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Home Alone With Dementia

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Abstract

The aim of this qualitative exploratory study was to investigate community care clinicians' perceptions of the challenges faced by people who have dementia and live alone at home. Data were collected through interviews and focus groups with 21 community health and social care clinicians who supported people with dementia in the community. The perceived challenges that were identified related to poor hygiene, inadequate nutrition, keeping safe, other health problems, managing money, coping with technology, and lack of support. Although the findings only represent the perspective of clinicians and so tend to focus on clinical issues, they nonetheless resonate with previous research demonstrating that the issues have persisted for at least two decades. There are a number of implications arising from these perceptions related to a person with dementia's potential capacity to care for their health, interact safely with other people, and live at home alone. As the severity of cognitive impairment increases, their ability to care for their health and well-being will be compromised. This highlights the importance of community care clinicians being engaged in the early detection of this population and the establishment of supportive routines. These issues will likely to be of international interest, as many countries are facing the challenge of providing community-based care for an increasing number of older people with dementia. However, providing this type of dementia care for people who live alone has received little attention in the literature, and problems remain with meeting the practical challenges faced by this vulnerable population.

Keywords

dementia, community, alone, support, living

Introduction

The global population is aging and projections suggest that this will continue during coming decades (Lutz, 2009). As a consequence, age-related conditions such as dementia are increasing (World Health Organization, 2012). The majority of people with dementia live in the community with family or friends; however, a significant proportion lives at home alone (Australian Institute of Health and Welfare, 2012). Given the progressive nature of the cognitive impairment that is the hallmark of dementia, people who live alone face many challenges. As the severity of cognitive impairment in people increases, living at home without support and supervision becomes more difficult. For this population, the provision of home-based dementia care is a critical component of support for their ongoing health and well-being. Home-based care also provides opportunities for the community care professional to intervene early to prevent or accommodate decline safely and in ways that optimize people's independence, self-management, safety, and dignity. But current information about the nature, scope, and priorities of home-based care for a person who has dementia and lives alone is limited.

This study was initiated to investigate what community health and social care clinicians perceive to be the challenges that are faced by people who have dementia and live on their

own at home. Based on these findings, the article explores some of the implications for the health and well-being of this population.

Background

Living alone in the community is significant for people with dementia because it means that some will have to cope with a deteriorating cognitive function with limited support. The onset of dementia is generally a slow insidious process, so that may delay the person recognizing that something is wrong. Onset symptoms of dementia include memory impairment, disorientation, impaired judgment, hallucinations, and difficulties with higher level tasks (Corcoran, 2009; Kang et al., 2004; Weiner, Hynan, Bret, & White, 2005). The combination of these cognitive changes makes living independently difficult and will bring a degree of risk for those people who lack regular support and supervision. Despite this, living at home may hold distinct advantages

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during the mild and moderate stages of dementia, because the familiarity of the home allows the person to function (Hyde, 2012). But these advantages may be gradually lost as the dementia progresses.

There is a growing body of literature addressing people who live alone with dementia that spans many years, yet continues to report similar challenges and difficulties (Alzheimer's Australia NSW, 2013; Alzheimer's Society, 1994). Research that directly involves people with dementia is very limited, primarily as a result of difficulties related to recruitment (Gibson & Richardson, 2014) and to poor cognitive function limiting their participation. So, despite the large number of people who have dementia and live on their own, relatively little is known about them (Edwards & Morris, 2007; Lloyd & Stirling, 2015).

Although it is well recognized that this population faces many challenges, these challenges have not been well described. Diagnosis of cognitive impairment is less likely in people who live alone (Edwards & Morris, 2007; Wilkins, Wilkins, Meisel, & Depke, 2005), and dementia-related memory loss can have a significant impact on their independence (Frazer, Oyebode, & Cleary, 2011). Caregivers of people who live alone tend to give less hands-on assistance (Ebly, Hogan, & Rockwood, 1999), and this may affect the person's health and well-being. Reports suggest that some people have difficulty with nutrition, medications, and technology (Nygard & Starkhammar, 2007; Tierney et al., 2001; Tierney et al., 2004). Others engage in behavior that puts them at risk from other people (Waugh, 2009). A study involving case managers and people who have dementia identified that the top five concerns for this population were medications, wandering, falls, malnutrition, and exploitation (Alzheimer's Australia NSW, 2013). As the dementia progresses, the person will eventually stop taking care of themselves and their home (Svanstrom & Sundler, 2015).

We know that some people with dementia work very hard not to make any big mistakes so as to avoid residential aged care placement (De Witt, Ploeg, & Black, 2009). Others change their routines to minimize the risks associated with activities such as cooking and baking (De Witt et al., 2009). The desire to keep cognitive impairment hidden increases the difficulty of identifying those who are not coping on their own. The secrecy also means that there is a risk that some may become invisible in the community, a hidden population beyond the gaze of other people. Because they have limited or no support, they are more likely to be isolated from formal sources of support (Miranda-Castillo, Woods, & Orrell, 2010), including health care. As a result, friends and neighbors are often used as care providers (Gibson & Richardson, 2014). Although the person with dementia may have daily contact with home care services, they may not be aware of why these people come into their homes (Svanstrom & Sundler, 2015). Similarly, home care service staff may not be aware of any deterioration in the health of the person they visit. However, the person who lives alone has fewer choices in a service

system that is designed around the needs of family carers, so they may transition to residential care as a result of their lack of options (Gabriel, Stirling, Faulkner, & Lloyd, 2014).

Little is also known about how service organizations can best support this population. One study found that outcome-focused care interventions improved the subjective well-being of the person with dementia who lived alone (Gethin-Jones, 2014). The outcome-focused services were defined as those that met the goals, aspirations, or priorities of individual service users. But optimizing health and providing care interventions for the person with dementia are complex activities. Although there is comprehensive information available about home-based dementia care (Alzheimer's Association, 2009), information about the application of this dementia care in the context of a person living alone is still quite limited. This study, therefore, sought to identify the challenges for the person with dementia who lives alone and to explore some of the practical implications for community dementia care.

Method

The aim of the study was to explore what community health and social care clinicians perceived to be the challenges that are encountered by people who have dementia and live alone in the community. The focus was on challenges reported by the community care clinicians, so reflected their care delivery perspective. It is acknowledged that a weakness of this study lies in the fact that people with dementia living alone were not included as participants, because this reinforces the invisibility of this group. However as previously noted, there are a number of practical challenges in involving this population in research. A qualitative study design, based on interviews and focus groups, utilizing a content analysis approach was employed. For the purposes of this study, a perceived challenge was defined broadly to include any form of difficulty, problem, or adverse event encountered by people living alone with dementia.

Participants

Given the hidden nature of the problem, it was decided to draw on the experience of those who came into regular direct contact with people with dementia living alone, rather than drawing on the direct experience of those with the condition, who might be unable, or reluctant to share. To help ensure that a broad base of professional experience informed the study, participants included social workers, nurses, allied health professionals, and dementia support workers. Eligibility criteria were that the person had to be a health or social care professional and had provided home-based support for people with dementia. Participants were recruited through direct contact with community support organizations, dementia support networks, and community professional groups. Potential participants were contacted initially

via email, the nature of the study was explained, and they were invited to participate through an ethically approved informed consent process.

Data Collection

Data collection was by both individual and focus group interviews. When there was a single participant from an organization, an interview format was utilized. When there were two or more participants from an organization, a focus group format was used. Interviews and focus groups were conducted at the participants' workplaces at a mutually agreed time and place. Interviews and focus groups were facilitated by the lead researcher (D.E.) and lasted between 45 and 60 min. Discussions were digitally recorded and then transcribed verbatim by a professional transcription service. At the interviews, the nature of the study was explained to participants and each interview started with a broad opening question: "What do you believe to be the major challenges to the well-being of people who have dementia and live alone at home?" Follow-up probes were then used to gather further detail about responses. A total of five interviews and three focus groups were conducted that involved 21 community health and social care clinicians.

Analysis

Qualitative content analysis was used to analyze the transcripts (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). Qualitative content analysis is a method for analyzing written, verbal, or visual communications to obtain a condensed and broad description of a phenomenon (Elo & Kyngas, 2008). Given that the existing literature on challenges faced by this population was limited, an inductive approach was used and categories were derived from the data (Hsieh & Shannon, 2005). The transcripts were read and reread, then the process of open coding was undertaken to identify key words and statements in the data related to challenges for people with dementia. As new codes were created during this analysis process to accommodate relevant sections of the text, these new codes were added to a coding template (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). Following open coding, data were grouped into broader higher order categories. This process of abstraction created a description of the phenomenon through the generation of categories (Elo & Kyngas, 2008). The abstraction was initially stopped at the level of the specific challenges faced by the person with dementia, and seven challenges were identified who related to poor hygiene, other health problems, inadequate nutrition, keeping safe, managing money, coping with technology, and lack of support. To ensure a clear focus on the aims of the study, these seven categories were then further condensed to three broader categories of challenge in the "Discussion" section of this article: capacity to care for themselves, interacting with other people, and living safely at home alone.

The initial categories and their descriptions were reviewed by the participating community health and social care clinicians to check for resonance and any gaps, prior to being written up. Despite the relatively small number of participants, the final interviews did not reveal any new challenges, rather they added to the richness of the descriptions of the challenges already identified. Ethics approval was obtained from the University of South Australia Human Research Ethics Committee prior to the recruitment of any participants into the study.

Limitations

There are several limitations to the study. First, the number of participants involved in the study was small and so may not represent the views of the larger population of community health and social care clinicians. However, the paucity of research in this area makes this study important and the findings worth noting. Understanding the complexities within the life of just one member of a community gives insights into the collective (Coles & Knowles, 2001). Another limitation was that descriptions of the challenges were based on the perceptions of clinicians working with people who have dementia and who were known by health and community support services. It is likely that challenges reported by individuals with dementia themselves may be quite different. It is also possible that the challenges reported by people who have dementia and who are not known by community support services may differ from challenges reported by people who are receiving some form of community-based dementia support. However, by exploring the experiences of the community care clinicians, we were able to gain some possible insight into the lives of this potentially neglected population. We should not underestimate the expertise and insight of those who work day to day with this client group. Although their views do not represent those with dementia living alone, they do represent important voices to be heard, when trying to understand the complexity of the issue.

Results

Analysis of the transcripts uncovered a diverse range of issues that community health and social care clinicians highlighted as challenges for people with dementia who live alone. The stories also revealed the various forms that living alone can take for people who have dementia (see Table 1). Most commonly, living alone took the form of a person with dementia being the sole occupant of a house, unit, or residence. But for some people, it meant being alone only during the daytime when family worked, or overnight when family and carers returned home and community services ceased. Others were alone for short periods of time as a result of illness of a spouse or a family holiday. But the stories also revealed that occasionally some people with dementia lived

Table 1. Types of Living Alone Situations.

• Living Alone Living in the community as the sole occupant of a house, unit, or residence.
• Alone During Day Alone at home during the daytime. For example, a person with dementia lived with her son who worked during the day but came home after work and prepared her evening meal, helped her settle for the evening and ensured that she was safe overnight (Interview 1). This person was alone for 8 or 9 hr during the day. She had access to her house and garden, but her son locked the front gate to achieve a balance between maximizing freedom for his mother while still maintaining a degree of safety.
• Alone at Night Alone at home during the nighttime. For example, a person with dementia in her 80s was totally dependent on others to organize her life, she had no awareness of her problem, was incontinent, and would not eat without prompting (Interview 1). Her three daughters visit 3 or 4 times each day to assist her and look after her home. There were also community services visiting every weekday and a community nurse to assist with medicines. However, at the end of each day, the three daughters returned to their own homes leaving their mother alone overnight.
• Temporarily Alone Living alone for a short period of time. For example, a person with dementia was left unsupported when her family left for a European holiday (Focus Group 2).
• Unexpectedly Alone A sudden change of circumstances resulting in the person with dementia living alone in their home. For example, one person was supported by her husband to such an extent that the rest of her family did not recognize her cognitive decline (Focus Group 2). When her husband died she was left alone in their home and was unable to cope. It was some time before her family realized the extent of her cognitive impairment.
• Alone Together When both husband and wife have dementia and live in their home together. For example, a husband who had dementia was trying to provide support for his wife whose dementia was more advanced (Interview 1).
• Alone With Someone Else Although technically not living alone, some people with dementia live with others who offer no meaningful support, supervision, or companionship. For example, a person lived with her daughter who had a drug and alcohol addiction. She received no assistance from her daughter and was eventually placed in residential care for her own safety (Interview 2). In another example, a female with dementia lived in a flat at the back of her ex-husband's home (Interview 1). It was a cluttered residence and she had very little room to move about. Her ex-husband would not allow anything to be removed from the flat. With the cats, mice, rats, and pigeons also in the flat, plus her own incontinence, it meant that she was living in squalor. In addition to this, the ex-husband lived at the front of the property and so controlled access to his ex-wife.

with others who offered no form of support, assistance, or supervision. So while these people were not really alone at home, the lack of any meaningful and practical support meant that they were alone from the perspective of fulfilling their daily needs, despite the physical presence of another person in the residence.

A large number of challenges for people with dementia were reported by the community health and social care clinicians. Given the clinical perspective of these community care informants, most challenges were defined in this way and reflected some of the potential practical difficulties of living alone for a person with poor cognitive function. However, it should be noted that a number of the community care clinicians also reported having clients with dementia who successfully lived on their own. This group of people had established appropriate links with family, friends, or community services early in their journey with dementia, so received appropriate support and assistance as their dementia progressed.

The two most commonly identified areas of concern for the community care informants related to nutrition and the management of other health problems. Informants reported that

maintaining an adequate nutritional intake challenged many people with dementia. The challenge of other health problems related to the difficulties of managing prescribed medicines and coping with other conditions such as diabetes. In total, seven areas of challenge were identified by informants:

- Poor hygiene
- Other health problems
- Inadequate nutrition
- Keeping safe
- Managing money
- Coping with technology
- Lack of support

Poor Hygiene

Community health and social care clinicians reported that as the severity of the dementia increased and the person's cognitive function declined, hygiene and cleanliness became a challenge for some. Poor personal hygiene concerned people forgetting to wash, or lacking the insight to realize that they were sometimes perceived by others as dirty. For some people,

it was about “. . . not changing their clothing anymore” (Interview 4) or a “. . . lack of laundry” (Interview 1). When incontinence was also a problem for the person, then hygiene became a much greater challenge. Informants described homes of some clients being littered with dirty continence pads and soiled floor coverings. One informant said,

It's a very sensitive area. People with dementia often believe that they are managing that quite well. They don't want anybody to help them in that particular area of their lives. (Interview 3)

Some homes were also in a very poor state as a result of inadequate cleaning and neglect. One informant noted that homes of some people “. . . can be quite filthy and require a lot of extensive cleaning and maintenance and things like that” (Interview 3). Clutter was a problem in a few homes and left little room for the person to move about. For one lady with dementia, the clutter “. . . stopped her from being able to do basic things like get to a bathroom easily or sit in a comfortable chair, to get on her bed she'd have to move things off” (Interview 1).

Other Health Problems

Looking after their own health was perceived to be a significant challenge for many who lived on their own. One informant said that some of her clients with dementia “. . . forget that they've got a medical condition . . . Why do I need this . . . I'm healthy” (Interview 4). Medicines and medication management were identified as a significant issue. One informant said, “It's often quite a challenge to introduce medication management for people with dementia, with their lack of insight” (Interview 3). For some, this challenge concerned forgetting to take prescription medicines; for others, it was that they took too many because they kept forgetting that they had already taken their medicines for the day. Remembering medical and health appointments was also a commonly identified problem. One informant said, “It's not only remembering they've got the appointment, but then remembering how to get there” (Focus Group 3).

Looking after other health conditions, for example, trying to manage the fine balance in controlling blood sugar levels with diet and insulin, was perceived to be a very significant challenge for the diabetic with dementia. Having dementia also affected a person's ability to recognize when things were going wrong with their health; living alone meant that there was no one else in the house to recognize the changes. One informant reported that “they miss symptoms that things are going astray, so they can be almost ready for hospital by the time that they realise something has gone wrong” (Interview 5). Managing dietary restrictions was considered to be beyond the capacity of some people with dementia. One informant described her experience with diabetic clients:

When you see people in the kitchen and they've got diabetes and they add their three, four tablespoons of sugar into their coffee and you sit there going “Oh gosh, they shouldn't be doing that” . . . (Interview 4)

Inadequate Nutrition

Nutrition was another area of perceived difficulty and several informants stated that it was one of the greatest challenges faced by their clients with dementia who live alone. There were a number of different aspects to this nutritional challenge including forgetting to eat, poor food storage, being unable to cook, and having difficulty shopping.

Forgetting to eat. Informants stated that forgetting to eat was a problem for some and they needed to have food on the table or be reminded before they would eat. Poor memory meant it was often difficult for community care clinicians to assess diet reliably. One informant said, “. . . they'll say ‘Oh yes I've had lunch’ but they haven't” (Focus Group 2). Another said, “Food services can assist, but only if they're going to eat” (Focus Group 3).

Poor food storage. Poor food storage was another identified area of concern for community care clinicians. It was considered to be a major challenge for some people with dementia because it meant that they were consuming food that was not fit to eat. One informant said, “Lack of food hygiene is a big problem, meat that has been in fridge for 4 weeks, vegetables all shrivelled up, food in pantry years past its use by date” (Interview 5). Lack of insight and an inability to recognize food unfit for consumption contributed to the problem of poor quality food. When refrigerators stopped working and the food started to rot, “. . . they don't really notice it or it's not a concern in their eyes” (Interview 3). However, managing the problem was difficult. Throwing food out was not always the solution because one informant reported having clients who would retrieve the food from their garbage bin. When the person with dementia received in-home support from a paid carer, the need to check cupboards and the refrigerator was often forgotten:

A lot of live-alones don't get a carer in that will check on those things [the food], if a carer goes in just to shower someone they won't check the fridge and stuff like that. (Interview 2)

Unable to cook. A number of informants reported concerns about people with dementia losing their cooking skills, so were unable to prepare meals. Some would start preparing their meal but then forgot what they were cooking and so abandoned it. Others would start to cook and then forgot that the meal was in the oven. One informant said operating a microwave oven challenged some “. . . things like that becomes an impossible task for people, they forget how to use it” (Focus Group 3). This meant they were unable to reheat

the frozen meals provided by food services. Distinguishing between different types of food such as salt and sugar became increasingly difficult for some people. One informant described her strategy for assessing the cooking skills of her clients with dementia:

I often watch them make a cup of tea for me to gauge how they are coping, I have had tea made with sundried tomatoes and with dishwashing liquid. (Interview 5)

Shopping more difficult. Informants considered shopping for food to be a complex challenge for people with dementia because of factors such as the loss of driving license, difficulty remembering how to get to the shops, and an inability to use money when making a purchase. Selecting food was a problem for some, "Shopping lists are often repetitive, they buy the same things each time but not necessarily the things that they need" (Interview 5). For example, one informant described a client who ". . . compulsively went out and bought pies and yoghurt, tubs of yoghurt . . . She had mountains of it in her fridge" (Focus Group 3).

Keeping Safe

Community care clinicians reported a number of challenges related to the safety of the person with dementia. Safety is a very broad concept, and most themes to emerge from the analysis related in some way to safety. However, a number of very specific safety-related issues were reported by informants that concerned the danger of fires, locked doors, and wandering/walking about and getting lost. However for some, the safety risk related to their vulnerable position in the community during encounters with other people.

Danger of fires. The risk of fire can be a challenge for many people with dementia, but the lack of supervision for those who live alone made fire a greater danger. A number of examples of ovens and oven tops catching fire were reported by informants. Fires were often a result of people who started to cook and then forgot about it. As a consequence, some had had their oven disconnected or a timer-switch installed as a safety precaution. However, heaters placed too close to flammable furnishings were also reported to be a risk for some. For one person, the risk of fire concerned "using her bar heater with the electric cord still wrapped around it" (Interview 4). Cigarettes were a risk for those who smoked; for example, one person smoked in his bed, and for another, ". . . when she was finished with a cigarette she used to just flick them onto the carpet" (Focus Group 2). Adding to the danger, some people lacked the capacity to recognize when things had gone wrong. For example,

. . . the fire alarm went off, the smoke detector went off and it was found by a neighbour . . . but the lady hadn't responded to it. It didn't register with her what the issue was even though the

house was full of smoke. It took us three weeks to get it [the smoke] out of the house. (Focus Group 2)

Locked doors. Locked doors posed another risk in both the house and car. A locked door was considered to be a special challenge because the person with dementia sometimes lacked the insight and capacity to manage the situation safely. An informant described a client's experience of being locked out at night during winter:

One lady locked herself out of her house but was able to find her way to the local shopping centre where she spent the night sheltering out of the rain in the shop's foyer. It turned out that she did have keys to the house in her handbag, she just didn't recognise them. (Interview 5)

There was also a risk of being locked inside of the house because some people locked their front door and then removed the key. Locked car doors posed a challenge for those who drive, an informant reported that ". . . one lady with dementia locked herself in her car, she sat in there for several hours because she couldn't work out how to unlock the door" (Interview 5). The nighttimes were identified as a higher risk period by one informant:

We can keep them busy during the day with different programmes in the community and stuff like that. But then you have the nighttime . . . how do we even know they sleep in their beds? (Interview 2)

Wandering and getting lost. Most informants identified wandering and getting lost as a significant and complicated challenge. The term *wandering* was commonly used by community care clinicians, but in fact, the behavior often entailed their clients walking about with purpose. It was considered to be a challenge because the lack of insight combined with memory and behavioral changes that accompany dementia made getting lost a constant risk when the person was out of their home alone. It was significant because of the vulnerability of this population when they were out in the community. It was complicated because living alone meant that there was no one to recognize that they had failed to return home and to raise an alarm for assistance. Several informants reported having clients who went out in the middle of the night to the shops. In one case, it was neighbors of the person with dementia who reported nighttime walking about to staff at community services. There were many examples given by informants of their clients getting lost. A female client of one informant ". . . was missing for 24 hours . . . she was eventually found walking along a railway line . . . heading towards one of her old homes" (Interview 4). No one was sure of what happened to her overnight or where she had gone.

Changing neighborhoods and streetscapes was considered to be disorientating for people with dementia. An informant

described one person's experience of walking in her neighborhood: "... she knows that's her corner and then the house got demolished and two got put in its place, so it starts to look unfamiliar" (Focus Group 2). Footpaths being closed was "... enough just to throw them off" (Focus Group 2). One person with dementia relied upon her dog to help her find the way home when she was out walking. But when she moved to a new house, the dog did not know the area: "She was being lost all the time" (Focus Group 3). However, it was noted by several informants that people with dementia who have a tendency to walk about do not do well living on their own. One informant suggested that community support services were more hesitant about accepting people with dementia who walked about as clients "... because a package is not going to be successful if they tend to wander" (Focus Group 2).

Vulnerable position in community. The trusting nature of some people with dementia and a lack of insight placed them in a vulnerable position during encounters with neighbors and other people in the community. People with dementia who exhibited risky behavior, such as not locking their doors or befriending strangers, were considered by some informants to be at even greater risk. Informants reported a number of examples of situations that they had concerns about. One lady with dementia "... wouldn't shut the front door" (Focus Group 2) and another "... will open the door to anybody" (Interview 5). The concern for one person was that "... a young man befriended her who she met in a shopping centre and she brought him home." For a man with dementia, it was his neighbors who were the source of concern because they would "... come in and take his food" (Interview 3). However, an informant cautioned that while there were risks for those who lived alone, there was also a lot of "scaremongering" in the community that exaggerated the danger that existed for this population (Interview 1).

Occasionally, it was the paid formal carers who posed the challenge for the person with dementia. The paid carer was the only regular visitor for some older people, so were viewed as friend or family. As a result, paid carers were in a privileged position in the caregiving relationship, one that some took advantage of. One informant described how this happened: "... they build a relationship with the person that comes in regularly ... they build a trust, and then that trust gets abused" (Focus Group 2). But the situation was complex because many of the people with dementia enjoyed and valued their friendship with paid carers, so in those situations the boundaries of practice were easily confused.

Managing Money

Community care clinicians reported that money and finances were often not well managed by people with dementia. The challenge of managing money also concerned the ease by which other people could take advantage of them.

Cannot manage finances. Managing finances, loans, and banking are complex activities for any person, but were particularly challenging for people with dementia. As the severity of the dementia increased so did the difficulty of managing money. Credit cards, automatic teller machines (ATMs), and electronic funds transfer at point of sale (EFTPOS) were highlighted by many informants as being particularly challenging for their clients. Some people "... forget how to do the EFTPOS machine and so they're asking strangers" (Focus Group 3). One person only used \$50 notes when shopping so that she did not have to calculate how much money to give to the shopkeeper. Her daughter "... changes the change into \$50 notes so she can go off and spend money again" (Focus Group 3). Some people managed quite well if "... they are set up from the beginning ... and go into the bank" (Interview 3). But an informant said it was more difficult implementing strategies when the dementia was more advanced "they're just not going to remember" (Interview 3).

Seen as a soft touch. Many informants reported that this population was very vulnerable because they were so trusting, even of strangers. A friendly smile and a nice chat was sometimes enough to win the person's trust. Because of this, they were seen by some people and companies as "... a soft touch ... a good way to get some money" (Interview 1). They were vulnerable because they would "... open the door to anybody" (Interview 5) and "... accept any telemarketer or doorknocker" (Focus Group 3). Another said, "It's the telemarketers that get them" (Interview 3). Dishonest trade people also posed a challenge because the person with dementia would sign up for a service and then promptly forgot that they had. Postal scams were seen to be a greater risk for this population, because the person failed to recognize the danger. It was also reported that they were easily talked in to buying goods when shopping. An informant described the experience of a person who had to take over the finances of her mother because of the progression of the dementia, she found that her mother had "... taken out multiple high interest loans for new TV's and heaters and things like that, so she was in quite a bad financial state" (Interview 3). Neighbors also posed a threat for some people, and one informant described how the neighbor of one of her clients with dementia "... cleared out her bank account" (Focus Group 1).

Coping With Technology

Many people with dementia were challenged by technology. Some were able to manage appliances that they had owned for a long time such as a TV, but were unable to learn how to use new appliances. The technology that was commonly reported to cause difficulties included household appliances, telephones, and ATM. Using household appliances, such as televisions, microwave ovens, and heaters, challenged some people. When older household appliances were replaced,

learning how to use the new appliance was particularly difficult for people with dementia. An informant said that “. . . when the bar heater is replaced because it’s too old . . . they then are unable to learn how to use the new replacement heater” (Interview 5). Televisions were also a challenging technology “Some can cope with remote controls okay . . . others know the on and off button” (Focus Group 2). One informant reported that “Things like ATM cards seem to be tricky too because you only get so many goes when you’ve forgotten your PIN before it disconnects” (Focus Group 1). Telephones were another technology that challenged many people with dementia. One informant said, “Most of them get the grasp of a basic phone . . . they just don’t go near the mobiles” (Focus Group 1). Being unable to use the phone had important implications, because family often maintains contact via the telephone. One informant reported that people with more advanced dementia are not able to initiate a phone call, but may still be able to answer an incoming call. However, another said that over time “. . . it takes two or three attempts to get them to answer the phone . . . a sign that they are not managing that sort of communication side of things anymore” (Interview 4).

Lack of Support

From a different perspective, another challenge reported by informants related to a lack of support from family and friends. This was considered to be a challenge because it concerned other people not understanding the nature of dementia or being reluctant to offer practical assistance. Some families had a poor understanding of dementia and the associated cognitive decline. Others did not recognize the dementia-related changes, which created difficulties when the person with dementia required their support. Families sometimes failed to recognize that their relative was struggling to manage, they told community care staff, “‘Mum’s still showering every day’ and in actual fact the soap never gets used, the shower’s never wet” (Focus Group 2). This lack of understanding occasionally presented as family conflict, as evidenced by one daughter’s comment to the community care staff “Mum’s not mad, she’s not insane. Mum’s manipulative . . . She’s doing this to annoy me” (Focus Group 1). Disagreements between family members also presented difficulties for the person with dementia who relied upon their support and assistance:

People can get caught in tug of wars because different family members have different perceptions about what is good . . . that can lead to tensions and strains . . . And the person can get caught in the middle. And people with dementia are sensitive to emotional stresses and strains in the same way that we all are, but they may not be able to make sense of them. (Interview 1)

For some people with dementia, the challenge concerned a lack of practical assistance and general support from their

family. This related to their family not being prepared to visit or provide assistance such as preparing meals or checking on the well-being of their relative. One informant said the risk with this lack of involvement was that the family did not see the changes in their relative “. . . they don’t come along the path with us. So you really have to pull them along the path with you by leaving them with a bit of responsibility. But some families . . . you pull them along kicking and screaming” (Focus Group 2).

Lack of support meant some people with dementia became disconnected from their family and friends. Others actively hid their dementia, even from their family, out of fear of being discovered and removed from their home. One informant said that some of her clients got “. . . frightened that you’re going to take away their rights, their homes . . . try and get them into a nursing home” (Interview 4). However, being disconnected from other people meant that when things went wrong, the person with dementia had to cope with the difficulties alone. For example, simple things such as a broken fridge, a broken fuse, a water leak, or a locked door presented a significant challenge. A broken light might not be replaced: “. . . people aren’t able to initiate or problem solve that the light globe needs changing” (Interview 4). More serious events were beyond their capacity to manage. An informant described an experience when she telephoned a female client with dementia to remind her that transport for her day care would be arriving at her house shortly. The client said, “I can’t come today. Well my house is full of water, there’s water everywhere, I don’t know where it’s coming from” (Interview 2). The community care professional was able to organize immediate assistance to manage the leaking toilet, but the person with dementia lacked the capacity to be able to respond appropriately to the unexpected problem.

Discussion

The findings of this study give an important insight into the difficulties that community health and social care clinicians have identified for people who have dementia and live alone. Although it has long been recognized that this population faces many challenges, the nature of the challenges and the magnitude of the problem have been difficult to determine (Newhouse, Niebuhr, Stroud, & Newhouse, 2001; Soniat, 2004). The findings of this study describe the concerns of community care clinicians related to the ability of the person with dementia to attend to hygiene, maintain adequate nutrition, keep safe, manage money, and cope with technology. Findings confirm reports in the literature about the risks that this population faces (Tierney et al., 2001; Waugh, 2009). Risks identified in other studies have related to theft and fraud, nutrition, medication management, and technology (Nygard & Starkhammar, 2007; Tierney et al., 2001; Tierney et al., 2004). Other reports have also suggested that some people with dementia engage in risky behavior such as letting strangers into their home, or locking themselves in and

refusing to open their door to visitors (Waugh, 2009). The different challenges that were identified by this study can be grouped into three broad areas: person with dementia's capacity to care for themselves, interacting with other people, and living safely at home alone.

Person With Dementia's Capacity to Care for Themselves

The findings highlight the many potential challenges that are part of the everyday life of the person living alone with dementia. These risks reflect the difficulties that are associated with poor memory, lack of insight, and inability to problem solve. The stories told by community care clinicians show how difficult it can be for some people to manage hygiene, nutrition, and continence. The stories also highlight how dangerous situations can easily develop when the person is using a heater, cooking, or when they accidentally lock a door.

Although people with dementia face many challenges trying to live independently, even general self-neglect can bring danger for the person. Some self-neglect is mild and poses little danger, but self-neglecting behaviors in vulnerable elders can sometimes be severe and bring extreme health and safety risks (Dyer, Pickens, & Burnett, 2007). Self-neglect is a complex phenomenon that is characterized by lack of attention to health and hygiene, often because the person is unable or unwilling to access support services (Pavlou & Lachs, 2006). The manifestations occur along a continuum and the negative impact on health is related to behaviors such as poor medication adherence, failing to keep medical appointments, ignoring serious medical issues, allowing food to spoil, and poor personal hygiene (Dyer et al., 2007). Living alone is an important predictor of self-neglect for older people, and conditions such as dementia and decreased social networks are also linked to self-neglect (Burnett et al., 2006; Longres, 1995). People with dementia who live alone tend to have more unmet needs (Miranda-Castillo et al., 2010) and are more likely to be malnourished (Nourhashemi, Amouyal-Barkate, Gillette-Guyonnet, Cantet, & Vellas, 2005). They are not only more likely to experience problems performing tasks of daily living, but also these problems can go undetected (Lehmann, Black, Shore, Kasper, & Rabins, 2010).

Waugh (2009) has suggested that this population may only become known when there is a crisis in their life. Their inability to recognize dangerous situations or to detect when things have gone wrong only serves to exacerbate the danger that may exist in normal activities of daily living. This danger has previously been reported by Gilmour (2004), who noted that when the helpers go home at night, no one is going to see the person with dementia until the morning. However, for some people who live alone, it is a considerably longer period of time before the next check of their well-being and safety. This emphasizes the importance of early detection and the establishment of supportive networks during the

early stages of dementia to assist the person to remain independent. Appropriately targeted resources such as in-home support, social support, and home modifications may minimize the risk of injury and self-neglect (Gabriel et al., 2014). However, early detection may be more problematic with people who live alone, because limited contact with family, friends, or community services may delay the recognition of the early signs and symptoms of cognitive impairment.

Assistive technologies and home modification established during the early stages of dementia may support the person to continue to function safely at home. *Assistive technology* is a broad term that refers to a product, equipment, or a device which helps people with disabilities to maintain their independence or improve their quality of life (Fleming & Sum, 2014). However, determining the effectiveness of assistive technologies is complex because the term covers a wide range of possible devices and expected outcomes are highly variable (Bowes, Dawson, & Greasley-Adams, 2013). In addition, current research is quite limited, so has been unable to establish whether assistive technologies make a positive difference to the lives of people with dementia (Fleming & Sum, 2014).

Findings also highlight the importance of planning for the future. People with dementia have the right to make decisions about their future, so it is important that they are given the opportunity to plan and record their wishes while they still have the capacity (Alzheimer's Australia NSW, 2012). This advanced care planning helps put the person at the centre of the care, knowing their needs, wishes, intentions, plans, and directives as early as possible. When used intelligently, these advanced directives provide an appropriate way to share decision making by the person with dementia, family, and professionals (Vollmann, 2001). In the context of people who have dementia and live alone, this planning process also provides a timely opportunity for community care clinicians to discuss strategies that will support the person in their home.

It has been recognized that an informed and effective workforce for people with dementia is needed (Department of Health, 2009), because an educated community-based workforce is a critical element for ensuring appropriate in-home support for this population. Generic core workforce dementia competencies have also been proposed (Tsaroucha, Benbow, Kingston, & Le Mesurier, 2011). An educated workforce will better understand the challenges faced by the person who has dementia, recognize the signs that the person is not coping, and be better able to identify practical strategies that may assist them to live independently for as long as possible. Although it is recognized that people who have dementia and live alone can have a shorter timeframe to entry into residential aged care, timely responsive services may delay admission to long-term care (Alzheimer's Australia NSW, 2013). Some people with dementia receive assistance from paid carers, who provide practical in-home support. But as noted by one participant in this study, if the

paid carer's duties are to assist with personal care such as showering, then they may not look any further than that task. So in addition to education, strategies such as checklists for paid carers should be considered. A paid carer workforce that is alert to the risks faced by people with dementia who are living alone would provide more effective in-home monitoring and enable early detection of those people experiencing difficulties with self-care. .

Interacting With Other People

The findings of this study highlight the dangers that may be present during social encounters as a result of the trusting nature and lack of insight of some people with dementia. Those who lack support are easy targets for unscrupulous people and companies. Community care clinicians in this study reported a number of examples where people with dementia were taken advantage of during encounters with other people. This reflects similar reports in the literature. Gilmour reported how a bogus tradesperson took a person with dementia to the bank to get money (Gilmour, 2004). A study by Tierney et al. found that the second most common problem faced by people living alone with dementia was failure to judge fraudulent activity or to ensure that their finances were secured (Tierney et al., 2001).

The risk of being exploited is not necessarily a part of older age, but age-related cognitive, physical, and social factors can contribute to a person's vulnerability (Kurrle, Sadler, & Cameron, 1992). Greenspan suggests that this vulnerability concerns credulity and gullibility, that people readily believe what is unlikely to be true and are susceptible to manipulation and deception (Greenspan, 2005). Old age itself does not predispose a person to being deceived and defrauded, but the vulnerability that can develop later in life does increase the risk (R. G. Smith, 1997). Even mild cognitive impairment may increase the risk of becoming a victim to a fraud scheme (Tueth, 2000). Fraud schemes target different populations, but seniors who are widowed, single, and living alone are often victims of these schemes (Cohen, 2008). Older people who have previously been victims of personal crimes such as robbery and theft are twice as likely to be a victim of fraud (Temple, 2007). Repeat victimization of older people by telemarketers is also prevalent, and it has been reported that lists of people who have been victims are sold to other telemarketers (Aziz, Bolick, Kleinman, & Shadel, 2000; Suh & Erdem, 2009). The disconnection from the community that often happens to people living alone with dementia may contribute to their risk of becoming a victim of one of these fraudulent schemes, because they must negotiate these social encounters alone.

Identifying people in the community who may be more susceptible to consumer fraud schemes is not a simple process; it is made more difficult by those people who attempt to hide their cognitive impairment. Cohen (2006, 2008) suggests that just as conmen have learnt to identify vulnerable

older people, the general public and those who work with seniors should also become more aware of the problem. It has been recommended that dementia clinics, physicians, and professionals who work with older people who may be more susceptible to fraud should familiarize themselves with consumer fraud schemes and routinely question their clients about their financial arrangements (Cohen, 2006, 2008). In addition, when making decisions about end of life care and planning for the future, advance financial planning should also be considered (Cartwright, 2011). Having strategies to assist the person manage their money may help reduce some of the risks that exist in the community. Education of family and informal carers may also be warranted to alert them to the potential danger of fraud and so help ensure that the support they offer to their relative goes beyond just their physical needs. Wider community dementia education has also been recommended for workers who have contact with people with dementia, such as chemists, general practitioners, bank tellers, and retail professionals (Alzheimer's Australia NSW, 2013). This education should outline the processes that make an older person with poor cognitive function more susceptible to consumer fraud schemes so that key community workers have a better understanding of the risks that accompany dementia, particularly for those with limited or no social support.

Living Safely at Home Alone

This study highlights the complexity of the concept of living alone, and the many different ways by which living alone can take shape in the lives of people with dementia. Some people with dementia have no immediate family to provide support, so they do live alone. Others are alone for a period of time each day, for example, overnight or during the day when family work. The common theme in these different constructions of living alone is that the person with dementia has periods of time with no support, supervision, or companionship. Table 1 lists the different ways that living alone took shape in this study. This highlights that it is not only those people who are the sole occupant of a dwelling who may lack the support needed to ensure their safety and well-being. Therefore, the findings highlight that a broader understanding of the concept of living alone may be needed to better represent the complexity of life in the community for the person with dementia. This broader understanding of living alone would better inform the allocation of community-based resources for people with dementia.

The findings of this and other studies suggest that some people with dementia withdraw into their home. Although many people with dementia hope to maintain an ordinary way of life (Fukushima, Nagahata, Ishibashi, Takahashi, & Moriyama, 2005) and value the outdoor environment (Duggan, Blackman, Martyr, & Van Schaik, 2008), the outside world can become an intimidating place. Duggan et al. described a "shrinking world" for people with dementia, a

decline in independence as outdoor places such as town centers become “no-go” areas (Duggan et al., 2008). People with dementia can sometimes find themselves in an unfamiliar world when they are outside of their home, and as a result are not able to cope (Phinney & Chesla, 2003). Going outside and engaging with the community reminds some people of their cognitive impairment (De Witt et al., 2009). The fear of exposure contributes to people distancing themselves from activities in the community. Some of the concern about engaging with the community may relate to the stigma associated with dementia, and the fact that acceptance of people with dementia by the public has changed very little despite the increased awareness of the condition (Batsch & Mittelman, 2012). Although many continue to go out into the community, some avoid socially demanding situations (Mitchell & Burton, 2006).

Withdrawal into the home and severing links to the community is a complex phenomenon because the home is far more than just a place to live. The home has been described as haven, retreat, and a refuge (Mallett, 2004). It has economic value and brings advantage for the home-owner, but is more than a shelter and an investment (Dupuis & Thorns, 1996). Importantly in the context of dementia, the home is a private and familiar realm that is removed from public scrutiny and surveillance (Mallett, 2004). This concept of home concerns the relationship between person and dwelling, the place where they “feel at home” (Gillsjo & Schartz-Barcott, 2010, p. 6). The home is a source of identity and status (Mallett, 2004) and also plays a crucial role as a source of comfort and connection to family (Percival, 2002). Continuing to live in the family home is important in the context of dementia because it assists the person to cope with the challenges of memory loss (Gabriel et al., 2014) and the daily household routines provide a sense of purpose.

It has been recognized that home is critical to the quality of life of people with dementia and that they are more likely than others in the community to spend a significant proportion of their time at home (Gabriel et al., 2014). However, decisions about whether it is still safe for the person to remain at home are difficult and complex. There is a tension for service providers that exists between allowing the person with dementia to have the opportunity to take risks and the obligations of duty of care (Alzheimer’s Australia NSW, 2013). This tension is about safety and supervision versus risk and independence (MacCourt & Tuokko, 2010). These decisions may be more difficult when there are no close family or friends to assist the person with dementia. The challenge for service providers is to find the best balance between freedom and risk. As previously noted, assistive technologies may allow some people with dementia to continue to live safely at home. For example, televideo monitoring may improve medication self-administration accuracy for the person with mild dementia who lives alone (G. Smith, Lunde, Hathaway, & Vickers, 2007). Home modifications may also have a place for some people, and participants in this study described

modification of home appliances such as ovens to minimize the risk of fire for their clients. In home, monitoring and wearable sensor devices may also have a role (Biswas et al., 2010). However as with other types of assistive technologies, the effectiveness of surveillance strategies to help support the safety of people with dementia has yet to be established.

Conclusion

The progressive deterioration of cognitive function that accompanies dementia makes living alone in the community difficult. Although it has long been recognized that this population faces many challenges, there is surprisingly little information about the nature of these challenges. The implications for practice, much like those who live alone with dementia, have been ignored for the last two decades. This study explored the stories of community health and social care clinicians and identified the risks that this population poses to themselves, the dangers that are present during encounters with other people, and the importance of the home for people with dementia. Findings give an important insight into the challenges that are faced by this population and emphasize the importance of adequate community-based support and broad-based community education. Implications for research include the need to reconsider how *home alone* is defined by researchers, to better represent the reality of life for people with dementia living in the community. There is also an urgent need to explore strategies and technologies that support the physical, social, and health needs of this population, and help them remain connected to their community, so that they can continue to live at home independently for as long as possible. Being mindful of the challenges faced by people with dementia will help community support agencies better meet their individual needs.

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