Title: Working with colleagues and other professionals when caring for people with dementia at end of life: homecare workers' experiences

Introduction:

The care of older people with dementia is becoming a major part of most health and social care practice regardless of employment setting or role. Across the globe, the impact of ageing societies and policy aspirations for more care to be provided at home (Stones and Gullifer, 2016) mean that in countries such as the United Kingdom (UK) a sizeable dementia workforce provides homecare services. While the term homecare may be more commonly used in the UK than internationally, the tasks and roles are common to services providing domiciliary care, in-home assistance, personal care aide, personal care assistant/attendance, home care aide, home care assistant, home health aide, direct care worker, support worker (ibid). Homecare workers predominantly work in clients' own homes. While experiencing a degree of autonomy at work, they often have little contact with other homecare workers employed by their agency (Abrams et al. 2019). Homecare may be provided on the basis of need or purchased by individuals who pay privately. In England the care sector is regulated by the Care Quality Commission (CQC) with over 4,515 registered providers or homecare agencies (Care Quality Commission, 2013), most of them in the commercial or private sector. In providing homecare their staff may undertake a variety of tasks, such as personal care, assistance with activities of daily living or support for family carers. As with others on the frontline of care in England, homecare workers are often paid at or around the National Living Wage and generally work part-time, sometimes with contracts that do not specify hours of work (Kingsmill, 2014). This mainly female workforce works in isolation from other staff, within people's own homes and when commuting to their clients. There are high levels

of annual staff turnover (30% according to Skills for Care, 2019) and many agencies find it difficult to make a profit and either cease to operate, or make extra demands on their staff (Burns et al, 2016). Homecare agencies may refuse publicly funded clients on the grounds that public funding does not cover their costs, with tensions around time use being a particular feature of the service (Rubery et al, 2015). However, despite these sector challenges, homecare workers provide the majority of non-clinical paid care for older people with dementia in England (Hussein and Manthorpe, 2011).

Few homecare agencies are funded to specialise in support for clients with dementia alone or in end of life care; most run on generalist lines (Challis et al., 2011). However, the numbers of home-supported people at end of life look set to increase as the trend to hospital being the location of death among people with dementia appears to be declining (Sleeman et al, 2014). Government statistics from Public Health England (2018) show that more people are dying in locations other than hospitals, while the greater change is in the number dying in care homes, between 2004 and 2016, the numbers dying at home rose by 5.1% . In 2016 46.9% of people died in hospital, 21.8% in care homes, 23.5% at home, and 5.7% in hospices. Some of those receiving homecare may have been using this service for several months or years, while others may be newly receiving care as their own or family carer's needs increase. Although several researchers have focused on medical and nursing care for people with dementia at the end of life at home (de Witt and Ploeg, 2016; McGarry, 2010), a recent systematically conducted literature review found that the role of homecare workers has not commanded substantial research interest (D'Astous et al, 2019). Briefly, findings from the systematic review were that there were high levels of role ambiguity amongst this workforce, there are indications that homecare workers may be experiencing emotional labour but limited research

into this and how they can be better supported, and that there is lack of attention paid to homecare workers' experiences of a client's death or their preparedness of it.

In the UK while older people living at home with dementia who are approaching life's end are likely to be provided with care and treatment by National Health Service (NHS) clinical professionals (such as General Practitioners, community nurses and palliative care teams), they may also be supported by homecare workers. Giacomini and colleagues (2012) identified that homecare could sometimes be part of generalist or specialist palliative care services, but was also likely to be part of supportive care. Not surprisingly, they found little clarity about roles and responsibilities between professionals working in dementia care. Those working for homecare agencies were less likely to report feeling part of a team or benefiting from the support of colleagues compared to staff working in care homes (Bjerregaard et al, 2015). Teamwork has been defined as "a dynamic process involving two or more healthcare professionals with complementary backgrounds and skills, sharing common health goals and exercising concerted physical and mental efforts in assessing, planning, or evaluating patient care (Xyrichis and Ream, 2008, p. 232). However, much research on inter-professional healthcare teams has been conducted in hospital-based, medical specialist care or primary care settings (Szafran et al, 2018). Thus, while homecare workers are sometimes a critical component of home-based dementia care up to the end of life, there is a paucity of research on homecare workers' views on inter-professional team working and their own team experiences. Therefore, the primary contribution of the current paper is to investigate how inter-professional team working and homecare team working at agency level are established and constructed by homecare workers supporting clients with complex care needs, such as arising from dementia symptoms and during end of life care (broadly defined but also covering palliative care). All participants highlighted the difficulties and dilemmas they faced in navigating their role while engaged in care provision to clients

with dementia in their own homes (Abrams et al. 2019). Factors contributing to these difficulties were often in relation to the different expectations, professional practices and power dynamics within multiagency and multi-professional input to the client, which are the focus of this paper.

Methods

Recruitment and participants

A total of 62 homecare agencies (all registered with the Care Quality Commission in England – CQC) (17 homecare agencies in South England and 45 agencies in Central London) were invited to participate in the study. These agencies were selected based on the type of care they advertised on their websites; with the inclusion criteria being that they provided homecare, or dementia care, or end of life care. Homecare managers were sent an initial invitation letter and an information sheet outlining the study. Follow up contact was made with agencies who did not reply, via telephone to assess their interest. Of those contacted, 10 agreed to participate. Those who declined gave reasons such as having limited time to support participant recruitment. Of the participating agencies, five provided care for both private and publicly funded clients, while three agencies only took privately funded clients and two agencies only accepted publicly funded clients. The majority (seven) of agencies employed between 19-46 staff, although two agencies had between 130-150 staff while another employed just three. CQC quality ratings were obtained from its public website for all participating agencies; six of which were rated as good, two as 'requires improvement' and two had been regulated but not yet rated.

Face-to-face interviews were subsequently arranged with all homecare managers (n=13) (some agencies had more than one manager). Homecare managers then emailed their staff with an invitation letter and information sheet. The details of those willing to participate were

passed to the research team, and the location and time of interviews were arranged directly. A total of 30 homecare workers and 13 managers volunteered to take part in the study and engaged in face-to-face interviews. We purposefully sampled at least 10% of our sample from migrant groups, both European Union (EU) and non-EU migrants (a prominent part (18%) of the care workforce, Skills for Care, 2018). Tokens of appreciation (vouchers £20 each) were given to participants post interview.

Table 1 presents the characteristics of the 43 participants in this study; four male and 39 female. This over-representation of women reflects the typical demographics of the homecare workforce, as does the spread of ethnicity, education and experience. The only aspect that varied is that the majority of participants reported being in full-time employment whereas part-time workers predominate in the homecare sector (Skills for Care, 2018). It should be noted that although 43 participants were interviewed, the demographics information equates to 42 because one participant did not return their demographics information sheet, despite a reminder. In some of the extracts from the interview data, participants referred to themselves or colleagues as 'carers' rather than care workers, we have not altered this save when the meaning may potentially confuse with family carers.

(INSERT TABLE 1 HERE)

Data collection

Semi-structured, face-to-face interviews were conducted by two researchers during April to October 2016. Open-ended questions were used to elicit their views and experiences of caring for clients with dementia up to end of life using prompts to gather as much relevant information as possible. The interview schedule included questions on a participant's typical workday, their experiences of caring for clients with dementia, their perceptions of a good death, their interactions with other health and social care professionals and with their clients'

family members or carers. Participants were specially asked questions relating to the contact with their colleagues and with wider health professionals (e.g. general practitioners (GPs), palliative care nurses, or district nurses) while caring for people with dementia. They were also asked to describe this interaction and specific questions related to whether they discuss dying or someone's death with other professionals, colleagues or their managers. Participants were also asked to recall specific experiences of end of life care they had been involved in at work, and asked about the impact of caring for clients with dementia up to end of life and any possible avenues of support.

Interviews were conducted at participants' workplaces or in public spaces (at their preference), such as local cafes during working hours. Prior to the interview, participants were provided again with the study's information sheet and asked to complete a demographic detail sheet and consent form. Interviews lasted approximately 30-60 minutes.

All participants were assured of confidentiality, but were told that confidentiality would have to be broken if risk of harm or neglect emerged. Interviews were digitally recorded with permission and participants were advised that they could stop the interview at any point if they no longer wished to continue and that data would be deleted. Pseudonyms are used to maintain anonymity.

Data analysis

Framework Analysis was used to analyse the data to obtain a realist description and interpretation of the particular phenomenon. It is a widely used method within cross-disciplinary research teams and operates as a data management process that enables researchers to organise data into coherent themes (Ritchie and Spencer, 1994). The presentation of data often occurs in a matrix format, which helps to facilitate an iterative process both within and between data sets (the participants). Prior to this, five stages are

involved in the development of data analysis. These include: (1) familiarisation (including free coding); (2) development of an initial thematic framework; (3) indexing and sorting of all data; (4) reviewing extracts for coherence; and (5) summarising data by theme (Ritchie and Spencer, 1994). A sample of transcripts was double coded independently by two members of the research team; these codes informed the construction of a coding framework. Regular discussions were held to review and define themes and then discuss emergent interpretations amongst all authors. The coding framework was added to NVivo 11 and two researchers applied this to all interview transcriptions.

Findings

An over-arching theme identified in the transcripts related to the perceived invisibility of homecare workers operating within a nexus of multidisciplinary care and support. The contributions that homecare workers make when caring for clients with dementia at the end of life emerged as both practical and emotional. Homecare managers and the homecare workers themselves acknowledged the visibility and significance of their role through both informal and formal practices of teamwork within their own employing agency. Yet within specialised care practices, such as end of life care, this visibility seemed to lose its significance amongst other healthcare professionals. Participants in this study discussed sometimes feeling side-lined by others as a result of their more dominant clinical expertise, even in the home environment, and experiences of frustration and conflict were commonly reported.

In order to identify the multi-faceted dynamics homecare workers experience within and beyond their own employing agency, the following themes were identified; (1) attempts at informal team working within homecare agencies and (2) working with other professionals and the potential for conflict, side-lining and invisibility within a multidisciplinary environment.

Both of these sub-themes are described below and are supported with participant quotes, which typify the detail.

Table 2: Table of themes and sub-themes

Theme 1: Informal team working within homecare agencies	Theme 2: Working with other professionals
• Within agency cultures and formal teamwork dynamics • Informal practices within agencies	• Perceptions of Conflict, Side-lining and Invisibility

Theme 1: Within the homecare agency

- *Within agency cultures and formal teamwork dynamics*

Participants described a sense of teamwork generally in relation to those with whom they worked at their employing agencies (for example, other care workers they 'double up' with on some shifts if two workers are needed). Teamwork was considered by participants to be integral to the care they delivered, particularly as they worked with older people with dementia

> *"Some of the runs (rota) are singular and so we'll go in on our own. But then during that run we could double up with another care worker. On some occasions we double up with a live-in care worker as well. There are always different people, we sometimes we double up with them as well. It varies."* (BO8 – female homecare worker, age not given)

Typically the organisational culture established by managers within homecare agencies dictated the formality and frequency of homecare worker interactions and their sense of team cohesion. These cultural practices included some homecare managers arranging supervisory observations and regular team meetings at specific points in the year, as this manager reported:

> "*Once, at least every three months we will make a meeting with that carer (care worker) and then I would sit and talk to them on one to one so they can tell me if there are any issues or any problems. Same for me if there is any concerns that I have … We also carry out what we call 'spot checks' so we will get a senior member of staff to go to a property while we know a carer is there, just to check everything is okay and they are aware what they should be doing.*" (P01, Female homecare manager, aged between 51-60)

Where possible, office-based staff would often spend time matching homecare workers to clients, to ensure a good fit, using client meet-and-greets as a practice of bringing a client into the folds of the agency's collaborative teamwork. These practices seemed to indicate traditional methods of teamwork, which foster a top down approach to establishing the social norms of an agency.

At times, the formal practices of teamwork worked alongside with an organisational culture that was sympathetic towards a homecare worker's need to connect with their peers or managers outside of the client relationship. For example, agencies that actively encouraged and facilitated interaction through 'open door' policies, providing homecare workers with a space where they could 'drop by' the agency's office unannounced appeared to help alleviate the isolation felt by some homecare workers not operating within teams or shared locations of care work:

"We have an open-door policy anyway, so carers can just ring me up and say, I really need to speak to you and then they come in and we have a chat" (P01, Female homecare manager, aged between 51-60)

"I would go to the office and just kind of, in my break, so you are just around other people to talk to" (P02, Female homecare worker, aged between 25-40)

In several agencies, frequent requirements to report to and notify managers in the office were mentioned. These routines and rituals that facilitate team working appeared to form a continuous communication loop in terms of information sharing and advice seeking:

"We have to call the office all the time anyway to keep them updated and if you come across any problems, you have to report that straight away so it can be actioned. That is kept in the client's journal in the client's house with the care plan and everything" (BO7, female homecare worker, age not given)

However, many participants considered that their managers could do more to formalise some of the in-house practices of teamwork. In the following example, one homecare worker expressed a wish for greater access to the knowledge and learning opportunities that she suspected were present but largely untapped amongst her colleagues:

"It would be nice if they [the organisation] would bring you in and you would all have a big like meeting of about ten or twenty carers and all talk. You would get their [other carers] experiences of what's happened, which I think is a really good thing to do. It doesn't happen very often" (P03, Female homecare worker, aged between 41-50)

These were deemed by some participants as missed opportunities to bring them together in more organised, formal spaces to foster peer learning and collaboration.

- *Informal practices within agencies*

In the absence of formalised team working arrangements between homecare workers themselves, several participants discussed their own organic formation of informal team working or communications. These enabled the communication of simple messages, such as forgetting to switch a light off or not having time to do the washing, and were generally facilitated by technologies of text and mobile phone:

> *"Some of us, what I would call the older carers, we keep in touch by phone and because we let each other know, say, like so and so is running short on (incontinence) pads, can you pick them up, or somebody's toilet wipes, this lady likes certain toilet wipes and whatever like that, which is, can be in our own time and whatever"* (P04, Female homecare worker, aged between 51-60)

Most care workers as well as managers said they strived to provide their clients with continuity of care. Some felt this was not always feasible in the context of dementia care particularly as the condition deteriorated and the severity of needs intensified. In these instances, team working and fluent communication between the different homecare workers appeared to be important in delivering continuity of care:

> *"We use encrypted instant messaging. We have teams as well, so we have the formal note takings and so they take notes and they take a picture of them and they email them into us, every day or after every shift. But for anything which is very important such as an emergency, a very important user preference, they will put it on the (Site), each client has a chat room and that way the whole team, which is again usually four or five people, know."* (BO17, female homecare worker, aged between 51-60)

In the absence of more formal learning opportunities within agencies, such informal teamwork within agencies helped facilitate exchanges of knowledge and work experiences between new

staff and others. Furthermore, these networks, whether face-to-face or phone, sometimes provided outlets for some discussion of the client-related challenges experienced by homecare workers:

> *"We will work in the team and we've got like three carers' teams for one client and then we talk about all information what happens and what they like and what they doesn't like"* (P05, Female homecare worker, aged between 25-40)

> *"We are all a team. You are going to find you have certain carers 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. Obviously, we don't give out confidential information, but just to say, 'what a day we've had'."* (P06, Female homecare worker, aged between 25-40)

In addition to this, some homecare workers noted that members of their own families were familiar with care work and provided useful informal support or acted as a helpful emotional sounding board. A few participants discussed making use of these informal and formal practices as a means to enable them to undertake their job more effectively. Within the working environment, when the agency's organisational culture fostered positive collaborations amongst homecare workers, it appeared to indirectly improve client care:

> *"Feeling there is someone looking out for you and that when you are ringing to report things, you are not being a bother, even though it is your job. Feeling that when you have reported things that it is followed up and actioned, so you don't have to keep reporting the same thing. You have an opportunity to talk about anything you are not happy with."* (P02, Female homecare worker, aged between 25-40)

Theme 2: Working with other professionals

Perceptions of Conflict, Side-lining and Invisibility

Given the sensitivity and often hard physical and emotional work when supporting clients with dementia at end of life, managers reported that continuity of personnel was often desired by those paying for homecare services and more frequent or longer visits became a feature of the homecare 'package'. Homecare workers discussed having more frequent or longer periods of contact with clients whose life was drawing to an end; enabling them to notice changes within a client's condition. Many participants felt that the regular intimate care they provided clients (particularly clients with dementia, who may have limited communication and/or memory problems), put them in a good position to highlight health problems to other practitioners. On the basis of their more established relationships with clients and being involved in providing intimate care, they reported feeling protective towards vulnerable clients, particularly at the end of life, whom they felt needed to be better looked after. Many recounted their experiences of 'crossing paths' with district nurses as they entered or left a client's home, or coming into contact with specialist teams such as palliative care teams or 'night nurses' during this time, and a small number mentioned working in rotation with privately paid live-in care workers employed by another agency. As noted above, among many homecare workers their relationship with a client substantially preceded those of other professionals meaning they often held more information about their clients than 'newly arrived' other professionals:

> *"You were working with them every day you see the - you get used to how they are every day and when there is a small little change comes, because as a carer, you have to be alert of every small thing. I said, the GP needs to come in. The district nurses would come and they would give him some laxatives. I was like, the blockage, there is a blockage in there and this is uncomfortable for him. We need to sort this out, because*

he's always in pain. And so the doctor came and they gave him an enema and he was fine" (P07, Female homecare worker, aged between 25-40)

At the end of life, it was common for homecare workers to work alongside other health professionals. Several participants acknowledged the value of other health professionals' contributions to clients' care at home and the importance of their own active involvement in working with other professionals. Homecare managers perceived the role and contribution of the homecare workforce to be potentially influential at the end of life, where several professionals might newly be coming into the home:

"With end of life care and there is so many different people that we tend to mix with and because we are in there a lot and they rely a lot on our information and what we record in our notes and things like that. We tend to be more aware of how they have been in the last sort of couple of hours. We play quite a big part within that team" (P01, Female homecare manager, aged between 51-60)

However, whilst often possessing extensive knowledge regarding their clients' conditions and personal preferences, many participants reported that they were frequently required to make explicit their ability to only deal with non-medical tasks. When interacting with healthcare professionals such as district nurses, doctors or paramedics, several participants reported instances where they had been asked to perform, or were expected to undertake responsibilities more appropriate to a clinical professional:

"Some district nurses are a bit, can be a bit lazy and will try and get carers to do more than they should" (P08, Male homecare worker, aged between 25-40)

"Sometimes we'll phone up the district nurse and ask for a district nurse to come and visit. They say, "What are you visiting for da, da, da?" It's the same when you phone up for an ambulance or a doctor and that's what you try and explain to them. I am not

medically trained. I am calling you, because I'd rather call you out and not need you,
than not call you out and need you to be fair." (B017, female homecare worker, aged
between 51-60)

While homecare workers generally wished to assist health professionals, their lack of
healthcare training meant that, at times, they needed to step away from tasks beyond their skills,
competence, or that were contrary to agency policy. Expressing this to other health
professionals could sometimes provoke conflict:

> *"She (client) had a (nurse) that usually comes in, she came in and then she would just*
> *like, say 'can you help us, help me turn her', I said 'we're not allowed'. She goes, 'well*
> *what are you doing here then? Why don't you go? What's the point in you being here if*
> *you're not helping, if you're not willing?'. I said 'it's not that we're not willing to help,*
> *we want to help but we're not allowed to'."* (P10, Female homecare worker, aged
> between 25-40)

Homecare managers thought that health professionals were not always aware of the limits of
the tasks their staff were able to undertake. They were sometimes asked to assist with clinical
tasks which were outside their job role and expertise:

> *"The guidelines we have to follow as care workers, there is certain things we can't do*
> *and it tends to be clinical elements. And other professionals would know that. They*
> *know that there are certain things we can't do.*" (P01, Female homecare manager, aged
> between 51-60)

Reflecting further on these dynamics, some managers considered that homecare workers were
seen as low status and not perceived as part of the multi-professional team working with people
with dementia at end of life, despite their presence in the home, knowledge of the client and
continuity of support:

"That's partly due to the fact that a lot of our staff kind of see GPs, district nurses, physiotherapists, whoever you want to sort of refer to as a multi-agency, they [the health professionals] kind of see themselves as somehow being in a superior role to them [the homecare workforce]" (P011, Female homecare manager, aged between 41-50)

"Sometimes some of them can be really difficult. Some of them treat us like we are beneath them. So yes, I would say they (district nurses) throw their weight around a bit on the lower class" (BO17, female homecare worker, aged between 51-60)

The concerns of homecare managers regarding expressions and attitudes of superiority amongst health professionals were confirmed by some homecare workers who perceived some dismissiveness from health professionals at times. Becoming drawn into disagreements between health professionals was frustrating, especially when a homecare worker's continuity of care provided them with detailed knowledge about their client that was not always accepted or respected:

"We once had a care worker phone the night nurses regarding an issue of a client with like a blocked catheter and the nurses phoned the next day to say that the care worker hadn't done this, this and this for example, but it wasn't quite the case. I think they were a bit dismissive towards her because of who she was." (P013, Female homecare worker, aged between 18-24)

Given that homecare workers frequently encountered increases in the number of visits from health professionals to their clients as they were approaching death, the quality of these interactions varied immensely. For example, some homecare workers discussed feeling

supported, respected and part of a highly cohesive team of professionals, particularly by specialist teams such as palliative care services:

> *"You felt that there was somebody else kind of caring for this person with you. ...The palliative side of things I think worked really well. I've not had any trouble working with palliative care team and all the night nurses that come in. They have to be involved. They have been good"* (P06, Female homecare worker, aged between 25-40)

Other homecare workers expressed difficulties in dealing with district nurses. These occurred because they felt unsupported or perceived that the district nurses had their own 'agenda' which did not take into account the emotional or physical needs of their clients:

> *"I am not a big fan of district nurses. Because they are on their own missions, you know. They don't have the clients in mind"* (P07, Female homecare worker, aged between 25-40)

As observed by some participants, such tense interactions could be attributed to the purpose and pressure of a district nurse's visit. For example, while homecare workers may feel responsible for supporting a client's emotional needs several understood that a district nurse might have to concentrate on improving the tangible, functional aspects of a client's wellbeing:

> *"They [district nurses] are just interested in what they are there for. If they are there for dressing (of ulcers), they are not interested in anything else"* (P03, Female homecare worker, aged between 41-50)

Discussion

In seeking to understand the perspectives of homecare workers and their managers towards teamwork, we observed that the themes that arise from the data aligned with the existing framework of inter-professional teamwork proposed by Reeves and colleagues (2010), which suggest that relational, processual, organisational and contextual factors influence teamwork. Relational factors include relationships and interactions between team members. Processual factors relate to operational aspects of teamwork such as, routines, time, tasks and task shifting. Organisational factors focus on the influence of the environment in which the team operates and contextual factors include the broader influences on teamwork, such as professional culture and socio-economic factors. Our findings suggest that homecare workers felt that team working (both within their agency and with other professional) was an integral part of care, and relational factors, such as team process and having clarity of roles, facilitated team working. Conversely, hierarchy and power dynamics with other more trained professionals created barriers to effective team working. Our findings also suggest that processual factors (such as informal routines, inherent rituals and formal processes facilitate team working) and organisational factors (such as regulations and policies within the organisation and managerial support) facilitated teamwork. Finally, consistent with Reeves et al.'s (2010) conceptual framework of inter-professional team work, our findings suggest that the perceptions of homecare workers about how other professionals view them and a perceived clash in professional cultures could act as barriers to team work.

A significant theme of the overall study was that within homecare agencies, the relational work of the homecare worker is often highlighted as central to the role and, while working on their own, they also make efforts to have contact with colleagues and managers. The potential value of providing opportunities for discussion and mutual support for homecare workers was recognised both amongst management and peers but proved difficult to operationalise since the usual cultural practices of a team in healthcare services are not resourced or part of

professional expectations in homecare agencies. Thus, there was no weekly staff meeting or allocation meeting in any of the agencies participating in this study, very little group or whole service training and development, and supervision and appraisal were infrequent. The part-time nature and lone-working of these jobs highlight the minimal opportunities for team or employer cultures to develop. Fundamental are the payment by client-contact nature of the business and little by way of agency overheads to spend on staff support. Both managers and homecare workers sought to make their own contacts with each other, but these were individually constructed and among some, their own family networks were a valuable resource. For some homecare managers the benefits of fostering a collaborative organisational culture were more evident than others, thus further research might improve our understanding of what enables such emphasis. Such matters are probably not confined to homecare because a recent small study of care home workers supporting residents with dementia similarly suggested that collegiality and peer support combined with instances of positive feedback helped frontline workers manage feelings of lack of recognition or being taken advantage of that might otherwise be overwhelming (Law et al, 2019).

The findings from this present study indicate a need to make the implicit more explicit in relation to the role of homecare workers. If employing agencies wish to benefit from a team culture where members of staff communicate well with each other and learn from those with more or different experiences, then this needs to be fostered and resourced. If funders of homecare wish for such an approach, then they may need to pay more for it. If high levels of turnover are related to the stress of the work and lack of support then these need attention (Bajic Smith, 2016). There is evidence that continuity of care is highly valued by clients and their families (Heaton et al, 2012) and, while this might mean having continuity of workers, it also applies to the situation when a small number of homecare workers operate as a communicative team to provide cover for each other. The views of healthcare professionals

about the value of team work with homecare providers have not been canvassed. We need also to acknowledge the difficulties for health care professionals when homecare agencies have high turnover and the agency's staffing pressures may give rise to a view that they are not functioning professionally. Interestingly, a recent focus group study of NHS community mental health professionals (Sutcliffe et al., 2016) revealed that they considered the main 'problem' with homecare services was their inflexibility, a self-assessment not shared by our homecare workers or their managers (Yeh et al. 2019).

The findings of this present study illuminate the inherent power dynamics within the home as a workplace when end of life care is being provided, especially between those who are clinically trained and those who appear not trained or qualified and possibly domestic in skills and orientation. There was little in this data suggesting that these dynamics were associated in the minds of the homecare workers or managers with the public sector status of the clinical staff and their possible reflections of themselves as morally superior to profit-making homecare agencies. This contrasts with the findings of a study of the views of private sector nursing home staff whose nurses thought this public- private sector demarcation accounted for their dismissive treatment by NHS staff (Thompson et al, 2016). Nonetheless, contestations over power and control can get in the way of collaborations and forging positive interactions between individuals (Saba et al, 2012). Modifying these power dynamics may address the persistent calls for 'recognition' amongst the homecare workforce; particularly that they may be well placed to provide insight into the small or subtle changes of a client's condition and some monitoring of this.

This study had a large sample for qualitative research and makes a significant contribution to the literature that is building up understanding of the dual nature of team work within a homecare environment. This includes the perspectives of the homecare workforce and their efforts to act as a team within their agency as well as their working practices and

relationships with healthcare staff. The organisation of homecare services matters because, according to a systematic review (Cooper et al, 2017), interventions that have improved client outcomes include training with additional organisational supports, such as regular supervision, care focused around clients' needs and goals, and improved communication with management and other workers.

There are limits to the study in that the managers of the homecare agencies acted as gatekeepers for this study's recruitment and may have intentionally or unintentionally selected or deliberately excluded members of their staff at their discretion in order to uphold their agency's reputations. 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 clients. Further research is required to understand different stakeholder perspectives, such as those of district or community nurses and end of life care specialists, including their perceptions of barriers and facilitators in relation to collaboration with the homecare workforce. Beyond professionals, the views of people with dementia and their family carers are important in considering how they see teamwork and what inter-professional communications at end of life might be optimal (Hill et al, 2016).

Conclusion

A recent editorial by van der Steen and Goodman (2016) argued that some subjects do not need to be studied any more in research on dementia and end of life because the evidence base is sufficient. This may be so in hospital, hospice and care home settings but care at home when provided by homecare staff is often overlooked (Abrams et al 2019). With policy aspirations for more care at home to be provided for people with dementia, the homecare workforce will be central to enabling this to happen. This means that quality of care may need to be fostered by better partnership or team working within and across agencies,

involving professional and non-professional staff, and by better resourcing of homecare

agencies to enable them to support their staff as well as their clients.

Conflicts of Interest

The authors declare that there are no conflicts of interest

Ethical Approval

This study was approved by both King's College London's (project number HR-15/16-2462) and Kingston/St George's (project number 1516CHA5) Ethics Committees. All participants provided informed consent prior to involvement in the study.

References

Abrams, R., Vandrevala, T., Samsi, K., & Manthorpe, J. (2019). The need for flexibility when negotiating professional boundaries in the context of home care, dementia and end of life. *Ageing and Society*, 39(9), 1976-1995. doi:10.1017/S0144686X18000375

Bajic Smith, J. (2016). *Emotional and psychological wellbeing in home care workers – a multi-method study* (Doctoral dissertation). Macquarie University, Sydney, Australia, http://hdl.handle.net/1959.14/1261596 (accessed 27 July 2019).

Birch, D. & Draper, J. (2008). A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *Journal of Clinical Nursing,* 17: 1144-1163. doi: 10.1111/j.1365-2702.2007.02220.x

Bjerregaard, K., Haslam A. S., Morton T. & Mewse, A. (2015). The shared experience of caring: a study of care-workers' motivations and identifications at work. *Ageing & Society,* 37: 113-138. doi: 10.1017/s0144686x15000860

Burns, D. J., Hyde, P. & Killett, A. (2016). How financial cutbacks affect job quality and care of the elderly. *Industrial Labour Relations Review,* 69: 991-1016.
doi: 10.1177/0019793916640491

Care Quality Commission. (2013). *Not just a number, Home care inspection programme.* London, Care Quality Commission, https://www.cqc.org.uk/sites/default/files/documents/9331-cqc-home_care_report-web_0.pdf (accessed 27 July 2019).

Challis, D., Clarkson, P., Chester, H., Davies, S., Sutcliffe, C., Xie, C. & Wilberforce, M. (2011). *Community Support Services for People with dementia: the relative costs, and benefits of specialist and generic dementia care services*. University of Manchester, Personal

Social Services Research Unit, Manchester:

http://research.bmh.manchester.ac.uk/pssru/research/ServiceArrangementsandIntegration/CommunitySupportServicesforPeoplewithDementia/ (accessed 27 July 2019).

Cooper, C., Cenko, B., Dow, B. & Rapaport, P. (2017). A systematic review evaluating the impact of paid home carer training, supervision, and other interventions on the health and well-being of older home care clients. *International Psychogeriatrics,* 29: 595-604. doi: 10.1017/s1041610216002386

D'Astous, V., Abrams, R., Vandrevala, T., Samsi, K., & Manthorpe, J. (2019). Gaps in Understanding the Experiences of Homecare Workers Providing Care for People with Dementia up to the End of Life: A Systematic Review. *Dementia,* 18(3): 970–989. https://doi.org/10.1177/1471301217699354

De Witt, L. & Ploeg, J. (2016). Caring for older people living alone with dementia: Healthcare professionals' experiences. *Dementia,* 15: 221-238.
doi: 10.1177/1471301214523280

Dill, J. S. & Cagle, J. (2010). Caregiving in a Patient's Place of Residence: Turnover of Direct Care Workers in Home Care and Hospice Agencies. *Journal of Aging & Health,* 22: 713-33. doi: 10.1177/0898264310373390

Dixon, J., King, D., Matosevic, T., Clark, M. & Knapp, M. (2015). *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. Canterbury, University of Kent, Personal Social Services Research Unit: https://www.pssru.ac.uk/pub/4962.pdf (accessed 27 July 2019).

Giacomini, M., DeJean, D., Simeonov, D. & Smith, A. (2012). Experiences of living and dying with COPD: a systematic review and synthesis of the qualitative empirical literature.

Health Technology Assessment Series, 12: 1–47. Retrieved from

https://www.ncbi.nlm.nih.gov/pubmed/23074423 (accessed 27 July 2019).

Gomes, B., Calanzani, N., Gysels, M., Hall, S. & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care,* 12: 1-13. doi: 10.1186/1472-684x-12-7.

Heaton, J., Corden, A. & Parker, G. (2012). 'Continuity of care': a critical interpretive synthesis of how the concept was elaborated by a national research programme. *International Journal of Integrated Care*, 12: e12. https://www.ijic.org/articles/abstract/10.5334/ijic.794/ (accessed 28 July 2019)

Hill, S. R., Mason, H., Poole, M., Vale, L. & Robinson, L. (2016). What is important at the end of life for people with dementia? The views of people with dementia and their carers. *International Journal of Geriatric Psychiatry,* 32: 1037-1045. doi: 10.1002/gps.45642016

Hussein, S. and Manthorpe, J. (2012). The dementia social care workforce in England: secondary analysis of a national workforce data set. *Aging and Mental Health* 16(1): 110-118. doi: 10.1080/13607863.2011.596808.

Johnson, E. K. (2015). The business of care: the moral labour of care workers. *Sociology of Health & Illness*, 37: 112-26. doi: 10.1111/1467-9566.12184.

Kingsmill, D. (2014). *Taking Care: An independent report into working conditions in the Care Sector.* London: Kingsmill Review.

Law, K., Patterson, T. G. & Muers, J. (2019). Experiences of healthcare assistants working with clients with dementia in residential care homes. *Dementia,* 18(2) 644-59 doi: 10.1177/1471301216688396

McGarry, J. (2010). Relationships between nurses and older people within the home: exploring the boundaries of care. *International Journal of Older People Nursing,* 5: 265–273. doi: 10.1111/j.1748-3743.2009.00192.x

Public Health England. (2018). *Official Statistics, Statistical commentary: End of Life Care Profiles, February 2018 update*, Published 6 February 2018, accessed 27 July 2019, https://www.gov.uk/government/publications/end-of-life-care-profiles-february-2018-update/statistical-commentary-end-of-life-care-profiles-february-2018-update

Reeves, S., Lewin, S., Espin, S. & Zwarenstein, M. (2010). *Interprofessional Teamwork for Health and Social Care*. Oxford: Blackwell Publishing Ltd.

Ritchie, J. & Spencer, L. (1994). 'Qualitative data analysis for applied policy research', in A. Bryman and R. G. Burgess (eds.), *Analysing Qualitative Data*, London: Routledge, pp.173-94.

Rubery, J., Grimshaw, D., Hebson, G. & Ugarte, S.M. (2015). "It's all about time": time as contested terrain in the management and experience of domiciliary care work in England. *Human Resource Management,* 54: 753–772. doi: 10.1002/hrm.21685

Saba, G. W., Villela, T. J., Chen, E., Hammer, H. & Bodenheimer, T. (2012). Annals Journal Club: The Myth of the Lone Physician: Toward a Collaborative Alternative, *Annals of Family Medicine,* 10: 169-173. doi:10.1370/afm.1353

Skills for Care. (2018). *The state of the adult social care sector and workforce in England.* Leeds, Skills for Care, Retrieved from Skills for Care website: https://www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2018.pdf (accessed 27 July 2019).

Sleeman, K. E., Ho, Y. K., Verne, J., Gao, W. & Higginson, I. J. (2014). Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001-2010. *BMC Neurology,* 14: 59. doi: 10.1186/1471-2377-14-59

Stones, D. & Gullifer, J. (2016). 'At home it's just so much easier to be yourself': older adults' perceptions of ageing in place. *Ageing & Society,* 36: 449-481. doi:10.1017/S0144686X14001214

Sutcliffe, C., Jasper, R., Roe, B., Jolley, D., Crook, A. & Challis, D. (2016). Inter-professional perspectives of dementia services and care in England: Outcomes of a focus group study. *Dementia,* 15: 1002-1020. doi: 10.1177/1471301214548692

Szafran, O., Torti, J. M., Kennett, S. L. & Bell, N. R. (2018). Family physicians' perspectives on interprofessional teamwork: Findings from a qualitative study. *Journal of Interprofessional Care,* 32: 169-177. doi: 10.1080/13561820.2017.1395828

Thompson, J., Cook, G. & Duschinsky, R. (2016). Experiences and views of nursing home nurses in England regarding occupational role and status. *Social Theory & Health,* 14: 372-392. doi: 10.1057/sth.2016.3

van der Steen, J. & Goodman, C. (2016). What research we no longer need in neurodegenerative disease at the end of life: The case of research in dementia. *Palliative Medicine,* 29: 189-192. doi: 10.1177/0269216315569998

Xyrichis, A. & Ream, E. (2008). Teamwork: a concept analysis, *Journal of Advanced Nursing*, 61: 232-241. doi: 10.1111/j.1365-2648.2007.04496.x

Yeh, I-L., Samsi, K., Vandrevala, T. and Manthorpe, J. (2018). Constituents of effective support for homecare workers providing care to people with dementia at end of life. *International Journal of Geriatric Psychiatry*, 34(2): 352-359. doi:org/10.1002/gps.5027

Table 1: Participant Characteristics (n=42)

		Home Care Worker (n=29)	Manager (n=13)
Gender	Male	2	2
	Female	27	11
Age	18-24	3	1
	25-40	8	3
	41-50	11	6
	51-60	5	2
	61+	2	1
Ethnicity	African	4	1
	Caribbean	4	1
	Indian	1	0
	Mixed Caribbean	1	1
	Other white background	5	2
	White/ English	12	7
	White/Irish	1	0
	White/Other British	1	1
Place of Birth	UK	16	9
	Non UK	13	4

Experience of social care work (years)	Under 1 year	6	3
	1-5 years	13	6
	6-10 years	6	3
	11-15 years	0	0
	Over 15 years	0	0
	Not stated	4	1
Hours worked	Full time	22	13
	Part time	7	0
Professional qualifications	Prefer not to say/not stated	16	4
	National Vocational Qualification (NVQ)	8	0
	Degree level	3	7
	Other	2	2