

Title: Caregiving by People with Psychotic Disorders in the Second Australian Prevalence Study of Psychosis

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Conflict of Interest

None

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Abstract

Increasing numbers of people living with psychosis are providing care for others, although the associated benefits and impacts are poorly understood. This innovative quantitative study investigated this life role using a population-based framework aiming to compare the mental health and functioning of those providing care to and/or receiving care from others.

Caregiving provided by people with psychosis was examined using data from the second Australian prevalence survey of psychosis. This epidemiologically based sample (n = 1822) was divided into four subgroups based on providing and/or receiving care from others. Independent functioning, cognitive functioning, social functioning, social connection and mental health were compared between the four subgroups.

One in seven participants were providing care to others. The majority of carers were female and half were living with the care recipients. Caregivers were more likely to experience better illness course and were more commonly diagnosed with bipolar disorder. Almost one third of caregivers reported that caring adversely affected their lives a great deal. Functioning and social connection were better in caregivers compared to non-caregivers, although cognitive functioning did not differ. People with psychosis who were neither providing or receiving

care were more likely to be single and perceive less warmth in their relationships. As expected, those only in receipt of care were living with greater disability and poorer illness course.

It is relatively common to encounter people with psychosis who provide care to others in clinical settings, and women in particular combine caregiving with multiple other roles. Despite most experiencing some negative emotional impact, caregiving is associated with enhanced social relationships which may provide meaning and purpose for recovery. Caregiving roles should be addressed in recovery and care planning so as to provide people with psychosis with adequate information and support to fulfil these potentially important life roles.

Keywords: psychosis, caregiving, prevalence, functioning

What is known about the topic:

- Caregiving by people living with mental illness is commonly reported within the context of them receiving care from their families.
- The limited studies of this topic show that caregiving by people with mental illness is rewarding to both parties.

What this paper adds

- Caregiving is provided by one in seven people with psychosis and those who provide care have better social connection and functioning than those who do not.
- Almost one third of people with psychosis can be adversely affected a great deal in their lives by caring for others.
- Mental health services can systematically identify people with psychosis who are performing caring roles and provide necessary information and support.

INTRODUCTION

Comparison of the first and second Australian national prevalence studies of psychosis showed a growing number of people with psychosis taking on caregiving responsibilities (Campbell et al., 2012; Evert, Harvey, Trauer, & Herrman, 2003; Morgan et al., 2011).

Clinicians do encounter service-users with mental illness who are caring for others but this caregiving role is under-recognised in current mental health practice (Williams & Mfoafo-

M'Carthy, 2006). The well-documented and often negative consequences of caregiving, such as caregiving burden, psychological distress, social isolation and poor quality of life (Awad & Voruganti, 2008; Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, 2015; Jansen, Gleeson, & Cotton, 2015; Poon, Harvey, Mackinnon, & Joubert, 2017), may also be experienced by people with psychosis who assume these roles. On the other hand, there is increasing recognition of some benefits for people with psychosis who provide care to others (Fossey, Bennetts, Saunders, McDermott, & Harvey, 2004; Szmukler et al., 1996), including a positive contribution to their own recovery (Bird et al., 2014).

Caring and support provided by people with psychosis to their families and peers has mostly been studied where people with psychosis were receiving care from their families (Chen & Greenberg, 2004; Greenberg, 1995; Greenberg, Greenley, & Benedict, 1994; Horwitz, Reinhard, & Howell-White, 1996; Schwartz & Gidron, 2002; Winefield & Harvey, 1994). Although studies are limited, they showed that those who received care from their family members were often involved in reciprocating this care by providing household assistance and help with running errands to their families (Chen & Greenberg, 2004; Greenberg, 1995; Greenberg et al., 1994; Winefield & Harvey, 1994). Family members and their relative with psychosis reported satisfaction with these arrangements (Horwitz et al., 1996; Schwartz & Gidron, 2002). People with psychosis commonly provided caregiving to their family members when they were living together (Greenberg et al., 1994; Horwitz et al., 1996). While greater severity of psychiatric illness was not related to greater or lesser caregiving contributions to their families (Horwitz et al., 1996; Schwartz & Gidron, 2002), higher functioning of people with mental illness was associated with greater contributions (Greenberg et al., 1994). Further, parents of adult children with mental illness who received reciprocal care reported lower caregiving burden (Greenberg, 1995; Schwartz & Gidron, 2002). However, most of these studies had small sample sizes or recruited participants using convenience sampling making generalisation of results problematic.

Studies examining caregiving by people with mental illness outside the context of their own receipt of care are uncommon and have typically used qualitative research methods (Coldwell, Meddings, & Camic, 2011; Granerud & Severinsson, 2006; Williams & Mfoafo-M'Carthy, 2006). These showed that people with psychosis desired to contribute through caring and that caregiving was rewarding to themselves and the care recipients (Coldwell et al., 2011; Granerud & Severinsson, 2006). Similar to those in reciprocal caregiving

relationships, people with psychosis provided emotional support, did household chores and ran errands for family members and friends (Coldwell et al., 2011; Granerud & Severinsson, 2006; Williams & Mfoafo-M'Carthy, 2006) and had better social connection with others, including their families (Coldwell et al., 2011; Granerud & Severinsson, 2006). This study attempts to further investigate this potentially important life role using quantitative research methods in a large population-based sample.

Social connection has a strong correlation with fewer psychiatric symptoms and higher functioning (Evert et al., 2003) and it may also drive improvements in symptoms and functioning. For example, in the five-year follow-up of people with schizophrenia in Camden, London, predictors of poorer illness outcome included social isolation and living apart from relatives (Harvey, Jeffreys, McNaught, Blizard, & King, 2007). If better social connection improves clinical and functioning outcomes in people with psychotic illness, then it is plausible that these in turn, may increase the extent to which people with psychosis take on caregiving roles. That is, caregiving and overall functioning may be mutually reinforcing. However, the inter-relationships between caregiving by people with psychosis and their levels of functioning and social connection are poorly understood and require further examination.

A quantitative investigation of caregiving in people living with psychosis conducted within a prevalence framework is an important advance since existing studies have been limited by small samples and convenience sampling. This fills a major gap in our current knowledge given that caregiving by people with psychosis is under-recognised and yet wider spread than is generally understood (Campbell et al., 2012; Evert et al., 2003; Morgan et al., 2011). In particular, caregiving provided by people with psychosis outside receipt of their own care is a potentially important life role which could benefit from further investigation. Further, examination of the mental health and functioning of people with psychosis who are caring for others would add to existing literature mainly focusing on the negative impacts of caregiving. The data within this study were collected during the second Australian national prevalence study of psychotic disorders, the Survey of High Impact Psychosis (SHIP). The study aims are to: 1) provide a descriptive profile of people with psychosis who were caring for others and/or receiving care from others and 2) compare the functioning, social relationships, mental health and illness severity of those providing care to others and/or receiving care from others. The sample was divided into subgroups based on whether they were providing care to others

and/or receiving care from others, to further understand relationships between characteristics of reciprocal/non-reciprocal caregiving and corresponding personal and clinical factors of people with psychosis.

METHODS

Overview

The SHIP screened people in contact with specialised public mental health services and non-governmental organisations providing support to people with mental health problems in seven catchment sites in 2010. 1825 participants who screened positive for psychosis were randomly selected for an interview. Institutional Human Research Ethics Committees of all seven sites approved the study. All participants gave informed, written consent to participate in the study. The full description of the catchment sites, methodology, and inclusion and exclusion criteria can be found elsewhere (Morgan et al., 2012).

Measures

Carer status: Participants were asked if they provided care, help, support or assistance to family members, spouse or others because of disability, long term illness or problems related to old age in the last 12 months. If they were providing such care, follow-up questions gathered data on type of care duties, time spent on care duties, to whom the care was provided, perceived negative impact of caring on their lives, ability to maintain caregiving duties in the past month and concerns expressed by others regarding caregiving. Parenting was not considered caregiving in this analysis and has been reported elsewhere (Campbell et al., 2012).

Receipt of care: Participants were asked if they received care from a friend or relative in the past 12 months.

Demographic questions included housing, income, education and employment. The ICD-10 diagnoses of SHIP participants were obtained using the Diagnostic Interview for Psychosis, and the description of the diagnostic method can be found elsewhere (Castle et al., 2006).

Course of mental disorder (single episode, multiple episodes with good recovery or partial recovery, continuous chronic illness with/without deterioration) was rated by the interviewers using responses throughout the interviews.

To assess functioning, three measures were used:

- Current cognitive functioning was assessed with the Digit Symbol Coding Test (DSCT) (Randolph, Tierney, E, & Chase, 1998) Higher scores indicated faster cognitive processing.
- Independent functioning over the previous four weeks was assessed by interviewers using the Multidimensional Scale of Independent Functioning (MSIF) (Jaeger, Berns, & Czobor, 2003). Lower MSIF scores indicated better independent functioning with an Overall Global Independent Functioning score of 1=independent functioning equivalent to community norms and a score of 7=total disability.
- The 100-point Personal and Social Performance Scale (PSP) was used to assess past year behavioural and social functioning and role performance (Morosini, Magliano, Brambilla, Ugolini, & Pioli, 2000). Higher PSP scores indicated better personal and social functioning.

Other measures:

- Warmth and closeness in personal relationships was rated on a single item (AQoL7) from the Assessment of Quality of Life (AQoL) (Hawthorne, Richardson, & Osborne, 1999) (rated 1-4, lower scores indicated greater warmth and closeness), and,
- Personal assessment of general mental health was measured with another AQoL item (AQoL14) (rated 1-4, lower scores indicated less anxiousness, worry or depression).

Data analyses

The data were analysed using SPSS version 22 (IBM Corp, 2012). Descriptive statistical analyses were conducted to summarise socio-demographic characteristics. The first set of analyses compared caregivers with non-caregivers using t-test (continuous variables) and chi-square (categorical variables).

Participants were then grouped into four categories based on their care-giving and/or care-recipient status with three participants excluded due to missing data on care status (giving a sample size of 1822):

- Group 1 – Independents (Not providing care to others and not receiving care from others), n=1183

- Group 2 – One-way Caregivers, hereafter referred to as Caregivers (Providing care to others only), n=191
- Group 3 – One-way Recipients, hereafter referred to as Recipients (Receiving care from others only), n=371 and
- Group 4 – Reciprocators (Providing care to others and receiving care from others), n=77.

Differences between the four groups were compared using chi-squared tests or one-way ANOVA for continuous measures with post-hoc Bonferroni corrections. P-value of less than 0.05 was accepted as statistically significant.

RESULTS

Characteristics of people with psychosis providing care to others

Of the total sample, 268 participants (14.7%) were providing care to others in the last twelve months (Table 1). Just over half were female (54.1%) and just under half were single (45.9%). Their mean age was 40.8 (SD=11.1) years old. Sample characteristics are summarised in Tables 1 and 2. A more detailed overview is also available in Morgan et al. (2012).

They provided personal grooming assistance (29.1%), did housework tasks including cooking meals (72.0%), ran errands such as shopping and paying bills (75.7%) and assisted with transportation (50.9%). While most spent 14 hours or less per week caring (62.5%), others spent 15-24 hours per week (15.4%) or 25 hours or more per week caring (22.1%). Three quarters did not receive any payment for caring (77.5%), whereas 18.0% received the carer pension or carer allowance, 3.4% payment in kind such as free rent and 1.1% received formal payment. More than half (55.6%) lived with those for whom they were caring.

Approximately one third of the caregivers reported their own life was adversely affected from caring ‘a lot’ (29.5%); others reported ‘not at all’ (19.4%), ‘a little’ (23.5%) and ‘some’ effects on their life (25.4%), averaging between a little and some effects (Mean=1.66, 95%CI: 1.53, 1.80; $p<0.001$).

Caregivers compared to non-caregivers

Compared with caregivers, non-caregivers were significantly more likely to be male (61.8% versus 45.9%) and younger (mean age 38.0 (SD=11.1) years) (Table 1). More than half of non-caregivers were unemployed (56.0%), 32.3% were employed, 4.6% were parenting, 3.7% were studying, 2.7% were doing voluntary or unpaid work and 0.7% were retired. A higher proportion of non-caregivers were unemployed or unqualified compared to caregivers. Caregivers were more likely to be involved in parenting and to do voluntary work compared to non-caregivers. These differences were statistically significant (Table 1).

Caregivers had better functioning and illness course overall than non-caregivers, except for psychological distress and cognitive functioning. They were less likely to experience continuous chronic illness and more commonly diagnosed with bipolar disorder (Table 2). The PSP scores of caregivers were significantly higher than non-caregivers and their MSIF scores were significantly lower than non-caregivers. Caregivers indicated they felt greater warmth and closeness within their personal relationships (lower AQoL7). However, the self-assessed mental distress (AQoL14 scores) of caregivers was significantly higher than non-caregivers and there were no statistically significant group differences for current cognitive ability using DSCT (Table 3).

Comparisons between the four groups

There was a statistically significant higher percentage of males in Independents and Recipients than other groups (Table 4). Compared to other groups, a statistically significant higher percentage of Independents were single, and Reciprocators were married. The mean age of the Caregiver group was significantly higher than Independents and Recipients. A slightly higher percentage of Reciprocators (57.1%, n=44/77) were living with the person they were caring for compared to Caregivers (55.0%, n=105/191).

Close to half (49.4%) of Reciprocators either had illness characterised by a single episode or multiple episodes with good recovery between; this was a higher proportion than for other groups (Table 5). A considerable percent (61.2%) of Recipients had multiple episodes with partial recovery or continuous chronic illness compared to other groups.

Across the four groups, the two most common mental disorders were schizophrenia and schizoaffective disorders. Almost three-quarters (71.2%) of Recipients were experiencing

schizophrenia and schizoaffective disorders. A higher percentage of Caregivers and Reciprocators reported experiencing bipolar disorder than the other two groups.

The mean Global Independent Functioning MSIF scores were significantly higher (greater disability) for Recipients compared with all other groups (Table 6). Independents' MSIF scores were higher compared to Caregivers but not to Reciprocators.

Independents and Recipients had poorer functioning than the two carer groups for the PSP (Table 6). PSP scores for the two carer groups (Caregivers and Reciprocators) were similar ($p=1.00$), but for non-carer groups, Independents had higher functioning than Recipients.

Both carer groups reported greater warmth and closeness within their personal relationships (lower mean scores on the AQoL7) (Table 6). After conducting post-hoc Bonferroni adjustment, there were significant mean differences between Independents and both caring groups. There were no statistically significant group differences found for self-assessed mental distress (AQoL14) or current cognitive ability using DSCT.

In summary, both Reciprocator and Caregiver groups were more likely to be females living with bipolar disorder. In addition, Reciprocators were more likely to be married, employed, and have experienced a better course of illness, whereas, Caregivers were more likely to be older and have post-school qualifications. Caregivers had the highest level of independent functioning (MSIF), and better behavioural and social functioning (PSP), but not significantly different from Reciprocators.

As for Independents and Recipients, both groups were more likely to be younger males who were living with schizophrenia. In addition, Independents were more likely to be single and perceive less warmth in their relationships, whereas Recipients were more likely not to finish secondary school and be unemployed, live with higher levels of disability (MSIF) and the lowest level of behavioural and social functioning (PSP), experience a poorer course of illness and be diagnosed with schizoaffective disorder.

DISCUSSION

Studies on caregiving by people with psychosis have been largely qualitative and this is likely the first quantitative study to investigate this life role using a population-based framework. A

stratified random sampling method was used to recruit a large representative sample of Australians with psychosis. Our finding that almost one in seven people with psychosis were caregivers suggests that it may be relatively common to encounter such service-users in clinical settings. The multiple roles undertaken by caregivers who experience psychosis, including working, parenting and caregiving, were consistent with previous studies showing that people with mental illness contribute socially in diverse and valued ways.

More women were involved in caring responsibilities perhaps linked with the multiple roles that women typically undertake in societies, including their greater tendency to be involved in caregiving (Norton, Stephens, Martire, Townsend, & Gupta, 2002). The greater severity of illness experienced by men with psychosis (Ochoa, Usall, Cobo, Labad, & Kulkarni, 2012) may also explain gender differences. Females with psychosis are more likely to be married than males with psychosis (Morgan et al., 2012), and this may provide more opportunities for caregiving (Campbell et al., 2012), although parenting was specifically excluded from our definition of caregiving within this study. As caregivers were older than non-caregivers, it is also possible that they were caring for their aging parents.

Caregiving relationships and functioning

The better functioning, lower unemployment rates and better course of illness of carers living with psychosis may reflect their greater capacity to provide care to others. Differences in functioning were mainly between caregiver subgroups and non-caregiver subgroups suggesting a close relationship between caring for others and better overall functioning. This is consistent with findings of Schwartz and Gidron (2002) in a cross-sectional study that showed greater severity of illness was correlated with less provision of reciprocal caregiving to family members. It is possible that better social connectedness and opportunities for involvement in caregiving may improve overall functioning and thereby contribute to reciprocal caregiving, as evident in outcome studies (Harvey et al., 2007; Ruggeri et al., 2004). Notwithstanding these positive findings, four in five carers in this study reported that caring for others had at least a little negative effect on their personal life.

Cognitive functioning was not related to caregiving status in our study. Other analyses of the same prevalence data showed that cognitive functioning of people with psychosis was lower than the general population (Morgan et al., 2014) but poor cognitive functioning did not result in greater loneliness in people with psychosis (Badcock et al., 2015). Taken together,

this shows that cognitive functioning does not limit people living with psychosis from providing care for others and suggests that there is potential for people with psychosis to contribute positively to caregiving despite cognitive impairment.

Caregiving relationships and social connection

Caregivers experienced greater warmth and closeness within their personal relationships than non-caregivers consistent with other studies (Coldwell et al., 2011; Granerud & Severinsson, 2006). Further, those who provided care to others were more socially engaged through employment and home duties. As anticipated, single men diagnosed with schizophrenia were least likely to be involved in giving or receiving care and also perceived less warmth in their relationships, highlighting their often reported social isolation (Stain et al., 2012).

There were interesting differences and similarities among the four groups in this study. Reciprocators and Caregivers showed similar warmth and closeness in personal relationships suggesting that providing care to others may be more influential than receiving care for establishing meaningful social connection. Both types of caregiving relationships commonly happened within the household in which the person with psychosis was living which again underscored the close relationships between social connection within the family and caregiving (Horwitz et al., 1996). It may be that their greater capacity in caregiving leads to greater ability to sustain living with their family. Alternatively, living with family results in greater opportunity to contribute in caregiving. These findings are consistent with most previous reciprocal caregiving studies where caregiving happened more commonly within families.

Supporting contributing lives for people with psychosis

It is significant that the caregivers identified in this study reported greater warmth and closeness in their personal relationships, since many studies have shown that people with psychosis experienced poor satisfaction with personal relationships and social isolation (Evert et al., 2003; Stain et al., 2012). Given the contribution of psychiatric disability to the widespread social isolation of people with psychosis (Stain et al., 2012), being involved in caregiving relationships is one potentially important way for them to contribute socially to their families and communities. This is consistent with other reports that care recipients appreciated caregiving support from people with mental illness (Coldwell et al., 2011; Greenberg, 1995; Horwitz et al., 1996).

Our findings suggest it is important to find ways to better acknowledge, encourage and support diverse social roles of people with psychiatric illness, including providing care for others. This includes providing care and contributing positively to their peers with psychiatric illness (Mahlke, Krämer, Becker, & Bock, 2014; Solomon, 2004; Williams & Mfofo-M'Carthy, 2006). Providing care to family is often seen as a normal familial expression but may be downplayed as a role by people with psychosis themselves. Developing and sustaining meaningful relationships is a commonly expressed goal for many people living with psychosis and taking up a valued caregiving role can enhance recovery, meaning and purpose in life, and self-esteem (Bird et al., 2014; Killackey, Harvey, Amering, & Herrman, 2015; Morgan et al., 2011; Thornicroft et al., 2004). Most of our sample were not receiving any payment for their contributions possibly due to the informal nature of caregiving. More recognition of caregiving through statutory financial support may be appropriate.

Interestingly, there were more Caregivers than Reciprocators in our population-based sample, suggesting the possibility that reciprocal caregiving is more likely to be unrecognised by people with psychosis, compared to non-reciprocal caregiving. Caregivers not living with the person they care for, may also go unnoticed and unrecognised in the clinical context, unless specifically enquired about. The clinical consequences of under recognition of caregiving by people living with psychosis include: missing the recovery potential of people with psychosis taking on meaningful roles (Borg & Davidson, 2008); and over-looking the potential consequences of people with psychosis being unable to sustain this caring role due to exacerbation of their own mental ill-health. This might result in delayed help-seeking among people with psychosis in caring roles and/or greater burden on their families or peers to take over those responsibilities so that the needs of those for whom they are caring can continue to be met.

Implications for practice in mental health

Clinicians should be aware of the possibility of, and encourage, caregiving by people with psychosis. The reported negative effects showed the need to review whether relevant supports are available to service-users with psychosis to support their caring roles. Firstly, clinicians should consider routinely asking service-users if they are involved in caregiving relationships and provide additional assessment of their caregiving needs and impacts. Routine completion of standard dependent care plans, available in Australia and elsewhere (Goodyear et al.,

2015) but often poorly implemented, would support this. Secondly, clinicians who are working with their service-users on their individualised goals should discuss their desires in pursuing caregiving roles so as to recognise and incorporate these within the recovery plan. Widely recognised supported employment approaches (Kinoshita et al., 2013) and emerging supported socialisation approaches (Davidson et al., 2004; Sheridan et al., 2015) could be usefully adapted to enable clinicians to provide supported caregiving interventions to enable their service-users to be involved in caregiving. Thirdly, clinicians can consider providing evidence-based family interventions that could provide information and skill-building support for caregiving, assessment of family life cycle demands, and care plans that support service-user caregivers in achieving their goals and fulfilling their responsibilities in caregiving relationships (Williams & Mfoafo-M'Carthy, 2006). Further, clinicians should recognise the multiple social and occupational roles of women with psychosis. Clinicians should provide adequate information and support to women carrying out caring responsibilities, including to those with bipolar disorder and those with young children (Campbell et al., 2012).

Limitations

As the SHIP was a cross-sectional research design, there was no longitudinal data to show the long-term effects of caregiving on participants or investigate inter-relationships between caregiving with other aspects of functioning and clinical course. Secondly, the SHIP interview did not fully explore relevant aspects of caregiving such as the nature of the relationship of the person with psychosis to the care recipient (such as spouse or daughter). Thirdly, mis-classification and under- or over-reporting of caregiving and care receipt status is possible since we were dependent on self-report only. Finally, there was no data collection from those who received care from people with psychosis. Data from care recipients might further illuminate the importance of caregiving relationships and how people with psychosis contribute to their families and communities. Therefore, future caregiving studies need to consider recruiting both caregivers and recipients, and collecting longitudinal data (Chen & Greenberg, 2004).

Conclusion

The importance of caregiving by people with psychosis is largely neglected in both services and research. This study shows the prevalence, associated personal challenges and benefits of caregiving by people with psychosis. With adequate support from clinicians and other agencies and the community, including better awareness and assessment of caregiving roles,

incorporation of these into recovery planning and provision of helpful interventions such as family interventions, people with psychosis will have a greater potential to contribute to their families and societies, leading to an improved sense of meaning and purpose in life, self-worth and recovery (Bird et al., 2014; Coldwell et al., 2011).

Ethical Standards

The study was approved by institutional human research ethics committees at each site. All participants provided written informed consent.

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Table 1 Socio-demographic characteristics of Caregivers versus Non-caregivers

		CAREGIVERS	NON-CAREGIVERS	χ^2 (p)
		N=268	N=1554	
		N (%)	N (%)	
Male (% within care status)		123 (45.9)	961 (61.8)	24.1 (<0.001)
Marital status (% within care status)	Single	123 (45.9)	992 (63.8)	36.60 (<0.001)
	Married/de facto	74 (27.6)	237 (15.3)	
	Separated/Divorced	66 (24.6)	310 (19.9)	
	Widowed	5 (1.9)	15 (1.0)	
Highest education (% within care status)	No certification ¹	62 (23.2)	551 (35.8)	30.8 (<0.001)
	Secondary school	42 (15.7)	261 (16.9)	
	Technical and Further Education/trade certificate	113 (42.3)	567 (36.8)	
	Diploma	11 (4.1)	48 (3.1)	
	Degree	34 (12.7)	86 (5.6)	
	Other	5 (1.9)	27 (1.8)	
Employment status	Employed	92 (34.3)	502 (32.3)	
	Parenting	33 (12.3)	72 (4.6)	
	Caring for relatives	14 (5.2)	0 (0)	
	Retired	2 (0.7)	11 (0.7)	

	Volunteering	15 (5.6)	42 (2.7)	
	Student	12 (4.5)	57 (3.7)	
	Unemployed	100 (37.3)	870 (56.0)	
Age	Mean (SD) ²	40.8 (11.1)	38.0 (11.1)	Not applicable
1.	No certification refers to all education levels below Year 12, including no formal education. Secondary education refers to Australian education year 12.			
2.	The mean age difference was -2.83 years old (95% CI = -4.27, -1.39, p<0.001).			

Table 2 Course of disorder and diagnosis of Caregivers versus Non-caregivers

		CAREGIVERS	NON-CAREGIVERS	
		N=268	N=1554	
		N (%)	N (%)	χ² (p)
Course of disorder	Single episode	23 (8.6)	124 (8.0)	9.05 (0.029)
	Multiple episode with good recovery	94 (35.1)	446 (28.7)	
	Multiple episode with partial recovery	89 (33.2)	490 (31.5)	
	Continuous chronic illness	62 (23.1)	494 (31.8)	
ICD-10	Schizophrenia	100 (37.3)	756 (48.6)	28.32

Schizoaffective	41 (15.3)	251 (16.2)	(<0.001)
Bipolar	76 (28.4)	243 (15.6)	
Depressive psychosis	14 (5.2)	67 (4.3)	
Delusional & non-organic psychosis	12 (4.5)	80 (5.1)	
Severe depression without psychosis	22 (8.2)	135 (8.7)	
Other ¹	3 (1.1)	22 (1.4)	

¹Screen-positive for psychosis but did not meet full criteria for ICD-10 psychosis

Table 3 Functioning, social connection and psychological distress of Caregivers versus Non-caregivers

	CAREGIVERS	NON-CAREGIVERS	CAREGIVERS Vs NON-CAREGIVERS		
	N=268	N=1554	Mean difference	Confidence interval	<i>P</i>
Global Multidimensional Scale of Independent Functioning scores	2.96 (1.02)	3.60 (1.34)	0.64	0.47, 0.81	<0.001

Personal and Social Performance Scale scores	62.31 (12.09)	55.59 (14.99)	-6.71	-8.61, -4.82	<0.001
Digit Symbol Coding Test	44.25 (17.74)	44.60 (21.09)	-	-	0.800
Warmth and closeness in personal relationships (AQoL7)	1.76 (0.83)	2.05 (0.99)	0.29	0.16, 0.41	<0.001
General mental health (AQoL14)	2.27 (0.91)	2.12 (0.94)	-0.15	-0.27, -0.03	0.018

Table 4 Four group analysis - Socio-demographic characteristics

		CAREGIVERS		NON-CAREGIVERS		χ^2 (p)
		Caregivers	Reciprocators	Independents	Recipients	
		N=191	N=77	N=1183	N=371	
		N (%)	N (%)	N (%)	N (%)	
Male (% within care status)		90 (47.1)	33 (42.9)	751 (63.5)	210 (56.6)	30.08 (<0.001)
Marital status (% within care status)	Single	87 (45.5)	36 (46.8)	781 (66.0)	211 (56.9)	98.43 (<0.001)
	Married/de facto	43 (22.5)	31 (40.3)	150 (12.7)	87 (23.5)	
	Separated/Divorced	58 (30.4)	8 (10.4)	242 (20.4)	68 (18.3)	
	Widowed	3 (1.6)	2 (2.6)	10 (0.8)	5 (1.3)	
Highest education (% within care)	No certification ¹	46 (24.2)	16 (20.8)	403 (34.4)	148 (40.3)	71.07 (<0.001)
	Secondary school	26 (13.7)	16 (20.8)	202 (17.2)	59 (16.1)	

status)	Technical and Further Education/trade certificate	85 (44.7)	28 (36.4)	441 (37.6)	126 (34.3)	
	Diploma	10 (5.3)	1 (1.3)	38 (3.2)	10 (2.7)	
	Degree	22 (11.6)	12 (15.6)	68 (5.8)	18 (4.9)	
	Other	1 (0.5)	4 (5.2)	21 (1.8)	6 (1.6)	
	Employment status	Employed	63 (33.0)	29 (37.7)	427 (36.1)	75 (20.2)
	Parenting	23 (12.0)	10 (13.0)	56 (4.7)	16 (4.3)	
	Caring for relatives	13 (6.8)	1 (1.3)	0	0	
	Retired	1 (0.5)	1 (1.3)	8 (0.7)	3 (0.8)	
	Volunteering	11 (5.8)	4 (5.2)	26 (2.2)	16 (4.3)	
	Student	8 (4.2)	4 (5.2)	42 (3.6)	15 (4.0)	
	Unemployed	72 (37.7)	28 (36.4)	624 (52.7)	246 (66.3)	
Age	Mean (SD) ²	41.63 (11.31)	38.75 (10.38)	37.80 (11.11)	38.50 (11.11)	Not applicable

1. No certification refers to all education levels below Year 12, including no formal education. Secondary education refers to Australian education year 12.
2. The mean age (post-hoc Bonferroni) difference between Independents and Caregivers was -3.83 years old (95%CI= -6.11, -1.54, p<0.001), and between Caregivers and Recipients was 3.124 (95%CI= 0.51, 5.74, p=0.010).

Table 5 Four group analysis - Course of disorder and diagnosis

		CAREGIVERS		NON-CAREGIVERS		χ^2 (p)
		Caregivers	Reciprocators	Independents	Recipients	
		N=191	N=77	N=1183	N=371	
		N (%)	N (%)	N (%)	N (%)	
Course of disorder	Single episode	16 (8.4)	7 (9.1)	107 (9.0)	17 (4.6)	46.85 (<0.001)
	Multiple episode with good recovery	63 (33.0)	31 (40.3)	373 (31.5)	73 (19.7)	
	Multiple episode with partial recovery	67 (35.1)	22 (28.6)	354 (29.9)	136 (36.7)	
	Continuous chronic illness	29 (15.2)	13 (16.9)	243 (20.5)	91 (24.5)	
ICD-10 diagnosis	Schizophrenia	72 (37.7)	28 (36.4)	575 (48.6)	181 (48.8)	56.78 (<0.001)
	Schizoaffective	28 (14.7)	13 (16.9)	168 (14.2)	83 (22.4)	
	Bipolar	53 (27.7)	23 (29.9)	193 (16.3)	50 (13.5)	
	Depressive psychosis	10 (5.2)	4 (5.2)	53 (4.5)	14 (3.8)	
	Delusional & non-organic psychosis	11 (5.8)	1 (1.3)	66 (5.6)	14 (3.8)	
	Severe depression without psychosis	14 (7.3)	8 (10.4)	107 (9.0)	28 (7.5)	
	Other ¹	3 (1.6)	0 (0)	21 (1.8)	1 (0.3)	

¹Screen-positive for psychosis but did not meet full criteria for ICD-10 psychosis

Table 6 Four group analysis - Functioning, social connection and psychological distress

	CAREGIVERS		NON-CAREGIVERS	
	Caregivers	Reciprocators	Independents	Recipients
	N=191	N=77	N=1183	N=371
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Global Multidimensional Scale of Independent Functioning (MSIF) scores ¹	2.90 (1.03)	3.12 (1.00)	3.47 (1.36)	4.01 (1.17)
Personal and Social Performance Scale (PSP) scores ²				
Digit Symbol Coding Test (DSCT)	44.78 (18.26)	42.93 (16.42)	44.33 (20.23)	45.46 (23.65)
Warmth and closeness in personal relationships	1.79 (0.86)	1.70 (0.75)	2.06 (1.00)	2.02 (0.95)

(AQoL7)³				
General mental health	2.24 (0.91)	2.34 (0.90)	2.10 (0.93)	2.19(0.95)
(AQoL14)				
1	The mean Global MSIF score (post-hoc Bonferroni) difference between Independents and Recipients was -0.53 (95%CI= -0.73, -0.33, p<0.001), between Caregivers and Recipients was -1.11 (95%CI= -1.41, -0.81, p<0.001), between Recipients and Reciprocators was 0.89 (95%CI= 0.47, 1.31, p<0.001), and between Independents and Caregivers was 0.58 (95%CI= 0.31, 0.84, p<0.001).			
2	The mean PSP score (post-hoc Bonferroni) difference between Independents and Caregivers was -5.23 (95%CI= -8.19, -2.27, p<0.001), between Independents and Reciprocators was -4.80 (95%CI= -9.26, -0.33, p=0.027), between Independents and Recipients was 6.75 (95%CI= 4.49, 9.01, p<0.001), between Caregivers and Recipients was 11.98 (95%CI= 8.60, 15.36, p<0.001), and between Recipients and Reciprocators was -11.55 (95%CI= -16.30, -6.80, p<0.001).			
3	The mean AQoL7 score (post-hoc Bonferroni) difference between Independents and Caregivers was 0.27 (95%CI= 0.07, 0.47, p=0.002), and between Independents and Reciprocators was 0.36 (95%CI= 0.06, 0.66, p=0.010).			

Author