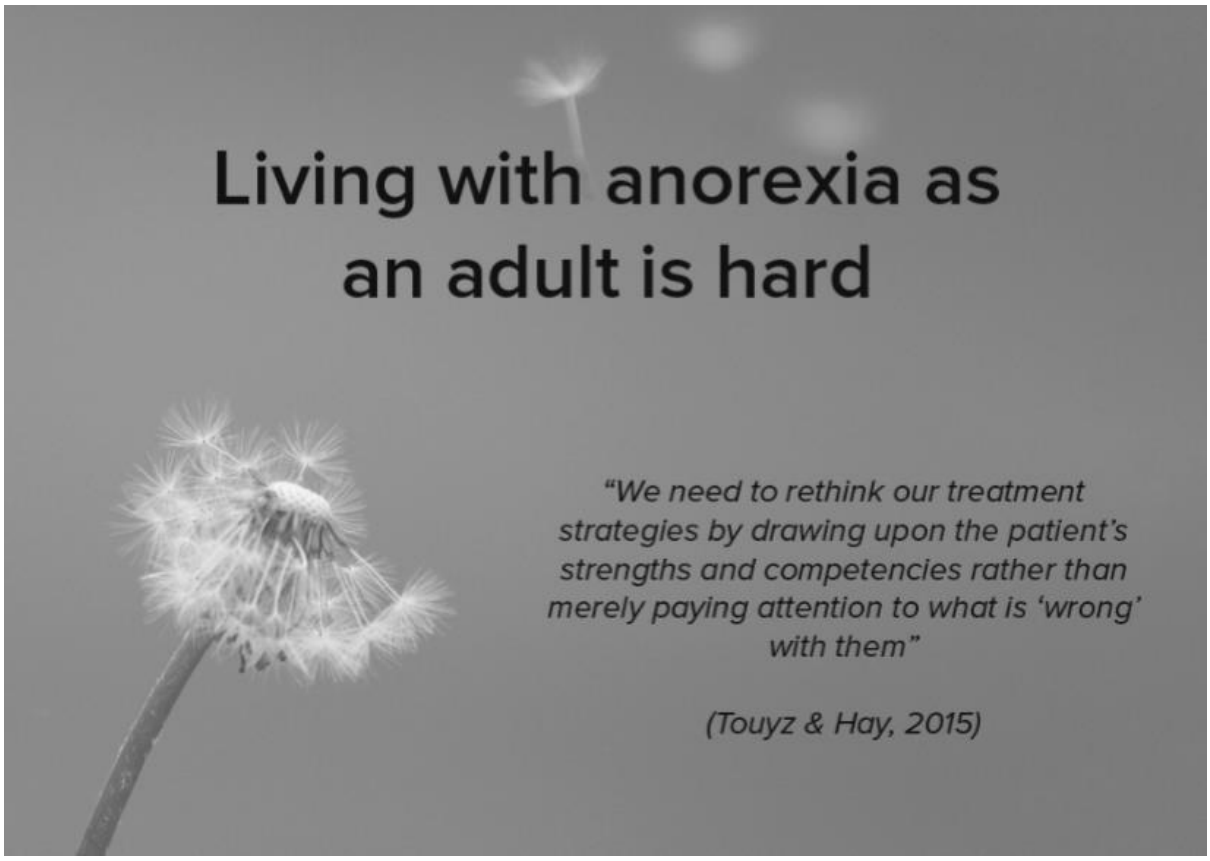
This study is especially interested in the skills, capabilities and knowledges that people use in getting on with life alongside the influence or effects of anorexia over the long term, or how they have reclaimed (even small) parts of their life from anorexia. Anorexia can be a difficult problem to help with and it's hoped this research will help us better understand how to respond to longer-term experiences of anorexia and make it more possible to assist people who feel they require help. It's also hoped that participants' own knowledge about getting by with anorexia may contribute to the lives of others who are managing similar circumstances.

For more information, or to complete the online survey please visit:

surveymonkey.com/r/enduringanorexia

If you have any questions please feel free to contact the researcher, Kristina Lainson, at:
klainson@student.unimelb.edu.au

Appendix 5 Social media invitation slide



Used on social media (Twitter) by @Enduringa with the following tweet:

If you have you lived with #anorexia as an adult and are willing to share some of your knowledge about coping or what helps, you are invited to an anonymous research survey from University of Melbourne http://bit.ly/2w8Nq6O

Appendix 6 Plain language statement: Embedded in survey and sent to interview participants

Plain Language Statement

Department of Social Work, Faculty of Medicine, Dentistry and Health Science

Project: Enduring anorexia

Dr Winsome Roberts (Responsible Researcher)

Tel: +61 3 8344 9422 Email: Winsome@unimelb.edu.au

Mrs Kristina Lainson (PhD student) Email: klainson@student.unimelb.edu.au

Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

This project aims to highlight and better understand the experience of living with anorexia over a long period of time. Whilst there has been a great deal of research regarding anorexia, it has rarely considered personal experience, particularly adults whose experience has spanned a long period of time. This research is wanting to find out about the effects on people's lives of living with anorexia, and especially the skills, capabilities and knowledges that it takes for a person to get on with living life alongside the influence or impact of anorexia.

It is hoped that this research will help us, as a society, better understand what might it means to endure experiences of anorexia, and inform service providers in ways that make it more possible to give appropriate assistance where people feel they require some help. It is

also hoped that participants' knowledge how they have made (even very small) changes as part of managing anorexia, will contribute to the lives of others who are navigating similar circumstances.

What will I be asked to do?

Should you agree to participate you may wish to do so in one or two stages. You can choose whether you identify yourself to the researcher and do not need to use your real name. Your personal details will not be shared, and every precaution will be taken to ensure you are not identifiable to others.

Stage one is an online survey. You will be asked to answer a number of questions about your experience of anorexia. You will not be asked a great deal about anorexia itself, but you will be asked how it has affected your life and about the ways in which you have managed your life, and what has or hasn't been helpful. You will also be asked about what it has been like for you, and if you have any ideas you wish to share with others.

Stage two is an optional interview to be conducted by the researcher. In the survey there is an option to provide your contact details if you would like to volunteer for a follow up interview. This will most likely be held over Skype. Depending on location a face to face meeting or telephone call may be possible. The interview will follow the same themes as the survey questions but will allow for a little more free-flowing conversation as well as further exploration of your responses. It will take between one and two hours, with opportunities for breaks if required. The interview will be recorded and, if you wish, a copy of the transcript will be emailed to you. You may choose to edit the transcript to ensure you are happy with what you said.

Invitation to participate

You are invited to participate in this research:

- If you have experience of living with anorexia, either constantly or intermittently, for a number of years
- If the time you spent living with anorexia either began or continued after the age of 18

- Whether your experience of anorexia was in the past, or if it is still ongoing
- If you have either been given a medical diagnosis of anorexia at some time, or if you have never have been given a diagnosis of anorexia, but relate to common definitions of anorexia.

You are the best person to decide if this research is appropriate for you, but please note that if you are in any way concerned about your own eating you are entitled to ask for extra support from your medical practitioner or other support person.

Often anorexia is written or spoken of as if it was a problem that affects only teenage girls and young women. We know that this is not the case. Anorexia occurs in all ages, genders, ethnicities, socio-economic groups etc. In fact, if you do not fit the 'stereotype' your voice may add to a fuller picture.

What are the possible benefits?

Participation is a very personal choice. Some people who have lived with anorexia have expressed a concern that they are more often 'spoken about' by clinicians and academics, than having an opportunity to speak for themselves. Research has also often emphasised the difficulties of anorexia, without acknowledging the abilities of those living with it. This project aims to give voice to 'insider accounts' of living with anorexia within the context of academic research, providing an opportunity for a diverse range of participants to contribute to knowledge about their experiences, challenges, understandings and skills in living.

Up to now there has been very little research on the effects and experience of living with anorexia over a long period, despite the fact that we know that more than 50% of people who receive a diagnosis at some point in their life have continued to live with it for years. First-hand experience and knowledge is valuable information, and yet there has been next to no research on the skills, abilities and knowledges which people experiencing anorexia use to manage their lives despite what might be considered a very unwelcome intrusion, or obstacle. There is growing awareness that anorexia is a complex matter which affects a

diverse range of people, and the more we know the better equipped we become to assist those who ask for help.

What are the possible risks?

Anorexia can be a very challenging and distressing problem. Some people find that speaking or writing about it can make them feel worse or find that the anorexia becomes more difficult to manage, whilst others find the opposite. If you think that writing or talking about your experience of anorexia will be too distressing, you might decide that it is not right for you to participate. You are the best person to decide whether that is the case. You may wish to discuss your decision with a trusted friend or support person. If you think participation may be just a little bit upsetting but feel strongly that you wish to participate anyway, please ensure that you have a support person available, or care plan in place. You will be provided with a list of websites/agencies who provide information on anorexia and accessing support, but unfortunately it is not possible to provide you with specific or local support people. If it is likely that someone else will be affected by any distress you experience as a result of participation in this study, please consider this before taking part, and share them with the list of websites/agencies provided.

There is a small risk that you, or someone else, could be identifiable as a result of the information you share. Please be assured that every precaution will be taken maintain the confidentiality of yourself and others; personal or identifying details will be left out or altered to protect the privacy of yourself and others.

Do I have to take part?

No. Participation is completely voluntary. You are able to withdraw at any time.
You do not have to answer all of the questions and you can stop at any time. There is no obligation to submit your responses to the survey questions, but once you have submitted them they will become part of the research. If you choose to participate in stage two (the interview stage) and you change your mind or become too distressed during the interview it can be stopped or paused at any time. You could choose to withdraw entirely from the interview, or take a break and continue later. Your decision will be respected fully, and responded to with compassion and understanding.

Will I hear about the results of this project?

Participants will be asked if they would like a summary of the results to be emailed to them.

What will happen to information about me?

Your information will remain confidential, and any answers referred to in the results will be done so anonymously. All information will remain in a securely locked filing cabinet and/or in a secure, password protected computer file. Each survey and interview will be analysed for themes which emerge. These themes will then be collated to see what similarities and differences occur. This will give a sense of the commonalities and the diversity of experience. The information will be used as the basis of a PhD thesis, and possibly as part of academic journal articles and/or talks to be given at conferences. Direct quotes may be included, but please be assured that every precaution will be taken maintain confidentiality; personal or identifying details will be left out or altered to protect your privacy.
University of Melbourne regulations require that the information remains stored, confidentially, for 5 years after reports on the research are published.

Is there any potential conflict of interest?

The research is being carried out by Kristina Lainson, who is a New Zealand registered counsellor. Kristina has, in the past, counselled a number of people in New Zealand who have experience of anorexia. If you are one of those people you may want to take that into account as part of your decision whether to participate or not. You are in no way obliged to participate, but you are welcome to do so. If you wish to remain entirely anonymous to Kristina you can choose just to participate in the survey stage, but all interviews will be conducted by Kristina. If you do choose to participate in an interview you will still be able to withdraw at any stage and your decision will be treated with the utmost respect.

Where can I get further information?

If you would like more information about the project, please contact the researchers;

Dr Winsome Roberts: winsome@unimelb.edu.au

Kristina Lainson: klainson@student.unimelb.edu.au

Who can I contact if I have any concerns about the project?

This research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Office for Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 2073 or Email: HumanEthics-complaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number of the research project.

Appendix 7a Consent form: Sent to interview participants

Consent Form

Department of Social Work, Faculty of Medicine, Dentistry and Health Science

Project: *Enduring anorexia*
Primary Researcher: Kristina Lainson (PhD student)
Additional Researchers: Dr Winsome Roberts, Prof Lynette Joubert

Name of Participant: _____

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.
2. I understand that the purpose of this research is to investigate first-hand experience of living with anorexia in the long term.
3. I understand that my participation in this project is for research purposes only.
4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.
5. In this project I will be required to complete an online survey about my experience of anorexia and possibly an optional interview on the same topic. I will also be given the chance to edit a transcript of the interview.
6. I understand that my interviews will be audio taped.
7. I understand that my participation is voluntary and that I am free to withdraw from this project anytime without explanation or prejudice and to withdraw any unprocessed data that I have provided.
8. I understand that the data from this research will be stored at the University of Melbourne and will be destroyed after 5 years.
9. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.
10. I understand that after I sign and return this consent form, it will be retained by the researcher.

Participant Signature: _____ **Date:** _____

HREC Number: 1748564.1 Project Start Date: 01-03-2017 Version: 06-01-2017

Appendix 7b Online implied consent statement: Embedded into survey

Consent Statement

There is no obligation to submit your responses to this online survey, but when you do you are agreeing for them to be included in this research.

PLEASE READ CAREFULLY BEFORE YOU PROCEED TO THE SURVEY:

1. I consent to participate in this project, the details of which have been explained to me in a written plain language statement, which I can download and keep.
2. I understand that the purpose of this research is to investigate first-hand experience of living with anorexia in the long term.
3. I understand that my participation in this project is for research purposes only.
4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.
5. In this project I will be required to complete an online survey about my experience of anorexia, and possibly an optional interview on the same topic. I will also be given the chance to edit a transcript of any interview I take part in.
6. I understand that my interview will be audio taped.
7. I understand that my participation is voluntary and that I am free to withdraw from this project anytime without explanation or prejudice and to withdraw any unprocessed data that I have provided.
8. I understand that the data from this research will be stored at the University of Melbourne and will be destroyed after 5 years.
9. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.
10. I understand that by submitting my responses to this online survey I will be consenting for them to be included in this research project.

HREC Number: 1748564.1 Project Start Date: 01-03-2017 Version: 06-01-2017

Appendix 8 Wellbeing statement: Embedded in survey and sent to interview participants

How will you ensure your wellbeing when taking part in this research?

Your wellbeing is important. If you think completing the survey or engaging in an interview may result in some unpleasant emotions, please consider whether taking part is right for you.

If you do decide to take part, it is advisable to think in advance how you will manage any distress or discomfort you experience. This might include withdrawing from the study, informing a trusted friend or loved one, ensuring that you have contact details for a local counsellor or support organisation, or engaging in a distracting or comforting activity.

If you decide you would like more information about anorexia you may find the following websites useful. Some of them provide helplines and advice on finding support in the region where they are located.

Australia based information
www.butterflyfoundation.org.au
www.ceed.org.au
www.nedc.com.au

New Zealand based information
www.ed.org.nz

UK based information
www.b-eat.org.uk

USA based information
www.nationaleatingdisorders.org

Men and boys
www.mengetedstoo.com

Recovery focussed websites
www.mirror-mirror.org
www.mentorconnect-ed.org
www.eatingdisorderhope.com
www.reachoutandrecover.com.au

Appendix 9 Survey welcome page

Welcome

Hello, welcome and thank you for your interest in this project. I'm Kristina and am undertaking this research for my PhD. I live in Aotearoa New Zealand, but am originally from the north of England, where I grew up in a three-generation household. Stories, particularly those of being resourceful in hard times, were an integral part of my childhood. Later, working as a counsellor and in community projects, I was struck by the stories of people who live with ongoing difficulties and became increasingly interested in the ways people manage in challenging circumstances.

Part of being able to help is hearing and understanding people's personal experiences, and that's what this research is about. I'm asking what it's like to live with anorexia for a long time as an adult, because there's a shortage of shared knowledge about this. This knowledge will be useful to people who want to help, such as counsellors, decision makers in services, friends and family, as well as people who are also living with anorexia. I hope people's personal insights into the difficulties they face, and what they know about coping, will help guide the ways support is offered in future.

Sometimes talking about our own ways of coping can be helpful in itself, as well as being useful to others. As such, I also hope that taking part in this project might be a beneficial experience.

Initially you will need to click and read through a few pages which contain important information to help you decide whether you want take part. This may take a few minutes. The survey itself can take as little or as long as you like, depending on how much you want to write.

You are welcome to email me with any questions you have about the research, or taking part: klainson@student.unimelb.edu.au

Appendix 10 Press release

N.B. The press release varied slightly according to recipient, e.g. in Aotearoa New Zealand I was named as "New Zealand researcher" whereas in Australia the University of Melbourne link was emphasised.

Mid and late-life anorexia is more common than you think

A global study currently being undertaken by University of Melbourne researchers is highlighting the fact that significant numbers of people diagnosed with anorexia nervosa when they are young go on to live with the problem for many years, or even a whole lifetime. Meaning mid and late-life anorexia may be more common than most of us realise.

Primary researcher, Kristina Lainson, says that anorexia is an ongoing struggle in the lives of many middle-aged and older people, contradicting a common misconception that it only affects teenage girls and young women. In reality, neither age nor gender is a barrier to anorexia, which affects people across all social groups. It is unclear how many adults are living long-term with anorexia and the number may be much higher than we already think, says Kristina, as many people are not accessing help or support. Early findings from the study suggest there are many reasons why people do not engage with existing services. Older generations in particular may never have sought help, nor given a name to the difficulties they experienced in the years before anorexia became a household word. Others say they found treatment approaches available to them when they were young unhelpful, and that they have not pursued help later in life because they believe themselves to be too old, or that the problem has gone on too long for help to be effective. Sadly, some say they do not think they deserve help. What is also evident is that those who do seek help, but who don't fit the assumed stereotype, can have a hard time getting their problems recognised and often experience great difficulty in accessing services. Lengthy delays and repeated roadblocks can result in them simply giving up trying.

Also of concern is a recognised gap in knowledge about how best to help. This is especially true where the person has been struggling for several years. Current therapies for teens are not necessarily suitable in adulthood, particularly where they rely on early intervention and parental input. Kristina says her community-based study, which is currently underway, aims

to assist us in better understanding how anorexia affects the lives of adults, and identify some of the unique challenges and barriers people face. A pioneering feature of the study is its especial emphasis on how people go about coping with these challenges over the long term. By asking what helps and what hinders, and learning how people cope with anorexia whilst managing their daily lives, the research hopes to provide new insights into what is an appropriate response, as well as to offer suggestions for improving therapeutic approaches and making services more accessible to adults impacted by anorexia.

If you have lived experience of anorexia as an adult and are willing to help out by completing the anonymous online survey you can find more details at:

https://www.surveymonkey.com/r/enduringanorexia

Kristina Lainson is a PhD candidate at the University of Melbourne, in the Department of Social Work. She is a published narrative therapist with extensive experience of working as a community-based eating disorders counsellor in Auckland, New Zealand.

Contact details for newsroom use:

klainson@student.unimelb.edu.au

+64224592636

Appendix 11 Interview question guide

Guide for Interview Questions

Participants who complete the online survey were automatically invited to volunteer for an interview based on the responses they have given to the survey questions. Participation in this second stage was entirely optional.

Interviews were semi-structured, with questions designed on a participant by participant basis drawing on the answers provided in the survey, inviting an expansion of their written responses.

The themes of the interviews remained the same as those in the survey, i.e.

- The impacts on life, and first-hand experience of living long term with anorexia as an adult.
- The special skills and knowledges that individuals may have about managing life alongside anorexia, including the means by which participants may have made some reclamations of life from anorexia.
- Personal knowledge about what has been helpful or unhelpful for them, particularly in relation to responses from others.
- Ideas and/or suggestions about what responses from others or ways forward for service providers might be helpful, particularly in terms of making assistance more accessible and useful to this particular group of people.

The following list of questions accompanied me at each interview, in case I lost my way, but was by no means rigidly adhered to.

1. How would you describe living with anorexia as an adult?

2. What challenges or difficulties have you faced as a consequence of living with anorexia as an adult that might be different to say a teenager?

3. You mention in your writing that (insert activity) has been helpful to you. How did (insert activity) come about? Was it something you already did, perhaps you were actively seeking something helpful?

4. How did you first notice that (insert activity) was helpful to you?
    a. Did this noticing change how often you (insert activity)?
    b. Has there ever been a time when anorexia could have stopped you from (insert activity) and you have had to actively maintain the decision to (insert activity)?
    c. How did/do you do that … what steps did you take?
    d. Has anyone else ever played a part in you (insert activity)?
    e. In deciding to (insert activity) what were you intending for your life?

5. Could you say a little about what in particular is helpful about (insert activity)?
    a. In a word or phrase, how would you describe the *essence* of what is helpful about (insert activity)?
    b. This (insert essence) that you experience when (insert activity). Is this (essence) a contrast to life with anorexia ... perhaps and escape or a relief from it … or is it similar to anorexia … so perhaps more like a replacement for it or an alternative to it?

6. What does your appreciation of (essence) say about you as a person, in terms of what you give value to in life, or what your hopes are for life?

7. When you turned away from anorexia, what were you turning towards?

8. If I can ask you to use your imagination for a moment. Supposing it was possible to switch places with someone, and for a little while they were going to be living your life, including living with anorexia. What advice would you give them to prepare them for getting by?

9. Is there anything that would be useful for you to know from other people's lives, i.e. people who have also lived with anorexia?

10. If we shift our attention now to people who don't have experience of living with anorexia. *E.g. Family and friends, employers/educators, health professionals etc* What would you like people to know or understand about what it's like to live with anorexia?
    a. How might their knowing that, be helpful for you or others?

11. You mention talking to (friend/therapist). What makes a good person to talk to, what do they do? What is 'being treated as a person?'

12. Is there a question you would have liked me to ask in this interview?
    a. Can you say a little about that?

Prompts:

- Can you tell me about a time when …?
- Could you describe an event that illustrates …?
- What would I need to know in order for me to better understand …?

Appendix 12a Data analysis: Extract from interview with coding

K: Perhaps we could start with just a very general question. How would you describe living with anorexia as an adult?

R: Uhm. You're not very well understood I don't think. Definitely not as well understood as a teenager. But I'd also describe it as a bit of a prisoner as well, to the anorexia. Uhm, yeah.

Kristina Lainson
Not being understood, especially as an adult
Being a prisoner to anorexia
Anorexia as something which acts on people

K: Perhaps if we just start with the 'misunderstood' as compared to a teenager, would you be able to say a little more about that?

R: I guess people expect to see it in teenage girls and people expect it to be image related, and to do with your looks and everything. Uhm, people are much less understanding when it comes to... I mean I'm nearly 40... and people are less understanding of particularly a mother of young children. You know, people judge very much more quickly. They kind of ask, 'Why can't you get better for your children?' It's much, much harder to explain.

Kristina Lainson
Meeting with less understanding as an adult
Expectations that you should be able to get better for your children
Feeling judged

K: So, perhaps an idea that.... I'm just interested in that question, 'Can't you get better for your children?' ... almost as if you had some choice in that?

R: Definitely. I mean, I think and I'm sure you already know this, that a large number of people think that it is a choice. Almost a lifestyle choice or something, rather than an illness or an affliction. Even my husband is, 'Well if you can't get better..... out you go.' So, yes definitely understanding is much lower.

Kristina Lainson
Being judged by husband and others – recovery perceived as a choice

K: And that lack of understanding leads to conflict and ....?

R: Yeah, and that in turn makes you worse. Because where there's little support from those around you in .... I spent about 6 weeks in [specialist residential treatment centre], and there were a couple of girls in their 20s. Everyone else's family were very supportive, whereas my husband just didn't get it.

Kristina Lainson
Families of younger girls seem to get it, but my husband doesn't

Appendix 12b Data analysis: Extract from coding table for one interview

R72 Line	Rescued words/data extract	Initial idiosyncratic code	2nd round inclusive codes establishing patterns
4	I use disordered eating. I've never had the diagnosis and I kind of feel like it's more a behaviour, I think.	. Anorexia as a behaviour . Uses the term disordered eating . Not had a diagnosis	• Developing own beliefs and philosophies of anorexia • Using language of ED
13	Yes, having anorexia as a thing that is portrayed. And I think in part it's because I don't fit into the stereotypes, I just don't feel like I can in any way relate to the word 'anorexia'. I know my eating is disordered but I don't feel like 'an anorexic' or someone who 'has anorexia'.	. Being and adult male excludes me from the stereotypes . Not fitting the stereotypes . I can't relate to the word anorexia	• Not fully represented • Consequences of lack of representation
24	Exhausting. It's an exhausting thing to always be thinking about.	. Living with ED as exhausting	Anorexia as exhausting
24	On the plus side, no-one will ever accuse you of having any sort of eating disorder because I'm a 30 something [exact age removed as a potentially identifying detail] year old man and 30 something year old men don't have eating disorders. Even when I've experienced extreme weight loss it's never brought up. Not even by my doctors, not by anybody.	. Going under the radar has its 'advantages' . Nobody suspects I have an eating disorder because I'm a 30 year old male – even when weight loss is extreme	• Consequences of lack of representation • There are places in adulthood where anorexia can be easily hidden or explained away
28	It's difficult to kind of spend so much time thinking about this stuff and to think also that I'm never going to get better. This is my life.	. Takes a lot of time and mental energy . No expectations of recovery	• Given up hope of change • Anorexia as both time consuming and rigid
34	All of the studies that suggest having an eating disorder for more than 5 years renders you	. Resigned to a lifetime of disordered eating . Read research and heard that after 5 years	• Given up hope of change • Messages of hopelessness from professionals

	incurable. And there's nothing I can think of that would fix the problem.	there's no hope of recovery . I don't know what to do about it	• Nothing I can think of that will fix the problem
40	It is depressing when I think of it like that. I suppose having had an eating disorder for, well now going on 12 years, getting better isn't really something I know if I'd want.	. Depressing to think recovery isn't possible . Don't know if recovery is something I want after all this time	• Messages of hopelessness from professionals as unhelpful • Don't know if recovery is something I want after all this time
45	I mean, I know how much work it would be and what kind of intensive therapy and that kind of thing that it would take. I'm not dying yet so I might as well keep going.	. Ideas of hard work and intensive therapy is discouraging . May as well keep going if I'm not critical	• Therapy as a daunting/exhausting prospect • Don't know if recovery is something I want after all this time
48	K: So, when you say that the disordered eating is exhausting… is that physically exhausting, mentally exhausting, emotionally exhausting? All of the above? R: All of the above. So, I'm not sure I've got the energy to deal with that and at least the early stages of recovery.	. I haven't got the energy to engage in therapy/recovery . All types of exhausting	Therapy as a daunting/exhausting prospect

Appendix 12c Data analysis: Extract from table of collated rescued words contributing to a code group

Code group: It has an appeal that draws you back in (This code group ultimately contributed to Theme 5: *I don't paint it in a fully negative light*)	
Inclusive code	**Rescued words/data extracts**
Anorexia as having positive elements	R29 L8 I also think it does serve a function. I don't want to say it's necessarily a positive thing, but there are positive elements to it … L11 for me it's a coping mechanism, perhaps a maladaptive one but a coping mechanism and it is one of the reasons I'm still alive. R29 L31-44 And I think it did serve an important function, it was there for me when nobody else was and it was for a long time … L35 sometimes when things are difficult I do miss that because it takes up so much time, it sucks up… you know, there's nothing anorexia doesn't touch and I think it does fill your head up … L37 when you can start to detach from that there's a lot more time to think and there's things that emerge and things I've had to deal with that I've had to keep very much at bay because I was so busy with being anorexic. …L44 There's a huge amount of grieving and various other complicated parts of, I guess, giving up that diagnosis as it were. R29 L234 So, I don't paint it fully in a negative light, and I think people would like to see it as, 'Oh, you know, it's this terrible thing,' but it's more complex than that … L243 there are times when I'm having to adult when I do miss the anorexia because it almost gave me… I don't know, if things went wrong in my life it was because I had anorexia… or I could attribute it to that… whereas now, if things go wrong in my life it's part of my life and as an adult it's for me to deal with. R47 L531 that feels nice because it kind of feels like a special relationship which sounds stupid. You feel like anorexia understands, but nobody else does. That's silly because it's you anyway.
Anorexia as comforting/comfortable	R2 L420 there are times when going back to the eating disorder could be comfortable but … yeah. R13 L209 For me at least it served as a friend in a way. It served as something that was always there for me R29 L58 It was my best friend for a long time and it's still my 'go to' when I'm stressed. R47 L384 you feel protected somehow from all the pain.

	R47 L531 that feels nice because it kind of feels like a special relationship which sounds stupid. You feel like anorexia understands, but nobody else does. That's silly because it's you anyway. R64 L265 Anorexia is your own little bubble. You don't talk to the world, and they don't talk to you. R70 L114 I've always know who I am, it's about having the space. And I guess, I just treat my eating disorder in that same way as everything else that I do, and that's why I take that approach. R84 L11 But it's also comforting.
Anorexia as intrinsic to sense of self	R29 L22 it served a function, but I also think it became a very strong part of my identity and something I am still untangling myself from … L24 and I think especially if you've lived with it through your teens, early twenties, mid-twenties… it's a long period of time, and you've already missed a lot of things within that period … L26 it can become very difficult to separate who you are… where the anorexia stops and you begin … L59 it takes a long time to disentangle and I don't know if I'll ever fully manage that … L74 It's just so interwoven throughout my life and that is very difficult to disentangle that. R29 L247 that's how people saw me. And you become entrenched and that's all I was. People viewed me as a patient, my family viewed me as a patient, I was 'that anorexic girl' and almost a bit of a tragic figure. I think you get very pigeon-holed and it took a lot of work, and I'm still doing a lot of work, to not be portrayed as that person. Years we're talking.
Anorexia as constant/familiar	R71 L3 It's like a background noise R72 L249 And also, to not always have weight and exercise and food in my head a lot. Any time I eat, I'm wondering if this is going to make me fat. If I exercise I'm thinking, 'If I keep doing this will I get thinner?' I'll even look at other people, just strangers on the street and the first thing I think is what my weight is compared to theirs. And I'd like to get rid of all of that. R72 L265 I guess it's the same way as you cope with anything. You just get used to it. R77 L36 It's been very difficult because everything is revolved [around food]. It's almost like an automatic thinking I've got in my head. Weight and food is all the time in my brain and everything is about that so
Anorexia as effective in numbing of emotions and experience	R2 L228 instead of feeling unloved by my mum or unlovable or anything like that, I could put all of my energy into not eating, and that was the way my head was going 'That's caring for yourself'

	because not eating numbed all the underlying emotions of not feeling loved R6 L66 Like addictions or other mental illnesses, you are hiding behind this mask to numb that internal pain and it's like using. When I used not eating and restricting it was like showing my internal pain on the outside because I couldn't express it with words. R13 L380 Right, and for me I think it was one of those things where I don't know how to process them, so I'm going to push them away and control them by not eating. R20 L445 Being able to feel properly, and it's not just to feel good things, it's not just to feel happy and to enjoy swimming, which I miss so much, or something. It's more also just the fullness of all feelings. To actually be able to feel really sad and to actually be able to be just a normal responsive human R29 L33 I think it buffered me from incredibly painful feelings, and it was never really about the weight that's just a distraction. And in some ways, it is a nice distraction … L37 when you can start to detach from that there's a lot more time to think and there's things that emerge and things I've had to deal with that I've had to keep very much at bay because I was so busy with being anorexic. R45 L354 it almost becomes your way of dealing with stress or difficult emotions, whether or not it started like that. It becomes a coping mechanism like someone who drinks or smokes, it's their way of dealing with stress and emotion. You don't get the extreme highs and you don't get the extreme lows … L359 when emotions I have been controlling quite well through the eating disorder start to bubble up, and that can be quite difficult. R47 L322 I think that control of my weight and eating was my way of burying the emotions and feeling a bit numb really. And it works because you don't feel emotional when you're not eating.
Anorexia as a bubble	R64 L265 Anorexia is your own little bubble. You don't talk to the world, and they don't talk to you.
Anorexia feels good and in control	R92 L115 honestly… it, it feels….. good. You feel in control and I needed a bit of control in my life at that point. So, I guess I just sort of transferred it into my diet and that worked for me.

Appendix 12d Data analysis: Final code groups that contributed to the 12 themes

N.B. The code groups that contributed to each theme, as listed here, are also depicted in figures 15-26, following each of the richly described themes.

Theme 1: ***Every single area of my life has been negatively affected by my anorexia***

- anorexia as exhausting and miserable
- anorexia as a disruptor of life
- anorexia as a daily struggle and a thief of life's richness
- the costs and consequences are mounting
- whole chunks of my life are missing
- multiple/all domains of life affected
- the long-term effects are profound
- anorexia never lets up – it is mean and demanding
- missed opportunities

Theme 2: ***It's a very lonely singular experience***

- social isolation and a sense of aloneness
- recovery as a solo endeavour
- there are so many places in adulthood where anorexia can be hidden away
- shame and stigma
- feeling different
- anorexia makes use of isolation
- being misunderstood and misrepresented
- nobody talks about this

Theme 3: ***It's difficult to still be struggling with what's viewed as a teenage disease***

- I ought to be over this by now
- shame & stigma at having a teenage disorder

- services aren't designed for me
- I’m not represented so nobody believes me – sometimes not even I believe me
- this is a teenage girl's problem
- other people's misconceptions mean it’s not taken seriously
- I assume stigma so don't tell anyone
- services don't know what to do with adults

Theme 4: ***The road to actually getting treatment for anorexia is difficult … there are a lot of barriers along the way***

- being excluded from services
- asking for help isn't simply a matter of choice
- I'm not sure if I 'have' this
- I've had bad experiences of therapy in the past
- lack of services and long waiting lists
- services aren't designed with me in mind
- services don't want to treat 'chronic' cases
- private therapy is expensive, and insurance doesn't cover it
- the problem gets minimised and I'm left alone with it
- poor or insufficient experiences of care from health professionals

Theme 5: ***I don’t paint it in a fully negative light***

- it has an appeal that draws you back in
- a thin body feels good
- it helps me feel safe and in control
- it’s a way of dealing with life challenges
- it helps me feel more acceptable
- there are some incidental benefits
- it gives me a feeling of capability and wellbeing

Theme 6: ***What you learn if you get out the other side is amazing***

- I learned a lot about myself and life through recovery
- I gained some helpful life skills as part of recovery
- I think the overall experience has made me a better person
- family relationships ultimately benefitted
- it was a transformational process
- I developed some new and lasting relationships
- a gradual but active process of shifting priorities

Theme 7: ***It's what you do to get around it***

- you have to keep going, life doesn't just stop
- managing life to keep well
- playing mind games with self and strategising
- taking a stand ... sometimes
- focussing on other goals and priorities
- what looks like symptoms might be a strategy
- finding ways to get around anorexia
- altering life circumstances
- making things just a bit better

Theme 8: ***Finding distraction, escapes and therapeutic practices***

- listening to and playing music
- reading, writing and journaling
- finding pleasure in antithesis & antidotes
- finding escapes and taking breaks
- practices which reduce or assist with distress
- being outdoors and in nature
- enjoying being with children and pets
- it's the simple things which help

- allowing myself some comfort
- being creative
- finding distractions and keeping busy
- finding fun

Theme 9: ***Seeking connection and taking up activism***

- not letting anorexia be everything there is
- seeking connection and community
- engaging in activism in many forms
- connections need to be made with discernment
- making social contribution and taking an interest in wider issues
- connection can counter anorexia
- connections to culture and heritage

Theme 10: ***Doing research, exploring feminism, and embracing the 'new and different'***

- actively engaging with new perspectives
- changing practices however difficult
- yoga, meditation, mindfulness and non-comparative communities
- doing internet research
- exploring feminism and body positivity
- making sense of experience through research
- researching health, nutrition, fitness and wellbeing

Theme 11: ***Recovery is more nuanced than currently portrayed***

- recovery is not just a return to bodyweight and an absence of symptoms
- I don't want to be told I can't recover
- recovery might not be for me
- shifting priorities and the desire for change
- recovery isn't separate from the rest of life

- recovery wasn't as I expected it
- recovery was about creating myself anew
- recovery is a daunting and exhausting prospect

Theme 12: ***Connection, community and 'being got' matter***

- recruiting support and finding connections
- please don't keep me in isolation!
- the importance of being 'got'
- connection as important
- connections around shared experience as helpful
- I can be trusted to communicate in non-destructive ways
- peer/mutual support as valuable

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