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Perceptions of intimacy and integrity in formal home care

Föreställningar om intimitet och integritet i hemtjänst och personlig assistans

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ABSTRACT

Sweden has a long tradition of providing social care and support to its citizens in their own homes through formal home care, delivered either by home care services or personal assistance. A majority of people given support by formal home care need assistance with personal and intimate care. The focus of this interview study was on exploring care recipients', care workers', personal assistants' and care unit managers' perceptions and experiences of intimate and personal care in the context of formal home care in Sweden. In total, 57 interviews were conducted with 42 persons. Three themes emerged in the analysis: *Personal Hygiene, Personal Sphere,* and *The Contextual Variability of Intimacy*. Interviewees described intimate care as being inseparable from a person's service needs as a whole. Highlighted was how caring for and washing intimate body parts, intrusion into recipients' personal spheres, and the need to preserve integrity vary depending on situational, temporal and relational aspects. To safeguard the care recipient's influence, integrity and dignity in the reception/provision of care work, home care services and personal assistance, it is important to raise awareness of the variation in perceptions of intimate and personal care in education and inhouse training.

ABSTRAKT

I Sverige får ett stort antal sköra äldre och personer med funktionsnedsättning omsorg i hemmet, i form av hemtjänst och/eller personlig assistans. För majoriteten av omsorgsmottagare utgör personlig och intim omsorg både ett centralt och vardagligt inslag i verksamheterna. Fokus för denna intervjustudie var att undersöka omsorgsmottagares, omsorgspersonals och enhetschefers uppfattning om och erfarenheter av personlig och intim omsorg i hemtjänst och personlig assistans. Totalt genomfördes 57 intervjuer med 42 personer. Tre övergripande teman framkom i analysen; *personlig hygien*, *personlig sfär* och *kontextuell variation av intimitet*. Intervjupersonerna beskriver personlig och intim omsorg som något som inte går att separera från behovet av omsorg som helhet. Analysen visar hur intim omsorg och överträdelser av omsorgsmottagarens personliga sfär, samt behovet av att trygga omsorgsmottagarens integritet, varierar beroende på situationella, temporala och relationella aspekter. För att säkra omsorgstagares inflytande, integritet och värdighet i samband med omsorgsarbete, är det viktigt att i utbildning och inskolning skapa en ökad medvetenhet om olikheter och variationer i uppfattningar av vad som räknas som personligt och intimt i hemtjänst och personlig assistans.

KEYWORDS

Intimate and personal care; formal home care; home care services; personal assistance; integrity and dignity

NYCKELORD

intim och personlig omsorg; formell omsorg; hemtjänst; personlig assistans; integritet och värdighet

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Introduction

Supporting individuals and groups in vulnerable positions, temporarily or throughout the lifespan, is at the core of social work. In the Swedish welfare system, formal home care is the most comprehensive sector of social work, and one third of the municipalities' total budget is reserved for elderly care and care for people with disabilities (SKR, 2020), a major part of which concerns formal home care. A majority of those receiving formal home care need help with intimate and personal care (National Board of Health and Welfare, 2020).

While legislation, such as the Social Service Act (SFS, 2001, p. 453), and guidelines concerning formal home care emphasize the importance of integrity, dignity, participation and influence, these relatively abstract concepts are presented without translation to what they imply in relation to good practice when providing intimate and personal care. Such translations are left to be solved by care workers in home care services and personal assistance, many of whom work without guidance in the form of a formal education, inhouse training (Guldvik et al., 2014), or support from care managers.

In their ground-breaking work 'to deconstruct the global term "intimate and personal care"', often used to 'describe a wide range of activities, from applying cosmetics to cleaning someone after they have been to the toilet', Cambridge and Carnaby (2000a) interviewed staff at a specialist unit in a day centre and a specialist residential service for people with profound intellectual disabilities. This resulted in a classification of intimate versus personal care tasks. Intimate care was defined as 'tasks associated with bodily functions, body products and personal hygiene which demand direct or indirect contact with or exposure of the sexual parts of the body' (Cambridge & Carnaby, 2000b, p. 6). Even though personal care tasks often involve touching another person, 'the nature of such touching is more socially acceptable, as it is non-intimate and usually has the function to help with personal presentation and hence social functioning' (2000b, p. 6.). Examples given of personal care included shaving, feeding, dressing and undressing to prompting care recipients to go to the toilet.

Like Cambridge and Carnaby's work, studies on intimate and personal care have mainly been conducted in institutional settings, such as hospitals, residential or nursing homes (e.g. Clark, 2009; Inoue et al., 2006; Wilson et al., 2009), and with a few exceptions (see Conder & Mirfin-Veitch, 2008; England & Dyck, 2011; Twigg, 2000), the voices of care recipients and care workers in formal home care have been lacking – with regard to their experiences and perceptions of intimate and personal care.

As social care and support in people's own homes differs significantly from care in institutional settings, there is a need to explore what intimate and personal care imply in the context of formal home care. Therefore, it is important to also explore and include the voices and experiences of all actors included in formal home care: care recipients, care workers, personal assistants and care unit managers.

The focus of the present study was on exploring and analysing care recipients', care workers', personal assistants' and care unit managers' perceptions and experiences of intimate and personal care, within the context of formal home care in Sweden.

Previous research and theoretical points of departure

Despite the importance of intimate and personal care for people in need of help and support in their everyday lives, researchers have noted that it has long been an overlooked topic in practice, policy documents and research (Clark, 2009; O'Lynn et al., 2017; Wilson et al., 2009).

Distinctions between intimate and personal care, such as those presented by Cambridge and Carnaby (2000a, 2000b), which are mainly based on tasks related to different body parts, have also been called into question. O'Lynn et al. (2017, p. 2709, 2715) argued that the intimate cannot be reduced to only concerning sexual body parts. What is considered intimate is situational, thus

it depends on context and how such care is performed and received, as touch in other areas (e.g. the feet or back of the neck) might also be perceived as intimate. Further, as Muldoon and Kirwan (2015) pointed out, assisted intimate and personal care 'happens as part of a spectrum of care interaction' (p. 99); they claimed that what is perceived as intimate and what is perceived as personal care are intertwined. Arguing along similar lines, Clark (2009, p. 28) stated that '[i]ntimate and personal care must be seen as holistic care, not just as physical care'.

As the research on intimate and personal care to date has mostly been conducted within institutional settings such as hospitals, nursing homes and group homes, it is important to consider the differences that might be created by the settings in which home care is done. When care is being performed in someone's home, the home takes on an ambivalent status – neither fully a home nor a workplace (cf. England & Dyck, 2011; Evertsson & Johansson, 2008; Glasdam et al., 2013). As Kalman and Andersson (2014) noted, care is further challenged by the fact that ordinary homes often are not adapted to this kind of work. Because bathrooms and toilets may be very narrow, undressing and washing of intimate body parts may have to take place in very cramped spaces or in the person's bedroom or sitting room.

The challenges mentioned above have consequences for the character of care work in formal home care, and several researchers have also pointed to the relational aspects of care work. Based on an interview study with care recipients and care workers, England and Dyck (2011) described the care work relation as 'an emotionally complex and deeply power-inflected one, and unlike work relations in an institution, the home-based care work relation has a greater potential to be shaped by intimacy, affective labour and ideologies of friendship and family' (p. 217). When interviewing personal home care clients, Cranford and Miller (2013) found that both management and care recipients expected the care worker to respectfully meet and anticipate clients' individual needs by providing a relational service, motivated by relationship building. Similarly, the care recipients interviewed by Conder and Mirfin-Veitch (2008) expected the caregiver to be competent, work efficiently and be able to anticipate their needs – that is, to do so without instructions.

Several studies have shown how difficult it can be to talk about the intimate aspects of care (e.g. Kalman & Andersson, 2014; Twigg, 2000, p. 4). In contrast, national policy and guidelines seem to rest on the assumption that care recipients inform and instruct the care workers about their personal preferences in the context of daily work. Some care recipients in formal home care are not even capable of giving instructions, due to different conditions, for example dementia or other cognitive disabilities. This means that the staff, who often have received little or no formal or inhouse training, are at risk of being left to devise their own methods or coping strategies, or resort to informal exchanges of information. This increases the risk that the basic care needs of care recipients will be overlooked, and that the quality of services will be reduced (e.g. Conder & Mirfin-Veitch, 2008, p. 20). One example is given by Wilson et al. (2009), who in their study of residential care found inconsistent practices when trying to meet the penile hygiene needs of men with intellectual disabilities. Because the researchers identified 'a widespread lack of policy, training and professional guidance for penile hygiene', they (p.112) promoted education for care workers.

Theoretical points of departure

The performance of intimate care work inevitably includes a transgression of territories of the self, which might cause feelings of embarrassment and shame for both parties in the care relation.

The *transgression* of or *intrusion* into territories of the self was described by Goffman (1971) as differing modalities of violation (p. 44), including how the nature of such violations depends on the context and relations in which people interact. One intrusion mentioned is that of glances, as a 'penetration of the eyes' (p. 45), and the heightened need for eye discipline in relation to nakedness.

Regarding embarrassment, Goffman (1967) further remarked that 'ego boundaries seem especially weak' (p. 99). Heath (1986), in his discussion of medical interaction, also described the

potential *embarrassment* inherent in 'the revelation of intimate parts of the body, the feel of another's hands and the attention of his look' (p. 125), noting how 'it is the *mutual* recognition that may give rise to embarrassment – seeing another see you in a certain fashion' (p. 126, italics added). Andersson and Kalman (2017) noted how

> [t]he potential embarrassment and shame when being exposed in one's dire need of help with intimate care, and the sense of impropriety and shame generated by the act of witnessing such vulnerability, thus presents a challenge for the recipient of care as well as the care worker. (p. 223)

However, ritualised social conventions – for example, talk, gestures and the orientation of bodies – may *embed* the social capacity in which participants are present and the participation framework for what is about to take place, in this case intimate and personal care. In this way, the participants' understanding of a situation is affected (cf. Emerson, 1970; Goffman, 1981), and situations that might otherwise be defined as challengingly intimate may, by way of ritual conventions and routines, be experienced as being less so.

The juridical context of Swedish formal home care

In Sweden, formal home care is provided by home care services or personal assistance, and both services are publicly funded within the social work sector. The Social Services Act (SFS, 2001, p. 453) authorises social services for all citizens, that is, for anyone who is unable to meet their own needs or have them met in other ways, such as help with financial support, addiction and dependence, housing and support with daily living. The individual shall be ensured a reasonable standard of living, and the services shall be designed to strengthen the individual's opportunities to live an independent life. Central to services are the following core values: a life with dignity and a sense of wellbeing – values emphasized in the recommendations given by the national guidelines from the National Board for Health and Welfare (SOSFS, 2012, p. 3). Services according to the Social Services Act are to be individually adapted and shall safeguard the individual person's right to a private life as well as bodily integrity, self-determination and participation. The legislation is general in nature, which allows municipalities to design services adapted to their own demographic and financial situation.

In addition to services authorised by the Social Services Act, people with certain disabilities have the right to services according to the LSS Act (SFS, 1993, p. 387, the Act concerning Support and Service for Persons with Certain Functional Impairments). According to LSS, services shall promote equality in living conditions, full participation in society, and ensure good living conditions. One of these services is personal assistance. To be considered eligible for personal assistance, the person must have a long-lasting and extensive impairment that entails support with basic daily needs for a minimum of 20 hours a week. Basic daily needs include help such as managing hygiene and meals, dressing and undressing, and communicating with others. If the criteria for basic needs are met, the person can receive assistance with other personal needs (household duties, leisure activities, and assistance with work or studies) if these needs are not met in another way.

Method and material

The present study is based on semi-structured iterated (1-2) individual interviews with care recipients and care workers, as well as on individual or group interviews with care unit managers working in formal home care. Apart from personal details, the themes addressed in the interview guide were focused on the interviewees' perceptions of intimate and personal care, and their experiences of receiving/providing care. The interviewees were recruited from three larger cities in Sweden. In the recruitment process, it was explicitly stated that we hoped to obtain breadth and variation in

interviewees regarding years in service and length of reception of services, as well as variation in participants' gender, ethnicity and age.

Directors of home care services and personal assistance were informed about the study. Then, at staff meetings, researchers informed the staff and handed out information letters. Attached to the consent forms were an envelope with prepaid postage, the goal being to ensure voluntary participation and anonymity. Different services were separated with regard to what group of participants was recruited: in some care units, the question of participation was directed to care workers, while in others, the care workers were asked to hand out the information to care recipients. This strategy was established to prevent a feeling of unease that might emerge if participants thought their mutual relation of care was being scrutinised. To safeguard confidentiality, staff were asked to distribute information letters to clients who were expected to be able to partake in interviews on their own. Furthermore, we asked them *not* to hesitate to distribute the information letters to clients who were dissatisfied with the service as well as those who were satisfied – as our study was not focused on evaluating individual care units. In a late stage, the recruitment process was supported by a recipient of personal assistance, who handed out information sheets in his/her broad network.

The interviews were conducted during 2019–2020, to begin with in personal meetings and later, due to Corona virus restrictions, via Zoom or telephone. All interviews except four were recorded. The average duration of the interviews was 33 minutes (12–94).

In total, 57 interviews were performed with 42 persons (see Table 1): seven recipients of home care services (RCWs), six recipients of personal assistance (RPAs), eleven care workers (CWs) in home care services, nine personal assistants (PAs), and nine care unit managers working in home care services (MHCS) or personal assistance (MPA). All interviewees were well experienced with the reception/provision of care. The age interval among recipient groups varied (RCWs: 39–92; RPAs: 40–66).

Analysis

The analytical approach was partly inductive. The transcribed interviews were read through by all four researchers separately. In iterative rounds of readings notes, keywords and codes were compared and discussed, and categories and themes worked out jointly. Critical, typical or otherwise qualitatively salient situations were then highlighted and analysed in light of earlier theorising and research (cf. Creswell, 2014, pp. 197–200).

Ethical considerations

The present study was approved by the Regional Ethical Review Board in Umeå (Reg. No. 2018/363-31). Participants received oral and written information in advance, and consent was obtained. Their voluntary participation was stressed, as was the possibility to redraw their participation at any time during the interview or later.

Table 1. The number of interviewees and interviews.

	Individuals	Interviews
Recipients of home care services (RCWs)	7 (6 women, 1 man)	14
Recipients of personal assistance (RPAs)	6 (3 women, 3 men)	11
Home care workers (CWs)	11 (9 women, 2 men)	13
Personal assistants (PAs)	9 (8 women, 1 man)	12
Care unit managers:	9 (5 women, 4 men)	7
(In home care services: MHCSs)	(2)	(3)
(In personal assistance MPAs)	(7)	(4, whereof one was a group interview)
In total	42	57

Results

When participants were asked to reflect on the questions 'How would you describe intimate and personal care?' and 'What would you say counts as intimate and personal care?' their descriptions covered a broad range of different aspects of what, in their view, intimate and personal care implies. The responses to these questions from all groups of interviewees largely coincided. The only exception was the descriptions of care conducted in public. Because people receiving HCS seldom leave their homes in the company of care workers, neither RCWs nor CWs gave any descriptions of these challenges.

Many described intimate care as something natural that simply has to be done. It was further referred to as something that cannot be separated from the person's need for services as a whole. Answers reflected issues such as caring for and washing intimate body parts, the intrusion into the recipient's personal spheres, and how the need to preserve integrity varies depending on situational, temporal and relational aspects. This will be further explored and described by the three themes that emerged from the analysis: *Personal Hygiene, The Personal Sphere,* and *The Contextual Variability of Intimacy*.

Personal hygiene

When reflecting on intimate and personal care, the first responses from most participants considered situations that included concrete actions related to personal hygiene, such as helping after toilets visits, support during showers or bathing, brushing teeth, and managing catheters or other sanitary and incontinence aids: 'It's of course the lower abdomen and all that'. (RCW4)

The unveiled body and the vulnerability of being exposed were emphasized, as was the need for help with things most wish to do in private.

> Situations when one must go to the toilet, take a shower and these things, I would say. Because you're often more than normally undressed on these occasions. (RPA4)

The worst and most intimate of all, is when I've been using the toilet and pooped and I'm in need of help. (RPA6)

Another common feature was the use of euphemisms such as: 'the lower parts', 'down there', 'number two', 'tired stomachs', 'stomach was alert', which might illustrate the difficulty of talking about the intimate, but also be part of a ritual convention that eases potential embarrassment on the part of both parties. 'It feels more intimate to change a diaper and to wash "down there" than to help out with clothes' (CW6). As shown in this quote, comparisons were sometimes made to describe differing levels of intimacy or challenges in relation to intimate and personal care.

> Brushing someone's teeth, I find a bit so. Whereas shampooing hair and such, not really. But feet, on the other hand, that feels intimate […] Then there might be emotionally intimate things as well. (PA3)

> Yes, for the most part, everything flows well. However, I've found such a thing as getting help with blowing one's nose difficult. […] Furthermore, it's something that's difficult to help others with, as we have different ways of blowing our noses. (RPA6)

Another way of comparing was when CWs and PAs made reference to themselves: 'It's something you think yourself … Something I do by myself and want to be left alone doing' (PA2). The ways in which overarching questions of privacy and integrity are connected to the provision and reception of care will be explored in the next section.

The personal sphere

When intimacy was connected to 'the personal sphere', it was often described in terms of thresholds or personal boundaries that were crossed. From the more obvious physical thresholds of, and in, someone's home, to the more fleeting dimensions that accompany the provision of care work in a person's social, emotional and relational life.

> At first, I was only thinking about when you touch the body and sensitive parts of the body, but as we are speaking, then what I feel is the most intimate is being in someone's home, which is almost like an extension of one's body. Here you see their atmosphere and things, it's intimate, the way I handle their things in general. (PA4)

Entering 'somebody's home, somebody's private place' (CW5), or having someone enter one's home, involves the crossing of a border that is seen as both intimate and personal. Nevertheless, the home is simultaneously a private place and someone else's workplace, which constitutes a challenge for staff. The ways in which homes were entered, with their ambivalent status as homes/workplaces, were often described as connected to the possibility of creating a good working relation for both parties.

> No, and I think so, it's a hard thing … and here I'm thinking for the staff; 'does anyone live in my workplace, or do I work in someone's home?' That you actually have to keep in mind that this is not my home I'm entering right now, but I actually have to relate to the fact that this is another person's home that I have to enter. I have to knock if the person wants that, and I should just go in immediately if the person wants it that way. All these little things help us create trust, and that they want us there. It can go very wrong if I thunder in the first time; then that trust is broken. (MPA-group)

Even for someone well experienced in receiving formal home care, awareness that the home per se represents a boundary of intimacy might not become obvious until this threshold has been crossed unexpectedly:

> For instance, the time when they entered [my home] without having announced their arrival, and I had to back off. At the time I was surprised to find that to be intimate – because I had never before felt it was intimate when people entered my apartment. Otherwise, I've always associated intimacy with somebody touching me, or me being naked in front of somebody who is dressed and with whom I have no relation, that is, somebody who is working. (RPA6)

The doors to the bathroom and bedroom represented other boundaries. One recipient of home care services explained not only the importance of physical thresholds or doors being connected to differing levels of integrity, but also pointed to certain temporal aspects of these thresholds. In her case, this was connected to the need to have come to a certain point *in her own morning schedule* before encountering the staff, and *where* they meet:

> Because otherwise it feels like they have come too close and come too close to my integrity. But it's another thing if they stop a bit outside the bedroom door and don't look, but ask 'do you want your sandwich, or how was it with the other thing?' … That they knock on the door of the bathroom and say 'Hi, I'm here now, and I was thinking of this and that … '. That feels good as well. It's the fact that they don't open the door to the bathroom and just … , and that they don't look into the bedroom unless one has prepared for them to come in. (RCW7)

Performing care work in someone's personal sphere thus inevitably includes being present and needing to navigate in relation to that person's social, relational and emotional life: [Sometimes] 'you get to know things even though you don't want to know, really … That's something I can think of as intimate' (PA7). The 'intimate' thus includes relating to conditions such as mental ill health, sadness and problems within the family.

> [W]hen they're sad and thinking about suicide, and sometimes due to their children not coming to visit. There is a longing in them, you have to be with them and listen – that goes a long way. To give them a pat, there is no need for words. (CW7)

> Yes, that there's always someone in your home. That you may never be able to express your feelings. […] Because if you think of yourself, then maybe you don't want to show everyone the whole emotional register to people around you. At my workplace, for example, I might never be sad, but I can be that at home, in solitude. They [care recipients] have a difficult situation. And it's also difficult to work with these people, it's not always easy to know how to interact. (MPA2)

For the care recipient, as well, there is the need to deal with what the care workers present of their personal and private lives, and this information might be experienced as a burden: 'I don't like it

when they talk about their own … I have my own things to deal with' (RPA1). The overlapping of the care providers` and care recipients' personal and private spheres, however, is not necessarily experienced as burdening the relation. On the contrary, glimpses of the other person's life may be appreciated and be part of relationship building: 'Some people find it strange that I relate to my assistants as my friends. But I really like them – even though I know they have a life of their own when they're not with me' (RPA6).

Part of respecting the personal sphere was for care workers to try to see the home as it is perceived by the care recipient, such as the need for a certain level of tidiness, to anticipate what might bring comfort and to foresee possible discomfort, for example the smell if the waste has not been taken out.

At the same time, the perception of an investigative eye on one's home might be felt as an intrusion. One care recipient reflected on her experience of other women's perception of her home:

> But it's also interesting to note that when I have had men helping me, it has felt much nicer because they have another way of helping that feels very relaxed, sort of … I wonder if it has to do with masculinity and femininity, because they [the men] don't check on the state of the kitchen sink in the same way … The feeling I get at times is that women who enter think 'oh dear, the state of this kitchen … '. (RCW7)

The organisational requirement to ensure that the performance of care is adapted to the individual, through detailed instructions regarding needs and preferences, represents another aspect of the far-reaching exposure of the person in need of care.

> And there it's also a question of some kind of integrity: 'this is too intimate for me to have it written down'. You don't want it to be written down anywhere, all my preferences – that would be difficult. (MPA group)

To sum up, in their reflections on the intimate, both receivers and providers of intimate care often included a lot more than the presence of unveiled bodies in need of being washed and taken care of: 'It's not how much one has to disrobe, but in general how much you have to expose yourself to another human being' (CW4). There was variation between individuals in their perceptions and experiences of the personal sphere, and these differences were shown to be connected to aspects of time and space.

The contextual variability of intimacy

What is perceived to be intimate or personal was generally found to be strongly connected to contextual aspects. As *spatial* and *temporal* aspects varied, so did the perceptions and boundaries of the intimate and of relations, which brought on different challenges with regard to integrity and dignity.

Space – private and public

Levels of threat to integrity were often connected to whether intimate and personal care was received in one's home or in public: 'It's tough, especially in a public space, if you're being fed. That is hard. But it's one of those things that I can manage today that I couldn't at the beginning' (RPA6). The differences described here stem from the responses of people receiving personal assistance, because people receiving home care services seldom leave their homes in the company of care workers. These situations also reveal the importance of the relation between care recipient and care worker.

One recipient of personal assistance gave a telling description of the ways in which the assistance might function as true support or be an inconvenience that actually gets in the way of one's full and unhindered participation in social events.

> Whether I'm fed at home sitting at my kitchen table, or whether I'm fed at IKEA or while sitting at a Nobel prize dinner – it's the situation that determines how I feel. And it's how this person beside me, how natural s/he carries her/himself in this group, that is almost … Let's say I'm attending a wedding, and then this person behaves awkwardly and simply doesn't function in a room, that spoils it all for me. […] I want the person to eat with us, partake in the conversation, and get on with the group. (RPA3)

For the PAs, as an effect of the spatial variability of the personal sphere, the need to foresee possible events and anticipate the person's needs is heightened:

> You make sure to bring a change of clothes … Yes, and to bring some kind of bag for vomiting, if that should happen. And if it should turn out like that when you're out and about you can find a lavatory and fix it. […] It's trying for the person it happens to. But, to work preventively as well, because *that* is more important than taking care of it when it's already happened. (PA7)

Here, the change of location, a spatial aspect, was shown to amplify an anticipatory dimension – thereby constituting a *temporal change* in the character of care work itself.

Temporal aspects – changing perceptions of intimate care

Temporal aspects are also present in gradual and lasting changes in health, abilities and in the care relation itself. As the need for help increases, earlier boundaries might have to be dismantled.

> It was a step to take when one needed help with wiping oneself … I couldn't do it the way I used to. Then it was … well, this is what one has to accept. Whatever it is you have to accept it. […] There are several steps. It's one thing if it's something I could ask a man in the street or my colleague at work to do … Use that as an example: if I can ask my colleague for help with it, then it's not that intimate. (RPA5)

Care workers, on their part, described the challenge of helping people let go of their boundaries. For example, they talked about the gentle coaxing needed to enable somebody to accept help with showering – something that in certain cases might take weeks and even months, and that relies on the capacity to build a relation: 'Time is important … Then you make a renewed attempt, until you succeed. You have to be able to get to know that person' (CW7).

> Some of them even find it belittling to need help with intimate washing – something they have been able to handle all their life. […] Yet, once again you ask the person what help they need, and you try to respect that person's personal sphere and space for self-determination. (CW5)

Another aspect is how temporal changes depend on whether, and if so how, the care relation has evolved in terms of regularity, knowledge about the person and how to get along with each other.

> I want as few as possible, because then you might come as far as to this wordless talk. You get to know each other if you are together often, you get to know the other as a person. I would like the care worker to share this and that. Not that they should be too private, but more personal. Like 'how are you today?' 'How was it last week?' That you can continue a conversation or that I remember that you were going to your cabin. Such an atmosphere! Then I dare to ask for more things. Help with other things and stuff. (RCW7)

When the participants have known each other for a long time and have established routines, it might also be difficult for the care recipient to ask for some things or to alter a routine.

> … when you've been to her a few times, I don't ask as often. I sometimes feel that I should ask more often – otherwise she may not dare to tell me that she wants me to wipe in some other way in the toilet. […] The more we become friends she and I … We have a lot to talk about and it might be harder for her to ask me for specific things. When you have a relationship like that, you may not want to be a burden. (PA4)

What is considered intimate and personal varies depending on spatial and temporal aspects of the context. The spatial aspect concerns whether care is performed or received in one's home or in public – and in what kind of public space. The temporal aspects affecting care included, for example, managing an increasing need for support and being able to create, sustain and navigate a good working relation over time.

Discussion

In the present study, the focus has been on the perceptions and experiences of intimate and personal care in the context of formal home care – on the part of care recipients, care workers, personal assistants and care unit managers. In the varied and reflected descriptions of situations, actions and

attitudes pertaining to transgressions of the care recipients' intimate and private sphere, abstract concepts such as respect, integrity, dignity and self-determination were substantialised. The breadth of and variation in perceptions of what is intimate and personal are important to be aware of in the provision of care (cf. Guldvik et al., 2014; Wilson et al., 2009), and generally in social work with people in vulnerable positions.

The concepts of 'intimate care' and 'personal care' were often used in conjunction – which they were in our interview questions as well. The accounts of intimate care ranged from concrete actions concerning personal hygiene to such care being an integrated part of a larger whole, as well as a fact of life. Interviewees often chose to use euphemisms or made indirect comparisons with less intimately sensitive situations or less intimate body parts. This can be interpreted as a ritualised social convention used to avoid verbal exposure of intimate body parts in an effort to ease potential embarrassment (cf. Heath, 1986, pp. 125–6; Kalman & Andersson, 2014). Descriptions of the difficulties of having to transgress territories of the self were not, however, restricted to situations of nakedness and sexual body parts (cf. Goffman, 1971, pp. 44–45). Other body parts, such as the nose or mouth, were at times considered to be more sensitive, as was the need for emotional privacy. When 'personal care' was used solely, however, it mostly referred to holistic accounts of care. But generally, most informants characterised the intimate and the personal in care work as being inseparable (cf. Clark, 2009; Muldoon & Kirwan, 2015; O'Lynn et al., 2017).

There was pronounced contextual variability in what was perceived to be intimate and personal. How levels of intimacy and the need for preserving integrity were experienced varied depending on spatial and temporal contexts as well as relational aspects (cf. Twigg, 2000, p. 77).

An important aspect of the intimate was represented by the lived 'personal sphere' of the care recipient. This included different modalities such as: the physical home, as demarcated by exterior and interior thresholds (cf. England & Dyck, 2011, pp. 211, 217); and the home as perceived by the care recipient with regard to appearance, smell and tidiness. The 'personal' was also a movable sphere. Situations in which dependency and the need for help were exposed in public were experienced as highly sensitive. This spatial aspect also concerned what kind of public space was at hand. Providing support with eating at social events puts greater demands on the personal assistant to act in a way that truly facilitates full participation in a context where personal dignity is especially desired.

The temporal aspects included, for example, managing an increasing need for help and both parties being able to create, sustain and navigate a good working relation over time. The importance of time and timing was evident: *time* for the participants in the care relation to get acquainted, *time* for embedding the social capacity of participants in the care relation at hand and *time* for working out and applying routines (cf. Cranford & Miller, 2013; Tufte & Dahl, 2016); *timing* in relation to the present state of the care recipient and her/his needs. The temporal dimension is intertwined with spatiality, as shown in the example of care workers arriving to the care receivers' home unexpectedly 'off-time', which was experienced as intrusive.

Seldom discussed in the literature are the oral and written instructions guiding care workers, sometimes to ensure that certain actions are performed, sometimes to even out the differences in different care workers' performance. Some care receivers experienced this as positive because it assured them that everything (from medication to being laid in a certain posture) would be done properly, whereas one of the care managers reflected on how intrusive such instructive lists of personal preferences and difficulties can be perceived.

As noted earlier, the intimate is generally experienced as a sensitive subject. In the present study, the opportunity for interviewees to focus and actively reflect on intimate and personal care was much appreciated and referred to as a valuable experience. In some cases, the interviewee had reflected a great deal on the topic beforehand, whereas others delved further into the topic during the second interview. As a result, we benefited from the interviewees' rich and nuanced reflections on this central function of formal home care.

If we are to develop practice that considers how to safeguard integrity and self-determination in intimate and personal care in the context of formal home care, further studies are needed. Such studies should focus on the active and conscious strategies chosen by care recipients and care providers when they are trying to manage the challenges of the intimate.

Limitations

We aimed to obtain variation in years of experience and in the participants' gender, ethnicity and age. This aim was largely fulfilled, with one exception: all interviewees were experienced with the reception/provision of care, which probably made it easier for them to participate. As this is a sector characterised by large staff turnover, it would be of interest to focus a similar study on the experiences of care workers with little experience in relation to their decisions to leave, or to continue, work in formal home care.

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