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Caring for people with dementia in their own homes: homecare workers' experiences of tolerating and mitigating risk

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Abstract
Little is known about risk management in homecare for people with dementia. We aimed to gain an understanding of the ways in which homecare workers assess and manage risk whilst caring for people with dementia in their own homes. We conducted a qualitative interview study with 17 homecare workers assisting people with dementia with their personal care. Interviews were face-to-face, semi-structured, recorded and transcribed verbatim. Analysis was inductive and thematic. A key theme of risk was identified, with three main sources: the client as a source of risk to the homecare worker, the clients' home and behaviours as a risk to the client, and the wider health and social care system as a risk to both clients and homecare workers. Three interrelated aspects of risk were found to influence homecare workers' decision making and actions: homecare workers' perception of the level of risk, their perceived ability to control the risk and their tolerability of risk. The higher the perceived risk, the stronger the action taken by the worker or agency to mitigate it and the greater the impact on the client. To support effective development of this workforce there is a need to devise training that incorporates the use of tacit knowledge and experiential learning. Risk management policies for homecare should acknowledge and utilise the expertise, experiences and values of homecare workers.

Keywords: dementia; homecare; risk; safety; domiciliary care

Introduction

The number of people in the United Kingdom (UK) living with dementia is estimated to be over 850,000 (Wittenberg *et al.*, 2019) and this number is expected to nearly double by 2,040 (Prince *et al.*, 2014). In the UK, approximately 61 per cent of people with dementia, over the age of 65, are living in the community (Prince *et al.*, 2014). Care at home is fundamental to community care policy (Taylor and Donnelly, 2006) and there is an ongoing policy drive to increase the number of people able to remain in their own homes (Carter, 2016). Whilst family carers may initially provide care for people with dementia (Polacsek *et al.*, 2020),

they often require, and instigate, additional support from paid homecare workers (Pollock *et al.*, 2021). Homecare workers provide help with washing, dressing, eating (Hayes and Moore, 2017), and essential physical, social and emotional support for older adults (Turner *et al.*, 2020).

As a workforce, homecare workers are most likely to work part time, often in isolation and to be female. They tend to be employed by care agencies and experience poor working conditions (Hussein and Manthorpe, 2012) including zero hour's contracts and low pay (Hayes and Moore, 2017). McLean (2007) describes care workers as an overworked, socially devalued group, with Hayes and Moore (2017) suggesting that the pay of private-sector homecare workers has at times been so low as to breach national minimum wage law.

Of the estimated 520,000 homecare workers who provided care for people with dementia in 2016, over a third had not received any training for dementia (Carter, 2016). There is also a suggestion that the homecare workforce have poor access to dementia training (Polacsek *et al.*, 2020) and inadequate supervision for their role, thereby potentially limiting their skills (D'Astous *et al.*, 2019). System and organisational factors such as these can be barriers to dignified care (All Party Parliamentary Group on Dementia, 2019).

Nevertheless, McLean (2007) suggests that homecare workers serve as 'prostheses' helping to preserve personhood by treating the person with dementia as an individual conscious being with valid needs and wishes. McLean (2007) further argues that preserving personhood is an immense charge for anyone, let alone those who occupy the lowest rung of the care-giving spectrum. Homecare workers can face significant risks in the homes of their clients including health hazards, injuries associated with moving and handling, and verbal abuse and aggression (Taylor and Donnelly, 2006); whereas people with dementia can face different risks such as those related to cooking, medication use or falling (Sandberg *et al.*, 2021). There can be few areas of practice more complex (Bailey *et al.*, 2013) and more difficult to cope with than managing risks in dementia care (Backhouse *et al.*, 2018), with homecare workers experiencing levels of responsibility and decision making (Clarke, 2009) that are often hidden (Neysmith and Aronson, 1996).

Risk, uncertainty and decision making in dementia care

Decision making in a situation of uncertainty is a central activity for all those who provide health or social care for people with dementia. Beaumont (1999) considers risk and uncertainty to be deeply intertwined. The term risk can be used to describe two interrelated aspects of uncertainty: firstly, the threat it poses to individuals and, secondly, the strategies used to manage those threats (Alaszeweski and Coxon, 2009).

For health and social care professionals, identifying and managing risk often involves gathering, ordering and analysing information from a variety of sources (Ruston, 2004) and using their professional judgement in order to underpin decisions about need, risk and human rights (Taylor, 2006; Waugh, 2009). In this context, risk is viewed as an objective certainty that can be quantified, regulated and managed (Dickins *et al.*, 2018).

In contrast, Douglas and Wildavsky (1983) suggested that risk is not an objective reality but rather a social, collective, subjective perception of danger and that

different groups will have different ideas about what is dangerous depending on their shared experiential contexts. Here risk is intertwined with danger. Similarly, Lupton (2013) describes risk as being virtual, a potential rather than realised threat or danger which involves visualising the consequences of an action or events that may need to be managed. Perceptions of risk and danger are shaped through the interaction with others, material objects and the environment (Lupton, 2013). Thus, when an individual weighs up risks they are deciding on how the risk phenomena fits with their values about what is acceptable and what is dangerous (Lupton, 2013).

Expert professional knowledge is often compared with lay knowledge and awarded a higher status (Baillergeau and Duyvendak, 2016). However, Zinn (2016) suggests that separating people into a rational domain of experts and non-rational domain of lay people understates the complexity and parameters of expert 'rational' decision making and neglects a whole range of in-between strategies, including trust, emotion, and the use of tacit or experiential knowledge to provide efficient ways to deal with risk and uncertainty.

The homecare sector experiences difficulties with recruitment, retention, funding and variation in the quality of provision (Bottery, 2019). Homecare clients with advanced cognitive impairment can pose unique challenges for homecare workers due to having high dependency, difficulties communicating (O'Brien *et al.*, 2019), and changes in function and understanding (Abrams *et al.*, 2019). However, in homecare, responsibilities and decision making can be unseen (Taylor and Donnelly, 2006). Indeed, homecare workers often make decisions about risks and perceived danger in the context of limited training and varied supervision (Dickins *et al.*, 2018). Thus, homecare workers as an undertrained, unregistered workforce fall somewhere between the expert professional and the lay person. This paper aims to gain an understanding of the ways in which homecare workers assess and manage risk whilst caring for people with dementia in their own homes.

Methods

Study design

The aim of the study was to improve our understanding of ways in which homecare workers experienced caring for people with dementia within their own homes. For this exploratory study, we used inductive semi-structured interviews.

Settings and participants

Twenty-four homecare agencies, which provided homecare for people with dementia and which were located within the boundaries of one clinical commissioning group in the East of England, were approached via telephone or email and invited to contribute to the study. Agencies that expressed an interest in their staff taking part were sent leaflets to be circulated to their homecare workers. Homecare workers who were interested completed an expression of interest form containing their contact details. They were then contacted by the research team who sent them information about the study and arranged a time and location for the interview to take place. All participants provided informed consent and signed a consent form. Seventeen sessional (not live-in) homecare workers from seven different homecare agencies were recruited.

Data collection

Interviews were conducted by AR, a female medical sociologist with over 20 years' post-doctoral experience of conducting research with vulnerable populations including patients, young and adult carers, refugees, people with head injuries and people with dementia. She has a public health background and has published widely in the field of risk and decision making, thus her research lens, probes and reflections on interviewee responses were likely to attend to notions of risk. The interviews were conducted at the main premises of homecare agencies or the home-care workers' homes early in 2020. An interview topic guide was used and included usual practice, personal care, training, knowledge and support. These themes were based on findings from a parent study (Pro-CARE) funded by the Alzheimer's Society, exploring care for people with dementia in a variety of settings. Interviews were one-time, face-to-face, semi-structured, audio-recorded and transcribed verbatim. Average interview length was 46 minutes (range 25–108). No field notes or member checking processes were used. A small honorarium voucher was given to participants as a thank you for their time.

Data analysis

We used inductive Qualitative Content Analysis (Elo and Kyngas, 2008) since knowledge about homecare workers' experiences is limited and fragmented. This approach enabled us to move from the specific to the general so that instances of reported behaviours and experiences could be combined to more general statements about homecare workers' experiences. These in turn provided greater insights into devising potential solutions to the problems they faced in caring for their clients. Themes were identified by both authors following listening to audio recordings and examining transcripts to develop familiarity with the data. Initial themes were discussed, followed by further engagement with data, discussions and modification of themes. Text covering risk was identified and then combined into three general thematic areas: risk identification, risk management and system risks (a further two themes, structural conditions and client dementia-related characteristics in relation to providing personal care, are examined elsewhere) (Backhouse and Ruston, 2022). Risk themes were further examined in order to ensure strength of the thematic areas. The location of data under the themes of the client as a source of risk to the homecare worker, the client's home and behaviours as a source of risk to the client, and the wider system as a source of risk to both the client and the homecare worker generated, what we perceived to be, thorough data saturation. Both authors coded data using NVivo12. A meeting with family carers of people with dementia (who constituted the designated reference group for the wider research programme on dementia care and had some experience of employing homecare workers for their relatives with dementia) took place to discuss and examine the interpretation of these themes.

Ethics

The Queen's Square Research Ethics Committee (London) reviewed the study (IRAS reference: 251339) and gave a favourable ethical opinion.

Findings

One participant was male and the average age was 38 (range 21–65). Sixteen out of the 17 were White British and one was White German. Participants had been working with their current homecare agency for an average of four years (range seven months to nine years), with an average of nine years' experience of providing care (range 1–43 years).

Identifying and mitigating risks emerged as key features of participants' work with their clients with dementia. They framed risks in terms of risk that they and their clients faced in the client's home, as well as risks associated with their low status within the health and social care system. Framing is a narrative by which meaning is constructed out of observation and other client information, and is an essential component of judgement (Taylor, 2006). Whilst acknowledging expected risks associated with a caring role such as experiencing a bad back or being exposed to cigarette smoke, our participants did not mention these. Instead, their framing of risk suggested that caring for clients in moderate- to late-stage dementia posed specific risks not identified when caring for clients without dementia.

Risks to homecare workers – the client as a source of risk

Clients with dementia could pose a potential risk to homecare workers by accusing them of things they did not do, such as stealing:

> …like she'll forget where she's put things and she'll ring up and she'll be like 'the carers have took this' and we have to reassure them like 'oh no, actually, you put it in here'. (S15, 6 years' experience)

However, our participants spoke of expressions of anger 'aggression' as the predominant source of risk they perceived from clients.

Participants reported experiencing both verbal and/or physical aggression as part of their day-to-day work with their clients. They described managing aggression as a normal, routine part of their job and as an inherent part of working with people with dementia:

> I think [homecare workers] would probably think that it's them [that they are the cause of the aggression] and you have to sort of say 'No, it's not you, this is just what they [clients with dementia] are like and you'll get used to it in the end, you're not doing anything wrong as a carer…' but yeah sometimes it can feel quite personal and you just have to think it's not, they're not aiming it at you specifically, it's just the way they are. (S04, 4 years' experience)

> …a lady, very aggressive, I was changing her, helping her change. She was absolutely fine and then one second later she got very angry and then went, went to hit me. Erm, she didn't actually hit me, she just got really angry, so I just stepped back, let her calm down, left the room for a second and then tried again … because I was on my own I was … worried. (S14, 9 years' experience)

The level of aggression that participants encountered defined how and whether they were able to cope with it. Verbal aggression was generally tolerated and often

mitigated by the homecare worker devising strategies to calm the client down and/
or to remove themselves temporally from the situation:

> I think nine times out of ten they don't mean it. It's just with their brain and stuff
> like that, they don't, nine times out of ten, they don't understand what they've
> done because I've [left the room] then gone back and gone 'have you calmed
> down now?' 'Yeah, nothing wrong with me'. (S09, 3 years' experience)

Distancing themselves from the risk situation was the most common method used
to mitigate risk and this was often used in conjunction with other strategies, such as
changing the tone of their voice or distracting the client. They also took steps to
protect themselves by ensuring they had the means to call for help if needed:

> You're completely on your own so you have obviously got to make sure that he is
> not going to lash out because he's in a bad mood. Obviously, we need to make sure
> we've got a phone near us if we need assistance. (S03, 19 years' experience)

The likelihood that a client could become physically or sexually aggressive was also
accepted as commonplace. Participants described being on the alert for the poten-
tial for this to happen. Their awareness of the potential danger and the likelihood of
it occurring was often based on participants' prior experience of client behaviours.
Prior experience provided them with the knowledge of the best way to avoid any
threats posed to them by their client:

> Always occupy the hands and always be careful with the feet because you never
> know – the foot goes out, out and erm you got a gentleman who actually can
> be very, well it's called sexual abuse, but they don't know what they are doing.
> You try to wash them, and they try and put a hand in between your legs …
> hands is another thing with the males. Avoiding it and coping with it. (S06, 9
> years' experience)

Aggressive behaviour was not usually deemed serious enough to require outside
assistance providing that it did not place the homecare worker in a position
where they were likely to become overwhelmed by the situation:

> …just discourage them of the behaviour, especially the sexual one, unless they are
> really forceful and that needs to be done something through the Social Services
> management, double assistance. When they are strong it's always recommended
> double assistance but a verbal one [verbal aggression only], well it's … just nothing
> … Just gets over the top of your head and carry on! (S05, 1 year of experience)

However, when the level of aggressive behaviour began to pose a substantial risk of
harm to the homecare worker or where the risks were unpredictable and the out-
come uncertain, the homecare worker and/or agency would act to remove the client
from their care:

He was a gentleman with poor mobility, he couldn't walk without our assistance. The kitchen was a sort of long sausage. He was sitting right by the back door and I was doing him, I think a cup of tea and I was talking to him and I just noticed, split second, his facial expression changed, and he jumped out of the chair. He grabbed me by my throat, pulled me down to the cooker, luckily, I hadn't cooked anything. I managed to push him away, but I pushed him away on a chair and he was sitting backwards to the kitchen door so I could not physically get out. He grabbed me again. I pushed him again and I think it was a split second, I put a foot on a chair jumped over the chair. And I stand in the hallway because I was calling my boss and he actually got out of the chair, walked, grabbed me by my wrist, I had bruises on my wrists as well, threw me out and chucked the care plan at me and locked all the doors. They immediately sent another carer. (S06, 9 years' experience)

Overall, participants presented a picture of being at risk of aggressive behaviour and needing to calculate the probability of harm to themselves. A certain level of risk associated with aggression was tolerated or accepted because it was considered part of the client's condition and something that clients did unwittingly. In response, they used their care experiences to develop their own preventative strategies in order to mitigate the danger associated with the aggressive behaviour. The preventative strategies were informed by their prior experience of their client's behaviour, their own level of tolerance of the risk and their perceived ability to control the situation. However, where the aggressive behaviour had the potential to result in visible or serious harm to homecare workers their tolerance of the risk was reduced. At this point the homecare worker or agency would act to eliminate risk and were more likely to withdraw care.

Risks to clients – the client's home and behaviours as sources of risk

Participants described a range of dispositional and contextual factors that heightened their client's risk of experiencing harm in or around their homes. These included risks ranging from falls, skin breakdowns or missed medications to setting their kitchen on fire or getting lost as a result of walking away from their homes. Clients' homes were described as locations of risk that stemmed from the client's behaviours, with the potential for everyday activities to turn into dangerous situations:

He smoked quite a lot, this gentleman, I mean 40–60 fags [cigarettes] a day. And we didn't deprive him, we gave him cigarettes while we were there so we could see what he was doing … and he'd got up and wandered into his bedroom … I don't know what he'd gone into the bedroom for, but I just literally walked into the bedroom door just as he was opening the wardrobe door to throw his cigarette in … if I hadn't of been there? … you don't know what could have happened. So, we took the cigarettes away and he only had them when we were sat there with him in the same room. (S17, 2 years' experience)

Limiting when the client could smoke his cigarettes to when the homecare worker could sit with him provided a means by which risk could be mitigated rather than

removed altogether, thereby providing a solution for both the client and the home-care worker. Awareness of the client's normal smoking patterns enabled the home-care worker to use the information to make decisions on how to deal with or control the risks associated with the dangers of smoking. However, when the client began to exhibit unusual behaviour that was not consistent with his normal smok-ing routine and which had the potential to put the client's life or home at risk, the homecare worker was forced to re-assess the situation and instigate surveillance measures in order to ensure that the risk mitigation strategies succeeded.

However, where a client's behaviour put their property or life at risk, participants framed the situation as high risk and therefore not necessarily amenable to mitiga-tion. From the perspectives of the homecare workers and the care agencies, elim-ination of the risk in the form of a cancellation of the care package was most likely to be selected as the method to control the situation. For example, partici-pants described situations where clients had put themselves in danger by accidently causing a fire in their home:

> I walked into a lady and her kitchen was on fire. She'd put her bowl with a tea towel on the hob and turned it on by accident. We had to have the fire brigade. You know, I even, I had to say to her 'come on, we've got to get out'. (S07, 43 years' experience)

> We had a couple of incidents with him where he'd like leave the cooker on with the frying pan with oil and stuff, leave the doors wide open. He'd walk over to the shops … and he'd go to the shop and just get lost, and the neighbour will have to bring him back home. I used to worry about it all the time and that's why in the end, we had to be like, he needs extra care, we can't look after him anymore because of how much he puts himself at risk. (S15, 6 years' experience)

Whilst participants may have been aware that there was a potential risk of fire in the client's home, the timing and outcome were not necessarily predictable. Therefore, in the context of an emergency, the participants reported needing to assess the risk quickly and respond instinctively in order to remove the client and themselves from the danger.

Participants also reported needing to be aware of the potential risks to their cli-ents if they went outside their home unsupervised. Preventing harm to the client in this situation represented a balancing act for homecare workers – they needed to weigh up the risks associated with locking people in their homes compared with the risks they may encounter outside their homes. Whilst locking clients in their homes eliminated the risks associated with going outside, this strategy was not necessarily seen as entirely safe:

> I think the worst one is obviously knowing that we're not allowed to lock that door. But knowing that it's the wandering, that does scare me really, that one does … and then if you do lock them lock them up and then there's a fire! It's a catch 22. If you don't lock them, they're then over the heath walking the dog and stuff. (S03, 19 years' experience)

Participants described experiencing emotional stress when considering the potential consequences of both options as a control measure. Their tolerability of the risk was put to the test. Where a client's condition or their surroundings were considered to present definitive dangers, it was more likely that the homecare workers and/or agency would consider that the situation was more than they could handle and efforts to eliminate the risks would be taken:

> So yeah, she's, she the lady who is quite independent … we have to lock her in because she quite often, I think a while ago liked to go out and it's not safe, it's not safe, erm if she is unsteady or she won't know where she is going or even weather dependent and if we turn up and she is not there! … I suppose you are confining them to their home, and they can't go outside. (S05, 1 year of experience)

Participants dealt with a wide range of risks to their clients and felt able to take action that would keep their clients safe. Based on their experiences of looking after clients with dementia, they had developed strategies to manage a range of situations within the home. These included using technologies of control including locking clients in, switching cookers off at the socket and using safety rails on clients' beds. Most control and removal measures were aimed at reducing the chance of the client engaging in harmful behaviour, having an accident or preventing the carer becoming injured.

However, where participants were suddenly faced with potentially life threatening, serious problems and the outcome was highly uncertain their tolerance of risk diminished further, and they sought a change of care arrangements to reduce negative outcomes.

In attempting to manage risk and dangers within their clients' homes, homecare workers were placed in a similar position to that previously found with social workers in this setting (Linzer, 2002), having to balance incompatible values, sometimes overriding their clients' wishes, reducing their freedoms or taking their rights away in order to protect their clients or themselves. This in turn had the potential to affect the right of the client to maintain autonomy and to place the homecare worker in a position where their actions might result in different types of harm to their client. Since no risk management strategy can ever completely control uncertainty or danger, homecare workers have to continually work and make decisions within a grey ethical zone. Therefore, there is an inherent ambiguity within their role.

System risks – homecare workers' status within the health and social care system

Participants described a range of system-related factors that they felt had the potential to affect the quality of care that they were able to offer their clients. Firstly, they acknowledged that their level of training was, at times, insufficient to provide safe care and that they may be putting their clients at risk:

> It was the first month of my work. I hardly had any adequate training whatsoever. I was doing a sit for a gentleman who had Alzheimer's and he was a gentleman with very poor mobility, he couldn't walk without our assistance. (S06, 9 years' experience)

So, I have only been in there a couple of times … but when I first went in, I didn't know she had dementia, so it was kind of a bit of a shock. (S12, 4 years' experience)

Secondly, participants suggested that despite their concerns about limited training, the level of decision making they were expected to engage in represented a significant responsibility – on a par with that undertaken by health and social care professionals such as doctors and nurses – but for which they were not necessarily equipped or supervised:

For what the carers do, have to do as well, erm I do think that they're not, they're not looked upon as a nurse, a doctor but they do make decisions, but they make decisions, not medical decisions but they make decisions that could potentially hurt somebody erm and I don't think unless you've actually done it yourself, I don't think everybody realises what they have to do. And you're always making decisions when you go in and you know. Do I need a doctor? (S03, 19 years' experience)

Thirdly, those participants with several years' caring experience identified a number of challenges they faced resulting from constraints within the wider health-care system. In their attempts to reduce the risks posed by their limited training and knowledge, participants described trying to contact health and social service authorities to support them to provide the best care for their clients but with limited success. Some participants suggested that the support they could draw on was adversely affected by a lack of integration between different health and social care sectors. This was perceived to jeopardise the wellbeing of their clients:

You can't ring them anymore you have to go through a direct hub … so you speak to a call handler and they take the information, and they say that somebody will call you back and rarely do they. We do have a generic email which is the same hub, which you can email but you rarely get a response quickly. (S02, 8 years' experience)

Other participants suggested that political and financial constraints in the health and social care system resulted in homecare workers being seen as an extra pair of hands and having to manage the gap in services:

Her surgery, they're not very forthcoming. I don't think they understand dementia at all. And so, they said, 'Can you bring her down? [to the surgery] Well not really because she's got dementia … So, the relative had to explain everything and eventually the doctor agreed with the carer's assessment. (S07, 43 years' experience)

But sometimes it does feel, and especially Social Service, sometimes they'll say, 'Well the carers can do that'. But we have so much to do. (S02, 8 years' experience)

With limited access to other health and social care professionals, participants felt that their clients could be endangered when they were expected to take on these

additional activities without appropriate training and which were beyond their capabilities. Here the squeezed health-care system, which caused homecare workers' difficulties accessing professional medical or nursing support, itself created and sustained risks, increasing the potential for risks in homecare practices.

Perceived control and impact of risks

Based on homecare workers' perceptions of being able to control risks or not, we utilised their perception of risks and risk mitigation strategies in order to categorise our data into three risk levels: low, medium and high. Low-risk situations were amenable to control by strategies individual homecare workers used in the moment, medium-risk situations were amenable to management where the wider homecare team was involved and high-risk situations were perceived as not amenable to management within the clients' homes in the long term.

Overall, the findings suggested that homecare workers' perceptions of the dangers they or their clients faced could be categorised as low, medium or high risk, which in turn influenced their perception of their ability to control and manage the situation. Table 1 provides an overview of the relationship between perceived risk levels, perceptions of their ability to control the situations and the impact on care provided to the client. As the level of perceived risk increased, the level of control that homecare workers felt they had over the situation reduced. Concurrently, the higher the level of risk, the greater the impact on the client, often resulting in loss of autonomy such as being supervised while smoking, restricted in their movements or ultimately losing their chosen care.

Table 1. Perceived control and impacts of risks

Risk level	Low risk	Medium risk	High risk
Risk situations	Verbal aggression Low-level physical aggression	'Wandering' Falls risk Locking clients in Smoking – fire risk Low status of homecare workers	Endangerment to homecare workers and/or clients: High fire risk / High-level aggression
Perceived control by homecare workers	High control by homecare workers: Managed within worker–client interactions or wider homecare team	Medium control by homecare workers: Managed with technologies of control / Managed by engaging with team and wider health and social care system	Low control by homecare workers: Not manageable: client removed from agency
Impact on clients	Low impact on client: Adapted interactions or care	Medium impact on client: Reduced autonomy / Regulated activity / Sub-optimal care	High impact on client: Care withdrawn - no longer receives service

Discussion

This article aimed to examine homecare workers' experiences of providing care for clients with dementia who are living in their own homes. The analysis presented is a novel examination of homecare workers' experiences of tolerating and mitigating risks in caring for clients with dementia. Three interrelated aspects of risk were found to influence decision making, action and the subsequent impact on the client: the level of the risk, homecare workers' perceived ability to control the risk and their tolerability of risk.

High-level risks included situations where the client and/or homecare worker were placed in potentially life-threatening circumstances such as a house being on fire or uncontrollable physical violence. In these circumstances, homecare workers had little control over the risk situation, their tolerability level was very low and they were unable to balance the clients' rights to positive risk taking with the risk being faced. The implications of this for the clients' rights to care may be severely restricted.

Medium-level risks included wandering, falls, locking clients in their homes, and dealing with the wider health and social care system. The homecare workers' tolerability of medium-level risks resulted in the instigation of strategies or techniques of control to protect the client. This in turn reduced the types of positive risk-taking activities in which the clients could engage. The impact of this risk mitigation approach on the client could be a reduction in autonomy through instigation of regulated activity. Controlling perceived physical risks was prioritised over potential risks to psychological wellbeing through loss of autonomy (Clarke and Mantle, 2016).

Low-level risks included such things as verbal or mild physical aggression which were tolerated by the homecare worker. Mitigating strategies that were used included avoidance and displacement activities which had become routinised.

The literature on risk presents a continuum of understandings of risk in long-term conditions. This ranges from preventing harm to positive risk taking for improved wellbeing (Clarke *et al.*, 2009). Risk taking can be used to improve an individual's quality of life by enabling them to maintain control or autonomy, however, it also has the potential to threaten their safety (Clarke, 2009; Zinn, 2019). There has been an ongoing policy drive to ensure that people with dementia have the same rights as everyone else in society – that is to have a say in the way in which they live their lives (Department of Health, 2015; Cahill, 2018). It is recognised, however, that giving people with dementia choice or control over their lives may well incur an element of risk (Morgan and Williamson, 2014).

Enabling people with dementia to maximise the quality of their life involves balancing risks with any potential harm associated with positive risk taking (Manthorpe and Moriarty, 2010). Risk enablement involves supporting people living with dementia to take risks by creating plans to minimise or manage potential negative outcomes. To achieve this, health professionals would be expected to engage in risk appraisal, risk identification and risk estimation in order to judge the acceptability and/or tolerability of a risk. Acceptable risks would be expected to incur minimal negative outcomes and would not normally require a risk

assessment or mitigation strategies (Boulder *et al.*, 2007; Renn, 2010); whilst risks that are deemed tolerable would be ones that are considered acceptable (Lupton, 2013) and worthwhile for the benefits they provide for the individual once the potential for harm has been minimised. Risk enablement provides a tailored approach to risk and allows for the fact that dementia affects people in different ways.

Although homecare workers often fulfil a role similar to that of health-care practitioners, their level of training would not necessarily be expected to equip them with the knowledge and skills to develop evidence-based risk enablement strategies. Data from the study reported here provide insights into the factors underpinning homecare workers' risk assessment and management decisions. Care agency-employed homecare workers follow agency policies and procedures, using client care plans to guide the way they care for their clients. Such care plans can represent and perpetuate a shared disciplinary perception of what is deemed dangerous or risky (Douglas and Wildavsky, 1983). The findings of this study suggest that homecare workers also drew on their own perceptions and tolerability of risk, shaped by experiential learning, interactions with colleagues and clients (Lupton, 2013), and their tacit experience and knowledge of their clients to assess and mitigate or manage risks posed to their clients or themselves (Zinn, 2016).

In England, the need for social care support is rising, yet this is coupled with tighter criteria for client eligibility and over 100,000 unfilled staff vacancies in the sector (Bottery and Ward, 2021). Lack of skilled workers could be due to low pay and high staff turnover (Bottery and Ward, 2021), as well as limited access to training (Polacsek *et al.*, 2020). These stress factors on the industry are key background factors surrounding homecare practices. Additionally, in terms of regulations, the Health and Safety at Work Act (1974) reflects a grey area in which it only applies to certain types of domiciliary work in private homes (Health and Social Care Services Unit, 2011). Ascertaining whether there has been a failure of regulation related to the homes of homecare clients which are workplaces for homecare workers, or a failure to apply regulations to the risks faced by homecare workers, was beyond the scope of this study and need further specific research.

The findings of this study provide important information for policy makers and homecare agencies in their efforts to provide client-centred dementia care. Firstly, the insights provided into how homecare workers identify, assess and mitigate risks suggest that whilst homecare workers tolerated a relatively high degree of risk in their role, the thresholds of risk at which they felt they needed to either instigate control measures or remove the client from care are potentially incompatible with the risk enablement agenda. Future policy on risk management or enablement in homecare should acknowledge and take account of the expertise, experiences and shared values of homecare workers to ensure that enablement strategies can be supported by homecare workers.

Secondly, homecare workers' use of tacit or experiential knowledge suggests that those charged with providing training for homecare workers should focus on experiential learning rather than didactic approaches detached from the care setting. Providing shadowing, mentoring on the job, including experienced homecare

workers in training scenarios/videos to familiarise homecare workers with the types of risk situations they may encounter and strategies for mitigating them are likely to be most effective for homecare workers. Risk management should consider the local context of each client (Bailey *et al.*, 2013), their needs, abilities, wishes and preferences (Dickins *et al.*, 2018). Involving family members and shared decision making should be key (Stevenson and Taylor, 2016). Training modules should be developed in collaboration with experienced homecare workers to think through how to achieve optimal care and how to create policies around safety, security and wellbeing for clients and homecare workers. Training programmes should support workers to balance the tensions between risk management strategies and the ethical pressures created by implementing them.

Thirdly, professionals within the wider health and social care field need to better understand the potential value and skills of the homecare workforce, and how this workforce could be utilised more effectively to improve dementia care with their support (Manthorpe *et al.*, 2019). Valuing and supporting this workforce are key if they are to better balance risk management with client autonomy, provide optimal support to people with dementia and safeguard themselves.

Limitations

The main limitation of this research is that it is an exploratory study located in one geographical area. However, participants were recruited from seven different care agencies, providing variation in the sample.

Conclusions

Although, dementia homecare workers are often poorly trained and lowly paid, they are expected to identify, tolerate and mitigate risks daily. Where risks were high and homecare workers' control low, the impact on the client could be significant, this limited clients' agency in determining their own care and/or any positive risk taking. There is a need to devise training that incorporates experiential learning and the use of tacit knowledge, and for future policies on risk management and enablement in homecare to acknowledge and draw on the expertise, experiences and values of homecare workers.

Conflict of interest. The authors declare no conflicts of interest.

Ethical standards. The research received approval from the UK Queen's Square Research Ethics Committee (18/LO/1677, IRAS Project ID: 251339). Participants received information prior to agreeing to take part in the study and provided written consent to interviews.

References

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

Alaszeweski A and Coxon K (2009) Uncertainty in everyday life: risk, worry and trust. *Health, Risk and Society* **11**, 201–207.

All Party Parliamentary Group on Dementia (2019) *Hidden No More: Dementia and Disability*. London: Alzheimer's Society. Available at https://www.alzheimers.org.uk/sites/default/files/2019-06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf.

Backhouse T and Ruston A (2022) Home-care workers' experiences of assisting people with dementia with their personal care: a qualitative interview study. *Health and Social Care in the Community* **30**, e749–e759.

Backhouse T, Penhale B, Gray R and Killett A (2018) Questionable practices despite good intentions: coping with risk and impact from dementia-related behaviours in care homes. *Ageing & Society* **38**, 1933–1958.

Bailey C, Clarke C, Gibb C, Haining S, Wilkinson H and Tiplady S (2013) Risky and resilient life with dementia: review of and reflections of literature. *Health, Risk and Society* **15**, 390–401.

Baillergeau E and Duyvendak JW (2016) Experiential knowledge as a resource for coping with uncertainty: evidence and examples from the Netherlands. *Health, Risk and Society* **18**, 407–426.

Beaumont R (1999) Risk assessment and prediction research. In Parsloe P (ed). *Risk Assessment in Social Care and Social Work*. London: Jessica Kingsley, pp. 69–106.

Bottery S (2019) *What's Your Problem, Social Care? The Eight Key Areas for Reform*. The King's Fund. Available at https://www.kingsfund.org.uk/publications/whats-your-problem-social-care.

Bottery S and Ward D (2021) *Social Care 360*. The King's Fund. Available at https://www.kingsfund.org.uk/sites/default/files/2021-05/social-care-360-2021_0.pdf.

Boulder F, Slavin D and Lofsledt R (2007) *The Tolerability of Risk: A New Framework for Risk Management*. London: Earthscan.

Cahill S (2018) *Dementia and Human Rights*. Bristol, UK: Policy Press.

Carter D (2016) *Fix Dementia Care Homecare*. London: Alzheimer's Society. Available at https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_homecare_report.pdf.

Clarke C (2009) Risk and long-term conditions: the contradictions of self in society. *Health, Risk and Society* **11**, 297–302.

Clarke C and Mantle R (2016) Using risk management to promote person-centred dementia care. *Nursing Standard* **30**, 41–46.

Clarke CL, Gibb CE, Keady J, Luce A, Wilkinson H, Williams L and Cook A (2009) Risk management dilemmas in dementia care: an organizational survey in three UK countries. *International Journal of Older People Nursing* **4**, 89–96.

D'Astous V, Abrams R, Vandrevala T, Samsi K and Manthorpe J (2019) Gaps in understanding the experiences of homecare workers in providing care for people with dementia up to the end of life: a systematic review. *Dementia* **18**, 970–989.

Department of Health (2015) *Prime Minister's Challenge on Dementia 2020*. Available at https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020#transforming-dementia-care-support-and-research-by-2020.

Dickins M, Goeman D, O'Keefe F, Iliffe S and Pond D (2018) Understanding the conceptualisation of risk in the context of community dementia care. *Social Science & Medicine* **208**, 72–79.

Douglas M and Wildavsky A (1983) *Risk and Culture: An Essay on the Selection of Technological and Environmental Dangers*. Berkeley, CA: University of California Press.

Elo S and Kyngas H (2008) The qualitative content analysis process. *Journal of Advanced Nursing* **62**, 107–115.

Hayes L and Moore S (2017) Care in a time of austerity: the electronic monitoring of homecare workers' time. *Gender, Work and Organisation* **2**, 299–344.

Health and Safety at Work Act (1974) *Health and Safety at Work Act 1974 (c. 37)*. London: HMSO. Available at https://www.legislation.gov.uk/ukpga/1974/37/contents.

Health and Social Care Services Unit (2011) *Guidance on Domiciliary Care and Section 51 of the Health and Safety at Work etc Act (HSWA)*. Available at https://www.hse.gov.uk/foi/internalops/sims/pub_serv/071105.htm.

Hussein S and Manthorpe J (2012) The dementia social care workforce in England: secondary analysis of a national workforce dataset. *Aging & Mental Health* **16**, 110–118.

Linzer N (2002) An ethical dilemma in home care. *Journal of Gerontological Social Work* **37**, 23–34.

Lupton D (2013) Risk and emotion: towards an alternative theoretical perspective. *Health, Risk and Society* **15**, 634–647.

Manthorpe J and Moriarty J (2010) *Nothing Ventured Nothing Gained: Risk Guidance for People with Dementia*. London: Department of Health. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215960/dh_121493.pdf.

Manthorpe J, Vandrevala T, Abrams R and Samsi K (2019) Working with colleagues and other professionals when caring for people with dementia at the end of life: home care workers' experiences. *International Journal of Care and Caring* **3**, 567–583.

McLean A (2007) The therapeutic landscape of dementia care: contours of intersubjective spaces for sustaining the person. In Williams A (ed). *Therapeutic Landscapes*. Aldershot, UK: Ashgate, pp. 315–332.

Morgan S and Williamson T (2014) *How Can Positive Risk Taking Help Build Dementia Friendly Communities?* York, UK: Joseph Rowntree Foundation.

Neysmith SM and Aronson J (1996) Home care workers discuss their work: the skills required to 'use your common sense'. *Journal of Aging Studies* **10**, 1–14.

O'Brien I, Smuts K, Fan C, O'Sullivan M and Warters A (2019) High prevalence of dementia among community dwelling older adults in receipt of state funded home care packages: implications for health care planning. *Irish Journal of Psychological Medicine* **36**, 139–144.

Polacsek M, Goh A, Malta S, Hallam B, Gahan L, Cooper C, Low L, Livingston G, Panayiotou A, Loi S, Omori M, Savvas S, Batchelor F, Ames D, Doyle C, Scherer S and Dow B (2020) I know they are not trained in dementia: addressing the need for specialist dementia training for home care workers. *Health and Social Care in the Community* **28**, 457–484.

Pollock K, Wilkinson S, Perry-Young L, Turner N and Schneider J (2021) What do family care-givers want from domiciliary care for relatives living with dementia? A qualitative study. *Ageing & Society* **41**, 2060–2073.

Prince M, Knapp M, Guerchet M, McCrone P, Prina M, Comas-Herrera A, Wittenberg R, Adelaja B, Hu B, King D, Rehill A and Salimkumar D (2014) *Dementia UK: Update*, 2nd Edn. London: Alzheimer's Society.

Renn O (2010) *Risk Governance: Coping with Uncertainty in a Complex World*. London: Earthscan.

Ruston A (2004) Risk anxiety and defensive action. *Health, Risk and Society* **6**, 25–38.

Sandberg L, Borell L and Rosenberg L (2021) Risk as dilemmas for home care staff caring for persons with dementia. *Aging & Mental Health* **25**, 1701–1708.

Stevenson M and Taylor J (2016) Risk communications in dementia care: family perspectives. *Journal of Risk Research* **21**, 1466–4481.

Taylor BJ (2006) Risk management paradigms in health and social services for professional decision making on the long term care of older people. *British Journal of Social Work* **36**, 1411–1429.

Taylor BJ and Donnelly M (2006) Risks to home care workers: professional perspectives. *Health, Risk and Society* **8**, 239–256.

Turner N, Schneider J, Pollack K, Travers C, Perry-Young L and Wilkinson S (2020) Going the extra mile for older people with dementia: exploring the voluntary labour of homecare workers. *Dementia* **19**, 2220–2233.

Waugh F (2009) Where does risk feature in community care practice with older people with dementia who live alone? *Dementia* **8**, 205–222.

Wittenberg R, Hu B, Barraza-Araiza B and Amritpal R (2019) Projections of older people with dementia and costs of dementia care in the UK 2019–2040. Care Policy and Evaluation Centre, London School of Economics and Political Science, CPEC Working Paper 5.

Zinn JO (2016) 'In-between' and other reasonable ways to deal with risk and uncertainty: a review article. *Health, Risk and Society* **18**, 348–336.

Zinn JO (2019) The meaning of risk taking – key concepts and dimensions. *Journal of Risk Research* **22**, 11–15.