

## RESEARCH

# Caring in Covid-19: Personal Assistants' Changing Relationships with their Clients' Family Members

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**Context:** The impact of Covid-19 on people working as personal assistants (PAs) or directly employed care workers potentially affects not only themselves and their clients but sometimes clients' family members or carers.

**Objectives:** This interview-based study aimed to hear directly from PAs of their experiences during the pandemic to inform policy and practice.

**Methods:** A sample of 41 PAs working in England were interviewed by telephone during the early months of Covid-19 (April–June 2020) in England. Interview data were analysed thematically and accounts of PAs' engagement with their clients' family members were explored.

**Findings:** Study findings illustrate the fluidity of relationships at this time within four dimensions: 1) some family members working more closely with PAs, 2) the development of tensions between PAs and family members, 3) displacement by family members of PAs and other care services, 4) PA accounts of working with clients who had little or no family contact or other assistance during the pandemic. Limitations: This study did not interview family members to hear their views of the relationships and circumstances discussed by the PAs.

Implications for research include a need to hear from other care workers operating as live-in PAs and from family members and employers and to follow-up with PAs as the pandemic progressed. Policy implications include the need to encourage contingency planning and to ensure support for PAs. Practice implications are for staff responsible for individualised funding to ensure PAs are known to their systems to enable their support.

**Keywords:** Covid-19; Personal Assistants; directly employed care workers; carers; family

## Introduction

Consumer-directed care, self-managed care, and usage of personal budgets are among the international terms used to describe individualised funding of disabled people to enable them to meet their own needs for care and support (Kelly et al., 2020). Despite the myriad schemes under which these operate (Fleming et al., 2019), common features include the ability to employ care workers directly instead of using home care agencies and aspirations to maximise choice, promote continuity of care, and shift power from service provider to the person needing support. In the context of the Covid-19 global pandemic that started in 2020, the strengths of such a model of social support were evident in that the relationship between client and directly employed care worker or personal assistant (PA) might help support vulnerable people living at home with a reliable, known, and acceptable care worker. Despite criticism that they mark the 'end of formal adult

social care' (Scambler, 2020, p.145), individualised funding arrangements are steadily expanding internationally (Fleming et al., 2019). However, little has been known of the workforce that is directly employed. Kelly et al. (2020) found that 19 of the 20 Canadian systems running such funding did not collect information on workers employed. In the English context, by contrast, more quantitative research is emerging from Skills for Care's surveys of PAs, the latest of which received 1,725 responses (Skills for Care, 2020) (recruited in the main from a direct payment support service organisation), and the growing numbers of qualitative studies, albeit generally with a small sample size (Kelly et al., 2020; Wilcock et al., 2021).

The Covid-19 pandemic has prompted further studies of wider home care services' functioning that are relevant to the directly employed or directly hired care workforce. Sterling et al. (2020) reported on interviews with 33 home care/home health workers in New York (US), revealing they were at considerable risk for contracting Covid-19. Their risk of infection had been exacerbated by inconsistent information on what they should do to protect themselves and their clients, inadequate personal protective equipment (PPE), and their heavy reliance on public

transport to reach their clients. In the UK (Giebel et al., 2020a, 2020b), some care users and family members were reported to have suspended home care services to reduce the risk of infection. Others have taken a forward view and predicted that close family and friends who were providing many hours of informal care during the pandemic to their family and then became unemployed might turn to care work (Mahoney, 2020).

The present study builds on an earlier interview-based study in England of 105 PAs in 2017–18 (Woolham et al., 2019) that had sought information about their working conditions, practice activity, and engagement with their clients' family members (Manthorpe et al., 2020). Three overarching themes emerged from these interviews: 1) possible complications over accountability and employment; 2) at times, PA provision of support for wider members of the family; and 3) PAs and family members forming in effect a care team characterised by mutual trust and close working. The first of these, complications, may include what Porter and Shakespeare (2019) report as 'trouble' in PA relationships that had affected all their study's interview participants (both PAs and people who were employers of PAs, not linked) at some point. These troubles were considered to take three distinct forms—practical, personal, and proximal—that subsequently developed into conflict-resonant (resolved or accommodated) or deviant-resonant (relationship conflictual or terminated) directions. This study was undertaken in response to the need to find out what was happening to PAs at the specific time of the early months of the Covid-19 pandemic in the UK but has its roots in these previous studies of home care, care worker relationships with family members, and PAs.

## Methods

### *Study design and orientation*

This was an in-depth qualitative study recruiting from a sample that had been recruited for a previous study (Woolham et al., 2019). The methodological orientation underpinning the study was epistemological, in that the reality of the world of PAs was considered under-explored, particularly in the context of Covid-19. A phenomenological approach (Marton & Booth, 1997) is taken in this present analysis to enable a concentration on the relation between the experiencer (the PA) and the phenomenon (relationships with the clients' family members during the Covid-19 pandemic).

### *Participant selection and recruitment*

Participants were recruited from a previous sample of 105 PAs who had been recruited to a study in 2016–18 and who had agreed to be re-contacted for any follow-up study (Woolham et al., 2019). They were re-contacted by email. Two proved uncontactable. Forty-eight did not respond to the request to be interviewed, and 14 responded to say they were no longer working as PAs. Some specified reasons such as retirement and pregnancy, while other reasons were unspecified. In total, 41 agreed to be interviewed.

It is not easy to reach PAs or directly employed care workers because they are not registered with any regulator or accessible on any database (Woolham et al., 2019; Shakespeare et al., 2017), meaning that any new survey

would likely take considerable time to recruit, so delaying the provision of evidence for our funders. As Vindrola-Padros et al. (2020) have argued in relation to the pandemic context, there is an obligation on researchers to respond to the immediacy of the situation and to share actionable findings. Evidence for policy makers (the Department of Health and Social Care) was needed in the early weeks of the pandemic; emerging findings were passed to them at several intervals prior to study publication.

Interviews were conducted by JW, an experienced qualitative researcher who had undertaken most of the interviews of the previous study and so had an established relationship prior to study commencement. Interviews were undertaken by telephone. As with the previous study, tokens of appreciation were sent to participants.

### *Data collection*

A semi-structured interview or topic guide was developed by the team. With consent, all interviews were audio-recorded. They lasted on average 45 minutes. Transcripts were not returned to participants for comment and/or correction, but all were offered a copy of the findings. All participants accepted this offer and received a copy by email.

### *Ethical considerations*

Ethical permission was received from King's College London (REF HR-19/20-18212). Participants were assured of anonymity in outputs, and confidentiality was assured unless the researchers were concerned about possible risks of harm. The stressful situation of national lockdown and fears about the pandemic were recognised, and the interviewer was alert to the possibility of participant distress; one participant became distressed towards the end of the interview but declined the offer of a break or for the interview to end. A minority of participants spoke of having contracted the virus and some of family bereavement from the virus.

### *Analysis*

Two members of the research team (KS and CN) coded the data. Both read a selection of transcripts repeatedly and independently identified main themes or consistencies in the data. Identified codes were discussed and any discrepancies resolved with assistance from the wider team. From this, a coding framework was developed and the codes were organised into overarching themes and sub-themes. The entire dataset was then thematically coded using the coding framework, and extracts were collated under each of these codes. QSR NVivo (QSR International, 2018) was used to manage the data during analysis. Emerging findings were discussed within the team and shared with members of the NIHR Policy Research Unit in Health and Social Care Workforce's patient and public advisory group that met online to discuss them. The team then re-examined corresponding data extracts to check for outlying data.

### *Findings*

A total of 41 PAs participated. They were overwhelmingly female (95%) and White (83%), with most (93%) of

British nationality. The mean age was 48.5 years. Nearly half (49%) were caring for another family member, with a similar proportion caring for children within their family. Most worked for more than one client. Participants came from all parts of England. Participants' characteristics are reported in **Table 1**.

Four main themes were identified in the data: (1) working closely with family, (2) developing tensions, (3) displacement and suspension, and (4) no carers to hand. These are extrapolated below, and participant quotations are used to illustrate the themes, using a participant number to ensure anonymity. Other identifiable information has been redacted.

**Table 1:** Participants' characteristics.

<b>1. Ethnic background</b>	<b>No.</b>	<b>%</b>
White	34	83
Multiple/dual heritage	3	7
Asian	2	5
Black	1	2
Total	41	100
<b>2. Age</b>	<b>Yrs</b>	
Minimum	21	
Maximum	71	
Mean	48.5	
<b>3. Gender</b>	<b>No.</b>	<b>%</b>
Male	2	5
Female	39	95
Total	41	100
<b>4. Caring for member of own family</b>	<b>No.</b>	<b>%</b>
Yes	19	49
No	20	51
Total	39	100
Missing	2	
	41	
<b>5. Caring for children/students in own family</b>	<b>No.</b>	<b>%</b>
Yes	15	49
No	20	51
Total	39	100
Missing	2	
	41	
<b>6. Nationality</b>	<b>No.</b>	<b>%</b>
British	38	93
Polish	1	2
Hungarian	1	2
Jamaican	1	2
Total	41	100

### **Working closely with family**

Some PAs described working more closely with their clients' family members during the pandemic, echoing the theme of team working that had been identified in the previous study (Woolham et al., 2019). If the PA was part of a wider team, this often involved adjusting rotas, but if the PA worked alone, the usual contingency was that immediate family members would step in if the PA was unable to work. Reasons for not being able to work included concerns about infection transmission to PAs' families and having to help members of their own family. In some instances, the client's family took on the PA's work, in others the family's assistance might include making some major decisions if home care became impractical:

...he (client) has two daughters, so it's not as if... neither of them are necessarily relying on one of their children, they both have more than one child, so one of their children would take over and see to any needs, whether it was having to go into a care home or whatever, really. DM550288

Other PAs spoke of proactive discussions between themselves, their client, and/or the client's family about the best course of action when the impact of Covid-19 was becoming evident and lockdown measures were on the horizon (March 2020). Some family members helped source equipment for the PA, to help with infection prevention, particularly when supplies of masks and gloves were getting short. In this case the PA said she felt involved in the eventual decision that her client would move back to her parents' home:

I raised my concerns... about (client) not really understanding the guidelines that had been put in place and could people make sure that they remind her about washing her hands when she went back in the house and all those sort of things, so that was the week leading up to when the lock-down came into place. I then had a conversation with her Mum, before the decision was made and we all knew that it was perhaps going to happen, I had quite a lengthy discussion with her Mum on the night before, saying what... we were really basically talking to each other about what we felt would be best for (client) if the lockdown were to happen, and it was during that conversation that I think we both agreed that (she) would be safest moving back into the family home for whatever period of time it took. DM550316

For a small number of clients, who lived in specialist accommodation that did not provide any form of care services, general visiting was prohibited, so family members could not support their relatives. In this case PAs were able to maintain their commitment, even though relatives might have liked to have done more:

(the accommodation is) on what you'd probably class as lockdown, there's no family allowed to visit

and deliveries are left at the door, but there was no questions asked about myself going in. DM550314

### ***Developing tensions and concerns***

However, tensions between PAs and family members relating to Covid-19 were also reported. The maintaining of social distancing (6 feet/2 meters between individuals) in a client's home was not always possible:

[The client's] Dad might be in the kitchen cooking tea for the rest of the family and I need to go in there to access meds (medication) or... I don't know, make a cup of tea, whatever, and it's a lot closer than six foot. It is almost impossible to do, but we try, we try as much as we can. DM550313

Such concerns related to Covid-19 prevention were generally around spatial proximity and cavalier behaviour in the home contrasting with the behaviour that was required from the PA:

I wear my mask and my apron, but the family goes in and does lunch and they don't wear any of it. So, I suppose that's a sort of a double standard, even though they bought it all for all the carers (care workers). I suppose they don't do her personal care, but they are in very close contact with their Mum. DM550307

However, more were concerned about the psychological impact to their clients of self-isolation under lockdown, not necessarily simply arising from loneliness and isolation, but also from possible stresses of proximity and lack of breaks from their family:

... obviously what she's (my client's) missing out on is going out and being away from the household, so in terms of her social and wellbeing needs being met, yes, that is affected because she's quite intense, and when the four of them are in the house together, that's Mum, Dad and the two of them with learning disabilities, and she's in her 40s, and so is he, it can be quite fractious because she is quite intense, and what she started to do is to write to me three or four times a day and call me, so I had to block her and only make it one day a week, which she's not happy about so I get bombarded with the longest letter you've ever seen on Thursday. So in terms of her... not her physical needs, but certainly her wellbeing needs, definitely, and also that of her family because, because she is... she rules the roost because of her behaviour, they're not able to get respite from it, and that was my... I would take her out so they can just have some breathing space... DM550309

### ***Displacement and suspension***

Under this theme were descriptions of how PAs' work had been altered as a direct consequence of Covid-19. Some had been temporarily (they thought) displaced by family

members who had stepped in to provide care themselves or who had made decisions to suspend a PA while keeping on other staff. Reasons for suspending the PA were not always clear to the PA, but some made a guess over what might have been influencing the family's choice, such as whether the local authority funding the care was continuing to do so if care was suspended. Such decisions to suspend were reported as often being taken by family members rather than the nominal employer. PAs felt that the decision was driven—whether taken by the client, their family, or both—by a desire to remain healthy and safe. Despite the loss of income, most of the PAs to whom this had happened understood and were sympathetic toward those who had decided to shield (reduce virtually all physical social contact or going out of doors) in addition to lockdown. In some cases, the essential tasks the PAs had formerly undertaken were being carried out by either family members or a smaller number of other PAs (where a team of PAs were employed) or by care workers from an agency who had been previously working alongside PAs.

In a small number of instances, displacement was not by mutual agreement. One PA (DM55030) worked for a client whose relative returned to the family home from a part of the world where the pandemic was at its peak at that time. The PA felt that if she had continued to visit this family, her own risk of contracting the disease was such that she would be putting her other client at risk (as noted, most PAs were working for more than one client). This led to her immediate dismissal:

...the government hasn't said (then) that people coming back from (X) had to self-isolate, he didn't see why he should have to self-isolate and I said that I couldn't work without informing my other clients, that I would then give them the choice because obviously losing 44 percent of my work, sometimes I would be better off working for them at this time, this is how I was thinking at the time, I would be better off keeping that job and not seeing someone I was only doing for two or three hours a week, but I needed to give everybody the option first. So, they... I wasn't the only care worker went in there, so I don't know what they're doing; they basically have not contacted me in any way since, and I worked for them for eight years. DM55030

### ***No carers to hand***

PAs had different contingency plans if they were unable to work—if they had been in contact with an infected person and had to shield or if they became ill themselves. In only one or two cases was a client so socially isolated that there was no one else who could take over. In these circumstances, PAs said they would contact the local authority in their area and ask them to help. Other PAs also provided accounts of working with clients who had little or no family contact or other assistance during Covid-19 or previously, and in one case a client had moved into residential respite care as a precaution because her family were not able to help sufficiently:



Fortunately, most do (have someone who can step in), which is why (name of employer) that's gone into the respite (care home): it's to prevent that scenario from occurring, because she wouldn't have any more help. She has a massive family and there's only one, maybe two members of the family that are prepared to help and that's not full-time, which is why I go in. So they would be absolutely caught short as well if I weren't there. DM550313

A few PAs expressed concern about the physical wellbeing of their clients because the part of their work that involved going into the home had stopped. Some described how the loss of support for their client was having a severe impact:

(pre-Covid) Their personal hygiene; when I see these people on a regular basis, I can see what sort of week they've had, how they present themselves, if they're wearing dirty clothes. One gentleman in particular, I cook all his meals for him in a week and batch freeze them for him; he can do beans on toast and things like that, but I go in and specifically cook him meals for a whole week... so that's having an effect on him, and to help him, or prompt him to tidy his own house. (Now) It's just the little things, and he really doesn't see anyone else and, because we've built up a good relationship, we had a very good social communication as well. That is all lost, really. DM550JH2

Owing to such close relationships, some PAs reported keeping in touch with their clients even though they had been asked to stop working. Many felt that over time, as the lockdown period continued, all their clients were at risk of experiencing some degree of mental distress, and some of their clients' families acknowledged this when the PA was unable to visit:

[Mother] also suggested that we call the client on the days that we should be working, just to catch up, maybe encourage the work that we know we should be doing with her, to make sure they're okay. So I actually WhatsApp call her, which I'll be doing after this conversation, just to get a visual on her, she can have the visual on me.[...] someone different to talk to, so yeah. So my employer (the mother) asked if we'd all do that, so we all do that on our days when we should be working (in person).

## Discussion

### *Strengths and limitations of the study*

Internationally, PAs are a workforce about which little is known (Kelly et al., 2020), so this study adds to the PA literature as well as the Covid-19 evidence base. Interviewing was undertaken by one researcher, enabling continuity. In the circumstances of the pandemic, face-to-face interviewing was not possible and telephone interviews enabled broad geographical coverage. Study findings are contex-

tualised to the initial national lockdown period in the UK, but experiences during the second wave of the pandemic and subsequently may differ as may other national contexts. In the present study, PAs were mainly working for older people or people with learning disabilities and with autism, not for clients with severe mental health problems. Family carers/members of this latter group have described the management of direct payments as often particularly stressful (Hamilton et al., 2017). The views of direct employers/clients and family members are missing from this discussion, and their perceptions would be interesting to explore alone or as part of the triad involving PA, family, and client (as suggested by McKinney, 2017).

None of this present study's participants was a live-in care worker, a group who Giordano (2020) terms as often being in a quasi-family relationship with their client and whose work may have intensified as they were in effect locked down with each other. In her study during the early first wave of the pandemic in Belgium, some live-in care workers were under particular stress as they were stuck in a foreign country, compounded for some by lack of official documentation and access to health services. However, her interviews also revealed that live-in care workers also had to negotiate with their clients' family members about their emotionally described obligations to the needy client. This suggests a need for research in the UK context to see how live-in care workers fared during Covid-19 so that contingency preparations can be made.

The findings reported here reinforce the previous study's findings of the range of relationships existing between PAs and their employers' family members and their importance for the PA. Few PAs in the present study were in the complicated positions of being family members of their clients and their PAs, although this may be more common elsewhere. Compared to the Skills for Care (2020) survey in England, where 53% of PAs were related to their client (which may have been an artifact of sampling), far fewer participants in the present study were related to their clients and none in Shakespeare et al.'s (2017) UK-based study of 28 PAs. In Sweden, approximately 20–25% of PAs are relatives of their clients (Olin & Duner, 2019). The present study highlights the prominence of many individual family members as employers, in that they are making the arrangements and determining the PA role either as official proxies for the client or often they are taking on the employment arrangements. Their role may be general or particularly prominent when clients have cognitive impairment; in one recent study (Pollock et al., 2020) of 14 home care workers in England supporting clients living with dementia, the hiring arrangements had been made by family members. What emerged during Covid-19 reflected this, and where this worked well, discussions could be held to explore contingency arrangements and, as events unfolded, to sustain communications. During Covid-19, all non-co-resident family members became distance carers (previously generally seen as those living some distance or time away from their relatives, see White et al., 2020) as social contact was limited and both travel and public transport were difficult and often regarded as risky. While Larkin (2015) observed

that many relatives of care users newly provided with personal budgets (individualised funding) felt easier about others taking over some of their caring activities and, as time went on, they gained greater confidence in the quality of the care provided, Covid-19 proved a disruptor to many such accommodations.

Some studies describe a three-fold relationship triangle or service triangle in consumer-directed care, namely between the client, PA or directly employed/agency managed care worker, and the funder in the person of the social worker or co-ordinator (e.g., Payne, 2019a, 2019b). In this present study, the funder of the social care—usually the local authority (LA)—was absent from most of the PAs' discussions, other than sometimes being referred to as a last resort. None mentioned having a LA contact or knowing of one; a few presumed that perhaps the family member or client might have one, and some who were in touch with a local support organisation would contact this. Some had an idea that the LA was their indirect funder in that the LA might still be paying the personal budget to their client, enabling suspension with pay to be a possibility, but did not feel that it was their role to interact with the LA; this was for the client or their family to do. No PA seemed to be involved in their client's LA agreed support plan or any LA contingency planning. As Wilcock et al. (2020) noted in a previous study of PAs' links with primary care, PAs are often unknown to such professionals unless they act in a role akin to family carers, making and attending appointments with their client, for example. Covid-19 has highlighted this lack of contact with wider LA and NHS services, leaving PAs, clients, and family members to negotiate ways of working. Such a situation appears to be contrary to the early expectations of the Care Act 2014 in England that carers would be more involved in assessment and review (Brooks et al., 2017).

Risk management was high on PAs' minds in Covid-19, adding to other insecurities (Christensen & Manthorpe, 2016) inherent in the role. Internationally, most governments seem to view consumer-directed care or direct funding as a way of reducing their contact with the workers employed through such funding, adopting an 'arm's length' approach (Kelly et al., 2020) and seeing this as part of clients' or their family members' choices (FitzGerald Murphy & Kelly, 2019). There was no evidence in this present study of PAs being enlisted as part of the Covid-19 workforce in which they might play a major role in infection prevention or to assist clients with the virus or in recovery, which might further support and assure family members. Scales (2020) has argued that Covid-19 provides an opportunity to consider revitalising the whole home care (home health) workforce to better deliver high quality services for an ageing population.

Other Covid-19 studies have explored reasons why family members might choose to withdraw formal care services (as well as noting the impact of closures of services, such as day centres). Giebel et al. (2020b) interviewed 15 co-resident carers of people living with dementia in the early months of the pandemic in England, finding that family carers were fearful of several different home care workers entering their home, especially as the virus took

hold, especially with the arrival of several new replacements of usual workers who were also visiting other vulnerable clients. In their study, those who made the decision to continue with care services did so because the tasks were very difficult (e.g., involved substantial lifting) or because they feared that once stopped they would be unable to resume care services (Giebel et al., 2020b). This present study reflects many of the same issues from the PA perspective.

This present study has illustrated how some of the perceived advantages for directly employed care workers such as PAs were helpfully maintained during Covid-19 by previous good relationships or team work with family members. However, Covid-19 was a major disruptor, and the advantages to all parties of direct employment were sometimes not so evident. Flexibility, for example, could be seen by family members as risky if it meant that the PA had more than one client or problematic if the PA needed to stop working to care for their own family. Flexibility in the space of the home, which was both a working environment for the PA and the client's and family members' own home, was hard to manage when risks of infection were paramount, although such tensions are not new (Needham, 2014) and would apply to the general home care workforce. Flexibility in terms of being able to suspend the PA was positive for some, who hoped this would be a temporary arrangement as they shielded or shielded others, but others felt displaced and many expressed concern about the impact of reduced social contact on their client and the extra work being taken on by family members.

### Conclusion

The study indicates a need for policy makers and those administering direct payments/individualised funding schemes to consider proactively the PA working relationship at times of crisis for both the PA client and family members, as well as for the PA. The longer-term impacts of the pandemic on PAs are unknown and merit research to further inform policy and practice. A focus on PAs does not undermine the need for disabled people and others receiving social care support to be better considered in emergency planning following the Covid-19 pandemic (Sabatello et al., 2020), but so too must the needs of their PAs be addressed.

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### Competing Interests

The authors have no competing interests to declare.

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