The experiences and needs of carers during mental health crises: A mixed-methods study

Helen Shann, *Psychologist,* Jade Sheen, *Associate Professor, Clinical Psychologist, MAPS,* Delise Francis, *BNurs, BAppsc(Psych), GCert (Psych), PGDipNirse (Periop), PGDipPsych(Hons),* and Jennifer Pohl. This work was supported by School of Psychology, Deakin University.

Introduction

Deinstitutionalisation of mental health care began in Australia in the mid-1980s, with inadequate provision of resources for community care (Doessel, 2009). At that time, there was a forced transition to community care, and minimal services were provided to support people experiencing mental health crises (Richmond, Sainsbury, Conoulty, & Rutledge, 1983). Crisis services for community mental health care in Australia continue to be under-resourced, which means that many people with mental illness have to be cared for by family and friends (Victorian Auditor General, 2019). Due to the lack of available mental health services, the Australian community relies on carers to take on the burden of looking after people with mental illness. A carer is defined as a person, often family, who provides unpaid supervision to a person with mental illness in the community (The Australian Bureau of Statistics, 2015). In 2015 in Australia, there were 2.7 million unpaid health carers who provided services worth $60.3 billion (The Australian Bureau of Statistics, 2015; Deloitte Access Economics, 2015)

A mental health crisis is defined as when an individual has an episode in which they are in danger of harming themselves or others due to irrational cognition coupled with extremely distressing emotions and an inability to cope (Boscarato et al., 2014). When carers are not able to manage a crisis, they need to know how to access support services. In Victoria, short term support or transport to hospital may be provided by community-based Crisis Assessment and Treatment (CAT) services, hospital emergency departments, ambulance staff, or police (Victorian Auditor-General's Report, 2009). Many carers have negative experiences when managing crises, and this can affect their psychological and physical health, a phenomenon known as *carer burden* (Aadil, Shah, & Wadoo, 2010; Ampalam, Gunturu, & Padma, 2012; Rowe, 2012; Perlick et al., 2016).

The experience of carers and the lack of resources available to them when managing a mental health crisis is an issue worldwide (e.g., Boye et al., 2001; Pejlert, 2001; Roick, Heider, Toumi, & Angermeyer, 2006; Lyons, Hopley, Burton, & Horrocks, 2009; Bauer, Koepke, Sterzinger, & Spiessl, 2012; Buus, Caspersen, Hansen, Stenager, & Fleischer,

2014; Al, Stams, Asscher, & van der Laan, 2014; Boydell et al., 2014). The first author (HS) reviewed the literature about the experiences of mental health carers and the resources available to them when managing a crisis. The review found four Australian studies, and 25 studies from other developed countries (defined as the original 20 members of the Organisation for Economic Co-operation and Development [OECD, 2014]).

Only a small number of studies have been conducted in Australia regarding the experiences of carers and their knowledge of the resources available during a mental health crisis (i.e., Fulford & Farhall, 2001; Siegloff & Aroni, 2003; Cleary, Freeman, Hunt, & Walter, 2005; Cleary, Hunt, Matheson, & Walter, 2008). The existing literature suggests that carers provide crucial support to individuals with a mental health illness and with a mental health crisis. In Australia, carers save the government billions of dollars each year, and yet minimal support is provided for carers themselves (Australian Bureau of Statistics, 2008). This has implications for both carers and Australians suffering from mental illness, especially when they are unable to access adequate treatment facilities (Fulford & Farhall, 2001). There is an urgent need to improve support for carers, and to study carers' views about what can be done to improve mental health care in Australia (Siegloff & Aroni, 2003; Cleary et al., 2005). More attention needs to be given to carers' needs by determining what supports they would find helpful in managing the mental health of their loved ones, particularly in times of crisis (Cleary et al., 2006).

The current study investigated three issues in relation to a mental health crisis: first, carers' experiences when they managed a mental health crisis; second, carers' views about the resources available to support them during a mental health crisis; and, third, carers' views about the resources available to support the person who is experiencing the mental health crisis. This study aimed to provide psychotherapists, counsellors, social workers, and other health professionals with knowledge and deeper insight about the issues that Australian carers are dealing with in the community and more effective ways to support them.

Methods

Participants

This study was approved by the Deakin University Human Research Ethics Committee. All carers gave informed consent prior to their inclusion in the study. The sampling strategy was non-random, with participants recruited through carer organisations in Melbourne, Victoria. People eligible for the study were providing unpaid care to a relative or friend with a mental illness, were over the age of 18 years, and were affiliated with a carer group in Victoria.

Carer organisations had the option of recruiting carers using either postal or online surveys. Postal recruitment involved sending carers a plain-language statement inviting them to complete and return the survey using a stamped addressed envelope. Online

recruitment involved carer organisations advertising the study in their electronic newsletter or by email, with a link to the plain-language statement and the survey. Data collection took place from July to September 2014.

Materials

Data were obtained using a survey that was based on a systematic literature review. Interface testing was used to establish the reliability and validity of the model survey.

This pilot study used a complementary mixed methods design with both quantitative and qualitative elements (Morgan, 1998). Eight 5-point Likert scale questions were used to yield quantitative data (see Table 1), and four unstructured questions were used to collect qualitative data. The qualitative questions were: (1) What are your experiences as a carer when managing an individual experiencing a mental health crisis?; (2) Do you have enough resources to assist you when managing an individual during a mental health crisis?; (3) What health agency or resources do you use most and why?; and, (4) How can any barriers you face as a carer managing a mental health crisis be addressed?

Results

Data collection and analysis

Seventy-one surveys were completed, including 44 online surveys, and 27 postal surveys (a total of 71 responses). Quantitative analysis was performed using the Statistical Package for Social Sciences version 22 (SPSS, 2014). Qualitative data were analysed using thematic analysis at the latent level, which identifies common issues and the main themes that summarise the data (Braun & Clarke, 2006). Six phases of thematic analysis were followed as outlined in Table 1 in Braun & Clarke (2006). Three researchers independently familiarised themselves with the data, and generated codes and then themes. The researchers then met to combine and refine the themes based on their separate generations, and a fourth researcher reviewed candidate themes to increase the reliability and validity of the identified themes. An inter-rater reliability analysis using the kappa statistic was performed to determine consistency among raters (Fleiss, 1971). The inter-rater reliability for Theme 1 found substantial agreement with kappa 0.64 (95% confidence interval [CI] 0.50-0.77), for Theme 2 fair agreement with kappa 0.37 (95% CI 0.23-0.50), and for Theme 3 substantial agreement with kappa 0.56 (95% CI 0.42-0.69). Because of missing data, some results do not include all 71 participants.

Demographics

Sixty two (87.3%) of the total respondants were female, 8 (11.3%) male, and 1 (1.4%) was unknown. Sixteen (23%) of the carers were aged 18-50 years, 23 (32%) 51-60 years, 22 (31%) 61-70 years, 8 (11%) were >70 years, and the age of one carer was unknown. The relationship of the carer to the person with a mental illness was mother in 36 (51%) cases, wife or female partner in 11 (15%), daughter in 5 (7%), father in 3 (4%), husband in 3 (4%), sister in 3 (4%), grandmother in 2 (3%), other in 5 (7%), and unknown in 3 (4%).

Quantitative

Forty four carers (62%) managed six or more crises within a three month period. Carers first called for help from the CAT team in 26 (37%) cases, a doctor in 9 (13%), hospital emergency department in 8 (11%), ambulance in 7 (10%), police in 5 (7%), family in 5 (7%), and other in 5 (7%). Other quantitative data are presented in Table 1.

Table 1. Frequency of carer responses to the survey questions

Survey question	Disagree strongly	Disagree somewhat	Unsure	Agree somewhat	Strongly Agree	**Total**
There are enough resources in the community to support my needs as a carer.	22	24	3	16	6	**71**
There are enough resources in the community to support the mental health needs of the individual in my care during a mental health crisis.	35	13	4	15	4	**71**
I know what to do when the individual in my care has a mental health crisis.	3	10	4	38	10	**65**
I am aware of the roles of all health professionals in relation to mental health.	3	10	9	38	10	**70**
I am able to rapidly access all of the resources I need as a carer.	24	24	7	13	3	**71**
I feel confident in managing a mental health crisis.	13	20	5	28	5	**71**

A majority of carers felt (strongly or somewhat) that there were not enough resources in the community to support their needs as a carer (46 of 71, or 65%; 95% CI 58%-76%) or the needs of the individual in their care during a mental health crisis (48 of 71, or 68%;

95% CI 58%-78%).

The majority of carers felt (strongly or somewhat) that they know what to do when the individual in their care has a mental health crisis (48 of 65, or 74%; 95% CI 61%-84%) and that they are aware of the roles of health professionals in relation to mental health (48 of 70, or 69%; 95% CI 56%-79%).

On the other hand, the proportion of carers who did not feel (strongly or somewhat) confident about managing a mental health crisis (33 of 71, or 46%; 95% CI 35%-59%) was the same as the proportion who did feel confident (33 od 71, or 46%; 95% CI 35%-59%).

Qualitative

Three key themes emerged from the survey data: *emotional reactions*, *response from services*, and *improvements for crisis management*.

Theme 1: Emotional reactions.

Carers reported that the behaviours that they had to deal with during mental health crises included self-harm, violence, yelling, drinking, aggression, mania, confabulation, paranoia, and psychosis including delusions and hallucinations. Carers often reported that they were confused because the person they were looking after was manipulative and dishonest.

Many carers reported not being able to get help from crisis services, which left them feeling isolated, angry, resentful, frustrated, and profoundly hopeless. The most commonly reported emotions were stress (21%) and fear (n=18%) Carers were afraid, at times for themselves as carers due to being unable to cope with the crisis symptoms, and other carers were afraid for the current and future welfare of their loved ones. Carers reported that, when there were frequent crises that lasted for several weeks, they often “burnt out” and became depressed, exhausted, and had an overwhelming sense of loss. They felt grief for the person who was unwell, and grief at the loss of their own freedom and independence. The following quotes provide examples of participants’ emotional reactions:

My first experience was terrifying as I knew nothing about mental illness… I don’t think there is enough room for me to tell you about the horrid, frightening experience we went through as carers, and my daughter went through as a person with mental illness. The experience still makes me very distraught and angry after 14 years. (Carer 2, mother)

It is incredibly stressful and traumatic also for the carer to see someone they love in such pain. (Carer 8, husband)

I’m scared. What is going to happen to him when I am gone? (Carer 77, mother)

Sadness: for the person you love, for the sense of loss. (Carer 45, wife)

There is a sense of despair/hopelessness about the mental health system with my son—who I love dearly—in the middle. (Carer 33, mother)

Theme 2: Response from services.

Communication with health professionals.

Thirty-five carers (49%) reported communication difficulties with health professionals. They often felt that staff had not listened to them, excluded them from the treatment process, used incomprehensible medical language, and had been prejudiced and judgemental. This was true for carers looking after people with many types of mental illness, but especially those with comorbid substance abuse issues. Twenty-three carers (32%) reported that they wanted health professionals to be more understanding and acknowledge carers' skills and expertise in relation to the person having a crisis. The following quotes convey common sentiments:

Not being heard by clinicians. (Carer 26, mother)

I believe that a major barrier to managing a mental health crisis is not being taken sufficiently seriously by clinicians and case managers, possibly because adult services in the public sector are heavily burdened. (Carer 30, mother)

It would help if the clinical/medical staff would talk in a less medical manner so carers could understand. (Carer 2, mother)

We can be considered as part of the treating team and be included and work collaboratively with the treating team… Effective communication is paramount; carers have a lot of knowledge and experience of the person with the illness that can help to achieve better outcomes for the person with the illness. (Carer 23, mother)

Greater appreciation of the role and care of the carer as well as the patient. (Carer 8, husband)

Access to services.

Fifty-eight carers (82%) reported that they either could not get any support from services or there was a long delay; this was mostly in relation to CAT services (39%), and to a lesser extent hospital emergency services (11%), ambulance (10%), and police (7.0%). The following quotes were typical of participants' experiences:

I've learnt over the years to manage crisis by myself and any help I get is a bonus. (Carer 11, mother)

The treating team doesn't respond. (Carer 10, mother)

Difficult to get help when needed. (Carer 39, mother)

When a crisis occurs, it feels like our situation is not assessed solely on need—availability of beds is taken into consideration. It should be the reverse—if the need is there, the bed is found… I need help. I am not superhuman. My family is suffering. (Carer 77, mother)

Eleven carers (15%) suggested that the most common reason for service delays was that health professionals and carers had different definitions of a crisis. Carers reported that they considered a crisis to be when the person they were looking after had early symptoms, such as an inability to cope. The carers' hoped to prevent the crisis from getting worse, but health professionals only provided support when the person had become severely unwell or was a physical risk. Support was sometimes inadequate even when carers had access to services, but health professionals were undertrained or overworked. Some patients were discharged when they were still very unwell, which carers reported as frightening. Additionally, many reported that there was poor communication between crisis services, which resulted in inconsistent approaches to care. The following quotes highlight some of the systemic issues that carers have experienced:

I've read that in Britain the criteria for intervening in a mental health crisis are "when the individual needs medication"… Our model, in a simplified form, is "harm to self or others," but my view is that this is too late if we are looking at shorter illness time, shorter hospital stays, and healthier functioning for the consumers. (Carer 21, partner)

Real difficulty in getting help, particularly after hours, even when our son was an existing client of CAMHS [Child and Adolescent Mental Health Services]… Once we managed to get someone to meet our child, they would then see a crisis admission was necessary, but getting to that point was incredibly difficulty, and staff continually tried to turn us away. (Carer 5, mother)

I'm tired of seeing the early warning signs but not being able to act, insist on medication being reviewed and commenced or altered, and then *waiting* until illness has set in so CAT can be called. If the crisis is past the ambit of the psychiatrist and I call CAT there are always delays, usually hours delay, in CAT attending. (Carer 21, female partner)

Responses to crisis should be appropriate and timely. The CAT team should be able to send a clinician out to assess the person after you ring them, but they always take days and days to bother responding. (Carer 3, daughter)

Theme 3: Improvements for crisis management.

Carers suggested several recommendations to improve crisis management: for services to be extended for the duration of the crisis, health professionals to be more supportive, and for the introduction of affordable respite and educational services for carers.

Long-term management of crises.

After patients had been discharged, carers often experienced a lack of long-term support. Twenty-six carers (37%) reported that they wanted more information about how to manage a crisis after discharge. Some mentioned the existence of privacy laws that prevented health professionals from communicating with them, leaving them frightened that the person in their care may relapse. The following quotes highlight difficulties that many carers face:

Once released from hospital, unless dad becomes violent or unstable again there are no other resources. Once the major crisis is over, life isn't plain sailing. More understanding and help to manage his affairs afterwards would be appreciated. (Carer 7, daughter)

There is no directory or information on what the processes are in hospital and no discharge plans or instructions on how to handle situations when the person is discharged. …We have had our person [with mental illness] discharged without us being informed and we found him wandering the streets in his bare feet. (Carer 23, mother)

The thing that I do not understand is that my family member is discharged from these services because her time is up! When she clearly needs continued support in the community in many areas of her life. (Carer 15, mother)

Twelve carers (17%) thought it would be helpful to have a written safety plan that was agreed by the carer and health professionals before the person with mental illness could be discharged. Carers said that the plan would need to involve the health professionals, and not just leave the carer to manage on their own. The following quotes illustrate barriers faced by carers and ways that health professionals can address these:

Education and planning. A written plan agreed on by all parties as to who to approach. Think of it being like an asthma management plan for mental health, for example; if this happens, do this… if that happens, take the next step… etc. This would help validate the situation with emergency or crisis services. (Carer 5, mother)

Agencies need to train carers a lot more. (Carer 45, wife)

To improve communication between the different mental health services, such as CAT services and hospital-based services, carers suggested the establishment of a central administrative service that collects relevant information on each patient, such as previous crises, medications, and the services involved.

Resources for the carer.

Eighteen carers (25%) reported that they wanted more information about resources available to them in the community. Carers reported that it had taken them years to discover available supports, such as respite care and carer groups. Carers recommended establishment of an up to date online collection of links to all the resources in Victoria. The following quotes suggest that existing resources are difficult for carers to find:

It has taken four years to get full awareness of these resources. (Carer 6, mother)

Accommodation [supported] is *much* needed to help with independent living skills and social isolation. (Carer 54, mother)

We carers need more resources that are easier to access and more information out there to make it easier to find. (Carer 15, mother)

Twenty-two carers (31%) reported that they would benefit from having more respite care, carer support groups, and counselling. Cost was a major concern for many, as they had given up full time jobs to be a carer. They also stated that, although there had been helpful resources for carers, the recent mental health service financial cuts meant that many resources were no longer available or were expensive. These quotes show that carers would like access to affordable psychotherapy services due to the impact on their own mental health:

It's a huge problem in getting enough psychologist appointments on an allied mental health plan. We need many more Medicare-paid appointments for the people in our care, and also for myself as a carer who is also affected with depression and anxiety. (Carer 15, mother)

Counselling with some strategies of how to deal with them (patient) when they are mentally unwell. (Carer 14, mother)

Governments, both state and federal, need to acknowledge the escalating crisis, i.e., how many ordinary citizens are affected by mental health. How it is impacting on patients, and carers, their ability to hold down meaningful employment, and stay in long-term relationships. I believe it is the biggest crisis our society has faced… it is up to the afflicted to somehow cope, without adequate, ongoing support." Carer 50 (wife)

Eighteen carers (25%) of carers reported that it would be helpful to have education programmes and training in order to learn how to provide better crisis care and develop better coping skills for themselves. These quotes illustrate resources that carers find helpful:

Education/respite/counselling. (Carer 2, mother)

I quite often feel lost as a carer… more support groups for carers. (Carer 17, partner)

Carers need to be informed of the processes, the illness, the prognosis, have family meetings with the treatment team, be consulted about discharge plans, informed of medication and its side-effects, and what to do when the person is discharged back into their care. (Carer 23, mother)

Discussion

This study increases understanding of carer experiences and the resources available to them when they are supporting a family member during a mental health crisis. The results provide information from carers themselves that could facilitate psychotherapists,

counsellors, and other health professionals to address mental health crises in the community. This article highlights the importance of empathic and collaborative communication with carers, and family centred care.

Experiences of Carers When They are Managing a Mental Health Crisis

Half of the carers in this study did not feel confident managing crises, and the qualitative data shows why they were not confident. Consistent with past research (Siegloff & Aroni, 2003), many carers reported that they have to deal with a range of behaviours in the patient, such as violence, psychosis, and attempted suicide, and this leaves them with negative feelings such as fear, distress, and desperation.

Over half of the carers had managed six or more crises, and the more crises they managed, the more confident they felt in providing support to the person having the crisis. On the other hand, carers also stated that the longer they had been caring, the more despondent they had become about the lack of support available to them, and this affected their own emotional and physical wellbeing. Carers described becoming stressed, depressed, feeling exhausted, and unable to cope. This is important because other studies have shown that if carers experience negative emotions over a long period of time, they are likely to develop carer burden with psychological and physical problems (e.g., Jones & Jones, 1994). The current study documents the importance of carer burden. Additionally, the current study suggests that increased economic investment is needed to support carers. In 2015, there were 2.7 million unpaid carers and they provided services worth $60.3 billion per annum (The Australian Bureau of Statistics, 2015; Deloitte Access Economics, 2015). Without carers to provide support during crises, there would be serious detrimental consequences for the mental health care system.

Resources Available to the Carer to Support the Person Who is Experiencing a Mental Health Crisis

There were three important findings in this study in relation to the resources available to support carers during a crisis. First, the quantitative data in this study show that nearly two-thirds of carers somewhat or strongly agree that there are not enough resources to support them during a crisis. Second, nearly two-thirds agree that they are not able to rapidly access the resources they need as a carer. Finally, nearly three-quarters of carers feel they know what to do when there is a crisis. These results are strongly supported by the qualitative data, where carers reported that they know what to do when there is a crisis but are often unable to do it. Carers reported severe distress and frustration at the long delays in getting access to the CAT services. A study in the United States found that when timely crisis support is provided and there are no access restrictions, carers' views and behaviour are more positive, with improved quality of care given during crises (Evans et al., 2003).

Carers in this study reported that getting access was even more difficult when the person with mental illness also had substance-abuse issues; carers in these circumstances report higher anxiety and more difficulty providing care (Cleary et al., 2008). This

suggests that these carers are in greatest need of support, but that it is more difficult for them to get help.

When carers cannot access services, this impairs their ability to care for the person with mental illness and it also affects carers' own mental health. Government initiatives are needed to increase the availability of services for carers managing crises. In this study, 37% of the carers reported that they call the CAT team first when they need support to manage a crisis, suggesting that increasing resources for CAT services is likely to be particularly helpful.

Carers reported that the need for informed consent before information can be shared with them reduces the quality of care they are able to provide to patients during a crisis. Conflict between patient confidentiality and the need for the carer to be fully informed raises difficult issues for health professionals, particularly when carers are the main support for people having a mental health crisis (Tuck, du Mont, Evans, & Shupe, 1997; Pejlert, 2001). When carers feel included and have cooperative relations with health professionals, they generally have a more positive view of crisis support services (Boye et al., 2001; Pejlert, 2001; Tranvåg & Kristoffersen, 2008; Boydell et al., 2014). The Victorian Mental Health Act recognises that carers are a valuable resource, and a government initiative has begun to facilitate supported decision making and strong partnerships between patients, health professionals, and carers (Department of Health, 2014). Perhaps governments need to make special provisions relating to sharing information with carers when the person they are looking after is too unwell to provide their own consent or is living at home and requires long-term crisis management. This would be likely to benefit all parties: the carer, health professionals, and the person with mental illness. People experiencing a mental health crisis need to be given independence; however, there are situations where they are not capable of caring for themselves, yet they are discharged from hospital or other crisis services because they are not ill enough to require professional assistance. While there are some limited provisions for the sharing of information with carers, it is usually only crisis situations that pose immediate risk. The current study suggests that information needs to be shared with carers before the mental health of the person they are looking after has deteriorated to crisis-point.

Carers stated that they need specific information about medication and its side effects, the diagnosis, the prognosis, appropriate treatments, and community resources. De Haan et al. (2001) suggest that the information given to carers is often too broad, and Grella and Grusky (1989) present evidence that individualised case management improves carer satisfaction with crises management because it offers carers information that is highly relevant to their situation.

Resources Available to Support the Carer During a Mental Health Crisis

When carers were asked about how to improve crisis management, a common suggestion was to improve respite, counselling, and education resources available to carers. There was inconsistency about what type of respite would be most helpful: some carers wanted more "halfway houses" and admission for the person with mental illness,

while others asked for in-home or drop-in respite. Respite care has been found to help carers develop a social support network, engage with non-judgmental staff, and give carers a break—and this improved carers' ability to manage mental health crises (Jardim & Pakenham, 2010).

In terms of counselling and psychotherapy, the carers in the current study wanted affordable psychotherapy for themselves as carers, to help them cope with the emotional burden that comes with caring for someone else with severe mental health issues. The qualitative information provided by carers demonstrated that they had good insight into their own emotional experiences; carers acknowledged the traumatic impact that managing a mental health crisis had on their own mental health. Psychotherapy is likely to help normalise and validate carer's own distressing experiences, and in turn develop their resilience for managing crises. Furthermore, psychotherapy helps to equip carers with strategies to reduce their own anxiety and with skills to appropriately care for their loved ones, particularly in times of crisis. Carers explained that while there were some immediate supports provided at the time of the mental health crisis, the long-term emotional impacts were often dealt with independently, and they wanted more on-going psychotherapy supports to reduce carer burden.

Carers in the current study volunteered that they wanted more education and training programs. Given carers wanted educational programs, it may be useful for carer organisations to investigate programs that have been implemented in other countries to develop a program in Australia. Some studies from the United States and the United Kindom provide evidence about education programs that have been shown to be helpful (i.e., Wolthaus et al., 2002; Roick et al., 2006; Al et al., 2014; Yesufu-Udechuku et al., 2015), but such programs play only a minor role in Australia. Brief psycho-educational support programs can improve carers' knowledge and attitudes, but only long-term psycho-educational interventions (greater than eight weeks) improve coping strategies (Roick et al., 2006). These education programs include intensive community based supports, as well as psychtherapy to help families learn adaptive ways to cope with difficult emotions, to develop strategies for managing crises, and to build on interpersonal skills (Roick et al., 2006). Education programs that include counselling are more effective because carers find it helpful to discuss difficulties they have when helping the patient (Szmukler, Herrman, Bloch, Colusa, & Benson, 1996). Crisis education programs for parents and their children have been shown to decrease the severity of crises symptoms, improve child safety, decrease the level of parent stress, and increase parents' confidence in managing crises (Al et al., 2014). In the current sample,over half of carers were parents, suggesting that the introduction of a parent-child education program might be useful.

Limitations

Due to time contraints, the number of carers participating in this study was limited. It would be useful to repeat the study with a longer time frame, and a larger sample size. Additionally, the sample in this study was recruited from carer groups, whose members are more likely to be aware of the available resources than carers not associated with a

carer group, so it may not be a representative sample. In future studies, it would be worth also recruiting carers who are not already a member of a carer support group. The carers in our sample expressed the view that there is a severe lack of support services,despite the fact that they are relatively well-informed carers who are in a position to know how to access the services that are available. It is likely that the lack of support is even greater for carers who were not sampled in this study because they are less likely to know what services that are available, which puts them at greater risk of burnout. Another limitation of the current study is that it did not include information about where the carers or patients lived, and it is important to know whether resources differ between regions.

Future research

There is a need for randomised trials in Australia that investigate the effects of providing increased support early in mental health crises, greater involvement of carers in decision making, and increased education and long-term counselling provided for carers. Given carers in the current study wanted psychotherapy, more research should be conducted on providing affordable psychotherapy for carers, and gathering evidence about the most effective therapeutic interventions. These studies should measure the effects on both carers and patients.

Conclusion

Carers are an important resource in the mental health care system and can provide valuable information about how to improve crisis management. In this study, carers suggested that the management of mental health crises would be improved if there were timely support for the management of early symptoms, greater involvement of carers in decision making with changes to privacy legislation, and the introduction of affordable education and counselling programs for carers. This study highlights the important role that psychotherapists and counsellors have in supporting carers to develop an understanding of mental health diagnosis, to develop their confidence in managing crises, and to gain evidence-based skills to look after loves ones who are affected by mental health issues. This study found that carers want access to sessions with psychotherapists and counsellors and that this is likely to reduce carer burden. Improving the support available to carers is likely to have a positive effect on the mental health care system by benefitting carers so they can be able to provide better support for people experiencing a mental health crisis.

References

Aadil, J., Shah, O., Wadoo, J., & Latoo. (2010). Psychological distress in carers of people with mental disorders. *British Journal of Medical Practitioners*, *3(3)*, 327-333.

Al, C. M. W., Stams, G. J. J. M., Asscher, J. J., & van der Laan, P. H. (2014). A programme evaluation of the Family Crisis Intervention Program (FCIP): Relating programme characteristics to change. *Child & Family Social Work*, *19*(2), 225–236. https://doi.org/10.1111/j.1365-2206.2012.00896.x

Ampalam, P., Gunturu, S., & Padma, V. (2012). A comparative study of caregiver burden in psychiatric illness and chronic medical illness. *Indian Journal of Psychiatry*, *54*(3), 239–243. https://doi.org/10.4103/0019-5545.102423

Australian Bureau of Statistics. (2008, October 23). *National survey of mental health and wellbeing*. Retrieved June 18, 2016, from Prevalence of Mental Disorders website: http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4326.0Main%20Features32007?opendocument&tabname=Summary&prodno=4326.0&issue=2007&num=&view=

Australian Bureau of Statistics. (2015). *Survey of disability, ageing, and carers*. Retrieved 2019, from Australian Bureau of Statistics website: https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

Bauer, R., Koepke, F., Sterzinger, L., & Spiessl, H. (2012). Burden, rewards, and coping—the ups and downs of caregivers of people with mental illness. *The Journal of Nervous and Mental Disease*, *200*(11), 928–934. https://doi.org/10.1097/NMD.0b013e31827189b1

Boscarato, K., Lee, S., Kroschel, J., Hollander, Y., Brennan, A., & Warren, N. (2014). Consumer experience of formal crisis-response services and preferred methods of crisis intervention. *International Journal of Mental Health Nursing*, 23(4) 287-295. https://doi.org/10.1111/inm.12059

Boydell, J., Onwumere, J., Dutta, R., Bhavsar, V., Hill, N., Morgan, C., … Fearon, P. (2014). Caregiving in first-episode psychosis: social characteristics associated with perceived “burden” and associations with compulsory treatment. *Early Intervention in Psychiatry*, *8*(2), 122–129. https://doi.org/10.1111/eip.12041

Boye, B., Bentsen, H., Ulstein, I., Notland, T. H., Lersbryggen, A., Lingjaerde, O., & Malt, U. F. (2001). Relatives’ distress and patients’ symptoms and behaviours: A prospective study of patients with schizophrenia and their relatives. *Acta Psychiatrica Scandinavica*, *104*(1), 42–50. https://doi.org/10.1111/j.1600-0447.1994.tb05865.x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.https://doi.org/10.1191/1478088706qp063oa

Buus, N., Caspersen, J., Hansen, R., Stenager, E., & Fleischer, E. (2014). Experiences of parents whose sons or daughters have (had) attempted suicide. *Journal of Advanced Nursing*, *70*(4), 823–832. https://doi.org/10.1111/jan.12243

Cleary, M., Freeman, A., Hunt, G. E., & Walter, G. (2005). What patients and carers want to know: an exploration of information and resource needs in adult mental health services. *The Australian and New Zealand Journal of Psychiatry*, *39*(6), 507–513. https://doi.org/10.1111/j.1440-1614.2005.01611.x

Cleary, M., Freeman, A., Hunt, G. E., & Walter, G. (2006). Patient and carer perceptions of need and associations with care-giving burden in an integrated adult mental health service. *Social Psychiatry and Psychiatric Epidemiology*, *41*(3), 208–214.

https://doi.org/10.1007/s00127-005-0017-z

Cleary, M., Hunt, G. E., Matheson, S., & Walter, G. (2008). The association between substance use and the needs of patients with psychiatric disorder, levels of anxiety, and caregiving burden. *Archives of Psychiatric Nursing*, *22*(6), 375–385. https://doi.org/10.1016/j.apnu.2008.02.001

De Haan, L., van Raaij, B., van den Berg, R., Jager, M., Houweling, P., Stockmann, M., … Wouters, L. (2001). Preferences for treatment during a first psychotic episode. *European Psychiatry: The Journal of the Association of European Psychiatrists*, *16*(2), 83–89. https://doi.org/10.1016/S0924-9338(01)00542-9

Deloitte Access Economics. (2015). *The economic value of informal care in Australia*. Carers Australia.

Department of Health. (2014). Victoria's new Mental Health Act [Guidelines]. Retrieved October 24, 2014, from http://www.health.vic.gov.au/mentalhealth/mhactreform/

Doessel, D. P. (2009). A historical perspective on mental health services in Australia: 1883–84 to 2003–04. *Australian Economic History Review*, *49*(2), 173–197. https://doi.org/10.1111/j.1467-8446.2009.00254.x

Evans, M. E., Boothroyd, R. A., Armstrong, M. I., Greenbaum, P. E., Brown, E. C., & Kuppinger, A. D. (2003). An experimental study of the effectiveness of intensive in-home crisis services for children and their families program outcomes. *Journal of Emotional and Behavioral Disorders*, *11*(2), 92–102.https://doi.org/10.1177/106342660301100203

Fleiss, J. L. (1971). Measuring nominal scale agreement among many raters.*Psychological Bulletin*, *76*(5), 378–382. https://doi.org/10.1037/h0031619

Fulford, M., & Farhall, J. (2001). Hospital versus home care for the acutely mentally ill? Preferences of caregivers who have experienced both forms of service. *The Australian and New Zealand Journal of Psychiatry*, *35*(5), 619–625. https://doi.org/10.1080/0004867010060510.

Grella, C. E., & Grusky, O. (1989). Families of the seriously mentally ill and their satisfaction with services. *Hospital & Community Psychiatry*, *40*(8), 831–835.

Jardim, C., & Pakenham, K. I. (2010). Carers' views on respite care for adults with mental disorders. *Advances in Mental Health*, *9*(1), 84–97. https://doi.org/10.5172/jamh.9.1.84

Jones, S. L., & Jones, P. K. (1994). Caregiver burden: who the caregivers are, how they give care, and what bothers them. *Journal of Health & Social Policy*, *6*(2), 71–89. https://doi.org/10.1300/J045v06n02_05

Lyons, C., Hopley, P., Burton, C. R., & Horrocks, J. (2009). Mental health crisis and respite services: Service user and carer aspirations. *Journal of Psychiatric and Mental Health Nursing*, *16*(5), 424–433. https://doi.org/10.1111/j.1365-2850.2009.01393.x

Morgan, D. L. (1998). Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research*, *8*(3), 362–376. https://doi.org/10.1177/104973239800800307

Organisation for Economic Co-operation and Development (2014). List of OECD member countries – ratification of the convention on the OECD. http://www.oecd.org/about/membersandpartners/list-oecd-member-countries.htm

Pejlert, A. (2001). Being a parent of an adult son or daughter with severe mental illness receiving professional care: Parents' narratives. *Health & Social Care in the Community*, *9*(4), 194–204. https://doi.org/10.1046/j.0966-0410.2001.00301.x

Perlick, D. A., Berk, L., Kaczynski, R., Gonzalez, J., Link, B., Dixon, L., … Miklowitz, D. J. (2016). Caregiver burden as a predictor of depression among family and friends who provide care for persons with bipolar disorder. *Bipolar Disorders*, *18*(2), 183–191. https://doi.org/10.1111/bdi.12379

Richmond, D. (1983). *Inquiry into health services for the psychiatrically ill and developmentally disabled* (Report No. 83 – 020). *Department of Health, Division of Planning and Research, Haymarket New South Wales.*

Roick, C., Heider, D., Toumi, M., & Angermeyer, M. C. (2006). The impact of caregivers' characteristics, patients' conditions and regional differences on family burden in schizophrenia: A longitudinal analysis. *Acta Psychiatrica Scandinavica*, *114*(5), 363–374. https://doi.org/10.1111/j.1600-0447.2006.00797.x

Rowe, J. (2012). Great expectations: A systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. *Journal of Psychiatric and Mental Health Nursing*, *19*(1), 70–82. https://doi.org/10.1111/j.1365-2850.2011.01756.x

Siegloff, S., & Aroni, R. (2003). Mental illness and "self"-management in rural Australia: caregivers' perspectives. *Australian Journal of Primary Health*, *9*(3), 90-99.

Szmukler, G. I., Herrman, H., Bloch, S., Colusa, S., & Benson, A. (1996). A controlled trial of a counselling intervention for caregivers of relatives with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, *31*(3-4), 149–155. https://doi.org/10.1007/BF00785761

Tranvåg, O., & Kristoffersen, K. (2008). Experience of being the spouse/cohabitant of a person with bipolar affective disorder: A cumulative process over time. *Scandinavian Journal of Caring Sciences*, *22*(1), 5–18. https://doi.org/10.1111/j.1471-6712.2007.00562.x

Tuck, I., du Mont, P., Evans, G., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing*, *11*(3), 118–125. https://doi.org/10.1016/S0883-9417(97)80034-9

Victorian Auditor General. (2019). *Access to Mental Health Services*. Victorian Government Printer. Victoria, Australia.

Victorian Auditor-General's Report. (2009). *Responding to mental health crisis in the community*. Victorian Government Printer. Victoria, Australia.

Wolthaus, J. E. D., Dingemans, P. M. A. J., Schene, A. H., Linszen, D. H., Wiersma, D., Van Den Bosch, R. J., … Hijman, R. (2002). Caregiver burden in recent-onset schizophrenia and spectrum disorders: The influence of symptoms and personality traits. *The Journal of Nervous and Mental Disease*, *190*(4), 241–247.

Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., … Kendall, T. (2015). Interventions to improve the experience of caring for people with severe mental illness: Systematic review and meta-analysis. *The British Journal of Psychiatry: The Journal of Mental Science*, *206*(4), 268–274. https://doi.org/10.1192/bjp.bp.114.147561

Return to Journal Articles