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FEATURE ARTICLE

Family carers' experience of caring for an older parent with severe and persistent mental illness

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ABSTRACT: While the burden of caring for older people with chronic medical illness and dementia has been well documented, considerably less is known about how carers develop the strength and resilience to sustain this important role with older family members with mental illness. The aim of the study was to understand the lived experience of primary caregivers of older people with severe and persistent mental illness, and to explore what, if anything, helps to sustain them in their caring role. An interpretative phenomenological analysis approach was adopted, and qualitative interviews were used with 30 primary caregivers. Two overarching themes, and related subthemes, were abstracted from the data. First, caring is a difficult and demanding responsibility. It affects carers adversely, emotionally, physically, socially, and financially, and their lifestyle in general. This is reflected in three subthemes: (i) physically and emotionally draining; (ii) grieving about the loss; (iii) and adverse effects on lifestyle and social relationships. Second, carers develop resilience in caring, which helps sustain them in their role, as illustrated in three subthemes: (i) caring as purposeful and satisfying; (ii) harnessing social support from others; and (iii) purposefully maintaining their own well-being. Community mental health nurses have a key role in assessing carers' needs and supporting them in their caring role.

KEY WORDS: experience of caring, mental illness, primary carer, qualitative research, resilience.

INTRODUCTION

As the proportion of people over 65 years of age, and the cost of health-care, continues to increase, government health policies are shifting increasingly towards care in the home (Kelly & Sharp 2013). As a consequence, an increasing number of older people are being cared for by spouses or their adult offspring. To illustrate, in Australia, approximately 80% of care and support for older people with

age-related illness is provided by informal carers such as spouses, family, and friends (Productivity Commission 2011). However, changing social and demographic trends, attributable to lower marriage rates, smaller family sizes, and increasing age of first-time mothers, mean there will be fewer informal carers relative to the number of older people in the population (Productivity Commission 2011).

Caring can come at a personal cost to many carers' well-being. Primary carers of older people can experience untoward effects on their own physical, emotional, and social well-being (Balducci *et al.* 2008; Kenny *et al.* 2012; Szmukler *et al.* 2003), with approximately one in five carers of people with mental health problems reporting that caring had a moderate to significant adverse effect on their general well-being (Pinfold & Corry 2003). Not only is the carer's health affected adversely, the whole family's physical and emotional well-being is affected as well (Kenny *et al.* 2012). In some cases, the burden of care placed on primary carers, in particular, can have

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significant undesirable effects on their ability to manage their own lives, manifesting as psychological distress, including grief, anger, depression, and anxiety (Bailey & Grenyer 2013; Ulstein *et al.* 2008; Zauszniewski & Bekhet 2014). As many spouses care for their partners with mental illness, relational dynamics are also shifted, reducing the quality of life for those in the caring role (Angermeyer *et al.* 2006; Peraica *et al.* 2014). In Australia, for instance, over a third of primary carers have a disability themselves in comparison with approximately one-sixth of non-carers residing in the same household (Australian Bureau of Statistics 2012). This is particularly salient for older carers, as their own declining health presents challenges for the continuation of their caring role (Byrne *et al.* 2011). Carers also frequently feel isolated (McGarry & Arthur 2001) and are unlikely to express their needs and difficulties to others (Digiacoia *et al.* 2013). Caring also reduces the amount of time they have for themselves (Lundh 1999a), and affects social life adversely (Angermeyer *et al.* 2006; Peraica *et al.* 2014) and family relationships (McCann *et al.* 2011a; Stjernsward & Hansson 2014), causing further stress and strain.

Factors within the caring relationship can place considerable pressure on the carer, especially if the care recipient is overly demanding and unappreciative (Lundh 1999a). However, there are positive benefits for carers, including feeling a greater bond with those being cared for, satisfaction from seeing care recipients being content and appreciative of their care, and experiencing a sense of increased personal development from being in the caring role (Lundh 1999d).

Most research on caring has concentrated on assessing the burden of caring for people with medical illnesses; however, the mental health carer's experience has received limited attention, especially in the care of older adults (McCann *et al.* 2011b; Wynaden 2007). As such, this experience remains predominantly out of the public gaze and, therefore, undervalued (Wynaden *et al.* 2006). In light of the increasing expectation on families to take responsibility for older members with mental illness, it is important to shed light on the experience of carers in this situation and to understand what helps to sustain them in this role. Information gained from the present study may give health professionals a greater understanding of the effects of caring on primary carers and what helps to sustain them in this important role. The aim of the study was to understand the lived experience of primary caregivers of older parents with severe and persistent mental illness, and to explore what, if anything, helps sustain them in their caring role. A qualitative approach was used

because our emphasis was on understanding carers' subjective experience, which is a valuable approach for helping to shed light on how they develop the resilience to sustain their caring role, especially in under-researched areas or settings.

METHOD

An interpretative phenomenological analysis (IPA) approach was used to guide data collection and analysis. Researchers using the approach attempt to examine how an individual (primary carer) in a given situation (caring for an older parent at home with mental illness) makes sense of a phenomenon (experience of caring). The main characteristics of IPA are hermeneutics, phenomenology, and idiography (Smith *et al.* 2009). The approach is founded on hermeneutics, the theory of interpretation. The approach is phenomenological because its focus is on comprehending participants' main life experiences. The approach is idiographic because of the emphasis on beginning with participants as the unit of analysis and then proceeding to abstract themes from the data. Finally, the approach is insightful where the problem is new or under-researched and complicated, and where the researcher attempts to understand process and change (Eatough & Smith 2006).

Participants and recruitment

Primary carers were recruited through an aged persons' mental health service, which provided inpatient and community services for older people with organic, functional, and age-related psychiatric disorders. The carers were recruited through a carer consultant employee of the service, who made initial contact with them to ascertain their interest in participating, and if interested, were followed up by a researcher. Purposive or criterion sampling was used to guide data collection (Parahoo 2006). The inclusion criteria were: (i) primary carer (or main support person) for an older relative, aged 65 years and above, with age-related mental illness; (ii) aged over 18 years; (iii) had not been in the role for more than 3 years consecutively; (iv) had not attended or accessed a support group for assistance; and (v) was able to communicate in conversational English. The exclusion criterion was: if the carer was currently experiencing an acute episode of mental illness.

Thirty-six primary caregivers were invited to take part in the study and, of these, 30 agreed to participate. The majority of carers were female ($n = 18$, 60%). The mean age of carers was 55.3 years (standard deviation = 12.7), and just over three-quarters of carers were married or in

TABLE 1: Sample of interview prompts relating to the primary carer's experience of caring

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1. What it is like to be the main support person?
 2. Tell me the good things, if any, about your experience as the main support person?
 3. Can you tell me the difficulties, if any, you face in your experience as the main support person?
 4. Tell me the things that could improve your experience, if any, as the main support person?
 5. What things, if any, do you and others do to help you cope with your caregiving role?
-

a long-term partnership. The majority of carers were adult offspring ($n = 24$, 80%), and the remainder spouses ($n = 6$, 20%), of the care recipients. Most were engaged currently in the caring role, while the remainder had, until recently, been in the caring role.

Procedure

Data collection took place, in private, in carers' homes, various public settings, or by telephone, as requested by participants. Semistructured, audio-recorded interviews were undertaken, each lasting approximately 1 hour. Broad questions were asked initially (Table 1). Answers were probed and examined further. At the end of each section of the interview, the researcher summarized the content to ascertain that the participant's perspective was expressed and understood correctly, a verification activity that increased the credibility of the study (Guba & Lincoln 2005).

Data analysis

Interview transcripts were analyzed in accordance with the IPA approach outlined by Smith and Osborn (2008). The data were read and reread to identify recurring themes about their experience of caring, a process facilitated through the use of Nvivo (version 10; QSR International, Doncaster, Victoria, Australia). *In vivo* coding was carried out, using words used by participants, which helps prevent the likelihood of researchers placing their predetermined theories and beliefs on the data (Holloway & Wheeler 2010). This was followed by clustering codes together into conceptual themes, which were then grouped into themes and linked subthemes. Simultaneously, data reduction occurred with initial themes inadequately grounded in the data being excluded. Then, a more detailed analytical rearrangement and refinement of themes and abstracting them to a higher level took place (Smith & Osborn 2008). The initial thematic analysis was undertaken by J. B. followed by an independent review of the process by T. McC. (Mays & Pope 1995). The abstracted themes and subthemes were discussed until consensus was reached.

Ethics approval

Ethics approval was obtained from Melbourne Health Research Ethics Committee. Participants provided written consent to participate. They were informed that their decision to agree or decline to participate, or to take part but subsequently withdraw from the study, would have no adverse implications for their own well-being or for the ongoing care and treatment of their older family member with mental illness.

RESULTS

Two overarching themes, and related subthemes, were abstracted from the data, reflecting carers' experience of caring for an older parent with severe mental illness and the ways they coped with their caring role: (i) caring as difficult and demanding; and (ii) developing resilience as a carer.

Caring as difficult and demanding

Caring was a difficult and demanding responsibility. It affected carers adversely, emotionally, physically, socially, and financially, and their lifestyle in general. This was reflected in three subthemes: (i) physically and emotionally draining; (ii) grieving about the loss; and (iii) adverse effects on lifestyle and social relationships.

Physically and emotionally draining

Caring was conceived as a physically and emotionally draining experience. It had detrimental effects on carers' physical health, making them more susceptible to, and taking longer to recover from, episodes of ill health:

I am often exhausted and take much longer to recover when I'm ill. Right now, for example, I am in the fifth week of a cold. (Interviewee 10)

Participants commented that their caring role was stressful and the stress was compounded if their older family member had to be admitted to residential care for ongoing care:

It's stressful because of the transition from home to the nursing home, and, initially, it was harder than it is now. (Interviewee 7)

Other participants found it very stressful to experience their relatives being under care and sedated:

The stress of having to adjust to medication, and I feel very, very. . . just to see your mum go through that, they got her 'drugged up' (sedated; heavily under the influence of drugs) and, you know, because of her behaviour, and

you see your mum 'drugged up' with drugs. (Interviewee 8)

However, participants' stress was not always related directly to their caring role but, indirectly, to coping with other family members who were critical of the way they fulfilled this responsibility:

What causes me stress is my husband who thinks that I'm not helpful enough to him or his mum. (Interviewee 3)

Grieving about the loss

Frequently, carers experienced sadness, depression, and guilt about what they perceived as a significant loss in their lives. They commented about feeling sad at the realization that their parent or spouse was no longer the independent person they once knew:

I feel sad that dad is like this. (Interviewee 15)

It's rather sad. My mother had always been there for us. (Interviewee 17)

The loss also brought about a role change, a transition, for some carers; in particular, a change from a daughter-to-father role to a carer-to-care recipient role:

Another 'bad' thing is the change of roles; me becoming the carer to dad. I sometimes feel I'm not his daughter anymore, if that makes sense. (Interviewee 10)

For a spouse, sadness extended to depressive feelings because of the transition in the marital relationship in her life, from a mutually engaging wife-to-husband relationship to a depression-filled, widow-like role:

I have depression. I don't want to admit it to myself that I was depressed and I was eating like a 'horse' (eating excessively). I put on a lot of weight, because I just sat in front of the TV, eating. Leaving my husband depresses me more because he is mentally and physically ill and he doesn't respond (to me) anymore. (Interviewee 19)

For a daughter, depressive feelings occurred because of feeling isolated, not being able to share the burden of caring, and having missed out on an opportunity to marry someone:

I feel so depressed because I have nobody to talk to. I'm not married and I wished I had (married). (Interviewee 12)

Sadness and depression also extended to feelings of guilt because of the loss they were experiencing, where the relative they were now caring for had changed from having a seminal role in the family to one of almost complete dependence:

I feel so guilty that the bread winner (the parent who once participated in paid work to support his family) who was so proud became like this. (Interviewee 14)

Participants also commented that their guilt was influenced by feelings of a lost opportunity to communicate with, and be more considerate towards, their older relative prior to the onset of severe mental illness:

It's the feeling of guilt, I feel guilty sometimes, although I shouldn't be. I was wondering if I should have been better to him when he is well because then he would know that I care. (Interviewee 16)

Adverse effects on lifestyle and social relationships

Caring also had detrimental effects on participants' general lifestyle and social relationships with other family members. They commented that the carer role placed restrictions on the way they conducted their life:

My life just stood still; I can't concentrate, I couldn't go out anywhere. (Interviewee 20)

I don't seem to get work done compared to before. (Interviewee 2)

They also revealed that their caring role had affected unfavourably their relationship with other family members:

I've been depressed, I've put on weight, not (because of) the transition process of putting mum into a nursing home, but (because of) fighting with my brother and sister-in-law. (Interviewee 7)

My husband and I seem to argue more than we used to. I am made to feel guilty by my husband. (Interviewee 5)

Some felt unsupported and isolated in their role. The following exemplars highlight the circumstances surrounding carers' intense feeling of isolation, a feeling that was unavoidable due to their changing circumstances but, nevertheless, was indicative of the loneliness some felt when caring for an older relative:

I have no one to help or support me. I have an extended family but they are in the . . . (overseas country). My uncle used to be in Melbourne but he went back to the . . . (overseas country) with his family. . . . I just go for walk and go for a drink. It's so lonely going home. No one is there. (Interviewee 11)

Developing resilience as a carer

Although there were unfavourable assessments of caring, there were also favourable appraisals. Favourable appraisals helped increase carers' resilience, to sustain them in their role, as reflected in three subthemes: (i) caring as

purposeful and satisfying; (ii) harnessing social support from others; and (iii) purposefully maintaining their own well-being.

Caring as purposeful and satisfying

For some participants, caring provided an opportunity, a sense of purpose and satisfaction by continuing to be engaged with their older relatives:

I am glad that it is me taking care of dad and not a stranger. I think it gives me a sense of purpose and makes dad more comfortable. (Interviewee 10)

Her comfort zone (the fact that her mother feels safe or at ease) actually supports me to feel at ease. Understanding that she's coping well. (The) support that I've received from her, especially when she has something to say. (She) always relates to her past and I'm there to be prepared to listen to her and support her, and, in return, I gain satisfaction, and we are holding each in that sense. (Interviewee 17)

A sense of purpose and satisfaction was also obtained when, occasionally, the care recipients expressed appreciation for the care being provided to them:

The good thing is that my mum is contented when she has good day. She is very appreciative of what I do. . . . She can't help me at all. The fact that she's appreciative is great. (Interviewee 13)

Carer satisfaction was also derived from observing their older relatives being content and happy within themselves:

Well, I'm happier now that he is happy. He doesn't say (he is happy) but we know it when my mum and I visit him; so what has improved is his being happy; that's all, really. (Interviewee 16)

I love seeing Dad have good days where he achieves things and feels well. I like feeling that I have supported him in getting to a healthier place in his life. Even small achievements mean a lot in the role of support person. (Interviewee 10)

Harnessing social support from others

Social support helped strengthen participants' resilience to cope with their caring role. Two types of social support – emotional and instrumental – were provided by family and significant others and an old age psychiatry community mental health service, to help sustain them in their caring role. Implicit in receiving these forms of social support was the perception that family and significant others understood the carer's situation and were attempting to help.

Emotional support from family and significant others was central to carers' coping. It was provided in various ways, such as listening and empathizing, and helped increase their resilience by alleviating their accumulated emotional stress and anxiety associated with caring for the older person with mental illness. In so doing, emotional support helped them feel supported and understood, and enabled them to engage frequently in discussions with family and significant others, to share and unburden their experience of caring:

I work and have my family to talk to so that's good and (my) family helps me by talking to them and by better understanding of my worries. (Interviewee 3)

As one carer commented, such discussions enabled her to 'download' (ventilate her feelings) with family and significant others. Some also commented that they included significant others, such as close work colleagues, friends, and relatives, in their support network:

I talk to my siblings and my dad, and my friends at work about my mum. One of the women at work, her father is also not well and had been in (name withheld) for a few months now, so she understands. (Interviewee 18)

I talk to my friends and relatives about my relationship with my husband since he got sick. (Interviewee 5)

Instrumental support, such as tangible or physical assistance, provided directly and indirectly by family and significant others, also helped strengthen carers' resilience. Direct instrumental support included family members sharing responsibility with the caring role, by engaging the older person with mental illness in projects and tasks that permitted primary carers to take a break from their role or to share their workload:

My older brother has tried to engage Dad in some handy work around his home which has been great. It has kept Dad busy, and has given me a short break from having to do things for Dad (Interviewee 16)

My children help me, my two daughters help me to visit him, we take turns and when he comes home, we all take him out for a walk, or to the seaside, or for a drive. (Interviewee 26)

For some carers, indirect instrumental support entailed family and significant others providing practical assistance with tasks to enable them to have some respite time to concentrate on their own lives and attend to routine domestic matters:

Dad helps mainly by taking mum to her medical appointments. This is a HUGE help to me, as it means I can cook,

shop for the family, attend to family affairs, attend appointments etcetera. Dad has also recently started mowing the lawns again, a huge effort considering how unmotivated he can be, and driving without my supervision to see my eldest brother. This means I don't have to drive him there myself. (Interviewee 10)

In recognition of the carer's significant sacrifice in caring, other family members provided instrumental support in the form of direct and indirect financial assistance to the carer:

Dad recently helped me financially to repair my car. He recognized that I needed my car to help in my role as carer, and to maintain my independence. This was a phenomenal gesture. I also pay no board or rent (in the family home), so I am not financially stretched living on a pension. (Interviewee 10)

Not all instrumental support offered to carers originated from within the family. Some was provided by the old age psychiatry community mental health service:

The APATT (Aged Psychiatry Assessment and Treatment Team) come to assess my dad. . . . They (APATT) provide 11 hours' (assistance) between mum and dad; someone to clean the house; mow the lawn; shopping. At first my father didn't want anybody to come to the house, but I got through to him that I couldn't do it (by myself). (Interviewee 2)

Purposefully maintaining their own well-being

Besides obtaining social support from others, carer participants also commented about the conscious and deliberate efforts they made to support themselves to cope with the negative emotional experience of being a carer. Some stated that they engaged in various forms of physical, social, and recreational activities, and, on some occasions, obtained professional counselling, to help sustain them in their caring role:

I go for a walk. I go and see my wife every lunch time to feed her. I go dancing on Wednesday night, and I love my footy (Australian Rules Football). I (also) support Manchester United. (Interviewee 20)

Other indicated they involved themselves in hobbies and, occasionally, went on holiday to help them cope with their caring role:

Craft – I come here, to my house, occasionally, to do my crafts. (Interviewee 2)

I'm going to a cruise, soon, to New Zealand. I'm looking forward to that. (Interviewee 7)

Carers commented that socializing with others helped them cope with their caring responsibilities. It increased their resilience by helping to reinvigorate and enable them to deal with the stress of caring:

I visit my brothers and spend time at their homes on the odd occasion when I need time out. I feel refreshed when I get to see my niece, or go out for a meal with my brothers and their partners. (Interviewee 10)

My grandchildren keep me alive. Make me (feel) young. They bring their friends, here. They jump all over the place. . . . I find that when I get up some mornings, I'm flat, crabby (irritable), and I would only go up there and talk to them. At least there's someone around. (Interviewee 26)

Finally, some participants commented that another way of strengthening their resilience was to obtain professional counselling to help them cope with the adverse psychological effects of caring:

I wonder, at times, if talking about these day-to-day experiences would be helpful. I see a psychologist, and there are times when I mention my concerns. (Interviewee 10)

DISCUSSION

In this exploratory study, we provide an in-depth understanding of the phenomenon of being a primary caregiver of an older person with severe and persistent mental illness, with an emphasis on ascertaining how carers are able to develop resilience to sustain them in their caregiving role. Resilience is the 'process of coping with adversity, change, or opportunity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protective factors' (Richardson 2002; p. 308). It acts as a safeguard to protect an individual's physical and psychological health during challenging life situations (Yi *et al.* 2008), such as caregiving.

In the present study, caregiving is conceived as a difficult and demanding responsibility, as reflected in three subthemes: (i) physically and emotionally draining; (ii) grieving about the loss; and (iii) adverse effects on lifestyle and social relationships. The difficult and demanding nature of caring for an older person with mental illness makes it particularly burdensome – emotionally and physically – for caregivers as they struggle to cope with the cognitive and behavioural manifestations of the illness at home and, in some circumstances, having to come to terms with the person being placed in residential care. A meta-analysis of 228 studies of carers in various contexts,

by Pinquart and Sorensen (2003a), indicated that the strongest predictor of caregiver burden is the care recipient's behavioural problems. At times in the current study, the stress of caring has a detrimental effect on carers' relationships with other family members. This stressful situation is heightened if these members criticize carers for the way they fulfilled their caring responsibilities, an event that occurs commonly in these situations among carers of people with mental health problems (Pinfold & Corry 2003). Caring in the present study also has unfavourable effects on carers' physical health, making them more susceptible to, and taking longer to recover from, episodes of ill health. This finding corresponds with other reports indicating that approximately one in five carers experience moderate to significant adverse effects on their health (Pinfold & Corry 2003), and carers of people with long-standing mental disorders experience a higher number of physical illnesses than non-carers (Smith *et al.* 2014).

Carers in the current study can experience grief about the loss of the, formerly independent, person they once knew, representing a loss in their own lives, as a daughter, son, or spouse, and is consistent with the findings of a study in Western Australia by Wynaden (2007). A consequence of this situation is it necessitates a role reversal; for example, from a long-standing daughter-to-father relationship to a carer-to-care recipient role, heightening carers' sense of loss. For some spousal carers, sadness about the loss, isolation, and lack of informal support can extend into depressive feelings (Wynaden 2007). Carers have a higher prevalence of mental health problems than non-carers (Smith *et al.* 2014); in particular, the problem of depression in carers is well-recognized, with, for example, 10–83% of carers of people with dementia being diagnosed with major depression (Sorensen *et al.* 2006). Moreover, the strongest predictor of carer depression is the care recipient's behavioural problems (Pinquart & Sorensen 2003a).

Sadness and depression also extends to feelings of guilt because of the loss carers in the present study are experiencing, where the relative they are now caring for has changed from having a figurehead role in the family to one of almost complete dependence. Guilt feelings also occur because of missed opportunities to communicate with, and be more thoughtful towards, their older relative before the onset of severe mental illness. They can also be attributable to self-blame, a finding reported as well by McCann *et al.* (2011b) in their study of carers of young people with first episode psychosis. It is important, therefore, that, in developing resilience, carers come to terms with or reconcile the dissonance between their past and

present relationships and roles (Byrne *et al.* 2011). Caring also imposes a financial burden on carers in the current study. This is an important finding because carers and other members of their household are more likely to experience financial hardship than households with non-carers (Australian Bureau of Statistics 2012). This situation, in turn, has undesirable effects on carers' well-being and ability to care (McCann *et al.* 2011b).

Developing resilience as a carer in the current study helps sustain them in their role, as reflected in three subthemes: (i) caring as purposeful and satisfying; (ii) receiving social support from others; and (iii) purposefully maintaining their own well-being. Some carers' resilience is strengthened from the increased closeness, sense of purpose, and satisfaction they obtain from being engaged with their older relatives (Pinquart & Sorensen 2003b). This sense of purpose and satisfaction is reinforced when, at times, the older care recipients express their appreciation for the care provided. It is also derived from seeing their older relatives being content and happy within themselves.

Carer resilience is also increased in the present study because of the social support they receive from family and significant others and community mental health services. Emotional support from family and significant others is critical to help sustain them in their caring role, as lack of informal support is associated with poorer physical health among carers (Pinquart & Sorensen 2007). It helps them to feel supported and understood, and enables them to express their feelings, and in so doing, to share their experience of caring. Instrumental support is also helpful because it brings a sense of relief, directly or indirectly. Direct instrumental support from family members, by taking some responsibility for the caring role, provides respite for carers and reduces their burden of care. Indirect instrumental support from family and significant others also provides respite through a range of practical and financial assistance measures to carers. Furthermore, instrumental support from old age psychiatry community mental health services provides respite, a benefit that has also been reported in psychiatric and non-psychiatric caring contexts (Evans 2013; Salin *et al.* 2009).

Carers in the current study take conscious and active coping measures to foster their well-being, helping to sustain themselves in their caring role, and is consistent with the findings of a Swedish study of carers in diverse contexts (Lundh 1999c). These measures are particularly important as a decline in their personal well-being has undesirable implications for the continuation of their caring role (Byrne *et al.* 2011). Carers in the present study engage in various forms of physical activity, such as

walking and dancing, and participate in recreational activities such as hobbies and occasional holidays. They socialize with others, and some gain some relief by obtaining professional counselling, to help them cope with the adverse emotional consequences of caring. Engaging in physical and recreational activities, and socializing, and in some circumstances obtaining professional counselling, together, helps strengthen carers' resilience by reinvigorating them and helping them cope with their carer responsibilities (Zauszniewski *et al.* 2009).

Limitations

There are two limitations to this study. First, this is a qualitative study, and the findings are context-bound to the participants and setting in which the study was undertaken (Hutchinson 1993). Despite the fact that generalizability is not an overarching prerequisite of qualitative research (Sandelowski 1993), the themes can be verified (Green 1999) and are applicable to carers of older relatives with severe and persistent mental health illness in other contexts. Second, recruitment through carers engaged with the service means that their experience of caring may not be the same for those who do not have contact with the service.

CONCLUSIONS

Primary care of an older family member with mental illness in the home is particularly difficult and demanding and has adverse consequences for carers' physical, emotional, social, and financial well-being. Carers adopt a complex range of coping strategies to strengthen their own resilience, and should be encouraged to continue to do so. At the same time, family and significant others can make an important contribution by providing direct and indirect forms of emotional (e.g. listening to carers expressing their feelings about their caring responsibilities) and instrumental (e.g. sharing the caring role) support to carers. Community mental health nurses have an important role in supporting and helping sustain carers in this important role by providing emotional (e.g. listening to and empathizing with carers), encouraging, and instrumental (e.g. providing information about aspects of caring and financial support for carers) support, and by enhancing carers' coping strategies. However, in light of the difficulties encountered, it is important that these nurses assess carers' needs and are vigilant for signs of adverse physical and emotional consequences of caring, including depression, and, if these occur, to intervene as early as possible. Moreover, nurses need to place emphasis on enhancing carers' well-being and, as a consequence,

helping to sustain them in this difficult and demanding role. Finally, the findings of our study highlight the need for mental health policy to make provision for concrete measures to strengthen carers' well-being and to provide them with a satisfactory level of emotional, instrumental, and financial support.

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REFERENCES

- Angermeyer, M. C., Kilian, R., Wilms, H. U. & Wittmund, B. (2006). Quality of life of spouses of mentally ill people. *International Journal of Social Psychiatry*, 52, 278–285.
- Australian Bureau of Statistics (2012). *Disability, Ageing and Carers, Australia: Summary of Findings*. Canberra: ABS. [Cited 12 Jan 2015]. Available from URL: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>
- Bailey, R. C. & Grenyer, B. F. (2013). Burden and support needs of carers of persons with borderline personality disorder: A systematic review. *Harvard Review of Psychiatry*, 21, 248–258.
- Balducci, C., Mnich, E., McKee, K. J. *et al.* (2008). Negative impact and positive value in caregiving: Validation of the COPE index in a six-country sample of carers. *The Gerontologist*, 48, 276–286.
- Byrne, K., Orange, J. B. & Ward-Griffin, C. (2011). Care transition experiences of spousal caregivers: From a geriatric rehabilitation unit to home. *Qualitative Health Research*, 21, 1371–1387.
- Digiacomio, M., Delaney, P., Abbott, P. A., Davidson, P. M., Delaney, J. & Vincent, F. (2013). 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services. *BMC Health Services Research*. doi: 10.1186/1472-6963-13-326
- Eatough, V. & Smith, J. (2006). 'I was like a wild wild person': Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology*, 97, 483–498.
- Evans, D. (2013). Exploring the concept of respite. *Journal of Advanced Nursing*, 69, 1905–1915.
- Green, J. (1999). Generalisability and validity in qualitative research. *British Medical Journal*, 319, 421.
- Guba, E. G. & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In: N. K. Denzin & Y. S. Lincoln (Eds). *Sage Handbook of Qualitative*

- Research*, 3rd edn. (pp. 191–215). Thousand Oaks, CA: Sage.
- Holloway, I. & Wheeler, S. (2010). *Qualitative Research in Nursing and Healthcare*. Oxford: Wiley-Blackwell.
- Hutchinson, S. A. (1993). Grounded theory: The method. In: P. L. Munhall & C. Oiler Boyd (Eds). *Nursing Research: A Qualitative Perspective*, 2nd edn. (pp. 180–212). New York: National League for Nursing.
- Kelly, J. & Sharp, D. (2013). *Visioning Modern Home Care*. Canberra: Aged and Community Services Australia. [Cited 12 Jan 2015]. Available from: URL: <http://www.agedcare.org.au/publications/visioning-modern-home-care>
- Kenny, C., Sarma, K. M. & Egan, J. (2012). An interpretive phenomenological account of the experiences of family carers of the elderly. *The Irish Journal of Psychology*, 33, 199–214.
- Lundh, U. (1999a). Family carers. 1: Difficulties and levels of support in Sweden. *British Journal of Nursing*, 8, 582–588.
- Lundh, U. (1999c). Family carers. 3: Coping strategies among family carers in Sweden. *British Journal of Nursing*, 8, 735–740.
- Lundh, U. (1999d). Family carers. 2: Sources of satisfaction among Swedish carers. *British Journal of Nursing*, 8, 647–652.
- Mays, N. & Pope, C. (1995). Rigour and qualitative research. *BMJ (Clinical Research Ed.)*, 311, 109–112.
- McCann, T. V., Lubman, D. I. & Clark, E. (2011a). Responding to stigma: First-time caregivers of young people with first-episode psychosis. *Psychiatric Services*, 62, 548–550.
- McCann, T. V., Lubman, D. I. & Clark, E. (2011b). First-time primary caregivers' experience of caring for young adults with first-episode psychosis. *Schizophrenia Bulletin*, 37, 381–388.
- McGarry, J. & Arthur, A. (2001). Informal caring in late life: A qualitative study of the experiences of older carers. *Journal of Advanced Nursing*, 33, 182–189.
- Parahoo, K. (2006). *Nursing Research: Principles, Process and Issues*. Basingstoke: Palgrave MacMillan.
- Peraica, T., Vidovic, A., Petrovic, Z. K. & Kozaric-Kovacic, D. (2014). Quality of life of Croatian veterans' wives and veterans with posttraumatic stress disorder. *Health and Quality of Life Outcomes*, 12, 136. Available from URL: <http://www.hqlo.com/content/12/1/136>
- Pinfold, V. & Corry, P. (2003). *Under Pressure: The Impact of Caring on People Supporting Family Members or Friends with Mental Health Problems*. London: Rethink Mental Illness. [Cited 12 Jan 2015]. Available from: URL: <http://www.carersandconfidentiality.org.uk/wp-content/uploads/2010/05/Under-Pressure.pdf>
- Pinquart, M. & Sorensen, S. (2003a). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 58, P112–P128.
- Pinquart, M. & Sorensen, S. (2003b). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18, 250–267.
- Pinquart, M. & Sorensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological Sciences*, 62, P126–P137.
- Productivity Commission (2011). *Caring for Older Australians: Report No. 53, Final Inquiry Report*. Canberra: Commonwealth of Australia. [Cited 12 Jan 2015]. Available from: URL: http://www.pc.gov.au/_data/assets/pdf_file/0004/110929/aged-care-volume1.pdf
- Richardson, G. E. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology*, 58, 307–321.
- Salin, S., Kaunonen, M. & Astedt-Kurki, P. (2009). Informal carers of older family members: How they manage and what support they receive from respite care. *Journal of Clinical Nursing*, 18, 492–501.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16, 1–8.
- Smith, J. A. & Osborn, M. (2008). Interpretative phenomenological analysis. In: J. A. Smith (Ed.). *Qualitative Psychology: A Practical Guide to Research Methods*, 2nd edn. (pp. 51–80). London: Sage.
- Smith, J. A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Smith, L., Onwumere, J., Craig, T., McManus, S., Bebbington, P. & Kuipers, E. (2014). Mental and physical illness in caregivers: Results from an English national survey sample. *British Journal of Psychiatry*, 205, 197–203.
- Sorensen, S., Duberstein, P., Gill, D. & Pinquart, M. (2006). Dementia care: Mental health effects, intervention strategies, and clinical implications. *Lancet Neurology*, 5, 961–973.
- Stjernsward, S. & Hansson, L. (2014). A web-based supportive intervention for families living with depression: Content analysis and formative evaluation. *JMIR Research Protocols*, 3, e8.
- Szmukler, G., Kuipers, E., Joyce, J. et al. (2003). An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 38, 411–418.
- Ulstein, I., Wyller, T. B. & Engedal, K. (2008). Correlates of intrusion and avoidance as stress response symptoms in family carers of patients suffering from dementia. *International Journal of Geriatric Psychiatry*, 23, 1051–1057.
- Wynaden, D. (2007). The experience of caring for a person with a mental illness: A grounded theory study. *International Journal of Mental Health Nursing*, 16, 381–389.
- Wynaden, D., Ladzinski, U., Lapsley, J., Landsborough, I., Butt, J. & Hewitt, V. (2006). The caregiving experience: How much do health professionals understand? *Collegian*, 13, 6–10.

- Yi, J. P., Vitaliano, P. P., Smith, R. E., Yi, J. C. & Weinger, K. (2008). The role of resilience on psychological adjustment and physical health in patients with diabetes. *British Journal of Health Psychology*, 13, 311–325.
- Zauszniewski, J. A. & Bekhet, A. K. (2014). Factors associated with the emotional distress of women family members of adults with serious mental illness. *Archives of Psychiatric Nursing*, 28, 102–107.
- Zauszniewski, J. A., Bekhet, A. K. & Suresky, M. J. (2009). Effects on resilience of women family caregivers of adults with serious mental illness: The role of positive cognitions. *Archives of Psychiatric Nursing*, 23, 412–422.