Managing the body work of home care

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Abstract

Body work is a key element of home healthcare. Recent restructuring of health and social care services means the home is increasingly a key site of long-term care. While there is a growing literature on the social dynamics between care recipients and their family caregivers, less is known about the formal work dynamic between paid care workers and care recipients and family caregivers. Drawing on interview data from an Ontario-based study of long-term home care, we explore how body work is negotiated through the embodied practices of care in the home and through care relationships associated with home care. In particular we focus on how the practices of intimate body care (such as bathing, toileting, and catheter management) show the diverse dynamics of care work through which caregivers, care recipients and homespace are constituted. We argue that the practices of care are shaped by a complex interweaving of regulatory mechanisms associated with home care along with the physical and affective dimensions of intimate body work. In turn this suggests the need for new ways of understanding body work in contemporary landscapes of care.

Keywords: body work, home care, embodiment, relationships, space

Introduction¹

I’m an attendant. We do anything the client needs to have done. It’s very different, varies from client to client, it’s mainly personal care. So everything – you get them up, dressed, showered, bed bath, catheter care, bowel treatment, anything; shaving, whatever the person needs (Alexa, attendant of Sarah, who has MS).

Alexa, who works for a non-profit, publicly funded home healthcare agency in Ontario, was responding to a question about what sorts of tasks her job involves. As an attendant providing personal care, Alexa’s occupation can be categorised as body work – jobs that involve intimate work done directly on other people’s bodies. Alexa travels to her clients’ homes to provide that care. Sarah is one of five clients Alexa cares for over the course of a week. She sees 50-year-old Sarah three mornings a week for two hours.

At various points during our lives we are each dependent on the care of others. For many, that dependency comes with old age, chronic illness or disability. In some instances, the care is provided by a family member or a friend; in other cases, it comes from a paid care worker such as a Registered Nurse (RN), a Registered Practical Nurse (RPN) or a Personal Support Worker (PSW). Sometimes, the care is given by a combination of both, as is the case with Sarah, whose primary caregiver is her husband, Andy, and in addition to Alexa, is visited by
Celia, a PSW, and Sandy, an RPN. Glenda and Robert are also in Ontario’s home care system, they too are cared for by family members and paid care workers. In this paper we draw on the experiences of these three care recipients, their family caregivers and their paid care workers in our exploration of the management of the material micro-practices of body work and care relationships in home care. Recent extensive restructuring of health and social care services means the home is increasingly a key site in the landscape of long-term care and is a space where meanings of both home and care must be negotiated. Our emphasis on the intimate care of the body points up the diverse dynamics of care work through which caregivers, care recipients and homespace are constituted.

In the first section of the paper, we discuss the conceptual framing. We then provide contextual material on the restructuring of home care in Canada, where the study on which we report was conducted, and we describe the study methods. The main themes emerging from the qualitative data are discussed in building our analysis of the active co-constitution of body work through the dynamics and management of the caregiver/care recipient relationship. We argue that the micro-practices of care in the home are shaped by a complex interweaving of regulatory mechanisms associated with healthcare reform and the affective dimensions of intimate care, which suggests the need for new ways of understanding body work in contemporary landscapes of care.

Care as body work

As Diemut Bubeck (1995: 160) states, ‘Care is a deeply human practice’. Each of us will receive and provide care over the course of our lives, and human life is deeply implicated in the inter-dependence of people who need and give care. There is a burgeoning literature on theorising and expanding the concept of care, including using it as a broad framework for making moral, political and policy decisions (see for example: Tronto 1993, Sevenhuijsen 1998, Kittay 1999, Held 2006). In this paper we use ‘care’ to describe the varied activities associated with the daily care of the elderly and people with illnesses and disabilities, following Bubeck’s definition of care. She opts for a ‘restrictive definition of care as an activity’ specifically ‘meeting the needs of one person by another person where face-to-face interaction between carer and cared-for is a crucial element of the overall activity and where the need is of such a nature that it cannot possibly be met by the person in need herself’ (Bubeck 1995: 129). She intends her definition to capture ‘the more active and face-to-face aspects of care’ including activities such as feeding, washing, lifting, and cleaning up the incontinent. Given our focus on the daily body work associated with home care, Bubeck’s definition captures key elements of our conceptualisation of body work: face-to-face interactions, the relationality of care and the provision of care to those who cannot perform those activities themselves.

In our analysis of this type of labour we address what Carol Wolkowitz (2006: 147) describes as ‘employment that takes the body as its immediate site of labour, involving intimate, messy contact with the (frequently supine or naked) body, its orifices or products through close proximity’. In this category of body work the focus is on the physicality of bodies. Michael Fine (2007: 171) argues that ‘recognition of the body and the precarious vulnerability of physical life provide a powerful conceptual tool with which to explore the central place that issues of care occupy in human societies’. However, the body’s physical vulnerability also needs to be understood within a conceptual framing which recognises the creative capacity of the human subject; as Grosz (1994: xi) has argued, ‘bodies are not inert, they function interactively and productively. They act and react’.

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In intimate body work the caregiver’s body is the direct apparatus of care (Twigg 2002). In recognizing the interaction of bodies (of caregivers and care recipients) in the production of lived experience, we are able to observe processes whereby powerful discourses concerning care are embodied in day-to-day encounters, such as those involved in home care. We find the lens of embodiment useful to our analysis: thinking about care from an embodied perspective, focuses on the experiential lived body (Twigg 2000, 2002, Wolkowitz 2006). For instance, in her study of the ‘dirty work’ of dealing with excrement in a mental hospital, van Dongen (2001: 205) notes nurses ‘disgust and contempt in relation to body wastes and care’. The affect (in this case, negative emotions) and power-laden relationship of care become particularly intense around the ‘leaky body’. Although experiencing disgust, van Dongen found that nurses, drawing on their professionalism, do not blame patients and ‘believe that even when cleaning, social, intimate contact is necessary’ (2001: 209). In the hierarchy of jobs within the hospital, those doing this close, dirty work carry lower status. Of interest here is van Dongen’s analysis of the ‘open’ body (that leaks and ‘fails’) as placed appropriately in the hospital or the home, the latter representing private space where orifices and their leaking are a ‘matter of care and intimacy’ (2001: 208).

The hierarchies in the organisation of intimate body work, its commodification in formal care provision systems and the overlapping of, or empirical distinction between, ‘caring for’ (task-oriented, physical labour) and ‘caring about’ (relational, therapeutic emotional labour) all come together in the complex material and discursive fields making up the contemporary landscape of home care (Tronto 1993, Grant et al. 2004, Theodosius 2008). The site of the home blurs the conceptual distinction between ‘caring for’ and ‘caring about’, and Yeates (2004: 371) notes that the former refers to the performance or supervision of tasks, whereas the latter points up the ‘perspectives and orientations, often integrated with tasks’, and might include, for example, listening to someone’s troubles and comforting them. At the same time, processes and policies associated with the neoliberal climate within which care is constructed reach deep into the actual practices of body work and the social practices of caregiving (Twigg 2002). In the rest of the paper we turn to these practices, first briefly discussing the contextualisation of the study in the national and regional framing of home care practice, its methods and data.

The study and its context

Home care in Canada is not covered by the federal Canada Health Act that regulates the provincial and territorial health insurance programs. Instead the provinces and territories determine the contours of formal home care provision in their jurisdiction, leading to variation across the country regarding eligibility and the extent and nature of home care provision (Coyte and McKeever 2001, Armstrong and Armstrong 2003). Ontario used to deliver home care primarily through the public sector, but in the mid-1990s introduced new public management techniques. Home care was restructured around a process of competitive bidding for contracts from service providers in the non-profit and the for-profit sectors. This was later accompanied by restricting eligibility, delisting some services and rationing hours of publicly funded home provision (England et al. 2007).

The restructuring of home care occurred within broader healthcare reform involving hospital closures, and releasing patients sooner to save money. Shorter hospital stays and faster discharges reveal cultural assumptions about home and a strong normative expectation that a network of family and friends is able and willing to step in to provide care at home. Shifting financial responsibility for care onto individuals may be potentially cost-saving from...
the perspective of the province, but the families often end up paying for supplies and services 
that would be included if the same care was in a hospital or nursing home. Home care reform 
has meant more and different work for workers and increasing the workload of family 

Our analysis draws from an ethnographic study and quantitative survey of clients from 
across Ontario who had received publicly funded long-term care services. The project 
explored different dimensions of this landscape of care. The ethnographic research dealt with 
17 home care recipients and their paid care workers and family caregiver (if they had one). 
The clients, family caregivers and paid care workers were interviewed separately and were 
asked about various aspects of their experiences with long-term care provision. The material 
arrangements of homespace were described and photographed. All the care recipients in the 
study were clients of service providers contracted by one of three Community Care Access 
Centers (CCACs) across Ontario. The paid care workers were allocated by organisations that 
won contracts paid for by the province via the CCACs. Data from the study as a whole 
inform the themes discussed, but we focus here on the cases of Glenda, Sarah and Robert, 
whose care arrangements are particularly useful in tracing divisions of labour in body work 
and exploring how social policy plays out within dominant discourses of ‘family’ and paid 
labour. We draw on data from interviews with the three clients, four interviews with family 
caregivers and seven interviews with paid care workers (nurses, personal support workers and 
attendants).

Glenda, aged 82, is housebound and suffers from diabetes and arthritis, but is dying from 
lung cancer. She needs an oxygen tube and carries the oxygen tank on a pulley. Glenda lives 
with her daughter, Donna, and her son-in-law, Ben. Her daughter is listed as Glenda’s 
primary caregiver, but Donna is also ill (with cancer) and is frequently bed-bound. So in 
practice, Glenda’s son-in-law (who works full time as a teacher) provides most of the care, 
not only for his mother-in-law, but also for his wife when she is less well. A neighbour is also 
involved in Glenda’s care arrangements. Sarah is aged 50 and has had Multiple Sclerosis 
(MS) for about 13 years and, while she needs a wheelchair, she is not housebound. She lives 
with her husband, Andy. Her paid care workers include Celia, a Personal Support Worker, 
Registered Practical Nurse Sandy, and Alexa, who is an attendant. The homemaker Celia is 
scheduled to work one hour each weekday with Sarah, but sometimes other workers do the 
shifts. Sandy, the RPN, visits Sarah approximately every third week (primarily for 
catherisation and assessment), and Alexa, the attendant goes in three times a week (other 
attendants go in the other days). Robert is 69 years old and he was diagnosed with MS about 
six years earlier. His wife, Diane, cares for him, and the paid care workers include PSW, 
Maggie, and Gina, an attendant. Maggie is there two evenings a week, and every other 
weekend evening for an hour. Gina visits Robert five mornings a week for 1.5 hours, two 
weekday afternoons for 30 minutes and a morning every other weekend.

Constituting care: body work as social and material practice

The data provided by the clients, workers and family caregivers in the three cases 
demonstrate the complexity of constituting care, a process that emerges from an interweaving 
not only of discursive understandings of family, homes and bodies, but also of policy and 
professional practice guidelines. Care is constituted through the interactions between 
particular bodies in the carrying out of care and, following Bubeck, the less tangible human 
dimension of care – one imbued with therapeutic emotional interpersonal labour. In home 
care, the client’s home is both a workplace and private domestic space which in turn sets
particular conditions under which care is provided. We consider this care space and then go on to themes emerging in the data that pertain to the negotiation and organisation of specific practices of body work.

The home is a workplace and domestic space
While the increased use of home care fits into the neoliberal frame of cost-containment and shorter hospital stays, it is also embedded in a discourse of being the preferred option, reiterated by care workers and family members. Nurses have long advocated more home-based rather than institutional long-term care. Their work keeps people in their homes for as long as possible. Sandy (Sarah’s RPN) commented, ‘I think it’s just so great to be able to go and see people at home and they’re in their own environment and it’s comfortable for them and it’s great’. And Shirley (Glenda’s RN) remarked ‘elderly people that I’ve been seeing for years and years, they see you as the person that’s trying to keep them at home. You’re the one who’s really trying to not have them go to a nursing home’. The clients and family caregivers also valued home-based care, indicating gratitude that this was possible. Donna, for example, facing the impending death of her mother said:

We’re quite aware of what the future will bring. Ahm, me, but I think she does too. We both know. I’m very, VERY thankful that we have had this time. Thanks to the system, we have gained time that we would never have had and I’m very fortunate.

In contrast with institutional sites, the home as a site of care is a private space, embedded with personal and symbolic meanings. It is this dimension of home care that illuminates the distinction of the body as an object of care and the body as self or social being. The conceptual distinction between ‘caring for’ (task-oriented physical labour) and ‘caring about’ (relational, therapeutic emotional labour) reminds us that care work that is ‘caring about’ is not readily commodified, in contrast to the more measurable tasks of ‘caring for’ (Grant et al. 2004). Yet, empirically, in the case of body work in the home, we might anticipate, as Wolkowitz (2006) comments, an overlapping of the two and variations in how they are combined. When body work occurs in the personalised spatial context of the home, it becomes more difficult to reduce the client to a mere physical entity. The care workers and the clients are, of course, brought together because of the client’s need for body work. While, from a social policy perspective, this might merely be a work relation based on ‘caring for’ the client’s body, in practice it is often one that is infused with emotional labour that inflects the care relationship. When asked to describe her relationship with Glenda, for instance, Laurie (Personal Support Worker) replied ‘She’s just like a grandmother to me. I can laugh with her, I can joke with her, I can cry with her’. Sometimes care workers linked the ‘caring about’ aspect of their job to the home as a workplace:

I do prefer it, though, because it is more personal, you get to know people but I mean you’re not buddy-buddy, but you do, you have more time to talk, and you can work more according to their needs and respect (them) (Alexa, Sarah’s Attendant).

The therapeutic emotional dimension of care transfers into how tasks are enacted. Maggie (Robert’s PSW) captures this as she describes the sort of work she does:

Each person has their own little thing that they want done. It could be something special like rubbing their back or making sure their feet are elevated enough that the heels don’t
rub on the sheet. Ahm, making sure that they have pads underneath them in case they are incontinent.

In Robert’s case, Maggie has noticed and responded to his discomfort around wrinkled sheets. She visits him in the evenings to get him ready for bed.

I make him feel comfortable. If there’s the least little wrinkle under him, he’ll let me know. And so you go back and fix whatever the problem is because you don’t want somebody to be uncomfortable (Maggie, Robert’s PSW).

Homes, however, are not designed for home care, and care workers encounter a wide variety of homes. Shirley (Glenda’s Registered Nurse), for example, estimated that she has about 30 clients, so in effect she has 30 different workplaces. Across all the cases in the project, conditions varied from small, cluttered urban apartments to large suburban or rural single-family dwellings. Glenda, Sarah and Robert all live in single-family homes, Glenda and Robert’s in rural villages and Sarah’s in a suburb. Sarah and Robert’s homes have been modified to accommodate wheelchair use and all three provide good working conditions for the care workers. The bedrooms and bathrooms of the clients are the most common spaces for providing intimate physical care of the body, the open, ‘leaky’ body – touching, lifting, undressing, giving enemas, changing catheters. Thus, this work transgresses the boundaries of ‘normal’ social interactions both in relation to bodily boundaries and in the use of ‘private’ homespaces. Respect, individuality, being mindful of their client’s privacy (within their home, but also at the scale of the body) and treating their clients with dignity were common themes in interviews. Sensitivity to ‘invasion’ of the home was talked about by several workers, who elaborated on how they tried to mitigate this:

When I first started this job our case manager was very ahm, strict and she made it very clear [...] we were to consider ourselves like a guest in their home and that we had to respect what they wanted done; and if there were things–like if they really didn’t want a bath, if they didn’t want certain things that we had to respect that (Shirley, RN for Glenda).

Nevertheless, the shift of homespace also to act as a workplace does have an impact on family caregivers’ use of their own homes. Ben (Glenda’s son-in-law) remarked, ‘I’m rarely here when they are. I just try to keep out of their way’. He accepts that at least for the time the care workers are in his home, it is transformed into a paid workplace. Parts of the home might be changed because of equipment in the home (patient hoist devices are a case in point) or a stream of care workers coming through the house over the course of a day. Robert’s bedroom is on the ground floor and his wife, Diane, lamented that in the evenings ‘the living room is no good to me now’. She moved the TV upstairs to her bedroom, because the paid care workers’ visits were an interruption. ‘Yeah, that’s what’s gone for me, is my privacy in my house. And there’s people coming and going pretty well all day long’. Household routines may also be adjusted to accommodate the care workers. Diane changed her morning routine: ‘I don’t want to interfere with the worker ’cause she’s only got so much time and I don’t want her having to wait while I get out of the bathroom’. In Glenda’s case, Donna (daughter) makes sure she is available if a worker needs to speak to her. She and Shirley (RN) spend a good deal of time reviewing Glenda’s condition and her medications to make sure the balance is right. Shirley commented:
When I go in I usually check (Glenda’s) vital signs, listen to her lungs, her blood sugars, see if she has had bladder infections. Usually I talk to Donna about the oxygen. I’m finding I’m having to check with Donna about more things because I don’t find that Glenda’s, ah, cognitive function is quite as good as it used to be.

Both family caregiver and paid care worker have similar goals in terms of the care of the care recipient, but their own experience of the same material space is tempered by the tension emerging as the meaning of home is re-worked when it is also enacted as a paid workplace. In addition, as we address in the next sections, the practices of body work are shaped by a complex interweaving of the regulatory mechanisms surrounding the provision of home care along with the physical and affective dimensions of intimate body work.

Regulating the body work of home care
Actual body work practices in the home reflect the reach of policy directives and the commodification of care. Competitive bidding for home care contracts bears the stamp of managerialism, with its emphasis on quantification and economic rationality. Yet in practice this emphasis and the difficulties in applying directives and their consequences are negotiated and may be resisted in bodily interactions of care workers and clients. Not all workers, however, have equal authority in such situations.

An important aspect of the commodification of care is that of time. As a way to save money and move workers more quickly through homes, agencies began quantifying particular tasks by allocating them specific amounts of time. Shirley (Glenda’s RN) described how she had her five minutes for a general assessment, 15 minutes to pour a week’s worth of medicines, and so on. She noted that ‘if my visits were too long, I would be told that I’m spending too long with the patients, [I’m told] what the acceptable amount of time is’. Nurses expressed general frustration that previously they had more autonomy and could use their professional judgement about their clients’ need for services. Clients noticed the shift; Sarah commented that care workers don’t have time. They’re trying to stay within a schedule. You’re allowed so much time, you know. They will stay if there is a problem or, you know, to finish off your little talk about something, but they are trying to work within a schedule.

Sarah hints at one of the problems of placing time limits on care tasks; this commodification is certainly significant in managing the ‘caring for’ dimension of care. However, unlike physical body work, therapeutic emotional work (caring about) is less amenable to quantification. The care workers were conscious of this empirical distinction and the importance of going beyond the strict categorisation in their work. Shirley (Glenda’s RN), for example, noted the time needed to provide care that went beyond simply the physical care of Glenda. After describing the tasks she carried out, she concluded: ‘basically that’s it, and I try to, you know, spend some time with her if there are things that she wants to talk to me about or if there’s things that are kind of worrying her’. Shirley remarked that initially she was only allocated 30 minutes to see Glenda, and asked for more time:

She’s a palliative but she hadn’t been coded that. So I coded her for emotional support, family support, I think I’ve got it up to 45 to 50 minutes. . . . (Glenda) felt the need to cry, she felt depressed about the fact she knows she’s dying and that she feels she has to be very brave and not cry in front of Donna (Glenda’s daughter), she’s just trying to, you know,
put up this, very stoic front. I just felt like how can I deal with this woman, give her any kind of comfort, and expect to do it in 30 minutes?

Personal Support Workers do not have the same power to recode or extend the time they are allocated to care for a client. It can be a struggle to fit everything into the time and there may be legal consequences of working beyond that allocated time. Celia (Sarah’s PSW) described a recent experience with another client:

She has a catheter and I was supposed to be in there for an hour to give her a bed bath, get her up in the Hoyer and get her into the living-room. Ah, it took an hour and a half because she’d had a BM [bowel movement] and she was mess from one end to the other and I had to clean it all up and ah, so it took longer. And we’re supposed to inform our company if we’re spending any time more than necessary at a client’s house because then we’re not insured with Worker’s Compensation.

Celia’s comment indicates that some of the agencies’ rules are informed by provincial regulations (in her case eligibility for medical care if she is injured on the job). Other agency rules govern which group of paid care workers can undertake what tasks. Gina and Maggie, Robert’s attendant and personal support worker, gave examples of the minutiae of these regulations:

We’re not, ah, able to put cream on an open [wound] or anything like that. If you’re washing somebody and they would like you to make sure that [the wound] is covered and cream put on, you know, things like that. If it’s not open we can apply cream, but if it’s open we can’t. They have to have a registered nurse [...] applying the creams to any open areas (Gina, Robert’s attendant).

We’re not allowed to take the medications out of the bottle and hand them to them. [...] that’s family or themselves or an RN that’s classified to do that. I can hand them the bottle, I open the bottle, but I can’t take the pills out of the bottle (Maggie, Robert’s PSW).

These comments reflect how agencies’ rules produce and reinforce a division of labour among the home care workers, as well as one between paid workers and family caregivers (discussed in the next section) and also highlight the potential negotiation of care that may emerge between care workers and clients. This was of particular concern when there were changes of care workers. How the agencies schedule workers can mean multiple carers and discontinuities of care, which potentially has more impact in home care than it would in a hospital or nursing home. The anxiety is around potential disruptions – particularly in terms of knowledge, whether this is knowledge about routine needs or the specifics about carrying out particular practices. For example, Diane (Robert’s wife) was concerned because one of the paid care workers was to have surgery and would be replaced temporarily:

It’s somebody new and you’ll have to go through where everything is and, you know, it’s a [...] sensitive thing, someone in your house every day. I think that the (agencies) feel that shouldn’t matter, just as long as you get somebody. But I think they are leaning maybe toward having a little more feeling for us, seeing it our way. I think the workers find it better too, if they’re here on a regular basis.
Diane and Sarah both expressed exasperation that they repeatedly had to explain the particularities of their situations because of the turnover in paid care workers or temporary replacements. Diane emphasised that Robert needed routine and consistency in his daily regime: ‘he likes things on schedule and it’s upsetting to him, even the little details, like he wants his coffee before he shaves’ and she relies on the care workers to help her provide that structured framework for Robert. For Diane, the turnover of workers, or more critically, when they do not turn up, causes her stress. She frames their role in Robert’s care in terms of expertise. She admits she can do some of the tasks, but feels ‘he doesn’t get the good care, you know. I can’t do all the little details like they would. I have to just cut corners and do what I’m able to do’.

For Sarah, lack of continuity could have a profound effect on her care. Her narrative, in particular, demonstrated her active agency in the management of gaps in the system. Sarah requires considerable intimate body work, and she is sometimes compelled to take control of this body work. She recounts the distressing experience of a new RPN who had problems inserting the urinary catheter. Sarah’s view was that the RPN was inexperienced, but later discovered that the RPN had written in her chart that multiple catheters were used because Sarah could not keep her legs open. This was not the case, so she asked that a different RPN be sent. She also devised a technique using a long sock to make catheterisations easier for the paid care worker and more comfortable for her, and proceeded to teach it to each care worker. Care is often presented as one-directional, something that is performed on a passive recipient. However, Sarah’s case shows that experiential knowledge of body work is transmitted back to paid care workers. Her RPN, Sandy, commented that Sarah is ‘very knowledgeable about her disease […] she’s also very realistic about it’ which made Sandy’s job easier. Sandy talked about Sarah giving her instructions about the ‘tricks’ that work for her: ‘she just tells you how to do it and yeah, so I mean that isn’t a problem’. Sarah had not always been so assertive. She had fallen from a patient hoist device twice before, and spoke frequently of being nervous about people lifting and moving her. Since the second fall she had decided to be more direct with the workers, ‘you feel vulnerable,’ she said, ‘it’s your body that’s going down on the floor, you know’.

In practice, to complete the body work for Glenda, Sarah and Robert requires a fine balance and that balance is often fragile. Oftentimes this fragility is revealed in the lack of continuity of care. It may also be because of a lack of care – the interview data included examples of care workers getting sick or snowed in and there was no-one available to replace them. This may well be an issue that is more problematic when care is carried out in the home rather than a hospital setting. Added to this is the need for family caregivers to attend to their own self-care, as they are a constant link in the chain of care, they are, as Diane (Robert’s wife) put it, ‘the back-up, the contingency plan’. In the next section we consider the divisions of labour in care that underpin the provision of care – both in terms of ‘caring for’ and ‘caring about’.

**Divisions of labour in body work**

When body care is provided by a combination of family caregivers and paid care workers, primary responsibility for specific tasks is usually assigned to particular people. These divisions of body work reflect not only professional practice hierarchies, but also a working out among family members, paid workers and care recipients, about who has responsibility for which care tasks. Our interview data indicate that divisions of labour (between family caregivers and paid care workers) in a particular home can become routinised, especially once all concerned have established relationships.
The occupational hierarchy within paid home care work in the community usually reflects the amount of education and training received, pay levels and prestige, and the specific tasks associated with each occupation. RNs are increasingly associated with the more technical, administrative and informational aspects of care, especially as they move up the ranks – and away from close bodily involvement. They are distanced from the ‘dirty work’ of actual intimate body work (Twigg 2000) and are more likely to do assessments and more technical care tasks. The personal support workers and attendants do more of the labour-intensive activities and the ‘dirty work’ associated with the close bodily care of others. How family caregivers are involved is less prescribed, and in the three cases considered here they participate in body work on the client in different ways and to varying extents.

Sarah actively created a division of body work that excluded her husband, Andy. She valued and made use of the gradations of difference between worker, friend and family member as care provider:

I prefer to have Andy’s help as a caregiver as little as possible, simply because if your husband becomes your caregiver, then he isn’t your husband any more. The relationship is blurred there. If I still want to be a person unto myself, then I don’t want to include him in some parts of care, like a bowel treatment or a shower day.

Andy, her husband, mirrored this when he described, a little awkwardly, his care responsibilities as ‘I guess mental companion, you know, someone to talk to. If necessary, physical care, ah, you know, getting her into her chair, getting her into the bed. Those would probably be it’. Sarah is very clear about her identity as a wife as well as her wish not to be reduced to be the object of body work.

Glenda’s care could be described as a mixed economy: she has formal care, informal care from her family, and private paid care. There was a clear division of duties between Ben (son-in-law) and Donna (daughter), as well as between them and the paid workers. For instance, Glenda’s twice daily insulin injections are given by Ben because of his knowledge and expertise. Donna said ‘we were both shown in the hospital how to do the needle. One of us paid attention, and that would be him’. Similarly, Ben is also in charge of the strong medicines because he ‘has a chemistry background’. However, Ben and the workers were all clear that Donna makes the decisions about Glenda’s care and she manages the division of responsibilities. Certain tasks fell directly in the mandate of the attendants: ‘They give her her bath. They don’t clean her room. They feed her, they prepare food, I think that’s the main thing, and they take care of her bed’ (Donna).

In addition to the two publicly funded paid care workers, Shirley (RN) and Laurie (PSW), Donna hired their neighbour, Irene, to help clean the house and provide additional personal care for Glenda not covered by the system. At a minimum, Irene is in their home twice a week, but she also drives Donna and Glenda to their medical appointments and to get their groceries. Irene is clearly a very important node in Glenda’s care; she was mentioned very warmly by all three members of the family, and even the PSW. Glenda enthused ‘I’ll always keep Irene; she’s part of our family. Irene’s like a piece of furniture here, she’s well liked, she’s become part of the household’. Beyond demonstrating that sometimes extra care is bought privately, Glenda’s situation shows how finely balanced care arrangements are. Glenda, Donna, Ben and the PSW each talked about an overnight trip Ben took to attend a conference and the complicated arrangements put in place to give Glenda insulin. In turn, Ben finds caring for ‘the ladies’, as he calls them, as well as working full time, very demanding:
I think one of the things that bothers me is that I have to be at a certain place at a certain
time. Mum needs her injections twice a day, Donna doesn’t like to do it, she needs her
medications, she needs her meals pretty much on time, and proper balanced diet. [...] So it’s
just ah, from morning to night it’s rush, rush, rush, get this done, get that done. I’m just
bone weary.

In Robert’s case, Diane depends on the workers because much of Robert’s care involves
lifting and moving him and she is physically unable to do that because of back problems. She
makes sure that he has opportunities to socialise with his friends; she is strict about getting
him to do his exercises and swimming weekly to keep his body supple so he can be moved
more easily. Diane has told the agency she does not want the assistance offered with cooking
his meals. She and Robert prefer that she makes his meals. In this way she is providing him
with some sense of domestic normalcy and continuity of their long-established domestic
arrangements. However, the most intimate personal care, like a daily bowel movement and
showering, is usually undertaken by PSW Maggie or attendant Gina.

(Robert) needs a bowel routine every morning, so I give him a suppository. And then he
just stays in bed until he feels that it’s going to work. [...] So he has his bowel movement
and then ah, I give him a shower and then dress him (Gina, Robert’s attendant).

Of course, that it is the attendant and PSW providing these most bodily of personal care
activities reflects broader occupational divisions. These aspects of body work are tasks least
likely to be undertaken by family members. Delegating these tasks to non-family members
can be seen as a means of maintaining the clients’ dignity within their families. Diane,
however, is still involved in such care from time to time:

Sometimes he’ll have a bowel accident in the chair so I try to clean that up, and ah...they
might send somebody in for that, but I think by the time they could find someone it might
be quite a while that he had to sit in it, so we do manage it.

The divisions of labour around the ‘dirty work’ of home care were striking. Diane will
deal with Robert’s excrement if need be, Sarah is extremely reluctant to have her husband
involved in that aspect of her care. Shirley (RN) and Sandy (RPN) did not do much of
the body work associated with body wastes. They did catheterisations and checked blood
levels, but cleaning up body waste and bowel routines were not part of their official
duties (this is also the general trend across the other cases in the larger project).
Reflecting Twigg’s (2002) observations about hierarchies in nursing, in home care the
work of RNs and even of many RPNs is ‘marked by distance from the body and direct
body work’ (Twigg 2002: 428). The ‘dirty work’ was more squarely the task of PSWs and
attendants like Maggie and Gina.

Discussion

In their anthology on care work, Zimmerman et al. (2006: 3–4) explain that they
deliberately chose the term ‘care work’ to refer to the multifaceted labour that produces
the daily living conditions that make basic human health and well-being possible. [...] (and)
because it acknowledges these multiple facets, especially the important emotional
dimensions involved (i.e. care), coupled with the complexity and physical demands (i.e. work).

While a useful definition as far as it goes, in this paper we have presented a more nuanced understanding of care work by focusing on the body, the care worker-client relationship and the home as a site of care work. The home in various ways shapes how care is provided and how all the parties involved experience homespace. The materiality and meanings of home provide conditions under which regarding the body as simply a physical object is hard to sustain. Caring for this body almost inevitably involves the forming of relationships between family caregivers, care workers and care recipients that are predicated on the interweaving of the materiality of the body to be ‘cared for’ and a sense of a self to be ‘cared about’ that subverts a reading of the body solely in terms of its physical care needs. The paid care worker/care recipient relationship is further informed by a desire to distance bodily needs from a valued identity on the part of the client, and their wish to engage in ‘normal’ social interactions.

Close bodily interactions associated with personal care are central to activities and experiences associated with home. When home care workers and family caregivers together engage in the intimate care of the bodies of clients, however, these bodily interactions are interpreted and enacted within a wider context of meanings about bodies and homespace. The home, as a material and symbolic space is imbued with a legacy of powerful notions of family, privacy and control. Home care workers transgress ‘appropriate’ personal boundaries, and also enter the most intimate spaces of the home (bedrooms and bathrooms) in the course of body work; consequently, established meanings of bodies and homespace need to be renegotiated (Dyck et al. 2005). Care work remains deeply gendered, and implicit in home care reform. Men, however, like Andy and Ben in this study, are increasingly involved in providing care to family members, raising new questions about how care work, often under valued and rarely recognised as a learnt skill and hard work, is accommodated in gender identities (Folbre and Nelson 2000).

Policy directives which commodify care also operate in particular ways to inform how care is put into practice and how specific decisions are rationalised. Furthermore, the organisation of paid care, particularly with respect to gaps in continuity of care, has effects on how the embodied knowledge of care recipients themselves may become a crucial part of their care (as in the case of Sarah’s instructions to care workers). While the divisions of labour between paid and family caregivers may seem clear-cut, our analysis reveals how coordination is an important aspect of ensuring good care for the recipient. A fine balance of the divisions of labour, sometimes fragile, is achieved as paid and family caregivers and care recipients come together in managing the body work in the specific space of a home that doubles as a workplace. This includes families reorganising their time and even their homespace to cope with their home as someone else’s workplace. There can be problems with home care, but all the clients and their family caregivers indicated gratitude for home care. Despite the stress in the families, it was highly valued, especially as a means of keeping their families together at home despite profound illnesses.

As Michael Fine (2007: 178) points out ‘the body in care is considerably more complex than a focus on the body of the care recipient alone might indicate’. The experiences of Glenda, Sarah, Robert, their families and paid care workers offer ‘lived body’ evidence supporting Fine’s claim. The relationship between care recipient and care worker is often 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. Using the case of publicly

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funded home care, we argue that body work should be repositioned, and analyses need to include the embodied knowledge of both those providing and receiving care. In foregrounding this knowledge, body work can be understood as actively co-constituted by caregivers and care recipients through negotiation of micro-practices in the home; practices which, however, are shaped by regulatory mechanisms beyond the home which interweave in complex ways with the affective dimensions of care and its intimacy. Drawing on, and extending the concept of body work to analyse the dynamics of long-term care relations and practices in private homes provides new ways of understanding both the material and non-material relations and processes of the shifting care landscape that shapes the lives of some of the most vulnerable of our populations.

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Notes

1 The names of the clients, family caregivers and care workers are pseudonyms. The empirical research for this paper is part of a larger project on home care in Ontario funded by the Social Sciences and Humanities Research Council of Canada. The research team was led by Principal Investigator Patricia McKeever, and includes Co-Investigators: J. Angus, M. Chipman, A. Dolan, I. Dyck, J. Eakin, K. England, D. Gastaldo, B. Poland, and Research Co-ordinator K. Osterlund.

2 Our ideas about emotional labour are informed by the ongoing lively debates about theorising emotion and identifying different sorts of emotional labour. Here we use emotional labour to mean the interactive (even collaborative) relational and reflective aspects of care work. We draw on Catherine Theodosius’s (2008: 146) notion of therapeutic emotional labour as the sort of emotional labour where ‘the nurse’s intention is to enable the establishment or maintenance of the interpersonal therapeutic relationship between nurse and patient in a way that facilitates their movement towards independent healthy living’. Also helpful is Liz Bondi’s (2008) conceptualisation of care work as a paradoxical, emotionally laden interpersonal relationship. Our use of ‘caring about’ also reflects, to some extent, the ‘caring about’ phase of Joan Tronto’s (1993) four ethical dimensions of care: being aware of and attentive to care needs and well-being of others.

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