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Mental health carers' experiences of an Australian Carer Peer Support program: tailoring supports to carers' needs

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Abstract

Carer Peer Support Workers (CPSWs) are people who have lived experience as carers / family members of persons with a mental illness, and are employed to provide support to other carers / family members. This qualitative study aimed to explore carers' experiences within a community-based CPSW pilot program in an Australian mental health service. Semi-structured phone interviews were conducted with 20 carer participants in 2015, 5-10 months following their last contact with the service. Thematic analysis uncovered that carers were generally positive about the CPSW's emotional support, practical support, shared lived experience and mutual understanding, and the 'ripple effect' the support had on service users. Some carers, on the other hand, felt that the support was unnecessary; either because they believed that it did not have a lasting effect, the focus should have been on the service user, or that they had previously received enough support. Nevertheless, the study highlighted some benefits of mental health services employing CPSWs and how best to utilise them. Moreover, to be most useful, the nature of the carer peer support work should be tailored to the specific needs of the carers; which may vary according to their culture, years of caring experience, and previous experiences with mental health services.

Keywords: **Carers, Peer, Family Support, Support Workers, Qualitative Research, Mental Health**

What is known about this topic:

- Carer burden is significant, and it can impact on service user recovery.
- Peer support is a growing field, and an increasingly important component of mental health service delivery.
- There is limited evidence for service user and carer peer support programs, but the limited evidence is generally positive.

What this paper adds:

- Provides additional evidence that carer peer support can offer beneficial emotional and practical assistance to carers.
- Demonstrates the importance of tailoring the service to the carer and service user's needs.
- May encourage organisations to consider employing carer peer support workers, and provides a framework for how best to utilise their services.

Introduction

The paradigm shift in mental health care delivery over the past 30 years from institution to community-based care has placed increased demands on families and carers of people with mental illnesses (Leggatt, 2005). Amongst their many roles, they provide informal and unpaid emotional support, financial assistance, advocacy, and housing to the people they care for (Dixon et al., 2004).

Although carers provide important support to service users (people diagnosed with mental illnesses who utilise mental health services) the role of carers can be burdensome and taxing. A recent multicentre survey of carers from 22 countries found that 1 in 3 carers experienced emotional burden and 1 in 3 felt their physical health had deteriorated as a result of their carer role (Vermeulen et al., 2015). Furthermore, a British study found higher psychiatric symptom scores in caregivers when compared to non-caregivers (Smith et al., 2014). There is also evidence to suggest that carer emotional burden and mental ill-health can negatively impact the

mental illness of the people they care for (Perlick et al., 2010; Perlick et al., 2004). Hence, interventions to support carers would likely improve the wellbeing of the carers themselves, service users, and the family unit.

Family psychoeducation programs that are run by professionals provide emotional support, education, and communication and problem-solving skills to carers, and have been shown to: improve carers' understanding of mental illnesses, treatment, and services (Day, Starbuck, & Petrakis, 2017), reduce isolation and the experience of stigma (Day et al., 2017), improve adaptive coping strategies such as maintaining social interests and positive communication with the service user (Sampogna et al., 2018). These programs also lead to reduced service user relapse rates, improved recovery (Dixon et al., 2004; Harvey & O'Hanlon, 2013) and better engagement in treatment and employability (Ran, Chan, Ng, Guo, & Xiang, 2015). Furthermore, a professional-led family intervention that focused on support, rather than education, showed reduced depressive symptoms and improved wellbeing in carers (Tremont et al., 2015). In addition, interventions that focus on supporting carers of people with other chronic illnesses such as cancer and dementia have been found to be beneficial (Harding, List, Epiphaniou, & Jones, 2012; Martin-Carrasco et al., 2009; Pinquart & Sorensen, 2006).

Peer support is a model whereby support is mutually provided by people with a history of mental illness to others sharing a similar condition, to help promote recovery (Solomon, 2004). Mead (2003) stated that peer support 'is about understanding another's situation empathically through the shared experience of emotional and psychological pain' and 'to 'be' with each other without the constraints of traditional (expert / patient) relationships' (Mead, 2003).

Studies have shown that service user peer support can reduce hospital readmission rates (Chinman, Weingarten, Stayner, & Davidson, 2001; Min, Whitecraft, Rothbard, & Salzer, 2007; Repper & Carter, 2011), increase community tenure (Repper & Carter, 2011), improve social functioning (Repper & Carter, 2011), and improve self-reported 'empowerment', 'confidence'(Resnick & Rosenheck, 2008) and 'hope' (Repper & Carter, 2011). Furthermore, a longitudinal qualitative study reported that service users enrolled in a peer support program had enhanced social support,

sustained work, stable income, and greater participation in education and training (Ochocka, Nelson, Janzen, & Trainor, 2006). However, positive functional outcomes have been less consistently reported in randomized controlled studies (Pitt et al., 2013).

Carer Peer Support Workers (CPSWs) are people who have lived experience as family members or carers of persons with a mental illness, and provide support to other family members or carers (Health Workforce Australia, 2013). Although CPSWs do not require professional mental health training, they are qualified in peer work designed specifically for mental health carers (Paton & Sanders, 2011).

Compared with other forms of peer support, carer peer support has limited literature, although initial findings have been positive. Carers participating in a family-to-family group education program in Australia valued the emotional support, shared lived experience, and the worker's informal and accessible personal approach; and a separate quantitative study of the same program, reported reduced 'worry', 'distress', and 'tension', especially in those caring for people with psychotic illnesses (Foster, 2011; Stephens, Farhall, Farnan, & Ratcliff, 2011). Another family-to-family education program in the USA was associated with reductions in subjective burden, increased empowerment, improved mental health illness and service knowledge, and improved self-care (Dixon et al., 2004). In a small qualitative evaluation of a peer support program in an Australian health service, carers reported that CPSWs had helped them feel supported and reduced their distress by sharing their coping strategies, increased their sense of hope for the recovery of the person they cared for, helped identify and build upon their personal coping strengths in their caring role, and assisted them in learning about the hospital system (Kling, Dawes, & Nestor, 2008).

There is also evidence regarding the positive effects of peer-led support programs for carers of people with dementia. A qualitative study that examined the impact of a volunteer peer support program found that carers felt less 'alone' and isolated, they valued the opportunity to talk freely about difficult experiences, and learned how others coped. (Greenwood, Habibi, Mackenzie, Drennan, & Easton, 2013). Similarly, a randomised controlled trial from Hong Kong that examined a family-led mutual support group found lower rates of caregiver burden, improved carer quality of life,

and reduced service user symptom severity, in the intervention group (Wang & Chien, 2011).

A government-funded community-based clinical mental health service in Melbourne (which is a large metropolitan city of Australia), received funding to establish a pilot peer support program for carers of service users who attended one of the community teams providing medical and case management services within office hours, Monday to Friday. The CPSW was employed in a part-time paid position, and had background training in Single Session Work, family therapy, carer consultancy, and experience in clinical and community mental health services (Smith, 2015).

Carer peer support was offered to families and carers of new and existing service users through verbal and written referrals from treating teams, and family/carer and/or service user initiated self-referrals. The CPSW program was designed to provide emotional support, advice about financial support, practical strategies, information, advocacy and referral to other services. The CPSW delivered the service to 122 carers over the first 12 months. 29% of contacts were in person, and 71% were via telephone. Face-to-face contacts occurred mostly in the Community Mental Health Clinic (88%), with the remainder in the carer's environment (10%) and the inpatient ward (2%). Contacts between the CPSW and carers ranged from 1 to 19 (median: 3), with 65% of carers having up to 3 contacts and only 16% having more than 5 contacts. The average contact duration was 30 minutes. Interpreters were accessed to support culturally and linguistically diverse (CALD) families (Smith, 2015).

In light of the paucity of evidence concerning the impacts of carer peer support in mental health and elsewhere, especially when delivered one-on-one rather than in group settings, this qualitative study aimed to understand carers' reported experiences of a Carer Peer Support program for individual carers of adults with mental illness in a community mental health service.

Method

Qualitative research methods were chosen to explore the quality and nature of the experience of carers involved in the Carer Peer Support pilot program. Qualitative

research provides a 'rich' explanation for concepts and experiences that are not possible with Quantitative methods (Whitley & Crawford, 2005) and is ideal for experiences of health care which are poorly understood (Fossey, Harvey, McDermott, & Davidson, 2002).

We endeavoured to interview carers who had participated in the CPSW pilot program, 5-10 months following contact with the Carer Peer Support Worker, to allow time for carers to attend groups or services recommended by the CPSW and determine longer-term outcomes.

In the interest of the internal validity, transparency, and 'permeability' of this qualitative research (as described by Fossey et al. (2002)) the authors openly discussed their own assumptions and predictions regarding the findings of the study. This allowed the researchers to be mindful of, and transparent about, any possible influence of their own views on data collection and thematic analysis. The authors predicted that carers, especially those who care for someone newly diagnosed with a mental health issue, would find the CPSW program beneficial particularly in terms of navigating the mental health system, accessing resources, and being provided emotional support.

Ethics approval was granted by the Melbourne Health Human Research Ethics Committee.

Participants

Eligible participants were carers of service users attending a community mental health clinic in the north-western suburbs of Melbourne, Australia, who had received a CPSW service with the last contact occurring 5-10 months prior. Carers were defined as people who identified themselves as providing informal and unpaid care to the mental health service user. An attempt was made to contact all (40) carers meeting the above inclusion criteria for this study, except for seven who had either declined follow-up or had been verbally abusive towards the CPSW. We utilised interpreters to include carers who could not speak English.

The mental health diagnoses of service users were not collected in this study. Local data concerning the diagnostic profile of service users attending the community mental health clinic shows that, at any one time, the vast majority of service users are diagnosed with a severe mental illness and between 60-70% of service users are diagnosed with a psychotic disorder. The population within the catchment area of the studied public mental health service were classified 'most disadvantaged' and 'more disadvantaged' by the index of relative socioeconomic disadvantage (IRSED) score (Department of Health, 2011); and 30% of the population were born overseas in a country where English was not the main language (Australian Bureau of Statistics, 2016). These statistics provide an indication of the likely demographic and diagnostic profiles of service users attending the mental health service studied.

Data collection

Questions were prepared by the authors with advice from the CPSW program steering committee, which was composed of experienced clinicians, researchers, and the CPSW. The questions covered demographic details, and provided a framework to explore carers' viewpoints regarding the CPSW program. Furthermore, the impact of the program on the carer and the person they cared for was explored. The list of questions are included in Table 1.

The questions were transposed into an online questionnaire using the 'Survey Monkey' platform, and ample space was left for the researcher to document participants' responses to questions, along with their elaborations. Phone interviews took place during August and September 2015. The purpose of the interview was clearly described and verbal consent was gained from each study participant. Phone interviews were manually transcribed in real time by the first author, and responses were read back to the participants to check their accuracy and to ensure the interviewer had not missed content. This method of online transcription allowed for ease of data handling and an efficient capture of participant responses.

The questionnaire was used as a semi-structured interview guide, which allowed for flexibility during the interview, and a focus on what was important to the carer.

The first author conducted all telephone interviews. Of note, the first author only worked at the mental health service in a research capacity and had never worked with the CPSW. This was explained to the participants when the first author made contact with them.

Data analysis

The first author kept a 'thought diary' during the interview process, to document emerging themes (see Table 2). Thematic analysis (as described by Braun & Clark (2006)) was used to examine the data gathered from the interviews with carers. After the transcript was read a number of times, codes were generated for as many patterns seen amongst the data as possible. Word processing software was used to list the codes, and numbers were used to link the codes to the quotes in the raw transcriptions. The quotes with their associated codes were then printed and rearranged into 'mind maps'. This allowed similar quotes to be grouped together to produce potential themes. During the later stages of this process the first and second author undertook detailed reflexive discussions to question, debate, provide alternative viewpoints, and derive further meaning from the data. The second author also proposed how certain themes could be consolidated.

An 'inductive approach' to thematic analysis was adopted, whereby themes were produced without a preconceived framework of theorised or hypothesised themes. In other words, the research and analysis was 'data driven' rather than literature or theory driven. This approach was appropriate for this field of study in which there has been limited research (Braun & Clarke, 2006).

Findings

Demographics:

There were 20 study participants, of which 18 were female. The relationship of the carer to the service user was varied, with the largest group being parents (8). A total

of 12 carers were from culturally and linguistically diverse (CALD) backgrounds, 4 of whom did not speak English. Further demographic information is provided in Table 3.

Thought Diary

As described earlier, significant patterns and emerging themes were documented in a 'thought diary', and some important findings are detailed in Table 2.

Thematic Analysis

Thematic analysis uncovered the following five themes:

The CPSW provided emotional support that benefited both the carer and the person they care for.

Carers described the CPSW as supportive and a good listener. They appreciated the opportunity to talk and to receive informal emotional support.

> 'I felt supported, if I needed support it was always there and I knew it. It was great to know that there was someone to have your back.' (Mother, Greek heritage, carer for 11-15 years)

Some carers referred to the support as 'counselling' (Sister, Anglo-Australian, carer for 11-15 years) and 'psychological support' (Wife, Italian heritage, carer for 11-15 years). Carers appreciated the opportunity to 'vent'.

> '[She was a] good listener and [it was] an opportunity for me to vent. She was not judgemental about my feedback.' (Friend, Anglo-Australian, carer for 3-5 years)

Carers also described feeling calmer, reassured, and more able to cope.

> 'She just calmed me, and made me feel that 'I can do this' 'I can handle this'' (Wife, Anglo-Australian, carer for 3-5 years)

Furthermore, carers often commented that the support provided by the CPSW had positive effects on the person they cared for.

> 'Perhaps if it helped me to calm down, and then had a ripple effect on her children and herself. I was calm, so I was better for her. I was not arguing as much, and arguing can make her illness worse' (Sister, Anglo-Australian, carer for 11-15 years)

Hence, participants reported that the CPSW contact was of assistance to both carers and service users through provision of informal emotional support to carers.

The CPSW's shared lived experience provided comfort, hope, and empowerment.

The shared lived experience of the CPSW and the carer allowed carers to feel comfortable and less judged. People with a similar experience were seen to have a better understanding of one's own predicament and challenges. Carers also felt less alone.

> '[It was good] knowing you are not alone, [there was] someone to talk to. She could understand and could relate, and was sympathetic.' (Sister, Iraqi heritage, carer for 3-5 years)

Knowing that the CPSW had been through a similar experience gave carers hope, including that their loved ones could also achieve recovery, and that they too would be able to get through the difficult times.

> 'She told us that she had a child with the similar illness; he healed, so we were given the support that [our son] would be healed too... The hope that was provided was the best thing. She showed us how to deal with a person with a mental illness, by giving her personal experience with her son.' (Father, Non-English speaking Turkish heritage, carer for <3 years)

The carers appreciated having someone seen as independent of the other mental health staff, especially when carers felt intimidated by the system or had past negative experiences with mental health services.

> 'It was really good and worthwhile, to have someone there for support. Somebody who wasn't trying to defend the treatment. She was independent. I felt reassured and supported.' (Sister, unknown heritage, carer for 6-10 years)

In summary, carers valued the mutual experience shared with the CPSW. It provided them hope, and allowed them to feel understood, listened to, acknowledged, and more comfortable in the service's professional environment.

The CPSW provided practical support

Many carers stated that they were provided information that helped them better understand the service user's illness, and the mental health system.

> '[The CPSW provided me with] handouts, lots of information. I used it a lot. Read about conditions, and how carers can be useful, and what sort of services are available for carers…. I had no idea. There was nobody else who would have explained it' (Sister, Greek heritage, carer <3 years)

Carers described that the CPSW provided them with referrals to other services and accompanied them to meetings with psychiatric treating teams.

> '[The CPSW] gave me a lot of information about other services that could *help me… s*pecifically: financial services, carer group support, and a few more but [I] can't remember.' (Ex-wife, Turkish heritage, carer for <3 years)

'[The CPSW] came with me to meet the Psychiatrist and Nurse Unit Manager. [She provided] moral support.' (Sister, unknown heritage, carer for 6-10 years)

Some carers were provided financial assistance through the CPSW.

'I had trouble with getting my two youngest sons' school books, and they helped me get them. I took the booklist in, and they sorted it out. They also gave me a couple of [supermarket] vouchers.' (Mother, Anglo-Australian, carer for 6-10 years)

In summary, the practical support provided by the CPSW such as financial aid, accompaniment to appointments, and referrals to other services were generally welcomed and appreciated.

The support provided by the CPSW was not needed, or did not suit the carer's circumstances

Some carers stated that it was not a priority to see the CPSW or attend other support sessions. This was usually because the person they cared for was too unwell and they were unable to leave them alone, or that they were too busy and had insufficient time to attend.

'Of course [extra services] would have been helpful, but I don't know if I would have had time to attend. I am very busy with my sister, I am with her at *all times…sometimes I need someone to take her out and look after her.'* (Sister, non-English speaking Iraqi heritage, carer for 6-10 years)

'She wanted me to drop everything and attend meetings - I couldn't do that. I work full time.' (Female carer, unknown heritage, carer 'for years')

Linked with this, some carers did not feel support for themselves was necessary, rather, assistance for the person with the mental illness was needed. They believed that this would have been more help than any support offered to carers.

'I would prefer that help be provided to my daughter rather than to me.' (Mother, Non-English speaking Turkish heritage, unknown length of caring)

Some carers stated that the emotional support that was provided by the CPSW was either not what they needed or did not have a lasting effect because their circumstances remained the same.

'[I felt] better on the day, but as for life the next day, it went back to the same.' (Mother, Anglo-Australian, carer for 11-15 years)

Some carers were not interested in further education sessions, carer support or services due to their previous satisfactory involvement with other services, particularly child and youth mental health services. These carers did not see information as unnecessary; rather the timing of services was not appropriate for them.

'Not really [interested in further carer education/support/services], we have *been through all of that in the past… [We] had a lot of support when [our]* son became unwell, *provided by [a] Youth Mental Health Service… when he first became unwell it was good to talk to others...[I] wouldn't like to see that* stop, it was very helpful.' (Father, Italian heritage, carer for 11-15 years)

Lastly one Non-English speaking woman of Turkish background stated how the stigma surrounding mental illness prevented her from seeking further assistance.

'I feel that sometimes it is better to hide these things. You don't want everyone to know that your daughter has a mental illness, it can be embarrassing. On the other hand, I can't help but feel that I am the only one, and I can see the benefit in speaking to and meeting others in a similar situation.' (Mother, Non-English speaking Turkish heritage, unknown length of caring)

In summary, some carers felt that the support did not suit their circumstances or was unnecessary; either because they felt too busy with their commitments, believed the focus should have been on the service user, thought that they had previously received enough support, or that it did not have a lasting effect. One carer openly discussed stigma. It was noteworthy that CALD and Non-English speaking carers were over-represented in this theme.

The CPSW program should be extended and provide a greater range of support, to better meet the carer's individualised needs

Carers were generally positive about the service, with a few suggesting that it required more funding so that they, and others like them, could receive more support.

> '[the service should be] better funded with more carer peer support workers available at more times. [The CPSW] was only available part time, which isn't enough' (Sister, unknown heritage, carer for 8 years)

Furthermore, many carers appreciated receiving support when the service user was acutely unwell or in crisis, and suggested that this should be when the CPSW is utilised.

> 'In our case, we didn't know that this was going on, it became a crisis. Meeting [the CPSW] at the time of crisis was good for us. It would not have been helpful any other time.' (Mother, unknown heritage & time as carer)

Some carers wanted more practical support for themselves and the people they cared for. Their suggestions included respite services, financial aid, education and courses for people with mental illness, and outings and social activities for inpatients and their carers.

> 'I needed financial and practical support for things such as education expenses, which [the CPSW] *was not able to provide…I could not buy* necessities for my children, this was the priority.*'* (Wife, Non-English speaking Turkish heritage, carer for >15 years)

There were some carers who wanted more education sessions, and meetings with other carers.

> '[I believe more] group meetings with other carers would be helpful. I would [also] be interested in information services - that is very important. They have support and information services for diabetes, why not for mental health?*'* (Wife, Italian heritage, carer for 11-15 years)

Hence, carers suggested that the CPSW program be extended and diversified; with further crisis, practical, social and educational support to better meet their specific needs.

Discussion

Consistent with existing literature, this study found that most carers reported benefit from a CPSW program (Foster, 2011; Hoagwood et al., 2010; Kling et al., 2008; Smith, 2015). Given the brevity of the service received by most carers, it is noteworthy that their interactions with the CPSW appeared influential and memorable months later. A prominent and almost universal theme amongst these carers was an appreciation of the emotional support provided by the CPSW and its benefits, such as an enhanced ability to cope. This was in-line with literature regarding both peer-led programs (Dixon et al., 2004; Foster, 2011; Kling et al., 2008), and professional-led programs (Tremont et al., 2015). The beneficial 'ripple effects' on service users that were identified by carers in this study is consistent with the findings of professional-led carer programs that showed reduced service user symptom severity (Wang &

Chien, 2011) and improved engagement with treatment (Ran et al., 2015). Furthermore, it is consistent with existing research on family-to-family peer support programs (Dixon et al., 2004).

Another prominent theme that was congruent with existing literature was the value placed on being supported by someone with lived experience, and the unique understanding of one's situation this brings (Foster, 2011; Greenwood et al., 2013; Kling et al., 2008). The CPSW enabled carers to feel that they were 'not alone' and less isolated in their experiences, which was similar to the findings of other carer support programs (Day et al., 2017; Greenwood et al., 2013). This interpretation may also extend to our finding that some carers requested further group meetings with other carers. Furthermore, our findings suggest that peer support workers may benefit people who had negative experiences with the mental health system by being an 'independent' person not attempting 'to defend the treatment'. Similarly, those who felt intimidated by traditional mental health workers utilised the CPSW for support during meetings. This aligns with findings from children's mental health service research on family support programs (Hoagwood et al., 2010). These points highlight the unique benefits that non-professional peer support workers can offer to service users and carers.

Furthermore, the interviews uncovered how different groups of carers may have different support requirements. For example, as noted in the thought diary findings (Table 2) and in line with the authors' predictions, relatively newer carers were more likely to make contact with services, programs, or groups than those who had been carers for more than 10 years. This may be because the needs of those that had been carers for longer had changed, in particular, they may have sourced supports elsewhere. In addition, the importance of the timing of services was emphasised by carers who stated that they had (or would have) benefited from increased supports when the person they cared for first became unwell or were in the midst of a crisis. This notion is supported by prior studies on family psychoeducation services, which have been found to be more readily taken up, when the family is in crisis (Dyck, Hendryx, Short, Voss, & McFarlane, 2014).

Non-English speaking and CALD carers also appear to have differing support needs to 'Anglo-Australians'. Three of the four Non-English speaking carers were reluctant to engage with services or supports due to feeling over-burdened by caring for the person with a mental illness. Furthermore, there was an over-representation of CALD and Non-English speaking carers contributing to the theme 'the support provided by the CPSW was not needed, or did not suit the carer's circumstances'. Previous research has suggested that CALD carers experience more carer burden (Poon, Joubert, & Harvey, 2015), and have higher drop-out rates from services (Kokanovic, Petersen, & Klimidis, 2006). Reasons may be multifactorial, including service factors (not meeting the specific needs of CALD service users and families, and especially those who are Non-English speaking), service user factors (more debilitating illness due to greater psychosocial risk factors, and barriers to accessing care), and carer factors (limited additional family members in the country, isolation, language barriers, poor mental health literacy, stigma, and other stresses related to migration and acculturation). A recent systematic review suggested that language barriers and concern about religious and cultural appropriateness were particularly important limitations for CALD carer engagement in services (Greenwood, Habibi, Smith, & Manthorpe, 2015). Hence, the approach of services may need to be adjusted to better align to the needs of Non-English speaking CALD carers. Our findings suggest that these carers would prefer greater practical support (including financial aid) and culturally appropriate respite services for the people they care for.

In addition, our findings showed that the CPSW improved carers' understanding of the service user's mental illness and of the mental health system, which is also in accordance with existing literature (Dixon et al., 2004) (Day et al., 2017) (Kling et al., 2008). However, our findings extend this literature by suggesting that those with prior experience with child and youth mental health systems did not seem to require this assistance, perhaps because these needs had already been adequately addressed. This might be expected, given that child and youth services are structured to involve families, especially in the case management framework (Department of Health and Human Services, 2008). Hence, the focus of carer peer support with these carers should be on individualised emotional and practical support, rather than education.

In terms of the authors' initial assumptions regarding the study, it was not predicted that the CPSW's practical support would be of particular and significant benefit to carers. It also came as a surprise that a number of carers did not find the support provided by the CPSW required, or suitable to their circumstances.

Limitations of the study

There were some possible methodological shortcomings in this study. We did not collect service user diagnosis and age from participants, and these details could have provided further richness to the findings. Furthermore, all interviews were conducted via telephone with the author transcribing in real time. It was decided that we use telephone rather than face-to-face interviews because of the carers' busy lifestyles, and to provide consistency with the CPSW work that also mostly occurred by telephone. Transcribing in real time may have meant the interviewer was distracted and missed some content. The interviewer attempted to minimise this by repeating the typed responses to the participants.

The study may have benefited from a larger sample size, and more male carers. However, the lower number of male carers (10%) reflected the lower number of men who are primary carers of people with a disability in the general population (31.9%) (Australian Bureau of Statistics, 2015).

There were also some limitations related to participant selection. People who declined the initial CPSW program or were verbally abusive towards the CPSW were not contacted in this follow-up study. Furthermore, people who were busy, had their phone disconnected, or did not answer their phone were not included. This likely restricted our ability to capture the entire range of carers' experiences, in particular those of carers who may have been most burdened, stressed, or had negative experiences with the CPSW program.

Furthermore, since the interviews were performed 5-10 months following their last contact with the CPSW, participants may not have remembered who had provided them with education, referrals, or information; and thus wrongly attributed services that were provided by other staff members (such as social workers or case managers)

to the CPSW. We attempted to minimise this by giving descriptions of the CPSW's appearance, further details of their role, and the specific month and location that the carer had seen the CPSW.

Lastly, participants and evaluators may have felt pressure to positively evaluate the CPSW program. However, the first author explained their independence of both the CPSW program and the clinical arm of the mental health service, which may have reduced the likelihood of such a response bias.

Implications for practice

Overall, the findings contribute to our understanding of how CPSWs could best be incorporated into a community mental health service, and highlight the unique benefits that they can provide to carers and service users. This is important in the current context of increased interest and roll-out of such workers (Department of Health and Human Services, 2015; Health Education England, 2017). From a mental health service perspective, the findings may have implications for resource allocation. From a clinician's perspective, the study suggests that engaging a CPSW may prove advantageous for both the service user and carer's wellbeing. There is scope for further research, particularly exploring the perspectives of service users, clinicians, and the peer support workers themselves. Nevertheless, given the consistency with the still limited literature, it is possible that findings are transferable to other similar contexts and diagnoses.

Conclusion

This study offers additional evidence that Carer Peer Support programs provide beneficial and valued emotional and practical support to carers by placing them at ease through mutual understanding and experience. It highlights the need of the CPSW to tailor their support to the specific requirements of carers, with consideration of their culture, stage of caring, and previous experiences with mental health services. In particular, CALD carers may require more practical assistance with caring for the person with a mental illness to better avail themselves for peer support, and further research into their specific needs, and how to effectively address these, is warranted.

Additionally, people who have been carers for longer are less likely to need further educational support. It is recommended that Carer Peer Support services prioritise new carers and carers of people who have developed a mental illness later in life (and therefore not had contact with child and youth mental health services), as well as all families experiencing a mental health crisis. Finally, it is important that Carer Peer Support services provided in multicultural settings are culturally sensitive.

CPSWs are an important complement to the professional workforce, as they provide a unique form of support that is highly valued by carers. The findings of this study support existing literature and international policy that encourages the expansion of the peer workforce and its inclusion in the paid workforce (Department of Health and Human Services, 2015; Health Education England, 2017). Furthermore, mental health service clinicians and managers should receive education and training to better understand the CPSW's role and unique benefits for carers, and how to structure services to enable CPSWs to meet the specific needs of carers.

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Table 1: Telephone interview questionnaire

Information about the carer and service user
Q1: What is your relationship to the service user?
Q2: How would you describe the support/help that you provide them? For example emotional / financial / assistance with personal care, etc.
Q3: And how long have you been providing care?
Q4: How long has the person you're supporting been experiencing their mental health problem?
Carer Peer Support Worker (CPSW) program
Q5: Please tell me something about the kinds of supports which were provided to you by the Carer Peer Support Worker
Q6: How did you experience & feel about this support
Q7: To what extent was it useful / helpful / what you wanted?
Q8: Were there any suggestions / information / referral to services made by the CPSW?
Q9: Did you follow up any suggestions made? Specifically?
Q10: Did you use any information provided?
Q11: Did you make contact with any services/programs/groups, which you discussed with the CPSW?
Q12: Was these useful or not? (Did you find the CPSW's information/suggestions/referrals useful?)
Better/worse questions (Participants were asked to expand on each of their responses)
Q13: Do you think the overall service you received made any difference (better / worse / no difference) to: Whether you felt able to cope with your situation or not?
Q14: Do you think the overall service you received made any difference (better / worse / no difference) to: Your amount/ severity of carer burden?
Q15: Do you think the overall service you received made any difference (better / worse / no difference) to: Your knowledge or information about the service user's mental health problem or behaviour?
Q16: Do you think the overall service you received made any difference (better / worse / no difference) to: Your knowledge or information about the mental health system and how to get help?
Q17: Do you think the overall service you received made any difference (better / worse / no difference) to: How you felt in yourself?

Q18: Do you think the overall service you received made any difference (better / worse / no difference) to: The recovery of the person you care for with the mental health problem?
Q19: Do you think the overall service you received made any difference (better / worse / no difference) to: Your understanding of how the rest of your family is feeling or coping?
CPSW program 2
Q20: What was the best thing about working with the peer support worker?
Q21: What was the worst thing about working with the peer support worker?
Q22: Thinking about the service you received from the peer support worker and from your own experience: Please comment on your preferred setting for contact with the CPSW
Q23: Please comment on your preferred timing for contact with the CPSW [i.e. time of day, weekday or weekend]
Q24: At what point in the service user's experience of receiving treatment within NWAMHS would contact with the CPSW have been most helpful for you? [i.e. when the service user first became unwell / when they were admitted / when they were in crisis and being visited at home by the mental health service / when they started attending the community clinic]
Q25: What suggestions do you have about how the CPSW service could be improved?
Q26: We would like to know whether you think anything else could have been helpful for you? [Meeting with other carers in a carers' support group / other types of support, education or information sessions for carers / respite services for carers / financial aid]
Q27: Would you be interested in attending sessions on practical advice and strategies on responding to the service user's symptoms or behaviours, if these were available?
Demographics
Q28: Do you identify as Aboriginal or Torres Strait Islander? Do you identify with a cultural or ethnic heritage?
Q29: Languages spoken at home
Q30: Interpreter required?
Q31: Sex of carer

Table 2: Key 'Thought Diary' themes

• 14/18 participants responded that the CPSW made them feel 'Better' in their ability to cope with their situation*
• 17/18 participants responded that the CPSW made them feel 'Better' within themselves*
• 3/4 of the Non-English speaking carers were reluctant to engage with services or supports, due to feeling over-burdened by their caring role
• Of the 7 people who had been carers for more than 10 years, none had made contact with services, programs, or groups that were discussed with the CPSW; as compared to 4/9 of the relatively newer carers (with less than 10 years of carer experience)
* Multiple choice question with 3 options: 'Better', 'Worse', or 'No different'

Table 3: Participant recruitment and demographic information

	Number
Total contacted	40
Complete interviews	18
Incomplete interviews*	2
Did not answer phone/ Disconnected	15
Declined interview/ Busy	5
Participants	20
Gender	
Male	2
Female	18
Length of caring experience**	
Carers for >10 years	7
Carers for <10 years	10
Relationship to consumer	
Mother	6
Father	2
Daughter	1
Wife	3
Ex-wife	1
Sister	5
Friend	1
Unknown	1
Cultural Heritage	
Anglo-Australian***	6
Iraqi	2
Turkish	5
Italian	3
Greek	2
Did not answer	2
Language	
English speaking	16
Non-English speaking (required Interpreter)	4

* Participants who indicated they had limited time, and were only asked a few questions

** 3 participants did not identify how long they had been carers

*** Those who identified their heritage as ‘Australian’, ‘Anglo’ or ‘English’ were categorised as ‘Anglo-Australian’