

## Research Article

# Problematizing Dominant Assumptions about Unpaid Support through Exploring Case Study Profiles of Older Home Care Clients

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Despite efforts to acknowledge diversity among unpaid caregivers, Canadian research, advocacy, practice, and policy tend to be based in and to reproduce dominant social and institutional expectations and assumptions about who provides unpaid support and why, and what this support looks like. The objective of this thudinal, qualitative research study. In that study, qualitative case study interviews were conducted with twelve home care clients, their identified family or friend caregiver, home care aide, case coordinator, and agency supervisor (129 interviews in total). Case study profiles compiled over time generated deeper information about the availability and capacity of informal sources of support for these clients, which prompted abductive analysis in relation to dominant assumptions typically made about caregivers in research, policy, and practice. Specifically, only one case (participant) had a caregiver whose profile closely matched dominant conceptualizations. In the remaining eleven cases, we found situations wherein: (a) caregivers grappled with physical or mental health challenges limiting their participation in care (sometimes meaning the client is themselves a caregiver, or the caregiver is also receiving home care services); (b) caregivers facing burnout sought to delimit their participation in care; (c) caregivers' participation was limited by older adults' reluctance to accept their help; (d) caregivers were largely unavailable, unreliable, or peripheral; or (e) client's unpaid support networks were diffuse without a clearly central or identifiable "caregiver." Findings are used to nuance and problematize widely held assumptions about caregivers, particularly their availability and capacity. Discussion highlights the need for research, policy, and programs related to unpaid caregiving to better reflect the lived realities of this support for older adults and often overlooked sources of diversity in caregiver circumstances and roles.

## 1. Introduction

The COVID-19 pandemic in Canada has exposed the hard work of many unpaid caregivers supporting older adults, making this labor more visible to the public and to policymakers [1–3]. Along with this, however, the pandemic has also indirectly led to a reinforcement of certain assumptions about caregiving in the public sphere, including who does it, why, and under what conditions. Analyses of public

discourse around care in research, advocacy, and policy, have documented dominant perceptions of unpaid caregivers as voluntarily self-sacrificing, fully available and able to step in, and of care as unidirectional [4–7]. These perceptions exist alongside the persistence of social expectations that family members, particularly women, function in this role (see also [8]). These assumptions persist in the public sphere even despite growing attention to other sources of caregiver diversity based on variation in "stages" of care

provision, life stage (including young caregivers), racialization, sexual orientation, or care recipients' medical conditions. Research has also explored the intersecting contributions of these kinds of demographic or categorical indicators of diversity to differential outcomes or correlates of care provision (e.g., [9]). Other sources of variation between caregivers that are less easily addressed through quantitative and demographic measurement remain less visible (or not formally diagnosed); this can include variation in orientations toward or identification with the caregiving role, for instance, [10–12].

Research over the years has identified problematic assumptions about unpaid caregivers that are embedded and reproduced in existing policies in Canada and elsewhere [13–16]. As an example, home care programs in some provinces also require clients to provide the program with contact information for a person who can provide “backup” care in the event of worker or service cancellation; this policy assumes each client has a person like this in their lives. Many home care programs also orient to caregivers as a resource, not a person with distinct needs from the person receiving care nor as someone who may want to be involved in decisions related to the care situation [17]. Moreover, despite growing a focus in research and policy on caregiver needs assessments in clinical interactions, many such assessments and their responses almost wholly focus on helping unpaid caregivers to remain in the role and on identifying future risks of burnout. An exception is the C.A.R.E. Tool (“Caregivers Aspirations, Realities and Expectations”), which prompts caregivers to reflect on when they might become unable to continue [18]. Among the spouses caring for a person with dementia in that study, such a prompt “may serve as a catalyst for taking action in their caregiving situation or turning to services for help” [19].

Similar assumptions about unpaid caregivers can be reproduced in interactions with professionals in health and social care services [20]. Indeed, even our traditional conceptions of “carer supports” and the suite of services provided might institutionalize dominant perceptions of carers. One assumption in this regard that has received critical attention of late is that caregivers will and/or should self-identify [21], or that this identity will take priority over other roles [22]. Another assumption is that of the predominant role of biological family [23], which has been challenged by increasing attention to fictive kin in LGBTQ+ older adults' networks and resulted in a broadening of definitions of “family” over the decades in policy documents. Sutherland et al. [24] have also examined gendered family care assumptions among professionals in hospice palliative home care, and the gendered nature of care is itself obscured in policy narratives or caregiver advocacy more broadly. Lastly, a critique of homogenizing assumptions about ethnocultural minority family caregivers of older adults has also emerged [25]) with Koehn et al. [26] countering that older adults' support from and “trust in family members should not be taken for granted, since family dynamics are complex” (p.83). Lastly, other scholars have pointed out that unpaid

caregivers are often older and/or themselves living with a disability [27, 28].

As aging in place at home gains increasing emphasis in the public and policy sphere, it is important to revisit and critically reflect on assumptions about unpaid caregivers, including but not limited to family members. For instance, existing research and advocacy foregrounds the voices of caregivers who self-identify and are fully committed to provide care (even if they face challenges to doing so). Those who are “reluctant” or trying to set limits on care [29] as well as those who do not self-identify are far less likely to participate in either research projects or public advocacy. As such, policies built on this evidence base tend to focus on helping to support unpaid caregivers to continue in their role, rather than to scale back or leave, even in unsafe situations [29, 30].

Assumptions about caregivers thus might further be inadvertently reinforced in research which starts with caregiver standpoints and perspectives. Foregrounding caregivers is a worthy moral and political endeavor, as well as reasonable from a research design and logistics standpoint. However, a more fulsome and comprehensive understanding of unpaid care for policy could also start from the standpoint of older adults receiving such support. As such, the purpose of this study is to explore access to unpaid care from the perspective of a small group of older home care clients (twelve “cases”) who participated in a broader longitudinal study of trajectories over time. The present analysis develops unique insights into these older adults' complex lived experiences of access to unpaid supports in the context of their familial, friend, and community relationships, as well as insights into sources of variation in caregivers' situations. In the discussion, we nuance and problematize dominant and institutionalized assumptions about caregiving and reflect on broadening the understanding of variation in caregivers' situations.

## 2. Methods

In Canada, the funding and provision of nonmedical home care supports is organized by each province or territory, meaning each province decides on the amount and types of publicly funded home care services that are offered, and how these are delivered. For instance, in Manitoba, public agencies deliver service, whereas in Nova Scotia, either not-for-profit or for-profit organizations are contracted. Across Canada, home care is positioned in policy as key to aging and place and addressing high costs of institutional forms of care. However, broader healthcare system pressures across the provinces mean that older clients with chronic and long-term care needs at home tend to be disadvantaged by growing diversion in home care program resource allocation toward clients with short-term postacute care needs.

Data for the present analysis came from the qualitative component of a larger, multimethod longitudinal research project that aimed to explore how particular configurations of home care programs and practices shaped the trajectories and service use of older clients receiving nonmedical supports, in the provinces of Manitoba and Nova Scotia [31].

Both provinces have similar population size, aging populations, and increased home care service demand and also grapple with providing this service in rural areas.

As part of the larger project, the team identified, recruited, and interviewed older home care clients, who were then asked to identify whether there was a caregiver (such as a family or friend) that they also wanted us to approach about being interviewed. Full details of recruitment are provided elsewhere [31]. In brief, home care clients were recruited from a list of eligible clients compiled by home care case coordinators in both provinces, who were asked to send study information to everyone on their list. In this study, clients were excluded if they had moderate or severe cognitive impairment, or if they were only receiving home care nursing services.

Home care clients, and where applicable, their identified caregivers, were interviewed at three points in time, along with an identified home care aide/support worker, and designated home care case/care coordinators (and in Nova Scotia, their agency supervisors). Even for clients where a designated caregiver was not identified or did not participate, these clients were asked about their access to sources of help, at each of the three interviews. In addition, home care workers, case coordinators, and agency supervisors interviewed for the study also often spoke about the clients' access to informal supports. All these data (129 interviews with 49 participants, as well as interviewer field notes and minutes from team discussions) contributed to the analysis presented below, as they contributed to and informed analytic case study summaries of clients' situations that focused on change over time. Background information relevant to the client and their informal supports is presented in Table 1. This table identifies whether there were any sources of informal support identified, as well as whether a caregiver was interviewed for the study. Pseudonyms are used.

Time points for data collection spanned both pre- and postonset of the COVID-19 pandemic in these two provinces. Qualitative, semistructured interviews lasted 43 minutes on average. Participants were asked about changes in the clients' home care services over time and how these came about, as well as other questions about channels of communication, use of services in addition to public home care, overall wellbeing, and suggestions or improvements for the home care system.

Preliminary data analysis grounded in the goals of larger project involved data familiarization among the team, followed by crafting descriptive, narrative-style case summaries of all interviews. Creating and reflecting on these were done in regular, ongoing analytic discussions among the research team over four years. These discussions also helped facilitate reflexivity among the team [32], especially as, over time, we sought to understand and position this emergent analysis as a distinct, but important offshoot of the larger project and its goals.

As we continued to explore and revisit our data on the unpaid sources of support of client participants (regardless of whether a caregiver was formally interviewed) over several years of the project, we also became attuned to the realities and conditions under which these individuals provided

supports. Theoretical sensitivity that led us to recognize the divergence between participants' informal supports and dominant conceptualizations of caregivers was likely informed by our disciplinary backgrounds and training in sociology, social gerontology, and critical social theory. Analytic comparison of our findings to mainstream policies, practices, and media accounts of unpaid support for older adults was further facilitated given that the first author was simultaneously conducting research into the latter topic at the time. Together, these forces further informed and shaped our abductive analysis [33], which helped us revisit and problematize dominant understandings of the conditions and sources of unpaid support for older adult home care clients.

### 3. Findings

A surprising, inductive finding that arose in the context of the early analyses (rooted in the larger project objective) was that the unpaid support received by these twelve older adults indicated that few if any had access to unpaid caregivers who aligned with mainstream or traditional perceptions. Instead, a diverse array of situations were documented and synthesized in our abductive analysis, including situations in which (1) family members grappled with physical or mental health challenges limiting their participation in care (sometimes meaning the client is themselves a caregiver or the caregiver is also recipient of home care services); (2) caregivers facing burnout sought to delimit their participation in care; (3) family members' participation was limited by older adults' reluctance to accept their help; (4) "caregivers" were unavailable, unreliable, or peripheral; or (5) client's unpaid support networks were diffuse (widely and thinly spread) without a clearly central or identifiable "caregiver."

To start with, we profile one client, Robert, who was the only participant of the twelve who could be considered to have access to a more "normative" family caregiver. Robert was a widower in his 90s who was described by his case coordinator (CC) as having uniquely low needs, though he did receive home care help with compression stockings at T1. For this reason, however, Robert's daughter did not consider herself as a caregiver, although she did participate in an interview for the study. She assisted her father with visiting, transportation, and some household maintenance and errands. He would bring groceries to her if he noticed they were on sale. After the onset of the COVID-19 pandemic, she started dropping off meals instead of having him over; she was also running some errands for him for a time. Robert experienced some social isolation during the pandemic but by T3 was visiting with family again. He had fallen twice since T2 and had some increased pain and trouble walking far distances. Although Robert was adamant about staying home, and his daughter spoke of wanting to respect his wishes, she expressed awareness in her interview of other options and has discussed them with her siblings. Should Robert's health decline, a clear plan had been developed. Robert therefore appeared, at this time, to have straightforward access to family support. Overall, there was a sense that should his health or function decline in the years ahead, his daughter may eventually self-identify as a caregiver.

TABLE 1: Overview of client participants and role of family/friend caregiver.

Client	Age range	Time with home care (TI)	Type of support (TI)	Previous occupation	Tasks completed by family/friend caregiver	Family/friend caregiver was interviewed for study
<i>Manitoba</i>						
Dorothy (1)	80–89	5 years	Morning and evening personal care. Bath 2x/week. Intermittent nursing	Health professional	Coresident son—meal preparation, laundry, transportation	No
Robert (2)	90+	3 years	Morning and evening personal care. Compression stockings	Communications	Daughter—weekly meal prep. Large household maintenance	Yes
Annette (3)	80–89	2 years	Morning and evening personal care. Compression stockings. Light housekeeping	Educator	Son—transportation, grocery shopping, large household maintenance	Yes
Carol (4)	60–69	15 years	Morning care (transfers, dressing/bathing, breakfast, physio). Midday and evening (heat and serve, catheter). Night-time (toileting, transfer). Bath 2x/week. Nursing care 3x week	Health professional	None	N/A
Margaret (5)	60–69	5 years	Morning and evening personal care. Medication assistance at lunch and supper	Homemaker	Coresident husband—personal care, cooking, household maintenance, cleaning, laundry, transportation	Yes
Ethel (6)	90+	2 years	Morning and evening personal care. Compression stockings. Light housekeeping	Manager	Niece—emergency contact	No
<i>Nova Scotia</i>						
Harry (1)	80–89	6 years	Light housekeeping. Bulk meal preparation	Manual laborer/civic bureaucrat	Sister-in-law—short-term, live-in support postsurgery	No
Agnes (2)	80–89	2 years	Light housekeeping	Educator/arts	Daughter/son-in-law—large household maintenance	No
Pauline (3)	60–69	2 years	Personal care. Light housekeeping. Bulk meal preparation. Oxygen services	Food services	Neighbor—grocery shopping, transportation	Yes
Ruth (4)	70–79	8 years	Morning personal care with shower. Compression stockings	Business owner/arts	Coresident daughter—housekeeping, laundry, transportation, animal care	Yes
Bertha (5)	60–69	6 years	Light housekeeping. Home oxygen. Nursing services for approximately 1 month after colon surgery	Receptionist/cleaner	Sister—transportation	Yes
Martha (6)	60–69	1 year	Personal care and light housekeeping and laundry. Postacute service	Clerical/accounting	Sister—occasional meals, shower supervision	No

*3.1. Caregiving Limited by Family/Friends' Own Physical or Mental Health Challenges.* For at least five client participants (Pauline, Ruth, and Bertha in Nova Scotia; Annette and Margaret in Manitoba), their close family or friends had their own physical or mental health conditions that limited their capacity to be more fully involved. The situations of Bertha and Pauline are elaborated below.

Bertha was a low-income woman in her 60s who lived on her own in a seniors' apartment building in urban Nova Scotia and had low levels of home care service at T1. Over time, cutbacks in her oxygen tanks and other issues led to considerable distress as well as lowered activity tolerance, reliance on oxygen tank support, and financial strain, by T3. Seven months before the start of the study, Bertha had been living with her sister, who was also in her 60s. Her sister remained her primary family caregiver and was identified as such for the study. However, when asked about other sources of family support, Bertha referred to both geographic distance and personal health challenges in her broader family:

*"Yeah, my daughter's going through some stuff and my son's out in [another province], my older sister well she's just as bad shape as I am pretty much, and my brother lives over in [another city], and he has emphysema."*

Bertha's sister experienced chronic health problems and mental health issues that limited her capacity for care involvement, which primarily involved taking her sister grocery shopping. This took about four hours at a time, a long and complicated process involving transferring oxygen tanks and accessing a key for the mobile unit in the store. Because of her sister's worry about driving on busy streets, Bertha usually drives the car to the store. In one case, Bertha fell when they were out, which her sister described in her interview as very difficult and stressful.

By T2, Bertha's sister was visibly upset and emotional in her interview about her sister's swift decline in wellbeing. She acknowledged both that her sister needs more care but also that she cannot provide it herself. By T3, Bertha was in a desperate situation but expressed that she was hesitant to call upon sister, stating "she's going through a lot herself" (referring to her depression).

Another Nova Scotia home care client, Pauline, was a low-income woman in her 60s who was close to the maximum hours of home care at T1 and whose health declined significantly over time. Pauline lived with her adult son who had mental health issues (including severe anxiety) that limited his own ability to care for himself, and he would not, according to dominant perceptions, be considered a caregiver for his mother. Instead, a friend and former neighbor who provided some support was interviewed as the caregiver for the study (she is discussed further in another section). In her interview, this neighbor positioned Pauline as in fact the primary caregiver for her son, noting how Pauline worried greatly about him during her periods of hospitalization. By T3, it was clear from multiple sources (especially the worker and neighbor) that a more accessible home or a residential facility might better address the client's

high physical care needs, but Pauline was determined to stay in her home. She stated that she would rather live in a largely inaccessible home with her son than anywhere that would be more comfortable for her but would leave her son on his own. Pauline expressed her frustration, however, about policy:

*"According to provincial housing, you are allowed to be handicapped and have a handicapped accessible unit, but only if you are on your own. . . They are basically saying, you can be handicapped or you can be a family but you can't be both."*

The linked lives of family members/friends who support each other in complex ways are evident in these cases yet are not well exemplified in typical understandings of unpaid support "received" by older adult home care clients. Especially in the context of mental and physical health issues and low-income situations, home care clients can be actively caring for and about others in their lives. Even as those around them strive to help to the best of their ability under difficult circumstances, these older adults' access to certain kinds of task-based support might in turn be limited, with implications for their quality of life and ability to age well at home.

*3.2. Caregivers Facing Burnout Sought to Delimit Their Participation in Care.* Identified primary caregivers for two Manitoba participants, Dorothy and Margaret, as well as Nova Scotia participant Ruth, became burned out over time due to care strain. In these cases, forces related to the COVID-19 pandemic and/or pre-existing physical or mental health limitations may also have contributed. Dorothy and Margaret's situations are analyzed in more detail in this section.

Dorothy was a former nurse in her 80s who lived with her adult son who worked full-time. She also had a daughter who did not live with her. Their CC explained that when Dorothy first started with home care about five years ago, she had "tons of service" and a poor prognosis. Although her health conditions did not change:

*". . . her functional status is slightly improved and we've been able to decrease her service. I think if it wasn't for the support of her family, as an informal caregiver, she wouldn't do as well as she does."*

Dorothy's son helped her get breakfast and lunch ready before leaving for work, removed her compression stockings, and did laundry and cleaning. Notably, a recent change in Handi-Transit policy (that would have required her to get her walker down the stairs herself to meet them at the curb) meant Dorothy also needed to rely more on her son to take her to doctor's appointments (for which he had to take time off from work). At T1, she also conveyed a sense of reciprocity in describing her busy day folding the laundry or doing dishes while sitting at her walker by the sink. At T2, however, she described her son as doing "everything." Over

the course of the study, with falls and increasing depression, Dorothy's home care services increased to the maximum.

At first glance, Dorothy's son might appear to be a picture of a normative caregiver. When asked if there was a caregiver we could interview for this research study, however, Dorothy suggested her son would be too busy to participate. She did not want to ask him because he was already doing too much. She also used a dismissive tone when asked if her daughter might be considered a potential caregiver (while referencing her daughter's poor physical health).

At T2, Dorothy mentioned that because of the pandemic, her son was home more to help, but would be returning to work in September. Dorothy's CC noted that the home care program added two nights/week of overnight care to prevent caregiver burnout, but the son called and asked for five nights because he was not managing well. By T2, the CC had met with Dorothy and her son and daughter to discuss the possibility of a move to long-term residential care, which had occurred by T3. As one healthcare aide (HCA) indicated, a lack of home care staff may have limited the ability for respite to be increased for the client (there were significant staffing constraints within the home care program after the onset of the pandemic).

At T3, it became apparent, from the interview with Dorothy's CC, that Dorothy's daughter advocated on behalf of her brother to prompt Dorothy's move to a residential care setting. Only the daughter, and not the son, attended the care planning conference. The daughter stated that her brother could not say "no" to his mother, and she intervened to insist that Dorothy could not return home. The CC also noted that it could have been possible to bring Dorothy home by shifting some services around, yet she stated, "the fact is that the, the son didn't really want her to come back home any more and he was burned out but he didn't really want to say that."

In Manitoba, Margaret identified her coresident husband as her caregiver. However, he himself had been experiencing physical health challenges around T1, for which he received some home care service as well. Indeed, when we first reached out to contact him, he was in hospital, simultaneously trying to coordinate his wife's home care service. By T2, Margaret's husband's health had improved. As such, Margaret's own home care services, which had been quite extensive at T1, were then at T2 reduced somewhat and her husband's own service ended. Margaret's husband was able to participate more in care, which was also facilitated by their move to a more physically accessible apartment.

Margaret's husband coordinated his wife's formal supports and completing most (if not all) household tasks. By T3 however, he needed respite—the stress of care responsibilities was compounded by stresses associated with the pandemic and Margaret's declining mood and wellbeing—and she had several falls since T2. By T3, Margaret's husband was doing all cleaning and household maintenance (they formerly paid their neighbor to do this, but this stopped after the onset of the pandemic). At a hospital's recommendation, Margaret's husband was given three respite hours of home care per week. Moreover, despite pressures on home care offices to pause

services during the pandemic, the CC did not cancel any client services, stating:

*"I kept the respite for [caregiver] and all of Margaret's priority 2 and 3 services because I don't want to create more stress for them because if he's not able to manage, then I don't know. Margaret might end up in a long-term residential care home. So, we need to take good care of [caregiver] as well, in order to take good care of Margaret."*

In Manitoba for example, priority 1 services are those that a client cannot go without (e.g., medication assistance), while priorities 2 and 3 services are not considered emergent or medically necessary, but rather as services that could be cancelled or rescheduled with more flexibility. Margaret's husband explained in his interview that he used respite hours to run errands and was hoping to request more respite once the pandemic is over so that he can take more of a break.

Both Dorothy and Margaret had coresident caregivers providing direct task-based forms of support, which helped to maintain their quality of life at home. As above, however, considering clients as "recipients" of family support is a simplistic way of understanding richer realities of reciprocity (mutual exchanges) and "caring about" (such as how Dorothy did not want to burden her son further with research participation). In addition, available informal support from family members appeared in both cases to have been directly tied at some points in these clients' trajectories to a reduction in formal home care supports in the home, as in a substitution model. This was then followed in both cases by later reactive increases to services when caregivers were then really struggling, trying to set limits on their involvement in care. For Dorothy, her son's respite or related support from the public system was insufficient to prevent caregiver burnout and admission to long-term residential care, and it is possible that a similar outcome might eventually happen for Margaret, even as the CC tried to prevent this.

**3.3. Home Care Client Does Not Want to Rely on or Burden Their Family Member.** In at least two situations, home care client participants' access to potential informal supports appeared to be limited primarily due to their reluctance to rely on family. The reasons for this, however, are not necessarily easily reducible to pride, but are revealed as more contextual and relational. Examples below are provided for Nova Scotia home care client Martha, a former caregiver herself, and Manitoba home care client Annette, who had three sons but no daughters.

Martha, a woman in her 60s on long-term disability benefits, had moderate needs at T1, and her home care services slightly increased over time. At some point in the past, she had declared bankruptcy and "lost everything," at which point her sister had invited her to move in. By T1, Martha had moved into a seniors' apartment building. At T2, Martha also expressed that it was hard for her to ask for help—she believes others need home care more than she does, and she also did not want to burden her family. She contextualized this by explaining that she had been

a caregiver for her parents in the past and experienced it as burdensome. Thus, even though Martha's daughter and sister helped (with shopping, delivering groceries) especially during pandemic-related service pauses, it was unclear how long this support would last or how comfortable Martha was with this situation in the long-term.

Annette was a woman in her 80s who lived alone. Though her needs for care were low at T1, they increased somewhat over time. One of her three sons lived nearby, and although he was uncomfortable identifying as a caregiver, he did participate in the research interviews. He assisted his mother by taking her on social outings, to appointments, picking up groceries, and installing home modifications. At T1, he had recently discovered that the home care program can provide more services and wanted her to receive assistance with bathing and meal preparation. Although he stated that his mother is a proud woman who likes to be in control and is reluctant to accept additional help, he also mentioned that she is anxious about worker and scheduling issues, which might inform some of her reluctance. Annette also appeared reluctant to engage her son's help, as her son stated:

*"Even with myself like when I go there, and I say, 'here I'll do this.' And then she gets upset with me. And she says, 'no, I'll do it, I'll do it.' And just let her be. So I just, instead of getting into an argument. . . you just [say], 'okay. Let me know if you need help. . . ' And then she says she doesn't want to overburden me either. And I go, 'Mom, it's okay.' Just, but. . . if I can do it, I'll do it. But if I can't, like I have my own kind of issues too. Like I have (medical condition), so I have a hard time walking."*

Although Annette's son emphasizes his desire to help, he is also aware of and expresses his sense of his physical limitations. More directly related to the present theme, however, is how the excerpt also reveals that Annette's "pride" may be a more relational concern for her son and these limitations. This is further reinforced in another excerpt where Annette emphasized the limits of what she would ask her sons:

*"I don't have daughters or anything, it seems to be people who have daughters or a close friend, female friend, that sometimes they can get more help that way. The boys are very nice. I can ask them anything and they will do anything. But I mean when it gets to that part, it's also the privacy part, you know? I wouldn't feel too comfortable having one of my sons coming in and giving me a sponge bath. I don't want to ruin his life for the rest of his life (laughs)! I don't want him to get so darn scared (laughs) with seeing Mom in the nude! That might shock the poor guy! (laughs)"*

By T3, Annette and her family had discussed the possibility of her move to assisted living (she had friends who recently moved there). In this way, Annette's reluctance to ask for more help from her sons especially with personal care may have been an underlying factor behind the decision to consider assisted living.

In sum, Martha's previous experience as a caregiver made her wary of asking for help from her family, yet her history of financial and health precarity restricted her ability to limit this help in ways that aligned with her preferences. For Annette, negative experiences with formal home care services combined with a gender-based reluctance to ask her sons to help put her in a difficult spot that could precipitate a potential move to assisted living setting.

*3.4. Potential or Actual Caregiver Is Estranged, Peripheral, or Nonexistent.* For a few client participants, access to reliable unpaid caregiving support could best be described as bounded or limited in some way (Ethel in Manitoba), or in one case (Carol in Manitoba), as nonexistent. Ethel and Carol's situations are outlined below.

Ethel was a widow in her 90s, whose health and mood declined over the period of the study. Though with no children of her own, at T1, she mentioned she frequently has supper with extended family. Although she did not identify or refer an informal caregiver to participate in the study, it appears the designated "home care backup" for Ethel (a requirement of the home care program) is her niece. Ethel stated, however, that her niece will not come over on short notice to help if services are canceled and will forget to phone Ethel and let her know that her services are canceled. She added:

*"I guess [the home care program] figure if they phone my niece she'd arrive and help me. But my niece, well, let's not talk about families. I just know that she won't come and help me at that end."*

Ethel expressed some frustration that a home care program policy requires her to have her niece listed as an emergency backup contact person in the case of cancellations. She does not understand why they would contact someone who faces challenges to responding to such calls, and would prefer that they contact her directly:

*"The last time they were cancelling, one of the nights I slept in my clothes was, they phoned my niece, to tell her that there wouldn't be anyone available. I guess they figured that she would come here and help me. Well, she's at the other end of [city]...Which would mean she'd have to come and come back in the morning and dress me and undress me and all the rest of it. Well, she's a grandma, she has other kids to look after, so she doesn't have to look after me. So, I said please, if you're going to make a change, please phone me, don't phone my niece. I'm the one that's home."*

The reasons behind Ethel's apparently "unreliable" support are complex. According to the CC, the niece's family was dealing with health issues and thus unable to help frequently. A cousin who had previously helped appears to have had an argument or falling out with Ethel. In the absence of reliable unpaid support, Ethel was herself keenly aware of her strong need for home care service to be able to stay in her own home. Her support network became even more tenuous during the pandemic, since she had even less

access to both family and friends, generating social isolation. Despite this, she was adamant about staying in her home.

Carol was a woman in her mid-60s with high needs and maximum services at T1. The help she needed included lift transfers and medical tasks. Carol's home care services were reduced during the pandemic, and her health declined over time; eventually, she could no longer leave her bed. She personally hired private home care agency services at great personal financial cost and stress, but also refused additional nursing care due to frustration with the nurses. A strong personality (that at times irked home care staff and the CC), Carol was strongly committed to staying in her home, which was becoming an increasing challenge given her complete lack of access to unpaid support coupled with home care service challenges, especially given the complex nature of her physical needs.

Such examples challenge assumptions about the nature and quality of family relationships, as well as access to an ideal vision of family-based unpaid support, that can be inadvertently embedded in policy and practice. Many relationships involve aspects of ambivalence as well as solidarity. Over time, reduced access to informal support can erode overall wellbeing and ability to stay at home especially when people are unable to purchase private sources of support. When systems are designed in ways to assume a certain level of commitment and involvement (especially of family members) in care, they marginalize older adults without meaningful access to these supports in their family relationships and further increase their need to rely on publicly funded home care services that, in the context of COVID-19, have become particularly precarious. A similar situation arises when unpaid support networks are more diffuse, as illustrated below.

*3.5. There Is No Specific "Point of Contact" but a Diffuse Network of Sometimes Weaker Ties.* Over the course of the interviews, it became evident that three Nova Scotia client participants (Harry, Agnes, and Martha) had access to what could be described as a more diffuse (spread thin) through proximal network of ties, through their neighbors in seniors' apartment buildings, or their geographic community. Their situations are analyzed further below.

Harry, a man in his 80s with low needs for service, developed a network of neighbors after he moved into a seniors' apartment building prior to the first interview. At T1, he did not have family support for care, though a sister-in-law had helped in the past for a brief period after his surgery. Harry's supports were in this way diffuse, and interactions between neighbors were negatively impacted by the pandemic. At T3, Harry expressed concern for the low-income tenants without cars and wished they could have someone drive them for groceries and to medical appointments. He regularly shops for one or two other tenants in this situation (thus assisting with care of others) but told us he cannot do more.

Agnes' network might also be classified as diffuse, though she was more highly embedded in stronger and more diverse ties within her rural community (including neighbors, Church, family, and workers). A woman in her 80s with low needs for service, Agnes also pays for some services

privately. Her neighbors and, to some extent, four children who live in the province (but are more geographically distant) help her with chores, though she emphasizes the empowerment associated with receiving home care services: "it helps you realize that oh yes, I can live here alone for quite a while. . . knowing that someone cares is tremendously important, someone besides my family." Being well surrounded, Agnes was only minimally impacted by the pandemic, with friends and neighbors filling in gaps that arose and mitigating social isolation.

Martha, whose family situation was described earlier, believed there was a good sense of community in her retirement building. She sometimes relied on other tenants who own cars, for transportation. At her third interview, however, she recounted, with a sense of shock, a story about a friend in the building who died unexpectedly and alone in her apartment. Martha and the other tenants did not realize that this had happened initially—during the pandemic, tenants were less accustomed to seeing or checking in on each other (for instance, as they previously would have at events like bingo nights). As such, this type of diffuse network could be viewed as weakened during the early period of the pandemic, even as Martha expressed that the incident had strengthened the resolve of her friends to try to keep a closer eye on each other.

What these examples demonstrate is how extended family, neighbor, and community networks can provide an important "latent matrix" of support for some older adults [34] especially in the context of community structures that facilitate this support, such as retirement villages or small rural areas (just as these older adults were also actively contributing to support others in these networks). Home care services should also be considered part of this matrix of support. These findings further suggest a role of social and cultural capital (as well as living arrangements) in these networks, with concerns that social exclusion can be compounded for those without access to such networks, especially when those older adults also have high needs for assistance.

## 4. Discussion

Our findings contribute to a body of scholarship, which highlights important complexities of care provision, including reciprocal exchanges of support in care relationships, reluctance to self-identify as a caregiver, situations of violence or a lack of love, and structural forces shaping the capacities of unpaid carers (e.g., [10, 21, 30]). Findings from the present study further expand, nuance, and problematize existing conceptual, methodological, and institutionalized perceptions and assumptions of caregivers, and should also prompt reflexivity about assumptions about older adults' access to fully capacitated and involved sources of unpaid support, both in Canada and beyond.

In addition, the findings highlight the need to consider complex sources of variation in older home care client's access to supports, even beyond those more typically being considered in caregiving research today (gender, socio-economic status, racialization, and urban-rural residence).



Specifically, normative assumptions in policy, practice, and some research that institutionalizes system reliance on unpaid care also obscure other circumstances that bound or limit caregiver involvement. This includes geographic distance, physical and mental health, relationship quality, gendered expectations, institutional policies, access to formal respite, and competing care responsibilities, among others. Considered together, the myriad of variations in situations shaping older adults' access to informal sources of support tends to go unrecognized within home care system policies. Instead, the extent to which such circumstances are considered in care planning relies largely on the professional judgment and experience of case coordinators.

Our findings suggest methodological reflection is needed on a collective knowledge base about unpaid and informal caregiving that is built primarily on voluntary convenience samples of identified caregivers (for a related argument, see [35]). Recent efforts to integrate diversity in the knowledge base are important, but need to integrate qualitative approaches that extend beyond demographic characteristics and categorical measurement to unpack complexity. Quantitative social network analyses of unpaid care (e.g., [36–38]), especially those that integrate considerations of bidirectional helping relationships, may also be helpful for further research. The overarching research project from which the present data were drawn did not specifically measure or map networks nor observe specific functions performed by unpaid caregivers.

To some extent, dominant understandings of “caregivers” were embedded our own recruitment process (even through the use of the term “caregiver”), although we did allow for a broad definition of family, as well as for nonkin to be identified by clients. Another limitation of this study is that some identified caregivers did not participate in an interview. Despite these gaps, and the reliance on self-report data, however, we were able to triangulate information from multiple participants familiar with clients' situations. Importantly, the participant selection process also meant that home care clients with significant cognitive impairment (that may be receiving more significant levels of unpaid support) were excluded. In addition, since racial and ethnic diversity was not a specific focus during recruitment, participants were all white, which is a further limitation. Clients from racialized and especially immigrant groups may have access to more family supports through multigenerational living or stronger expectations of familialism, although we also need to be cautious about such assumptions [25]. Indeed, future research with larger and more diverse samples of client participants, for instance, in terms of characteristics such as sexual orientation, might reveal even more complexity in informal care situations and circumstances.

These important nuances related to care were further identified in this analysis. For instance, the reciprocal nature of support in caring relationships was exemplified in clients who provided care for coresident children who were struggling, as well as clients who expressed a desire to protect and “care about” their family member or friend by not asking for help. In addition, whereas most research on caregiver wellbeing tends to focus on health outcomes of

care provision, the present analysis reminds us this is a distinct circumstance preceding the client's need for care (though it may be exacerbated further by care provision). The ways that mental health conditions can delimit the ability of a family member, friend, or community member to provide expected care should also be explored in ways that help care providers move beyond stigmatizing judgments about capacity. Lastly, although our findings highlight potential benefits of locally based yet peripheral or diffuse networks for older adults' access to informal supports, it is unknown whether these would be sufficient to help people age in place with high care needs. Moreover, such networks may be more likely to develop for those with high social capital, or who have lived for a long time in a small community—for instance, what happens to these networks when older adults have to move from these home communities to receive healthcare services in urban areas, or when those living in affordable seniors housing buildings are displaced when these buildings are sold or privatized.

Although we did not set out to document substantive differences between the experiences of a diverse range of people providing unpaid support (because our primary point of contrast was against dominant perceptions, assumptions, and conceptualizations of caregiving), this should also be explored more fully in future research. The situations of most unpaid support persons may have diverged from self-identified, nonrandom caregiver samples in terms of baseline physical and mental wellbeing, willingness, and availability. It is also possible that when unpaid supports are more peripheral or diffuse, support persons may be less likely to express caring out of a strong love or bond; additionally, no one person may feel responsible for doing “everything” or being a “watchdog” vis-à-vis healthcare providers (e.g., in contrast to a more traditional sample of caregivers [39]). Moreover, when tasks like care coordination are done by close family caregivers experiencing significant health challenges, this can compound struggle and worry (e.g., as experienced by Margaret's husband when he was hospitalized just prior to T1).

## 5. Conclusions

This analysis invites us to consider how our assumptions about unpaid caregivers can inadvertently infuse and reinforce dominant conceptualizations of caregiver needs, with important implications for older adults and their families. Further research is needed to document the extent to which public narratives continue to promote universalizing views of unpaid caregivers as fully skilled, willing, and able to help. Such conditions could marginalize families and older adults whose situations are more complex. Fundamentally, we also need to continue to better ascertain the nuanced realities of access to unpaid forms of support to age in place in aging populations, moving beyond efforts to identify one “designated” caregiver or “backup” within healthcare systems to encourage professionals to practice critical reflexivity and nonjudgmental, comprehensive assessment of persons providing informal support, beyond their potential role as resources to support aging in place.

## Data Availability

To protect the privacy of participants, qualitative interview data used to support the findings of this study are restricted by the University of Manitoba Research Ethics Board 2 (HS22462), the WRHA Research Access and Approval Committee (2019-003), and the Nova Scotia Health Authority Research Ethics Board.

## Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

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