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**Suicidal ideation and resilience in family carers of people with dementia: A pilot
qualitative study**

Abbreviated Title: Suicidal ideation in dementia carers

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Aging and Mental Health

Abstract

Objectives: Family carers of people with dementia have higher than average rates of depression, anxiety and hopelessness. While these are all risk factors for suicide, there has been no research on suicidal ideation in this population. The aims of this pilot study were to conduct an initial exploration of carers' experiences of suicidality and identify factors associated with risk and resilience, which could be used to guide further research.

Method: A descriptive qualitative approach was taken. In-depth interviews were conducted with nine carers of people with dementia (four male, five female) and transcripts were analysed thematically.

Results: Three themes were identified in the data – 'experiences of suicidal ideation', 'risk factors', and 'resilience'. Four of the nine participants had experienced suicidal thoughts and two had made preparations for a suicidal act. Risk factors included pre-existing mental health problems, physical health conditions, and conflict with other family or care staff. Factors positively associated with resilience included the use of positive coping strategies, faith, social support, and personal characteristics.

Conclusion: Some people contemplate suicide while caring for a family member with dementia. Further research is required to confirm the rate of suicidal ideation in the caring population and the relative contribution of factors associated with risk and resilience. In the meantime, service providers and health professionals should be taking steps to identify and support carers currently experiencing suicidal thoughts.

Keywords: Suicide, mental health, resilience, caregivers, dementia

Suicidal ideation and resilience in family carers of people with dementia: A pilot qualitative study

Introduction

Nearly 300,000 people in Australia, and more than 35 million worldwide, have dementia. (Alzheimer's Disease International, 2009; Australian Institute of Health and Welfare, 2012). As a result of the combination of cognitive impairment and behavioural problems, caring for a person with dementia (PWD) is acknowledged to be more burdensome than caring for a person with a physical disability (Access Economics, 2009).

The majority of community-dwelling Australians with dementia are cared for by a family member and 25% of family carers provide 40 hours of care or more per week (Access Economics, 2010; Access Economics, 2009). More than two-thirds of those carers maintain that level of care for more than 12 months, with one-third caring at that level for five years or more (Access Economics, 2009). This intense and demanding work can lead to poor physical and mental health (Sorensen et al., 2006). In fact, as a group, carers are known to experience higher than normal rates of depression, anxiety and hopelessness (Pinquart & Sorensen, 2003; Cohen, 2000), with estimates of depression among family carers ranging from 25% to 70% (Access Economics, 2009).

Depression, anxiety, and hopelessness have all been linked to suicide in other populations (Conwell & Thompson, 2008). Despite this, there have been no specific studies of suicidal ideation or suicide risk in family carers of people with dementia.

There has been one study, however, of suicidality in carers of another population. In that study, more than 50% of spousal carers of gay men with AIDS experienced suicidal ideation (irrespective of their own HIV status) and these thoughts were associated with a perceived lack of social support, lack of social integration, and caregiver burden (Rosengard

& Folkman, 1997). Due to the social and political context of AIDS care in the mid-1990s, however, these findings may not translate to carers of people with dementia.

The only other evidence on suicidality in carers comes from studies of homicide-suicides committed by older adults. In those studies, up to 50% of homicide-suicides were committed by spousal carers, with approximately 20% of those caring for a spouse with dementia (Cohen, 2000; Bourget et al., 2010). These studies, however, necessarily rely on information collected from medical reports and third parties after the event and provide only limited indication of suicidal thoughts during the caregiving journey.

It is also important to note that not all carers experience or succumb to the negative sequelae of caring. These carers could be considered ‘resilient’. That is, they are able to recover from, resist, or adapt to the physical and psychological demands of caring (Herrman et al., 2011; Zautra, 2009). Resilience has been found to predict lower levels of depression in spousal carers of people with dementia over time (O’Rourke et al., 2010) and is considered an important factor in suicide prevention (Heisel & Flett, 2008; Johnson et al., 2011).

The aims of this pilot study were to (1) conduct an initial exploration of carers’ experiences of suicidality and (2) identify possible factors associated with risk and resilience in this population, which could be used to guide further research. As the research was exploratory, a descriptive qualitative approach was taken.

Methods

Participants

Carers were eligible to participate if they were English speaking and identified themselves as the primary provider of care for a family member, friend, or spouse with dementia who was either living in the community, was in long term care, or had died within the past 2 years. The inclusion of former carers was justified by the fact that distress and health problems in carers

can increase in response to transitions in the caring role (e.g. Nikzad-Terhune et al., 2010; Haley et al., 2008) and that Rosengard & Folkman (1997) found suicidal thoughts to be more prevalent among bereaved carers than those whose care recipient was still alive.

A target sample of 12 participants was set, based on Guest, Bunce and Johnson's (2006) assertion that data saturation can be reached in as few as six to 12 interviews if the interviews are relatively structured, the participants are similar in terms of the experience of interest (e.g. being carers), the domain of inquiry is specific (e.g. suicidality), and the goal is to identify overarching themes (rather than provide a fine-grained analysis).

Thirty invitations were sent to people who met the inclusion criteria in Brisbane, Australia, and surrounding regions. These carers were randomly selected from the database of Carers Queensland (the peak body representing and providing services for carers in Queensland, Australia). Carers Queensland conducted the selection process and distributed invitations on behalf of the researchers, to maintain carer privacy. On the basis of previous experience they estimated a response rate of 50%. Selected carers were invited to participate in an interview about their caring experience. Although carers were informed that the interview would include questions about suicidal thoughts and attempts (as stipulated by the ethics committee), the study was framed as research on the wellbeing of carers and prospective participants were not made aware that suicidality was the primary focus.

Procedure

An interview protocol was developed in consultation with a Consumer Advisory Panel. The Panel comprised representatives of aged care providers, peak bodies for carers and people with dementia, a national telephone counselling service, and former carers.

A semi-structured interview guide comprising 17 probes was used with additional questions asked, where appropriate, to further explore participant responses. The questions

focused on experiences and challenges of caring, participant approaches to managing stress and maintaining wellbeing, and experiences of suicidal ideation or suicide attempts. The questions varied slightly depending on the status of the person with dementia; at home, in long-term care, or deceased.

The interviews were conducted one-on-one, with all but two interviews taking place in participants' homes. Two interviews were conducted at the University campus and by telephone, respectively. All interviews were digitally recorded and transcribed verbatim. The interviews ranged in length from 40 minutes to 2.5 hours.

The University Human Research Ethics Committee approved the study and all participants provided signed, informed consent. Participants also provided contact details for their general practitioner and next of kin, who could be contacted in the event the participant became distressed during the interview and the interviewer felt they required additional support following the interview. After the interview, all participants were provided with a list of telephone support services for carers. The wellbeing of participants was monitored with a phone call from the researchers the day after the interview.

Analysis

A thematic analysis approach followed the steps identified by Braun and Clarke (2006): data familiarisation through reading and re-reading the transcripts; generating initial codes in a systematic fashion across the whole data set; identifying themes within identified codes; reviewing themes to ensure internal and external validity; and defining and naming themes. One researcher (**author initials removed to allow anonymous review**), who had not been involved in developing the interview questions or conducting the interviews, conducted the initial analysis. After the initial analysis was complete, the codes, sub-themes, and themes were reviewed by the other researchers (**author initials removed to allow anonymous

review**) and refined by all three researchers in discussions and reviews of the data until consensus was reached. Data management and coding were conducted in Atlas.ti 6.2 (Atlas.ti, Berlin).

The carers discussed a range of issues and experiences in the interviews. As the study aimed specifically to explore suicidality, the analysis focused only on the data pertaining to suicide risk and resilience in the face of caring challenges (Braun & Clarke, 2006; Guest, Bunce & Johnson, 2006). Three themes were identified that together contribute to an understanding of how suicide risk arises from the caregiving experience and the factors that contribute to carer resilience.

Results

Participants

Ten carers responded to the invitation to participate. One, however, responded after the timeline for the study had passed. The remaining nine all participated in an interview.

These carers were aged between 25 and 82 years and four were male. The majority lived in urban locations and held post-high school qualifications. None were working full-time and all reported some degree of difficulty managing on their current income. Four were caring at home, three had placed the PWD into long-term care, and two were recently bereaved. Time spent caring ranged from six months to 11 years. Table 1 provides a description of each carer.

No participants experienced suicidal thoughts as a result of the interviews and, in the follow-up calls, all but one said the interview had been a cathartic experience. The other participant regretted some comments he had made about the PWD and was referred to Carers Queensland's counselling service.

Table 1

Themes

Three themes were identified in the data: experiences of suicidal ideation, resilience, and risk factors. ‘Resilience’ and ‘risk factors’ both included sub-themes that reflected distinct but complementary aspects of risk and resilience (see Table 2). The themes and sub-themes are discussed below, with representative data extracts provided to illustrate the theme/sub-themes.

Table 2

Experiences of suicidal ideation

Four of the nine participants experienced suicidal thoughts during their time as a carer. There were no obvious differences between those who had contemplated suicide and those who had not in terms of education, employment, income management or location. Suicidal thoughts generally arose when participants were fatigued or overwhelmed, with suicide seen as a release from the relentless demands of caring. For these participants, thoughts of suicide were not thoughts of death per se (despite knowing this could be the outcome of any suicidal act), but rather thoughts of reprieve.

“I was just so tired that I just wanted to sleep. I don’t want to die. I’ve never wanted to die; I just wanted to get off the merry-go-round. I just wanted it all to stop.” (Participant 2)

One participant also described suicidal thoughts that were financially motivated. For him, suicide was a way to be relieved of the burden of care while ensuring, through pensions and superannuation payouts, that the PWD would be afforded good quality care for the rest of

her life. For this participant suicide represented, at least in part, a selfless act designed to ensure the person with dementia's quality of life.

“A couple of times there I thought about how I could get away with bumping myself off... because my insurance and all my stuff would've set [my wife] up forever.” (Participant 6)

The frequency, severity and intentionality of the suicidal thoughts varied. Two participants described thoughts that had occurred on multiple occasions throughout the caregiving journey. One participant described only one suicidal experience, but the thoughts were severe and described as the culmination of a long period of emotional distress and poor physical health. The other participant described her thoughts as rare and 'fleeting'. No participants had attempted suicide while caring, but two had made preparations for a suicidal act: “The thoughts are there; I've even sat the tablets down and looked at them.” (Participant 3). For these carers a sense of responsibility for the PWD was the main reason for not acting on their thoughts. This sense of responsibility was not linked to love, but rather was an acknowledgement that the PWD was vulnerable, had been forsaken by other friends or family, or was completely reliant on the carer.

“I've always had that bargaining chip... I can't abandon her, everybody else has. So it's good that one's there, so [I've] got a little escape hatch.... Yeah, I would never do that to her. That sense of 'she needs me, so you don't abandon a baby' is stronger than the need for me to do anything to myself.” (Participant 2)

[Q: What stopped you from taking your life?] “Fear and knowing that she had no one else, because her family had dropped her, her daughter had dropped her.” (Participant 6)

Some carers also felt a sense of responsibility for other significant people in their lives and worried about the impact a suicide might have on them. Grandchildren, particularly, were a commonly cited reason to resist suicidal thoughts: “I would never leave that legacy for my grandchildren.” (Participant 2).

While a sense of responsibility protected against suicidal acts, it did not alleviate the physical and emotional strain of caring. Even though they had not attempted suicide, these carers continued to experience the high levels of emotional distress and physical fatigue that had initially precipitated the suicidal thoughts. So while the responsibility was protective, it did not facilitate resilience. This was evident in the fact that some of these participants felt there would be no reason to refrain from suicide after the PWD died or moved into care. These comments were not about grief or loneliness, but the simple fact that the PWD’s death or departure would remove the only barrier to suicide.

“I remember saying, ‘I can go when Mum goes, but I can’t go before her’.” (Participant 2)

“I’ve thought ‘there is nothing for me’. After he’s gone to care, I’m going to have to try and get [public housing]. Why don’t I just walk under a bus?” (Participant 3)

Carers who had not contemplated suicide were perplexed by the idea that others had, even in the face of similarly challenging care situations. The idea of suicide simply had not occurred to them.

“Actually, until I read it in your letter - I’ve never thought of it.

Why would you do that?” (Participant 4)

Risk factors

Within the data three factors clearly distinguished carers who had experienced suicidal thoughts from those who had not: mental health problems prior to becoming a carer, serious physical health problems while caring, and intense conflict with family or service providers. These were the factors that appeared to have propelled carers from ‘stressed’ to ‘suicidal’ and, as such, they could be considered risk factors for suicidal thoughts in this population.

Pre-existing mental health problems The presence of pre-existing mental health problems clearly differentiated carers who had experienced suicidal thoughts from those who had not, particularly when these problems were exacerbated by the stress of caring. The three carers who reported pre-existing mental health problems all reported suicidal ideation while caring (Participants 2, 3, and 6). These carers had received diagnoses of depression, anxiety, and post-traumatic stress disorder prior to becoming carers, with two of the three also reporting suicidal thoughts and/or suicide attempts prior to becoming a carer. Two of the three said the isolation and physical and emotional demands of caring compounded their mental health issues, making them feel ‘helpless’. The presence of mental health problems seemed to reduce these carers’ capacity for managing the physical and emotional challenges of caring and limit their ability to engage with others or seek help.

“It’s almost like something’s pulling me down, and I could do
so much more if I didn’t have that.” (Participant 2)

Among those who had not experienced suicidal thoughts, most said they had never experienced the level of depression or despair they felt would precede such thoughts: “I have been down, but not down enough to [do that].” (Participant 8). This also included Participant

1, who described her suicidal thoughts as ‘fleeting’ and reported never having experienced mental health problems.

“I’ve never really felt that low and it’s always been a mystery to me, that people could feel that low that they can’t see light at the end of the tunnel, it’s something I don’t really understand.”

(Participant 1)

Current physical health problems Physical health problems were linked to suicidal thoughts when the conditions were chronic or extensive, exacerbated by the caring role, or limited the carer’s ability to care for the PWD or engage in self-care. Three of the four carers who reported suicidal thoughts also reported physical health problems that were aggravated by the caring role and the limited opportunity for self-care. Two of these carers admitted to inappropriate and excessive use of pain medication in order to ‘get through the day’. One reported a co-dependent relationship in which the PWD provided support for her physical problems, while she supported for his cognitive problems.

“Looking after Mum...has certainly escalated my health condition.” (Participant 2)

“He still provides me with that physical [care] and I provide him with the mental [care]. They assessed me at [social services] and I went through quite a few tests...and they said ‘we’ll put you on a disability pension’. But then when he was diagnosed they said ‘well he’s the worse’ so I’m his carer.”

(Participant 3)

For these carers, the interconnectedness of worsening physical health, increasing care demands, and decreasing time for self-care became a vicious cycle which left them

concerned about their ability to continue providing physical care and in fear of having to place the PWD into long-term care. These carers seemed to become particularly isolated when their *inability* to seek support, as a result of exhaustion, was coupled with an *unwillingness* to seek support for fear of being seen as incapable and having the PWD removed from their care.

Although carers who had not reported suicidal thoughts had also experienced fatigue and care-related injuries, none of them reported multiple chronic conditions, ongoing pain, or extended use of pain medications. This was also the case for Participant 1, whose suicidal thoughts had been less extensive.

Conflict Almost all the participants reported conflict with family members or service providers during the caregiving journey. Examples included legal disputes over money or guardianship, a failure by family or staff to provide urgent practical support, and family or staff questioning the carer's decisions. All the carers felt such conflict added unnecessary stress to an already difficult experience. For carers who reported suicidal thoughts, however, the conflict was more extensive, exacerbated existing emotional distress, and frequently stemmed from pre-existing relationship problems with siblings or step-children. As a result, these carers had a heightened sense of helplessness, isolation, and vulnerability.

“I was being pushed into a corner [by the care staff] and it was even mentioned at one point, we’ll revoke your enduring power of attorney and we will put him under guardianship.”

(Participant 1)

[Q: So it seems that the family conflict has really influenced your experience of caring for your mum and that it could have been a very different experience if those family relationships

hadn't been the way they were] "If it had been more inclusive, it would've been [different]. I just so envy the ones at the nursing home, who have three sisters, or they've got a husband and a daughter...But then we never had that as a family, as kids, either. We've never had a whole family; I don't know what it is to have a whole family." (Participant 2)

Resilience

Four factors were identified as fostering carers' ability to cope with or adapt to the challenges of caring for a PWD: practical coping strategies, personal characteristics, social support, and faith. These factors enabled carers to persevere, despite serious and ongoing adversity, and withstand (or even prevent) the onset of poor physical and mental health. As such, they could be considered factors that cultivate resilience in carers.

Practical coping strategies The use of practical, positive coping strategies, such as seeking information and support, engaging in enjoyable activities, becoming active in the carer community, and making use of respite services, seemed to ameliorate stress and re-energise carers. Practical, positive coping strategies seemed to be most beneficial when carers engaged in them proactively (rather than being coerced by others) and when they felt empowered by their choice.

"I [got] involved somehow with advocacy [for other carers]... I quickly became empowered...and then I was actually advocating for other people, so that was one way that I coped." (Participant 2)

“I love getting up in the morning at 5am, going for my hour’s walk, and that’s my time ...that’s my ‘clear my head’ time. If I didn’t have that right now, I think things would be different, but it’s just giving me that little bit more strength to think straight.” (Participant 4)

Due to the constant physical demands of the caring role, however, most carers were unable to engage in these activities as often as they felt was necessary for physical and mental wellbeing. Some carers also faced financial restrictions, which made regular use of these coping strategies almost impossible.

“The panel [at the carers’ seminar] kept saying, you know, ‘you have to look after yourself’ and, you know, ‘art class, blah blah blah’. And I’m thinking ‘now wait a minute; we’re not all...independently wealthy. I can’t get away from it’.”
(Participant 3)

Furthermore, not all participants employed positive coping strategies. Participant 1, for example, used alcohol to relieve stress and escape from the realities of caring: “I probably drank a lot, far too much more wine than I should have. At night we’d often share a bottle of wine with each other cross-eyed.”

There were no obvious differences between carers who had experienced suicidal thoughts and carers who had not, in terms of which coping strategies they employed. There were differences, however, in the frequency with which they used those strategies. Carers who had experienced suicidal thoughts reported engaging in information seeking and self-care activities (e.g. reading, exercising) less frequently than those who had not experienced suicidal thoughts. They also reported fewer opportunities for engaging in social activities.

Personal characteristics Many carers felt their ability to cope with or adapt to the challenges of caring was a result of internal, personal characteristics such as flexibility, determination, and compassion: “It’s your person, it’s what you’re built of, I think.” (Participant 4).

Most participants felt these characteristics had been developed by past experiences. They described a sense of ‘fate’ or ‘serendipity’ in the order of events, with some feeling that past events had been specifically designed to prepare them for caring. Carers who took this approach seemed to more readily accept the situation they were in and respond more proactively to the challenges they encountered.

“I believe my military background... prepared me greatly because I was able to adapt, think outside the box...because as we always talk about in the military world ‘on the battlefield no plan goes to plan’, you’ve got to have flexibility to change on the spot.” (Participant 6)

There were no obvious differences between carers who reported suicidal thoughts and those who did not, in how they described these characteristics or the degree to which they felt they were beneficial.

Social support All the carers talked about the importance of receiving support from family or friends *and* service providers. This included practical and emotional support within the caring role, as well as time away from caring to engage in self-care and maintain other relationships. This support and respite allowed carers to rest, recover and ‘recharge’.

[Q: So that family support is really important?] “Yes it is, I think if I didn’t have that, it would be a shocker.” (Participant 8)

For two male participants, vital social support took the form of online role-playing games. These participants enjoyed escaping to an alternative reality, even if only for a short time, and engaging with other people without having to disclose their role as a carer. For Participant 6, suicidal thoughts arose when that online support was not available.

“It’s a social thing, like, I’ve got friends on there ... I find that is my escape.” (Participant 8)

“Obviously when I was on the road I wasn’t interacting with World of Warcraft [a multi-player online fantasy game], so I didn’t have my built-in escape.” (Participant 6)

Participants who seemed the most resilient were able to assertively communicate with family and service providers about their need for support and, as a result, received higher levels of support.

“I have three brothers as well. When they’re not working, or they’re available to give me a little bit of their time, they come in and let me go to places that I really have to go to, like the children’s school things. [This year] I said to them, every Friday night, between the three of you, I’d like you to work out who’s [coming] - it’s your choice, but you have to work it out.”
(Participant 4)

Participants who had difficulty accessing support, due to lack of knowledge, lack of assertiveness, or family conflict, seemed the least resilient. Furthermore, carers who had experienced suicidal thoughts reported a poorer knowledge of available support services, less involvement from family, and more difficulty accessing services, than those who had not.

“I didn’t know I could have got counselling in that first year with Mum, I didn’t know that it was available to me free, and I desperately needed it.” (Participant 2)

Faith Many participants talked about the importance of faith, which seemed to foster resilience by providing a framework for reflecting on their experiences, focusing on their hopes for the future, and situating the caring experience within a ‘bigger picture’. Faith also allowed them to believe the challenges they were experiencing had a purpose, were finite, and would eventually pass. Only one carer made reference to social support provided by church communities. For the others, faith was a deeply personal and individual concept not necessarily linked to religious practices or communities.

“I was never a religious man. However I did turn to the Bible, I did actively go seeking answers, especially just after I put my wife in a nursing home. Obviously I never found all the answers... but I have faith now that there’s a good chance that we may see each other again in another life.” (Participant 6)

“Faith for me is a purpose and a meaning. It’s about a higher purpose, and what was I destined to do, and what seems like trials, when in actual fact, they’re just challenges for me to go through.” (Participant 2)

For one participant, the parameters of her faith provided reasons not to act on suicidal thoughts. Similarly, some carers who had not experienced suicidal thoughts cited faith or religion as a key reason.

[Q: So do you think that if you hadn't been as secure in your faith, that this would have been much worse?] "I'd have gone under, no doubt. I'd have no doubt gone under." (Participant 5)

"I suppose it's not in [our] belief system." (Participant 1)

Discussion

This is the first study known to have explored suicidality in family carers of people with dementia and the findings suggest some carers do experience suicidal thoughts. Nearly half the participants had experienced suicidal thoughts while caring and half of those had made preparations for a suicidal act. These findings are consistent with the work of Rosengard and Folkman (1997), who reported suicidal ideation in more than 50% of spousal carers of gay men with HIV. Also, all the carers in the current study displayed characteristics of resilience, in the sense that they had not experienced suicidal thoughts, despite challenging care situations, or had refrained from acting on suicidal thoughts. The themes of 'experiences', 'risk' and 'resilience' provide a framework for understanding the carers' experiences.

While the experiences of suicidal ideation described in the data are largely self-explanatory, the concept of responsibility identified within that theme warrants further discussion. A sense of responsibility, particularly to family, has previously been reported in the suicide literature as an important 'reason for living' (Linehan et al., 1983; McLaren, 2011). In the current study, although responsibility was protective (in the sense that it stopped carers from acting on suicidal thoughts), it did not facilitate resilience or alleviate distress. It is important, therefore, that suicidal thoughts in carers are not discounted on the basis that a sense of responsibility will prevent suicidal acts, but rather seen as a reflection of physical or emotional suffering that needs to be addressed. This is particularly pertinent in light of

Britton et al.'s (2008) finding that in depressed older adults a sense of responsibility *increased* the association between hopelessness and the severity of suicidal thoughts. Similarly, suicidal ideation should be given particular attention when the PWD is nearing the end of life or going into care and bereavement or separation might impel the carer to act on suicidal thoughts they had previously resisted. It is also important to note that for at least one participant there was a rational aspect to his suicidal ideation. For some carers, suicide may represent a legitimate solution to the financial challenges of providing high quality care for a person with dementia, particularly in the presence of a strong sense of responsibility.

With regard to risk, the factors identified in this study – mental health problems, physical health conditions, conflict – are consistent with those reported in the suicide literature more generally (e.g. Conwell & Thompson, 2008). In the current study these factors tended to be pre-existing and exacerbated by the caring role. This suggests they could be identified at the onset of the caring role (i.e. the time of dementia diagnosis) and treated or managed from the outset to avoid exacerbation and minimise suicide risk. For people already caring, targeted interventions addressing these risk factors are required and should incorporate best practice from both the caring and the suicide literature (e.g. Pinquart & Sorenson, 2006; Sorenson et al., 2006; Lapierre et al., 2011).

Resilience was fostered through social support, faith, positive coping strategies, and personal characteristics. These factors have been linked to improved wellbeing and reduced burden in previous carer research, and to resilience to suicidality in the general population (Brodaty & Donkin, 2009; Johnson et al 2011). For coping strategies in particular, the key to resilience appeared to be not just employing appropriate strategies, but employing them often. While in-home or residential respite care services should allow carers to engage more frequently in positive coping strategies, many carers in the current study felt these services failed to provide an acceptable standard of care, were unaffordable, or had limited hours. This

is consistent with recent research on caregivers' beliefs about the value of in-home and day centre respite (Phillipson & Jones, 2011; Phillipson & Jones, 2012).

The use of online role-playing games by two younger male carers was unexpected. While these games have been linked to negative psychosocial consequences, there is also evidence to suggest that, for men in particular, they can be an important source of interpersonal connection, pleasure and escapism, as well as a way to release frustration and exert control (Frostling-Henningsson, 2009; Longman et al 2009). For these younger male carers, online games appeared to provide the important social support and emotional release that older female participants reported finding through 'real' interactions with friends, family, and carer support groups. There were no other obvious differences between men and women in the current study, but future research could explore gender differences in larger samples.

The qualitative method, the small sample, and the dementia-specific focus could all be considered limitations of this research. A qualitative approach was deemed appropriate for a preliminary exploration of suicidality (Sofaer, 1999) and, on the basis of this, quantitative research can now be conducted to confirm the rate of suicidal ideation in this population and the relative contribution of factors associated with risk and resilience. Although the sample was small, there was reasonable diversity in age, caring experience, caring situation, and socioeconomic indicators. Furthermore, no new themes emerged from the last two interviews, which may be taken as an indication of data saturation (Guest, Bunce & Johnson, 2006).

While participants may have self-selected (either in or out) upon being informed the interview would contain questions about suicide, this was unavoidable under the study's ethical framework. There was, however, no indication that carers who reported *not* experiencing suicidal thoughts were withholding such information, or that carers who *had* experienced suicidal thoughts had self-selected into the study for this reason. It is also possible that carers recruited through Carers Queensland are not a representative sample and

so these findings could be an underestimation or an overestimation of suicidal ideation in carers. Additional recruitment methods will be needed in future research to ensure a broader cross-section of carers is represented. Finally, while increasing rates of dementia and the substantial burden experienced by dementia carers provided a clear imperative for the current study, it is possible that carers of older people with other long-term illnesses may also contemplate suicide and this should be a focus of future research.

Despite the preliminary nature of this research, the findings are alarming and suggest a substantial proportion of carers might contemplate suicide. While further research is required to confirm these findings, service providers and health professionals should begin taking steps to identify and respond to carers already experiencing suicidal thoughts.

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Notes on contributors

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