

## **‘I know they are not trained in dementia’: Addressing the need for specialist dementia training for home care workers**

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### **Abstract**

Global population ageing has meant a rapid increase in the numbers of older people with dementia, most of whom live in their own homes. Staying at home is an important determinant of health and wellbeing. As care needs increase, the quality of community support older people receive directly influences their capacity to remain in their own homes. While many are supported informally by family carers, formal support provided by home care workers often enables them to remain at home for longer. However, providing community-based care for people with dementia can be challenging. Workers often lack training in dementia-specific care for clients with increasingly complex needs, and typically work without direct supervision. As the demand for person-centred home care for people with dementia increases, specialist dementia training for home care workers is urgently needed. In this qualitative study, we used in-depth interviews of a purposive sample, comprising 15 family carers and four older people with dementia, to understand the experience of receiving community care. Data analysis was guided by Braun and Clarke’s approach to thematic analysis and revealed five overlapping themes, relating to home care workers’ understanding of dementia, person-centred care, communication and rapport, mutual collaboration, and the influence of organisational constraints on continuity of care. Although participants acknowledged that service providers operated under challenging circumstances, they were frustrated with home care workers’ lack of dementia knowledge and inconsistent staff rostering. Conversely, an understanding of the lived experience of dementia, effective communication and rapport, and continuity of care contributed significantly to a positive experience of receiving care. The findings of this study will be used to inform the essential elements of a training program aimed at enabling and empowering a skilled, specialist home care workforce to support older people with dementia to live well at home for as long as possible.

### **Keywords**

Caregivers, dementia, family carers, home care, qualitative

### **What is known about this topic**

- Most older people want to remain in their own homes, including after receiving a dementia diagnosis
- Older people with dementia need increasing levels of support
- Providing community-based care for people with dementia is complex and challenging

### **What this paper adds**

- Demand will continue to grow for high quality, person-centred community care
- There is an urgent need to improve home care workers' dementia knowledge and skills
- People with dementia and family carers want to contribute to the development of dementia-specific training programs

## 1 INTRODUCTION

Global population ageing has heightened interest in understanding what it means to age well and how quality of life in older age can be optimised. One of the most significant influences in this regard is the older person's ability to remain at home (Nosraty, Jylhä, Raittila, & Lumme-Sandt, 2015; Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Globally, older people want to remain in their own homes as they age (Hansen, Hauge, & Bergland, 2017; Hjelle, Tuntland, Førland, & Alvsvåg, 2017; Low, White, Jeon, Gresham, & Brodaty, 2013; Wiles et al., 2012). However, growing care needs often jeopardise the ability of the older person to stay at home (Lillo-Crespo et al., 2018; Nosraty et al., 2015). This is most challenging for older people with dementia, who require increasing levels of support to stay as independent as possible and in their own homes (Allen & Wiles, 2014; Toot, Swinson, Devine, Challis, & Orrell, 2017).

Dementia is an overarching term that describes a collection of progressively worsening symptoms caused by disorders affecting the brain. It can affect a person's ability to think, reason, remember and communicate. Other symptoms include, apathy, withdrawal and the loss of ability to perform everyday tasks. Consequently, people with dementia become increasingly dependent on support to complete activities of daily living. Older people still want to remain in their own homes after a diagnosis of dementia has been received (Hansen et al., 2017; Hjelle et al., 2017; Wiles et al., 2012).

In response to growing worldwide demand for health and social care, policy makers and service providers are developing strategies and interventions that reflect their capacity and resources, and align with their country's public health principles, priorities and culture (Manthorpe & Samsi, 2016; World Health Organization, 2017). The standard and availability of support available to people with dementia has a direct influence on their independence, health and wellbeing, which, in turn, determine their quality of life (Eggenberger, Heimerl, & Bennett, 2013; Hallberg et al., 2016; Rothera et al., 2008). A person-centred framework is accepted widely as the gold standard in this regard (Downs & Collins, 2015; Love & Pinkowitz, 2013). Commonly associated with the work of Kitwood and Bredin (1992), the principles of person-centred care recognise that each person with dementia has an enduring sense of self that comprises their individual feelings, thoughts and preferences (Manthorpe & Samsi, 2016). Fundamental to person-centred care are effective verbal and non-verbal communication, developing rapport, and being focused on the person, rather than completing a task (Hansen et al., 2017; Livingston et al., 2017). Care should be provided in a way that considers what the person with dementia understands and wants, and what they may be attempting to communicate with the carer. In addition, carers should reflect regularly on their practice, to ensure that their support remains person-centred (Berglund, Gillsjo, & Svanstrom, 2018).

While family carers often provide initial assistance with a person's activities of daily living, additional support is frequently needed to maintain the health, independence and safety of the person with dementia, particularly as their symptoms progress (Lyberg, Holm, Lassenius, Berggren, & Severinsson, 2013; Toot et al., 2013). This additional support is typically provided by service providers that receive payment from the individual or via government-subsidised arrangements (Shiba, Kondo, & Kondo, 2016). In Australia, for

example, aged care services are provided through the government's Commonwealth Home Support Programme (CHSP) or Home Care Packages program (HCPP) ([www.agedcare.health.gov.au](http://www.agedcare.health.gov.au)). As an 'entry level' program, the CHSP provides relatively low intensity services to older people who need minimal support to help them maintain their independence and continue living in the community. The second tier of support is provided by the HCPP program, which provides coordinated packages of services to enable older people with complex care needs to live independently at home. The four levels of HCP provide different subsidy amounts towards the cost of service and care delivery.

The frontline workforce that visits and cares for people in their homes, often on a daily basis, is made up of home care workers (also called community carers or personal care attendants). They complete tasks such as personal care (e.g. showering, toileting, and dressing), domestic duties (e.g. cooking, cleaning, and gardening), transport (e.g. to medical appointments and social engagements) and respite (e.g. companionship). Appropriate support reduces unmet needs and enables the person to remain connected to family and community for longer by delaying or preventing a transition into residential care (Rapaport, Livingston, Murray, Mulla, & Cooper, 2017; Samus et al., 2014). In addition, being in a familiar home environment and neighbourhood can help the person with dementia to cope better with their everyday lives, particularly as the home gradually becomes the locus for everyday activities (Sixsmith et al., 2014).

However, providing community-based care for people with dementia is challenging: the needs of the client are usually complex; home care workers are often inadequately trained in providing dementia-specific care; and they typically work in isolation and in varied environments which bring their own challenges (Eggenberger et al., 2013; Hallberg et al., 2016). While improvements have been made to the quality of dementia care provided in residential (long term) aged care facilities, particularly in developed countries (Gilster, Boltz, & Dalessandro, 2018; Travers, 2017), it is unclear whether community-based services are meeting the needs of people with dementia and their family carers (Vecchio, Fitzgerald, Radford, & Fisher, 2016). The extent to which the fundamental principles of person-centred dementia care are applied in the community care setting are also uncertain (Love & Pinkowitz, 2013). While evaluations of policy and practice should be considered from the perspectives of clients, carers and service providers, the literature shows broad agreement on the importance of person-centred care and the need to improve the standards of home care for people with dementia (Goh, Gaffy, Hallam, & Dow, 2018; Hansen et al., 2017; Low et al., 2013).

As the demand for person-centred home care for people with dementia continues to increase, the need for specialist dementia training programs for home care workers is clear (Goh et al., 2018). To ensure that these programs genuinely meet the needs of those receiving care, they should be developed in collaboration with people with dementia, family carers, home care workers and service managers. The aim of our overall study was to develop an evidence-based dementia specialist training program for community dementia care. Using a co-design approach, we asked people with dementia and their carers about their experiences of receiving home care, how their experiences could be improved and what main elements should be included in a specialised training program aimed at effecting a highly skilled, knowledgeable and

empathic workforce. The specialist Promoting Independence Through quality dementia Care at Home (PITCH) program is currently being evaluated through a randomised controlled trial (ACTRN 12619000251123). In this paper, we present the findings from in-depth qualitative interviews with older people with dementia who were receiving support through the Australian government's CHSP or HCP programs, and their family carers. The purpose of the interviews was to explore their experiences of receiving home care services and to invite suggestions for improvements to community support for older people with dementia. The experiences and recommendations of home care workers, case managers and service managers who participated in the study will be reported elsewhere.

## **2 METHOD**

### **2.1 Design**

A qualitative approach to data collection and analysis was considered appropriate for this study, as it allows the emphasis to be placed on the subjective experience of receiving home care as a person with dementia and as a family carer.

### **2.1 Participant recruitment**

A purposive sample of people with dementia and family carers was sought. Inclusion criteria were: (i) women and men of any age, with a formal diagnosis of dementia of any type and stage, currently receiving home care services funded by the Australian government; and (ii) family carers of any age or sex, who care or previously cared for a person with a diagnosis of dementia, who meets criteria (i). Individuals who met either criterion were eligible to participate on their own or with the person who receives or provides care. The exclusion criterion was: a person who is unable to provide informed consent.

Project partners distributed information on the study to recipients of home care services. Partner organisations included non-profit, private, and multicultural providers of home-based services. Advertisements and letters of invitation were also disseminated across stakeholder groups known to the research team. Those interested in participating were asked to contact the researchers directly, at which point information on the study was provided by telephone or mail. If they met the inclusion criteria and wished to take part, arrangements were made for individual interviews to occur at a place and time of their preference.

### **2.2 Data collection**

Data were collected using semi-structured, qualitative interviews by members of the research team. This approach enabled the collection of rich and in-depth data. The interview questions were developed in conjunction with a project advisory group, which included people with dementia, consumer consultants and family carers. In this collaborative forum, the research team identified the key issues to be addressed during the interviews. The flexible interview schedule allowed the researchers to move from broad, open-ended questions to more specific, probing questions. Although participants were invited to describe the experience

of receiving a dementia diagnosis, and their understanding of the type and/or stage of their dementia, the focus of the interviews was their experiences of home care (Table 1). After discussing a particular topic, the researchers summarised and verified participants' responses. This increased the credibility of the study (Holloway & Galvin, 2016). Each interview lasted approximately 90 minutes and was audio-recorded and then transcribed verbatim by a professional transcription service.

\*\*\* Place Table 1 about here \*\*\*

### **2.3 Data analysis**

The researchers followed Braun and Clarke's (2013) six-step approach to qualitative data analysis to identify and develop themes from the data. Initially, anonymised interview transcripts were read and reread to gain a broad understanding of participants' perceptions and experiences (Step 1: familiarisation with the data). These were grouped together to provide an account of the experience of receiving formal home care. The researchers then coded scrutinised transcripts in NVivo (Version 11) (QSR International, Melbourne, Victoria) (Step 2), and then clustered codes into themes (Step 3). As data analysis progressed, themes were refined further and related sub-themes identified (Steps 4 and 5). The use of exemplars to illustrate each theme (Step 6) supported the authenticity of the findings and transferability to other situations (Braun & Clarke, 2013).

Initial data analysis was undertaken by MP, followed by independent review by AG. This is a reflexive activity, as the researchers ask generative questions of the data, make comparisons and identify possible themes and sub-themes (Denzin & Lincoln, 2013). The process of fracturing the data compels researchers to address any preconceived notions and reduce subjectivity or bias (Holloway & Galvin, 2016). In the current study, any differences in coding or theme identification were resolved through discussion until consensus was achieved. Although broad themes were informed by the overall research question, the researchers identified latent themes comprising ideas, patterns and assumptions. Thus, data analysis was theoretical and deductive ('top down'). A semantic analysis of the data progressed from initial description and summary, to interpretation and discussion. The use of *in vivo* codes—that is, in participants' own words—add to the credibility of the findings, as they provide an accurate representation of participants' experiences and the meaning they attach to them. Although participants were not asked to review preliminary findings, most extended their participation in the study by attending co-design workshops, held several months after the individual interviews. In those forums, participants were given the opportunity to verify their experiences or question the combined preliminary findings from the interviews.

### **2.4 Ethical considerations**

Ethical approval was obtained from Austin Health Human Research Ethics Committee (HREC/17/Austin/537). All participants received written information on the study and were informed of their right to withdraw from the study at any time. Written consent was obtained before the interviews commenced. Data were de-identified and pseudonyms allocated. Two participants elected to use their own names.

### 3 FINDINGS

#### 3.1 Description of the sample

Four people with dementia and 15 family carers were interviewed (n=19). By coincidence, all four older people with dementia had received a diagnosis of Alzheimer's disease. One person received formal support through a Commonwealth Home Support Programme, while three received a Home Care Package. Of those three, two were at Level 4 (the highest level of support available) and one at Level 2. Demographic details are presented in Table 2.

\*\*\* Place Table 2 about here \*\*\*

#### 3.2 Themes

The main themes identified through data analysis related to home care workers' understanding of dementia, providing person-centred care, the importance of communication and rapport, the need for mutual collaboration, and the influence of organisational constraints on continuity of care. Each theme presents negative and positive experiences of receiving community care from the perspectives of people with dementia and family carers.

##### 3.2.1 Home care workers' understanding of dementia

Overall, participants perceived that home care workers lacked appropriate knowledge and understanding of dementia. Poor knowledge of the symptoms, behaviours and needs of the individual had a negative effect on the experience of receiving care.

*People just expect that you'll be this, that and the other thing because you've got the 'D' word [dementia]. They don't understand it's a set of symptoms ... there's very low knowledge (Marie, family carer).*

*I don't think all [understand dementia]. I think some just think, "Oh, it's just forgetful, just old age." And I've heard that repeatedly. But it's not old age (Sofia, family carer).*

Although participants assumed that dementia training had been provided to home care workers, they questioned whether it was being applied appropriately in a practical setting.

*I have the impression that if they had been given any training, I wasn't sure how ... there's a difference between doing the training and actually being able to apply it (Erica, family carer).*

*It was clear that she didn't really know [about dementia]. I think a lot of them [think], "Oh yeah, we learned that," but don't really put it into practice (Joan, family carer).*

This was most apparent in the ways in which home care workers made assumptions about the person's behaviour or abilities.

*They need to know that the messages aren't getting through. So, it's no good saying, "Do you want to go to the toilet?" because Dad is not going to know if he needs to go (Caroline, family carer).*

*They should understand that the behaviour can go haywire [be unpredictable]. Understand that the brain is preventing or causing these aggressive behaviours ... it's not that person, this is not who they are ... this is what the disease is doing to them (Joan, family carer).*

Conversely, appropriate knowledge of dementia enabled a positive experience of receiving care. Several examples were given to illustrate appropriate and effective support, and the sense that a connection could be forged between the home care worker, person with dementia and family carer.

*[Home care worker] was just friendly. She was someone that would be nice to chat with. And she'd come and do some social things, rather than coming in and saying, 'Okay, time to have a shower, time to clean, time to do this.' (Helen, family carer).*

### **3.2.2 Providing person-centred care**

Participants explained how a home care worker's person-centred approach influenced positively the care experience for the person with dementia and their family carers. Person-centred care required knowledge of dementia and familiarity with the needs and preferences of the person with dementia.

*Personalised care is terribly, terribly important, and the understanding of the disease, the illness is very, very important (Sofia, family carer).*

*Knowing about dementia and knowing about the person you're caring for are two different things. I think they [home care workers] probably need a little briefing on the person they're caring for, because every person is different (Helen, family carer).*

Person-centred care was strengthened when family carers could inform and educate home care workers of the best way to tailor tasks and activities in a way that reflected the individual needs of their loved one. Referring to the importance of maintaining a sense of autonomy and choice, participants wanted home care workers to be sensitive and responsive to their individual needs and preferences.

*I think you ought to speak to people before you start doing things and give them a choice [enable] of feeling self-esteem (Debra, person with dementia).*

*A lot of them [home care workers] don't stop talking and I'm not a person that talks a lot and half the time I'm not really interested in what they're trying to tell me anyway (Trevor, person with dementia).*

When they focused on the person rather than the tasks, home care workers demonstrated quality of care that had a positive effect on the person with dementia and their family carers.

*Most of the people who come are lovely and fantastic ... it's a bit like having a friend, it's not just ticking the boxes of 'he's had a shower' and 'he washed this and this and this'. It's got to do with the quality of that time (Carol, family carer).*

*They ended up as part of the family, as far as I'm concerned ... they just became friends doing a job (Petro, person with dementia).*

### 3.2.3 The importance of communication and rapport

Participants regarded rapport as essential to developing a connection or relationship with home care workers. While rapport happened naturally for some, a process of consciously building rapport was sometimes needed to ensure effective care for the person with dementia.

*One of the ladies [home care workers] had a good rapport with mum ... she had a good way of handling and dealing with her and getting things done and just made mum feel comfortable (Helen, family carer).*

*Just talking to me ... we talk about stuff that that I can understand. I can talk to him ... he's a good guy and he's helpful for me, as much as he does (Trevor, person with dementia).*

Several examples were given of how home care workers had developed rapport with the person with dementia, based on effective communication. This was often related to social engagement and participation in meaningful activities.

*There's another lady that came and for some reason she really connected with me more than the others. I could relate [to her]. I felt they just really didn't care and then the lady that has recently come in, she seemed just to connect (Trevor, person with dementia).*

*By the time [home care worker] has finished, we're roaring with laughter about a joke that I said or she said, or we ended up playing a packet of cards that she put out and we started playing funny cards (Pedro, person with dementia).*

However, an understanding of effective communication skills and strategies for developing rapport with a person with dementia were often lacking. This often reduced opportunities for meaningful engagement with the person with dementia.

*They just need basic rapport building skills that you would need in any hospitality situation, and they appear to not have it ... I know they're not trained in dementia (Ruth, family carer).*

*I would prefer, obviously, someone who can engage. I'm looking for someone who is very experienced with dementia, someone who will take Mum out, give her some engagement (Joan, family carer).*

### 3.2.4 The need for mutual collaboration

Family carers highlighted the importance of improving the collaboration between themselves and home care workers. They wanted to share the knowledge and skills they had developed, to enable effective care for the person with dementia.

*They have to listen to the other carer, like me, because I'm the one that's doing it 24-hours a day, seven days a week. I'm living it. So, if I don't know what's going on, nobody else is going to know what's going on (Caroline, family carer).*

To improve communication and collaboration, several family carers had implemented a 'message system', whereby they and the home care workers wrote notes to each other. This served as a form of

handover between family carers and different home care workers. However, family carers were unsure whether the message books were effective.

*We've got the communication book, but they weren't filling it in because they had different people all the time. We've now said, 'Okay, fill it in' and I can fill it in, too, if I've got stuff here that I have to tell them and they can write what they've done during the day, which is working out much better (Helen, family carer).*

*We have a book that we write things in ... and the carer [home care worker], there's space for them to write a comment. So that did work for a little while, but I think we've lost the book (Kim, family carer).*

Concerning the ability to collaborate on the care provided to the person with dementia, one point of contention related to the common policy of service providers that family carers were unable to contact home care workers directly. Although most understood the reasons for this policy, they were frustrated with the roundabout way in which they had to communicate with home care workers.

*One of the frustrations is that you have absolutely no contact. The agencies are very strict on no mobiles, but it means that you've got no contact. If I desperately need some medication to be picked up and I just need to say, 'Hey, could you on your way there go to the chemist?'... I've got no way ... (Suzy, family carer).*

*There has to be communication. This business of 'they can't talk to me' ... how can I tell them anything of what's going on with him? It doesn't make sense to me (Caroline, family carer).*

The importance of mutual collaboration was described by several participants.

*I need to know that things are okay with [husband]. So, it's as much engaging with me as it is with him (Carol, family carer).*

*When they're handing my mum over [at the end of a shift], I need to know what's happened in those four hours. I also see it as a part of my role to give them whatever information they need to do their job (Maria, family carer).*

### **3.2.2 Organisational constraints and continuity of care**

Notwithstanding organisational constraints, there were clear benefits to those who could develop rapport and collaborate with their designated home care worker. Consistency between home care workers and continuity of care was valued by all participants.

*Consistency does help mum and dad ... having the same person, having the routine of 'he comes on this day' ... we're trying to establish a relationship with someone (Erica, family carer).*

*He needs that connection and he needs to be understood and he needs to be respected and he needs to be liked. And that doesn't just mean, you know, ticking the boxes [only doing tasks] (Carol, Family carer).*

However, multiple examples were given of difficulties that occurred with new home care workers arriving for shifts.

*It's very confusing for someone who has no short-term memory to have different people coming in all the time. They get very anxious and they're also very suspicious (Francis, family carer).*

*It's a variation all the time. It's totally different to anything I'm used to. I think the people that come to see me, they're different. I don't know why [they're] different ... and they change all the time (Trevor, person with dementia).*

Although participants acknowledged that service providers operated under challenging circumstances, their frustration with inconsistent routines and staffing was evident.

*It's only when we get the fill-ins that the problems arise, because they've got no clue what they're doing (Caroline, family carer).*

A lack of staff continuity had a direct effect on family carers, as they had to be available to inform and guide new staff who were unfamiliar with the client's needs and preferences.

*That's the one thing, the lack of continuity, that's very frustrating ... it's three days, three different people. Whenever there is someone new, I've taken mornings off work so I can at least meet the person (Helen, family carer).*

#### **4 DISCUSSION**

This study furthers understanding of the experience of community-based dementia care from the perspectives of older people with dementia and their family carers. The main themes abstracted from participant interviews related to home care workers' understanding of dementia, person-centred care, communication and rapport, the need for mutual collaboration, and the influence of organisational constraints on continuity of care. These themes are interconnected and typically influence each other.

Consistent with the literature (see, for example, Berglund et al., 2018; Goh et al., 2018; Low et al., 2013), there is a clear need for improved dementia knowledge and competence in dementia-specific care, flexible approaches to care, continuity of care and ongoing staff education. Overall, participants reported that home care workers lacked a fundamental level of dementia knowledge. Examples were given of inaccurate or misguided assumptions made of the person with dementia, particularly concerning their capacity to communicate, engage and participate in activities. Poor knowledge had a direct influence on the experience of receiving person-centred care that was tailored to the needs and preference of the person with dementia, and informed by family carers.

As participants articulated fundamental principles of person-centred care, they highlighted the importance of communication and rapport, and the need to focus on the individual rather than on completing a practical task. These descriptions are supported by ample evidence in favour of communication and rapport as a determinant of health and wellbeing of older people with dementia, and integral to person-centred care (Hansen et al., 2017; Lillo-Crespo et al., 2018).

Care that is well-adapted to the needs of the person with dementia and family carers is more likely when services are coordinated to support continuity of care. In a study of factors which may lead to crisis for

people with dementia and family carers, Toot et al. (2013) highlighted the importance of continuity of care in enabling a level of familiarity that allowed the care worker to recognise and respond to the person's needs. From family carers' perspectives, continuity of care reduced the burden of having to renegotiate services or reorient workers to their particular context. It also enabled a level of predictability and familiarity that is highly valued by people with dementia and family carers (Hansen et al., 2017).

Integral to the experience of receiving care, the predictability made possible by continuity of care facilitated the development of effective and trusting relationships with home care workers. Participants described the positive effects of being able to establish an effective relationship with home care workers and the importance of mutual collaboration to best meet the needs of the person with dementia. However, person-centred care is possible only when staff demonstrate the required values and practices, and work in a suitable environment with supportive processes that enable person-centred outcomes (Low et al., 2013; Manthorpe & Samsi, 2016). Thus, the extent to which improvements may be achieved depends on service providers' ability to ensure quality and continuity of care in a fragmented industry whose workers who are typically employed on a casual or part-time basis (Berglund et al., 2018; Palesy, Jakimowicz, Saunders, & Lewis, 2018). Notwithstanding organisational constraints, the value attributed to continuity of care, rapport and communication by people with dementia and family carers, it is likely to be a case of 'when', rather than 'if', these practices will need to be addressed (Reid & Chappell, 2017).

#### **4.1 Limitations**

There are several potential limitations to this study. First, the findings of qualitative studies are context-bound to the participants and settings in which data collection occurred. While generalisability is not a requirement of qualitative studies (Sandelowski, 2015), the themes can be verified, thus supporting the potential to apply this new knowledge to other settings and conditions. Second, only a small number of people with dementia and no male carers were interviewed. In addition, the fact that only diagnoses of Alzheimer's disease were reported means that the different needs of people with other forms of dementia were not captured. Consequently, rather than achieving data saturation as a "generic quality marker" (O'Reilly & Parker, 2013, p. 191), we were able to explore a richness of information from participants. Third, recruitment occurred through study partners, which may have resulted in an atypical sample of older adults and family carers who were well supported by home care services. Finally, by focusing on recipients of government-subsidised services, the study did not include full-fee paying clients, whose experiences of the quality and accessibility of home care may have differed.

## **5 CONCLUSIONS**

Older people want to remain at home, in the community, as they age, including after receiving a diagnosis of dementia. Demand will continue to grow for high quality, person-centred dementia community care, to enable them to remain at home for as long as possible. There is a clear need to improve home care workers' dementia knowledge and skills, to enable the provision of person-centred care based on effective

communication and rapport, tailored activities and mutual collaboration with family carers. These findings have formed the core of a new evidence-based training program for community dementia care, developed through a co-design process with older people with dementia, family carers, home care workers and service managers. On the service provider level, changes are needed to enable continuity of care in a way that optimises the home care worker's understanding of the individual client's needs and preferences. The findings of this study directly inform current policy and also future research, particularly the expression of need from family carers for the development of a dementia-specific training and education program for them, which ideally should be co-developed with end users.

## REFERENCES

- Allen, R. E. S., & Wiles, J. L. (2014). Receiving support when older: What makes it ok? *The Gerontologist*, 54(4), 670-682. doi:10.1093/geront/gnt047
- Berglund, M., Gillsjo, C., & Svanstrom, R. (2018). Keys to person-centred care to persons living with dementia: Experiences from an educational program in Sweden. *Dementia*. doi:10.1177/1471301218754454
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Denzin, N. K., & Lincoln, Y. S. (2013). The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The landscape of qualitative research* (4th ed., pp. 1-41). Thousand Oaks, CA: Sage.
- Downs, M., & Collins, L. (2015). Person-centred communication in dementia care. *Nursing Standard* (2014+), 30(11), 37-41. doi:10.7748/ns.30.11.37.s45
- Eggenberger, E., Heimerl, K., & Bennett, M. (2013). Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*, 25(3), 345-358. doi:0.1017/S1041610212001664
- Gilster, S. D., Boltz, M., & Dalessandro, J. L. (2018). Long-term care workforce issues: Practice principles for quality dementia care. *The Gerontologist*, 58(suppl\_1), S103-S113. doi:10.1093/geront/gnx174
- Goh, A. M., Gaffy, E., Hallam, B., & Dow, B. (2018). An update on dementia training programmes in home and community care. *Curr Opin Psychiatry*, 31(5), 417-423. doi:10.1097/YCO.0000000000000438
- Hallberg, I. R., Cabrera, E., Jolley, D., Raamat, K., Renom-Guiteras, A., Verbeek, H., . . . Karlsson, S. (2016). Professional care providers in dementia care in eight European countries: Their training and involvement in early dementia stage and in home care. *Dementia*, 15(5), 931-957. doi:10.1177/1471301214548520
- Hansen, A., Hauge, S., & Bergland, A. (2017). Meeting psychosocial needs for persons with dementia in home care services: A qualitative study of different perceptions and practices among health care providers. *BMC Geriatrics*, 17(1), 211. doi:10.1186/s12877-017-0612-3
- Hjelle, K. M., Tuntland, H., Fjørland, O., & Alvsvåg, H. (2017). Driving forces for home-based reablement: A qualitative study of older adults' experiences. *Health & Social Care in the Community*, 25(5), 1581-1589. doi:10.1111/hsc.12324
- Holloway, I., & Galvin, K. (2016). *Qualitative research in nursing and healthcare* (4th ed.). West Sussex, UK: John Wiley & Sons.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing & Society*, 12(3), 269-287. doi:10.1017/S0144686X0000502X
- Lillo-Crespo, M., Riquelme, J., Macrae, R., De Abreu, W., Hanson, E., Holmerova, I., . . . Tolson, D. (2018). Experiences of advanced dementia care in seven European countries: Implications for educating the workforce. *Global Health Action*, 11(1), 1478686. doi:10.1080/16549716.2018.1478686
- Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., . . . Cohen-Mansfield, J. (2017). Dementia prevention, intervention, and care. *The Lancet*, 390(10113), 2673-2734. doi:10.1016/S0140-6736(17)31363-6
- Love, K., & Pinkowitz, J. (2013). Person-centered care for people with dementia: A theoretical and conceptual framework. *Generations*, 37(3), 23-29.
- Low, L. F., White, F., Jeon, Y. H., Gresham, M., & Brodaty, H. (2013). Desired characteristics and outcomes of community care services for persons with dementia: What is important according to clients, service providers and policy? *Australasian Journal on Ageing*, 32(2), 91-96. doi:10.1111/j.1741-6612.2012.00625.x
- Lyberg, A., Holm, A. L., Lassenius, E., Berggren, I., & Severinsson, E. (2013). Older persons' experiences of depressive ill-health and family support. *Nursing Research and Practice*, 2013. doi:10.1155/2013/837529
- Manthorpe, J., & Samsi, K. (2016). Person-centered dementia care: Current perspectives. *Clinical Interventions in Aging*, 11, 1733-1740. doi:/10.2147/CIA.S104618
- Nosraty, L., Jylhä, M., Raittila, T., & Lumme-Sandt, K. (2015). Perceptions by the oldest old of successful aging, Vitality 90+ Study. *Journal of Aging Studies*, 32, 50-58. doi:10.1016/j.jaging.2015.01.002

- O'Reilly, M., & Parker, N. (2013). 'Unsatisfactory saturation': A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative research*, 13(2), 190-197. doi:10.1177/1468794112446106
- Palesy, D., Jakimowicz, S., Saunders, C., & Lewis, J. (2018). Home care in Australia: An integrative review. *Home Health Care Services Quarterly*, 37(2), 113-139. doi:10.1080/01621424.2018.1438952
- Rapaport, P., Livingston, G., Murray, J., Mulla, A., & Cooper, C. (2017). A systematic review of the effective components of psychosocial interventions delivered by care home staff to people with dementia. *BMJ Open*, 7:e014177. doi:10.1136/bmjopen-2016-014177
- Reid, R. C., & Chappell, N. L. (2017). Family involvement in nursing homes: Are family caregivers getting what they want? *Journal of Applied Gerontology*, 36(8), 993-1015. doi:10.1177/0733464815602109
- Rothera, I., Jones, R., Harwood, R., Avery, A. J., Fisher, K., James, V., . . . Waite, J. (2008). An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods. *The International Journal of Geriatric Psychiatry*, 23(1), 65-72. doi:10.1002/gps.1841
- Samus, Q. M., Johnston, D., Black, B. S., Hess, E., Lyman, C., Vavilikolanu, A., . . . Lyketsos, C. G. (2014). A multidimensional home-based care coordination intervention for elders with memory disorders: The maximizing independence at home (MIND) pilot randomized trial. *The American Journal of Geriatric Psychiatry*, 22(4), 398-414. doi:10.1016/j.jagp.2013.12.175
- Sandelowski, M. (2015). A matter of taste: Evaluating the quality of qualitative research. *Nursing Inquiry*, 22(2), 86-94. doi:10.1111/nin.12080
- Shiba, K., Kondo, N., & Kondo, K. (2016). Informal and formal social support and caregiver burden: The AGES Caregiver Survey. *Journal of Epidemiology*, 26(12), 622-628. doi:10.2188/jea.JE20150263
- Sixsmith, J., Sixsmith, A., Fänge, A. M., Naumann, D., Kucsera, C., Tomsone, S., . . . Woolrych, R. (2014). Healthy ageing and home: The perspectives of very old people in five European countries. *Social Science & Medicine*, 106, 1-9. doi:10.1016/j.socscimed.2014.01.006
- Toot, S., Hoe, J., Ledgerd, R., Burnell, K., Devine, M., & Orrell, M. (2013). Causes of crises and appropriate interventions: The views of people with dementia, carers and healthcare professionals. *Aging & Mental Health*, 17(3), 328-335. doi:10.1080/13607863.2012.732037
- Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of nursing home placement for older people with dementia: A systematic review and meta-analysis. *International Psychogeriatrics*, 29(2), 195-208. doi:10.1017/s1041610216001654
- Travers, C. (2017). Increasing enjoyable activities to treat depression in nursing home residents with dementia: A pilot study. *Dementia*, 16(2), 204-218. doi:10.1177/1471301215586069
- Vecchio, N., Fitzgerald, J. A., Radford, K., & Fisher, R. (2016). The association between cognitive impairment and community service use patterns in older people living in Australia. *Health & Social Care in the Community*, 24(3), 321-333. doi:10.1111/hsc.12212
- Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. (2012). The meaning of "aging in place" to older people. *The Gerontologist*, 52(3), 357-366. doi:10.1093/geront/gnr098
- World Health Organization. (2017). Global action plan on the public health response to dementia 2017-2025. Retrieved from [http://www.who.int/mental\\_health/suicide-prevention/en/](http://www.who.int/mental_health/suicide-prevention/en/)

Table 1: Sample of interview questions and prompts

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Can you tell me about your experience of receiving formal/paid home care?
Type and frequency of support
Alignment with current needs
Can you tell me what you like/do not like about the home care you receive?
Type and frequency
Level of interaction/engagement with home care worker
Appropriateness to current needs
Can you tell me about the role the home care worker plays in your life?
Compared to family member
Working as a team
Communication and engagement
Feeling when the home care worker leaves after a shift
How much do you think the home care worker understand about dementia?
Impact on the individual and family
Types and/or stages of dementia
Ways to provide appropriate support to a person with dementia
What do you think should be included in the PITCH training program?
Dementia knowledge
Practical strategies for providing care
Attitude and communication

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Table 2: Participant demographics

People with dementia (n=4)	
Mean age in years (range)	80 (70-92)
Gender	
Female	1
Male	3
Mean age in years at diagnosis (range)	75 (68-80)
Mean time in years since receiving diagnosis (range)	7.5 (1-15)
Family carers (n=15)	
Mean age in years (range)	64.2 (48-92)
Gender	
Female	15
Male	0
Relationship to person with dementia	
Partner or spouse	6
Daughter	9
Son	0
Mean length of time in caring role in years (range)	6.1 (1-13)