

FINDINGS



Key messages

- Personal assistance relationships are complex, variable, and involve power, ethics, emotions;
- PA is empowering, flexible and desirable for both employers and workers;
- However, PA can go wrong, relationship sometimes become wounded, or even ruptured;
- Managing PA relationships is complicated and hard work;
- Dysfunctional relationships may be emotionally fraught and disempowering;
- Disabled employers and PAs must be supported to gain skills and knowledge needed to manage relationships effectively.

Study aims

- To understand the diversity and complexity of the personal relationships involved in PA.
- To explore the nature of the role of personal assistant and how it is experienced.
- To understand power dynamics in personal assistance relationships, and how conflict or other difficulties are negotiated/avoided.
- To explore the potential contribution of psychosocial approaches to the study of caring relationships and in disability studies.

Background

Personal assistance is a model of support where disabled people take control of recruiting, training and managing the people that help them. Personal assistance differs from other forms of social care, such as domiciliary care, because the disabled person is in control of how they are supported, when, and by whom. It is for this reason that personal assistance has been key to the ongoing struggle towards independent living and the empowerment of disabled people. In England, an estimated 65,000 disabled people are employing 145,000 personal assistants (Skills for Care 2016).

In the UK, disabled people are free to employ whomsoever they wish, to organise their support however they desire, and the relationships that ensue do so without oversight from government, professional or third sector agencies. This freedom offers great rewards — when disabled people have control over their support arrangements it leads to better outcomes. But there are also risks, PA relationships frequently involve conflict, and without support managing PA relationships can be demanding and emotionally fraught.

Photo: Charlie with his PA Hayley (not participants in the study)

Metaphors to work by

“Staff”: PAs and their employers have separate lives. PAs may take a more subservient role — they follow orders, do as they are told, and don’t make suggestions. This metaphor may entail difficulties for the worker, such as feelings of subordination.

“Professional”: Professionals have very clear roles and responsibilities. When we interact with professionals, we expect them to complete their duties to a high standard. Professional relationships focus upon tasks and tend not to involve social activities.

“Colleague”: The primary aim of colleagues is to do the best possible job they can. We may get on with our colleagues, and have interests and opinions in common with them, but not always. As such, colleagues may socialise together, but this tends to be on rare or special occasions.

“Paid friend”: Paid friends emphasise the social and emotional aspects of PA relationships. Tasks are important, but they are only part of the activities, which include companionship. Paid friends tend to know more about one another, and even take an interest in one another’s lives. Paid friends can be a rewarding social and emotional relationship, but they are not for everyone.

“Family”: Family-like relationships are marked by deep affection and a mutual sense of duty. This kind of PA relationships may mirror real family relationships – we may feel that the person we work with is more like a parent, child or sibling to us. This metaphor brings benefits, but the danger of relationship breakdown if it becomes too intense.

Boundaries

Informality, it’s the *‘nature of the job’*

‘they’re doing quite personal things like showering you. They’ve got to be people you trust intimately and people that you know, very, very well, and because of that you’ve got that relationship going... I don’t differentiate between the friendship side of it and the work side of it. The two go together as far as I’m concerned’

Risks and rewards

‘because she’s a friend and she wants to do something for me and she wants to help me and being friends they want to help you’

‘when they feel they’ve got their feet under the table... they don’t do as much or do things correctly, they try to cut corners’

Shared lives, private realms

‘her life is my life, I don’t want my life to be hers’

Conflict

All participants reported some form of dissatisfaction or disaffection in their PA relationships. Three distinct but related forms of conflict were common:

- **Practical** conflict involves dissatisfaction with practical processes or outcomes.

'She was quite challenging to work with. She got very upset because in her experience working in a care home she was used to having bleach and certain materials locked away in a cupboard, and of course this being a private house I just had my bleach under the sink not locked away or anything like that'

'this lady has six birds, I hate birds, I don't like them, I feel they're dirty so I don't feel comfortable with it, but I have to do it because I am doing it for her. In that way it is more acceptable, but I don't really think that is in the role of the personal assistant'

- **Personal** conflict involves antagonistic personalities or values

'that's part of my life that I have struggled with for many, many years to feel comfortable with... and by attacking my values... I had to let her go'.

'she employed someone that shouldn't have been employed, and it was a bit like she chose him over me. Even though I had given her years of utter devotion and exceptional, exceptional PA support'

- **Proximal** conflict stems from the social and practical organisation of personal assistance. Personal assistance work usually involves working with a single person, often for prolonged periods of time in relatively close confines. These dynamics of proximity were identified by several informants who said they exacerbated existing problems between employers and workers.

'I was there a lot. She is disabled... but it doesn't mean she always wants someone around. It is a lot to have somebody in your home'

'you're with someone all the time, little things... something they may forget to do – because people aren't perfect we all make mistakes – you have to give space for that to compensate. But when you're with someone too much, it becomes too much'.

Recommendations

Seek a good match of employer and worker;

Respect difference;

If possible, have multiple workers;

Clear communication and listening;

Vet applicants;

Probation period;

Offer guidance around tasks;

Expect to do emotional work;

Dialogue is vital;

Support groups for employers and workers;

Forum for safe conflict;

Third party resolution;

Remember: one person's home is another person's workplace—and vice versa.

Funding is needed for training and support of both employers and workers to understand roles and improve relationships, and for mediation.

Methodology

The data presented in this paper are taken from an ESRC funded study into personal assistance relationships entitled 'Personal Assistance and Disabled People: Emotions, Ethics and Power' [ES/L007894/1]. The aims of this study were to gain a better understanding of the relationships that occur when disabled people directly employ PAs, and to explore how both parties experience and manage challenges within these relationships.

Disabled informants were sampled using purposive sampling. Disabled informants were identified and recruited through a network of disabled people's organisations (DPOs). Efforts were made to recruit participants with a range of impairments, backgrounds, and in rural as well as urban areas. Exclusion criteria included being under the age of 18 years and lacking mental capacity to provide informed consent.

PA informants were sampled initially using purposive sampling and later through snowball sampling. PA informants were recruited through informal contacts within the same network of DPOs, and through blogs, and the study was also advertised on a national internet based PA forum; the informants garnered through these efforts then provided further contacts through snowball sampling.

The majority of disabled informants took part in a face to face interviews, all but one of which took place in informant's own homes, the other took place in a public space. The majority of PAs took part in telephone interviews, largely because they were geographically more dispersed than disabled informants. Interviews followed a topic guide informed by extant literature and refined iteratively throughout data collection. All interviews were transcribed verbatim. Data storage, administration, and analysis were conducted using QSR Nvivo 11. Constructivist Grounded Theory (Charmaz 2006) provided the framework for analysis. The stages of focused and theoretical coding were subjected to peer review by all members of the research team, with the aim of cross-validating data interpretation.

Online training

A short training for PA employers and workers, drawing on the study findings, is in preparation, funded by ESRC Impact Accelerator Grant.

For news of training or copy of report, contact:

Prof. Tom Shakespeare
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
01603 591952

tom.shakespeare@uea.ac.uk
www.uea.ac.uk/med

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