# Title: Perceived needs of carers of people with psychosis: An Australian longitudinal population-based study of caregivers of people with psychotic disorders

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## Conflict of Interest

No conflicts of interest have been declared.

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## Abstract:

Studies have documented the perceived needs of carers of people with psychosis but most recruitment has utilised convenience sampling resulting in limited understanding of carers' needs. This longitudinal study was conducted within the second Australian prevalence study of psychosis, aiming to obtain generalizable findings regarding perceived needs of carers of people with psychosis.

Semi-structured interviews were conducted with 98 carers of people with psychosis recruited in the Australian prevalence study of psychosis. Seventy-eight of the carers were reinterviewed one year later to measure changes in their perceived needs. Correlational and paired T-tests were conducted to identify relationships between perceived needs and carer's health and wellbeing, and changes in levels of perceived needs over time. Qualitative responses were structurally coded by segmentation according to the Carers' and Users' Expectations of Services – Carer version. Thematic analysis of common words and phrases was undertaken to identify key themes concerning carers' perceived needs.

There was minimal improvement in carers' perceived needs over time and their needs were closely related to their perception of their own social connectedness, psychological health and quality of life. Five themes were identified: Greater involvement of carers in the treatment plan, Provision of relevant information to carers, Multiple biopsychosocial support for carers, Wellbeing and independence interventions for people with psychosis, and Choice to care and alternate caring arrangements.

Although policy recognises the need to support carers, findings show that focused interventions are required to address carers' perceived needs more holistically in current mental health services. To support carers' recovery, services need to include carers in treatment planning, and consider ways to address their needs and improve their own health and wellbeing.

**Key words:** carers, perceived needs, psychosis, population-based, caregiving burden, mental health

What is known about the topic:

- Needs of carers of people with psychosis are unclear as most studies recruited carers using convenience sampling.
- Limited understanding of changes in carers' needs over time.

What this paper adds:

- Carers' needs are correlated to their own health and wellbeing.
- Most aspects of carers' needs are unchanged over time and are largely unaddressed by services.
- Services need to include carers in the care plan and provide biopsychosocial interventions to support their recovery.

## Introduction

Carers of people with psychosis commonly report needing support to cope with caregiving responsibilities. The types of support include: needing information regarding illness, services and management of the illness, support to improve relationships between carers and those for whom they care, and emotional support to talk about their experiences (Cleary, Freeman, Hunt, & Walter, 2005; Coker, Williams, Hayes, Hamann, & Harvey, 2016). In addition, caregivers typically experience social isolation, poor psychological health and diminished quality of life (Awad & Voruganti, 2008; Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, 2015). Studies have indicated that higher levels of perceived unmet needs had a negative effect on carers' quality of life and extent of caregiving impact (Cleary, Hunt, Walter, & Freeman, 2006; Zahid & Ohaeri, 2010). Studies have highlighted the neglected needs of carers in mental health systems for a long time (Hoenig & Hamilton, 1966), particularly due to limited availability of family interventions (Watts & Hodgson, 2016; Zahid & Ohaeri, 2010).

Most studies that identified needs of carers recruited research participants conveniently from support groups or psychiatric facilities (Drapalski et al., 2008). This resulted in limited understanding of the range and severity of the needs of carers of people with psychosis. More importantly, there is limited understanding of changes in carers' perceived needs over time within a population-based framework. The Carers' and Users' Expectations of Services – Carer version (CUES-C) measures multiple caregiving constructs (Lelliott et al., 2003), and has satisfactory psychometric properties and high acceptability for carers (K. Harvey et al., 2008). CUES-C was used recently in an Australian study (Coker et al., 2016).

This longitudinal carer study was conducted as an adjunct to the second Australian prevalence study of psychosis, aiming to obtain generalisable results regarding the perceived needs and health and wellbeing of carers of people with psychotic disorders. An earlier publication of this study showed that there were no improvements in carers' health and wellbeing over time (Poon, Harvey, Mackinnon, & Joubert, 2017) but this report focusses specifically on the perceived needs of carers. The main aim of this report is to understand the perceived needs of caregivers of people with psychosis within a population-based framework. The secondary aims are to measure changes in perceived needs of carers of people with psychosis over time, and to identify relationships between perceived needs of carers and their health and wellbeing. The term 'consumer' is used in this report to refer to people with mental illness, which is consistent with the definition of people receiving mental health services in Australia (Department of Health, 2013).

## Method

The 2010 Australian prevalence study of psychosis randomly selected people who were identified in seven catchment sites and screened positive for psychosis to participate in an interview (Morgan et al., 2012). This carer study was conducted in the two Victorian catchment sites. Within a policy framework emphasizing family inclusion in service delivery (Department of Health, 2013),  the two sites provided individually-focused psychiatric services to people with mental illness and one site initiated a trial of a form of family psychoeducation, Behavioural Family Therapy (Hayes et al., 2015). Moreover, within both sites were voluntary organisations providing education, support and respite services for carers. After consumer participants had completed the prevalence survey, written consent was sought and obtained from ninety-eight consumer participants and their carers to participate in this additional caregiver component. Validated questionnaires were then administered to assess the health and wellbeing of the carers, and their perceived needs. At one-year follow-up, 78 of those carers were re-interviewed. Full details of the carer recruitment strategy can be found in the earlier publication (Poon et al., 2017).

Consumer participants' socio-demographic and clinical characteristics were obtained from the prevalence study interviews. The Personal and Social Performance Scale (PSP) was used to measure the personal and social functioning of people with psychosis on a 100-point scale and higher scores indicated better functioning (Morosini, Magliano, Brambilla, Ugolini, & Pioli, 2000). The International Classification of Diseases 10th Revision diagnoses for mental disorders were assessed using the Diagnostic Interview for Psychosis (Castle et al., 2006). This caregiving study was approved by Melbourne Health (Reference: 2010.011), St Vincent's Hospital (Melbourne) (Reference: 111/11) and the University of Melbourne (Reference: 1034494.1) Human Research Ethics Committees.

The health and wellbeing of carers were assessed using:

1) Kessler-10 (K10) which measured carers' psychological distress and higher scores indicated greater psychological distress (Kessler et al., 2002);
2) Friendship Scale (FS) which measured carers' social connectedness and higher scores indicated greater social connection (Hawthorne, 2006);
3) Mental Illness Version of the Texas Inventory of Grief (MIVTIG) which measured feelings of grief in caregivers (Miller, Dworkin, Ward, & Barone, 1990) and higher scores indicated more prominent feelings of grief;
4) World Health Organisation Quality of Life BREF (WHOQOL-BREF) which measured carers' perceived quality of life and higher scores indicated greater satisfaction concerning the respective domains: Physical Health, Psychological Health, Social Relationships and Environment (World Health Organisation, 2004); and
5) Involvement Evaluation Questionnaire (IEQ) which measured caregiving consequences and higher scores indicated greater caregiving consequences (van Wijngaarden et al., 2000). The Sum IEQ scores were used for this study.

CUES-C was used specifically to assess carers' perceived needs (Lelliott et al., 2003). Carers were first asked to rate their perceived satisfaction using a three-point scale: 1=Satisfied a lot, 2=Satisfied a little and 3=Not satisfied at all. Second, they were asked to rate their levels of perceived need within another three-point scale: 1=Would like more help, 2=Unsure and 3=No. Higher scores for question 1 indicated poorer satisfaction and lower scores for question 2 indicated greater perceived needs. Open-ended responses regarding participants' perceived needs were also collected.

Quantitative analyses were conducted using SPSS version 21 (IBM Corp, 2012). Pearson correlations (r) were used to identify relationships between carers' CUES-C domains and their health and wellbeing variables at baseline. Paired T-test was used to analyse changes in CUES-C scores over time. Statistical significance level was set at 0.05. Qualitative responses obtained using CUES-C were first thematically coded, segmented by the domains in CUES-C (Guest, MacQueen, & Namey, 2012). After structural coding by segmentation of words and/or phrases, common codes were derived (Guest et al., 2012). The codes were then categorised and their respective quotations across the domains were grouped together in the codebook and thematically analysed by repetition to derive initial themes by the first author who conducted the interviews (Guest et al., 2012). The other authors subsequently reviewed the quotations and refined the corresponding themes, and lastly, all authors reviewed and agreed on the final themes.

## Results

### Socio-demographic characteristics of carers

More than three-quarters (n=74, 75.5% out of 98) of carers were female. The mean age of carers was 57.1 years (SD=12.1). Most (63.3%) of them were employed. A higher percentage of carers were parents of people with psychosis (62.2%) compared to spouses/partners (15.3%), siblings (11.2%), friends (7.1%) and others (4.4%). One third (36.7%) of carers were receiving financial assistance. Close to three-quarters of carers (71.4%) were born in Australia. A high percentage (87.8%) of caregivers spoke only English at home.

### Socio-demographic and clinical characteristics of consumers

The median age of people with psychosis was 33.0 years (range=18-62) and most of them were male (n=64, 65.3% out of 98). Close to half were unemployed (46.9%) and the others were working (43.9%), studying (2.0%), performing home duties (4.1%), volunteering (2.0%) or caring for relatives (1.0%). The ICD-10 diagnoses of the consumers included: schizophrenia (38.8%), schizoaffective disorder (17.3%), bipolar disorder (21.4%), depressive disorders (16.3%), delusional disorders and other non-organic psychoses (5.1%) and major depression without psychosis (1.0%); all were screen positive for psychosis in the screening phase of the prevalence study. The median duration of their experience of mental illness was 10.0 years (25th percentile=5.0 and 75th percentile=19.0 years). The median PSP scores were 56.5 (Range=21-87) indicating marked difficulties in one or more areas of personal and social functioning.

### Quantitative findings concerning CUES-C domains

The three domains of carers' highest satisfaction (i.e. "satisfied a lot") at baseline were: Stigma and discrimination (81.3%), Relationship with family and friend (74.0%) and Own life (65.3%) (Table 1). The four highest unmet needs (i.e. “would like more help”) at baseline were: Information about care workers (49.0%), Involvement in planning and care (44.8%), How to get help and advice (40.0%) and Information about mental health and services (40.0%) (Table 2).

Most CUES-C satisfaction domains were correlated with carers’ health and wellbeing (Table 3). Lower satisfaction was associated with greater psychological distress, greater social isolation, higher caregiving consequences, more prominent feelings of grief and lower perception of quality of life. Satisfaction regarding involvement in planning of treatment and care, and stigma and discrimination were not correlated with any carers’ health and wellbeing variables. Carers’ satisfaction with their wellbeing (as measured by CUES-C) was correlated with all health and wellbeing factors.

All CUES-C perceived need domains were correlated with at least one carer’s health and wellbeing variable (Table 4). Perception of greater needs was associated with greater psychological distress, greater social isolation, higher caregiving consequences, more prominent feelings of grief and lower perception of quality of life. Carers’ need for help with their own life (as measured by CUES-C) was correlated with all health and wellbeing variables.

The average difference between baseline and follow-up scores of ‘Needing help with information about care workers’ of 0.25 (95%CI: 0.02, 0.48, n=77) was statistically significant (p=0.036). The carers perceived that there was a reduction in needing help regarding information about care workers. The average difference between baseline and follow-up scores of ‘Needing help in dealing with risk or safety issues’ of 0.29 (95%CI: 0.09, 0.49, n=76) was also statistically significant (p=0.004). The carers perceived that there was a reduction in needing help regarding risk or safety issues. There was no other statistically significant change in CUES-C domains over a one-year period.

### Qualitative findings concerning CUES-C domains

The first three themes emerged as the most frequently discussed by carers.

### Theme 1: Greater involvement of carers in the treatment plan

Most carers reported that they would like to be more involved in discussion and planning of treatment of those for whom they were caring. Some carers commented that they were not involved at all or involved minimally.

> "I speak to his psychologist briefly at each appointment but I would like to have an appointment with him myself. As the carer, I don't get much information as to how he's going….I would like to be included in all aspects of his care." Carer 45

Carers identified three main service issues limiting their involvement. Some carers perceived that clinicians portrayed an attitude that they knew more than the carers and this limited the involvement of carers.

> "They [mental health professionals] do not consider me desirable and necessary because when I say that I am a carer – 'you have nothing to add [and what I say] becomes not important'." Carer 4

The second issue is the frequent change of case managers in mental health services resulting in carers needing to reengage with the new case managers and recommunicate their stories.

> "Case workers come and go, work part-time or go on extended leave. So care is discontinuous and you have to start again each time to convince someone that [what] you are talking about, it's like you have to repeat the same mistake each time there is a relapse or incident – so frustrating." Carer 9

The third issue is clinicians privileging the privacy of consumers in mental health services, which resulted in carers feeling that they were excluded from discussion of the treatment plan of those for whom they were caring.

> "When he was seeing a psychiatrist, I was not allowed any information due to patient confidentiality. That sucks as I was the person holding things together. I felt I needed to know more information to see if I needed to make changes and at least have some understanding." Carer 118

However, some carers felt that they should reduce their involvement as they were experiencing severe caregiving burden or/and had many other responsibilities.

> "I used to be involved. Now, I have stepped back. It is [a] burden and it is difficult. I feel like I need to establish [a] strong boundary. I have continued to maintain [a] close relationship [with her]. My husband was sick and I had to care for her [and him at the same time]." Carer 127

A small number of carers who were satisfied with their level of involvement, reported that they had either received adequate information from case managers or psychiatrists, or had known the psychiatrists for many years.

> "I have this support because I have sought it myself and [now] work in the [mental health] field. However, during the period of treatment I was not offered carer support options. Even the waiting room [of the clinic] had little information for carers. I had to ask to see a Carer Consultant. However, what was great was my involvement with [my son's] caseworker and psychiatrist. They would always include me in the last part of the appointment and returned my calls. This was possible however due to my son's consent." Carer 13

**Theme 2: Provision of relevant information to carers**

Many carers also shared their views regarding the importance of getting relevant information from mental health services. Information can be grouped into two categories: general mental health knowledge and information on their relative's specific mental health status. General knowledge consists of information regarding diagnosis, symptoms, duration of illness and types of treatment that are not specific to any consumer.

> "It is important to know what services [are available] and when to use what services." Carer 5

> "[I want to know more about] medications information [sic]. I also don't know what to ask [regarding the illness and medications]. A fact sheet on

> medications will be better than to google on medications on the net [sic]."
> Carer 57

More importantly, carers voiced the need for consumer-specific mental health information such as prognosis of illness, adjustment of medications, progress of current treatment and specific ways to cope with the illness.

> "Information should be available to all carers – all about the mental health illness and the TRUTH about the prognosis no fairy-tales – that all will be well [sic].'' Carer 35

> "Information is limited and not specific to us…. [I also need] more help to deal with her at home." Carer 47

For those carers who felt that they had obtained sufficient information, they had attended some educational sessions before, were informed by clinicians previously or had learnt about the illness over a long period of time.

> "Most of my knowledge has come about through the many years of experiencing the mental health system – both public and private – but this has come about through my own efforts in the past and more recently through the mobile support team." Carer 20

**Theme 3: Multiple biopsychosocial support for carers**

Carers also reported they need multiple types of biopsychosocial support. Carers expressed their need for emotional support from their relatives and other carers to cope with social isolation.

> "[I need] a chat group with other carers to share stories and ideas on how to manage the course [of illness and] talking [sic] with a professional to alleviate the feelings of loneliness." Carer 41

> "[I hope that my] extended family to be able to engage with my mother [sic]. They stay away because they don't know how to deal with her. They only visit occasionally." Carer 43

Carers suggested a range of activities to support their emotional health such as availability of professionals or support groups to share their experiences.

> "The team ran a series of workshops on psychosis for carers – there were 4 or 5 I recall. These were excellent and they should be further enhanced and extended. They were very informative, and it was really useful to meet other carers and to hear about their trials and tribulations." Carer 122

Support for physical health is another area that carers wanted help in. Several carers talked about the need for respite services and help with "house and general living conditions" to support them when they were sick or needed a break.

> "Difficult when I am not well or have to be hospitalized. (There is) no support provided….We have cared and looked after her since birth. Sometimes, things make me tired and overwhelmed." Carer 131

> "The only time it is difficult for me is when my brother is very unwell. This usually occurs about [every] two to three years. Also I work between 28 to 30 hours a week and have a house and family to look after and still have to look after the cleaning and the garden at my brother's unit. I find this very difficult as he does not do any housework or gardening himself ever." Carer 6

Financial support is another way to help carers to cope with their caregiving responsibilities. Some suggested that there should be financial support to cover out of pocket expenses for healthcare, a regular carer allowance and short-term ad-hoc financial support from the government to cover both ongoing expenses and sudden extraordinary expenses.

> "It would be great if private practice psychiatrist could bulk bill [100% payment by government] so it would be affordable and makes life easier for my son [sic]." Carer 2

> "More support from Centrelink [government financial assistance organisation]. In fact Centrelink cancelled some payments last week. I usually don't eat so that two of them [consumers] have enough to eat." Carer 4

This financial difficulty arose due to two main reasons: poor budgeting skills of people with psychosis and their financial dependency on carers. Carers often felt they had to sacrifice their own needs to support them.

> "My main concern is about assisting our son with his financial issues. It is also difficult to manage the tension that arises over borrowing money from us." Carer 20

The last type of perceived reported need was crisis support. Carers wanted to receive training regarding how to deal with crises, as well as being informed about phone and in-vivo services that are available 24 hours every day.

> "I do not care for my brother day to day, I get involved when something goes wrong – relapses etc [sic]. I would like 24/7 availability of someone who I can speak with in an acute situation, who will action a situation, not just put me off and off as long as they can [sic]." Carer 9

Related to this, some carers had concerns about their own safety especially when consumers were experiencing a relapse.

> "Emergency support is extremely important and we have been fairly fortunate in being able to draw on this support many times over the years.…. Issues of safety are always present as the mental health of my son can vary." Carer 20

### Theme 4: Wellbeing and independence interventions for people with psychosis

Other than safety issues, carers were also concerned about the wellbeing of those for whom they were caring. Carers suggested that there should be community groups that provide leisure activities for consumers, and information about such activities should be made available to them.

> "Having more community groups for mother to attend, like leisure activities. More contact with social worker for me as well as her. More places [for her] to go outside the house [sic]." Carer 43

Other suggested ways to improve the wellbeing of people with psychosis were individual counselling or group therapy to support consumers to cope with difficult situations and to improve their communication skills.

> "Group meetings for mentally ill people where they encourage people to meet with others. ….he [consumer] exhibits abnormal character…. Therefore, if he could become more confident in using his skills in front of people effectively without showing nervousness." Carer 121

**Theme 5: Choice to care and alternate caring arrangements**

Most carers felt that they did not have a choice with regard to their caring role. They wanted to care for their loved ones with psychosis because of their love for them and sense of family responsibility to care for ill family members.

> "I do not have a choice. Theoretically, I can walk away. But I am not this way so it is not possible. Make the best of it. I love them." Carer 4

> "You never stop being a mother." Carer 35

Some carers wished that they were not carers themselves and had thoughts of moving away from the consumers due to severe caregiving burden. Although carers expressed a willingness to continue caring, they felt that there should be more support available as well as alternate care arrangements in the future.

> "Sometimes we have no choice. He is better off here……but it put the responsibility back to us. We just need more support, not to end the role. If

> we’re not around, we wonder how he can cope. If there are more programs for him, then we can do more things on our own.” Carer 56

## Discussion

One of the strengths of this study was the recruitment of carers of people with psychosis who were participants within the Australian prevalence study of psychosis. The national prevalence study used probability sampling in recruiting participants, so the data concerning carers’ perceived needs were likely more representative of carers of people with psychosis than other caregiving studies that used non-probability sampling methods. Secondly, longitudinal data was available to capture changes in carers’ perceived needs over time which is uncommon in the literature. Thirdly, this study collected qualitative responses of a relatively large and diverse sample of carers to better understand their perceived needs.

There were several key findings from this study (Table 5). Almost three-quarters (74%) of carers were satisfied with their relationships with family and friends and these satisfaction scores were correlated with FS, likely showing the relationships between the impact of caregiving with carers’ social relationships and their sense of social isolation. The importance of supporting carers’ social relationships was discussed in our earlier publication (Poon et al., 2017). Quantitative results showed that carers experienced perceived needs across many areas, consistent with findings of another Australian study showing the importance of holistic assessment of carers as part of routine care of people with mental illness (Watts & Hodgson, 2016).

There were no changes except for reduced needs for information about care workers and for help in managing risk and safety issues over the course of one year. Carers’ needs were also correlated with their health and wellbeing. Important caregiving themes emerged from carers’ qualitative responses: carers wanted to be more involved in the consumers’ treatment plan, most needed more relevant information and multiple biopsychosocial interventions for themselves and wellbeing and independence training for their relative with psychosis, and some carers identified a need for alternate caring arrangements. Given the growing emphasis on involving carers in routine treatment discussion and planning (Cohen et al., 2013; Killackey, Harvey, Amering, & Herrman, 2015), this study shows the ongoing need to consider the needs of carers while involving carers in the intervention process. Carers’ needs may be addressed by clinical mental health services themselves and/or by available voluntary organisations which provide education and training, support and respite. However, access to the latter depends on the discretion of clinicians to refer carers or carers' own awareness of such organisations so they may independently seek help. Failing to consider the needs of carers and adequately support them to access appropriate assistance may be counterproductive to their relative's and their own recovery (Fox, Ramon, & Morant, 2015).

In the context of minimal carer interventions provided within the two Victorian sites, carers' perceived needs were reduced in two areas. The reduction in need for information about care workers likely reflects the importance of the role of case managers in mental health services in providing relevant information about the services available, including explanations about their role (Morgan, Korten, & Jablensky, 2006). As for the reduction in needs for help to manage risk and safety issues, this is likely partly due to the efficacy of antipsychotic medications and remitting nature of psychosis (Harrow & Jobe, 2013); thus, after a period of receiving anti-psychotic medications within case management, consumers' mental states likely improved and led to less risk and safety issues consistent with findings of greater needs of carers associated with more disabling illness and shorter duration of illness (Drapalski et al., 2008). The emphasis on assessing and managing risk within contemporary mental health services may also explain our findings (Mulder, 2011). The absence of improvement in other areas showed the ongoing need to provide relevant carer support and intervention programs to address the diverse perceived needs of carers. With carer education and support programs in place, we should expect improvements in other areas of need as found in an intervention study (Coker et al., 2016).

The consequences of caregiving were only moderately related to carers' perceived need for help in contrast to the high correlations found in an Australian study (Cleary et al., 2006). This may be due to the representativeness of our population-based sampling method compared to the other study which recruited carers of people discharged from inpatient facilities. Although higher levels of stigma have been associated with greater carers' needs (Drapalski et al., 2008), we found a low percentage (5.3% at baseline) of carers needing help with stigma. This may be due to our sampling strategy or differences in measures suggesting that further research is required to understand stigma of mental illness for carers in Australia. The low percentage of perceived needs related to stigma may also be due to Australian national campaigns in public mental health education which have had an effect in reducing stigma in society (Reavley & Jorm, 2012).

Considering the diverse identified carers’ needs, it is insufficient for mental health services to deliver a single interventionto carers and then consider necessary support has been provided; assessing carers’ needs and providing adequate interventions to support carers should be flexible and ongoing as required (Killackey et al., 2015; Watts & Hodgson, 2016). Mental health services need to improve current practices concerning inclusion of carers in the treatment plan (Department of Health, 2013) and develop ongoing educational and support programs for carers, such as support groups and family psychoeducation groups, within routine care provided to people with mental illness (Harvey & O’Hanlon, 2013). Given that unmet carers’ needs in mental health services have been reported in many countries for a long time, a shift in mental health practice is therefore required to ensure holistic care to people with psychosis, and dignity and respect to their carers are given, consistent with the recovery framework (Australian Health Ministers' Advisory Council, 2013).

Mental health services should also address the need to provide wellbeing and independence training programs for people with psychosis as suggested by carers and consistent with earlier studies (Chaffey & Fossey, 2004; Poon et al., 2017). Neglecting the social needs of people with psychosis and the practical needs of carers may result in overburdening of carers over time (Fossey, Harvey, Mokhtari, & Meadows, 2012; Werner, 2012). Mental health services can consider providing psychosocial rehabilitation programs to improve consumers’ independent functioning and partnering with voluntary organisations to address social participation and leisure needs of people with psychosis (Evert, Harvey, Trauer, & Herrman, 2003; Fossey et al., 2012). In addition, given the fragmentation of mental health services providing clinical treatment to those with mental illness while voluntary organisations focus on psychosocial rehabilitation and socialization needs, carers’ needs may be neglected in the process. These difficulties are likely exacerbated in Australia and elsewhere by funding shortfalls due to the mixed economy of the welfare state and increasing marketization. Greater integration of clinical and rehabilitation services is crucial, along with scrutiny of the adequacy of current resource and policy settings.

## Limitations

Although, a duration of more than one-year between baseline and follow-up might be better able to detect changes in carers' perceived needs, this population-based study has provided findings concerning changes in perceived needs of carers over time. As the prevalence study excluded consumers with limited English-speaking ability, most of the recruited carers could speak English; therefore, future studies should identify the perceived needs of carers from non-English-speaking communities.

## Conclusion

Despite policy and services emphasizing the importance of supporting the recovery of consumers and carers (Australian Health Ministers' Advisory Council, 2013), carers still have considerable unmet needs. This indicates the importance for services to commit to an intentional shift towards including carers and their needs in the consumer's holistic care plan.

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**Table 1 CUES-C Question 1 – Satisfaction**

| | Satisfied a lot | Satisfied a little | Not satisfied at all |
|---|---|---|---|

| | Baseline | | Follow-up | | Baseline | | Follow-up | | Baseline | | Follow-up | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | N | % | N | % | N | % | N | % | N | % | N | % |
| How to get help and advice | 48 | 50.5 | 34 | 44.2 | 23 | 24.2 | 28 | 36.4 | 24 | 25.3 | 15 | 19.5 |
| Information about care workers | 46 | 47.9 | 38 | 49.4 | 31 | 32.3 | 27 | 35.1 | 19 | 19.8 | 12 | 15.6 |
| Information about mental illness and its effects | 54 | 56.3 | 47 | 61.0 | 31 | 32.3 | 17 | 22.1 | 11 | 11.5 | 13 | 16.9 |
| Involvement in planning of treatment and care | 45 | 46.9 | 35 | 45.5 | 28 | 29.2 | 16 | 20.8 | 23 | 24.0 | 26 | 33.8 |
| Support for carers | 41 | 43.6 | 34 | 44.7 | 20 | 21.3 | 14 | 18.4 | 33 | 35.1 | 28 | 36.8 |
| Your own life | 62 | 65.3 | 50 | 65.8 | 29 | 30.5 | 18 | 23.7 | 4 | 4.2 | 8 | 10.5 |
| Relationship with the person you care for | 59 | 61.5 | 45 | 59.2 | 30 | 31.3 | 24 | 31.6 | 7 | 7.3 | 7 | 9.2 |
| Relationship with family and friends | 71 | 74.0 | 60 | 78.9 | 23 | 24.0 | 11 | 14.5 | 2 | 2.1 | 5 | 6.6 |
| Money | 54 | 56.3 | 40 | 52.6 | 32 | 33.3 | 27 | 35.5 | 10 | 10.4 | 9 | 11.8 |
| Your wellbeing | 47 | 49.0 | 43 | 56.6 | 43 | 44.8 | 25 | 32.9 | 6 | 6.3 | 8 | 10.5 |
| Stigma and discrimination | 78 | 81.3 | 56 | 73.7 | 16 | 16.7 | 14 | 18.4 | 2 | 2.1 | 6 | 7.9 |
| Risk and safety | 55 | 57.3 | 52 | 68.4 | 36 | 37.5 | 19 | 25.0 | 5 | 5.2 | 5 | 6.6 |
| Choice to care | 60 | 63.8 | 54 | 71.1 | 16 | 17.0 | 7 | 9.2 | 18 | 19.1 | 15 | 19.7 |

**Table 2 CUES-C Question 2 - Need help**

| | Would like more help | | | | Unsure | | | | No | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Baseline | | Follow-up | | Baseline | | Follow-up | | Baseline | | Follow-up | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| How to get help and advice | 38 | 40.0 | 26 | 33.8 | 15 | 15.8 | 10 | 13.0 | 42 | 44.2 | 41 | 53.2 |
| Information about care workers | 47 | 49.0 | 29 | 37.7 | 13 | 13.5 | 11 | 14.3 | 36 | 37.5 | 37 | 48.1 |
| Information about mental illness and its effects | 38 | 40.0 | 28 | 36.4 | 10 | 10.5 | 6 | 7.8 | 47 | 49.5 | 43 | 55.8 |
| Involvement in planning of treatment and care | 43 | 44.8 | 30 | 39.5 | 11 | 11.5 | 15 | 19.7 | 42 | 43.8 | 31 | 40.8 |
| Support for carers | 33 | 35.5 | 23 | 30.3 | 15 | 16.1 | 14 | 18.4 | 45 | 48.4 | 39 | 51.3 |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Your own life | 15 | 15.8 | 10 | 13.2 | 13 | 13.7 | 10 | 13.2 | 67 | 70.5 | 56 | 73.7 |
| Relationship with the person you care for | 22 | 23.2 | 17 | 22.4 | 16 | 16.8 | 6 | 7.9 | 57 | 60.0 | 53 | 69.7 |
| Relationship with family and friends | 8 | 8.3 | 12 | 15.8 | 14 | 14.6 | 4 | 5.3 | 74 | 77.1 | 60 | 78.9 |
| Money | 21 | 21.9 | 18 | 23.7 | 9 | 9.4 | 10 | 13.2 | 66 | 68.8 | 48 | 63.2 |
| Your wellbeing | 19 | 19.8 | 12 | 16.0 | 13 | 13.5 | 13 | 17.3 | 64 | 66.7 | 50 | 66.7 |
| Stigma and discrimination | 5 | 5.3 | 5 | 6.6 | 5 | 5.3 | 4 | 5.3 | 85 | 89.5 | 67 | 88.2 |
| Risk and safety | 20 | 20.8 | 6 | 7.9 | 8 | 8.3 | 7 | 9.2 | 68 | 70.8 | 63 | 82.9 |
| Choice to care | 5 | 5.4 | 6 | 7.9 | 7 | 7.5 | 7 | 9.2 | 81 | 87.1 | 63 | 82.9 |

## Table 3 Baseline correlations of CUES-C Question 1 – Satisfaction

| | | **K10** | **FS** | **IEQ** | **MIVTIG** | **WHOQOL Physical** | **WHOQOL Psychological** | **WHOQOL Social** | **WHOQOL Environment** |
|---|---|---|---|---|---|---|---|---|---|
| How to get help and advice | *r* | 0.285 | -0.333 | 0.099 | 0.050 | -0.183 | -0.143 | -0.261 | -0.335 |
| | *p* | 0.005 | 0.001 | 0.342 | 0.635 | 0.076 | 0.000 | 0.011 | 0.001 |
| Information about care workers | *r* | 0.297 | -0.351 | 0.007 | 0.026 | -0.215 | -0.266 | -0.139 | -0.269 |
| | *p* | 0.003 | 0.000 | 0.945 | 0.806 | 0.035 | 0.009 | 0.177 | 0.008 |
| Information about mental illness and its effects | *r* | 0.296 | -0.355 | 0.117 | 0.076 | -0.310 | -0.287 | -0.145 | -0.228 |
| | *p* | 0.003 | 0.000 | 0.256 | 0.469 | 0.002 | 0.005 | 0.160 | 0.026 |
| Involvement in planning of treatment and care | *r* | 0.077 | -0.152 | -0.056 | -0.058 | -0.186 | -0.088 | -0.126 | -0.136 |
| | *p* | 0.454 | 0.138 | 0.585 | 0.584 | 0.070 | 0.396 | 0.220 | 0.188 |
| Support for carers | *r* | 0.281 | -0.329 | 0.053 | 0.158 | -0.152 | -0.255 | -0.169 | -0.315 |
| | *p* | 0.006 | 0.001 | 0.609 | 0.134 | 0.144 | 0.013 | 0.103 | 0.002 |
| Your own life | *r* | 0.305 | -0.274 | 0.202 | 0.248 | -0.157 | -0.294 | -0.336 | -0.255 |
| | *p* | 0.003 | 0.007 | 0.049 | 0.017 | 0.128 | 0.004 | 0.001 | 0.013 |
| Relationship with the person you care for | *r* | 0.306 | -0.218 | 0.357 | 0.258 | -0.181 | -0.286 | -0.378 | -0.204 |
| | *p* | 0.002 | 0.033 | 0.000 | 0.013 | 0.077 | 0.005 | 0.000 | 0.047 |
| Relationship with family and friends | *r* | 0.322 | -0.446 | 0.144 | 0.301 | -0.087 | -0.252 | -0.410 | -0.299 |
| | *p* | 0.001 | 0.000 | 0.161 | 0.003 | 0.397 | 0.013 | 0.000 | 0.003 |
| Money | *r* | 0.334 | -0.290 | 0.254 | 0.102 | -0.331 | -0.353 | -0.357 | -0.572 |
| | *p* | 0.001 | 0.004 | 0.012 | 0.330 | 0.001 | 0.000 | 0.000 | 0.000 |
| Your wellbeing | *r* | 0.557 | -0.499 | 0.385 | 0.461 | -0.369 | -0.478 | -0.531 | -0.438 |
| | *p* | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 |
| Stigma and discrimination | *r* | 0.086 | -0.020 | 0.072 | 0.024 | -0.102 | -0.047 | 0.074 | -0.134 |
| | *p* | 0.405 | 0.850 | 0.484 | 0.820 | 0.321 | 0.646 | 0.472 | 0.194 |
| Risk and safety | *r* | 0.200 | -0.128 | 0.455 | 0.370 | -0.150 | -0.141 | -0.169 | -0.058 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | *p* | 0.050 | 0.213 | 0.000 | 0.000 | 0.146 | 0.170 | 0.100 | 0.573 |
| Choice to care | *r* | 0.199 | -0.126 | 0.279 | 0.217 | -0.007 | -0.065 | -0.190 | -0.055 |
| | *p* | 0.055 | 0.225 | 0.006 | 0.039 | 0.947 | 0.536 | 0.066 | 0.600 |

r = Pearson correlation

## Table 4 Baseline correlations of CUES-C Question 2 – Need help

| | | **K10** | **FS** | **IEQ** | **MIVTIG** | **WHOQOL Physical** | **WHOQOL Psychological** | **WHOQOL Social** | **WHOQOL Environment** |
|---|---|---|---|---|---|---|---|---|---|
| How to get help and advice | *r* | -0.372 | 0.374 | -0.470 | -0.303 | 0.169 | 0.288 | 0.335 | 0.355 |
| | *p* | 0.000 | 0.000 | 0.000 | 0.003 | 0.102 | 0.005 | 0.001 | 0.000 |
| Information about care workers | *r* | -0.185 | 0.328 | -0.236 | -0.336 | 0.158 | 0.170 | 0.191 | 0.238 |
| | *p* | 0.072 | 0.001 | 0.021 | 0.001 | 0.125 | 0.098 | 0.062 | 0.019 |
| Information about mental illness and its effects | *r* | -0.250 | 0.260 | -0.320 | -0.184 | 0.190 | 0.191 | 0.178 | 0.198 |
| | *p* | 0.015 | 0.011 | 0.002 | 0.076 | 0.065 | 0.064 | 0.085 | 0.055 |
| Involvement in planning of treatment and care | *r* | -0.203 | 0.217 | -0.226 | -0.284 | 0.055 | 0.066 | 0.194 | 0.107 |
| | *p* | 0.048 | 0.034 | 0.027 | 0.005 | 0.596 | 0.525 | 0.059 | 0.301 |
| Support for carers | *r* | -0.312 | 0.358 | -0.389 | -0.244 | 0.211 | 0.172 | 0.318 | 0.342 |
| | *p* | 0.002 | 0.000 | 0.000 | 0.019 | 0.042 | 0.099 | 0.002 | 0.001 |
| Your own life | *r* | -0.486 | 0.345 | -0.413 | -0.274 | 0.217 | 0.269 | 0.350 | 0.308 |
| | *p* | 0.000 | 0.001 | 0.000 | 0.008 | 0.035 | 0.008 | 0.001 | 0.002 |
| Relationship with the person you care for | *r* | -0.308 | 0.262 | -0.387 | -0.250 | 0.131 | 0.159 | 0.328 | 0.227 |
| | *p* | 0.002 | 0.010 | 0.000 | 0.016 | 0.207 | 0.124 | 0.001 | 0.027 |
| Relationship with family and friends | *r* | -0.203 | 0.322 | -0.305 | -0.269 | 0.006 | 0.133 | 0.246 | 0.260 |
| | *p* | 0.047 | 0.001 | 0.003 | 0.009 | 0.955 | 0.196 | 0.016 | 0.010 |
| Money | *r* | -0.277 | 0.277 | -0.331 | -0.235 | 0.155 | 0.162 | 0.291 | 0.463 |
| | *p* | 0.006 | 0.006 | 0.001 | 0.024 | 0.132 | 0.115 | 0.004 | 0.000 |
| Your wellbeing | *r* | -0.518 | 0.494 | -0.448 | -0.344 | 0.162 | 0.320 | 0.436 | 0.371 |
| | *p* | 0.000 | 0.000 | 0.000 | 0.001 | 0.114 | 0.002 | 0.000 | 0.000 |
| Stigma and discrimination | *r* | -0.140 | 0.136 | -0.312 | -0.184 | 0.075 | 0.003 | 0.060 | 0.153 |
| | *p* | 0.177 | 0.188 | 0.002 | 0.078 | 0.469 | 0.974 | 0.564 | 0.140 |
| Risk and safety | *r* | -0.158 | 0.180 | -0.412 | -0.314 | 0.168 | 0.052 | 0.139 | 0.179 |
| | *p* | 0.124 | 0.079 | 0.000 | 0.002 | 0.102 | 0.613 | 0.175 | 0.082 |
| Choice to care | *r* | -0.201 | 0.268 | -0.281 | -0.161 | 0.107 | 0.122 | 0.257 | 0.086 |
| | *p* | 0.053 | 0.010 | 0.006 | 0.129 | 0.309 | 0.243 | 0.013 | 0.413 |

r = Pearson correlation

## Table 5 Summary of findings

1. Carers of people with psychosis experienced low to moderate levels of perceived needs in multiple areas.
2. Carers perceived that they had a reduced need for help regarding information about care workers over time.
3. They also perceived that there was a reduction in their needs for help regarding risk or safety issues over time.
4. There was no other improvement in the extent of their perceived needs over time.
5. Their perceived needs were related to their health and wellbeing.
6. Caregivers reported wanting to be more involved in the treatment plan of those whom they were caring for.
7. They also expressed their need for relevant information and multiple biopsychosocial support.
8. In addition, they perceived that consumers need training to improve their wellbeing and independence.
9. Carers faced issues regarding restricted time and choice in caregiving that had an effect on the quality of their lives.