



“I just don’t focus on my needs.” The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study



Gemma Tatangelo^{a,*}, Marita McCabe^a, Ashley Macleod^a, Emily You^b

^a The Institute for Health and Ageing, Australian Catholic University, Australia

^b The University of Melbourne, Australia

ARTICLE INFO

Keywords:

Dementia
Health needs
Offspring caregiver
Partner caregiver
Qualitative research

ABSTRACT

Background: Family caregivers of people with dementia have significant unmet health needs. There is a lack of research that differentiates between the needs that are specifically relevant to partner and offspring caregivers.

Objective: The aim of this study was to examine the health needs of partner and offspring caregivers of older people with dementia, including the barriers they experience in meeting their needs.

Method: Semi-structured interviews were conducted with 24 family caregivers of community-dwelling people with dementia. Of these, 12 were partner caregivers (4 men, 8 women) and 12 were offspring caregivers (2 men, 10 women). The interviews were transcribed and analysed using thematic analysis.

Results: Five themes were identified within the data. The first theme represents caregivers’ overall assessment and perception of their health needs. The remaining four themes represent the most important aspects of caregivers’ health needs; mental health, emotional support and social relationships, healthy diet and exercise, and personal time. While these themes were similar for offspring and partner caregivers, the specific needs and barriers within these areas were different. A prominent barrier for partner caregivers was that they had difficulty in acknowledging their needs. Despite this, partner caregivers demonstrated unmet emotional support needs, as they no longer had emotional support from their partner with dementia. They also had an unmet need for time away from the care-giving role, yet they were reluctant to leave the person with dementia. Offspring caregivers’ unmet health needs were easily identified and were focused on their unmet mental health needs and feeling socially isolated. These unmet mental health and social support needs were related to their unmet health needs in other areas such as exercise, diet and having time to themselves.

Conclusion: Caregivers have significant unmet needs and these are often complex, multidimensional, and they often differ between partner and offspring caregivers. Gaining a more detailed understanding of the needs and barriers that are particularly relevant to either partner or offspring caregivers will assist in the development of interventions that are tailored to the unique needs of caregivers.

What is already known about the topic?

- Family caregivers of people with dementia have significant unmet health needs and barriers to addressing their health needs.
- There is a lack of qualitative research that differentiates between the needs and barriers specifically relevant to partner as opposed to offspring caregivers.

What this paper adds

- While there are similarities between the health needs and barriers of offspring and partner caregivers, there are also several important differences.
- Partner caregivers had difficulty in identifying and acknowledging

their needs, whereas offspring caregivers were overwhelmed and discussed significant unmet mental health needs.

- This paper adds a more detailed understanding of caregivers needs and barriers and will assist in the development of more personalised interventions.

1. Introduction

Dementia affects 46.8 million people globally and this number is forecast to increase to 131.5 million by 2050 (Prince et al., 2015). Similar to many other developed countries, Australia faces a significant shortage of paid caregivers (Access Economics, 2011). As a result, unpaid/informal caregivers play an important role in caring for people with dementia who are living in the community. Currently,

* Corresponding author at: Institute for Health and Ageing Australian Catholic University, Level 6, 215 Spring Street, Melbourne 3000, Australia.

approximately 70% of Australians with dementia live in the community and 92% of these individuals receive care from one or more informal caregivers. Family caregivers play a central role in caring for community-dwelling older people with dementia in Australia, as is the situation in many other countries (Ball et al., 2015; Smith et al., 2015; Söderhamn et al., 2013). Informal caregivers of people with dementia are often a spouse/partner (42%), or a son or daughter (44%). In addition, most informal, co-residing caregivers (94%) provide continuous care and 81% provide 40 or more hours of care per week (AIHW, 2012). Due to the expected increase in the numbers of people with dementia and the lack of formal workforce, family caregivers will increasingly play a central role in looking after people with dementia. Consequently, family caregivers will require increasing support from health professionals including nursing practitioners, to assist them in managing the needs of the person with dementia and also ensuring their own health needs are met. In order to provide effective support, an in-depth understanding of caregivers' unmet needs is critical.

The emotional and physical impact of the caregiving role is such that family caregivers of people with dementia have been referred to as 'invisible second patients' (Thies and Bleiler, 2013). Family caregivers experience high rates of depression, stress and physical illnesses (Argimon et al., 2005; Eters et al., 2008; Fonareva and Oken, 2014). For example, the prevalence of depression among family caregivers of people with dementia is 30%–80%, compared to 6%–9% in the general population of adults over the age of 55 (Schoenmakers et al., 2010). These health problems are often exacerbated because caregivers' health needs are not met (McCabe et al., 2016). Caregivers have a range of needs in regard to their care giving role and also in the maintenance of their own health (McCabe et al., 2016). These include the maintenance of physical health, psychological health, and lifestyle factors (McCabe et al., 2016). These needs are often interrelated and many caregivers have difficulty in meeting their health needs for a variety of complex reasons (Acton, 2002; Furlong and Wuest, 2008; McCabe et al., 2016). Yet, most studies that have examined the unmet needs of family caregivers have done so from the perspectives of health professionals or used survey or quantitative methodologies (Gaugler et al., 2005; Miranda-Castillo et al., 2013; Rosa et al., 2010). However, these approaches may not provide an in-depth understanding of the specific needs of caregivers, including the ways that needs differ depending on the caregivers' situation.

There is also a lack of research examining the needs of family caregivers of people with dementia that differentiates between partner and offspring caregivers (Chappell et al., 2014; McCabe et al., 2016). It is important to explore this topic, given that the majority of family caregivers of people with dementia are partner and offspring caregivers (both representing over 40%, as described previously). Partner and offspring caregivers are likely to have different health needs and different barriers to addressing their health needs for a number of reasons. Due to their advanced age, partner caregivers have been found to have poorer physical health (Ott et al., 2007; Sanders et al., 2008). On the other hand, offspring caregivers appear to have poorer mental health than partner caregivers, although the reason for this is not clear (Conde-Sala et al., 2010). Partner caregivers are more likely to reside with the care recipient and therefore tend to assume a full-time caregiving role (Kim et al., 2012). Offspring caregivers are likely to juggle caregiving and other roles such as employment and supporting their own families (Pinquart and Sörensen, 2011). Overall, research has indicated that the caregiving experience is very different for offspring and partner caregivers (Chappell et al., 2014). However, the way in which these differences may affect the specific needs of caregivers is not well understood.

This study aimed to examine and compare the health needs of partner and offspring caregivers who were caring for community-dwelling older people with dementia in Australia. Specifically, the objective of this study was to utilise a qualitative approach to identify and compare the specific needs of partner and offspring caregivers,

including an examination of the barriers that prevent partner and offspring caregivers from addressing these needs. The findings have the potential to inform the development and implementation of intervention programs that are tailored to address the distinctive needs of partner and offspring caregivers. Moreover, the findings may have important implications for nursing practice, informing nursing practitioners on how to provide targeted support to help family caregivers of people with dementia to better assume their caregiving role and address their health needs.

2. Methods

2.1. Participants

Eligible participants for this study were primary caregivers. Primary caregivers were defined as the person who takes primary responsibility for the care of the person with dementia. In addition, the caregiver had to be caring for a parent (mother or father) or partner (husband, wife or de-facto partner) with dementia who was living in the community.

2.2. Procedure

Approval to conduct the study was granted by the university human ethics committee. A semi-structured interview guide was developed based on a review of the literature and advice from nursing and aged-care professionals. The interview questions were designed to capture needs in relation to caregiver health and barriers to address the needs. The specific topics covered by the interview schedule included exercise, healthy eating, family and social relationships, sleep, physical health and emotional support, as well as any other health needs identified by their caregivers. Some examples of specific questions are 'While caring for your husband/wife/mother/father, have you thought about your needs and what they might be?' and 'What prevents you from addressing these needs?' Research partners who provide community aged-care packages publicised the study and assisted in the recruitment of participants via notices in care agency newsletters and e-newsletters. Participants telephoned the researchers to register their interest in the study. Prior to obtaining participant's consent, participants were provided with detailed information about the study. They were also informed that the interview would be audio recorded, their anonymity would be protected, and they were free to withdraw at any time without disadvantage. Twelve partner and 12 offspring caregivers were interviewed. This sample size was determined by data saturation, a point at which no new data emerges from new interviews, which is frequently adopted in qualitative research. The interviews were conducted at the participants' house and lasted for approximately 60 min (on average). The interviews were audio-taped with participants' consent and transcribed verbatim. Interviewers were two female psychology graduates (AM and AK) with experience in interviewing and counselling. Interviewers were unknown to the participants.

2.3. Data analysis

The transcripts of the interviews were analysed systematically using a thematic analysis approach (Attride-Stirling, 2001; Braun and Clarke, 2006). This method involved several stages of identifying, analysing and reporting patterns or themes within data (Braun and Clarke, 2006). Data analysis was conducted using NVIVO software. Initially the transcripts were read and re-read in order for the researchers to become familiarised with the overall content. During this time, notes were made about potential codes. The second phase of analysis involved the development of a list of codes that identified any feature of the data that was interesting and noteworthy. An inductive approach was adopted whereby coding was strongly linked to the data. Three researchers independently coded two transcripts and a good level of inter-rater agreement was found. Two of the researchers then coded the remaining

Download English Version:

<https://daneshyari.com/en/article/5120916>

Download Persian Version:

<https://daneshyari.com/article/5120916>

[Daneshyari.com](https://daneshyari.com)