

Care parading as service: Negotiating recognition and equality in user-controlled personal assistance.

Abstract

This article addresses aspects of the relationship between disabled people and their personal assistants within the user-controlled personal assistance programme in Norway (BPA). Within this programme, a disabled person and her/his personal assistant (PA) form a working relationship in which the disabled person functions as a supervisor for her/his PA. The purpose of the programme is to enable the supervisor to live as independently as possible, equal to any other member of society. In a study conducted about the work relationship between physically disabled persons and their PAs, we found that many supervisors wanted service, not care, from their PAs. Furthermore, the supervisors' image of the ideal PA was one who was invisible. In this article, we wish to address the tensions between supervisors' hard-won rights to personal assistance in order to live independent lives and the gendered work-related implications of positioning PAs as invisible service workers within this work relationship.

Keywords: Care work, service, personal assistance, emotions, disability

Introduction

Since the 1960s, disabled people within the Independent Living movement have struggled to be treated as equals to non-disabled people in Western European countries, Japan and the US (Williams-Searle, 2008), and their history is in many ways similar to that of women and the feminist movement in their struggle for equality and recognition (Davis, 1995; Garland-Thomson, 2009; Morris, 2001). The movements diverge, however, in at least one important and work-related area, namely, the conceptualisation and understanding of care and care work (Kelly, 2013; Morris, 2001; Williams, 2001). To many disabled people, care connotes oppression, whereas for feminists, care connotes invisible, underrated and low-paid work.

In the empirical material on which this article draws, these two positions, but particularly care as oppression, surfaced in interviews with disabled people and their personal assistants (PAs) within the user-controlled personal assistance scheme for disabled people (BPA—brukerstyrt personlig assistanse) in Norway. The other position, care as invisible, underrated and low-paid work, was mainly carried by us. The users and providers of BPA sought to ground personal assistance in a concept of service rather than in the concept of care, hence repositioning the relationship from one between a provider and a receiver of care to one in which the user is a receiver of service. When personal assistance is granted, the user and the provider of assistance form a working relationship in which the user is the employer and supervisor and the PA is an employee (see also Askheim, Andersen, Guldvik, & Johansen, 2013; Shakespeare, Porter, & Stöckl, 2017). Many supervisors in our empirical material depicted their PAs metaphorically as their “hands and feet”, and they described the ideal PA as invisible and mute.

Troubled by the “hands and feet” metaphor and its implication for PAs’ subjectivity, while acknowledging supervisors’ needs for participation and recognition, we wish to unpack some of the empirically situated theoretical and political problems embedded herein. Central to our concern is the status of recognition of the parties within in this relationship and the way the relationship is framed as service. Service denotes brief encounters between persons who do not know each other and intersects with commodification as well as with the wider societal lack of emphasis on recognising dependency as a shared trait in all human existence (Fraser, 2013; Payne, 2009).

In this article, our aim is to discuss why the use of the word service, rather than care, as a description of the personal assistance work, is problematic. Here, we include disability scholars and the Independent Living movement's criticism of care and care work to rearticulate our understandings of care in personal assistance without decoupling care and care work from its political feminist ramifications.

Attentiveness to the question of why the term and practice of 'care work' has been rejected by the disability field not only in Norway but also internationally forms an important background for the focus of our attention (e.g., Kelly, 2011; Morris, 2004; Shakespeare, 2006). We will suggest, therefore an alternative take on care and care work that moves from Kari Wærness' (1992) significant work on care work as rational and emotions based to Annemarie Mol's (2008) conceptualisations of good care practices. To Mol, good care is anchored within 'the logic of care' rather than 'the logic of choice', which relates to free choice, service, and consumption and the marketisation of current welfare policies (see Bonfils & Askheim, 2014 p. 65 on current developments in personal assistance in Scandinavia). Mol grounds her understanding of good care in practices characterised by respectful, collaborative encounters between care professionals and their clients rather than in an emotions-based understanding of care (Noddings, 1984), emphasising the "care" in care work as an emotional prerequisite of compassion and love (Held, 2006; Wærness, 1992). While arguing for an understanding of care practices as collaborative practices, we do not imply that this particular grounding of care will serve as a guaranty against harm and the misuse of power. Professional care practices will always involve a risk of harm due to structural power relations that may contradict professionals' (good) intentions and how their actions and practices are understood and received by the user (Doel et al., 2010; Kelly, 2013; Kelly & Chapman, 2015). Nevertheless, we contend that framing good care practices as collaborative actions may serve as a productive point of departure for rethinking current articulations of the work relationship between supervisors and their PAs as service.

We will start our inquiry by giving a condensed overview of recent developments in BPA in Norway and connect these developments with some central ideas on empowerment and independency in the Independent Living movement. We empirically engage our concerns with the use of the hands and feet metaphor and invoke G. W. F Hegel (1976) and Simone de Beauvoir (2010) to unpack the difficulties we see with regard to recognition and that we imagine are important to individual PAs and supervisors as well as to the gendered politics of

welfare services under capitalism. We suggest, not denying the important critique from disability scholars and others on the workings of power and oppression embedded in all care work, framing the supervisor-PA relationship as a collaborative enterprise striving towards mutual recognition. First, however, we will briefly engage with current debates relating to care as oppression vs. care as undervalued and invisible women's work, clarifying what is at stake in these debates.

Care, assistance, and commodification

Among disability scholars and feminist care theorists, care, as activity, emotion and politics, given, received and shaped in formal and informal relationships, is contested and ambiguous. For many feminist disability scholars, care connotes disabled people's experiences with oppression, vulnerability and devaluation within care regimes (Kelly, 2013; Morris, 2001; Shakespeare, 2006; Watson, McKie, Hughes, Hopkins, & Gregory, 2004). However, for feminist care theorists, care is a site for political engagement with gendered norms and practises in the private and public spheres of unpaid and paid care work (England, 2010; Fraser, 2013; Held, 2006; Ungerson, 2005; Williams, 2001). As such, the concept of care contains several tensions with regard to power and empathy in itself as well as with regard to its standing in feminist research and feminist disability studies as Christine Kelly writes (2013, p. 786),

Indeed, as disability scholarship so effectively demonstrates, the potential for daily practices of "care" to veer into pain and oppression is high. (...) but the disability critiques of care also have limits as they often ignore the gendered nature of care work and the potential to oppress the individuals who work as care providers, many of whom are transnational and racialized subjects.

While disability scholars have seen care in relation to oppressive medical regimes and patriarchy and disabled people have claimed their rights to independent living and personal choice, feminist care theorists have sought to ground care in an ethics of care based on generalised ideas on human interdependency, opposing liberalist and neoliberalist ideals of the autonomous individual under capitalism. Hence, feminist disability scholars and feminist care theorists enter these debates from opposite positions in the care work relationship. Additionally, and importantly, the move against care amongst disability scholars is a move away from paternalism and patriarchy in welfare regimes and not necessarily a generalised stance against

the political importance of recognition and interdependency (e.g., Reindal, 1999; Shakespeare, 2006; Watson et al., 2004; Williams, 2001). While not straightforwardly, care among feminist care theorists denotes a move against capitalism in an attempt to politicise women's care work and to emphasise the importance of recognising our common interdependency and need for care (Fraser, 2013; Held, 2006; Hochschild, 2012).

Feminist disability scholars have attempted to tackle the dilemmas embedded in care vs. assistance, but not service, theoretically by, for example, suggesting alternative words for care, such as help (Shakespeare et al., 2017) and accessibility (Kelly, 2013). Fiona Williams (2001) and Watson et al. (2004) have suggested that Jane Tronto's (1991) four-fold understanding of care, attentiveness, responsibility, competence and responsiveness, must form the foundation on which we articulate care and its dynamics of power and help. While we acknowledge these re-articulations from feminist disability scholars and the relational thinking on which they are based, the surfacing of the ideal of the invisible and mute PA providing her supervisor with service in our material is deeply disturbing and calls for continued discussions of what care and care work could or should be. In particular, this worry is intensified when personal assistance work framed as service is seen in connection with commodification and the general ideals and stakes placed on individualism, privatisation, marketisation, and personal autonomy under capitalism in neoliberal societies (Fraser, 2013; Hochschild, 2012).

Nevertheless, and key to our argument, the question remains whether this commodification is due to the structural workings of capitalism and the marketisation of welfare services rather than to a specific connection with feminised gender. The fact persists, however, that far more women than men are employed in positions as care workers throughout western Europe and the US (England, 2010), and personal assistance is not exempt from this (Christensen & Pilling, 2014; Kelly, 2013). Hence, to rearticulate care as service involves more than displacing one word with another, as language mirrors discourses that are constitutive for practice (Dunn & Neumann, 2016; Grue, 2012; Morris, 2001). The move from care to service in BPA not only denotes a possible disconnection of a respectful, collaborative, yet always open to the use and misuse of power relationship between the supervisor and the PA but also places care, both as value and as activity, on par with oppression, thus undermining the importance of recognition, solidarity and interdependency altogether (Fraser, 2013; Rummery, 2011). In addition, the work of the PA has little to do with service in the way we normally understand the term. Service work refers to brief encounters with customers, typically demonstrated by routinised encounters in

call centres, hotels and restaurants (Payne, 2009, p. 359). This description does not fit the work conducted by PAs, who are involved in a number of personal and intimate encounters with their supervisors over time. We will return to this. First, we will position our study in the current welfare political developments in Norway.

Independent living and BPA

Since the 1990s, and recently in Norway, a number of European countries, the US and Japan have initiated welfare arrangements aimed at rectifying past wrongs perpetrated against disabled people and providing assistance, in principle, to facilitate the participation by disabled people in working life and in society at large (cf. Christensen, 2012; Guldvik, Christensen, & Larsson, 2014; Shakespeare, 2006). One of these initiatives is user-controlled assistance for disabled people with physical impairments (BPA). Throughout the 1990s, disabled people were increasingly given the opportunity to receive day-to-day assistance through user-controlled personal assistance within the BPA programme. In Norway, the BPA programme was established as a legal right in 2014 (§ 2-1d in the Patient and User Rights Act, January 1 2015). In 2013, there were approximately 3000 users of BPA in Norway (Askheim et al., 2013), and in 2016, there were approximately 3300 users of BPA (SSB, 2017).

For some disabled people, the transition from municipal home-based services to the BPA arrangement have represented a shift from mainly receiving limited day-to-day help from home carers and home-based nurses employed by the municipalities to a more tailor-made and individually-adapted arrangement. Thus, disabled people, at least ideally, have been given more control over decisions about from whom they receive assistance, when they need assistance and with what tasks they need assistance (Christensen, 2009) rather than being dependent on home carer's schedules and day-to day capacities and never knowing who will come to assist them.

The idea of user-controlled personal assistance arose from the Independent Living movement (IL movement) in the US, which emerged as a protest movement inspired by the struggle for American civil rights (see e.g., Davis, 1995; Williams-Searle, 2008). The IL movement has been important in placing the conditions of disabled people on the political agenda, and central among its main goals has been improving quality of life for disabled people in the struggle for their liberation. Internationally positioned disability organisations in Norway, of which the main actor is Uloba (Independent Living Norway SA) have, in collaboration with disability

scholars, provided policy makers with four important insights that form the knowledge base of the BPA programme. These four insights are the social model, empowerment, user control and the peer principle.

Most important among these insights is the attempt to create awareness within political, public and academic arenas of the challenges faced by disabled people in their everyday lives and that these challenges should be seen not as individual medical problems but rather as problems created by society (cf. Davis, 1995; Morris, 2001; Shakespeare, 2006). This entails shifting away from seeing disabled people as injured, ill, or in need of repair to a perspective recognising that social, material, and attitudinal barriers are the real impediments for disabled people (Hague, Thiara, & Mullender, 2010; Morris, 2001; Shakespeare, 2006).

The goal is that everyone, with or without an impairment, should be allowed to be active participants in their own lives and contribute to society based on their own needs and preferences (see also Williams-Searle, 2008), hence the use of the phrase “disabled people” rather than “disabled persons” or “persons with disabilities” (Morris, 2001). In this shift in perspective from individual impairment to socially created barriers, empowerment plays a crucial role. Empowerment positions disabled people as capable of independent decision making and not as passive victims dependent on other people’s care. Experiences of insult and paternalism in medical- and nursing-based care regimes have spurred the IL movement’s opposition to the idea of basing disabled people’s need for assistance on assistance rather than care (Kelly, 2013). Hence, when in need of personal assistance, user control is crucial (Bonfils & Askheim, 2014). In practise, this means that disabled people should be able to choose how, from whom, and for what assistance should be given (Askheim et al., 2013; Guldvik et al., 2014). The peer principle underscores empowerment and claims that advisors working for organisations administering the BPA system for the municipalities in Norway should be disabled people themselves who have experiences with personal assistance, as they are the people who are fit to help others in similar situations.

Empirical background and the positioning of the PA

In the research project on which this article is based, we conducted 17 interviews with six PAs and eleven supervisors over a two-year period. The two-fold aim of the study was to investigate the experience of having a body that is someone else’s area of work as well as the experience

of having another person's body as a work focus. Additionally, we asked supervisors and PAs about their views of and experiences in making the relationship between assistants and supervisors function in a mutually satisfactory way (Authors, 2014).ⁱ This relational focus gave rise to our interest in the positioning of the assistant as an invisible provider of service.

All the assistants we interviewed were young women, and three of the eleven supervisors were men. The interviews lasted from one to three hours, and we conducted five of the interviews together. Two of the interviews were completed telephonically, while the remainder were conducted face to face. With the exception of two telephone interviews and one face-to-face interview with a PA, all the interviews were tape recorded and later transcribed. During five face-to-face interviews, we were also allowed to observe the interactions between supervisors and their assistants. In one of these interviews, four PAs, all young women, were present, and in four interviews, one assistant, also a young woman, was present. The interviews during which we observed interactions between supervisors and PAs provided opportunities to focus on the practice of assistance.

Our informants were recruited partly through the disability organisations involved in the BPA system in Norway and partly through the snowball method. Two supervisors were recruited because of their visibility in the media, and one supervisor had been a participant in an earlier research project conducted by one of the authors of this study (Author, 2013).

Although there are some variations in our material with regard to the positioning of the PAs, the image of the PA as an invisible provider of service dominated. In two exceptions, one supervisor felt lonely and was hopeful for friendship with her PA, and one PA described her work as a professional friendship, much in the same way that Karen Christensen (2012) has typified (see below). Hence, our efforts to understand the bodily aspects of this work relationship led us to observe a marked tension between care and service. With a few exceptions, both the PAs and the supervisors articulated the expectation that the ideal assistant should be invisible, keeping herself quietly in the background. This was also how the PAs appeared to us when we observed them working during the interviews. Relatedly, we were struck by the ability and determination of the PAs to appear invisible and with their capacity for a concentrated presence and extensive sensitivity towards their supervisors' verbally and non-verbally communicated needs (see also Dodson & Zincaavage, 2007).

Only one PA stated explicitly that she felt her supervisor treated her badly and that she was “pimped out” to the supervisor’s friends. The supervisor lent the PA to a friend to accompany the friend to the swimming hall without first asking the PA, the PA mowed a neighbour’s lawn during working hours, and she did house work on Friday nights while the supervisor and the rest of the supervisor’s family had dinner and watched TV. Hence, it is important to note that it is mainly our questioning of the mechanisms at work in this relationship, not the PAs’ or supervisors’ own problematisations that forms the basis of the queries in this article.

We realise that a feminist researcher stance on behalf of PAs is not ethically unproblematic when setting out to understand the PA-supervisor relationship. While one of us has had a disabled child, none of us are disabled ourselves, and we read our material from our current position as privileged, middle-aged white women, once young and vulnerable ourselves (for situated research, see Neumann & Neumann, 2018). Hence, it is easier for us to identify with the PAs and the general political situation of young women in the gendered labour market than it is to identify with the supervisors and their lives and rights-based claims. This, however, allows for a personal and politically-situated gaze that offers an opportunity to engage critically with both the problems of service as well as with disability scholars’ criticism of care.

The unskilled and flexible worker

Personal assistants do a number of different tasks. Typically, PAs’ tasks include cooking, cleaning, laundry, maintenance, shopping, transportation, and accompanying the supervisor to facilitate the active use of her/his leisure time. Some supervisors also need assistance for personal hygiene and simple medical routines. Most of the supervisors in our study emphasised the significance of having unskilled assistants. By this, they meant that the PA should not be educated in health or social work, which is also Uloba’s recommendation. The primary reason stated by supervisors is that skilled health workers have a top-down attitude towards their clients or patients in the sense that they know best and can therefore easily take control (Christensen, 2012). According to the experiences of the supervisors and the field in general, skilled health care workers are less likely to listen to a supervisor’s own needs and wishes (Shakespeare, 2006, p. 144). A male supervisor in his late 40s explained this as follows:

My experience is that it is better to employ people without much experience from the health care sector. People who have worked for a long time as health care

workers tend to be stuck in their own ways. They have that care work mentality. And personal assistance is not about care work. It is a service. If I notice signs of a top-down attitude, it's all over.

Supervisors expressed that they experienced the “care work mentality” as an expression of a lack of recognition of their autonomy, and some reported experiences of offensive episodes leaving lasting impressions. A female supervisor expressed this in the following statement:

The field of care work, that is, people educated in care work, has scarred me deeply. I have had personal assistance for the past 20 years now, but the biggest scars have come from care workers.

Interviewer: *I have heard this from several others as well. Why do you think that is?*

Well, it's the offensive behaviour that becomes apparent when someone really wants to take care of and repair someone. As soon as someone steps into the house of someone who is blind, is in a wheelchair, has Cerebral Palsy, why do they raise the pitch of their voice and talk to them as if they were children? You don't talk to people like that.

Another female supervisor mentioned assistants who acted like mothers when answering questions about the types of assistants with whom she did not like to work:

There are assistants who take on a motherly caring role—who are caught up in nursing and care. I want service. They follow me around and nag and ask if I need anything all the time. I mean, if I need something, I'll ask. I have to be able to be alone when I need to. I have to be able to go into my room and be alone, and that does not work with a certain type of person.

Upholding the principle of service, not care, implies a distancing in what supervisors understand as intrusive care work, which is seen as highly gendered and is based on experiences with care workers who do not acknowledge the supervisor's needs, wishes, and self-efficacy (Shakespeare, 2006; Shakespeare et al., 2017). When justifying their reluctance to employ

health care professionals as PAs, supervisors state that skilled health care workers not only possess knowledge of how to perform certain (medical) care tasks but also have particular ethical standards and expectations with regard to how these tasks should be performed: with empathy and compassion for the situation of the other (see also Held, 2006, p. 10). Thus, the image of the helping, (and feminine-gendered) carer stands in stark contrast to the positioning of the autonomous supervisor who wants service.

The supervisors reported wanting to choose their own unskilled and flexible assistants. Unskilled implies an absence of education and skills in health care professions and, preferably, that the assistants should have interests that correspond with the particular needs and wishes of the supervisor. One male supervisor expressed this as follows:

You can actually ensure the quality [of life] by choosing the right assistant. If you like cooking, you hire someone who likes cooking. Then you have ensured that. But it is mostly about day-to-day tasks, which people, to a greater or lesser extent, can be trained to do. Because we all have a lot of routines. We get up and go to bed, primarily in the morning and at night. And we eat dinner. So, there are basic things that everyone is familiar with. And it is about me needing assistance in performing some of these things. Then there are other, more exciting, things, such as painting the hallway. You can secure that quality by having an assistant who has been a painter, so then you at least get your house painted. If that was the goal. I think that people with different skills can be trained to do most things. I think the main element in choosing my assistants is that they consider me an equal individual who just has some assistance needs.

An additional challenge with skilled care workers, according to this supervisor, is their lack of flexibility, and many supervisors reported desiring flexibility. One male supervisor placed the rationale for wanting flexibility within a reciprocal framework:

My assistant works for several supervisors. Whether it is enough to make a full-time position, I'm not sure, but she has other jobs as well. Another assistant I had was a stay-at-home mother who needed something to do. It was very practical for me to hire her because she lived in my neighbourhood and could be on call. And we see students who can work part-time, so there is a great deal of part-time work

in this, and that is why we are so commonly used by people who study because the work can be adapted to their needs.

Not all supervisors need full-time assistance, and many only need assistants who can be on call. Access to flexible workers, meaning workers who need part-time work, therefore fits the needs of many supervisors (Guldvik et al., 2014). As indicated in the quotation above, this is seen as a win-win situation for both supervisors and PAs. This flexibility, however, implies a decoupling from the desired goal of permanent full-time workers in the workforce in Norway and stands in opposition to feminist concerns regarding increased part-time work among women and mothers in particular (Halrynjo & Lyng, 2009) (for Europe and US, see Lister, 2009; Weeks, 2011).

Hands and feet

Christensen (2012) discussed dilemmas arising from the assistant-supervisor relationship in a study comparing personal assistance in Norway and Britany. She identified challenges in balancing the relationship in terms of power/hierarchy and the degree of emotional involvement and commitment. She distinguished three types of assistant-supervisor relationships: master-servant (both supervisor and assistant can be either master or servant), solidarity-strong emotional involvement (in which the relationship is characterised by a strong emotional involvement that can be problematic for both parties), and professional friendship (see also, Shakespeare et al., 2017). In the Norwegian context, Christensen found that the ideal assistant-supervisor relationship was one characterised by a pragmatic attitude exhibited by both parties, one in which a professional friendship formed the basis for the relation.

In our material, we found one example of the professional friendship relationship that was reported by an assistant who cared very much for her supervisor. A more striking finding in our material was that some PAs and many supervisors emphasised that assistance should be understood as service, not care. One PA reported,

I don't do any care work for the supervisor, I give him service. I don't say 'Let's get you out of bed, and I'll give you a good bath'. My boss comes up to me and says do this and do that [...] I was trained by my supervisor who was above me, had more knowledge about personal assistance, and of course more knowledge

about his own life and what kind of assistance he needed. And it was a very simple relationship to deal with. As a personal assistant, you don't have any health care education, no previous competence, and it wouldn't have helped if I had had a health care background. There is a power pyramid here, where the supervisor is at the top and I am at the bottom. I was trained by Uloba, where they knew better than me. And it is very easy to deal with.

In addition to emphasising service, not care, this PAs' understanding of the supervisor-PA relationship places all power with the supervisor and resembles the Hegelian master-slave relationship (cf. Christensen, 2012; Shakespeare et al., 2017; Watson et al., 2004) However, Uloba trained the PA who provided this quote, and assuming a subordinated position was not difficult for her. Rather, her subordination connects with a political stance against paternalism and patriarchy in medical regimes associated with care, perhaps not in an ontological sense but in an epistemological sense. Her main concern is with respecting the supervisor's self-knowledge and agency. He knows better than she does.

Our main interest at this point, however, is in the metaphor guiding the articulations of the supervisor-PA relationships, framed within specific terms of power and service, and relatedly, how these articulations connect to the fact that the notion of the ideal PA is referred to as the supervisor's "hands and feet". The reference to "hands and feet" was the metaphor most often used by the supervisors in our material when asked to elaborate on what they expected from an ideal PA. The problem with metaphors is their truth claims and consequences for action (Lakoff & Johnson, 2003, p. 157) (see also Watson et al., 2004):

Metaphors may create realities for us, especially social realities. A metaphor may thus be a guide for future action. Such actions will, of course, fit the metaphor. This will, in turn, reinforce the power of the metaphor, to make experience coherent. In this sense, metaphors can be self-fulfilling prophecies.

What is at stake is the metaphorical reinforcement of, and legitimation of, the invisible and muted position of the PA. Here, the institutionalised subjugation within the BPA scheme is key to our analyses, but the question of how this subjugation is feminine gendered reappears considering that some men occupy positions as PAs and many others take part in work-life as

subordinated subjects (Cameron & Moss, 2007). In addition to the scripting of women as primary carers at home and as undervalued earners in the market in current societies, feminine gendering concerns the positioning of the PAs' subjectivity. This subjectivity intersects with the value placed on the work itself for those employed in work as personal assistants, mostly women, with regard to knowledge and recognition (Watson et al., 2004, p. 339). The problems of recognition were seen by Hegel (1976 (1807)) and later developed by Simone de Beauvoir (2010 (1949)) through the master-slave dictum. Hegel explained the lord-bondsman problem as follows:

(..) one is the independent consciousness whose essential nature is to be for itself, the other is the dependent consciousness whose nature is simply to lie or to be for the other. The former is lord, the other is bondsman (...) for what the bondsman do is really the action of the lord (p. 115-116).

As we will show, many of the actions of the PAs go unacknowledged because their actions are seen as the actions of the supervisor. Following Simone de Beauvoir's readings of the Hegelian master-slave quandary, it is the recognition of the other's subjectivity, the woman as the other, that is under attack (Beauvoir, 2010). This not only relates to a struggle for visibility through recognition as such but also ties in with the historically situated marginalisation of women workers (McRobbie, 2009; Scott, 1999; Skeggs, 2002).

A supervisor who related a story of a friend who was seriously ill and in hospital gave one of many examples of how the "hands and feet" metaphor was put to use. The supervisor and her friends took turns taking care of their hospitalised friend. Because the supervisor had a PA, she was able to do her share, similar to the others. When we asked her if the assistant joined her in the hospital room, she replied,

Yes, she did and she [the assistant] did what I would have done. It was my responsibility to make sure that my friend was comfortable. She [the assistant] was my hands and feet.

Here, the "hands and feet" metaphor serves as a narration of the kind of service the supervisor wants in contrast to being cared for. This understanding of service, while consistent with the

rejection of repression and pain documented by the IL movement and disability scholars, ties in neatly with service as the logic of choice (Mol, 2008) (see also Bonfils & Askheim, 2014, p. 65 on empowerment and consumer choice), to which we will return shortly.

The truth claim of the “hands and feet” metaphor is that it is the PA’s limbs, not her head, that are involved in the conduct of the supervisor’s care for her friend. This implies not only a reification of the other’s body but also an annihilation of her agency, and it denies her recognition as a sentient actor (Hochschild, 1983, 2012).

Other supervisors reinforced this image of the PA as dependent on the supervisor, who is in charge of deciding both needs and priorities. This occurred even in situations in which conflict arose between the supervisor’s wishes and a common understanding of right and wrong in regard to, for example, truancy. When asked what characterises a good assistant, Roger replied,

A good PA... that is a person who is my arms and feet. Only that. I have a head of my own. If I wake up on a Monday morning and don’t feel like going to work, I won’t. I can make my own decisions.

Understanding assistance work from this perspective implies that PAs efface themselves and assume an invisible and mute position (Ardener, 1993; Guldvik et al., 2014). One assistant articulated her experiences as follows:

Yes [in many ways I have to stay invisible], and I think that this comes naturally for some people but not for others. It is not for everyone to work as an assistant. If you need to feel like the centre of attention, it can be very difficult because everything you do is on behalf of the supervisor. So, if I mow the lawn or plant flowers, I have to accept that the work is performed by me but praise is given to the supervisor, but it depends on who takes the initiative. I always cook dinner, and when the supervisor has guests over, she decides the menu, and even though the meal is cooked by me, guests will praise her and say, “you’ve made such good food”. But once she asked me what I thought she should serve for dessert, and I suggested something and made it. And when the guests ate the dessert and said it was good, my supervisor said that I had made it.

This assistant has accepted the fact that she is not supposed to be the centre of attention, and she is praised when she has been “the head” and has not simply performed tasks for her supervisor. However, balancing invisibility and activity/initiative can be a challenge. Mistakes are easily made, as several supervisors pointed out:

Yes, there are many challenging situations. When I was going through a separation, my ex-husband visited, and the assistant served him coffee. Just to be nice. She was a smart girl, so I realised that I could talk to her about it. I explained that she had crossed a line. She did it with the best intentions, but her role was not to be a hostess. It is important to raise awareness of these things.

This situation is complex and can be interpreted in a variety of ways and on different levels. The assistant served coffee to the supervisor’s ex-husband on her own initiative without the supervisor’s consent or presence. One possible interpretation, made by the supervisor, is that the assistant does as she pleases and acts as a hostess because the supervisor’s dependence on her allows the PA to do just that. Hence, the PA overrides the supervisor’s agency, challenges the power balance and signals a lack of respect (Christensen, 2012). This interpretation makes sense if the image of the PA as the supervisor’s “hands and feet” is the ruling metaphor. The PA’s job is to assist when needed and asked. That she also has to be sensitive towards, and knowledgeable about, the supervisor’s body language and specific bodily needs is not relevant here. Alternatively, seen from the PA’s perspective, the PA’s action could be seen as an expression of equality and reciprocity in relation to the supervisor. Good colleagues help each other out (Cullen, 2013). When the supervisor is not present and friends come to visit, the PA assumes the role of hostess and acts in the same way she presumes the supervisor would have acted. Continuing from this, a third interpretation could be that the assistant acted from a pure service impulse. Accordingly, she, as a subordinate, performed a service in much the same way a secretary would if the manager’s clients arrived early.

With this empirically based analysis in mind, we will move our queries regarding the tensions between service and care from Kari Wærness’ emotions-based understanding of care work to Annemarie Mol’s understanding of good care as something associated with cooperation around practicalities, grounded in mutual interest and respect.

Care work and the logic of care

Being other-oriented and sensitive towards “an other’s” articulated needs, bodily signs and gestures is often associated with care work (Christensen, 1998; Held, 2006; Tronto, 2009 [1993]). In professional care work, such as nursing and social work, one person is present in a relationship with the knowledge and power to help, support, and take care of another person who depends on this help to a greater or lesser extent (see also Twigg, Wolkowitz, Cohen, & Nettleton, 2011; Wærness, 1992). Since the late 1980s, the Norwegian sociologist Kari Wærness has been a notable thinker in deciding the content of care work and some of its inherent dilemmas. She developed a position based on an ethics of care that involved a conceptualisation of care work as action and emotion and as a kind of work that should be conducted with empathy, compassion, and even love (see also Held, 2006). Wærness’ conceptualisation of care work and the rationality of caring was also based on an important interface for service work—one of the exploitation and alienation of women’s care work and emotion work, masked and devaluated as service (Hochschild, 1983). Hence, what defines service, as opposed to care, is that service is associated with the logic of consumer choice in which relations are framed within a limited time period and freed from the consequences of interconnectedness in long-term relationships and of the realisation of interdependency (Lymbery, 2012; Mol, 2008; Payne, 2009; Reindal, 1999).

One of the difficulties in Wærness’s theorising of care work is that it prescribes exactly the kind of emotionally (over)involved care (ethics) that the disability movement and disability scholars reject (Christensen, 2012; Kelly, 2011; Morris, 2001; Watson et al., 2004). While Watson et al. (2004) have acknowledged the need to reconcile the interests of disabled people and women based on their common experiences with oppression, particularly relevant when they are forming a working relationship as in BPA, they have pointed out possibilities by theorising interdependency on the political rather than the specific relational level. Here, Annemarie Mol (2008) has offered an alternative by explicitly refraining from engaging in feminist debates on women’s paid and unpaid care work and instead setting out to explore the logic of care. Her objective is to excavate what is involved in good care rather than the logic of choice based on the assumptions of the autonomous individual, and she bases her analyses on what constitutes good caring relations between diabetes patients and health personnel (medical doctors, nurses

and others). Mol (2008) finds that good care involves practices grounded in mutual interest and respect:

Chronic diseases make life even more difficult than it already is. The logic of care is attuned to that difficulty and concludes from it that patients deserves support (advice, encouragement, consolation) (p. 29).

Good care is dialogical and practical, and Mol's understanding of good care downplays emotions such as compassion and instead emphasises collaboration around practicalities. The supervisors and their PAs are engaged in a relationship revolving around the practical needs of the supervisor in order for her/him to live a fulfilling and autonomous life. Mol is not only arguing against the logic of choice. Her understanding of good care implies an answer to the overly involved care that supervisors resist. Hence, good care is understood as a collaborative, fleeting and indecisive endeavour. Good care goes both ways, even in a professional caring relationship, and it opposes service. According to Mol (2008, p. 20) this is not because service is wrong or proposes cold and unkind relations but because service "is delineated as the product on offer" (see also Watson et al., 2004, p. 340). Care, on the other hand, write Mol is a process:

It does not have clear boundaries. (...) For care is not a (small or large) product that changes hands, but a matter of various hands working together (over time) towards a result (p. 21).

Thus, Mol warns us of the logic of commodification inherent in service, which Hochschild (1983) has problematised with regard to the alienating effects service has on the sense of self for flight attendants (see also Avril & Cartier, 2014) and for personal assistants (Hochschild, 2012). In particular, the tensions between care and service are activated when we try to articulate the competencies involved in the work of the PA. These competencies, which in our opinion are encompassed in the defining features of good care, consist of the PA's ability to exercise concentrated presence and sensitivity and to read the supervisor's verbal and bodily signals. The good "service" sought by supervisors requires and is based on a variant of collaboration and competencies that is precisely the kind of conduct associated with good care as articulated by Mol. In addition, in order to be a good PA, a PA must assume an insider position in relation to the supervisor. She must be able to think and act based on the supervisor's particularities. An assistant described her work as follows:

My supervisor needs assistance when she eats. She does not have much mobility in her wrists, so I have to assist her, and so feeding has become a habit: one bite for her and one bite for me. But it was challenging in the beginning. I mean, you have to figure out how much food you can put on the fork without it falling off, and then her mouth is a lot smaller than mine, I open my mouth wider and take bigger bites, so I had to pay a lot of attention in the beginning to how she wanted it and what she could do. After a while, you can almost read from the supervisor's body if she's hungry or thirsty or has to use the toilet; you can tell before she mentions it, and that is of course connected to the good training she gave me. When her mouth twitches, I know that she wants more to drink.

To perform these kinds of services requires the ability to attempt to see the world from the supervisor's position (see also Lakoff & Johnson, 1999ch. 4 on empathy) and to prioritise sensitivity and cooperation in relation to practicalities. Being the hands and feet of the supervisor, and not her head, seems to be an unsuitable metaphor for this work.

Conclusion

In our material, the supervisor's desire for liberation is denoted by the PA's invisibility and muteness as a provider of service. For reasons regarding both the PA's knowledge and what needs to be seen, understood and carried out at work, non-recognition of the provision of service, or care, is ethically and politically problematic (Watson et al., 2004, p. 340). Framed as service, the BPA scheme is presently at risk for establishing the PA subject position as "feminised worker", which rests on the premise of keeping oneself in the background and of being unacknowledged as a subject, and this runs counter to any feminist project of recognition. It means, in effect, that disabled people can only be liberated at the expense of someone else. Concurrently, we have asked if and in what ways the demand for service may serve as a useful corrective to the emotions based understanding of care work among some feminist care ethicists (Weeks, 2011, p. 67). Here, the display of emotions like compassion and love are seen as pivotal to the realization of good care work (Held, 2006; Wærness, 1992), which is exactly what the supervisors in our material do not want.

The traumas experienced by disabled persons in society and within the medical regimes legitimizing the “service, not care” approach to personal assistance in Norway, have been high on the political agenda in other European countries as well as in the US and Australia (Hague et al., 2010; Williams-Searle, 2008). What is at stake is the fight for recognition, to be enabled as productive citizen, and to escape oppressive, paternalistic and overinvolved care under welfare patriarchy. As earlier noted, the rights-based welfare arrangement of personal assistance has been one of the prominent results of this struggle. However, as the findings of our research have indicated, this welfare arrangement is at risk of promoting a reductionist and de-humanizing approach towards personal assistance. Hence, by dissociating personal assistance from the logic of care, BPA is opened up for being based on a young, flexible and unskilled woman who knows how to transform care into service, and who (temporarily) is willing to refrain from recognition of her subjectivity and to take on the position as invisible and mute.

This arrangement rests on a naturalized and feminized understanding of care and care work that have been opposed by feminists for several decades (Farris & Marchetti, 2017; Skeggs, 2002; Williams, 2016). Moreover, it is an arrangement disconnecting care work from knowledge and recognition, furthering the diffusion of care as feminine gendered into an already gendered labour market associated with women’s lower pay and prestige comparative to that of men (Avril & Cartier, 2014; Held, 2006; Herd & Meyer, 2002; Hochschild, 1983; Leira, 1992; Watson et al., 2004; Weeks, 2011).

If we instead place the conceptualization of care in a position based on an ethics of responsibility and cooperation (Mol, 2008), the competent sensitivity performed by the good assistant could be based on an interdependent professional ethos for the PAs, as collaborators.

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1. The project was approved by the Norwegian center for research data (NSD), and we have followed national ethical standards for research. All informants gave their written consent, and we granted their complete anonymity. The informants were also informed that they could withdraw their consent at any time, without any consequences, and we did not record any actual names or other sensitive personal information. For the NSD, see: <http://www.nsd.uib.no/nsd/english/index.html>. Accessed June 23, 2017.

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