

ARTICLE

Ageing in place with non-medical home support services need not translate into dependence

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Abstract

Older adults who age at home independently are often celebrated as having anticipated and planned for their care needs in the later stages of life, whereas those who receive assistance from home support services are often stigmatised as dependent and characterised as a ‘drain on the system’. However, this thematic analysis of interview data from 12 home care clients in two Canadian provinces offers evidence that counters the assumption that home care clients are passive recipients of care. Extending Corbin and Strauss’ theorisation of how individuals manage chronic conditions alongside Dorothy Smiths’ conception of work, we explore how home care clients ‘work’ to receive care as they age in place. Specifically, home care clients not only engage in daily life work, illness work and biographical work, but also advocate for themselves and their workers, co-ordinate and negotiate with members of their caring convoys and networks, and adapt in various ways to navigate personal, relational, structural and policy-level challenges. We suggest that work done by older adults who are ageing in place be addressed, acknowledged and incorporated into care planning and operational policy development to challenge both the stigma of dependency and neoliberal narratives of self-sufficiency.

Keywords: home care; work; older adults; co-ordination; adaptation; advocacy; thematic analysis

Introduction

Stigmatisation has been defined as a ‘process whereby certain individuals and groups are unjustifiably rendered shameful, excluded, and discriminated against’ (Holm *et al.*, 2014: 1; World Health Organization and World Psychiatric Association, 2002). Ageing and disabled bodies are often stigmatised, socially marginalised (Hansen and Kamp, 2018), and wrought with notions of death, decay and dependency. Neoliberal ideologies, which establish and propagate ideas of personal responsibility and economic privatisation (Duggan, 2012) reinforce ideals of

healthy ageing, wherein older adults should be responsible for their own health and wellness, and ask for as little outside 'help' as possible (Glasdam *et al.*, 2013b; Dalmer and Huvila, 2019). While the World Health Organization and European Union continue to advocate for 'active ageing' in both policy and practice, this term is often used inconsistently, and can reinscribe old age, as well as marginalise those who are dependent or unable to age 'successfully' (Lassen and Moreira, 2014). This cultural politics risks further stigmatising older adults, as once an individual is no longer perceived as productively contributing to society, they may be viewed as an economic 'drain on the system' – this is reinforced through deep-rooted and persistent tendencies, in policies and public discourse, towards apocalyptic demographic thinking (Gee, 2002; Gutman, 2010).

Ageing in one's own home is often idealised for reasons related to comfort, community, safety and economy (Dalmer, 2019), and ageing in place generally signals that individuals have prepared for the later stages of their life and are committed to remaining independent for as long as possible (van Dyk *et al.*, 2013). Neoliberal ideologies which impacted trends towards deinstitutionalisation in Canada in the 1990s (Chappell and Penning, 2005; Funk, 2013) ended up placing increased responsibility for caring for older adults on their family and friend care-givers. Herein lies a compelling contrast – older adults who manage to age in place at home are celebrated for being more 'independent', and while this may sometimes be the case, it is also a possibility that their dependent relationships are merely less professionalised and less visible than those who live in long-term care homes. As home care need for ageing adults continues to grow and this care work becomes increasingly professionalised, it remains largely invisible – taking place in intimate domestic settings, often undertaken by racialised and female members of society whose skills are taken for granted or minimised. Within health-care contexts more generally, 'good' patients are compliant and agentic – actively working to get well and make good choices about their health as if future outcomes are solely in their hands/within their control; the issue of dependency is fraught (Parsons, 1975; Lassen and Moreira, 2014; Dalmer and Huvila, 2019). Patients whose behaviour aligns with these ideals tend to be viewed more favourably by health-care providers. In the context of home care, workers are sometimes discouraged from providing 'too much' for clients, as it is believed that this may increase their *functional* dependency; however, some workers and managers extend this idea to interpret service use itself by equating service receipt as antithetical to empowerment (Funk *et al.*, 2011; Hansen and Kamp, 2018).

Home care is difficult to define precisely (Contandriopoulos *et al.*, 2022; Peterson and Brodin, 2022) but is generally designed to assist individuals with functional or cognitive impairments to allow them to live for as long as possible in their own homes. This can include a vast array of specialised medical and supportive non-medical care and services. Although home care is often characterised as helping individuals to retain their independence, home care clients are often referred to as 'dependants' (Bourennane *et al.*, 2013; Barnay and Juin, 2016; Morisaki, 2017) or, in more consumerist terms, as service 'users' (Whitehead *et al.*, 2015; Aase *et al.*, 2021), signifying reliance upon health and/or social care systems. This language matters and stigmatising ageist and ableist discourses can contribute to making those receiving care, including but not limited to older adults,

feel like a burden on friends, family and the health-care system (Fine and Glendinning, 2005; Barken, 2017; Dalmer, 2019). At the same time, however, as Barken (2019) has argued, home care itself challenges the binary between dependence and independence, as trying to maintain one's independence can entail asking for and engaging help from others, including service providers. Clients may need to balance their need for support with neoliberal expectations of personal responsibility (Clotworthy, 2017). For this reason, discussing one's services can reinforce clients' feelings of vulnerability or shame for being dependent (Aronson, 2006), and thus may negatively impact one's sense of self-worth.

Gerontological research may have inadvertently reproduced ageist conceptions of passive home care clients by focusing primarily on studying home care 'utilisation'. Even in research exploring older adults' subjective experiences of using or receiving home care, clients' own agentic responses are rarely foregrounded. Moreover, although research has addressed the extensive work done by family/friend care-givers of older adults living at home (Penson *et al.*, 2000; Barken *et al.*, 2017; Funk *et al.*, 2021; RANQ, 2020), a considerable gap remains in exploring the work done by the clients themselves. Just as unpaid work (such as care work and reproductive work) has been an important aspect of feminist scholarship, it is important to better illuminate and understand how the unpaid and often invisible work of older adults receiving home care, most of whom are women, is structured in particular ways and often involves co-ordinating with paid care workers, who also tend to be women. Doing this may help challenge systemic ageism, ableism, and outdated myths of personal responsibility within home care systems, clinical practice and academic research.

To address this gap, exploring the 'work' older adults receiving home care engage in, without defining it against neoliberal conceptions of self-sufficiency, our study investigates how a group of older adult home care clients in two Canadian provinces 'work' when receiving care designed to assist them to age in place. Starting with and extending Corbin and Strauss' (1985) foundational research on the three kinds of work (biographical, identity, illness) involved in managing chronic illness, we challenge the notion that home care clients are passive recipients of services. We further extend analytic consideration to Dorothy Smith's (2003) broader conception of work that acknowledges emotionality, and that one's work is never theirs alone but is co-ordinated with others.

Theoretical framework

Dorothy Smith explicates that how we see, discuss and discover 'work' is usually invisible – indeed, her feminist sociological conceptualisation defines work as anything 'people do that takes some effort and time, that they mean to do, that relies on definite resources, and is organized to coordinate in some way with the work of others' (Smith, 2005: 46). Smith (2003: 63) has also specified that work involves 'time, thought, and ingenuity' while also incorporating the 'individual's subjectivity and their experience'. Notably, this conception of work in many ways parallels that used within occupational therapy, whereby clients are supported in their 'changing patterns of purposeful "doings" ... that bring joy, meaning, and belonging to their lives' (Canadian Association of Occupational Therapists, 2019: 2). Smith's research,

grounded in the often unpaid and invisible care and reproductive work of women in the home, explicated how this work almost always involves some sort of interaction with others and operates within a complex system of social organisation.

Research has begun to illuminate aspects of work done by home care clients and the resulting outcomes. For example, *resolving conflicts* informally with workers may help clients feel they are 'good' people, and build trust and loyalty with workers (Hoffmann, 2009). Some clients maintain their sense of agency more broadly through *interpretive strategies* (e.g. finding joy in simple things) or through tangible activities (e.g. reading a good book or watching the clouds) (Bjornsdottir, 2018). Home care clients in Bjornsdottir's (2018) study engaged in a *web of relations* that included their family, friends, home care workers and even technology. Although home care clients are often unable, due to structural constraints within systems, to make decisions about various aspects of the services they receive (Glasdam *et al.*, 2013a), clients at times 'take charge' of their home care services by *setting physical and personal boundaries* (Clotworthy, 2017), e.g. when striving to maintain privacy (Aronson, 2002). Some clients also instruct their workers how to cook and clean in ways that best suit their needs (Aronson, 2002; Cranford and Miller, 2013). They may also choose not to take the advice of medical professionals regarding dietary restrictions and instead eat foods that align with their cultural beliefs (Rivero-Jimenez *et al.*, 2020).

The literature also reveals that older adults actively work to maintain relationships with family and friends and home care providers (Warner *et al.*, 2012). This complicated work requires both *emotional labour and relational skills* (Barken *et al.*, 2017) as roles and emotions change frequently throughout the illness trajectory. Learning how to take on new roles while actively participating in decision-making is rarely straightforward and requires special skills to navigate through challenges and conflicts (Barken *et al.*, 2017). *Communication work* can also involve *avoidance work* when deciding not to disclose particular information to some people depending upon the nature of the relationship (Dalmer and Huvila, 2019). Deciding how and when to share information is an active process known as 'meaning-making', and it may help older adults feel in control of their circumstances (Brünner and Andersen, 2018). For example, older adults receiving care may use humour to deflect sad experiences, end sad stories on a positive note, blame their current situation on bad luck or even normalise decline through modesty – embracing doing more with less (Brünner and Andersen, 2018).

In addition to navigating communication with friends and family, clients – especially those without available family or friend care-givers – also learn how to *navigate the new layers of bureaucracy* within service organisations and agencies. Clients will seek information about their health care (Cooper and Urquhart, 2005), and often require an in-depth understanding of the structure and organisation of systems (Barken *et al.*, 2017) – in this case, the home care system. Advocating for one's self (to receive needed support) is often balanced against not being 'too assertive', which may result in being labelled as challenging or difficult, resulting in negative repercussions for care (Aronson, 2002, 2006; Barken, 2017). For instance, Barken *et al.* (2017) found that clients often needed to control their emotions while receiving care, so as not to harm their relationships with the staff, while Glasdam *et al.* (2013b: 89) found that clients needed to 'accept the rules of the

game [home care policies] to receive assistance'. Clients needed to work *with* staff and use negotiation and mediation skills to advocate for changes (Barken *et al.*, 2017). Such examples align well with Smith's definition shared above pertaining to the deliberateness, time, effort and 'co-ordinating' of one's work with others. Scheduling, for example, was a primary concern of clients, and this finding confirms a vast body of existing research into the experiences of receiving home care services (Holmberg *et al.*, 2012; Callaghan and Towers, 2014; Barnay and Juin, 2016; Shafir *et al.*, 2016; Blaakilde, 2018). As found by Blaakilde (2018), changes to habitualised activities and schedules can be particularly disruptive for older adults.

Corbin and Strauss (1985) identified three different types of work that clients engage in when managing a chronic illness at home: *illness work*, *everyday life work* and *biographical work*. *Illness work* involves precisely managing the illness trajectory itself, such as diagnostic work, working to prevent a crisis and managing symptoms. *Illness work* can be both routine and unusual but is always managed around daily routines. *Everyday life work* includes everything that goes into managing daily life tasks, such as housework, child care, social and emotional work, and fundamental tasks such as eating and bathing. While managing an illness, everyday life work may take longer, be done less efficiently, or in new and creative ways. Similar to the findings of van Dyk *et al.* (2013), older adults may engage in 'busy talk' to counter the narrative that they have plenty of free time in retirement. *Illness* and *everyday life work* are interspersed with *relationship and interaction work* with family, friends and health-care professionals (Corbin and Strauss, 1985). Additionally, everyday life work can also include *information work* whereby home care clients seek information relating to their health and/or available care services (Barken *et al.*, 2017; Dalmer, 2019; Dalmer and Huvila, 2019). Finally, *biographical management* is the continual work of reconstructing one's life and sense of self alongside the illness. According to Corbin and Strauss, the

[r]eciprocal impact of trajectory and biography is ongoing. It is not limited to an initial impact at the time of onset; rather, it occurs throughout the trajectory. So, any change in the status or phasing of either trajectory or biography can have drastic consequences, with implications for the management of either. (Corbin and Strauss, 1985: 231)

In other words, the individual can impact an illness trajectory, just as an illness can impact the individual and their sense of self.

Managing one or more chronic illnesses requires a lot of time and effort, which can leave clients with little time and energy for other activities. Self-management strategies take time and effort (Audulv *et al.*, 2019), and though they can improve quality of life, clients may struggle to achieve an equilibrium of effort that works best for them, their illness and their lifestyle (Corbin and Strauss, 1985; Audulv *et al.*, 2019). Moreover, any slight change in one's life or illness trajectory can impact the type and nature of the work required of older adults with chronic illness. Different phases of chronic conditions will require a different type of work and individuals may be managing multiple conditions at once that often necessitate asking for help, which invokes stigmas of old age and dependency.

In this paper, we challenge neoliberal ideas of dependency that frame home care clients as passive recipients of care, or an economic drain on the system (Corbin and Strauss, 1985). We do this by asserting that we are all, no matter our age or body abilities, dependent on one another to a certain extent, and by investigating the ways in which home care clients engage in meaningful 'work' while receiving publicly funded home care services. We also explore the impacts and structuring conditions associated with this work.

Methodology and design

We engaged in thematic analysis (Clarke and Braun, 2016) informed by critical gerontology and feminist conceptions of 'work' as well as Corbin and Strauss' (1985) classic notions of 'work' as it pertains to managing chronic illness.

Qualitative data were collected as part of a larger project (Keefe *et al.*, 2020), the purpose of which was to explore the experiences of home care clients and other key system actors, home care attendants, care/case co-ordinators and, where applicable, family care-givers and agency supervisors, to better understand client pathways through services over time in two provinces – Manitoba and Nova Scotia.¹ As part of this project, semi-structured qualitative interviews were conducted with various care actors at three points in time, approximately eight months apart, to understand the longitudinal trajectory of home care client pathways. The present analysis will focus only on client interviews from Time 1, conducted in the summer and autumn of 2019. These interviews took place in person in clients' homes in both Nova Scotia and Winnipeg. Each interview lasted between 25 and 60 minutes.²

Data collection

Data were collected from six home care clients in Manitoba and six home care clients in Nova Scotia. To be eligible for the study, clients of home care had to be over the age of 60 years, cognitively well and receiving home care for at least one year. Participants ranged in age from 60 to 96 years and had been receiving home care for 6 months to 15 years. They received mostly non-medical support such as assistance with compression stockings, housekeeping and personal care, and were cognitively well, and not ethnically diverse. Appendix 1 outlines descriptive information about each client participant. Case/care co-ordinators who agreed to participate in the study were asked to identify and send recruitment letters to clients whom they felt might be willing to participate and would improve, maintain or decline over the next 18 months.

Interviews were conducted in person by five trained interviewers (four authors-KK, LMF, GW and MM) using a semi-structured interview guide. Clients were asked to describe a typical day and outline any changes to their home care services (*e.g.* type(s) and timing of services, amount of services, type(s) of workers) since they started on the programme. Clients were also asked about any changes that they would like to see made to the home care system. While clients were not specifically asked about work or independence, this topic was identified inductively within the data during the preliminary phases of analysis.

Data analysis

Following transcription, initial analysis began when descriptive summaries of interviews were created. These descriptive summaries, along with interview transcripts, were reviewed by a larger group of researchers (including KK, LMF, MM, GW, ML and JR) to discuss inductively themes that were present in the data. Themes were compared across constellations for consistency and rigour. Independence was a theme that was identified by this larger team. Abductive analysis (Timmermans and Tavory, 2012) was used to help us bring an abundance of data together to relate to existing frameworks that identified particular types of work, such as the categories offered by Corbin and Strauss (1985); while simultaneously allowing us to identify inductively additional types of work that are often invisible or unacknowledged. While our interviewees did not explicitly ask client participants to outline the 'work' they did on a daily basis, when reviewing transcripts and analysing data collected, it became clear that certain categories of 'work' did exist and were common amongst participants. Some aligned well with Corbin and Strauss' framework, while other types of 'work' likely would not have been categorised as such by participants had they been asked directly about the 'work' they do, because these patterns extend beyond themselves as individuals or specific tasks, and are in the affective realm – often involving co-ordinating relationships with care-givers, and adapting to structural forces that impact these relationships.

Findings

Our analysis revealed home care clients to be agentic and effortful, and much of the work they do could be framed as upholding dominant narratives that home care clients are independent and self-sufficient. Although participants were not explicitly asked about their work as home care clients, the work involved in 'maintaining independence' or ageing in place emerged in every interview. Interestingly, findings also illuminated that much of the work clients do is co-ordinated with the work of others – often even deliberately advocating for themselves and paid home care workers, and calling out flaws in the system within which they are working. Applying a feminist sociological lens that connects individual daily actions with institutional processes, our analysis moves beyond a thematic accounting of *how* clients described their work, towards an exploration of *why* they opted to use certain examples and descriptions of their work during interviews. We suggest that some of the comments pertaining to illness, daily life and biography work especially may, at least in part, represent clients' interpretive defensive responses to questions about 'home care use' by foregrounding their agency, perhaps even to maintain a valued identity as 'productive' and 'not a burden' (Sinding and Aronson, 2003).

We have separated the following sections into broad categories of work, starting with the three categories that Corbin and Strauss (1985) identified, to reveal deliberate and straightforward ways that participants' work aligns with extant research in related fields, before deepening the conversation to reveal how work that may be more taken for granted (control and advocacy, co-ordination, and adaptation and persistence) connects the individual to places and people beyond the self. We argue that acknowledging these social relations paints a clearer, more nuanced picture of interdependency; one that disrupts tidy neoliberal narratives about home

care and personal responsibility. These experiences will be explicated further below, with analytic attention to the context and consequences of particular types of work.

Illness work

Illness work includes management of the daily signs and symptoms of chronic conditions that can be routine or novel, and preventative or reactive (Corbin and Strauss, 1985). An example of routine illness work comes from Manitoba (MB) Client 1, who when asked to describe a typical day begins by saying that she ‘tests her sugar and then takes her insulin’. MB Client 3 also commented that her day begins by taking her medication and checking her blood sugar. More novel work is described by MB Client 3 who ‘researched three medications that [he had] taken in the past’. Nova Scotia (NS) Client 4 researched non-medical treatments to counteract the thinning effects of the steroid cream that she was prescribed for psoriasis, and uses coconut oil to strengthen the skin on her legs and prevent blisters.

Depending on the client’s background or degree of health-care knowledge, their illness work varies in terms of feeling comfortable managing their illnesses. Clients with more developed expertise seemed particularly equipped for active or agentic involvement. For example, MB Client 4, a former nurse, appeared particularly well-informed regarding her diagnoses and illness management strategies. After having problems with her catheter, MB Client 4 visited a doctor and did her own research about the problem. She expressed having a good handle on her condition, stating

all the material that I’ve read seems to equate long-standing indwelling catheters with stone formation. This is very common and according to the statistics that I’ve read, it primarily is because of some untreated undiagnosed bacteria, which is going on in there, inside my bladder.

She goes on to describe how she learned that being on a particular prescription might create dental problems, which she does in fact have. She concluded by saying, ‘So, I looked all that up, but ... Anyways, it’s all, it’s kind of complicated.’

Illness work is not only reactive but can be proactive as well. For example, MB Client 6 is aware that she is at high risk for falls. She tries not to use her stairs often and will ask home care workers to retrieve things from the basement to avoid the risk. She states:

like if I fall on the floor now, I can’t get up. These knees won’t get me up. So that’s why I have to be careful about the staircase ... so it’s very, it’s essential that I try to avoid falling.

NS Client 1 also does all he can to delay or prevent his Parkinson’s disease from worsening, including ‘walk[ing] down the hall to keep my legs going ... of course, I use my exercise bike too’. Another example is NS Client 5, who relies on oxygen tanks to breathe and has a limited income; she cannot afford to pay for more tanks than she is offered each month. Daily she must plan her outings to ensure she has enough oxygen to last the month, which has a significant impact on her social life and ability to remain independent (she cannot grocery shop, for example).

The illness work demonstrated by the participants suggests that although they may have chronic conditions that will not improve, they do whatever they can to maintain their current health status. In addition to managing day-to-day medical conditions, clients also went above and beyond by researching symptoms and maladies to ensure that they were well informed and able to choose the right trajectory of management. Illness work looked different for different clients, but it became clear that most involved in this study did their best to mitigate risk in everyday tasks.

Daily life work

Daily life work involves keeping a household running. Home care clients in this study, regardless of the extent of their care needs, all continued to engage in various forms of daily life work. Clients spoke of washing dishes and reading the news to stay informed on current events (MB Client 6, NS Client 1), managing finances and paying bills, folding laundry (MB Client 1), grocery shopping, driving (NS Client 1, MB Client 2) and cooking (NS Client 4). In addition to the daily house and yard chores and cooking, NS Client 2 enjoys using her wood stove and attending to the fire. Although it creates extra dirt and additional cleaning, she does not like electric heat and wants to continue using her wood stove for as long as possible. MB Client 3 speaks of having a lot of appointments to attend, and yet having a lot of other 'in-between work': 'Because I live in my own home, I have other things to do with the upkeep of the home and everything.' She adds that she enjoys maintaining her home because it ensures that her daily routine is never dull. MB Client 6 also refers to maintaining the upkeep of her home and sending cards for everyone's birthdays and anniversaries. This helps her stay connected with friends and family.

MB Client 2 only receives help from home care with his compression stockings and has a high level of functional independence. He speaks about doing his own cooking, cleaning and grocery shopping – sometimes also for his adult children. He is very aware of the food that he eats, and emphasises that he does his best to ensure that it is a balanced diet. He can bathe, shave and dress himself, and each day MB Client 2 compiles a list of tasks that he needs to do around the house, such as fixing a broken window. MB Client 2 is also very involved in his church, and does the audio on Sundays and for special events. MB Client 2 mentions that due to his age, others feel that he should be taking it easy and resting more. He elaborates, 'I'm trying to get to bed earlier because of my age and everything else. And I should be. I do not take a nap in the afternoon...' because he simply has too much to accomplish during the day.

Daily life work also involves managing emergency situations and problem-solving. For example, during a severe winter storm, MB Client 3 experienced power surges in her home resulting in some of her appliances overheating. In addition to her alarm clock and coffee machine breaking, she was without heat and needed to call a furnace repair person. This 'created a lot of commotion, that broke [her] routine' yet she managed.

MB Client 4 receives the most home support services in this study, and has reached the 55-hour maximum allowed by Manitoba home care, yet still engages in daily life by booking and scheduling transportation through Handi-transit and

doing her own grocery shopping. She does not want to be limited in her life to only tasks that public home care can assist with, thus, she also hires additional private home support and is in charge of managing her support workers' schedule, hours, tasks and pay. MB Client 4 enjoys maintaining her garden and indoor plants with the help of her hired support worker.

Aligning with the often gendered nature of work, male clients in this study discussed more instrumental tasks such as fixing windows (MB Client 2) and gardening (NS Client 1), while the females perform more organisational tasks, such as arranging their schedules and workers (MB Client 3, MB Client 4, MB Client 6, NS Client 2, NS Client 3, NS Client 4). Many of the tasks outlined in the examples above are tasks that home care services are unable to assist with, such as grocery shopping, household maintenance, transportation, gardening and managing emergency situations. Many aspects of daily life work indeed transition into biographical work, therefore, they may be reasserting their personhood by demonstrating that although they have accepted assistance from home care, there is still much that they can and want to do on their own. Clients in this study may be sharing this 'busy talk' and all of the tasks they can engage in independently to preserve a productive identity, despite needing assistance with some tasks. While some of the daily life work tasks outlined in this section may appear 'basic' and merely linked to everyday survival, feminists remind us that the time and effort that goes into satisfying subsistence needs is indeed 'work' even if uncompensated and unrecognised. Relatedly, many of the daily life tasks shared here were multi-layered and symbolised deeper desires/aspects of client identities.

Biographical work

Biographical work involves managing one's self-identity; identifying this work analytically involved consideration of how a participant narrates their life and presents themselves not only in interactions with other key network actors, but within the interview context. We looked, for instance, at how they reassert other, non-client identities, as with NS Client 2, who, in answering questions about her receipt of home care, wove in a narrative of her role as a church organist and community-builder. Biographical work also necessitates an understanding of the larger structuring contexts of receiving home care as an older adult (as associated with burden, lack of productivity, *etc.*) in which interview participants situate themselves. How interview participants present biographical work in the context of an interview extends Corbin and Strauss' (1985) conceptualisation.

MB Client 5's physical limitations have impacted her entire life; she is often tired and needs to rest her legs. As such, she may be attempting to justify her lack of 'productivity' to maintain a valued identity as independent and/or 'busy': 'I don't do a whole lot because I have a lot of physical disabilities that make it impossible for me to operate on full steam.' In contrast, when asked about why he first started with home care, NS Client 1 listed a whole host of reasons, including Parkinson's disease, lack of strength, unstable balance and shakiness. However, he concludes by remarking, 'not too bad though, I'm not too bad. Overall, I'm not too bad'. NS Client 1 may be trying to minimise his functional limitations to the interviewer and present himself as capable. This relates back to Smith's definition of 'work':

NS Client 1 is deliberately framing himself as capable not for his own benefit but in co-ordination with others – the researcher, home care workers – in response to how he might imagine others perceive him.

Another example, MB Client 1, who is almost completely housebound, suggests that her days are ‘pretty busy’ because she is on diuretics ‘so [she] go[es] every two hours to the bathroom (laughs)’. The laughter here may represent MB Client 1’s emotional work and attempt to lighten the narrative, addressing any potential embarrassment about referring to her bathroom habits in the interview interaction, and thus indirectly any potential impact on her identity.

MB Client 1 also draws on her previous occupation as a nurse to inform and interpret her own daily experience of receiving home care, and to maintain her previous identity. She refers to her own discomfort when she is sent unfamiliar workers:

What bothers me most is, it was a terrible time for me too. I looked after people, and I kinda felt that some of them were a little embarrassed to be taken care of. But when it came to me it was hopeless, I just couldn’t. So, when I got these two people I got like, used to them, it was so hard if they send somebody strange.

This client’s prior experience attuned her to the difficulties of having to rely on others for assistance, yet as she articulates, this knowledge was not sufficient enough to mitigate her own discomfort. It did allow her to identify, however, that having the same workers permitted her to build trust with workers, even though becoming a home care client represented a major shift in her identity from caring to being cared for.

MB Client 3’s previous job as a teacher also informs her experience as a home care client, and she asserts her biographical identity in the interview interaction by stating:

It’s a continuous change. And, I will tell you from my point of view, that is not easy to take sometimes. Because being a teacher of nature, I feel organisation is important and I feel consistency is important. And of course, it’s not complicated to come and put socks on. But, still there’s a procedure to follow. And so, I insist on the new ones that come, I have everything all organised, they had the slider, they have the rubber gloves they’re supposed to use, three sizes, so whatever size they need. I have to repeat this if I want it done.

This client believes that her organised preparation assists new workers who may be unfamiliar with her routine, as well as regular workers, since it speeds up the process, so they may have time to sit and have coffee. Essentially, she resumes the role of ‘teacher’ for her workers until they are ‘trained’ how she likes things done. Moreover, MB Client 3 advises that to maintain continuity in the home care system, arrangements for substitutions of absent workers should be modelled after the school system process. Along the same lines, MB Client 6, who previously worked as a manager, suggests that ‘I would have been fired if I had done things like that at the office’, regarding scheduling and lack of continuity.

Previous employment clearly influences how clients engage with their home care services and how they present themselves to workers and members of the research team. Using experiential knowledge from employment to suggest improvements for the home care system may help clients reaffirm their expertise to the interviewer. Making suggestions and relying on experiential knowledge may also suggest that clients should not just be considered recipients of home care or as doers of tasks, but holistically, as people with full and meaningful lives, who once were more 'productive' than they are now, and who contributed to society in ways respected by a capitalist economic system. Additionally, how clients present themselves to the interviewer, and to home care providers, may help to orient them to the client's viewpoint, preferences and needs – knowing the clients' biography may aid in promoting respect and an understanding of the desired role clients want to play in decision-making and having their needs met with satisfaction.

Control and advocacy for self and workers

In addition to the work identified by Corbin and Strauss (1985), these home care clients regularly advocate both for themselves and their workers. It is worth noting, however, that these clients are not receiving regular nursing supports and are cognitively well, which may enhance their ability or willingness to engage in advocacy work. Advocacy work may both increase one's sense of control over their situation and represent a form of resistance to inflexible and unaccommodating home care systems and structures. This work and its narration might be connected analytically to (a) a desire to maintain a valued independent identity when receiving home care, and/or (b) an expression of continuity of gendered caring identities (when advocating for workers).

For example, MB Client 1, who began the interview cautiously, vehemently explained that she opposes letting home care supervisors into her home to monitor her workers, and by extension, watch her bathe. She remarks:

like if there's no complaints, why are you shadowing my worker? Why are you going to come and watch when the worker's helping me shower? No. I never allowed it ... And I know without them telling me that they're not comfortable with somebody standing and watching what they're doing over their shoulder.

MB Client 1 advocates strongly in her interactions with co-ordinators, both to maintain privacy and to protect workers from what she believes is unnecessary supervision.

Although she has the most home care services and daily visits (four per day) MB Client 4³ is particularly vocal when advocating for herself and communicating her needs. She emails her case co-ordinator each morning to co-ordinate when and which services will be provided, and asks that her co-ordinator send her a reply. She has repeatedly asked her case co-ordinator and team manager for a later bedtime. She recognises that she is not 'their typical client I guess who is basically not home, not going anywhere, waiting for their worker'. Explaining that she likes to go out during the day, this client works to assert a valued (independent/busy) identity, and the participant uses this identity to justify her need to know exactly when her

workers will arrive. The structuring condition prompting advocacy work here is an inflexible home care system that expects clients to work their schedules around the needs of the system. MB Client 4 expresses a sense of pride in her ability to advocate for herself, which itself might be an assertion of a valued – independent – identity within the context of the interview.

MB Client 3 also self-advocates and is confidently calling her case co-ordinator when there are repeated scheduling issues. She explains:

I've complained to my case worker about what stops the scheduling clerk or whatever you call that person at the main office to let the client know that their, the replacement is going to be a half an hour or an hour later as it happened the beginning of this week when I blew my top. It was just too much!

Because of self-advocacy, a scheduling clerk began phoning MB Client 3 regularly if her schedule was being changed. MB Client 3 is also not afraid to tell the case co-ordinator if she is unhappy; MB Client 3 emphasised in the interview that inconsistent scheduling can impact her mood for the entire day. MB Client 3 is also concerned about the impact that poor scheduling practices have on workers, who are not 'machines' who can easily get from one appointment to another in the allotted time. MB Client 3 elaborates that the workers are not even given enough time for bathroom breaks, so she regularly offers her bathroom to her workers even though she is not supposed to. Similarly, MB Client 6 suggests that home care workers are not always treated with respect, care or compassion by the system. She says she treats her workers with respect, and views them not as housekeepers, but as trained medical professionals.

NS Client 4 acknowledges that she can be stubborn, and characterises herself as 'not the kind to let it go'. She requested assignments of only female workers because she felt uncomfortable, and advocated for VON,⁴ the home care nursing service, to stop applying cream on a leg sore/wound that was not infected. NS Client 4 also contacted her agency supervisor when she believed a particular worker was judging the clutter in her home by displaying or revealing her discomfort. She explains:

For somebody who's a cleaning fanatic, to come into this house, there's a lot of clutter. And they would be very uncomfortable and I know that. But I don't want them to show *me* how uncomfortable they are. And make *me* uncomfortable. Because this is my home. So I spoke to her about that and she was changed.

This example not only demonstrates advocacy but reveals how client self-identity can be threatened through the receipt of home care (in this case, through the behaviour and/or moral judgement of a worker). The client's response can in fact be seen as prompted by a desire to assert and maintain a valued identity in the process of receiving care.

As a final example, NS Client 6 self-advocates directly with the care workers. She notices that some of the workers do not completely clean the entire bathroom, or will overlook some things. She has made the workers aware of this if they return to the house. NS Client 6 also self-advocates by refusing a bath – explaining that she is uncomfortable bathing in front of so many different workers, and will sometimes

wait until her sister is home to help her instead. In this case, the context prompting advocacy or agentic reaction is that of inconsistent care and high turnover of workers.

This group of participants may be more willing to advocate for themselves and their workers, as they chose to participate in the study, and want to see changes in the home care system. Additionally, because of the recruitment process, case/care co-ordinators were asked to identify clients whom they felt would want to participate. Likely, clients who have more regular contact with their care/case co-ordinators, perhaps to advocate for themselves, were more likely to be suggested as potential participants. However, even though clients regularly advocated for themselves, in many cases they only did so when they felt it was absolutely necessary, as they noted they did not want to be perceived as a 'squeaky wheel'.

Interestingly, acquiescence (passive assent without protest) also takes effort and can be conceptualised as agentic. As an example from these data, MB Client 5 expressed dissatisfaction with her lack of control over her home care services and closed her interview by saying:

this all just seems like a bad dream. And I just wish that I was well enough to just say, go home! (laughs) I don't want you here. But, I'm very grateful that I have this extra care because I've realised that I just can't do it on my own.

This excerpt may represent a kind of, albeit resigned, acceptance that while frustrating, the home care she receives is vital. This acceptance may require emotional and identity work on the part of the client. NS Client 3 shared a similar perspective about 'taking what she can get' without complaint, as having some services is better than having none at all. NS Client 3 is unhappy with her home because they cannot move around comfortably in a wheelchair, and it is too small for her disabled son with whom she lives. Regarding provincial housing, she explains that 'you can be handicapped or you can be disabled, but you can't be both ... the house is not ideal but we're together. So I maybe put up with a little more shit from home care because of that'. This type of emotion management is similar to the work of acquiescence discussed previously. It involves clients managing both their emotions and their expectations so as not to lose services, or because this is the only service they think they can get.

Communication (co-ordinating with the work of others)

Communication/co-ordination is a common kind of work performed by home care clients, especially in the context of systemic problems with information flow, infrequent assessments and fragmentation in home care systems. Indeed, when asked in the interview to suggest improvements to home care services, clients in both provinces most frequently referred to improving communication with direct service staff, schedulers (in Manitoba) and case/care co-ordinators. As we have addressed in a previous publication (Keefe *et al.*, 2020), in both provinces, infrequent assessments by case/care co-ordinators, accompanied by poor continuity of direct service staff (and exacerbated by the absence of family care-givers) set up a situation in which clients are expected to report changes in service need to the case/care

co-ordinator (or in Nova Scotia, the agency supervisor). As such, the work of co-ordination, including prompting schedule changes and communicating changing needs, often becomes the responsibility of clients.

MB Client 4 advocates for herself by reaching out daily to her case co-ordinator via email to better understand her schedule for the day and to know which workers will be coming. This very agentic stance is uncommon among clients, but MB Client 4 is adamant that she receives confirmation from her case co-ordinator:

I usually give her a report every morning about if I want to cancel somebody. So, I'll say good morning ... I'd like to cancel my lunch visit for today, and let me know. And confirm. Because more often than not, something's happened I don't hear from her, and all of a sudden the message never got through.

MB Client 6 will call her case co-ordinator if her evening workers do not show up – which means she must sleep in her day clothes. She believes that connecting in this way will not only improve her services, but the home care system in general. As such, she keeps track of all her experiences with home care in a notebook. She explains, 'by telling her [case co-ordinator] some of the things I have, and I've got them written down here, the CC [case co-ordinator] was able to improve things at her end too'. However, this work of constantly co-ordinating her own needs and working with home care can be exhausting, especially during periods of disruption, and in the context of what she identifies as poor system responses to scheduled worker absences. For example, when her regular worker was removed from MB Client 6's schedule for three months, she states:

for those three months, I had to call almost every night to see if someone was coming to help me. They knew in plenty of time that [worker would be away]. So, why wasn't someone put in place for those three months?

Although NS Client 3 characterises herself as someone who only contacts home care supervisors for big or important issues ('I try not to bug them if something's wrong'), she reported calling when there are concerns about a worker. Her comment implies a social norm around 'not complaining' unless absolutely necessary. Similar concerns were expressed by NS Client 5, when insufficient numbers of oxygen tanks were impacting her quality of life:

I don't try to take advantage of things. So and I think she [care co-ordinator] realises that when I do ask, and anything that I *have* asked for has made a tremendous difference in my quality of life.

Co-ordinating various aspects of one's own work with that offered by others is an essential part of a functional home care system, however, some clients try to reserve their communication only for emergencies or significant issues. Clients may feel that they do not want to be a 'burden' to their workers or case/care co-ordinators if they complain 'too' much. This may also relate to their desire to be seen as independent, and able to manage as best they can with as little support as possible. Being perceived as a 'good' client may also be a strategic tactic, as clients may

feel that they are more likely to have their concerns managed if they only reach out occasionally, as evidenced by NS Client 3 and NS Client 5.

As evident in the present analysis, the enhanced need for co-ordination work often falls to clients – of prompting and communicating – when their service needs or schedules change, or if they have questions or emergent issues. This can be difficult work when clients are unable to easily reach their care/case co-ordinator or after-hours support. To add a further layer in Nova Scotia, home care services are delivered by private agencies, thus clients need to determine whether to call their agency supervisor or case co-ordinator, depending on their particular needs. Although many clients did not seem troubled by their need to reach out to professionals, in some cases this co-ordination work of communication was very time consuming, and lack of communication could impact a client's entire day.

Interestingly, scheduling is the main concern raised by nearly all the clients in this study, and where schedules are most significantly disrupted and unpredictable, clients are most effortful with respect to struggling to keep on top of the schedule for their services. They work to ensure that they have a backup plan in place, as their services and times are not guaranteed within the current policy context in either of the two provinces. This has particular implications for the amount and extent of work done by clients. For instance, clients are having to engage regularly in co-ordination work by calling or emailing case/care co-ordinators to learn the schedule, cancel their services or find out about a missing worker. Clients may also have to initiate mandated backup plans with friends, family members or neighbours when home care is unavailable, which can put them in a vulnerable position of having to once again ask for help. If clients' backup plans are not available, or they do not have a backup person to call, they do without services and try to manage on their own. Notably, all of the clients in this study had the cognitive capacity to manage, negotiate and communicate their scheduling needs and concerns, thus, they may not be typical of all home care clients.

Adaptation and persistence

Study findings not only highlighted how clients actively worked to adapt to home care services but also at times developed innovative strategies and adaptations to everyday tasks to age in place; these strategies and adaptations need to be understood within the context of limited/inflexible services as well as the broader context of a desire to avoid 'being a burden'. Some adaptations mentioned by participants included relying on family for help during Christmas holidays, so that workers can get time off (MB Client 2), trying to do dishes through repeated attempts and rest breaks, when the worker is unavailable (NS Client 6, MB Client 6), sitting on her walker and pushing herself down the hallway, to conserve energy/oxygen when the tanks were too limited (NS Client 5), and incorporating more 'shortcuts' into food preparation, to compensate for the extra time that this now takes, noting that these food-related shortcuts often result in higher salt content (NS Client 4).

Others spoke of adaptations to their home environment or equipment which helped them age in place. NS Client 6 removed her bedroom door so she could get her wheelchair through and MB Client 1 attempted to fix her broken walker

by taping a missing screw hole with electrical tape – although she eventually had to get a new walker. NS Client 1 purchased a spray shower and sat on a chair to be able to continue to clean himself without help. Because NS Client 3's bathroom is so small, she has put her commode in her bedroom. She also adapted her home to accommodate her wheelchair by asking her landlord to install a ramp, and asking a neighbour to rehing the refrigerator handle to the other side of the door.

In an example of the work of adapting one's own life to meet the needs of the system, MB Client 3 rearranged her own personal morning routine to better meet the needs of the home care workers. She explains:

I usually have my breakfast after. I used to have my breakfast before, but we got a conflict there sometimes because I was still in the tub when home care came, and I was getting upset and so on. So, I changed my schedule because I figured it's easier for me to leave my meal than it is to get out of the tub.

Moreover, MB Client 1's son must take time off work when MB Client 1 has an appointment, since Handi-transit is unable to help MB Client 1 down the stairs.

Instead of waiting for help to arrive, MB Client 5 described an innovative way to get herself up if she falls. She explains:

I literally crawled on my back around on this carpet, to a doorway there, and that's the staircase that goes downstairs. So, once I get there, I get my feet on the banister and grab ahold of the wall, and then I can get up.

Lastly, likely the most drastic adaptation was made by MB Client 4. She was previously limiting her fluid intake because she needed home care to assist her in going to the washroom. The previous arrangement required a Hoyer lift and a toilet commode that she characterised as reducing her quality of life. As such, she suggested to her doctor that she have an in-dwelling catheter inserted to limit trips to the washroom. The client believed this improved her life since she no longer has to wait for home care or limit her fluid intake.

The adaptations made by clients reinforce that in many cases they will use all of the resources at their disposal before asking for additional assistance. Clients are truly taking a neoliberal, individualised approach to caring for themselves before admitting to needing additional assistance. In some cases, the independent adaptations may increase risk for the client, resulting in the need for additional support in the long term. For example, MB Client 1, who attempted to fix her walker with electrical tape, cut herself on her walker and needed nursing support to manage the wound.

Discussion

It is evident that home care clients are not passive recipients of care. There are multiple ways in which they demonstrate and maintain their independence that goes beyond Corbin and Strauss' description of biographical, daily life and illness work to also include advocacy, adaptation and persistence and deliberate 'co-ordination' with the tasks and needs of others in imperfect systems that align

with Dorothy Smith's feminist sociological conception of work that often goes unnoticed. Clients in this study engage in different types of work depending on their functional abilities, personal biographies and location on their illness trajectory. For example, clients who previously worked in health care are more knowledgeable when it comes to understanding and managing their health conditions, while clients who were previously teachers or managers excel at managing their daily routines around the schedule of home care workers. Indeed, even 'acquiescence' might be a particularly overlooked aspect of receiving home care that requires effort on the part of older adults. Acquiescence can be less about passivity and more about coming to terms with some level of dependence, a kind of secondary control strategy (Chipperfield *et al.*, 1999; van Dyk *et al.*, 2013).

The current neoliberal climate certainly favours narratives of independence, self-sufficiency and personal responsibility. As this project has illustrated, many clients in the study have internalised this messaging and used this project's interviews as an opportunity to express, proudly, how home care, despite its imperfections, offers them a kind of independence they likely could not maintain otherwise. They also shared innovative ways they have managed to uphold their sense of self, maintain control as they age and their bodies and needs change, and adapt creatively to difficult circumstances. That said, the very fact that these clients are receiving and do need home care support means that they are not, in fact, fully independent. Focusing on these narratives of independence risks undermining and making invisible the labour care workers offer. While no clients in the study were still 'working' in the capitalist sense of the word (earning income and paying taxes or contributing economically to society), critical feminist sociologists like Dorothy Smith remind us that such definitions of 'work' are fundamentally flawed. A key aspect of 'work' that extends beyond Corbin and Strauss' categories is the 'co-ordination' work clients do to communicate with home care providers and navigate their way through imperfect systems. Sometimes this work takes the form of direct communication about schedules and setting boundaries, other times it reflects a willingness to advocate for their workers who are also trying their best but are not always treated well within these systems. This unique brand of co-ordination reflects, to a certain extent, what disability justice scholars might refer to as 'intimate assemblages' (Fritsch, 2010). In order to have their subsistence needs met, these clients rely on others who in some ways become an extension of the client themselves. That is to say, the work of both client and paid care workers are intertwined in unique and almost invisible ways. Because this work (bathing, personal care, meal preparation, *etc.*) takes place in the domestic space, it is often hidden from the general public. Additionally, the intimate nature of the work, traditionally performed by family members, is unique and falls outside traditional capitalist employer-employee relationships. Essentially, part of the co-ordination work being done involves redefining what work and working relationships mean as our country's population ages. Increasing numbers of older adults will want to remain as independent as possible while also reconciling with the fact that they will need assistance from others in new and increasingly intimate ways. The work is both practical and deeply affective.

Although it did not emerge as a dominant theme in our particular dataset, emotion work done by clients can also be implicated, not only within and across the

other forms of work we examined but also within the interview itself, as participants strove to manage and protect valued identities in the interview interaction (Aronson, 2002). Emotion work can entail both embodied emotional responses to stressors associated with ageing in place, but also the affective aspects of trying to suppress or invoke particular emotions in interactions with other network members (Milligan, 2005). With regards to the former, for instance, the stress and time required for co-ordination work, especially when there is a lack of communication 'from above', can negatively impact a client's mood for the entire day. Additionally, the need for advocacy work often stems from an unpleasant emotional experience such as feeling unnecessarily observed by strangers during personal care. Clients may also believe that they need to manage their emotions so as not to be perceived as the 'squeaky wheel' that requires too many services, thus rendering them a 'bad' client.

One of the key findings of this study that challenges the stigma of dependency in old age is that of adaptation and persistence. In our own experience (as researchers, clinicians and persons with lived experience), stigma manifests in some policy makers' and practitioners' assumptions that once home care clients are in the system, they will continue to push for more, even 'taking' more than they need. The data in this study clearly challenge that suggestion, as the clients do whatever they can do to maintain aspects of independence for as long as possible, and often refuse additional services until absolutely necessary. Clients do not want to be perceived as a 'burden' and will adapt how they approach tasks, even if it takes them longer (such as taking multiple breaks to wash dishes). In some cases, this persistence and desire to avoid 'being a burden' can be considered problematic, such as when clients put themselves at risk before asking for help (e.g. MB Client 3 who will crawl across the floor after falling instead of making a call for help). Further challenging the 'burden' stigma, clients will assist their workers by changing or reducing their own schedules to alleviate stress on workers or give them a break. Clients in this study make every effort not to take more services than they need, and in some cases are not using *enough* services because they want to stay as independent as they can for as long as possible. This, again, can be a double-edged sword – especially when the receipt of services might have preventive or health-promoting benefits in the long term.

Clients in this study generally, with a few exceptions, had fairly high levels of independence and were cognitively well, which reflects our eligibility criteria; those with more independent and conscientious identities may also have been more likely to consent to an interview. These clients, with few exceptions, also relied very little on family members. High levels of independence and empowerment may mean, in turn, that participants in this study were perhaps more able to engage in advocacy for themselves and their workers, or to resist in other ways. For example, MB Client 4 was once a member of a regional home care advisory council, and thus may be more willing than others to state her concerns with home care without fear of reprisal. In contrast, clients who are not cognitively well may have less capacity to advocate for themselves or others and thus would rely more heavily on family caregivers, if available. It is thus important to note that this is not a comprehensive picture of all the types of work done by home care clients. Additionally, the clients in this study were receiving relatively low levels of home support (compression

stockings, housekeeping, laundry, meal preparation), and intermittent or low-level nursing supports. Reflecting their high functional independence, they are engaging in more physical work activities than other home care clients.

This analysis is a snapshot in time of the work that home care clients do. Further research could follow the trajectories of home care clients to determine whether the work they do changes the longer they are with the home care system. Moreover, the COVID-19 pandemic occurred after these data were collected, and future research could ascertain how pandemic-related changes to home care services in the two provinces may have added to the work required by clients to age in place. Further, as a limitation, only two male clients were interviewed; we do believe our data suggest that male clients may be more likely to complete instrumental tasks, while female clients engage in organisational tasks (similar patterns have been observed in research on gendered differences in approaches to family care-giving). Future research should continue to explore gendered differences in clients' approaches to the work of ageing in place, and reflect on gendered inequities that can arise in this regard.

The work done by home care clients must be foregrounded. They are not simply passive recipients of care, but do everything within their power to age at home, maintain their independence and ensure that their workers feel respected. This work may be overlooked by case/care co-ordinators and other health professionals because, like health, ageing is something that we do not think about until we experience a detriment. It may be assumed that older adults are simply 'ageing well' when they are not asking for help because they continue to do the tasks that able-bodied adults can do. Since the focus of home care workers and health professionals is to assess risk and assist with tasks that clients can no longer perform, tasks that they are still able to do may be taken for granted.

Conclusion

Clients who receive home care in this study are independent and agentic. They are not 'dependants' or 'recipients' who rely solely on the home care system for services, but are active participants in their care and in their desire to age at home. They also have a unique standpoint, because they are not entirely independent. Thus, part of the 'work' they do involves forging a way forward for the rest of us who will also one day rely on co-ordinating with others deliberately to ensure our subsistence needs are met while disrupting neoliberal romanticising of self-sufficiency.

The complex and co-ordinated work home care clients engage in serves as a stark contrast to narratives of burden and system drain that are prevalent in practice, policy and media arenas that focus on apocalyptic demography. It is important for clinicians, including home care workers, to acknowledge the work done by home care clients as integral to their wellbeing and to willingly co-ordinate and continue to provide supports that compliment, and do not replace, their continued contributions. Respecting biographical work and agency is something that varies depending on the approaches of health-care professionals. Thus, there is a need for structures that support and value, and even encourage client input, while respecting clients' preferences for involvement in particular kinds of work.

Findings from this study suggest that a nuanced approach to understanding client agency and engagement is needed. In particular, requirements to engage in particular kinds of effortful work can be conceptualised as necessitated by the broader context of how home care services are structured and delivered, and in some cases, the findings have highlighted forms of work that can be experienced as points of struggle (as when trying to stay on top of ever-changing service schedules) or resistance (as when trying to advocate for oneself within the context of limited services). Moreover, the findings highlight the potential for gendered differences to emerge, and further research is needed to ascertain the extent to which gender identity shapes not only how clients engage in particular types of work, co-ordinate with one another in domestic settings and interact with key actors in their care convoys, but also how gender, as a social location, shapes access to service over time. Further research may also include a sample of participants who have more diverse physical and cognitive capacities, as well as an ethnically diverse sample to determine if ethnicity shapes the work of home care clients. It may also be useful to investigate how the larger care team interprets the work done by home care clients. A broader, client-centred approach to operational policy development within home care service agencies and health authorities, as well as a gender-based lens, would help recognise when the appropriate policy response would require *reducing*, not increasing, the kinds of work we ask clients to do to receive health-promoting services and to age in place at home with supports.

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Ethical standards. Ethics approval was obtained using a two-site model, with site-specific clearances received for the Client/Service Data Stream and the Constellation Data Stream, and secondary clearances received from the study lead's institutional research ethics board at Mount Saint Vincent University. Constellation Data Stream: primary ethics approval for the WRHA (Manitoba) study site was obtained from the University of Manitoba Psychology/Sociology Research Ethics Board (protocol number P2018:146 (HS22462)) and by the WRHA Research Access and Approval Committee (reference number RAAC 2019–003). Primary ethics approval for the NSHA (Nova Scotia) study site was obtained from the Nova Scotia Health Authority Research Ethics Board (file number 1024409). Secondary approvals for each study site were obtained from Mount Saint Vincent University Research Ethics Board (file number 2018–087 (Manitoba); file number 2018–202 (Nova Scotia)).

Notes

1 While both provinces have publicly funded home care, the Nova Scotia Home Care Program is delivered through private agencies.

2 Ethics approval was obtained using a two-site model, with site-specific clearances received for the Client/Service Data Stream and the Constellation Data Stream, and secondary clearances received from the study lead's institutional research ethics board at Mount Saint Vincent University. An informed consent form was

mailed or emailed to each participant approximately one week in advance of their interview, to allow the participant an opportunity to review the form and raise any questions. Written informed consent was then obtained by the person conducting the interview during an informed consent discussion prior to the interview commencing.

3 This client was previously a member of a home care advisory council; as such, she knows who to ask questions of, and what kinds of questions need to be asked.

4 Victorian Order of Nurses for Canada.

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Appendix 1. Client profiles

Client	Gender	Age	Time receiving home care	Type of support	Number of hours of support per week	Previous employment
Manitoba Client 1	Female	86	5 years	Morning and evening personal care; bath twice a week; intermittent nursing	9	Nurse
Manitoba Client 2	Male	96	3 years	Morning and evening personal care; compression stockings	7	Radio broadcaster
Manitoba Client 3	Female	86	2 years	Morning and evening personal care; compression stockings; light housekeeping	9	Teacher
Manitoba Client 4	Female	65	15 years	Morning care (transfer from bed to wheelchair via a sling, dressed/bathed, breakfast, 45 minutes of physiotherapy); midday and evening (heat and serve, catheter care); night-time (toileting and transfer to bed); bath twice a week; nursing care three times a week	55	Nurse
Manitoba Client 5	Female	67	5 years	Morning and evening personal care; medication assistance at lunch and supper	10.5	Homemaker
Manitoba Client 6	Female	96	2 years	Morning and evening personal care; compression stockings; light housekeeping	9	Manager
Nova Scotia Client 1	Male	84	6 years	Light housekeeping; bulk meal preparation	3	Civic address co-ordinator/stevedore
Nova Scotia Client 2	Female	84	2 years	Light housekeeping	2	Music teacher
Nova Scotia Client 3	Female	61	2 years	Personal care; light housekeeping; bulk meal preparation; oxygen services	30	Cook
Nova Scotia Client 4	Female	76	8 years	Morning personal care with shower; compression stockings.	5.5	Business owner – ceramics

(Continued)

Appendix 1. (Continued.)

Client	Gender	Age	Time receiving home care	Type of support	Number of hours of support per week	Previous employment
Nova Scotia Client 5	Female	60	6 years	Light housekeeping; home oxygen; nursing services for approximately 1 month after colon surgery	1	Receptionist/maid
Nova Scotia Client 6	Female	64	6 months	Personal care and light housekeeping and laundry; received increased services (not specified) after her surgery, and a hospital bed and sock aid	5	Bank teller