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Home-care workers' experiences of assisting people with dementia with their personal care: a qualitative interview study

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Conflict of Interest statement

There are no conflicts of interest

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Abstract

Home-care workers are increasingly caring for clients living with dementia. Workers usually have limited dementia training, are low paid and often lone working. Little is known about how home-care workers assist people with dementia with their personal care. We aimed to explore the experiences of home-care workers and the knowledge and skills they rely on when providing personal care to people with dementia. In 2020, we conducted 17 semi-structured, face-to-face interviews with home-care workers in the East of England. Analysis was inductive and thematic. Two key themes were present in the data: ‘structural conditions’ and ‘clients’ dementia-related characteristics’. For each of these we examined the challenges faced by home-care workers and the strategies they used to manage these challenges. Challenges included time allocation for visits, completing care plan tasks, lone working, communication and understanding, refusals of care, and client behaviours. To mitigate these challenges home-care workers utilised system support, time management, training and experience, and enacted a caring relationship, thought about their approach, and used distraction and communication skills. Workers relied on skills such as, relationship building, team working, observation, communication, decision-making, and interpersonal sensitivity. They drew on knowledge about the person, the person’s needs, their own abilities, company policies and procedures, and their role and responsibilities as a home-care worker. Home-care workers had more scope to mitigate client-based challenges by adapting care within client interactions, than to manage structural challenges where there was a limit to what workers could do. Despite a commissioning focus on time- and task-based care, when caring for people with dementia, home-care workers used interaction as a way to bring the person along and complete care activities. Home-care services should acknowledge the importance of interactions with people with dementia within home care and support their workers to develop interpersonal sensitivity.

Keywords: dementia, home care, domiciliary care, relationship, communication, skills, knowledge

What is known about this topic

- Home-care workers are increasingly assisting people with dementia in the community.
- Home-care workers receive limited dementia training and are often viewed as low skilled workers.

What this paper adds

- When caring for people with dementia home-care workers faced structural challenges including time allocated for visits, completing care plan tasks and lone working and challenges related to clients' dementia including behaviours, difficulties with communication and understanding, and refusal of care.
- Home-care workers used multiple skills such as communication, observation and relationship building, and drew on several forms of knowledge such as of the person, job role and their own capabilities to assist people with dementia with their care.
- Home-care workers used interpersonal interactions to get people with dementia to accept and participate in care.

Introduction

Home care, also known as domiciliary care, refers to social care provided to people in their own homes. Home care can be delivered through one or more short visits during the day or on a live-in basis. The predominant service is to provide assistance with personal care (such as washing, medications, dressing, toileting, and/or eating), although shopping, cleaning and re-enablement work can also be involved (Jefferson et al, 2018). Over the last two decades, policy changes across Europe have created a shift towards home care and away from institutional care (Prince et al, 2013). In England, those on or close to the minimum wage often staff home-care services (Jefferson et al, 2018). These services typically have persistent difficulties recruiting and retaining staff (Hall et al, 2017; Jefferson et al, 2018). The projected number of older people using publicly and privately funded home care in 2020 in England is 343.9 per every 1000 older persons (Wittenberg and Hu 2015).

In the United States, 37% of older people using home care have a dementia (Prince et al, 2013). Whereas, in England, at least 60% of people using home care services have some cognitive impairment or dementia (Carter, 2016). People with cognitive impairment or dementia often have communication difficulties, high dependency with care activities and thus need more home care hours than those who are cognitively intact (O'Brien et al, 2019). Dementia care workers are more likely to be working in home care than care homes, often working for small or medium organisations on an 'as and when required' basis (Hussein and Manthorpe, 2012). Home-care services offer important support for family carers of people with dementia (PwD) (Kampanellou et al, 2019). Family carers and home-care workers (HCWs) both have key roles in supporting the person; as such, relationships and collaborations between both parties are desirable for good overall care (Pollock et al, 2020; Larsen, Normann and Hamran, 2019). However, many people with cognitive impairment or dementia live alone making the role of HCWs key (O'Brien et al, 2019).

Home-care workers focus on reducing and managing risks to their clients, meeting their needs and assisting them to maintain their independence and human rights (Waugh, 2009; Lord et al, 2020; Sandberg, Borell, and Rosenberg, 2020). Making a positive difference to people's lives, maintaining good relationships, having autonomy, and support from the organisation have been found to contribute to high levels of job satisfaction (Ryan et al, 2004). Often HCWs spend extra time with clients or do tasks, which are outside their job description, a type of volunteerism working beyond their specified role (Turner et al, 2018; Schneider et al, 2019). However, this may be due to a perceived lack of clarity defining the HCW job role (D'Astous et al, 2019).

More dementia training for HCWs needs to be developed and evaluated (Polacsek et al, 2019; Goh et al, 2018), along with more support from other professional occupations (Manthorpe et al, 2019). Particularly since staff can experience dementia-related work stress, adding to the emotional labour required from their day-to-day work (D'Astous et al, 2019).

Commissioning in this social care area focusses on time- and task-based care (Jefferson et al, 2018). Therefore, the physical needs of the person are often prioritised higher than their psychosocial needs. HCWs are perceived to be responsible for meeting both needs (Hansen, Hauge & Bergland, 2017). Not meeting a client's needs is viewed as a serious failure (Schneider et al, 2019). However, both physical and psychosocial needs can be met when staff attend to the person at the same time as the body (Schneider et al, 2019). As part of this, person centred communication can contribute to client well-being (Riachi, 2018).

Considering the complexities of attending to the person as a subject and their body as an object while also compensating for losses associated with dementia and being often the only worker present. We aimed to understand HCWs' experiences of, and knowledge and skills for, providing assistance with personal care to PwD.

Methods

Settings and participants

We contacted 24 home care services in one clinical commissioning group area, crossing two counties in the East of England via telephone or email. To services expressing an interest, we sent leaflets to be distributed to their home-care staff. Home-care services were situated in the target geographical area and supported people living with dementia. Home-care workers had experience of supporting PwD with their personal care. Interviews took place at home-care services' main premises and HCWs' homes. Participants were informed about the goals of the study and informed consent was taken. An interview topic guide was refined as the study progressed and covered areas such as usual practice, personal care, training, support and risk. AR (PhD), a female researcher experienced in qualitative research and health and social care research with vulnerable populations conducted the interviews. After an initial phone conversation to make introductions and arrange the interview, interviewees had a one-off private contact with the researcher. Interviews were semi-structured, face-to-face, and audio recorded and transcribed verbatim. No field notes or member checking were used. Participants received a small honorarium voucher as a thank you for their time. One potential participant could not make time for an interview. We have used the COREQ reporting checklist for qualitative research (Tong, Sainsbury, Craig, 2007).

The Queen's Square Research Ethics Committee (London) reviewed the study and gave a favourable ethical opinion. Reference: 18/LO/1677, IRAS Project ID: 251339. Pseudonyms are used throughout.

Data Analysis

Inductive Qualitative Content Analysis was used (Elo and Kyngas, 2008). Both authors individually engaged with the audio recordings and transcripts to become familiar with the data and start to draw out major themes. A meeting was held to discuss initial ideas, following this, further engagement with data, refinement and meetings took place. Interviews continued until key themes were clear. Both authors coded data to agreed themes, using NVivo12 to aid the process. A meeting with patient and public representatives who were family carers of PwD took place to discuss and interrogate the findings.

Findings

Study participants

We recruited 17 HCWs (sessional, not live-in care) from seven different home-care services. One participant was male, 16 out of the 17 were White British and one was White German. Average age was 38 (range 21-65). Participants had an average of 9.2 (range 1–43 years) years' experience of providing care and had been with their current home care companies an average of 3.7 years (range 7 months – 9 years). Interview length ranged from 25.39 to 108.47 (average 46 minutes).

The findings demonstrated two key analytical themes in relation to providing care for PwD (a further separate theme of risk is explored elsewhere): 'structural conditions' and 'clients' dementia-related characteristics'. For each of these we examined the challenges HCWs faced, the care strategies used to mitigate these challenges and the knowledge and skills drawn on by HCWs to employ these strategies. See Table 1 for an overview of the findings.

Structural conditions

Structural challenges

Challenges for HCWs stemming from structural conditions included time allocation for visits, completing care plan tasks, and lone working. See Table 2 for illustrative quotes.

Time allocation for visits

Time was a major challenge. Home-care workers stated that PwD often took more time to get through the care process than those without it:

> You need time for people with dementia. They're not going to go as quickly as you want them to because you've got half an hour (Ben, 9 years' experience)

Workers thought that PwD could and should not be rushed. Often clients with dementia did not understand the care visit was only for a certain length of time.

Completing care plan tasks

Completing all of the activities required on the care plan could create a challenge for HCWs. Workers felt it was their duty to get all necessary actions on the care plan completed:

> We obviously have a care plan so we have to do everything that we're told to do (Kate, 19 years' experience)

Time restrictions and clients' dementia-related characteristics created and intensified this challenge.

Lone working

Home-care workers were often lone working with clients with no immediate back up. They were sometimes the only person who saw the client that day. This brought with it a sense of responsibility:

> It is a lot of responsibility. When I first started, my mind was like 'oh my goodness, how am I going to cope with this?' (Beth, 1-year experience)

The physical isolation from other team members intensified the perception of responsibility. Onus was on workers to assess condition changes in their clients and make decisions on the actions needing to take place, particularly when PwD could no longer make decisions for themselves. These decisions had the potential to have negative consequences if not made well. For example, not noticing or not acting on a chest infection could mean the client would become very ill. Observation skills were key to assess PwD for changes such as in health or mood status.

Strategies to cope with structural conditions

Home-care workers utilised three key strategies to manage structural challenges: time management, drawing on training/experience, and using the system (see Table 2).

Time management

Workers often multitasked to make the best use of the time they had. Each day could be different and they were unaware of whether they would run late until they were in the situation. If time ran out a few HCWs would leave non-urgent tasks uncompleted such as putting out the bins. However, all HCWs would try to make sure key tasks such as medications, visits to the toilet, and meals were completed. Most HCWs reported they would often go over time providing care to PwD prioritising the person they were with until essential care was completed. This meant they would become late for the next person's visit. Some HCWs would try to make up this lost time:

> …then when you go to the next one, if you're supposed to be there for half an hour and you only took 15 minutes, you've then made some time up. So it's robbing Peter to pay Paul all the while (Kate, 19 years' experience)

If a client's needs increased, HCWs would tell the office staff who would try to negotiate extra time for the care package. Decision-making skills were key in enabling staff to determine the best course of action in fluctuating situations. For example, whether to prioritise completing care plan tasks or going to the next client.

Drawing on training/experience

Dementia training was part of HCWs' induction training and a few workers had received extra training, either in previous jobs or with their current organisation. Workers spoke of their training as useful; however, they thought they learnt more in practice:

> You learn so much more from being on the job than being sat in a room and someone's telling you" (Lucy, 6 years' experience)

Shadowing other HCWs helped new staff gain some experience before visiting clients on their own.

Using the system

If completing care was difficult, for example, the person was refusing assistance or time was a factor, HCWs tried to mitigate these challenges. Occasionally HCWs arranged for another worker to meet them and help them with the care:

> One of my colleagues was really stuck at this particularly lady's and so she rang up and somebody else went and helped her, even though that client is a single, it took two of them. (Emily, 4 years' experience)

Other strategies included trying to complete the care at different times such as at the next call if it was the same care worker or formally passing the outstanding task/s on to the next HCW, perhaps with a note. Workers informed the organisation's office staff of any refusals or timing issues meaning care was not completed. If they were experiencing difficulties or needed guidance, some HCWs contacted the office for advice mid care call. Team working skills were used to work with other HCWs and seniors to enable care to be completed or information to be passed on.

To manage challenges stemming from structural conditions, HCWs drew on knowledge of their own job role and responsibilities, company policies and procedures, and the help available from the organisation.

Clients' dementia-related characteristics

<u>Challenges due to clients' dementia-related characteristics</u>

Table 3 shows challenges for HCWs due to clients' dementia-related characteristics. These were communication and understanding, refusals of care, and client behaviours.

Communication and understanding

Home-care workers found working with clients with dementia challenging due to difficulties in understanding and communication. These factors meant that it was hard to find out about the person, their preferences and routine:

> …you can’t ask a dementia client how they like to do things, whereas you can ask anybody else… they might get angry with you because you’re doing it wrong but you don’t know you’re doing it wrong (Emily, 4 years’ experience)

When HCWs did not know the person, they felt less confident and unable to support PwD properly. Workers could not easily explain what they were doing to their clients. Difficulties in understanding and communicating meant HCWs best intentions were not always acceptable to clients.

Refusals of care

People with dementia sometimes refused assistance with their care. If there was an obvious need for care and the person refused, this put the staff in a difficult position. The person could be at risk if care was not completed, but the client may not understand this:

> …they’re at risk of sores and things because maybe they don’t want to change their pad … you can’t see if they’re sore anywhere. They don’t understand that this is a risk or that they are sore (Emily, 4 years’ experience)

Workers did not force the person to receive assistance with their care. However, HCWs felt pressure to complete all the work in the care plan before they left the client. Refusals of care made this difficult and created a tension with their duty of care and in some cases a risk to the person.

Client behaviours

Client behaviours such as agitation and aggression, however understandable, could be a challenge for HCWs:

> You’re very vulnerable. Erm in regards to obviously if they’re going to become agitated, if they’re going to lash out at you, you’re not going to scream and somebody’s going to hear you (Kate, 19 years’ experience)

Workers acknowledged clients’ behaviours were due to their dementia, but reported that when coping with aggression or agitation they could feel vulnerable particularly when lone working.

Strategies to cope with clients’ dementia-related characteristics

Strategies employed to manage challenges due to clients’ dementia-related characteristics were enacting the caring relationship, distraction techniques, becoming inoffensive and familiar, and communication strategies. See Table 3 for illustrative quotes.

Enacting the caring relationship

Caring relationships were key for successful care interactions in dementia and could assist in completing care. Relationships relied on HCWs knowing the person and building a connection with them. To successfully complete care, workers drew on the rapport they had with the person and previous shared experiences. Therefore, at a first call to a new client, workers were less well equipped to draw on their usual strategies, such as talking about the person’s interests or relying on previous connections. Where dementia was very apparent, using observation skills to notice clues and cues from the person was useful to assess their needs:

> She doesn’t like to have people around her a lot of the time … And then you would use the visual clues as to did she need anything or was she just saying she didn’t need anything (Lorraine, 10 years’ experience)

Sometimes visual cues would alert the care worker to something the person may need even if they were saying that they did not need it. In this way, workers used their intuition and decision making skills to work out whether to trust the person’s verbal answers or to override them.

Distraction techniques

Home-care workers used several ways to distract or divert the person to get them through caregiving tasks. Often they would draw on the person’s interests. This demonstrated the importance of relationship building and knowing the person. Other times the workers would start with a different aspect of the care or work they needed to carry out and work round to the necessary care over time. One frequent practice was using a cup of tea as a way to deflect from the outstanding care for a short while.

Involving the person in the care activity was another way to distract them. Giving the person something to do worked by letting the HCWs carry on:

> Her personal care is done on the bed … she's so scared that she's going to fall that she lashes out …so we gave her …a blanket, and it's got dangly bits that they can play with so we take her mind off it by giving her something, the blanket to hold… (Kate, 19 years' experience)

The use of distraction demonstrated HCWs' knowledge that PwD may not be able to understand reasons for their actions, so better to 'bring them along' or divert from the task by keeping them occupied on something else.

Becoming inoffensive and familiar

Home-care workers adapted their approach to bring the person through the care activity. Workers reported that a quiet, patient approach could help the person to be calm. They described positioning themselves in non-threatening positions away from the persons face. Such positioning had a dual purpose, that of protecting the worker from any aggressive actions and to approach the person in a non-threatening way:

> …maybe I'll get to their level. Like if they're sitting in a chair, I'll sort of bob down. Maybe touch them on the knee (Emily, 4 years' experience)

Giving the person space was viewed as important. Home-care workers would create personal space for the person through their positioning and by leaving the situation before returning to try again. Strategies such as leaving the person for a little while when they refused care before going back or calming the person took time; exacerbating one of the structural challenges workers faced.

The use of routines enabled HCWs to have a link with the person, sometimes through embodied memories:

> We’ve got a little thing with the talcum powder. So once I’ve washed her, I’ll be like ‘ray of sunshine coming on now’ and she’ll be like that ‘you always say that’… I think if you keep to that routine, they remember it. (Mary, 5 years’ experience)

This routine action enabled the person to remember the care worker, which enabled the HCW to meet the person’s needs through continued relationship building and maintaining rapport. To be able to become inoffensive and familiar workers needed knowledge of the person, the person’s routine, their role as a HCW, and insight into the potential impact their own actions may have on the client.

Communication Strategies

Communication strategies were key to overcome difficulties in communication and/or understanding and help progress the person through the personal care routine. Carers used a combination of strategies and employed them as and when needed. These included coaxing or encouraging, using humour, explaining their actions, adapting their tone of voice, using the word ‘please’, praising, minimising the sound of the care action or talking it up, offering a choice of when the action happened, not if it would, and offering limited choice options. A minority of workers reported using a persistent or firm approach to get the person to assent or consent to care.

Coaxing included encouraging the person to proceed with care, for example saying ‘come on’ (Karen, 2 years’ experience). The use of coaxing was predominantly reported by HCWs with less years’ experience of caring. No other differences in the amount or variety of strategies used by HCWs of differing experience levels was present. Some workers would point out undesirable consequences of the person not receiving help with care such as feeling uncomfortable or being dirty. A good sense of humour was viewed as being helpful to bring the person along. Staff had to use their insight to work out when and with which clients this would be appropriate.

Choice was offered, however this was often a limited choice such as two options or for ‘when’ a task would take place and not ‘If’ the person would like it to:

> Instead of ‘would you like to go for a wash?’ How about ‘let’s go have a wash before we have our breakfast.’ … But if you, if you ask the question when you can give an answer no, you always get answer no. (Fay, 9 years’ experience)

Here an illusion of choice was offered. Avoiding asking questions which could be answered with a ‘no’ helped workers circumvent any impasses or conflict. Wording questions as though assuming the action would take place rather than to see if it would take place was viewed as useful. However, this did limit the agency of the person, particularly if their cognitive impairment made it difficult for them to articulate what they would like.

Workers demonstrated relationship building, interpersonal sensitivity, and communication skills in their approaches. The workers had to adopt a flexible approach making decisions and changing routines in the moment, while also trying to anticipate how the person may react to their actions.

Discussion

We used semi-structured interviews to explore the experiences of HCWs when assisting PwD with their care. Our findings show HCWs faced distinct challenges in relation to ‘structural conditions’ and ‘clients’ dementia-related characteristics’ when caring for PwD in their own homes. To address these challenges, HCWs employed multiple strategies to bring the person along the care journey and complete necessary care actions. Time management, using the system, drawing on training and experience, enacting a caring relationship, distraction techniques, becoming inoffensive and familiar and communication strategies were all key devices to get care completed.

When employing strategies, HCWs demonstrated a variety of skills and knowledge. HCWs used observation, decision-making, team working, relationship building, interpersonal sensitivity and communication skills to cope with challenges. These skills were particularly important when assisting PwD who were unable to contribute to caregiver/client interactions in the way those with no cognitive impairment could. Challenges from clients’ dementia-related characteristics could increase dementia-related work stress (D'Astous et al, 2019). Meaning care interactions often required emotional labour from HCWs who had to repress their own emotions to professionally manage care situations (Hochschild, 1983). This involved balancing emotional detachment and engagement with clients; protecting workers own emotional selves while being attached enough to PwD to meet their needs (Johnson 2015; Bailey et al, 2015). Workers had to draw on their inner personal resources to manage this process.

Many strategies and skills identified align with person-centred care, which promotes valuing people, providing individualised care, identifying personal viewpoints of PwD and creating reassuring social environments (Kitwood, 1997; Brooker, & Latham, 2016). For example, interpersonal sensitivity, which involved an intuitive, empathetic, and responsive approach was essential for many of the strategies HCWs employed, was person centred, and also relied on the HCW's own characteristics as a person. A reliance on workers' personal attributes in dementia care has been identified in care home healthcare workers in relation to communication skills (Stanyon et al, 2016), but has not been identified in HCWs or in relation to overcoming challenges.

Knowledge demonstrated by HCWs was of the person and their routine and needs, the job role, worker responsibilities, company policies and procedures. These forms of knowledge would be expected and covered as part of staff training. For example, in England, since 2015, new health and social care staff are expected to complete the Care Certificate. An introductory training covering 15 standards setting out skills, knowledge and behaviours for social care staff as part of their induction training (Skills for Health, Health Education England and Skills for Care, 2015). The Care Certificate covers many of the skills and knowledge our findings found such as 'understanding your role' and 'communication'. However, HCWs also demonstrated reliance on other types of knowledge such as of their own abilities and insight into the potential impact of their own actions on the PwD. Self-awareness appeared to be key in navigating care interactions with PwD. As with skills in interpersonal sensitivity, this knowledge relied on workers personal attributes, how insightful and in tune they were with their own potential impact, this knowledge is absent from most training and is arguably harder to learn. Home-care workers are in a unique care position compared to other care services; they are often on their own with the client with no one in close proximity to call on (Abrams et al, 2019). Therefore their skill and knowledge resources are key.

NICE guidelines for home care (2015) state that there should be enough scheduled time for visits and HCWs should be able to identify and act on common medical conditions, care needs, support needs and deterioration in health or conditions. Our findings show that scheduled time can be problematic in dementia care where the time needed fluctuates depending on each person’s needs, each day. Individual responsibility for decision making on common medical conditions was also a challenge for HCWs. Generally, HCWs had more scope to mitigate client-based challenges by adapting care within client interactions, than to manage structural challenges where there was a limit to what workers could do. We recommend home care organisations acknowledge the importance of interactions with PwD within home care and support workers to develop interpersonal sensitivity. Home care organisations should work to support HCWs to manage structural conditions in their daily work practices. Other professions could have a role in supporting HCWS (Manthorpe et al, 2019), particularly with clinical decisions.

Home-care workers are often overlooked as part of the dementia workforce. Although recent work has started to illuminate their experiences (D’Astous et al, 2019; Schneider et al, 2019; Polacsek et al, 2020; Sandberg, Borell and Rosenberg, 2020), there are still many unknowns about this sector of dementia care. We anticipated that HCWs experiences would emphasise the practicalities of providing personal care for PwD, however, our findings show a heightened focus on the interactional psychosocial side of care. Engaging with the person well was paramount to bring them along the care journey and complete the tasks on the care plan. Although HCWs are responsible for meeting both practical and psychosocial needs (Hansen, Hauge & Bergland, 2017), it could be that the understanding and communication difficulties inherent in dementia make interpersonal connections more crucial. Hence, the practicalities of physical work on the body become less prominent in workers' thoughts. Attending to the subjective person was the major focus of HCWs and necessary in order to be able to complete physical work on the body. Attending to the body as a subject and object is not new (Twigg et al, 2011; Schneider et al, 2019), however in dementia, the subject may be more important if the person is to be brought along as part of the care journey. Care worker – client relationships in home care have been identified as emotionally complex and our findings echo this (England and Dyck, 2011; Gallagher and Vanlaere, 2016).

Strengths and limitations

Strengths include a similarity between most participants' experiences. Our study relied on a relatively small sample area and size, therefore it potentially provides a partial picture of experiences. Our aim was to learn about dementia care, therefore our findings do not relate to home-care in general. We do not know whether our participants use the strategies they reported in practice or whether they are effective.

Conclusion

Home-care workers are often portrayed as low skilled, however in this study they demonstrated the use of multiple skills, and a broad knowledge base requiring a high level of self-awareness. Despite commissioning focussed on time- and task-based care, when caring for PwD, HCWs prioritised interaction with the person as a way to complete practical care activities. HCWs had more scope to mitigate client-based challenges by adapting care within client interactions, than to manage structural challenges where there was a limit to what workers could do. We recommend home-care organisations acknowledge the importance of interactions with PwD within home care and support workers to develop interpersonal sensitivity. Organisations should also work to support HCWs to manage the structural conditions in their daily work practices for example, by linking with other professions.

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Table 1: Structural conditions and characteristics of clients with dementia

	Structural conditions	Clients' dementia-related characteristics
Challenges	**Time allocation for visits** -People with dementia take more time **Completing care plan tasks** **Lone working** -Individual responsibility -Assessing condition changes	**Communicating and understanding** -Not knowing person/person's routine -Cannot ask person **Refusals of care** -Risk to the person -Tension with duty of care **Client behaviours** -Agitation -Aggression
Strategies to manage challenges	**Time management** -Multitasking / using time wisely -Prioritising -Late for next person **Drawing on training/experience** **Using the system** -Double ups or send someone else -Try at different times -Pass on to next call -Pass on to senior staff	**Enacting the caring relationship** -Finding out about person -Drawing on relationship -Picking up on cues **Distraction techniques** -Draw on person's interests -Start with different aspect of required care -Use cup of tea -Involve person in care activity **Becoming inoffensive and familiar** -Calm approach/mannerism -Positioning / personal space -Leave and try again -Routine (embodied memories) **Communication Strategies** -Coax -Humour -Explain what doing -Use tone of voice -Be firm -Praise -Minimise sound of task/talk task up - Offer choice rather than yes / no questions -Offer limited choice
Skills demonstrated	Observation Decision making Team working	Relationship building Interpersonal sensitivity Communication
Knowledge of	Job role and responsibilities Company policies and procedures	Person Person's routine Own ability Potential impact of own actions

Table 2: Structural conditions: illustrative quotes for challenges and strategies

Challenges	**Illustrative quotes**
Time allocation for visits People with dementia take more time	"In the past, we have had people with an hour and a half each morning when they've had dementia erm because they need a bit longer" (Lauren, 8 years' experience)
Completing care plan tasks	"If you ask my workplace, I'm very well-known of running late and I do not prioritise, I have whatever is in the care plan, and that will be done" (Fay, 9 years' experience)
Lone working	
Individual responsibility	"that client could be in a wet bed and whether they're lashing out at you or not, they're going to end up breaking down on their skin if they're late so probably you do more because it is only you there…Where sometimes in a care home, it's easier to walk away and let somebody else come in." (Kate, 19 years' experience)
Assessing condition changes	"you're always making decisions when you go in and you know 'do I need a doctor, don't I need a doctor, is it a chest infection, is it just a cough?" (Kate, 19 years' experience)
Strategies	**Illustrative quotes**
Time management	
Multitasking / using time wisely	"I go and do something else in the kitchen while I'm leaving her to wash her hands – she comes and joins me and I have to go back in the bathroom just to check that the tap is off." (Beth, 1 year experience)
Prioritising	"you do have to prioritise main things, like the personal care, the meal, the medication and think "oh God, I haven't got time to empty the bin today, you know, I've got to go now."" (Sharon, 12 years' experience)
Late for next person	"I never rush. I'd rather be late for the next person and make sure that that person is safe and had the care that they need" (Lauren, 8 years' experience)
Drawing on training/experience	"once you've done it for like for a long time, I think you then sort of find your own feet and your own methods of doing things" (Anna, 6 years' experience)
Using the system	
Double ups or send someone else	"Or if a carer can't do it alone, sometimes we'll try and send a second person and then that might help" (Lauren, 8 years' experience)
Try at different times	"if they didn't want to wash in the morning, we'd try again at lunchtime or we'd try again at teatime" (Lauren, 8 years' experience)
Pass on to next call	"I'd always inform the office as well that you know, we couldn't change her pad this visit. She refused erm and then I'd always leave a note for the other carers, to make sure that she definitely did get it the next time." (Julie, 4 years' experience)
Contact senior staff	

I would rather leave it, contact the office and say “look, point black refused today, I’ve tried my upmost best” and the office always know that I’ll try. (Rebecca, 6 years’ experience)

Table 3: Clients' dementia-related characteristics: illustrative quotes for challenges and strategies

Challenges	Illustrative quotes
Communication and understanding	
Not knowing the person/person's routine	"You don't know where anything is, you don't know who this person is, they don't you and you do, you have to, I think you have to be confident enough to sort of crack on with it really and then the more you go in you know, you learn more about them" (Emily, 4 years' experience)
Cannot ask person	"if you've been to someone new that's when you struggle more because you have to sort of work out what works for them and it's, very much trial and error to see what works for someone. If you find out that you've tried something that you've tried with someone else and that doesn't go very well – scrap that, start again!" (Beth, 1 year experience)
Refusals of care	
Risk to the person	"there are times when you have people that just won't accept any personal care whatsoever, which is really difficult because you know that they need, sometimes you know that they're soiled and you know that they need to be clean and they're neglecting themselves but you can't, you can't force them" (Lauren, 8 years' experience)
Tension with duty of care	"And they refused. We have to just try and like because we have a duty of care but then if they have their own capacity, it's up to them" (Lucy, 6 years' experience)
Behaviours	
Agitation/Aggression	*Care Worker* - she can get very agitated….And she kind of, she'd flap her arms about and I think she can tell you to get out erm if she doesn't like your face, it doesn't fit kind of thing. …she was flapping her arms at me …And it's quite scary. *Researcher* – And how did that make you feel? *Care Worker* – A bit on edge. I just kind of, just got out of her way." (Julie, 4 years' experience)
Strategies	**Illustrative quotes**
Enacting a caring relationship	
Finding out about person	"I think if you get a rapport with them and you take that extra time with them and then they get to know you so you know each other's quirky little ways" (Rebecca, 6 years' experience)
Drawing on relationship	"oh you're the one who warms my knickers up on the radiator, you're the one that makes me laugh." … And that's how I, and they'll know that the minute I walk through the door" (Lorraine, 10 years' experience)
Picking up on cues	"to recognise those small winces of pain or when they're upset or the thigh rubbing if they're anxious…You know picking up on those

	little signs are so much more important than anything else" (Lorraine, 10 years' experience)
Distraction techniques	
Draw on person's interests	"She has little rhymes and little poems she likes to say so maybe if you say the start of one, you say "oh er how did this one go?" And you sort of say it and then she'll carry it on and she'll forget that we're hoisting her. She won't even realise what's happening because she's too busy thinking about this poem that she's reciting." (Emily, 4 years' experience)
Start with different aspect of required care	"I think trying to persuade someone with dementia, they just, not everyone but some people just get, the more frustrated and angry they get, so I try to distract. So say they've refused to wash, erm I'll maybe distract with a cup of tea and then the breakfast and then after they've had a cup of tea and their breakfast, they might be in a more willing mood to have a wash." (Ben, 9 years' experience)
Use cup of tea	"trying to distract them off other things. Like if you can make him a cup of tea and put it beside the bed and get him sat up, you're halfway and you know. Sometimes we couldn't even get the person off the bed to the bathroom so we used to bring the bowl of water to him." (Karen, 2 years' experience)
Involve person in care activity	"She doesn't like feeling wet after we've just dried her, which is, it's understandable but I say "oh would you like a little bit on your hands?" So she rubs a bit on her hands while I do her legs. So near enough she doesn't even realise that we're doing it. …so it's just a case of a distraction in one way but also just saying "why don't you help me do something?"… So it's like teamwork." (Beth, 1 year experience)
Becoming inoffensive and familiar	
Calm approach/mannerism	"seeing where, what generation they're at and just try to be calm with them, you know there's no point in getting angry with somebody." (Julie, 4 years' experience)
Positioning/ Personal space	"the first thing what you do, never get that face, close face to face because, I know it is scary but you have to be careful." (Fay, 9 years' experience)
Leave and try again	"my personal experience is I'll tend to walk out of the room first, come back in and nine times out of ten they're fine …I'd leave the room, let her calm down first then re-enter the room, which nine times out of ten worked" (Sophie, 3 years' experience)
Routine (embodied memories)	"if you keep them in their routine, I notice even with people who are bed bound with severe dementia, after you come in the same person, if you keep a routine, you could see that twink [twinkle] in their eyes, they recognise the voice. ..They don't like the change of routine at all." (Fay, 9 years' experience)

Communication Strategies	
Coax	“he still wouldn’t move, you know, so you had to take the duvet off and you know and then he’ll go “it’s cold, it’s cold.” Like you know “well come on, you’ve got to get up and get dressed” like the bed could be soaking wet” (Karen, 2 years’ experience)
Humour	“Erm this particular lady we were going to, she might be soiled first thing in the morning and you would need to find a way to be able to wash her hands and for somebody that doesn’t like people, erm and so we could use humour with her.” (Lorraine, 10 years’ experience)
Explain what doing	“this lady was bed care only so we would just erm explain what we were doing…Erm probably explain it a bit more like step by step what we were doing, just to reassure the person.” (Anna, 6 years’ experience)
Use tone of voice	“just to be understanding. Erm the way that you talk as well…Erm your mannerism. And I do think you have to be a special kind of person to look after dementia clients; the tone of your voice.” (Julie, 4 years’ experience)
Be firm	“I was being quite persistent like “come on, take these tablets.” She was like “I’m going to give you a thick ear” and I was like “well that’s not very nice, would you like it if I said that to you? No.” And like you have to be a bit stern sometimes.” (Emily, 4 years’ experience)
Praise	“I just say “I’m going to pop a little bit of cream on” … then obviously I put that on and then say “right, we’re all done my darling, that was really good” like “you done it ever so well.” And just sort of praise her and make her think ‘oh it’s actually not that bad.’” (Beth, 1 year experience)
Minimise sound of task/talk task up	“”I’ll go “right, two seconds now let me give you a lovely wash and then I’ll take you home.” And then we take her into the living room and I’m like “see, I told you it wouldn’t be long.”” (Rebecca, 6 years’ experience)
Offer choice rather than yes / no questions	“so I’d say “what would,” – instead of “shall we get dressed now?” It’s more like “would you like er to wear this today or wear this today?”” (Ben, 9 years’ experience)
Offer limited choice	“Sometimes options like this lady doesn’t like to get into a nightie, so if you get two nighties out, she’ll say “I’ll have that one instead of that one.” Make her feel like she’s chosen to put that nightie on and then she’ll feel better, you’ll feel better and it will actually work” (Emily, 4 years’ experience)