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The Bond We Share: Experiences of Caring for a Person with Mental and Physical Health Conditions

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Additional information is available at the end of the chapter

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1. Introduction

The purpose of this chapter is to improve service providers' understanding of how to work with, include and understand the experience and expertise of mental health carers. This information is useful for service providers in clinical mental health, psychosocial rehabilitation across government and non-government, and primary health care settings, and also for managers of services, to help determine training offered to their employees. It may also be useful for carers and carer support organisations, as well as for those who teach undergraduate and postgraduate health professional students.

After reading this chapter, readers will be able to:

- Understand the significant impact of caring for a person with a mental & physical health conditions, from the carer's perspective, and their day-to-day experience of caring;
- Understand how carers can contribute as positive partners with health care providers, in supporting people with mental and physical health conditions;
- Critically analyse and reflect on their practice knowledge, skills and attitudes, in particular, their consideration of carers' input to enhance the clinical and psychosocial outcomes for people with mental and physical health conditions;
- Recognise strategies within their own practice that engage and support carers.

A review of the international and Australian research on mental health carers' experiences of caring for a loved one with mental illness provides a background to the issues. This is followed by a report on the results of a large study conducted in South Australia in 2010, with mental health carers, to explore and examine the issues in more depth.

Family carers are people who provide unpaid support to family members and friends who have a disability, mental illness, chronic physical health condition, terminal illness or who are frail aged. Within an overall population of 22.5 million, Australia has almost 2.6 million family carers. Almost half of all carers have a disability themselves [1-3].

Mental illnesses account for 27% of disability costs in Australia and 60% of disability costs for 25 to 40 years olds. Mental illness often requires long term support and management by the person, informal carers and health systems, posing significant burdens on health and wellbeing for individuals, families and communities [4-6]. The extent and complexity of these burdens on people with mental illness and their carers is not well understood, in particular, the complexities of managing physical health, lifestyle risk factors, and mental health [7]. As the population ages and the incidence of disability and chronic illness increases [8], the role of these carers will become increasingly apparent and the impacts of caring increasingly felt. This is compounded by major policy changes, in Australia and in many other countries, focused on shorter hospital stays and a shift from institutional care to greater care in the community [9]. In Australia, carers contribute substantially to the national economy through unpaid care, yet they are amongst the poorest, most disadvantaged people in our community [10]. In 2005, the productivity loss of this care was estimated at approximately \$4.9 billion; a substantial comparison to the \$30.5 billion provided for formal aged and disability care services in Australia [11]. Carers spend around 40 hours a week providing care [1]. For carers of someone with a mental illness in Australia, the average time spent providing care is around 104 hours per week [12]. Family carers are usually at the centre of community mental health care, providing the bulk of support and assistance with little or no specialised training [10]. Similar figures have been found in the United Kingdom with 5.8 million carers, of which many are mental health carers [13-15]. In the United States, there are 65.7 million carers of which 7% or nearly 0.5 million are mental health carers (not including Alzheimers or dementia) [16]. Outcomes for people with mental illness are therefore highly dependent upon the quality of in-home support. Yet there have been few community-based support services put in place in Australia, or in other countries, to aid the shift to deinstitutionalisation of care for people with mental illness [8]. These phenomena are not isolated to the Australian context [6,17-29].

We do know that mental health carers face unique challenges in their caring role, related to the nature of mental illness itself and that the role entails both positive and negative impacts [30,31]. Tasks of caring such as personal care, involvement in medication monitoring and distribution, support for shopping, household chores such as cleaning and laundry, budgeting and bill paying support are understood as common across caring roles where physical frailty and dependence are evident. Though many mental health carers also undertake such tasks within their caring role, the predictability of these roles does not necessarily apply to mental health caring, especially given mental illness often has marked fluctuations and ever changing impacts on the person with the illness [14, 32-35]. Such fluctuations require mental health carers to navigate their roles within a fine balance of ever-changing need which in turn gives rise to further unique issues for mental health carers that must be understood in order to provide them with effective support in their caring role.

2. Impacts of caring on carers

Caring for someone with a mental illness often comes with enormous personal costs, particularly on the health of carers who experience a broad range of impacts as a result of their caring role [3,36,37]. Research has shown that mothers show the highest level of burden, “because they usually are the key carer and assume the totality of the patient care.” (p.722) [38]. Carers have significantly higher levels of depression and stress, and lower levels of subjective wellbeing, self-efficacy and physical health than those without carer responsibilities [9, 39-42]. More than one third of Australian carers experience depression, and being a carer for someone else can be a leading cause of their depression [9]. Similar impacts have been found to affect mental health carers in other countries [21,42-44]. Almost half of all mental health carers’ psychological distress is based on difficult personal issues about duty, responsibility, adequacy and guilt [12]. Carers’ wellbeing is closely linked to how services respond to individuals and families, partnership orientation, knowledge provision, support and counselling. Individual carer characteristics such as age, family status, employment, education, and language also impact on carer wellbeing [45].

Of significance, carer wellbeing has a direct impact on the recovery rate of the person being cared for [46], with greater use of hospitals and longer hospital stays for those without carer contact [47]. Caring for someone with a mental illness can be difficult because many families, “attempt to care for someone who may Caring for someone with a mental illness can be difficult because many families “attempt to care for someone who may have bouts of acute psychosis; exhibit little motivation for most activities; be self-absorbed much of the time; hardly contribute to the household; and have cognitive difficulties giving rise to forgetfulness, misunderstandings, irritability, frustration, and sometimes outright hostility” (p.1)[48].

A decade of national mental health policies and standards promoting the inclusion of carers, combined with an array of practice reforms and Carer Recognition Acts in many Australian State jurisdictions appear to have had little impact on improving the care and support experiences of carers. Within service systems, carers have reported that they often receive little or no information about their family member’s illness and that they are not typically involved in care planning or have their views about the cared for person’s needs sought by services [49,50]. This is despite almost two decades of research from which the findings have recommended greater collaboration and partnership with carers [10,51,52]. Carers in other countries have also reported feeling marginalised by services [53]. Carers’ role and expert knowledge is often ignored, rejected or seriously undervalued by services, sometimes with detrimental consequences for the person’s care, and carer and staff safety [10,50,52,54-56]. Carers report that they are best supported by routine contact and trusting relationships with service providers [57]. Realistic and targeted education and support, appropriate to what families need at particular stages, has also been found to be useful and to improve the health and wellbeing of carers and care recipients [10,58,59].

3. Problem statement

Being a mental health carer is hard work. Carers' health needs are often hidden behind the needs of the person they care for. Building the skills of the mental health, psychosocial rehabilitation and primary health care (PHC) workforce [60,61] is essential for effective support to people with mental health and co-existing physical health conditions, and their family carers. This understanding must go beyond superficial constructions of carer burden and token offers of respite, education and information. Otherwise, there is a danger that service providers will assume that they have understood and addressed carers' needs, and be dismissive of the ongoing and enduring needs that carers have as a consequence of their unique caring role. Policies and programs that understand and address effectively the day-to-day needs and experiences of carers are needed.

The current study supports and builds on the view that 'carer' is an ambivalent term that "fails to do justice to the complexity of interpersonal relationships in the context of mental health problems" (pp.475-476)[34]. Wong uses the term 'chronic stressors' to denote the complex and ongoing nature of the difficulties mental health carers face [29]. Much research on mental health carers has focused on measuring carer burden as a construct in isolation from other processes and impacts associated with the role [62]. Research has also clearly described mental health carers' grief as often prolonged and experienced over the full course of the cared for person's life [63]. Mental health carers have been 'studied' and have provided consultancy to many carer research projects. However, little research has been conducted exclusively by mental health carers, from the carer perspective.

4. Methods

A qualitative design was selected for this study due to the exploratory nature of the study and the need to provide participants with an interview method in which an interpersonal dialogue could take place around potentially highly sensitive and personal information. To achieve this, the study involved focus groups, a large survey and in-depth interviews with mental health carers in South Australia. Results were triangulated and will be discussed comprehensively in the context of how workers in mental health service and primary health care services can work effectively with mental health carers to support the person with mental illness, and help address carers' caring needs.

Ethics approval was granted by the Flinders Clinical Research Ethics Committee. The project was steered by a diverse expert reference group that included mental health carers, representatives from carer organisations and mental health services, and university nursing and social work academics. Across these members, all were mental health carers.

5. Description of the sample and recruitment

Participants were voluntarily recruited through organisational newsletters and communication provided directly by project team members at regular meetings for 12 carer organisations and groups responsible for providing service and/or support to mental health carers across metropolitan and regional South Australia. The researchers were also members of the SA Department of Health Mental Health Unit Carer Advisory Group and have, as their mandate, dedicated and expected links with the field as part of their advocacy and communication roles. Two of the researchers have links across several carer organisations and are heavily involved in training and support group facilitation groups in these organisations. Reference Group members also offered their capacity to link with carer groups. The project team also approached each known carer agency, or support group, and formally invited them to be involved in consultations. We believe that this enabled us to canvass a diverse range of carers. Sampling was therefore purposive for carers and based on convenience of access to a range of carer groups.

5.1. Data collection

In-depth semi-structured interviews were conducted in participants' homes or other confidential and convenient location nominated by participants (only one interview was conducted by phone). Interview topic areas for exploration were informed by extensive literature review prior to commencement of data collection and further established by the expert reference group. Interviews guide questions were as follows:

- Carer role (context, length of time, extent)
- Looking back, experiences of becoming a carer
- Telling their story of being a carer
- Positive aspects /difficult aspects of being a carer
- Impacts on self and others
- Maintaining personal health and wellbeing in the carer role
- Experiences of engagement with services and others as part of the carer role
- What they want workers to understand about their carer role

Interviews were voice-recorded, following consent from participants, and professionally transcribed then checked by the project manager. Extensive notes were also taken to enhance recall of the context of interactions. Carers in regional and rural areas were contacted by phone where indicated. All interviews were performed by the project manager to enhance consistency. Transcripts of interviews were returned to interviewees for checking, verification of data accuracy, and further comments, if they wished to provide them.

Three focus groups were conducted with mental health carers. These were organised to occur within existing mental health carers support groups, and three different types of groups were sought, to ensure a variety of the carer population were canvassed.

Discussions in each focus group were aided by the following question areas, with room for open discussion beyond these areas of interest:

- Positive aspects of being a carer?
- The hardest thing about being a carer?
- Effects of becoming/being a carer on you, your family, and friends?
- What do you do to keep yourself going in your carer role?
- What has been your experience of engagement with mental health and other health services, as part of your carer role?
- What are the most important things that you want workers to understand about you, as a carer?

The first focus group (n=12 carers) was conducted with a Carer Support and Respite Centre Carers Group, that is, carers who had contact with services specifically for support in their caring role. They tended to be carers who were not involved in carer advocacy, and tended to be older carers. The second focus group (n=15 carers) was conducted with an Association of Relatives and Friends of the Mentally Ill (ARAFMI) Mental Health Carers Group. This group contained some longstanding carers and several people new to their caring role, and of all ages. The third focus group (n=12 carers) was conducted with the State Department of Health, Mental Health Unit Carers Advisory Group. This group contained many longstanding carers who were also actively involved in advocacy and committee work throughout the mental health system in South Australia, and national involvement. Data from two of the three focus groups were recorded and professionally transcribed, then checked by the primary researcher. Extensive notes were taken for the third focus group.

A state-wide survey was conducted with electronic and hardcopy surveys distributed through the previously mentioned carers organisations and groups. This included advertising of the survey by the peak state information and support organisation (Carers SA), and the Private Mental Health Consumer and Carer Network Australia (PMHCCN)(open to SA carers only) which both have a regular large electronic and hardcopy mail out of their newsletter to carers. Similar to the focus group guide, the survey contained the following questions:

- What is the best thing about being a carer for someone with mental health and physical health conditions?
- What is the hardest thing about being a care?
- What worries you the most in your role as a carer?
- What effect has being a carer had on you personally?
- What effect has being a carer had on your family and others close to you?

- What are the most important things that you want service providers to understand about your needs and your role?
- Any other comments?

Focus groups and interviews occurred across the same time period and data from each were used to test and generate further question areas for exploration across the interactions with participants. All focus groups and interviews were conducted by the lead author, to ensure consistency. There was no crossover of participation by carers in each method of data collection.

5.2. Data analysis

A thematic analysis of focus group and interview data was undertaken using components of grounded theory [64] within a framework analytic approach [65]. During the first stage of data analysis, the first two authors reviewed the transcripts several times then performed manual open coding, independent of each other. The authors then met to discuss, debate and compare codes as part of inter-rater reliability testing [66] and constructed a detailed codebook/framework to capture key issues and concepts before proceeding with further analysis. Themes were generated as part of constant comparison of the data, using regular meetings between the researchers to discuss the meaning of emerging ideas as interviews proceeded and for accuracy and agreement on codes/categories. The next stage of analysis involved grouping data into broader, conceptual themes based on recurrent patterns occurring across codes. Presentation to and discussion of themes within the expert reference group served as additional verification of face validity for the analysis. An independent expert qualitative researcher checked the themes and subthemes for consistency and logic of presentation prior to them being finalised. Survey data were kept within each clearly structured survey question and a thematic content analysis [67] was performed, with subthemes determined by the researchers, as per the description of methods provided above. In this way, each dataset informed and strengthened the themes found across all methods of data collection (interviews, focus groups, survey).

6. Results

6.1. Demographic details

Sixteen carers were interviewed, including three husband/wife couples caring for adult children. These interview data were treated separately, recognizing that each parent may experience their carer role differently [36]. Carers' experience ranged from seven to more than 50 years. All were caring for someone with serious mental illness that required support from specialist mental health services. Four carers were caring for more than one adult child and one carer had continued to care for her foster son but had also cared for her own son prior to his suicide. Seven carers were sole carers, whilst nine carers had support from their spouses. Carers ranged in age from 20-30 to 80-90 years (median 60-70 years, or at a life-stage when retirement would otherwise be their priority and also when personal physical health prob-

lems are likely to emerge if not already present). Of concern, eight carers reported having a diagnosed mental illness and five a diagnosed heart condition. Only two carers did not report having a physical or mental health condition. For many carers, the person lived with them, or very nearby. Fourteen participants were active members of carer support groups or advocacy groups, often in leadership roles with several years of experience at local, state or national level. Several participants were also carer consultants on local, state or national, mental health sector committees and working parties.

Demographic information for focus group participants was not collected. The number of focus group participants has been reported above. A total of 79 survey responses were received. Demographic information for survey respondents was not collected. However, from an audit of the survey responses, the researchers determined that:

- 56 respondents were carers for adult children (Eight were caring for more than one adult child)
- 16 respondents were carers for their spouse (10 were women caring for their male partner. Six were men caring for their female partner.)
- 6 respondents were caring for their sibling (Four were a sister caring for a brother. Two were a sister caring for a sister.)

As we have no way of knowing the total number of mental health carers within the database for Carers SA and South Australian carers within the PMHCCN database, or whether all blank hardcopy survey forms were distributed, we cannot determine a meaningful response rate. However, we have estimated that the total of 124 mental health carers who participated represent less than 5% of the state's mental health carer population. This statistic is not known, either at state or national level, which is a finding in and of itself (personal communication, Carers Australia).

The combined interview/focus group thematic analysis is provided first; then a summary of the survey results follows. Pseudonyms are used to de-identify all participants and direct quotes are used to exemplify themes.

7. Focus group and interview themes

Participants' comments fell into 9 main themes, many that mirror themes found in the existing research literature, such as the day-to-day experience, burden, grief and loss, obligation, problems with communication of needs with services, personal growth, strained relationships with others, and impacts on their own health and wellbeing [37,40,41,62,63,69,70]. These themes were:

The Experience of Being a Carer

Living with Mental Illness

Cycles of Grief, Trauma, Fear and Vigilance

Communication with Services

The Carer/Mental Health Professional Experiential Divide

Consequences and Trust

The Impact on Relationships

The Impact on Health

How Carers Cope

7.1. The experience of being a carer – ‘The burden never ends’

All participants described the impact of being carers on their day-to-day lives, describing a range of burdens that were perceived to be never-ending and which changed many parts of their lives. This often included their capacity to take holidays, maintain careers, maintain friendships and relationships with others, attend to their own health and live a quality life for themselves. Overarching these impacts was the intensity and constancy of the caring role.

(Charlotte and Stanley) We keep going because we have to, there is no option. Who else is going to love her and look after her? There is no realistic option. Until there is a lot better service. Until we die, we're it... We didn't ask for this, we didn't want it, but we're parents, we have no option. We love her so that's it.

(Joan) I'm constantly on alert. I can't go out freely because my husband is suspicious...My son recently called the crisis team without me knowing. My husband blamed me when they arrived at the door unannounced...I had to stay with a relative for two weeks after that because he wouldn't let me back in the house.

Within this constancy, participants also described their role as like ‘shifting sand’, with them constantly stepping in and out of the caring role as the person's mental health status also shifted constantly, often on a day-by-day basis dependent on what stresses were present in the person's life at the time. This challenged understood assumptions that workers held, and information carers had been provided about mental illness being episodic. Carers spent each day never completely free of thinking and worrying about the person.

7.2. Living with mental illness – ‘Do they think the fairies do all these things?’

All participants believed that service providers had a limited view of what the experience was actually like for the person living with mental illness and their carers. Many carers thought that this was one of the reasons why their views were often dismissed or excluded from decisions about care made by service providers. They compared their life-long knowledge of the person with health professionals who come and go and only see fragments. They also spoke of the over-reliance of service providers on medications to ‘fix everything’.

(Gladys talking of the mental health services plans to allow the person to manage their own finances) That's okay as long as they put a plan in place to help him learn how to manage it. But they didn't, they just gave him the money. They just dropped him in it. Do they think the fairies are going to show him how to do it? No they won't. And that's a gap. Like who do they think does these things, and it's usually some carer in the background quietly doing stuff isn't it?

(Elizabeth) If I never went along to any of the appointments with my son, and if they (service providers) went completely on what [son] was telling them... he would never have gotten better and the worker would never have even understood what was going on. We wouldn't have got a service in the first place, despite him being completely psychotic...there's a whole layer that they just don't even see...if they really knew, they would have detained him a 100 times over according to their limited criteria.

7.3. Cycles of grief, trauma, fear and vigilance – 'It just becomes par for the course'

All participants recounted their experience of being a carer as involving some level of grief for the lost potential they saw in their loved one, and trauma which, for several, was ongoing as part of their everyday experience. This has a range of implications for how carers are supported when their relative first becomes unwell, but also for the ongoing health and wellbeing of carers. The level of this trauma was something that these carers felt others didn't and couldn't fully understand. It made their day-to-day experience often feel surreal and their connection with others sometimes distant. Several carers had become accustomed to a level of trauma which they usually concealed from others, as part of their coping within what many said felt like living in two worlds. On the one hand, they maintained their daily routines of family life, social relationships, community relationships or work and other roles as if all was well, so that others who came into contact with these carers perceived this to be so. This often masked significant, regular, distressing events and interactions with the cared for person that required the carer to continually switch back and forth in their vigilance around the person.

(Gladys of her eldest son who suicided 30 years earlier) I just came home from work one day and found him hanging in the backyard, which was pretty ghastly, but if it was his choice, that's his... (Pause, looking into the distance) So that's the way it is.

(Susan) People can say 'Just phone the police or mental health services' but it's the consequences there and then. My husband is twice my size and strong and at 12 o'clock at night when he's saying he wants to shoot all the neighbours and the crisis team is one person on a phone on the other side of the city the consequences are a bit more real...I bear the consequences... [the mental health crisis service] just don't get it...what that actually means, whether you like it or not picking up the pieces, is that the consequences for you can be diabolical and for me - I've got a small child who he was making constant threats to, that he was going to take away with him, and they will be found dead somewhere? The phone crisis worker said to call the police. They came in the middle of the night and took him to ED. I got a call an hour later that he was on his way home. They hadn't detained him despite what had occurred, his history and his recent admission to hospital. They just put it down to alcohol. Even the police were alarmed by this. We were so frightened.

(Clare) When our sons were feeling suicidal, at the time you almost become hardened to it all. The trauma of just the barrage of it just becomes par for the course...and then later on you can crack up afterwards but you have to be strong at the time.

7.4. Communication with services– ‘They didn’t even ask’

All participants reported that they felt service providers’ communication and interaction with them needed improvement. This ranged from service providers just not understanding the extent of carers’ input with the person and the nature of their experiences, ignoring and not listening, to actively excluding carers in decisions and dialogue about the person’s care and treatment. For many carers, communication was largely one way.

(Sandra) You’re a source of information and once they’ve got the information they don’t need you to do anything and they don’t need you anymore...You end up being the navigator all the time when the person needs help, and then you’re ignored.

These carers strongly believed that they had a unique understanding of the person cared for and therefore much to contribute to what support was needed and how it was developed and delivered. They felt like members of a team of support around the person, but invisible players in that team, in which their input was not realised fully by formal service providers. These carers found this situation frustrating and senseless, given their long-standing relationship with the person, knowledge of them as a ‘whole’ person and ability to often pick up signs of illness early because they knew the person best.

(Judith) It’s the people that know him – you’ve known him all his life. You can tell, and it’s not necessarily anything that they say, it’s just a way that they look or a gesture; you just feel it. It’s hard explaining that to other people, particularly workers...(Upon trying to alert the worker) His Case Worker said, ‘Oh well, he seems alright when he presents to me’. And we really felt quite deeply that she hadn’t respected our observations.

7.5. The carer/mental health professional experiential divide

All participants believed that service providers had a limited view of what the experience was actually like for the person living with mental illness and their carers. Many carers thought this was why their views were often dismissed or excluded from decisions about care made by service providers. They compared their life-long knowledge of the person with health professionals who come and go and only see fragments. They also spoke of the over-reliance of service providers on medications to ‘fix everything’. Unfortunately, all participants reported similar situations where they simply were not listened to and this added to the experience of distress for all concerned, especially the person and their carer. This seemed to be linked to the service providers not understanding or having empathy for the experience of carers, of being removed from the impact of their actions or inactions.

(Ruth) It wasn't until the point of crisis that they took notice of us. And then that was traumatic for us because we had to get the people to come and see him [because he refused to go to them by that point]...and it finally reached a point one night when we could hear him treading up and down...I was shivering in my bed and I said, 'I can't stand it'. The next day I rang them and I said, 'Please come', I really begged, I said, 'Please come and get him'.

(Charlotte and Stanley) They kept on telling us that it was all behaviour... 'She is bipolar but really she's just a bad, bad girl; she's nowhere near as ill as you think', until five years ago, she proved to them exactly how ill she was when she burnt down her unit.

7.6. Consequences and trust – 'You just don't want to go there'

Participants recounted a number of consequences for them as part of the day-to-day management of risk, especially when the person they cared for was unwell or suicidal. They said this impacted all parts of their lives, usually requiring a number of personal systems in place for emergencies. They felt a clear sense that they were shouldering much of the load and that services could be contributing more. Though several participants reported receiving good support when services worked with them as a team, they also reported some challenges to this process, involving the journey of mental illness itself. The following lengthy examples demonstrate some of the inherent dilemmas in caring for a person with mental illness and consequences for mental health carers:

(Susan) The nature of mental illness is often that the person doesn't recognise when they need help and, when they're highly distressed, and agitated, it's the very last thing they are actually going to do, often. So it needs someone, and it's often the carer, who says "Enough. We have to do something here". And it's a very tricky dilemma to involve police or ambulance or mental health services because you know that is going to be difficult for the person; and you, as the carer, are going to have to face the consequences for that because you often get blamed for things you've not done at all, because the person's either delusional or paranoid, and it's just very emotional. And you spend so much emotional energy giving, so that when the person throws it back at you, it's very difficult...The carer faces the brunt of that [service involvement...I think a lot of carers are put in these sorts of situations that are not always realised by workers...and you almost don't ask for the help when it's needed because you just don't want to go there because it opens up a whole other can of worms that you never intended.

(Jenny) Services often see it as carers just being over-involved, emotional or anxious, but it involves trust also, because there are always consequences for me and the children in engaging with services. With caring for my mum, I always felt isolated from the treatment and involvement with services and like we were just being acted upon rather than in partnership all working together and them utilizing our lived experience and expertise. Because there was no trust in our first five months with the system, it was a fearful system. I didn't want to put my mum through that. She wasn't the same. My experience of that system [mother in hospital] was that my mum just sat on the floor or on the bed the whole time rocking back and forward. I literally had to rip her out of there, then us isolating ourselves as a family. At

least she stopped rocking back and forward and found some joy with the children; (pause) but we were all alone. It was a very lonely journey.

7.7. The impact on relationships – ‘It certainly made us appreciate who our real friends were’

Participants discussed the impact of caring on their relationships with each other, other family and friends and how they mediated the caring role within their relationships with others. Some carers said that becoming carers for a person with mental illness had brought them closer together, though not without this being a learning process. For others, there were different challenges.

(Yvonne) We had many times when we’ve thought about splitting up...We didn’t agree on everything and that has been the biggest problem.

(Stanley) It certainly made us appreciate who our real friends were because several of them walked away. They were sympathetic but didn’t really want to think about mental illness at all. And our other children, although we didn’t realise it at the time, but they told us later that we were kind of putting a lot of pressure on them by not giving them a fair share of our time and by kind of putting expectations on them to be the ‘normal’ ones...I don’t think we knew we were doing it except by saying, like, ‘Thank God you’re okay.’

7.8. The impact on health – ‘I’m not allowed to get sick’

All except two of the interview participants reported problems with their physical or mental health as a direct result of their caring role, and its impacts. Of the eight carers who reported having a diagnosed mental health conditions, seven had depression. Five carers reported a diagnosed heart condition; four of these were men. Some carers were now actively looking after their health, whilst others were not. All participants experienced ongoing burden. One carer’s description demonstrates the complexity of self-care for carers:

(Sandra) The frustrating thing for me is I’m not allowed to get sick. I’m not allowed to get emotional. I’m not allowed to say how I’m feeling because, although he says that I should do that, when I do that, it actually makes his symptoms worse and it’s like he just takes it internally and it becomes this whole other thing which I never intended, and he never expected. It’s like they can’t give you their empathy, it’s like a type of selfishness...So I just don’t bother to say anything. It’s just easier that way.

7.9. How carers cope – Advocacy, support and ‘just getting on with it’

Participants described a range of strategies they use to deal with the impacts of their caring role. This included their views on respite support, carer support groups, support from family and friends, and developing clear limits and boundaries with the person they care for.

Several participants were members of support groups with long experience of being carers, and several had become assertive advocates. They also emphasised the need for carers to look after themselves and seek out support.

(Charlotte) I fall in the deepest of holes and I just want to go to bed and pull the covers over, and that's when Stanley takes over. I just say, 'I can't do this'...And then, as I get better, Stanley might fall into a hole and that's when I would take over... I think we've always talked...There have been times that we've disagreed...but most times it works positively and we counter-balance each other.

(Stanley on service providers and respite support) They think that all we need is respite and therefore...We get away and we'll be right. And it doesn't - it isn't. We've done that - we never did it because we thought it would help, we did it - to shut them up basically...What we've learned is you've got to believe in those feelings that you have. When you feel that something isn't right, then it isn't right. Believe in yourself and then develop the confidence to do something about it.

(John) I really can't do anything much for my sons to be really honest. I can't fix them or anything. All I can do is to stand around and support them a bit. As a result, I drifted and drove myself into advocacy.

(Sandra) Sometimes you get annoyed and sometimes you just resign to it and then other times you just want to wake up and it's not there...And then you sit yourself down and just sort of resign to it and on you go.

Several participants spoke of the importance of adequate accommodation and community support for the person they cared for. One carer, who recounted a period of nine months when health services worked well with each other, the person, and with them as carers, summed it up this way:

(Stanley) We've always said - fix the system so our daughter is taken care of and you'll take care of us.

8. Results – Survey

Each survey question areas is listed, with themes from within each domain described in order (most to least) of the number of respondents whose comments spoke to that theme. However, this does not mean that the more commonly described ideas are necessarily more important to carers than less commonly described ideas. Many comments made across the survey questions were, at times, overwhelmingly powerful and quantifying them is arguably inappropriate. Respondents could provide more than one response to each question.

8.1. The best thing about being a carer

Good Outcomes

Thirty of the 79 participants spoke of good outcomes for the cared for person's health as the best thing about being a carer. This reflected their primary focus and concern for the well-being of the person cared for. Good outcomes included the person accepting their mental illness and the need for medication, and keeping a positive attitude, the carer recognising small achievements made by the person, being grateful and enjoying the times when things were going well, carers being pro-active rather than reactive, and effectively providing a safe environment for their loved one.

- Knowing that the person you care about is respected, loved and treated well.
- Seeing them achieve goals no matter how small.
- I have learnt to be really thankful for the times when things are going well. This morning, he's happy. I can tuck that away as a memory for when times may not go so well.

Sharing the experience through connection with others

Fourteen carers stated that sharing their experience with other carers and having a connection with others with similar experiences provided friendship, support and knowledge that they would not have otherwise had. Support groups also provided hope, real empathy and understanding, alleviating their sense of isolation and stigma. For some, support groups gave them a new purpose, role and courage to stand up.

- Finding a support network where friendships and information help to carry the load.
- Knowing I'm not alone; there is a carer support group.
- I have been inspired to become more involved in advocating for those more vulnerable in our community. I have met some extremely brave and inspiring people.

Having Purpose

Ten carers talked about the positive sense of purpose that the caring role provided to them. This included the gratitude received from the person cared for, the sense of making a worthwhile contribution to the person's wellness, keeping the person as safe as possible, and the knowledge that they are cared for.

- To know that you are doing something and helping someone you love.
- It's a good feeling to know they know you'll always be there for them.

Nothing

However, 10 carers' responses reflected the overwhelming sense of burden, grief, struggle and negative impact that the arrival of mental illness can have for some families. These carers were quite clear that there was no best thing about being a carer, despite the immense love and commitment that they expressed for their loved one.

- There's absolutely nothing.
- As I'm caring for my husband who has developed mental illness since I married him, I fail to see that there is a best thing about being a carer.

Love

In contrast, 8 carers' responses showed the immense love they held for the person and the importance of being able to show this. The intensity of these feelings was a mirror image of the adversity and trauma they also described in their responses to other questions.

- I think I can show her that I care about her unconditionally and will be there for her.
- The bond we share. He knows my love for him.
- The journey we have shared has involved some of the worst times of my life. Yet, my love for him is beyond measure because I'm so proud of his courage in spite of this.

Learning

The comments of eight carers reflected their capacity to be resilient and to grow from the experience. They described the best thing for them as finding the resources to educate themselves about mental illnesses, and becoming more accepting and open minded generally, that is, becoming better people for the experience.

- I have educated myself in areas that my friends would not even consider.
- It stretches you to find resources in yourself previously undeveloped.
- It helps me to be more aware of others with disabilities and more accepting. I have learned to be more open minded of others' behaviour.

8.2. The hardest thing about being a carer

Grief in the face of changed lives

Twenty-six of the 79 respondents described the grief and anguish experienced, by now having a family member with mental illness, as the hardest thing about being a carer. This involved seeing their loved one's suffering or having experienced trauma (sometimes whilst in systems of care), coming to terms with the illness and its impact on all of their lives. Some described this as watching a self-destruction process, seeing their loved one living such an isolated lifestyle, experiencing a 'roller coaster' of emotions, and grieving about the person's lost potential for what could have been.

- Seeing my two sons living a very isolated lifestyle, without friends, partners, employment or meaningful activities.
- To watch the suffering of a serious victim of a mental health illness. As family and friends cannot understand the changes in the person that occur as the disease progresses and the anguish they witness. Five or six serious attempts on her own life and time spent at hospital emergency waiting as staff fight to save the life.

Vigilance and never able to relax

Eighteen carers described constant stress, alertness and vigilance that they experience in relation to the person with mental illness as the hardest thing for them about being a carer.

- The stress never leaves me, though it does lessen when she is in a good period, and I dread the phone ringing.
- Not knowing how each day/hour/minute will pan out and trying to steel yourself for whatever happens...Waiting for the next crisis to occur.

Fear

Further to their feelings of vigilance, 14 carers described a fear of not knowing if what they are doing is beneficial for the person, fear for the future when they are dead or cannot care anymore, feeling helpless and hopeless at times, fears about their own capacity to find and maintain employment with the unpredictability of the caring role, fears for their financial security, and fears for the safety of the person and themselves when the person is unwell.

- The guilt I feel when I don't cope and contribute to their misery instead of helping them and the feeling of helplessness.
- Being faced with a son in a very psychotic state, and not knowing what to do about it.

Consequences of system failures / 'The carer is always responsible'

Sixteen carers described the system's failure to provide adequate support to the person as one of the hardest things they have to deal with, explaining it as a major contributor to their enforced vigilance and fears. These system failures included inadequacy of support, difficulties caused by privacy and confidentiality rules, and indifference and neglect of care shown in some situations by service providers. Carers said that they were routinely left to pick up the pieces, frustrated and angry with service providers.

- Having all the responsibility of everything, and that often you personally are seen as the baddie (the one who is pushy).
- There is an apparent indifference displayed to a great degree by 'the system' and the result that carers are left to battle on largely unaided in any meaningful way.

Being heard, understood and included

Twelve carers described their experience of trying to navigate within and express their needs to mental health service providers as the hardest thing about being a carer. This included trying to convince services when the person needed help, a general lack of understanding of carers' perspectives by service providers and, being dismissed, ignored and labelled by services.

- Trying to find a doctor and psychiatrist who are understanding and show empathy and talk to me as a parent.
- Being told by service providers that my 'expectations are too high' regarding their services and supports for my two sons.

Isolation

Eight carers rated their isolation in the caring role as the hardest issue to deal with. This involved physical isolation from supportive others, as relatives and friends distance themselves once the carer became subsumed in their caring role, but also emotional isolation from others as a result of their carer experience.

- The hardest is feeling sometimes that you're the only one, especially when other family members cannot come to terms with the mental illness of the person in question. I feel that they know I will always be the carer, and will leave it all up to me.
- We have no friends any more.

8.3. What worries carers the most in their carer role

Several respondents reiterated issues they found most difficult about their caring role, including never being able to relax. Six respondents mentioned worry about finances, and a further six described worry for the quality of life and future of the person cared for, especially as they observed increasing, insidious physical health problems emerge for the person over time. Fourteen carers expressed their greatest worry being their lack of knowledge of how to best help the person; whether they were doing the right thing. Four carers expressed their main worry as concern for their own physical safety, in particular, their powerlessness in the face of the person's paranoia where the carer was routinely threatened, blamed and accused by the person. Overwhelmingly, respondents detailed a range of worries that reflected and demonstrated their deep concern for the person's welfare, for the future and for the welfare of others as a consequence of mental illness being present in their lives:

Concern for the person's future when the carer is not there

Thirty-two, or almost half of respondents, cited their main worry as care for the person when the carer was no longer able to provide care.

- I worry about what will happen to my daughter if I die and there's no-one there for her.
- What will happen to my son when I am no longer able to protect him?

Suicide

Eight carers rated fear of the person suiciding as their greatest worry. For some, this was linked to observing the person's poor physical health and quality of life, and grief for what they perceived as the natural order of theirs and their loved one's future.

- Suicide risks with two sons who suffer from depression and anxiety illnesses and have deteriorating physical health. I believe that it is likely that my sons will die before I do.
- Our family member with a mental illness does not live at home, so I worry about suicide, as this has been attempted numerous times in the past.

Fears/Consequences for others

Fourteen carers expressed their main worry being for others as a consequence of the person's mental illness. This ranged from concern for others who were missing out on the carer's attention and time due to the focus on the person's needs, to worry about family members developing mental illness due to their genetic relationship and shared environment with the mentally ill person. Some carers expressed the tension of being stuck in the middle as the primary supporter of the person, and protector, or shield, for other family members.

- I am frightened she will have a manic session and kill some innocent person whilst driving her car.
- Being made aware of and constantly worrying whether it might happen to other members of the family, especially the children. Every now and then I see the signs and it horrifies me. I'm torn between my commitment to the person and trying to make my children's life as normal as possible, which is pretty difficult with a paranoid person in the house.

8.4. Effects of caring on carers personally

Being a carer for a person with a mental illness had many significant potential negative effects on carers but also many significant positive effects for them. For respondents, the effects were often a double-edged sword, and present together for the carer as part of their resignation to the role, and the reality of their circumstances.

Physical health

Twelve carers cited experiencing physical health problems and perceived these as a direct consequence of their carer role. Blood pressure and heart conditions were particularly cited and were linked by carers to the level of worry and vigilance inherent in their carer role.

Mental health

Thirty carers described the negative effects of caring on their own emotional wellbeing and mental health. They described feelings of sadness, grief and loss, difficulty in relaxing, having diagnosed depression and anxiety as a direct result of the accumulative effects of caring, and loss of self-esteem and confidence as a result of isolation within the role. They described doubts about their effectiveness, severe stress, feelings of being emotionally drained, angry and frustrated, feeling powerless, and feeling much of their life was out of their control.

- I feel terribly sad because I have lost my son.
- I suffer with chronic glaucoma, but this discomfort is minimal compared with the sadness and heart break suffered at seeing a grown man who will never reach any satisfaction with his life. This leaves me in a state of endless despair.

Loss of own quality of life

Accumulated pressures inherent in the day-to-day experience of carers had clear negative impacts on their quality of life. Twenty-two carers described this as their inability to look

too far ahead, the limits now placed on their social life and leisure time, the inability to travel, and their disconnection from friends and other family due to the burden of caring.

- I've lost my network/social life. I have lost my husband now I live with a stranger. I've gone from being cared for to being a carer. I lost my self-esteem, I feel trapped – frustrated with the system and lonely.
- I'm practically in retirement and my life plans are destroyed.

Loss of career/Financial impacts

Ten carers stated that their caring role had finished their career, whilst others continued to juggle having time off, shifting to part-time work, or to less stressful work. This led to deteriorating financial circumstances and, for some, this meant actual hardship when the cared for person's life was in turmoil due to manic spending or debt.

Finding new purpose

Some carers had effectively turned their frustrations with their role and the systems of care into advocacy for broader mental health reform, and a thirst for more knowledge. Twelve carers clearly articulated the personal growth they experienced because of their caring role.

- It has given me reason to communicate a lot more with others in a similar situation, to learn and be more aware.
- It has totally changed my life; different job, different outlook on life, different attitudes.

8.5. Effects on family and others close to the carer

In response to this question, respondents demonstrated the dichotomy of experiences that are likely present for carers. Some families appeared to pull together, as a consequence of mental illness entering their lives, while other families were torn apart.

Greater cohesion

Twenty-four carers described the experience of caring as bringing them and their family closer together, strengthening relationships between partners, unifying the family around the person, and enabling them to have more meaningful relationships generally.

- More love is shown to my daughter by her beautiful friends and a few of her relations.
- It brought me and my wife closer; supporting each other...We have an exceptional close group of friends who understand.
- Our daughter's illness has united the family.

Greater tension

Equally, 24 carers described the experience as creating unwanted tension within their families and friendship networks, with some withdrawing to cope, and carers isolating themselves from others as a result of their priorities shifting, as the burden of caring is taken up by some and left by others, as differences in understanding emerge, and as family members

blame each other and take different paths in their attempts to cope, grieve and variously move on.

- The rest of the family stays away and doesn't even ask how he is. They don't want to know or understand...We're all still grieving.
- They (other family) distance themselves or feel sorry for me. They've no constructive help or support. They try to give advice but don't know anything about the illness, which causes conflict; they judge how I handle things and blame me when things go wrong.
- It demonstrates clearly those who care as opposed to some family members, who see their role as not wanting to know.

Exclusion/Fragmentation of family

Sixteen carers described, in more specific detail, a range of negative impacts that the caring role had on them personally. This was often couched in concern for their relationships with, and concern for, the impacts on other family members, especially children.

- Our other daughter has been affected by thinking she always had to behave well and make up for her sister. She does not have a good relationship with her sister and feels she never really had a sister.
- My immediate family can't cope with being sworn at, so I am the only one at present that my son will relate to and then only on his conditions.
- The other siblings have felt neglected at times and have some resentment.

8.6. Important things for mental health services to understand about carers' needs

Carers had many, often forthright, concerns that they wanted to express to mental health services. These ranged from the need for more understanding of the realities of the caring role, to more inclusion and say in the treatment and care plans for the person cared for, to be listened to and have their views respected more, and to have better services for the person and for carers.

More inclusion, acknowledgement, recognition and listening to carers

Fifty-six of the 79 survey respondents said that they wanted to be acknowledged more for their input and expertise related to the person's needs. They perceived themselves as an untapped resource that was often neglected by services, sometimes with adverse consequences for the person and the carer. They particularly stressed their role in early intervention support for the person and were keen to work collaboratively with service providers. They also saw themselves as a reliable source of information about what was really going on day-to-day for the person, especially when the person's own account or perceptions did not always reflect the facts, according to carers.

- That professionals need to trust what carers say, that we know the person, that this behaviour is out of character, or that the problem is not drug related, but a mental health issue. We need to be listened to. We need to be included. We need to be taken seriously.

We need to be informed; we need to be included in decisions because, as carers, we can help early in the 'flare ups' of the illness.

- I spend all day with him and I know when something is not right.

Better support

Twenty-six carers spoke of the need for more and better support for the person they cared for. Of these, only 4 carers put this directly in the context of their own needs as carers. Most respondents couched their responses as part of the need to improve the person's wellbeing, and that this would directly or indirectly improve their own wellbeing.

- It takes a great deal of effort to get someone to agree to get help, and then the help is not available. I know if my son could have seen someone sooner, he would not have got to such a bad state.

More information and education for carers

Only eight carers made comments about a range of needs related to more information and education for carers. This ranged from where to find support, how to build resilience for themselves and the person they cared for, understanding signs and symptoms of particular mental illness, understanding medications, how to communicate with the person (especially someone with psychosis), and how to communicate with service providers.

Policy-related issues

Only eight carers made mention of broader mental health issues and their policy implications. These issues ranged from moves to address stigma, medication availability, formal carer recognition, accommodation, support funding, and carer payments.

9. Discussion

Being a carer for a person with mental illness can be highly challenging, with many impacts on carers. For participants of this study, impacts were both positive and negative, as others have also found. Several studies have reported recurring themes involving overwhelming feelings of burden on carers' daily lives [7,37,62,70,71]. Looking at the body of comments made here, the selflessness of carers is very apparent. They made little reference to their own physical health and wellbeing, seeming to focus most of their attention and energy on the person cared for. This has implications for neglect of their own needs [39]. Our participants described the caring role as physically and emotionally draining, with many experiencing depression and related physical illness. The strain of caring often caused friction in relationships within the family and loss of friends. Some family units became stronger and shared the support when needed. The high prevalence of chronic illness and risk factors among carers is clearly echoed for this small sample of mental health carers. The prevalence of heart disease, particularly among male participants, warrants further investigation. The incidence of heart disease in female care givers has been studied [72].

These results show that the actual experience and impact of a loved one developing a mental illness cannot be overstated. They mirror many of the fears, dilemmas and concerns highlighted in other international studies [21,35,69,74]. Likewise, other studies have spoken at length about the personal impact on carers in managing day-to-day care of the person and enduring the caring process [14,32-34,37,41]. Of note in our study, these carers were not new to the role, yet they continued to experience significant burden, distress and trauma, suggesting that more needs to be understood about the constantly shifting nature of mental illness and its impact on carers [3,35-37]. These carers also knew a great deal about mental illness. Many were advocates within the system, yet this didn't necessarily shield them from the reality of the experience. The unique nature of mental illness also meant that standard respite support was perceived as virtually useless.

The findings emphasise that, like health service providers, what carers want is improved wellness of the person they care for, and therefore the two groups should be able to work cohesively together for everyone's betterment. Yet, they also confirm that carers often feel excluded and their input not realised, or worse, ignored. Other studies have similarly concluded that carers frequently feel undervalued and marginalized and that the impact of the person's mental illness on the carers themselves has been largely ignored and invisible [10,46,52-57,71,75]. One Belgian study reported that more than one third of carers felt excluded from decision-making by service providers. Coincidentally, this study also found that many carers felt they were best supported by routine contact and trusting relationships with service providers [57]. Trust and understanding were highly valued by our participants.

Another striking feature of the results is what was not mentioned or only mentioned by a small number of participants. One example is the lack of reported need for more information and education. This suggests that there is a significant mismatch between what service providers think carers need and what carers say they need, given that much of the existing focus on support appears to be on 'educating' carers [59]. A large Netherlands study of 19 community-based psycho-educational groups investigating objective and subjective burden concluded that psycho-education, "should concentrate on helping relatives cope with the strain on the relationship with the patient and on improving their ability to cope with the patient's behaviour" (p.375)[76]. Fortune [77] found that coping through seeking emotional support, faith, acceptance and positive reframing of the carer's and the person's situation were associated with less distress, whereas self-blame led to greater levels of distress. Yet, the effectiveness of support groups for mental health carers have shown mixed results [78].

What our study shows is that providing education about mental illness to carers is but one part of providing effective support to them. It has also shown the challenges that mental health carers face regardless of the level and type of support, information and education that they are offered. The findings suggest these challenges go to the very heart of the nature of mental illness itself, with some issues being potentially unresolvable within this unique role. Our study demonstrates that caring for a person with mental illness is a complex role that requires a multifaceted understanding of carer stress and the centrality of the caring role.

10. Limitations

The findings of this study are limited to experiences of mental health carers within the Australian context. They suggest that further trans-national research and research exploring gender and relationship differences (child, spouse, parent) in carer experiences would be useful. The purposive sample and its size also pose limits on the generalizability of the findings. As suggested by Hsiao and Van Riper [79], more research is needed to explain why some carers adapt successfully to the carer role, whereas others do not.

11. Conclusions

This study highlights the mental health carer role as never ending and unrelenting, with many impacts on carers. Like Wong, who uses the term 'chronic stressors' to denote the complex and ongoing nature of the difficulties mental health carers face [29], our study confirms this chronicity within the caring role, what we call a 'living grief'. Carers stress that the nature of the illness is so unpredictable at times that there is no room for complacency, especially as they watch the person they care for develop physical illnesses and then the carer then finds themselves caring for someone with a multitude of ailments.

Successful negotiation of the mental health system, early intervention and partnership with service providers have become the key strategic directions for mental health services in Australia, and internationally. Coping, management of the illness, knowledge about illnesses and treatments available are the key mechanisms by which families and people with mental illness can be empowered to navigate the mental health system, to best enhance their well-being. Evidence indicates that providing education, support and a family/carer inclusive approach to treatment improves carer wellbeing, has a direct positive impact on the recovery of the care recipient [46,59]. Pivotal to these processes and to the delivery of meaningful support is for service providers to have a clearer understanding of what it is really like to be a mental health carer.

Many of the issues impacting on carers reflect larger problems in providing adequate care to people with mental illness [80,81]. Carers experience significant pressures in their caring role, largely due to their unmet needs for support, information and understanding from health service providers. The experiences of carers are not fully understood and this serves to alienate them from the very supports they need. Moreover, translating an understanding of carers' personal experience of caring into tangible, respectful and meaningful dialogue with service providers, as part of a shared approach to providing support to the person with mental illness, is vital for all concerned.

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