Carers' Perspectives on Sustainability of Informal Care for People With Dementia

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Abstract

The majority of people with dementia, even at advanced stages, receive most of their care and support from family members, friends, and neighbors, rather than formal support systems. This qualitative research undertaken in the Australian state of Queensland explored how family carers of people with dementia living in the community successfully manage and sustain informal caring. It also considers challenges these carers anticipated in continuing to support their family member with dementia in the future. What emerges through this analysis of the carers' perspective on the sustainability of care is the impact of factors including the living arrangements, generational cohort and life stage of the carer, financial issues, and ability to effectively combine caring with their other roles and responsibilities in life.

Keywords

dementia, carer, caregiving, informal support, Australia

Introduction

Dementia is acknowledged as a significant disability that requires considerable long-term care. The World Health Organization estimates show that in 2010 there were 35.6 million people across the world with some form of dementia, with the numbers set to double by 2040 (World Health Organization, 2012). A large proportion of people with dementia receive in-home support from family carers. Caring for a person with dementia can result in physical, psychological, and economic impacts on the carer, which are often greater than in caring for people with other conditions associated with aging (Barnett, 2013; Brodaty & Donkin, 2009). These impacts are primarily related to a number of symptoms resulting from memory loss, challenging behaviors, and gradual loss of ability to carry out activities of everyday living, which necessitate intense support from carers.

The most recent data from Australia estimate that more than 332,000 Australians are living with dementia (of a total population of just more than 21.5 million people) with the numbers set to rise significantly in the next two decades (Alzheimer's Australia, 2014). Across Australia, it is estimated that 70% of people with dementia continue to live in the community (rather than in residential care) and the vast majority (92%) receive informal care and support from one or more people (Australian Institute of Health and Welfare [AIHW], 2012).

In their recent review, Rummery and Fine (2012) identified three interconnected facets of care, each of which have

implications for the family care of people with dementia: The first facet they identified was care as a disposition toward another as both a cognitive and emotional orientation. This orientation incorporates taking an interest in the life of the person along with a degree of responsibility for their well-being. The second facet was care as a form of labor, foregrounding such issues as workload, physical demands, and the costs of care. The third facet was care as a social relationship, through which both the care recipient and caregiver may lose autonomy due to the acceptance of dependency and responsibility. The sustainability of the work, or labor, of informal care is often assessed as "perseverance time," or the time that an informal carer anticipates he or she can continue to care under their current conditions (Kraijo, Brouwer, de Leeuw, Schrijvers, & van Exel, 2011, p. 114).

There is acknowledgment of a need for researchers to consider, in some breadth, the emotional and physical demands on informal carers who are supporting a family member with dementia to continue to live in the community (Bjornsdottir, 2009; Cash, Hodgkin, & Warburton, 2013). The research

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profiled in this article investigates the lived experiences and expectations of family carers in Australia on the sustainability of the care they provide to allow their family member with dementia to continue to live in the community.

At least 200,000 Australians are actively involved in providing informal assistance to people with dementia living in the community, of whom two thirds are co-resident carers, or living in the same household as the recipient of care (AIHW, 2012). Sixty-five percent of all informal carers of people with dementia are women, and 71% of primary co-resident carers are women (AIHW, 2012). It is estimated that 81% of the primary co-resident carers and 42% of non-resident informal carers of people with dementia living in the community provide 40 or more hours of care per week (AIHW, 2012). However, the impact of informal caring on the co-resident carer cannot be predicted only through measuring the amount of time the primary carer spends caring (Grose, Frost, Richardson, & Skirton, 2013). This is because a key factor that often distinguishes informal family care and formal care provision is the degree of "emotion work" that is involved (Chappell & Funk, 2011, p. 358). Hochschild (2012) distinguished between the management of emotion that occurs among family and friends in the private-self sphere, which she labeled "emotion work," and the commodified or marketized form of care that occurs in the public sphere, which she labeled "emotional labour." Informal care necessitates emotion work whenever there is a gap between the implicit social rules and expectations about emotions and the array of emotions experienced in the caring relationships (Hochschild, 2012). In these circumstances, it is important to acknowledge that there are both positive and negative aspects to the experience of becoming a family carer (Brodaty & Donkin, 2009). Providing informal family care for a person with dementia is a complex and evolving process.

Previous research, undertaken both in Australia and elsewhere in the world, has highlighted how supportive informal networks of care play a significant part in community-based care for people with dementia (Beeber & Zimmerman, 2012; Bjornsdottir, 2009; Edgell, 2012; Fauth et al., 2012; LaFontaine & Oyebode, 2014; Lloyd & Stirling, 2011; Nuffield Council on Bioethics, 2009; ter Meulen & Wright, 2012). In particular, the demands of caring can have health, relational, social, and economic implications for the family carer, which then affect the quality of the support they are capable of providing for the care recipient (AIHW, 2012; Australian Human Rights Commission [AHRC], 2013a, 2013b; Bowman, 2011; McDaid, 2009; Orpin, Stirling, Hetherington, & Robinson, 2014). The study detailed in this article was a response to the paucity of research on how informal carers sustain their caring role (Singh 2009). It reflects the "presupposition that caregivers will be available" through the dominant cultural, moral, and economic discourses framing aged care policy in Australia (Cash et al., 2013, p. 668). In this context, as Cash and her colleagues (2013) highlight, "It is crucial that we do not lose sight of the human factor" in informal family care (p. 670). The sustainability of informal caregiving is an important issue that requires an understanding of both how the family carers' family and non-family roles interrelate over time, and in considering the physical, emotional, and socioeconomic impact of these roles.

The study described in this article was a qualitative study, conducted in the state of Queensland in Australia, and focused on the carers' perspectives. It examined the broader question of how family carers of people with dementia living in the community successfully manage and sustain informal caring at present, and how they will continue to provide care in the future, by identifying the challenges associated with the continuation of their care. It included consideration of person-specific factors, family dynamics, and also the social, community, economic, and service environments within which informal care was being provided. A detailed description and discussion of the mismatch between the needs of individuals with dementia and the carers' experiences of interactions with various levels and types of health services has been described in another article (Singh, Hussain, Khan, Irwin, & Foskey, 2014).

Method

The study used a qualitative descriptive design with thematic analysis of family carers' experiences in providing care for their family members with dementia. This method was chosen as it allowed for an in-depth understanding of the informal caring experience of family carers of people with dementia and enabled the experience of carers to be presented from their own point of view. Full institutional ethics approval was sought and granted before data collection commenced.

Recruitment for the study was through advertisements in local papers, along with distribution of information through two key non-government bodies in the state: the Alzheimer's Association and Carers Queensland. The selection of participants was based primarily on the person's experience of caring for a family member with dementia living at home, irrespective of the duration, frequency, or status of the carer relationship. The sampling was based on purposeful and open sampling techniques as recommended by Strauss and Corbin (1998) and Barbour (2008). The initial recruitment phase based on advertisements in local newspapers only yielded five participants (P1-P5) over several weeks. The remaining participants were recruited through the two above-mentioned organizations. The 17 carers who participated in the in-depth interviews were residents in diverse settings including metropolitan Brisbane (the state capital and third largest city in Australia), regional cities, including Townsville and Cairns in far north Queensland, as well as rural and remote communities in southeast Queensland. In addition, they came from a broad range of backgrounds and experiences of caring. These included different age groups; had

varied employment statuses including full-time work, part-time work, and no work involvement; and most were primary co-resident carers. There was some difficulty in recruiting male carers for interviews. Many cited time constraints and others suggested proxy respondents such as spouse to provide details. This issue is discussed in the "Limitations" section of the article. No observable differences were found in the demographic or other caregiving characteristics of those who volunteered through newspapers advertisement versus through agencies.

A semi-structured interview guide incorporating key issues that had emerged from a preliminary literature search on the sustainability of informal care was designed to allow participants to describe their experiences in some detail. The issues explored within the interviews included the family dynamics of caring, role changes associated with caring, the carers' approaches to caring and their coping strategies, along with the experiences of carers in accessing services, and the future sustainability of their informal care. Eight of the interviews were conducted face-to-face and nine were conducted via telephone—including all those with participants living in the regional cities and rural and remote areas of the geographically large state of Queensland. The interviews were audio-recorded, with prior consent, and transcribed verbatim.

The methodological approach for data analysis included combining the application of a descriptive thematic framework with the constant comparison method of Grounded Theory providing the opportunity to better understand the process involved in informal caring (Glaser & Strauss, 1967). The interviews were undertaken in stages and transcripts of original interviews were reviewed to develop a description coding of the emerging themes. The research question was also revisited a number of times during the data collection phase to ensure its relevance, currency, and validity to the data collected. Although the number of respondents who agreed to take part in the study was greater than the study sample of 17 participants, further data collection was stopped when the interview data began to provide strong support for the emerging thematic structure.

Once all 17 interviews were transcribed, the interview transcripts were read several times by the first author as well as most of the co-authors (R.H., L.I., A.K.) to develop a coding scheme based on thematic analysis of the data (Boyatzis, 1998). The descriptive analytical framework allowed for an in-depth understanding of the informal caring experience of family carers of people with dementia and enabled the experience of carers to be presented from their own point of view. This process included identifying repetitive occurrences strengthening the analysis to assist in confirming the facts (Boyatzis, 1998), an iterative process providing the flexibility to revisit the data for the purpose of refining themes (Barbour, 2008), and a comparison of each situation, while also treating them as unique (Boyatzis, 1998). To supplement the descriptive analytical framework, a constant comparison method with roots embedded in Grounded Theory was also used in comparing incidents applicable to each category to understand and give meaning to the themes and codes in a given caring situation (Glaser & Strauss, 1967).

In the study reported here, 10 of the family carers were below the age of 65 years and 7 were aged 65 years and above. All the older family carers (>65 years) were spouses (*n* = 7) and the younger carers included spouses (*n* = 2), sons (*n* = 2), daughters (*n* = 5), and a daughter-in-law (*n* = 1) of the care recipients. The research participants included 2 males and 15 females. The majority of the younger carers were involved in paid outside work either in a full-time or part-time capacity. All the participants spoke English as their first language.

Results

In this study, the critical factors that influenced carers in managing their caring responsibilities emerged as the carer's background, age (younger or older carer), and relationship of the carer (spouse or other family member). A number of themes related to the informal caring environment were also recurring throughout the interviews: the shifts and changes carers experienced in taking on the role of a carer, their approach to caring, family dynamics, financial issues, and the intersection of work and care (see Figure 1).

Role Changes

The changes associated with taking on a primary caring role frequently required the family carers to carry out tasks for the family member they had not previously undertaken. No matter how small the task or everyday job, this added to the carer's sense of responsibility, which was already significant due to the care recipient's loss of normal functions and change in behaviors. This is illustrated in this example, from a wife/carer who explained how it was not simply the major shifts in the relationship, which characterized caring:

> I do all the driving even then it is surprising. You get into the car and you find yourself going somewhere, it is a major change in the role, which makes it different. I have never put petrol in our car, it was something that was always there. And the little things, . . . it is the little things that really get to you, I know I have to do it. So yes, life has totally changed. (Participant 1, older spouse)

The transformation of the everyday life of the family carer and care recipient when taking on a caring role had also involved changes in the living arrangements of the carer or their care recipient. Some of the younger non-spouse family carers had opened their own home to their family member with dementia, bringing them into an extended, multi-generational household. Other non-spouse carers had come to live close by the person with dementia, while other family members had moved into the home of the person with dementia. Carers involved in three-generation living arrangements, in
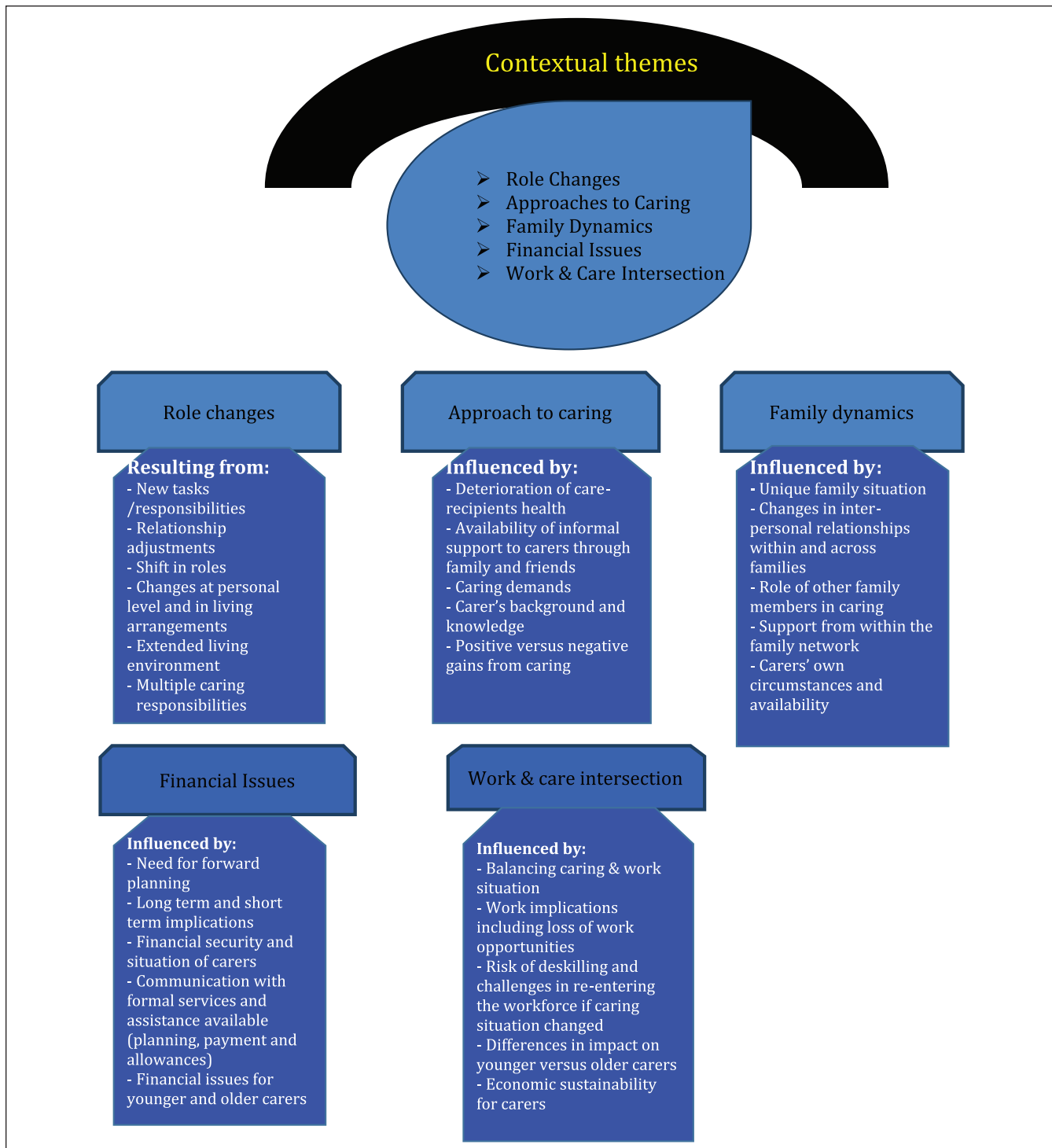
Figure 1. Contextual themes surrounding the caring environment.

particular, highlighted the impact across generations as everyone in the family adjusted to the new routines required of a changed family situation. A son/carer explained this as follows: "affected, like how my son and I communicate in the house and do things and how we go out" (Participant 10, middle-aged son).

A daughter caring for her mother with dementia, while simultaneously supporting her frail father, provides another example of the role changes experienced by non-spouse family carers. She explained the shifts in family dynamics inherent in taking on the role of primary decision maker in the family unit:

You know, so we said we've got to try and make decisions for Mum here and if she's distressed and you're not giving any really good reason why we should put her through this then maybe we won't and that means we lose my dad's support as well because we're not doing what he wants us to do. She went on to explain: I have a level of difficulty ascending to the role of parenting the parent. I'm not comfortable with it at all. (Participant 13, middle-aged daughter)

A number of non-spouse carers described such role changes as a form of role reversal as illustrated in this description by a daughter/carer:

It's like I'm the mum and Mum's the child now. Mum is at a stage now where she cannot be left alone. She can be left alone, but can't be left to wander. And she's incapable of making any decisions for her own safety or anything like that. (Participant 17, middle-aged daughter)

Through this process, the control in the relationship was gradually shifted from the care-recipient to the family carer, who justified the significant shift in family dynamics through referring to safety concerns for the care recipient.

Approach to Caring

What emerged through the analysis process was the impact of caregiving on the family carers relationships. Each family carer's approach to caring was influenced by his or her particular perspective on the caring situation. Many of the carers explained how they were reaching out to different forms of support to alleviate the burden of taking on the responsibility of caring for a family member with dementia. This included accessing informal support through their existing family and social networks, and peer support through carer support groups. For some of these family carers, it had also included accessing professional support. These primary family carers indicated how critical immediate and extended family members could be to how they experienced their situation, both practically and emotionally. An older wife/carer explained, "I got good support in the family. My two sons are both very supportive, I truly don't know where I would be without them, particularly the older one" (Participant 1, older spouse).

The younger carers seemed most likely to draw on the support of friends and other informal networks in negotiating the emotional work of caring. In this example, a daughter-in-law/carer begins with her most intimate family ties and gradually extends her lens to incorporate her friends and workmates as crucial sources of emotional support:

But me and my husband talk to each other. We are good support. I think, we get all the, between friends and our families we pretty much get all the emotional support we need, workmates and things like that. (Participant 4, middle-aged daughter-in-law)

Those carers who were active within a carer support group perceived their involvement in the group as being vital in sustaining their capacity to care. As one wife/carer explained, "Carers can come to the support groups without feeling that they're being unfaithful to their husbands or, sneaky, or anything else" (Participant 6, older-aged spouse). Participation in a carer support group in which they found others shared similar experiences allowed these carers to explore their experiences and in doing so assisted in alleviating the burden of care.

As one wife/carer explained, "I go to a meeting and we will all have a chat about husbands or wives or sons or daughters and share about the same problem and come away with a feeling that was not such a big issue" (Participant 11, older spouse). Those who had participated in a carer support group also identified how such group discussions had often prepared them for situations they may not otherwise have anticipated.

Despite this informal and peer support, several carers still identified their need for and/or a willingness to consider accessing professional counseling services in dealing with the emotional demands of caring. For example, this younger wife/carer in response to a question on type of support needed to sustain her carer's role suggested that she may need to access professional counseling to manage the increase in caregiving responsibilities in the future: "So I suppose I think that, mainly the counseling I think, there be more counseling available if people wanted to take up the offer you know? I suppose I think I may want to one day" (Participant 9, middle-aged spouse).

Family Dynamics and Conflicts

Overall, caring was perceived to be a "whole of family situation" irrespective of the contribution of individual family members to caring responsibilities. The accounts of caregivers illustrated that the impact on relationships extended well beyond the dyadic relationship of primary family carer and care recipient to other family relationships such as with their spouses, children as well as sibling relationships. In the example below, a daughter-in-law/carer describes the impact of caring on her marital relationship. She went on to explain how giving primacy to her mother-in-law's needs had introduced tensions within the marital relationship, which had not previously existed:

Caring has impacted on our marriage, [for] it can be very stressful if one of the people you are caring [for] in the couple is their parent, but it was meant to, we cope quite well with it. And there are beliefs in the family and she definitely comes first. (Participant 4, middle-aged daughter-in-law)

In some instances, the care responsibilities affected intragenerational and intergenerational family interrelationships beyond the person with dementia. Some of the carers described the ongoing adjustments required of other family members to accommodate their responsibilities as the primary family carer. The younger carers in three-generation

households, in particular, indicated they were concerned at the impact of their caring responsibilities on the youngest members of their family network. For example, a daughter/carer described how the situation affected the family's quality of life:

> Our quality of life is poor, which also affects our families. For example, when I am asked there is a function here, can you come I have to say, no sorry I can't come. Can we have a kid's party here, no we can't have a kid's party here. My son can't have a kid's party. (Participant 8, middle-aged daughter)

A number of the carers interviewed described how they had purposely engaged with family members who avoided any involvement in direct care to assist them in understanding what was involved in caring for a person with dementia. This was motivated by the belief that if these family members better understood the practical and emotional effort involved in caring for the family member with dementia, then this would improve the supportive family network available to them in their role as the primary family carer. In this example, a daughter/carer describes how she perceived an offer of informal respite by her brother as offering him greater insight into the day-to-day demands she experienced as the primary carer:

> My brother has offered, you know like, him and his wife have offered to even come over here and sleep in our house if my husband and I wanted to go away. Well I think that will have to happen in the future. That will give him an insight into what he's got to look for. (Participant 15, middle-aged daughter)

The family carers interviewed also acknowledged that it had not been possible to access emotional and other support from other family members in every situation. They reported how, in spite of their efforts, some family members explicitly refused to take part in, or understand, any of the additional responsibilities associated with caring for a family member with dementia. In such circumstances, some carers explained how they felt that they have not had a choice but to take on the role of a primary carer. This is illustrated by a son/carer who explained how:

> I've got a sister but she doesn't want to go near the responsibility. Since Mum got sick, she said that you know, she's got her life and she doesn't want to give anything up. (Participant 14, middle-aged son)

Several of the carers' descriptions highlight the assumptions, within family networks, that the (often already marginal) circumstances of a particular individual meant he or she was most available to look after the person with dementia. In such circumstances, as described by this rural daughter/carer whose family lived nearby, there was no guarantee that the primary carer would have access to family support:

> I have six brothers and sisters that live in a big town close by, who are married and they all have children, or most do. And their children now have children, and they're mostly in their 30s. Nobody even offers to help. (Participant 17, middle-aged daughter)

Thus, while family support emerged as vital to the sustainability of care, the interpersonal dynamics within families can also mean that such support is not readily accessible, even where the extended family may live close-by.

Financial Impact of Caregiving

The financial impact of caregiving was an aspect of care where the carer's attention tended to focus on the medium- and long-term implications of care, and not simply on immediate concerns. Assistance in financial planning became more important as the needs of the care recipient changed, and their condition deteriorated. This was illustrated by a younger wife/carer who had already sought financial advice but felt that access to such advice would need to be ongoing to enable her to sustain her caring responsibilities:

> Even though we own our own home etcetera, because we're only in our 50s I have to allow probably for a normal life span of 70 say you know, so I have to work out to that time, and what is the best way to go about it, I don't know . . . it's like everything, you can go once but then you need to continue, think about it until things change and that sort of thing, so therefore your need to follow up with ongoing assistance on these things. (Participant 9, middle-aged spouse)

Almost two thirds of carers interviewed in this study received some financial assistance from the Australian Government, in the form of a Carer payment and Care allowance. They explained that although this assistance was helpful, they found it was insufficient to meet the additional and ongoing demands of their caring situation. Carers described how they had incurred out-of-pocket expenses to meet the basic needs of the care recipient, noting how this added extra financial stress on their caring situation. Carers also highlighted the difficulties they had experienced in communicating their financial situation to service providers. They noted, in particular, a lack of flexibility by service providers in responding to their particular needs and circumstances.

In particular, younger carers described the financial difficulties they were experiencing as a result of the impact of their caring responsibilities on their employment. Financial stress, combined with the physical and emotional burden associated with caring for a family member with dementia, affected these carer's perceptions of their ability and capacity to manage and sustain their caring role into the future. This perception is evident in this description by a daughter/carer:

> It's just like to me that the government wants us to stay home and look after people that need looking after, and which I want

to do, but I believe they have to help more and stop penalizing us for caring. (Participant 17, middle-aged daughter)

In contrast, for carers with access to greater financial resources, this made it easier not only for the carer to cope financially but also freed them up emotionally and psychologically to attend to the other demands of their caring situation.

Challenges in Intersection of Work and Care

In this study, several carers described their attempts to balance their caring situation with continuing their work arrangements. Working lives were cut short by the demands of caring for a family member with dementia leading to their early retirement.

As a wife/carer explained,

. . . when he was diagnosed, and, when he gave up work and I gave up work at the same time, but then I was coming 60 so there it goes, you know, I mean, and then I'd like to be working now, but anyway . . . (Participant 5, older spouse)

Other carers were not able to negotiate an effective balance between their caring responsibilities and paid work due to the lack of flexibility on the part of their employer. In this example, a daughter/carer explained how the unpredictable nature of informal caring in dementia, and lack of flexibility in formal respite care services, had resulted in her loss of employment. She explained,

But because all the respite centers were shut I had no one to look after mum, so I couldn't go to work, and I do believe that impacted and I do believe that that's one of the one of the reasons that they fired me. Because I couldn't attend work because I couldn't attend work, because I had to look after mum. (Participant 17, middle-aged daughter)

These carers explained how they had experienced a total change in their lives due to their caring responsibilities, which meant that their lives rotated around what the care recipient could, and could not, do. Caring felt to them as if it were more than a full-time job. Other carers who continued in paid employment anticipated that a choice would have to be made at some point between continuing to work and their dementia caring responsibilities. As a daughter-in-law/carer explained, "To look after her fully, eventually one of us will have to stop working or work part-time" (Participant 4, middle-aged daughter-in-law).

The impact on younger carers' lives, in particular, was significant for they had to make more adjustments to their lives to manage other commitments such as work, while meeting their caring obligations. In some cases, taking on a caring role reduced employment options, as a daughter-in-law/carer explained: "My mother-in-law is only 55 and we have moved interstate to care for her and because we live in a semi-remote location, there is not a lot of work" (Participant 4, middle-aged daughter-in-law).

The younger carers who were no longer in paid employment were particularly concerned about their ability to re-enter the workforce when their caring arrangement came to an end. Their concerns included deskilling and/or losing confidence about their ability to meet job requirements. This was compounded where additional barriers were anticipated in seeking to re-enter the workforce at an older age. As one older wife/carer who had previously been self-employed explained,

I work for myself but in the end I just had to stop it completely. Now when I try to get back into the workforce, I think the years of being out of the workforce really has had a negative impact on that. (Participant 16, older-aged spouse)

A daughter/carer, who had dual caring responsibilities, for both a child with a disability and a parent with vascular dementia, explained how it was the unpredictable demands of caring for her mother that led to her decision to delay her long-planned return to paid work:

Round about this time last year it became obvious that my son who has a learning disability was starting to get it together and I was no longer required to care for him to that extent, and we talked about me returning to work and about our financial commitment. And almost within days my mum had another little stroke and things happened that made me realize that it was not possible again that though I might be able to work this week, next week something could go wrong. (Participant 8, middle-aged daughter)

As indicated in the "Method" section of this article, some of the participants recruited into the study lived in rural and regional areas of the state of Queensland. The effect of residential location in relation to caregiving was reported to be associated primarily with lack of access to appropriate community-based aged-care and specialized health services for family member with dementia as well as adequate and timely information for the carers. These issues are reported and discussed in a previous publication (Singh et al., 2014). In relation to the findings of the current article, the key issue of rural and regional location was the lack of options for appropriate and relevant employment in the formal sector.

What emerges from the findings presented in this article is that the burden of caring for a family member with dementia has the potential to have long-term effects, not only on access to employment but also on the quality of life of the family carer. Some carers felt they were being forced to choose between continuing with paid work and long-term financial viability and sustaining their care of a family member with dementia. Assessing the sustainability of care includes the long-term implications for the carers and, in three-generation caring arrangements, their immediate family's economic sustainability.

Discussion

Sustainability of informal caregiving is an important issue that requires an understanding of how the family carers'

family and non-family roles interrelate over time. Sustainability as a concept refers to viability of informal care and the impact of delivery of long-term care at the community level on carers (Knapp, Challis, Fernandez, & Netten, 2004). Medves and Davies (2005) argue that sustainability in the health arena should focus on building the capacity of families as the core of the community so that they can respond to and manage their caring situation and be able to develop responses to broader issues affecting them.

This research has helped highlight how taking on a caring role involves many changes in the lives of family carers of people with dementia. It is important to acknowledge that caring for a family member with dementia combines "emotion *and* labour *and* relationship" (Rummery & Fine, 2012, p. 329, italics in original). The focus in research and practice on informal dementia care has often remained on the dyad of carer and care recipient, which can lead to a tendency to configure such changes as inherently private and individual. For example, other researchers have found that it is those family carers with a belief in their abilities and a sense of competence, who may be least vulnerable to the stress associated with the burden of caring for a family member with dementia (Contador, Fernández-Calvo, Palenzuela, Miguéis, & Ramos, 2012). This study helps highlight the importance of not only family support but also social support and financial security to the sustainability of family care.

The first facet of care identified by Rummery and Fine (2012) was care of another as a disposition encompassing both emotional and cognitive orientations. As this study illustrates, carers are seeking to comply with "the feeling rules of being a good caregiver" (Simpson & Acton, 2013, p. 52), but this can lead to emotional dissonance where this comes into conflict with other feelings and beliefs. Caring responsibilities result in extensive change to family relationships beyond the dyad of carer and care recipient, most apparent in the current study in circumstances where caring incorporated three-generation co-residence households. In such circumstances, the carer needed to negotiate complex, and often competing, role demands alongside "the experience of changing and contradictory identifications of home" (Edgell, Bond, Brittain, & Jarvis, 2010, p. 105). This is illustrated, for example, where the daughter carer described being unable to meet her young son's request to invite his friends to a birthday party held at home, and other events because her mother's needs took precedence.

The second facet of care identified by Rummery and Fine (2012) was care as a form of labor. In this study, the social and economic arrangements of family carer's lives also emerge as multiple and complex. Carers can experience emotional dissonance as they seek to comply with the normative assumption that their private caring responsibilities can be kept separate from their other roles and responsibilities in both the private and public spheres of their life. In the current study, the caring process emerged as being complex and iterative, rather than predictable and linear. Carers have

uneven access to support networks, and also differ in how are they are able to mobilize family, friends, and other systems for practical and emotional support and labor (Edgell et al., 2010). Poor family functioning, in particular, can increase the stress and strain on the family carers of people with dementia (Heru, Ryan, & Iqbal, 2004).

As mentioned in the introductory section of the article, the sustainability of the work, or labor, of informal care is often assessed as "perseverance time," or the time that an informal carer anticipates he or she can continue to care under his or her current conditions (Kraijo et al., 2011, p. 114). However, as shown through this study, the demands and changes faced by family carers cannot be predicted solely by measuring the amount of time the carer spends caring for the person with dementia. Carers are constantly negotiating competing, and conflicting, time demands as they allow and take the time to care (Keating & Dosman, 2009). The strain this causes leads to emotional dissonance as the carer struggles to negotiate and adapt to the different feeling rules and competing time orders of the various aspects of their lives including those of family, medical and care systems, government bureaucracy, and the workplace.

The inherent tensions between the cyclical, organic, and temporal character of caring for a family member with dementia and the "linear, abstracted, unvarying form of time" (Twigg, 2008, p. 240) that tend to underpin both formal service provision and contemporary employment practices also emerged in the study. The younger carers, in particular, were often caring for the family member with dementia at home while simultaneously negotiating the more abstract and "instrumental quality of time efficiency" (Twigg, 2008, p. 240) associated with their paid employment. Tensions then arose as these different time orders inevitably came into conflict. This conflict had significant implications when, for example, a daughter/carer attributed her loss of employment to the inflexibility of the formal care system that had meant she was unable to access respite care at short notice.

Several carers described feeling forced to choose between differing forms of labor, that is, the labor associated with continuing to care for their family member with dementia and the labor associated with either seeking employment or remaining in paid employment: for example, among the young carers, the loss of employment, delayed return to paid work, and the reduced employment options of moving to care for a family member in an area with few employment opportunities. This echoes the findings of a recent Australian Human Rights Commission's (AHRC; 2013b) inquiry on care, which noted the negative impact of the provision of unpaid care on both informal carers' participation in employment and on the work hours of those who were employed.

In the current study, it was often the family member who was already out of the workforce, marginally engaged in the workforce, perceived as the most mobile, or close to retirement who took on the full-time role of caring for the family

member with dementia. The risk was that this would simply compound their already marginal social and economic circumstances when their caring responsibilities came to an end (AHRC, 2013b).

Financial stress has been identified in a range of research (e.g., Lilly, Robinson, Holtzman, & Bottoff, 2012; Lai, 2012) as being a significant factor in the burden of care experienced by family carers, a finding reinforced through this study. Several carers in this study noted that the financial costs associated with caring for a family member with dementia not only had implications for the sustainability of their care but also their own long-term financial viability. As the Australian Human Relations Commission pointed out, the financial implications can result in "a significant impact on the incomes of carers over their life course [as well as increase the carer's] risk of poor mental health and poverty in later life" (AHRC, 2013c, p. 2). In these circumstances, improving the sustainability of care will not be achieved solely through supporting the carer in the short term.

As other researchers have noted, estimates of cost of informal care for people with dementia do not usually include the real cost that includes lost work time and the cost to social relationships through the intensity of caring responsibilities (Brodaty & Donkin, 2009). This highlights a need to consider the long-term implications of sustainability of informal care for the primary carer and their family network and to consider ways to offer more sensitive and nuanced support to those who could be vulnerable to poverty and ill-health once the care responsibilities end.

Rummery and Fine (2012) also focused on care as a social relationship in which both the caregiver and care recipient can gradually lose their autonomy. The loss of autonomy by the carer occurs as being ascribed as the primary carer by the formal care sector gradually transforms care from a private good into a "marketized domestic life [which draws] on complex mixes of both work and family cultures" (Hochschild, 2012, p. 204). This process can tend to reinforce the intensely bonded dyadic relationships between carer and care recipient in ways that can be detrimental to both the care recipient and carer's other relationships and hence their quality of life (Kraijo et al., 2011).

The normative expectations underlying formal care and support services are that a particular family member will be designated as the primary carer, and take on greater responsibility for the management of the needs of the family member with dementia as his or her condition progresses (AIHW, 2012; Välimäki, Vehviläinen-Julkunen, Pietilä, & Koivisto, 2012). Such responsibilities result in fundamental changes in the relationship as the family carer takes on an increasingly managerial role in ways that can undermine other aspects of the relationship (Roberto, McCann, & Blieszner, 2013). This is illustrated by the younger carers who described the change in role associated with taking over decision making as a form of role reversal. Yet, there may be limited negotiation within the formal health and care system and the family network, as

to who is to be ascribed that responsibility (Välimäki et al., 2012; Willyard, Miller, Shoemaker, & Addison, 2008). Yet, paradoxically, as this responsibility is also associated with negotiating a reduction in their opportunities in other aspects of their lives, such as continued participation in paid employment, the carer may be gaining this responsibility while reducing his or her own autonomy. This is a loss of autonomy that may well have long-term implications.

In relation to the gendered nature of caregiving, women still outnumber men in relation to being primary caregivers with the latest national Disability, Aging, and Carers Survey indicating that women make up 70% of primary carers and 56% of overall carers (Australian Bureau of Statistics [ABS], 2014). This situation may change further as gender roles become more blurred (McDonnell & Ryan, 2013) as an ascribed expectation as highlighted by the son carer in the present study who felt there was little choice but to take on a primary caring role when his sister refused the responsibility. In turn, taking on the primary caring role had an impact on his relationship with his own son. As McDonnell and Ryan (2013) suggest, there may be a need for greater attention by researchers to the experiences and issues for male carers in informal dementia care as more males are designated as the primary family carer.

The limitations of this research are inherent in the confined nature of this research with a focus on carers across a single state of Queensland in Australia. Whereas the approach taken allowed an in-depth analysis and study of carers' experiences, the design was limited to a single interview that limits any longitudinal analysis of caregiving issues. The available resources were limited and the requirements to complete the data collection within a 12-month period precluded the possibility of repeat interviews some months later, and additional resources for transcription of interview data.

It would be useful if future studies used a longer time frame to examine in more depth the challenges associated with caregiving. Another limitation is that the findings might not be reflective of all the factors affecting the sustainability of informal care at a national Australian level. This is particularly so, as the study did not include minority migrant groups from other cultures, who may have a different set of issues associated with caregiving as shown by some recent studies (Benedetti, Cohen, & Taylor, 2013; Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos, 2011). The vast majority of the carers (88.2%) who volunteered their participation in the present study were women. Although this is largely consistent with the caring patterns in Australia, it is important to acknowledge that the findings from this study could have been different if more male carers had been included. As stated earlier, recruitment of male carers was difficult, and from the available pool of volunteers, there were only two male participants, both of whom were included in the study.

Despite these limitations, the present study has provided many valuable findings, contributing to the discussion on the

sustainability of informal care of people with dementia. It also suggests that the current view of sustainable care needs to be broadened to include not only the capacity of a primary carer to sustain caring at an individual level but also the impact of care on the family network, and over the long term.

Conclusion

What emerges from this study of family carers of people with dementia from Queensland, Australia, is the vital importance of considering the wider social and economic context in which informal caring relationships occur. The study reported here has helped illustrate how the shifts and adjustments required in interpersonal relationships were not restricted to the dyad of family carer and the family member with dementia but extended to other relationships: family, friends, and work-related. In seeking to enhance the sustainability of care for the person with dementia, it is therefore vital that we pay attention not only to the quality of the care being provided to the person with dementia by the primary carer but also the supportive systems in which they are located.

It is important to pay attention to the social, emotional, and economic well-being of all those involved in caring for the person in both the short and long term. A failure to pay attention to the interlinking systems in which care relationships occur undermines more than the immediate sustainability of the informal care being provided to the family member with dementia. Such failures can affect the family carer's ability to sustain his or her vital roles as partner, worker, and community member in the long term. This has consequences for the family carer's health and well-being, the quality of his or her relationships, and long-term financial stability. Such complexity needs to be recognized and acknowledged in the policy and practice seeking to support family carers in sustaining their care.

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