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Constituents of effective support for homecare workers providing care to people with dementia at end of life.

Running Title: Support for homecare workers caring for people with dementia

Authors: I-Ling Yeh[1], Kritika Samsi[2], Tushna Vandrevala[1] & Jill Manthorpe[2]

[1] Kingston University, London

[2] Social Care Workforce Research Unit, King's College London.

Corresponding author:

I-Ling Yeh, Kingston University, Penrhyn Road, Kingston, Surrey. KT1 2EE

Email: i-ling.yeh@kingston.ac.uk

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ABSTRACT

Objective: The aim of this study was to enhance understanding about homecare workers providing care to people with dementia at end of life by exploring homecare workers' perceptions of challenges and the support they needed and sometimes received.

Methods: Qualitative semi-structured interviews were conducted with 29 homecare workers and 13 homecare managers in England. Framework analysis was used to analyse the data.

Findings: Four overarching challenges were identified: working with clients with dementia, including clients' sometimes unpredictable responses, communication difficulties, and mood changes; caring for the dying; conflict with family members; and working alone, which often left homecare workers at risk of exhaustion, fatigue, and a sense of isolation. When their work entailed high levels of emotion, such as a client's death or getting embroiled in a client's family conflict, they felt emotionally drained, under-prepared and overwhelmed. Supportive elements include receiving encouragement and learning from experienced peers and their feelings being acknowledged by managers at their employing homecare agency. Some workers were offered time off or encouraged to attend the client's funeral as a means of supporting the process of bereavement.

Conclusions: Peer and manager support are essential and effective in coping with work pressures. There is a need to develop models of effective support to alleviate staff's practical, emotional and interpersonal pressures. However, due to the isolating nature of homecare work, managers may not recognise early signs of their staff finding stress unmanageable and miss the opportunity to mitigate these negative effects.

Key Points:

- Due to the isolating nature of homecare work, homecare workers may experience stress when providing care for clients with dementia.

- The difficulties encountered in homecare work potentially have negative impact on workers' physical health and psychological wellbeing.

- Peer and managerial support is perceived essential and effective to alleviate homecare workers' practical, emotional, and interpersonal pressures.

Introduction

Government policy in England advocates for people to die in the place of their own choosing (Department of Health, 2015; Leadership Alliance for the Care of Dying People, 2014). In the United Kingdom, there are 850,000 people living with dementia. The Alzheimer's Society (2011) reports that 83% of people with dementia would prefer to stay at home while only two thirds of people with dementia live at home. Many people with dementia find it difficult to stay in their own home without community support. Homecare services enable staying at home for increasing numbers of people with dementia who choose to live and die in their own home by providing personal care (Bökberg et al., 2015; Clarkson et al., 2016; D'Astous et al., 2017; Guerriere et al, 2015). An estimated 873,000 people received local government funded community-based care between 2015-2016 in England (Health and Social Care Information Centre, 2016), mainly delivered by a large part-time, non-professionally trained workforce (Hussein & Manthorpe, 2012). Homecare workers provide a wide range of services, in particular intimate personal care, assisting with activities of daily living, managing household chores (NICE, 2016), assisting with the taking of medications (Morgan et al., 2016), and offering social and emotional support (Herber & Johnston, 2013; Piercy, 2000).

Homecare provision for people with dementia is under-resourced and the quality of homecare often fails to meet the expectations of clients and their families (Care Quality Commission, 2013; Clarkson et al., 2016; Devlin & McIlfatrick, 2009; McDonald & Heath 2008). Contributory factors include: lack of funding leading to high turnover; lack of training (Herber & Johnston, 2013; Hussein & Manthorpe, 2012); missed or late homecare visits (Devlin & McIlfatrick, 2009); time constraints (Devlin & McIlfatrick, 2009; National

Institute for Health and Care Excellence, 2016); and limited communication with family carers or with health professionals (Care Quality Commission, 2013; Devlin & McIlfatrick, 2009).

The homecare sector encounters particular difficulties in maintaining sufficient and experienced staff and the consequent high turnover can negatively impact on continuity of care and high-quality care (Beach & Chaykowski, 2007; Fleming & Taylor, 2007; Skills for Care, 2016), that may particularly affect people with dementia (Lee et al., 2017). The reasons for the sector's problems are often described as multifactorial (Beach & Chaykowski, 2007; Dill & Cagle, 2010; Herber & Johnston, 2013; Mittal, Rosen, & Leana, 2009). Factors underpinning high turnover include organisational characteristics such as wages, benefits, work schedule (Dill & Cagle, 2010), working conditions and environmental influences, such as inadequate management, and conflict and difficulties at work (Denton, Zeytinoğlu, Davies, & Hunter, 2006; Mittal, Rosen, & Leana, 2009), lack of supervisory support (Denton, Zeytinoğlu, Davies, & Hunter, 2006; Mittal, Rosen, & Leana, 2009; Soini & Vlimki, 2002) and burnout (Butler, Simpson, Brennan, & Turner, 2010; Denton, Zeytinoğlu, & Davies, 2002; Devlin & McIlfatrick, 2009). Zeytinoglu and Denton (2006) suggested that better job security, increased support from employers and colleagues, fair pay, and greater recognition of homecare workers' contribution may heighten job satisfaction and subsequently reduce staff turnover (Sherman et al., 2008).

Homecare workers work independently in clients' own homes. While experiencing a degree of autonomy at work, they often have little contact with colleagues (Abrams et al., 2018; D'Astous et al., 2017). Many report encountering risks relating to their personal safety (Denton, Zeytinoğlu, & Davies, 2002; Sherman et al., 2008) and maintaining professional

boundaries (Abrams et al., 2018). Other possible difficulties include insufficient time to deliver quality care (Brown & Korczynski, 2015; Fleming & Taylor, 2006), ineffective interactions with clients' family (McBride, Beer, Mitzner, & Rogers, 2011), and insufficient communication with their managers or healthcare professionals (Denton, Zeytinoğlu & Davies, 2002; Devlin & McIlfatrick, 2009; McBride, Beer, Mitzner & Rogers, 2011; Soini & Vlimki, 2002). Moreover, work-related stress may be heightened when caring for older people with memory impairment or dementia (Denton, Zeytinoğlu, & Davies, 2002; Herber & Johnston, 2013). Soini & Vlimki (2002) observed that homecare workers may experience escalating physical, mental and emotional demands when providing care for older people with deteriorating health condition and complex care needs. Additionally, homecare workers may experience negative emotions when the work environment or other circumstances impedes them from giving their best (Funk, Waskiewich & Stajduhar, 2013; Swedberg, Chiriac, Törnkvist & Hylander, 2013).

While family carers of people with dementia may experience high stress levels and exhaustion (Schoenmakers, Buntinx & Delepeleire, 2010), little is known about homecare workers' experience of providing care for older people with dementia who are approaching death (D'Astous et al., 2017). Even where homecare agencies offer support to their employees, little research has explored what might be the most effective elements of such support.

Methods

Aims

This paper is situated within a wider study aimed at exploring homecare workers' views and experiences of providing care to people with dementia up to the end of life. Given the unpredictable nature and trajectory of dementia, and the challenge with specifying when end of life is approaching, in the current study 'end of life' is conceptualised as the 'last years of life' (D'Astous et al., 2017; Vandrevala, Samsi, & Manthorpe, 2015). In this paper we report findings related specifically to challenges and their impact experienced by homecare workers; as well as the sources of support they both used and needed.

Participants and recruitment

Using the principles of purposeful sampling and aiming for a variable sampling matrix, we recruited and conducted 42 face-to-face interviews between April and October 2016. Sixty-two homecare agencies based within the Greater London and South England areas were approached and 10 homecare agencies were recruited. Twenty-nine homecare workers and 13 homecare managers participated in the current study. Inclusion criteria for homecare agencies were: providing care for older people in their home, including older people with dementia, that they took on clients paid for by the public sector (local government) or paid privately. Eligible homecare workers and managers needed to understand English to participate in the study. Homecare agencies ranged between employing 20 to 150 homecare workers. Half of the homecare agencies were funded by both private clients and local government. The majority of study participants were female, and more than half of the participants were aged between 25 and 50 years. Slightly above half of homecare workers and 70% of homecare managers were British-born. The participants' demographic characteristics were consistent with the social care workforce in England (Skills for care, 2016), except three quarters of homecare workers and all homecare managers were working full-time.

Ethical approvals and relevant permissions were obtained from the Faculty Research Ethics Committee at King's College London and the Faculty Research Ethics Committee at Kingston University before commencing recruitment.

Procedure

Thirteen homecare agencies were recruited to the study. Managers of eligible homecare agencies were sent an invitation letter and study information sheets. These invited managers to participate in interviews. We also asked them to disseminate our information sheets to their staff which invited homecare workers to contact us separately.

Interviews were conducted in either the workplaces or mutually convenient public spaces. Informed consent was obtained. Participants were assured of confidentiality, anonymity when using their data, but informed that this would be breached if risk of harm or neglect to clients emerged during interviews. With participants' permission, interviews were audio-recorded and demographic information was collected.

Data were generated through semi-structured interviews. This format was chosen to ensure that core questions were asked of all participants while providing scope for participants to explore relevant but unanticipated domains of experience and reflection that were important to them. The interview schedule was developed by the researchers following a systematic review of the literature (D'Astous, et al 2017) covering participants' views and experiences of providing care for clients with dementia up to the end of life. The interview guide for homecare workers included questions relating to: their experiences of providing care for clients with dementia up to the end of life; the support they received; and their perceptions of interacting with clients' family members and health professionals. The interview guide for

managers focused on the organisational aspects of providing care for clients with dementia up to the end of life, any support and training provided to their employees, and their role in facilitating the provision of homecare. Interviews lasted approximately 30-60 minutes. All participants were offered a £20 voucher to thank them for their time.

Data analysis

All recorded interviews were transcribed verbatim and checked for any inconsistencies or omissions. The Framework method of analysis (Pope & Mays, 2006) was applied to all transcripts. This allows researchers to capture the different aspects of the research topic and to systematically develop explanatory accounts from the data (Smith & Firth, 2011). Steps of Framework Analysis includes: data familiarisation; developing an analytical framework; indexing the data using the existing framework; charting the data and mapping and interpreting the data (Gale, Heath, Cameron, Rashid & Redwood, 2013; Spencer et al, 2014). A subset of randomly chosen transcripts was coded by other research team members. Regular discussions between the team were held to consider emerging themes, concepts and second-level interpretations. Any disagreements were discussed until consensus emerged. NVIVO 11 was used to manage the data. Identifying details have been removed to ensure anonymity of all participants, and an identification number was used to refer to their responses.

Findings

The homecare workers interviewed were a diverse group (see Table 1). Their accounts revealed that care was provided in sometimes challenging situations, often necessitating the negotiation of multiple organisational boundaries as well as dynamics of inter-professional relationships. This paper focuses particularly on the reported challenges experienced by

homecare workers and the sources of support they were able to access. Managers'

perspectives add to the diversity. Findings from participants' accounts reflected four main

challenges: (1) working with clients with dementia, (2) caring for the dying, (3) conflict with

family members, and (4) working alone; and three support strategies: (1) preparedness for

death and bereavement, (2) professional support provided by their employer, and (3) peer

support. Table 2 provides an overview of the themes and sub-themes and Table 3 presents

illustrative quotations.

(Insert Table 1, 2 and Table 3 here)

1.Challenges of everyday work

1a: Working with clients with dementia

Homecare workers frequently described providing care for people with dementia as more

stressful and difficult than care for other clients. It necessitated increased time and effort

since physical care took longer, and allowances were needed for unpredictable responses,

communication difficulties and mood changes among clients. Over the course of care

provision, decisions needed to be made in the clients' best interests and creative ways

developed to fulfil clients' wishes and needs if possible. These were often inhibited by time

constraints and the need to manage competing priorities of providing instrumental and

emotional support in the limited time available. Some talked about taking these tensions

'home' with them (See table 3, 1a).

1b: Caring for the dying

Clients who were now in bed round the clock and approaching the end of life presented other

emotional and practice challenges. Some participants had long-standing relationships and

attachments with some clients, so found providing care at the end of life particularly emotionally draining. Feelings of sadness, being upset, feeling under-prepared and overwhelmed when learning of or witnessing a client's death often evoked memories of the death of their own relatives (See table 3, 1b).

1c. Conflict with family members

Varying levels of interaction with clients' family members was reported. Most felt that families provided them with useful information and context about clients. In some circumstances, it was difficult to discuss clients' increasing care needs with their family, especially when the family failed to recognise or accept their relative's deteriorating health or capacity. At the end of life, if families' expressed wishes conflicted with what homecare workers perceived as best for the client, this created additional distress for the homecare worker. Participants who had been asked to take on additional tasks by a client's family (not covered by the care plan) sometimes felt resentful. Some also found themselves caught up in family conflicts, creating tension and stress. One described removing themselves from the client's homecare rota as the only means of decreasing such stress (See table 3, 1c).

1d. Working alone

Due to the isolating and intense nature of homecare work, working without sufficient breaks could occur. One participant described substantial psychological exhaustion and physical fatigue after five days of working alone, which not only influenced her work but also affected her home-life. Moreover, many felt that sole working put additional strains on already pressurised situations, sometimes leading to overwhelming exhaustion, fatigue and a sense of isolation (See table 3, 1d).

2. Support Needs

2a. Preparedness for death and bereavement

Being prepared for the death of a client went a long way to alleviate the uncertainty and shock experienced by many homecare workers on learning a long-standing client had died. In some instances, news that a client was dying was often communicated to homecare workers informally via email by the manager or by family members. Being mentally prepared meant that homecare workers would, *"go in knowing that actually ultimately this person hasn't got long to live"*, as well as walking in, *"knowing what to expect"*. However, this knowledge did not always prepare them in terms of knowing what to do or how to respond.

When clients' death was unexpected it seemed more difficult to process. There was some evidence of good practice with support services in place at such times, for example when homecare managers understood the possible impact of an unexpected death on their staff's emotions and acknowledged that time off work might be helpful. However, this was not reported as common practice in agencies. Experience also appeared to help workers prepare for clients' deaths, and some observed that inexperienced or new homecare workers may require additional support. Some homecare managers said they encouraged their staff to attend their client's funeral in order to support the process of bereavement, and that this helped acknowledge the close bond they may have had with a client. Some homecare workers felt that going to a client's funeral acted as a form of closure; however, few reported being given the opportunity to attend the funeral during work time (See table 3, 2a).

2 b. Agency-provided support

Despite some homecare managers saying that they cultivated 'open door' practices where staff could 'drop in' or call anytime, approaches to supervision and staff support varied across agencies. There appeared to be some discrepancy between what managers said was available and what homecare workers perceived as accessible to them. Generally, little emotional support appeared to be available. In just one agency, counselling was available, although homecare workers generally had to ask for it or seek it out themselves. Many said they would have welcomed more group meetings or opportunities for interacting with one another. Some managers acknowledged the emotional toll that working with clients with dementia at the end of life had on their staff and described providing avenues for reflective supervision on an ad-hoc basis, or, much less often, experts to help staff manage their distress (See table 3, 2b).

2c. Peer support

In the absence of professional support, informal networks amongst homecare workers had evolved as a way of connecting and supporting each other. Forming supportive bonds with other homecare workers also helped to alleviate some of the loneliness experienced on the job, as well as facilitated knowledge sharing between new and more experienced staff. These networks also provided an outlet for the pressures of care work that occasionally build up (See table 3, 2c).

Discussion

The purpose of the current study was to investigate the challenges and impacts that homecare workers experienced when providing care for older people with dementia at end of life and to learn about the effective supports that help homecare workers cope with daily challenges. The

findings add to our knowledge of homecare work especially when providing care for clients with dementia. The difficulties homecare workers experienced could lead to higher levels of psychological exhaustion and physical fatigue, as noted in other studies (Denton, Zeytinoğlu & Davies, 2002; Herber & Johnston, 2013; Soini & Vlimki, 2002). The isolating nature of working in a client's home, while providing some welcome autonomy, exacerbated the difficulties frequently associated with working with clients with dementia. Using creative solutions to provide person-centred care while balancing the needs of the client for personal care (such as help with washing or eating) was the implicit strategy adopted by homecare workers to address this dilemma (Brooker, 2003).

Our study contributes to understanding the challenges but also highlights the positives of working with clients with dementia up to the end of life in their own homes. Homecare workers and their managers identified support strategies that could alleviate some of the practical and emotional pressures, such as open communication to prepare for a client's likely imminent death, opportunities for learning from sharing practice, formal supervision and other avenues for emotional support. Individual managers and agency cultures appear to have a crucial role to play in being attentive to the emotional needs of their staff. These are particularly relevant in an environment where little supervision is offered, and staff work in isolation with fluid role expectations. Homecare managers need to recognise signs of their staff experiencing increasing distress or unmanageable stress at work. If not, they may miss an opportunity to mitigate these negative effects. Previous research from other contexts has emphasised the benefits of peer support (Swedberg, Chiriac, Törnkvist & Hylander, 2013).

Homecare workers in the current study discussed some difficulties in relation to the interpersonal interactions with clients' family members. Many found that some family

members had expectations that were not in line with the contracted homecare provision (as set out in the care plan). In many of these instances, homecare management's involvement was needed to resolve such tensions. There is increasing expectation that homecare workers will possess the knowledge and skills in order to meet older people's complex needs (Devlin & McIlfatrick, 2010; Fleming & Taylor, 2007; Herber & Johnston, 2013), thus the development of professional support within homecare agencies to sustain this might be critical. Others have observed that homecare workers perceive support from management and colleagues as essential and effective in coping with work pressures (Denton, Zeytinoğlu, & Davies, 2002; Soini & Vlimki, 2002); yet not much has been developed in this field. Homecare workers may experience distress at work. Their distress seems to be exacerbated when the care needs of clients with dementia changed significantly and the care provision became difficult to manage. Effective communication and managerial support may have an impact on reducing homecare workers' distress.

The current study utilised a large sample for qualitative studies and contributes to understanding how homecare workers and their managers deal with the challenges and impact of working with clients with dementia at the end of life. Recruitment of participants was restricted to homecare agencies where managers facilitated access to participants and therefore it is possible that they might have intentionally selected or deliberately excluded participants at their discretion. The study is further limited by relying on workers' accounts and they may have wished to present themselves in a positive light or been protective of their employing organisation, clients or client's families. Further research is required with those staff who have left homecare work about whether the pressures described contribute to their exit from the work and what might have enabled them to stay. We also know little about the

potential for health care professionals to offer some support to homecare workers if they are providing care in family contexts that are emotionally stressful or conflictual.

Homecare workers tend to work independently (Abrams et al., 2018; D'Astous et al., 2017). In the current study the lack of homecare worker peer support was mentioned as a concern. Peer support is an under-explored subject in homecare and it would be useful for researchers to develop models of effective support in helping homecare workers to diminish their sense of isolation, to make sense of their work experiences, and to develop coping strategies at work. Further, more evidence is needed about what approaches can best be taken by homecare managers to act as a bridge to convey information about clients' care needs and as a mediator to facilitate the communication or reduce tensions between staff and clients' family members. Homecare managers seem to have to act as a protector on two fronts: first to ensure the quality of homecare and second to assure the safety and wellbeing of their homecare workers. Peer to peer communities (face to face or virtual), where people with common interests share experiences and provide emotional, informational or affirmational (appraisal) support (Dennis, 2003; Eysenback et al, 2004) can perhaps be used for homecare workers as social support interventions. Supervision or facilitation by managers or professional moderators (Dennis, 2003) may enhance the impact of peer support and assist in reducing some of the problems of high turnover and lack of continuity of care.

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Table 1. Participants' demographic characteristics.

Participants	Homecare Worker (N=29) N (%)	Manager (N=13) N (%)
Gender		
Female	27 (93.1%)	11 (84.6%)
Male	2 (6.9%)	2 (15.4%)
Age		
18-24	3 (10%)	1 (7.7%)
25-40	8 (27.6%)	3 (23.1%)
41-50	11 (37.9%)	6 (46.2%)
51-60	5 (17.2%)	2 (15.4%)
61 and over	2 (6.9%)	1 (7.7%)
Place of Birth		
UK	16 (55.2%)	9 (69.2%)
Other	13 (44.8%)	4 (30.8%)
Ethnicity		
White	17 (58.6%)	10 (76.9%)
Black/African/Caribbean/Black British	9 (31%)	3 (23.1%)
Asian/Asian British	1 (3.4%)	0 (0%)
Not stated	2 (6.9%)	0 (0%)
Hours worked		
Full time	22 (75.9%)	13 (100%)

Part time	7 (24.1%)	0 (0%)
Years of care work experience		
Under 1 year	6 (20.7%)	3 (23.1%)
1-5 years	13 (44.8%)	6 (46.2%)
6-10 years	6 (20.7%)	3 (23.1%)
Not stated	4 (13.8%)	1 (7.7%)
Professional qualifications		
Prefer not to say/not stated	16 (55.2%)	4 (30.8%)
National Vocational Qualification (NVQ)	8 (27.6%))	0 (0%)
Degree	3 (10.3%)	7 (53.8%)
Other	2 (6.9%)	2 (15.4%)

Table 2. An overview of themes and categories

Theme	Sub-themes
Challenges of everyday work	Working with clients with dementia
	Caring of the dying
	Conflict with family members
	Working alone
Support	Preparedness for death and bereavement
	Professional support provided by employer
	Peer support

Table 3: Quotes (illustrative) from participants

1.Challenges of everyday work	1a: Working with people with dementia	*"You have to be very, very patient, you know, because they will change quite a lot, even from one hour to two hour they become a completely different person"* (P27, Female homecare worker, aged between 41-50).
		"It's harder to make a choice in some things when somebody can't direct their own care or they don't want it done and you know they need it done for hygiene reasons and things like that. It is trying to find something that will allow them to let you do it" (P07, Female homecare worker, aged between 51-60).
		"Something it's difficult for me at least is when they say, it's up to you. I ask them, what would you like to eat today? They don't know. You have to think for them and that's something difficult for us" (P23, Female homecare worker, aged 61 and over).

| | | "*Nobody is saying he's got dementia. You can only encourage at a certain point if you think of maybe he's stubborn. He doesn't want to, he's not ready. You just woke him up and he needs to wake up slowly. And then they've just given you thirty minutes. ..., It's not enough. It is a challenge*" (P28, Female homecare manager, aged between 41-50).

"*It is hard to get longer, because you know, you are told you can do this this and this in thirty minutes and it is a bit of a rush. And then you haven't got that time then to spend, you know, sitting there and chatting and things. Somebody that's living on their own with dementia as well or if they haven't got any family you would like to spend time with them, but obviously, you can't*" (P17, Female homecare worker, aged between 41-50).

"*I know like the first days I'll go home and, I would just go in the bathroom and I lock myself in ..., you just go and you've seen it for the first time and you like fret and then you have to like really pull yourself together*" (P37, Female homecare worker, aged between 41-50). |

	1b. Caring for the dying	*"She was diagnosed with dementia, but when we'd taken her on (as a client) she was already bed bound, ..., She didn't know what was going on when we were trying to wash her and change her. ..., She would lash out at you. No matter how much you tried to reassure her, ..., she was frightened, ..., I suppose in her mind she doesn't know what's going on"* (P17, Female homecare worker, aged between 41-50). *"You develop a rapport, a good working relationship and you probably have a good rapport with the family as well. So it is hard. It is upsetting"* (P12, Female homecare worker, aged between 51-60). *"it was like the initial shock of once I knew, or got the confirmation (of client death) when the husband broke down and started crying and calling her name, it's just like, I got like a ball, it's like a knot in my stomach and it's like a burning sensation and then instantly my hands started shaking and I felt like I was going to faint, so I said okay, I just need a little bit of air, let me just go downstairs and try and calm myself down. But that was the first time I walked in on a client and found them*

		passed away…It was, it brought back memories a little bit because I lost my mum in 20XX, so it brought back memories a little bit of watching her die and then coming in and seeing her, so it was hard for me to contain my emotions a little bit once leaving the room. It brought back so much memories and it made me break down a little bit. Then I had to be professional as well and not do it in front of the family members" (P32, Female homecare worker, aged between 25-40).
	1c. Conflict with family members	*"She started to actually look towards me as I was helping her to put her socks and shoes on and things, which the year before I wouldn't have done, …, She was perfectly capable of doing that. …, there came a point where I just thought, this is not enough, she needs more. Her daughter couldn't see a way of putting a live-in carer in. Because she was kind of in denial about her condition"* (P04, Female homecare worker, aged between 51-60). *"We find it a lot that with end of life, …, sometimes they (family member) want them sitting up in a chair and we know they don't really want to get out of bed. If you explain it to them that they will probably be in pain and that sort of thing, they tend to listen to what we are saying. You do get some*

		that don't. But that's always going to happen" (P21, Female homecare manager, aged between 51-60).

"We were really, really abused over there by not by the client, but his wife. ..., because she was always like saying what we should do and it's not in the care plan. I said to her, it's not in the care plan and I am not going to do it. ..., I was like labelled the stubborn one" (P38, Female homecare worker, aged between 51-60).

"He lived with the wife and the wife was thirty years younger. She sometimes didn't understand how I treated him and why. There was conflict between her and him and me and I didn't like it very much, because I didn't want to make her upset ..., It was a difficult situation for me. ..., It came to a point, I said to her, look, I cannot work like this. I am very sorry, but I think another care worker is going to come, maybe she can manage better than me. I couldn't manage it" (P23, Female homecare worker, aged 61 and over). |

	1d. Working alone	*"I have done five shifts, five consecutive days with one particular individual and I said, 'I've just hit a wall.' They call it a marathon wall, ..., It suddenly hits and you get fatigued, because you suddenly realise, you actually, you know, your focus goes and your concentration goes, everything kind of goes, because you just feel tired. I literally came back and just zonked out. I wasn't able to do anything. I was just physically and mentally kind of exhausted"* (P24, Male homecare worker, aged between 41-50). *"It had taken me on one particular occasion a very long time to get him dressed and ready to go out in the first place. And then twenty minutes before he was due to be there he needed really major personal care. And it all happened in such a short time and so the pressure was enormous on me and it was unhelpful to me and it was a very pressurised situation. When you are on your own trying to do that, that's very difficult"* (P24, Male homecare worker, aged between 41-50).
2. Support Needs	2a. Preparedness for death and bereavement	*"I was hearing horror stories of other agencies and I didn't want that for our staff, where they would go to a person and perhaps they had just passed away and then they would be ringing them to say,*

		you are due at your next call and things like that. You hear of that quite a lot. It's not good enough" (P21, Female homecare manager, aged between 51-60). *"Because I've been through so many people coming and going, passing (dying). I think over the years you build that strength, it just comes I think naturally, you know, it's almost like you prepare yourself. You know, Mrs so and so is going downhill, you prepare yourself because you're seeing it every day. You're living it with them, you know. Wherein a family member is always going to be in denial, you know"* (P36, Female homecare worker, aged between 41-50). *"Sometimes the client's family will do open funeral and then have like open dates (at the family home). If any of the care workers do wish to attend they could obviously—if you are working [with] the same clients for three years, it is nice to attend and say your goodbyes with the rest of the family. Obviously, if you are close to the family as well, it's a nice send-off"* (P19, Female homecare worker, aged between 18-24).

	2b Agency-provided professional support	*"It's quite ad hoc if I am honest. We don't have like a, you know, a person, we don't have like a, what do you call them, a therapist or a counsellor or anything for people to go to. I think any of the office staff here would always listen and lend an ear to the care workers"* (P14, Male homecare worker, aged between 25-40).
		"I don't think my care company have any support services in place, because when that person dies with dementia, we didn't get anything after. All I had was that night, we didn't have, not even a text the next day saying, 'thank you for last night' or anything like that. No recognition or nothing. I just thought, we were there for like what, three and a half hours, four hours. It was just… there was nothing" (P16, Female homecare worker, age not revealed).
		"There is good sides, but there is often especially if you look after someone with dementia, there is also a lot of stress. And so what we've done to help reduce that stress is every month we have one of

		the directors who has (a faith based background). This person does reflective supervision with the staff" (P25, Male homecare manager, aged between 25-40).
	2c Peer support	"We are all as a team. You are going to find you have certain care workers that you connect with and so you offload. Even in the office you can go in there and go, uuurgh and have a little rant. Even the pub. Obviously we don't give out confidential information, but just to say, what a day we've had and then just I had to do this and I had to do that and then it all just comes out, because otherwise it will just build up and build up." (P08, Female homecare worker, aged between 25-40).