article

'It's a real fine balancing act': directly employed care workers' experiences of engaging with health services

Jane Wilcock, j.wilcock@ucl.ac.uk
University College London, UK

Jill Manthorpe, j.manthorpe@kcl.ac.uk
Jo Moriarty, jo.moriarty@kcl.ac.uk
King's College London, UK

Steve Iliffe, s.iliffe@ucl.ac.uk
University College London, UK

Little is known of the experiences of directly employed care workers communicating with healthcare providers about the situations of their employers. We report findings from 30 in-depth semi-structured interviews with directly employed care workers in England undertaken in 2018–19. Findings relate to role content, communication with healthcare professionals and their own well-being. Directly employed care workers need to be flexible about the tasks they perform and the changing needs of those whom they support. Having to take on health liaison roles can be problematic, and the impact of care work on directly employed workers' own health and well-being needs further investigation.

Introduction and background

Care at home is becoming increasingly important for the growing population of older people with long-term health conditions or disabilities. Lack of supportive care in the home causes problems for older people and their family carers, as well as the

National Health Service (NHS), particularly if it leads to avoidable hospital admission or delayed hospital discharge. Increasing numbers of older people in England pay for their own social care services from their own resources or receive local government funding in the form of a personal budget, which they may take as a direct payment option, subject to eligibility and means-testing assessments. Estimates have reported that by 2020, 48,000 older people would be receiving direct payments for 'community care' services, compared to the 214,000 estimated to be receiving local authority-commissioned services (Wittenberg et al, 2018: 7). Directly employed care workers are not included in current attempts to integrate health and social care, but they may offer valuable continuity of care and personalised support for their employers, with potential benefits for healthcare services (Wilcock et al, 2020). As of the start of 2021, there is no guidance about managing working relationships between directly employed care workers and NHS professionals.

Several studies across the globe have explored older people's experience of receiving state support to meet their care needs in a form of individualised funding (Fleming et al, 2019). In England, if they choose to make arrangements themselves, using their own or local government resources (or a combination of both), they may do so by employing care workers and/or spending monies on equipment or other items. For those eligible for (needs- and means-tested) local government funding, these arrangements are generally referred to as personal budgets in the form of direct payments. These were extended to older people (aged 65 years and over) in 2000. However, for a variety of reasons, such as the limited size of funding allocations, concern about practical responsibilities (FitzGerald Murphy and Kelly, 2019) and satisfaction with existing arrangements, the option of direct payments is not as commonly taken up by older people compared to others. This may explain why outcomes may not substantially improve for older people with personal budgets compared to others receiving services from a home care agency (Woolham et al, 2017). Such findings echo those of an earlier evaluation by Moran et al (2013), which enabled comparison between older people and other adults, and found that gains for older people were often less evident. In addition, while only interviewing a small sample of older people employing staff directly, Rodrigues (2019) observed that these latter arrangements brought high levels of uncertainty and emotional investment, and often necessitated reciprocal gift exchanges. The impact of reduced local government funding as part of UK government policies of austerity may have further diminished the attractiveness of personal budgets among older people (Locke and West, 2018), as well as reducing the numbers of older people entitled to publicly funded social care support from local government.

In contrast, there is limited information about self-funders – people paying for their own care and support – who may not have approached local government or not been considered eligible on grounds of need or means testing. Wittenberg et al (2018) estimated that by 2020, these would number about 126,000 older people. A recent study reporting on interviews with 20 self-funders receiving home care (Baxter et al, 2020) found that their information needs were largely unmet; this has implications for people employing care workers in that they would largely seem to 'work out' employment relationships on their own. As Woolham et al (2019) found, this leads to considerable variation in the contracts and also expectations of directly employed workers.

This present study explores relationships between directly employed care workers, sometimes referred to as 'personal assistants', and community nurses, general practitioners (GPs) and the older person (defined as age 65 years and over) or family member employing the care worker. These were not specifically addressed by Woolham et al (2019), though they did ask their sample of personal assistants about their views of undertaking more health-related tasks, finding that interest was tempered by caution (Wilcock et al, 2020). In this article, we report the views of directly employed care workers on their experiences of engagement with NHS professionals and healthcare systems. We highlight a need to consider the impact of this type of employment on their own health and well-being.

Aims and objectives

The overall aim of this study is to explore the communication and coordination of care from the three perspectives of directly employed care workers, NHS professionals and older people receiving care and support (and their family where applicable), hereafter referred to as 'clients'. We illuminate aspects of these relationships that might optimise the well-being of older people and all those supporting them. Our objective is to learn about the working relationships between older people (the care worker's employer) or their proxy – a family member – with their directly employed care workers and NHS professionals working in the community. Findings from interviews in 2019 with NHS GPs have been published already (Wilcock et al, 2020).

Methods

We chose a qualitative approach using in-depth semi-structured interviews with directly employed care workers. Other studies have not found it easy to reach directly

Table 1: Demographic profile of directly employed care workers

Age (years)	
Mean age	50
Age range	26–69
Gender	
Male	20%
Female	80%
Ethnic group	
White	90%
Black and minority ethnic (BAME)	10%
Nationality	
British	90%
Other European Union (EU)	7%
Non-EU	3%
Dependent children	
Yes	23%
Family carer (for own family)	53%

Note: *N* = 30.

Table 2: Thematic analysis summary

Overarching theme	Themes
Role content	Complex needs of client that increase with ageing; undertaking health-related tasks
Communication with healthcare professionals	Maintaining client autonomy; knowing client and local services; challenging professionals; teamworking
Impact of role on directly employed care workers	Physical and emotional strain; training helps manage role; GP support/communication helps

employed care workers who are not registered with any regulator or accessible on any database (Shakespeare et al, 2017; Woolham et al, 2019), meaning that a survey was likely to be unsuccessful. Internationally, this is a workforce about which little is known (Kelly et al, 2020). Their employers are also an unknown group, with those using public funds to pay for their care not necessarily known to public services, and those using their own resources (self-funders) rarely identifiable. While directly employed care workers are found across the UK, our focus was on England, where there is much policy interest in increasing the choices open to older people with eligible care needs to consider employing their own care workers (as reinforced by the Care Act 2014) as part of the personalisation of care. In the knowledge that directly employed care workers are not comprehensively listed with or accessible via any organisations, we used a range of approaches to recruitment. For example, we asked the principal investigator of an earlier research study that had recruited such care workers nationally, though did not cover contacts with health systems as part of their research, if they would re-contact his participants and offer them the opportunity to be interviewed for this present study. We further used snowballing methods (Atkinson and Flint, 2001) to ask participants if they knew of other people who might meet our inclusion criteria and asked other known contacts to circulate our recruitment literature.

Potential participants were invited to take part in an interview through an introductory email from the research study referred to earlier and our other methods. The email included the study participant information sheet. Expressions of interest were followed up by email and telephone by the members of the research team. Seven participants were recruited by snowballing methods. We interviewed until no new themes emerged (34 interviews in total).

Interviews

Semi-structured interview schedules were developed from the literature (building on Manthorpe and Hindes, 2010) and the advice of our study advisory group. Following piloting (four interviews), the schedule was further modified to incorporate new themes identified from the initial interviews, which included participants' health status and emotional support. Some themes were removed as they were outside the scope of this study; these mostly related to practical workforce data, such as pensions, paid leave and financial payments. The four pilot interviews were conducted face to face and were different from the telephone interviews. Participants in the pilot phase were recruited via snowballing and all worked in one locality. The pilot interviews lasted longer in length than the telephone interviews (2–3 hours versus 30–60 minutes). For

these reasons, the pilot interviews are not included in the data set reported here (30 interviews) (for participant information, see Table 1). Interviews gave participants the opportunity to lead the discussion (Ritchie and Spencer, 1993) and took place at a time convenient to them. While we offered face-to-face or telephone options, all wished to be interviewed by telephone, which is similar to Shakespeare et al (2017), where most of their 28 personal assistants/directly employed care workers were interviewed by telephone. Reasons for preferring telephone interviews included: convenience due to geographic location (England-wide study); the length of time the care worker had available; and that the interview timing could be flexible in terms of shift-working or other commitments, such as caring for children and working in the older person's home, when interviews tended to take place at a time when the employer was settled. Interviews were also arranged with the interviewer by texting that it was a good time to call on a pre-specified day. Interviews were digitally recorded and transcribed verbatim. Fieldnotes were made directly after each interview to record contextual information. These aided interpretation and analysis. Key interview questions covered:

- their clients' needs, needs of the family and their own roles;
- experiences of recent healthcare service interactions and what was good and what could have been improved; and
- experiences of information sharing and what was good and what could have been improved.

Analysis

Data were analysed using a detailed thematic approach. Once the entire data set was thematically coded, data extracts were collated under each of these codes. Coding of the data was then checked by two researchers (JW and SI). The codes were then organised into broader themes and sub-themes. We took an inductive approach to analysis (that is, it was data-driven) and linked themes directly to the data. Themes were then reviewed by re-examining corresponding data extracts and checking for disconfirming evidence with un-coded, outlying data.

Older people's involvement

We consulted with older people and carers about the planning and conduct of this research. Members of the User and Carer Advisory Group of the National Institute of Health Research (NIHR) Policy Research Unit in Health & Social Care Workforce and NIHR Applied Research Collaborative (ARC) South London, King's College London, UK, were involved in the shaping of the study research questions and methods. We shared our study documentation with wider members of the study-specific advisory group and sought their comments and advice, particularly with the interpretation of emerging findings.

Ethics

Ethical permissions were received for the study from King's College London Research Ethics Committee (Ref HR-18/19–8771). The research team took care to reassure participants that their anonymity would be protected but that if there were serious

concerns about the welfare of participants, then the relevant authorities would be contacted.

Findings

Table 2 presents a summary of the overarching themes that emerged, with sub-themes indicated. These are addressed in turn, though there were overlaps. While the participants used different terms to refer to their work, we use the term 'directly employed care worker' (though some were self-employed); likewise, we refer to the older people for whom they were working as their 'clients'. Other UK research and sector support agencies often use the term 'personal assistant' when referring to directly employed care workers but this is not so common internationally (see Fleming et al, 2019) and does not include people who are employing care workers from their own rather than public resources.

Role content

The wide-ranging nature of the care worker's tasks was described by many participants, who reflected on the substantial needs of their clients for assistance with daily living. Several participants described their work as being tantamount to nursing care, and while the client's high level of need had generally been relayed to them by the family at the start of their work, their clients' health was often deteriorating:

> 'I'm not a live-in nurse, but I notice that there is more and more – I think because of the cost – people feel that they say, "My mum has become old and frail", but it's very much more than that but they can't possibly stretch the costs to it [nursing care]. So, many people [have high needs] – this lady [my client] as well has got a hospital bed at home – and some of them have to have a hoist to move around. It's a very responsible job.' (DECW05)

For other participants, particularly those working with clients with progressive neurological disorders, the extent of a client's need was substantial from the outset of their employment:

> 'He had limited use of his hands, fingers; he could use one arm partially, with very limited movement; he could twist his head, very limitedly, and he could wiggle his toes. So, his care needs were – he needed full bed assistance, through washing, personal care, dressing, then hoisting into his motorised wheelchair and then dressing from there, and then I would feed him. And then through the course of the day, if he needed the toilet again, it usually involved hoisting back onto the bed to use a bottle, and obviously hoist onto the toilet.' (DECW11)

For those who described working for clients with severe dementia, it was evident that the client or employment relationship was not so much with the older person since family members made the arrangements and set out the parameters of the job. This meant that information was mediated by family members: "I've got many frail

people who suffer from dementia and can't really communicate, or understand, or talk for themselves, or tell me what their needs are really at times" (DECW05). Of the few who had undertaken training, sometimes in previous jobs, the challenges of dementia symptoms had been useful to discuss: "I've really benefited from having training in groups with other carers and other family members and topics around challenging behaviour and things" (DECW19). The physical and emotional needs of clients with dementia could both fluctuate and present high-level risks of harm to themselves, as in the following example of having to be careful about the risk of choking amid the changes associated with physical decline:

> 'She [98-year-old client] had dementia, and it kind of came and went. She was very often very sharp and you wouldn't experience the dementia but then she might have a bout of it. It kind of came and went, which can be quite unusual. She had physical needs. She used a wheelchair and … she would suffer certain things like, for example, one of the things, as I say, was choking; you had to really kind of be careful about how you're presenting food to her and how she's eating it because she very often would start talking and then choke. And physically she was very, very frail; physically very, very frail.' (DECW09)

In another example, personal care tasks were joined by support with orientation and with encouragement to accept assistance with activities of daily living:

> '[Would help with] washing. I used to cut her hair, yeah, changing clothes, getting her to have a rest, a lot of physical care. She was very petite, so … she would need assistance in the bathroom, and it took her a long time to accept that because she was quite proud, so … yeah, but she did eventually.… She had some medication; nothing heavy-duty. Another thing I did a lot with her, which is one area I'm interested in, I'd spend a lot of time finding ways to remind her of things. So, just like leaving her, well, actually at the end she was having 24-hour care, but initially, I would do things like make a big sign as to what day it is, what time it is and who's with her and all the information so she could just … because she would forget. She might ask you a question, so she could just look at it and see for herself certain things. Just practical things, like if she went into the wrong bathroom there was a big bright sign in the bathroom, please go to the other one, that type of thing, yeah.' (DECW09)

Undertaking health-related activities

Several accounts illustrated the overlap between what might be considered both social care and health-related care, as illustrated by some earlier quotes. Some participants held the view that some of their work should be done by a qualified nurse, even though they seemed to be confident in doing the tasks themselves and were contributing to a formal care plan or monitoring:

> 'You have to work in the reality, and a silly thing is that we have a pain morphine patch, like a plaster, that I change once a week and that's also one

of those things that should be dealt with by a nurse. Anyhow, I do it and I fill a record out for it.' (DECW05)

In another example, a care worker was helping a client with regular catheter care and pressure sore prevention, with a district/community nurse visiting and being available for assistance:

'Then she had a procedure and they inserted a catheter into her bowel, and then after a couple of days, she was brought home. So, in the last year, she was living with that catheter, and that catheter I have to change every – of course, I can't remember – three, four, five times a day probably. The nurse will come every day if she was looking around at everything, it's fine with the catheter. So, the needs were becoming more complex, and complex. So, pressure sore, catheter, so everything was there.' (DECW06)

Difficulties created by the client sometimes made health-related activities particularly problematic for the care worker, though some mentioned that equipment was helpful in the home:

'She was on the floor, just like she was getting in the bed at night, she fell against the heating and there was on the floor. And I had to put a sheet underneath her and pull from the bedroom to the bathroom and then put the sling under her to get her up, and she's quite big [the client refused to allow an ambulance to be called].' (DECW27)

Not all health-related activities were so risky or onerous, but some did require infection control: "occasionally dressings have come off and I've reapplied a dressing because the district nurses can't get there or they can't come back out and I can't have something open, so I've just reapplied a dressing, obviously with gloves and apron" (DECW25). Others described medicine management at home, illustrative of the many long-term conditions of several clients: "He had a huge quantity of things [medications] that he took. Some of it he got in a blister pack but there was a whole array of bottles of different things that I had to put into a little pot for him to take, that was about it" (DECW18). Finally, a minority accompanied their clients outside the home to appointments with various healthcare practitioners in primary and specialist NHS teams and locations: "I go to all his appointments with him, them sorts of things, really…. All, like, urology, epilepsy doctors, diabetes, chiropodist, all the everyday sort of stuff" (DECW10).

Communication with healthcare professionals

In this second theme, communications and systems of contact with healthcare professionals were described as well organised by some but were often impacted by the level of involvement by family members with the care of their older relative:

'We always expect to have a telephone list with the GP and district nurse team and so on. It's a part of our job to liaise with them or try to engage

with occupational therapists. It depends on [how] near the relatives live and on how much they are involved in that part of things.' (DECW05)

Positive experiences of collaborative working with other disciplines were described by several participants:

'The physio[therapist] was absolutely amazing. He was very, very well trained, very knowledgeable, and he had a lot of outside interests in holistic therapies and things like that, so he would offer a very good physio service, very motivating and uplifting. We had a lot of shared interests. So, it really, really was good at times when the three of us were conversing on things, talking about … the physio that were being done and mental health issues and things like that. We were always very respective of the client, so he would lead the conversation but the conversation then would open up and then the physio … sometimes would help him with … his low moods, and if I had anything to offer from my studies … then I would offer it, and again it would get into a three-way conversation.' (DECW11)

'[Palliative care nurses] have been really, really good. Supportive to the family, supportive to the person, really supported me in terms of maybe what action to take next or talking to the family, regularly visiting the client to monitor how things are.' (DECW25)

'The dentist was absolutely amazing. She'd [client had] been to him before but he [dentist] seems to be used to dealing with people with mental health issues and … he was really good. I just sat with her and she held my hand and that, and I just reassured her and he was so good and just exactly knew how to put her at ease … it kind of came from the heart, you could just tell that he was naturally very good.' (DECW14)

For those clients with no relatives or none nearby, some care workers proactively made contact with healthcare practitioners:

Interviewer: 'If you needed to phone the GP does that tend to go quite well, are they happy to speak with you?'
DECW05: 'Yes, that's rarely a problem. I've been with patients to hospitals many times during the years, and that goes quite well.'

In such encounters, some felt that they needed to advocate for their client, that is, taking on the role of an involved family member while seeing this as part of their professionalism:

'Well, the main appointment is for him but they tend to usually ask me after they've listened to him – "Any concerns or anything you need to tell us?" – because he's not very good at expressing himself. So, you know.… No, to be fair, I'm quite hot on all appointments and actually anything that I need to get across; it's more that he doesn't relay that, so it's more down to me to do, to be honest with you.' (DECW10)

Indeed, there were reports of healthcare practitioners addressing the care worker directly rather than trying to talk with the client, which some care workers thought undermined clients' independence or dignity. Some reported being willing to challenge this:

'I think it's a real fine balancing act. This is where I think a lot of people become a bit unstuck because you are expected to maintain people's independence and yet, as my experience has been throughout my entire working life, people are … there's still a terribly paternalistic attitude towards disabled people: "Does he take sugar?", type of thing. That still goes on, unfortunately, and I think it's really difficult to stand back a little bit and say, "Well, it's not me, it's the person I'm looking after", do you know what I mean? People still address you instead of the disabled person…. In fact – this is just a personal thing from very long experience – I think the general public's attitude to disability has become much, much better, but the professionals, it hasn't changed very much at all.' (DECW08)

More than one had spoken up on behalf of a client when considering that some healthcare professionals were not behaving respectfully:

'One thing … there was a couple of things that I wasn't happy about with regard to the lady, this 98-year-old lady, which is you might get someone come to do her feet, or district nurse give an injection, and they would call her "sweetie" and "sweetheart" and "my lovely", and that's so inappropriate and really patronising, because she found it patronising; she was a very intelligent person and she felt like they were treating her like a silly old woman…. So, in the end, after that happened a few times, I would kind of say politely to people that they should address her by her name only…. Generally, I'd say my experience has been – apart from this patronising thing – my experience has been very good, really.' (DECW09)

Participants commented on the ways in which they felt attuned to their clients' individual needs and preferences because of the continuity of their relationship with clients, as well as their independence from the NHS or local authority and professional models of care:

'I didn't get the feeling that they [healthcare professionals who visited the house] were particularly open-minded about … how [client] was experiencing his illness, and I just got the feeling it didn't fit with the way they saw things, and so it wasn't a good match, if you know what I mean, they weren't particularly helping him in the way that … he was approaching it himself…. Too much a standard model, yeah, too much a standard model that they were trying to impose on him and not really understanding how it was.' (DECW18)

While not employing professional language such as 'person-centred care', there were many indications that participants put their client at the centre of their concerns and felt proud about this distinction.

Liaison with healthcare professionals

There were several examples of participants considering that it was their role to call on health services if they were concerned: "Again, she [client] was getting red, she was getting, yeah, the blood pressure and so on, special blood pressure, very high. So, I had to call the GP, and the GP would come for the blood pressure of course, because of her mental medication, because of her worries" (DEHCW06). Less common were accounts of when healthcare professionals seemed to accept the care worker as part of the team supporting the client and communication was two-way, as illustrated by the following less frequent experience of coaching and support provided by one community (district) nurse to the care worker:

> 'I went to a lady who had been diabetic since she was five and now she was in her 80s. She was struggling to manage with her insulin, and one particular district nurse was very supportive and really brilliant. 'Cause she had a bad turn whilst I was with this lady, and the district nurse guided me through everything over the phone, 'cause it was a bit frightening at the time. So, yeah, I met some really nice, really good, supportive district nurses.' (DEHCW07)

More common were accounts of having to contact health professionals in emergencies or to report concern about perceived changes in a client's health:

> 'Well, I've found one or two [clients] on the floor and managed to help them to get up and phoned the GP to ask for a home visit. Or, if they become more confused, because a lot of problems are with urine infections in later years, where they become very confused but they're not aware that they are. So, yes, that was a concern. But very often, even then, it was the district nurse that would come out and test them.' (DEHCW07)

Participants' previous employment experiences of helping older people or of healthcare work themselves were sometimes drawn upon, and many had experiences of care work or of caring for family members, reflecting the demographics of other samples (Woolham et al, 2019). In the following example, a participant was familiar with care planning and used this to provide a system for communication with others involved in a client's care:

> 'So, someone that … maybe we had to get someone from the agency to do a couple of days or someone to do respite, just so they'd know all about her; they could write … just read instead of having to work with her a lot and just know things about her.' (DECW09)

There were occasional complaints that it was not always easy to arrange an appointment with a GP on behalf of a client, but such experiences seemed to be commonly experienced by participants in their wider lives:

> 'The only times it got more awkward were when you needed home visits, and it always seemed to be that they would say, "The doctor's really busy right now", and you would kind of assume they would try and pull up

the client's details on the screen and see that he were fully disabled and he couldn't just go in, whereas sometimes you almost felt like you had to fight for them to really put you on a priority.' (DECW11)

Some remarked on increased responsiveness among primary care services to their concerns as part of growing capacity to treat long-term conditions in the community, and noted that skill mix was affecting many parts of the NHS: "They do seem to be putting more onto the district nurses. I don't know how the district nurses feel about that. Some can even write prescriptions. So, that work seems to be going out, instead of just it being the GPs that do these things" (DECW07). Some participants thought that where the GP knew that their patient was employing a live-in carer, this was particularly reassuring to them and fostered communication, as noted by the following respondent reflecting on calling the GP for a visit:

> 'It was an experience, yeah, it was a response, but they'll come, of course, but they knew her because they knew her for years, so they didn't rush in a sense, they knew that it was not urgent, especially because they knew that a carer lives with her, so she's safe. In many senses, in the worst-case scenario, I would call the emergency [service], but she was safe. They knew that she was safe, she's not alone, she's not living alone.' (DECW06)

However, there were circumstances where the client insisted that the care worker called the GP on their behalf, which the care worker accepted as reassuring for the client but felt unnecessary. Such situations were not common, but provided a sense of the obligations of these care workers to obey their client's wishes rather than seek guidance from a supervisor or manager in a home care agency who might be able to suggest alternatives to calling the GP:

> 'So, this provides them assurance that everything is going to be fine. They see it as just a routine, just to – well, because frankly this is an issue with old people, and I'm getting old myself – in many cases, sometimes I would say, in many cases, the old – I would say, people in general – but people, including [client], she was unnecessarily calling the GP, and I was sometimes reluctant because I knew that there was nothing wrong, it could be fixed by myself. But she was insisting and I couldn't refuse. I was calling … because if she knew that I had called the GP, she was relaxing.' (DECW06)

Working as part of a team

It was not always evident that the care worker was part of a team, but in some descriptions of their work, there was a strong sense that the care worker was acting with others to implement an agreed care plan:

> 'Yes, when they [healthcare professionals] came, there was a kind of care plan, what you have to do, especially she.… Yes, the care was quite good from the nurses because when she was bedbound, she had pressure sores on her feet, so they were coming every day to change, to clean. So, it was quite good, yes. So, we were working as a team because we're in the house, you

will come, "Okay, we'll chat to each other what [client] needs today, what she most needs", etc.' (DECW06)

However, when healthcare professionals failed to communicate, this could be irritating:

'There was one other thing, though, which I thought was a worry, and that was that the doctors would come … initially, she'd spend a bit of time on her own but then it was deemed that it wasn't appropriate, but during that time, you could come round and a doctor might have just come and given an injection without actually, or a district nurse, without actually making an appointment, and that was a bit annoying because she's very vulnerable and we're teaching her [98 year old client] not to speak to people, give information on the telephone or open the … allow anyone to come through the front door, that type of thing. So, that was one thing that did used to happen.… Yeah, that was either you'd come round and someone's arrived and given her a flu jab, yet no one had any idea that they were coming.' (DECW09)

Health-related impact of the role

As other studies have noted (Woolham et al, 2019), the work of a directly employed care worker or personal assistant is often financially precarious. Participants reported the informality of some arrangements, which might impact on their own health-related behaviour, such as feeling that they should go to work if they were not well (data were collected before the COVID-19 pandemic): "No, I pay tax but I'm.… No, I will have to.… No, I can't see how I would get any sick pay; I have had to pay that myself by not being able to take a booking" (DECW05). The mental health-related demands of the work were introduced inductively as a question as interviews proceeded. These were expressed by those who were live-in care workers and seemed linked to their financial position:

DECW05: 'The work intensity on 24 hours, you don't do very much, but you are very much in demand all the time and it's very absorbing, and I'm also very tired after the two weeks [working two weeks as a live-in care worker then four days off]. I'm often exhausted.'
Interviewer: 'Is that enough for you to recharge if you're quite exhausted sometimes?'
DECW05: 'Yes, I am but also I can't really afford being off.'

Most participants were not live-in care workers, but they also talked of growing pressure as their clients' needs increased:

'[The] emotionally … and psychological impact was in the last year, when she [client] was bedbound. I would say probably two years, but in the last year, she was bedbound and, yes, she was deteriorating, she was already.… So, in a sense, the last year was the most demanding because I had to stay almost 24/7 there.' (DECW06)

Other participants had made decisions about limiting their work hours to protect themselves from emotional demands:

> 'This guy I look after now, for me, I come home… I only do one evening a week now simply because I come home full of her [client's wife] problems.… So, I do find that, yeah, it plays on my mind. Because I live [nearby], if she has got any problems, she does tend to turn to me. She has turned up a couple of times in just a total state, so I just have to talk to her. There were others that I've come home and thought, oh.… In fact, I have actually gone back out when I've clocked off and gone back and checked on someone if I've got concerns.' (DECW07)

One participant expressed her gratitude for the support provided to her by her own GP, who knew of her work stress, but thought that this support was uncommon:

> 'Yeah, it's a hugely stressful role, physically and emotionally. So, my GP, who I've mentioned, that service is exceptional, and I've always been down as a carer, so before I was employed as a PA [personal assistant], and I know that that has … that influences decisions, that has an impact when they review my record. I don't think the other PAs that we've come across that have worked for our family have had that level of support from their GP; I just haven't encountered that.' (DECW19)

Despite the demands of the work, many respondents spoke of their job satisfaction and how this compensated, in part, for stress and other uncertainties:

> 'I think the best thing is that you work just for one person and you know each other very well. It's kind of … it's quite rewarding, I think, as well; you know that you're helping them and you know your job so well. So, I think it's just this feeling of being good at your work, even with, as complex as it is, and actually it is quite stressful that someone relies on you, but it's actually a good feeling that someone is looking in for your support and your knowledge.' (DECW29)

Discussion

Three main themes arose from the interview data: the broad range of activities covered by directly employed care worker's role; interactions with healthcare professionals; and their work's impact on their own health and well-being. Several gave accounts of supporting people whose problems fluctuated and whose health declined rapidly, most often related to dementia. This perhaps relates to our research focus on older people and their directly employed care workers; other studies of direct care workers have interviewed those employed by younger age groups, such as younger adults with learning disabilities (Graham, 2015) and younger physically disabled adults (Graby's 2018). These studies provide accounts of supporting people with activities outside the home, including access to employment. Our study is limited by the interview method, in which recall may have been partial and exceptional events recalled more readily than the usual. We did not observe the participants at work, which might have

helped better understand their routines and relationships; this lack of observation studies of care at home is widespread (Leverton et al, 2019). Furthermore, as many in our sample had been interviewed in a previous study, participants were likely to have remained in their work and had not quit this work for various reasons, such as major dissatisfactions, better opportunities or poor health. However, the strengths of our study are that we recruited participants from different parts of England and our interviews were able to probe for experience and identify new themes. Our study is the first to explore relationships with healthcare professionals from the perspectives of directly employed care workers in the UK in any depth, adding to the evidence about working relationships in this developing area of social care.

For those clients who had no family or whose family were not substantially involved, the role involved some liaison with NHS staff as needed; this included ensuring their client's safety, as well as advocating for their needs and dignity. Interactions with healthcare staff were few and mostly positive but sometimes involved attitudinal challenges of professionals, use of the care workers' knowledge of the client and use of their own experiences of health systems to advocate for their clients. Rather than commenting on their perceptions of the adequacy or nature of clinical treatment, concerns about healthcare professionals related to their behaviour and included not being informed about visits, being spoken to instead of the client and witnessing patronising or disrespectful behaviour. None seemed to question medical or nursing interventions and, as Reckrey et al (2020) found in their interviews with older people, proxies and care workers in the US, direct communication between care workers and the healthcare team was rare. There were few reports in the present study of care workers providing regular information to healthcare professionals and no reports of communicating regularly to those local authorities who were generally indirectly funding their employment. The use of information technology seemed limited to the personal use of participants' own telephones to keep in touch with clients and their families, or to make calls on their behalf. As Barr et al (2017) cautioned, if there is no prior working relationship, then installing information and communication technology (ICT) will only make things worse. Use of other technology was rarely mentioned.

The lack of engagement of directly employed care workers with healthcare professionals is similar but not identical to the experiences of UK agency-employed home care workers interviewed about their relationships with healthcare professionals visiting their clients at home (Wilcock et al, 2020). This suggests that it is being a home care worker, not being professionally qualified and not being part of the NHS or statutory social care sector that affects the feelings of healthcare staff about who merits being a 'team member', whose skills and respect for confidentiality and for the norms of professionalism can be taken for granted. Hall et al (2017: 24) also heard from care agencies of a 'lack of respect' for their services. Our participants situated themselves in the context of care work rather than nursing, suggesting that moves to encourage them to take on healthcare tasks (as explored by Wilcock et al, 2020) will require shifts in attitudes, not just in commissioning practice. What Porter et al (2020: 206) referred to as the need to understand the 'micropolitics of interpersonal cooperation' in personal assistance relationships would seem to extend not just to the employer and employee relationship, but also to their engagement with others.

Our study suggests that the relationship between health status and the specific nature of the direct employment of care workers needs further exploration, supporting Graby's (2018) recommendations to do this. There were indications that some

participants' health and well-being were being compromised by the emotional impact of their clients' conditions, a sense of professional isolation, sleep disturbance and the difficulties of maintaining boundaries between work and other aspects of their life. This stands in some contrast to the circumstances of care workers employed by an agency, where managers are potential mediators between their employees and clients, addressing possible over-commitment as well as the risks of blurring boundaries (see Woolham et al, 2019), or, as Shakespeare et al (2017: 23) described it, 'giving too much'. In home care agency work, contracts of employment exist between staff and the employing agency, and there are contracts between clients and the agency outlining the responsibilities of all parties. Other studies have commented on the stress associated with the directly employed care worker (personal assistant) role through personal investment in the role (Ahlström and Wadensten, 2012), especially when it is accompanied by immigration uncertainties (Christensen and Manthorpe, 2016). However, Shakespeare et al (2017: 24) also noted that some directly employed care workers were adept at maintaining their 'personal realm', indicating the need to avoid stereotyping.

Conclusion

Directly employed care workers need to be flexible in managing both the range of tasks they perform (some of which may entail nursing procedures), the emotional labour of their work and the changing needs of those whom they support. In healthcare tasks, they need to be more professional in their approach than in other aspects of work, which may be more negotiable. Having to substitute for family members in health liaison, care management or advocacy roles can be problematic if healthcare workers do not seem to show them respect. The impact of work on directly employed care workers' own health and well-being merits further investigation.

Conflict of interest
The authors declare that there is no conflict of interest.

References
Ahlström, A. and Wadensten, B. (2012) Enjoying work or burdened by it? How personal assistants experience and handle stress at work, *Journal of Social Work in Disability & Rehabilitation*, 11(2): 112–27.
Atkinson, R. and Flint, J. (2001) Accessing hidden and hard-to-reach populations: snowball research strategies, *Social Research UPDATE*, issue 33, https://sru.soc.surrey.ac.uk/SRU33.PDF.

Barr, N., Vania, D. and Randall, G. (2017) The impact of information and communication technology on interprofessional collaboration for chronic disease management: a systematic review, *Journal of Health Services Research and Policy*, 22(4): 250–2. doi: 10.1177/1355819617714292

Baxter, K., Heavey, E. and Birks, Y. (2020) Choice and control in social care: experiences of older self-funders in England, *Social Policy and Administration*, 54(3): 460–74, doi: 10.1111/spol.12534

Christensen, K. and Manthorpe, J. (2016) Personalised risk: new risk encounters facing migrant care workers, *Health, Risk & Society*, 18(3/4): 137–52. doi: 10.1080/13698575.2016.1182628

FitzGerald Murphy, M. and Kelly, C. (2019) Questioning 'choice': a multinational metasynthesis of research on directly funded home-care programs for older people, *Health and Social Care in the Community*, 27(3): e37–56, doi: 10.1111/hsc.12646

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F. and Stainton, T. (2019) Individualized funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review, *Campbell Systematic Reviews*, 15(1–2). doi: 10.4073/csr.2019.3

Graby, S. (2018) *Personal Assistance: The Challenge of Autonomy*, *PhD thesis*, UK: University of Leeds.

Graham, K. (2015) Cash payments in context: (self-)regulation in the new social relations of assistance, *Disability & Society*, 30(4): 597–613. doi: 10.1080/09687599.2015.1037951

Hall, P., Jefferson, L., Dale, V., Bennett, L., Birks, Y., Bloor, K. and Murray, R. (2017) *Understanding Domiciliary Care in England*, York: University of York and The King's Fund, www.york.ac.uk/media/healthsciences/images/research/prepare/UnderstandingDomiciliaryCareInEngland.pdf.

Kelly, C., Jamal, A., Aubrecht, K. and Grenier, A. (2020) Emergent issues in directly-funded care: Canadian perspectives, *Journal of Aging & Social Policy*, Apr 22, 1–21. doi: 10.1080/08959420.2020.1745736.

Leverton, M., Burton, A., Rees, J., Rees, J., Rapaport, P., Manthorpe, J., Downs, M., Beresford-Dent, J. and Cooper, C. (2019) A systematic review of observational studies of adult home care, *Health and Social Care in the Community*, 27(6): 1388–400, https://doi.org/10.1111/hsc.12831. doi: 10.1111/hsc.12831

Locke, P. and West, K. (2018) Direct payments for older adults in an age of austerity, *Ethics and Social Welfare*, 12(3): 216–28. doi: 10.1080/17496535.2018.1505930

Manthorpe, J. and Hindes, J. (2010) *Employing Direct Care Workers through Public and Private Funding: A Scoping Review*, Leeds: Skills for Care.

Moran, N. et al (2013) Older people's experiences of cash-for-care schemes: evidence from the English individual budget pilot projects, *Ageing & Society*, 33(5): 826–51. doi: 10.1017/S0144686X12000244

Porter, T., Shakespeare, T. and Stockl, A. (2020) Performance management: a qualitative study of relational boundaries in personal assistance, *Sociology of Health & Illness*, 42(1): 191–206. doi: 10.1111/1467-9566.12996

Reckrey, J.M., Geduldig, E.T., Lindquist, L.A., Morrison, R.S., Boerner, K., Federman, A.D. and Brody, A.A. (2020) Paid caregiver communication with homebound older adults, their families, and the health care team, *The Gerontologist*, 60(4): 745–53, https://doi.org/10.1093/geront/gnz067.

Ritchie, J. and Spencer, L. (1993) Qualitative data analysis for applied policy research, in A. Bryman and R. Burgess (eds) *Analysing Qualitative Data*, London: Routledge, pp 173–194.

Rodrigues, R. (2019) Caring relationships and their role in users' choices: a study of users of direct payments in England, *Ageing and Society*, 1–21, doi: 10.1017/S0144686X19000035.

Shakespeare, T., Porter, T and Stockl, A. (2017) *Personal Assistance Relationships: Power, Ethics and Emotions*, Norwich: University of East Anglia, www.skillsforcare.org.uk/Employing-your-own-care-and-support/Resources/Information-for-local-authorities-NHS-and-support/Reports-and-research/Personal-assistance-relationships-study-June-2017/Personal-assistance-relationships-research-report.pdf.

Wilcock, J., Iliffe, S., Moriarty, J. and Manthorpe, J. (2020) Under the radar: general practitioners' experiences of directly employed care workers for older people, *Health and Social Care in the Community*, 28(3): 1099–108, https://doi.org/10.1111/hsc.12943. doi: 10.1111/hsc.12943

Wittenberg, R., Hu, B. and Hancock, R. (2018) *Projections of Demand and Expenditure on Adult Social Care 2015 to 2040*, London: London School of Economics and Political Science, http://eprints.lse.ac.uk/88376/1/Wittenberg_Adult%20Social%20Care_Published.pdf.

Woolham, J., Daly, G., Sparks, T., Ritters, K. and Steils, N. (2017) Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75 who have a managed personal budget or a direct payment, *Ageing and Society*, 37(5): 961–84. doi: 10.1017/S0144686X15001531

Woolham, J.G., Norrie, C.M., Samsi, K. and Manthorpe, J. (2019) *Roles, Responsibilities, and Relationships: Hearing the Voices of Personal Assistants and Directly Employed Care Workers*, London: NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute and King's College London, https://kclpure.kcl.ac.uk/portal/en/publishers/nihr-policy-research-unit-in-health-and-social-care-workforce-the-policy-institute-kings-college-london(ae9ef990-b03f-48ee-8d04-1db8f5208202).html.