REVISIONING SENIOR CARE IN NEW BRUNSWICK: WHAT CAN WE LEARN FROM INFORMAL CAREGIVERS?

RÉFORME DES SOINS AUX AÎNÉS AU NOUVEAU-BRUNSWICK: QUE POUVONS-NOUS APPRENDRE DES PROCHES AIDANTS?

Michelle N. Lafrance, Lynne Gouliquer, Carmen Poulin, Cassandra Swift, Valérie Godin, Lauren McWilliams, and Moira Kinney

Abstract

The COVID-19 pandemic has laid bare the significant challenges that exist throughout Canada's approach to senior care. In this research, we explore the accounts of forty-four informal caregivers (Anglophone and Francophone) of older adults aging-in-place in New Brunswick with a view to understanding their challenges in providing care. Interviews were conducted between 2016 and March 2020, when the lockdown came into effect in New Brunswick. The participants' most common complaint was the health/home care system itself, which they described as disjointed, opaque, and confusing. Drawing on authentic extracts in both English and French, we detail the challenges they faced, the strategies they used to cope, and their suggestions for change to policy and practice.

Résumé

La pandémie de COVID-19 a mis à nu les défis importants dans l'approche du Canada en matière de soins aux aînés. Dans cette recherche, nous explorons les témoignages de quarante-quatre proches aidants (anglophones et francophones) d'adultes âgés vieillissant chez eux au Nouveau-Brunswick afin de comprendre leurs défis dans la prestation de soins. Les entrevues ont été menées entre 2016 et mars 2020, lorsque le confinement est entré en vigueur au Nouveau-Brunswick. La plainte la plus courante des participants concernait le système de santé et de soins à domicile lui-même, qu'ils ont décrit comme décousu, opaque et déroutant. En nous appuyant sur des extraits authentiques reproduits en anglais et en français, nous identifions les défis auxquels ils ont été confrontés, les stratégies qu'ils ont utilisées pour y faire face et leurs suggestions de changement de politiques et de pratiques.

Introduction

The purpose of this research is to highlight the voices of informal caregivers of older adults in New Brunswick. The COVID-19 pandemic brought sharp attention to the profound problems with the ways in which older adults are cared for in Canada. While Canadian researchers have been sounding the alarm about senior care for years (Banerjee; Funk; Keefe; Molinari and Pratt; Armstrong and Lowndes; McGeorge and Bateman), the pandemic has brought public focus to the issue, with the bulk of the attention understandably falling on the crisis in long-term care (LTC) homes. The ability of these homes, which are understaffed and under-equipped, to provide adequate care crumbled under the weight of the pandemic, leaving a devastating death toll (National Institute on Aging [NIA] 5). As the crisis revealed, deep investment in revisioning LTC is urgently needed. And it is just the tip of the iceberg. What is being overlooked in the dialogue around senior care are the serious inadequacies beyond the walls of LTC facilities. Although older adults in LTC represent the frailest amongst Canada's seniors, only 6.5% of Canadians aged sixty-five and older live in LTC homes (Garner et al. 13). To address limitations in senior care in Canada in a serious manner, the lived realities of all seniors who require supports (in and out of residential care) must be considered. Furthermore, it must be noted that the bulk of care delivered to older adults is provided by unpaid informal caregivers and not by paid professionals (NIA 7). Knowing that older adults were safer outside of LTC homes during COVID-19 (NIA 5) and that most care work is carried out by unpaid caregivers highlights a critical need to understand the caregiver reality.

Informal caregivers are the spouses, adult children, family members, and friends who provide unpaid assistance to individuals often with serious and ongoing needs (Roth et al. 310). They account for a significant proportion of the Canadian population, representing more than one in four citizens, or over 8 million people (Turcotte 1). Caregivers engage in a range of tasks, including the following: cooking; housework; house maintenance and yard work; scheduling appointments; providing transportation; managing finances; administering medical treatment; and helping with personal care, including bathing, dressing, and toileting (Lee 31; M. Sinha 3). While often invisible in the health care system, informal caregivers provide the vast majority of the care work performed and the country's health system could not operate without them (Wiles 189). Indeed, the NIA asserts that "in Canada, family and friends are the greatest source of ongoing care for older people" (19). Accordingly, informal caregivers have been described as the "backbone of the health and Long-Term Care system in Canada" (Canadian Healthcare Association 63).

However, more and more care work is being shifted to this invisible backbone, and as a result, the state of informal care in Canada is at a critical juncture. The COVID-19 crisis has exacerbated public distrust of the LTC system, all the while politicians are extolling the need to divert older adults to homecare. Ubiquitous terms such as *homecare* and *community care* continue to erase from view the work that informal caregivers do to enable such arrangements. Yet, informal caregivers often face tremendous challenges in occupying this important role, including high rates of depression and reduced mental health, financial strain, and poor physical well-being (NIA 7; M. Sinha 3; Turcotte, 1). Thus, it is widely acknowledged that "although family caregivers perform an important service for society and their relatives, they do so at a considerable cost to themselves" (Schulz and Beach 2215). While informal caregiving is regarded as cost-saving by governments, the long-term costs to caregivers (and, frequently, their own subsequent reliance on the health care system) are not acknowledged (Wiles 194).

With an aging population, increasing rates of chronic disease, and decreased hospital spending, the need for informal caregivers has been escalating at a dramatic rate. For example, the number of individuals requiring homecare in Canada increased almost 100% between 1995 and 2006 (Canadian Healthcare Association 28). Adding to this, the number of older adults requiring care alone is expected to double by 2040 (Keefe 12). Many of these population trends represent good news as people are living longer, remaining in better health over time, and predominantly aging in place (Statistics Canada, "Portrait of the Canadian Population in 2006," 11). At the same time, the number of individuals available to provide such care is on a sharp decline due to population trends over the past several generations, including declining family size, higher divorce rates, increased participation of women in the workforce, and greater geographical dispersion of family members (Roth et al. 310; Williams and Crooks 244). Therefore, we are experiencing a *caregiving crunch* of increasing need in a time of reduced capacity (Zimmerman).

This caregiver crunch is acutely felt in New Brunswick, which has one of the highest proportions of older adults in Canada, second only to Newfoundland, and a province that is aging quickly (Statistics Canada, *Annual Demographic Estimates*, 21). Whereas in 1930 the average life expectancy in New Brunswick was sixty-one years, today it is eighty-one years (New Brunswick Council on Aging 5). By 2040, it is expected that there will be three seniors for every two young people (Atlantic Provinces Economic Council 1). In reflecting on these demographic trends and the crisis in health care for seniors in the province, McGeorge and Bateman warn of a new reality, while asking incisive questions: "The population will continue to age; the rural north will continue to depopulate; the pressure for change will continue to mount. Is the province up to informed, constructive change to meet the challenge? *What will it take to prompt the change that is required?*" (24; emphasis added). If we do not address the crisis in senior care in New Brunswick now, then when will it be addressed? Given that the provision of care for seniors relies heavily on the availability of informal caregivers, New Brunswick needs to care for and about this invisible unpaid workforce.

The purpose of this paper is to shed light on the experiences of informal caregivers of older adults in New Brunswick (Anglophone and Francophone, urban and rural), with a view to harnessing the COVID-19 crisis for positive change in a post-coronavirus reality. As Pat Armstrong and Ruth Lowndes write, "In order to understand what works when improving care, it is a good idea to speak with those doing the actual caring" (41). We draw from our interviews with these invisible pillars of our health and care systems to ask two key questions. What are the challenges that informal caregivers face in providing care for older adults in New Brunswick? And what changes in policy and practice are required at both provincial and federal levels to better support older adults and their caregivers?

Methods

Participants

Participants were forty-four informal caregivers of older adults aging in place in New Brunswick. They were recruited via advertisements in flyers, community newsletters, and social media (Facebook post). Twenty-seven were Anglophone and seventeen were Francophone, ranging in age from thirty to eighty-nine. Most participants were women (37), and participants were evenly distributed between living in urban (23) and rural (21) locations. Participants were recruited from across the province and represent a wide range in terms of income levels (from $5,000 to over $150,000/year) and educational background (some high school to graduate degrees).

Most participants described being a primary caregiver for one individual (28), with the remaining caring for two (11) or more (5) individuals. Participants provided care for parents (28), spouses (11), in-laws (5), siblings (4), as well as other relatives including cousins, aunts, and sisters-in-law. Participants cared for individuals with a variety of health conditions including dementia (19), cancer (12), cardiac disease (8), macular degeneration or blindness (6), post-operative complications (6), mental illness (5), stroke (4), Parkinson's (2), renal failure (2), and muscular dystrophy (1). Of course, many care recipients experienced multiple health conditions (e.g., cancer and dementia) that also overlapped with a host of additional conditions such as diabetes, arthritis, physical immobility, pneumonia, vertigo, incontinence, difficulties with eating, and frailty. Most participants described providing intense levels of care (e.g., feeding, bathing, and administering medical treatments that ranged from medication to at-home dialysis). Many participants were also working while providing care (20), while some were retired (23), and one was unemployed. All participants described providing care in the home (either their own home or the home of the care recipient) at some point, with many also relating receiving homecare support and/or transitioning to residential care.

Methodology

After being fully informed about the nature and purpose of the study, participants were interviewed in a location of their choice (e.g., their homes or an office on campus). Interviews were conducted between 2016 and 2020, with the last one taking place just before the COVID-19 lockdown in March. Interviews were handled in either English or French, then audio-recorded and transcribed verbatim. Interview recordings and transcripts were subsequently analyzed in the language in which they were spoken, and both English and French quotes are authentically presented in this paper. Analysis was conducted using the Psycho-Social Ethnography of the Commonplace Methodology (P-SEC; Gouliquer and Poulin). P-SEC is an interdisciplinary qualitative approach developed to examine the sociological and psychological worlds of marginalized groups. It has been successfully used to investigate the experiences of various groups, including LGBT soldiers (Poulin et al., "Violating Gender Norms in the Canadian Military…"), military gay servicewomen and their partners (Gouliquer and Poulin); women firefighters (Poulin et al., "Pompières…"); women correctional officers (Burdett et al.), and older adults living at home (Gouliquer et al.). Its theoretical pillars include feminist standpoint epistemology (Harding), institutional ethnography (Smith 1987, 2005), and schema theory (e.g., Beals; Bem). P-SEC represents a structured approach to explore the complex interplay between the social, organizational, and political contexts of people's lives, their psychological experiences, and their resilience.

Analysis began with reading and rereading transcripts while listening to audio recordings. To make the data set manageable, transcripts were first coded into recurring topics and the current analysis began with an exploration of all codes related to participants' interactions with the system (homecare, hospitals, doctors, social workers, long-term care, etc.). These codes were then analyzed together according to the four stages of a P-SEC analysis. First, we conducted a thematic analysis of the data (Braun and Clark, 2006, 2013). Second, we identified the "organizational moment," which is an ordinary, everyday event, situation, or circumstance that arises at the intersection of the political and the personal. Organizational moments are borne out of institutional practices, policies, rules, or regulations that serve the needs of organizations, but they structure and complicate the lives of individuals who must operate within their confines (Gouliquer and Poulin). Third, we identified and defined the complications for participants that resulted from the organizational moment. Fourth, we analyzed the data for the cognitive and behavioural coping strategies that participants employed to deal with the organizational moment. Finally, we are mobilizing the results of this study for social change, which includes the production of this open-access article. In conducting research from the standpoint of those providing informal care on the ground and learning from their experiences, a central goal of this research is to develop policy recommendations that will be most beneficial to those directly affected.

Results

Organizational Moment: New Brunswick's Approach to Caring for Older Adults

A central and defining element of the organizational moment—New Brunswick's approach to caring for older adults—was the disjointed, opaque, and confusing system participants had to navigate. In fact, this is not one system but an agglomeration of several overlapping systems, spanning different governmental divisions (notably, the Departments of Health and Social Development), and various public and private services. As a result, people did not know where to turn for help. As Isabella said, "Les gens ne savent pas où aller frapper" [People don't know which door to knock on]. The following extracts exemplify participants' struggles in navigating the system:

> Where are you going to find out? You're the daughter and you have to put your mom in a home. It's gotten to that point she can't live alone anymore […]. Like, what do I do? Where do I start? Who do I talk to? (Diane)[1]
>
> I want to find out about foot care. Do I go to Social Development? Do I go to Public Health? Do I go to her health insurance? Do I go to homeworkers or to a private agency? By the time you make those five phone calls you might have an answer […]. It's all scattered. There's no cohesiveness at all. (Margaret)
>
> La bureaucratie, c'est vraiment terrible. C'est un des points les plus difficiles. On ne sait pas où aller, on ne sait pas quoi faire, on ne sait pas quelles sont les ressources, on ne sait pas. [The bureaucracy is really awful. It's one of the most difficult points. We don't know where to go; we don't know what to do; we don't know what resources there are; we don't know.] (France)

Participants expressed particular confusion about all the different levels of long-term care. In New Brunswick, long-term care is fragmented into special care homes (Level 2) for those needing low to moderate degrees of care, and nursing homes (Level 3A) for those requiring full-time nursing care. These are further subdivided into general care (Level 3G), memory care (Level 3B), and care for those with more complex needs (Level 4). These are privately owned and operated but inspected and licensed by the Department of Social Development. Not surprisingly, many struggled to understand the system. As David said, "[I] wasn't really sure what the difference was between a special care home and a nursing home." Carolyn, a nurse, described how the language used in the system is "intimidating" and obstructs public understanding. She noted, "People don't understand."

Several participants were also confused by the evaluation process for long-term care and questioned why assessments are conducted by a social worker at the Department of Social Development. Instead, a number of participants insisted that this role requires medical expertise. Chris exclaimed, "You would think it would come from the doctor," and Jennifer said, "I don't know that Social Development is the right person to assess a person's needs. […] I don't think that social workers should have to have that call." Similarly, Denise articulated, "It should be an RN doing the medical assessment. […] It should be someone with special skills who can do the assessment not just the paperwork. And that's what I find is happening."

Complications

The Burden of System Navigation

New Brunswick's approach to caring for older adults complicates the lives of participants because it takes time and energy to navigate the system and find services. The disjointed approach to care at the policy level has concrete and negative effects on the lives of older adults and their caregivers. As Margaret's account above suggests, searching for information and services consumes copious time and energy, which are often in short supply for caregivers. Stephanie's experience corroborates Margaret's account: "The advocacy piece is just exhausting. […] I found it was really like a second job." She described eventually having to leave her job to be able to offer full-time care for her mother, who had cancer. Lucienne, who was seventy-five years old at the time of the interview, described regularly spending full days trying to track down supports for her ailing cousin who lived with her:

> Je courre partout. […] J'appelle Fredericton, j'appelle … il y a une journée, j'ai passé la journée sur le téléphone avec les travailleurs sociaux, le développement social, à essayer d'y trouver de l'aide. Ça n'a pas de bon sens. […] Il y a des journées là, c'est du plein temps juste pour elle. [I run everywhere. I call Fredericton, I call … A day ago, I spent the day on the phone with social workers, Social Development, to try to get help. It does not make sense. […] It's days doing that, it's full-time just for her.] (Lucienne)

Compounding this complication and reflecting the disjointedness in how care is organized in New Brunswick was that participants very often received inconsistent information from different sources. For instance, Chris described receiving contradictory information from different long-term care homes: "You go into these nursing homes, one group tells you one thing, another group tells you something else you know, and you're never getting—you go to four homes, you almost get like four different answers […] and then you're lost." (Chris)

Tracy also expressed frustration with the fragmentation in the system and its consequences for the care that her ninety-nine-year-old mother received. When Tracy's mother was discharged from the hospital, she was eligible for short-term services under the Extra-Mural Program, which is managed by Medavie Health Services New Brunswick. Through this program, Tracy arranged to have homecare services, which in turn involved hiring a private agency. Her mother liked the homecare worker and Tracy was grateful for the care her parent received. After several weeks, however, her mother's file was transferred to the Department of Social Development, and she was told that she had to switch agencies and was no longer able to hire this care worker. She recounted her conversation with her social worker at Social Development as follows:

> "'No, no. You can't keep that agency.' / 'Well, why?' / 'Well, they're not on our list.' So, part of the problem right there is there are two lists. Social Development has a list, and Extra-Mural has a list. So, the companies, they're not the same. The lists are different. So, we had to switch. Which is very - when you're ninety-some-years-old, it's upsetting. It's upsetting to me; it's very upsetting to her." (Tracy)

This poignant excerpt shows the high level of frustration experienced by caregivers and the elders for whom they are responsible while navigating a system organized in a way that seemingly does not make sense. As Tracy's account illustrates, this disjuncture in the system had serious implications for her mother's well-being as well as her own. Fragmented systems result in fragmented care. Participants' accounts make evident that the disjointed, opaque, and confusing way in which the system is organized compounds their care burden by disrupting care, requiring the expense of time and energy, and introducing layers of frustration.

Unreliable Services

Fragmentation was described as a problem *across* departments, agencies, and services, as well as *within* the same service. Many participants described homecare services as particularly unreliable. First, they noted the high rate of turnover among paid caregiving staff, resulting in the regular introduction of new people into the home. Marilyn complained that this interruption in care is distressing for her mother. She said: “My mom has social anxiety [...] and so it’s hard to keep changing homemakers on her.” Such disruptions are also hard on caregivers who must scramble to educate incoming staff. Mary and France both described the kind of personalized knowledge and relationship required to provide proper care:

> It’s a challenge when somebody new comes. […] It seemed like every Monday there was a new person, so when you’re bathing somebody […], I mean if somebody new comes in she doesn’t, remember, right? […] But the challenge is on us because then suddenly it’s like, “Okay so somebody new is coming.” Then somebody has to be there to explain to them, “Here’s the routine.” Yes, there’s a book and yes, there’s notes, and yes, there’s information but it’s the particular foibles of, “Okay [mother-in-law]’s going to say she’s full after three spoonfuls, but you’re still going to have to figure out a way, like you do with a little kid, cajole and baby and say, you know, [speaking quickly and playfully] “Oh no there’s only, five spoonfuls! Five spoonfuls! Five three three three three two two…. last-one, last-one, last-one, okay we’re done!” Right, that’s the kind of stuff you have to tell people because it’s hard to read that information in a book. (Mary)
>
> Elle [l’employée] sait où sont les affaires, elles sont habituées [elle et ma mère], elles s’adorent, elles s’adonnent bien ensemble, elle sait ce qu’elle aime manger, comment elle aime coiffer ses cheveux, à quel coiffeur elle va, comment ça marche ses médicaments, qu’est-ce qu’elle fait quand elle se gratte, comment la faire arrêter de se gratter, tout ça, c’est tissé serré pis ça marche; on a aucune…, “no complaints.” Puis là, tu prends une nouvelle madame, puis il faut tout recommencer à zéro. [She (the employee) knows where the stuff is, they are used to each other, they adore each other, they get along well, she knows what she likes to eat, how she likes to style her hair, to which hairdresser she goes, how it works with her medication, what she does when she scratches, how to stop her from scratching, all that, it’s tightly woven, and that works; we have no…, “no complaints.” Then, you get a new woman and you have to start again from zero.] (France)

As these accounts highlight, care work is relational. It is not simply about having a person physically present to perform a set of tasks (like a mechanic working on a series of cars). Instead, care requires trust, intimate knowledge, and intimate acts, including dressing, bathing, and toileting. In short, good relationships are required for good care.

Also challenging was the common problem of having homecare workers simply miss scheduled shifts, with little or no warning. This was a frequent complaint across the interviews. As Janet described, “Maybe they’ll come or maybe they won’t come. Maybe they won’t call! So, there are a lot of problems with the homecare providers.” Jennifer recounted extensive problems with her mother’s homecare agency who routinely cancelled shifts at the last minute:

> It was like every other day, “Oh so-and-so can’t come today” or “So-and-so has a doctor’s appointment and can’t get there ’till two.” So, it was... just juggle juggle juggle all the time! It was generally either an email or a phone call at 8:30 in the morning and they were supposed to be there at 9:00! (Jennifer)

Jennifer described her attempts to maintain her full-time job while juggling the constant cancellations as a “complete nightmare” that took a significant toll on her health. To add insult to injury, Jennifer, Bernard, and many others complained about the lack of accountability of private homecare agencies and the government that funds them. In particular, participants complained that homecare agencies were being paid for services that were never rendered:

> If a person is approved for twenty-five hours a week and the homecare agency is awarded to provide that care, what happens when they're calling at 8:30 saying "Oh nobody's going to be there that day"? Like where are the checks and balances? How do we know that they weren't getting paid for those hours? The worker I know wasn't getting paid, but how do we know the agency wasn't getting paid? (Jennifer)
>
> Les heures qu'eux autres [les employés] sont payés! Ils sont payés pour le nombre d'heures, […] donc, si je suis censé avoir quarante heures par semaine, puis [les employés] sont payés pour quarante heures malgré qu'ils m'en donnent juste vingt-huit ou trente? [The hours that they (the employees) are paid! They are paid for the number of hours, … so, if I am supposed to have forty hours per week, then (the employees) are paid for forty hours even though they give me only twenty-eight or thirty?] (Bernard)

Chris described being "infuriated" by the constant cancellations and the fact that his mother had to continue to pay for services not rendered:

> I contacted the head office [homecare agency] and said, "Well, we've lost nineteen hours this week. We'd like to make it up." She came back and told me, "We don't have to make it up. [...] That's company policy." And here I am thinking to myself, company policy! My mother is paying for a service where through no fault of her own, your worker doesn't have to show up, and you're telling me you don't have to make up for those hours which the province says I'm allowed to have, and which I pay, which I need to keep my family together! (Chris)

Like Chris, Diane talked about confronting the homecare agency that billed her for hours she did not receive. Diane described her incredulous and angry response to being shown signed timecards in her father's name:

> I said, "Well that's not my father's signature." "Well, how do you know?" I said, "Well number one, he lives with me! Number two, I've got tons of stuff he's signed over his lifetime. Number three, nobody showed up. And number four, I'm an ex-employee at [nursing home]." […] Somebody called me forty-five minutes later and says, "Oh well, there's no charge." (Diane)

In sum, participants described significant challenges in locating and securing good care as a function of the disjointed and confusing maze that makes up how care is officially organized in New Brunswick. Participants' accounts highlight a fragmentation of services spanning numerous departments and agencies that left gaps in care. They also noted issues of accountability by private agencies contracted by the government to provide services. Before continuing to explore the challenges that they faced, we should also highlight that some participants did report finding good care and that this made all the difference.

Exceptions: Finding Good Care

Naomie described being fortunate to have found wonderful care staff to help look after her ninety-four-year-old mother. She said: “J’ai des bonnes femmes, j’suis chanceuse, j’ai vraiment des bonnes femmes.” [I have good women, I am lucky, I really have good women.] Along with her two sisters, and five homecare workers, Naomie and her supporting team ensure that her mother receives around-the-clock care. Naomie further noted that having care workers who are kind and caring with her mother gives her peace of mind: “J’ai des femmes qui la gâtent, qui sont bonnes avec elle. Ça fait que […] je n’ai pas besoin de m’inquiéter.” [I have women who spoil her, who are good with her. That means that … I do not need to worry.]

Margaret also noted the importance of good relationships for quality care. She hired a woman to stay with her mother while she was in the hospital awaiting placement in long-term care. She said that her mother was “attached” to this woman and that they “get along very well.” Many participants talked about the critical difference that caring staff made in their lives and the lives of those for whom they care. Doctors, social workers, nurses, homecare workers, and long-term care staff were all described as helpful by being caring, attentive, supportive, and responsive. Moreover, participants’ accounts highlighted that good care also involves skill and the provision of practical support. For Barbara, who cared for her husband with advanced dementia, finding a “good cook” and a “good cleaning lady” who were “very caring and nice” helped significantly to ease her workload.

Although many participants found small pockets of help, their talk of the governmental care system was dominated by talk of struggle. Helen, who was eighty-nine years old at the time of the interview, stood out as an exception. She had undertaken palliative care at home for her husband, who died of cancer. Because of his terminal medical condition, he qualified for care under the Extra-Mural Program, which she described in glowing terms:

> [Extra-Mural] set the whole thing up and had somebody coming at the drop of a hat and […] the doctor in the palliative care, she came every Monday regularly. First thing Monday morning she’d turn up, so I always knew I had really good backup. And it gives you confidence to carry on when things get difficult. […] I don’t know that I could’ve done it without. (Helen)

Helen ended our interview by stating that the reason why she participated in our study was her desire to highlight the value of the Extra-Mural Program. At the time, there were rumours (soon to be verified) that the program would be partially privatized, as Helen mentioned: “I really wanted to talk about Extra-Mural and emphasize that because... I just think... I’ve heard rumours that it could be privatized. Or I don’t know what they’re planning, but if they ever decide they can’t fund it, then that would be really cruel.” As Helen articulated, the provision of consistent and responsive support by a team of experts enabled her to conduct the intense work of caring for her husband at home. Good care was not solely a function of *good people* but a *good system*. Her situation comes into sharp relief against the accounts of other participants who recounted story after story of insensitive and indifferent care.

Unresponsive and Uncaring Care

Participants voiced several common complaints about their experiences with how care was organized. One disadvantage was having to rely on professionals who did not respond to their questions and calls for help. As Cynthia described: "Trying to get a hold of people, people not calling back, […] that piece was hard." Judith and Chris both described frustrating attempts to deal with the Department of Social Development to secure long-term care:

> They never got back to me. The lady that was looking after it [her husband's application for long-term care] apparently was on stress leave. Anyway, I don't know where my messages kept going to, but I never got a call. (Judith)
>
> I'm sending emails off to try to get answers out of them. She [social worker] won't reply to me via email […] and then you have to call her up in order to try to get the answer that you've been waiting for two weeks. Thinking that she's working on it, but she never was, and that was the exhausting part of working with the government. (Chris)

France and Gérard also lamented the unresponsive service. France described her social worker as being like a "robot" who answered questions with as minimal effort as possible. Similarly, Gérard characterized his social worker as being on automatic pilot, telling him to fill out forms, but leaving his questions unanswered. Both participants articulated feeling very alone, confused, and frustrated:

> Elle [la travailleuse sociale] là, c'est vraiment difficile d'en parler. On a vraiment l'impression de la déranger. […] Elle n'est pas intéressée. Elle fait le strict minimum pour répondre aux questions. Comme un robot. C'est vraiment tannant. [She (the social worker), that, it's really difficult to speak about it. We are really under the impression that we are bothering her. […] She is not interested. She does the bare minimum to answer questions. Like a robot. It's annoying.] (France)
>
> On l'attend là. On dirait qu'elle [la travailleuse sociale] ne travaille pas avec moi. Elle travaille seulement si c'est par cœur. "Tu dois remplir ce formulaire-là dans cette affaire-là, puis voilà!" C'est tout! J'ai dit: "Oui, mais tu sais, c'est moi qui dois essayer de trouver mes propres solutions, tout seul, sans aide, sans personne." [We are waiting for her there. We could say that she (the social worker) does not work with me. She works only if it's by heart. "You must fill out that form in that thing there, then there you are!" That's all! I said, "Yes, but you know, it's me who has to try to find my own solutions all alone, without help, without anyone."] (Gérard)

A lot of participants also complained about the quality of care provided by homecare agencies and their staff. In contrast to those who described securing caring and skilled care, many were surprised and dismayed at the level of service they received, which Judith described as "very, very basic." Furthermore, participants depicted homecare workers who spent the time watching television or scrolling on their phones. Chris recounted that one worker "fell asleep several times." When asked what homecare workers did in the home, Jennifer replied: "Sitting. Some of them brought knitting, some of them brought books, some of them had crafts they worked on, some of them just sat and watched TV. She [Mother] was usually in the room with them but a lot of sitting." Tracy also complained about markedly inattentive care that left her mother frightened: "They would leave my mother in her TV room unattended for hours. And I'd come home and the girl that was in charge […] would be at the kitchen table with her laptop doing her office work. And my mother told me 'I was afraid.' She said, 'I thought I was here by myself.'" Participants often contrasted this level of care with what they had hoped to receive—active and engaged help in the home. As a paraplegic in a wheelchair, Katherine's father needed a lot of help to remain living at home.

They had hoped to get help with getting groceries, running errands, paying bills, and house cleaning, but each request was refused by the homecare agency that they hired. She recounted her father's frustration:

> Mais dans leur concept du travail, non, ils ne lavaient pas les vitres, ils n'avaient pas le droit de faire ça, bon. Papa, lui, il disait: "Bon bien, as-tu lavé mon fourneau?" […] Non, eux autres, ils ne lavaient pas ça. Ce n'était pas dans leurs tâches. Laver l'intérieur du frigidaire? Non, ce n'était pas dans leurs tâches non plus. Pis bon, mon père a dit: "C'est quoi que vous pouvez faire?" [But in their conception of their work, no, they did not wash windows, they didn't have the right to do that, good. Dad, him, he would say, "Well then, did you wash my stove?" … No, them, they did not wash that. It was not amongst their tasks. Washing the inside of the fridge? No, that was also not in their tasks. Then well, my father said, "What is it that you can do?"] (Katherine)

Many participants connected such poor-quality homecare to the low educational requirements and pay associated with this work. Denise said, "They're sitters is all they are. They're sitters! […] And they get paid for what they do. And that's all they do. There's no education." Similarly, Jennifer stated: "I don't know about standardized training. I don't know what they have to be a homecare worker, but most times it was glorified babysitting."

Participants also expressed significant concerns about the quality of care in nursing homes. For instance, when asked if she had considered long-term care for her mother-in-law, Mary responded that it would be her "death sentence," as they would not be able to spend the hours it takes to get her to eat enough to survive. Chris, too, feared for his mother: "If you have such deep love for your mum, you're almost scared of putting her into the system." Participants expressed concerns that nursing homes were "short-staffed" (Tracy) and workers were "stressed out and overloaded" (Amy). Cantin was a former employee in a nursing home. He linked these staffing issues to compensation, stating that the government was dreaming if it thought more people would want this kind of hard work for poor pay: "Il y a de moins en moins d'employés, puis ils [les gouvernements] sont en train de rêver là; ils font des promesses, mais ils [les employés] ne sont pas payés." [There are fewer and fewer workers and then they (the governments) are in the process of dreaming there; they make promises, but they (the employees) are not paid.] Notably, care recipients also shared these fears. Noémie reported that her mother refused to go to a nursing home since she was well aware of the dangers: "Elle a écouté les nouvelles, elle connaît les nouvelles." [She heard the news, she is aware of the news.] Since the time of these interviews, however, the news about long-term care in Canada has only gotten worse as COVID-19 swept through.

Although perhaps not intentional, New Brunswick's approach to caring for older adults appears to remain in place because it effectively benefits the system by preventing the public from fully accessing services. That is, the fragmented and opaque organization of care discourages and deflects people away from an already overtaxed system, thereby reducing costs (at least in the short term). As a result, informal caregivers must shoulder the work themselves or pay for it out-of-pocket. This can be understood as a form of "privatization by stealth" (Macarov 71) in which cumbersome bureaucratic processes discourage the use of public services.

Cognitive and Behavioural Coping Strategies

In the next sections, we outline the myriad ways in which caregivers attempted to make sense of and cope with the complications resulting from the organizational moment—New Brunswick's approach to caring for older adults.

Fighting

Given the multiple and intersecting challenges they faced, participants talked about having to constantly "fight" the system. Janet said, "You have to fight for what you want. It's not easy!," while Chris lamented, "I shouldn't have to fight through the system like I was." Similarly, Anne-Marie talked about having to go to battle to get care for her mother: "Je me suis battue pour maman" [I fought for my mom]. This ongoing battle requires energy, stamina, and tenacity. As Katherine said, "Il faut être tenace" [one must be tenacious]. As Stephanie articulated, however, remaining in "bulldog" mode is also taxing: "The advocacy piece is just exhausting. [… That] was my experience, like I'm worrying about mom's health and then, I still have to be on and fighting all the time to make sure she's getting good care." Katherine described this constant struggle: "Mais c'est tout comme ça: à la graine. À la graine, à la graine. Je te dis, c'était toujours des grands débats pour des petites victoires." [But it's all like that: … I am telling you, it was always great debates for small triumphs.] Thus, in addition to providing care for an older adult, participants were in the strange and difficult position of having to *fight for care*.

Giving Up

Many participants who talked about "fighting" also talked about "giving up." For instance, after recounting having to fight the homecare agency to pay back lost hours, Chris stated that he gave up when the care worker continued to miss shifts: "It just came to a point where I didn't want to fight anymore" (Chris). Isabella expressed the futility of constantly trying to fight for care: "Bien, on laisse pas tomber les bras, mais on donne des coups d'épée dans un océan." [Well, one does not stop fighting, it's like swinging a sword in the ocean.] Similarly, José stated that the constant battle to find help is simply not possible for everyone, and at a certain point, people just give up:

> Ce n'est pas vrai que tu peux toujours commencer à contacter toutes ces personnes-ressources là pour essayer d'avoir du service ou de l'aide à la maison. Tu sais, ce n'est pas vrai. Tu aimerais bien ne pas en parler à une [intervenante] qui pourrait répondre à toutes tes questions tout de suite. Mais c'est toujours un combat, puis à un moment donné, les gens donnent leur démission; ils arrêtent. [It's not true that you can always start contacting all those resource people there to try to get service or help at home. You know, that's not true. You would like not to talk to a (helper) who could answer all your questions right away. But it's always a fight, and then at some point people resign; they stop.] (José)

Echoing José's account, Émile also described being forced to pick his battles: "On choisit nos batailles. Mais des fois, c'est désolant." [We choose our battles. But sometimes it's sad.] Émile said that he had to give up the fight in order to preserve his energy just to survive: "J'ai-tu cette énergie-là moi, non. J'ai juste assez d'énergie pour travailler puis prendre soin de ma famille, puis de survivre." [Do I have that energy? No. I have just enough energy to work, then take care of my family, then survive.]

Silence

Despite their anger and dissatisfaction, many participants talked about holding their silence for fear of retribution. Participants were afraid to jeopardize the governmental support they did receive, even if there were significant problems. France described having to walk on eggshells with her mother-in-law's social worker whom she described as terrible: "On marche sur des œufs là avec elle." [We walk on eggshells there with her.] She worried that asking for a different social worker would mark her as a difficult client, and potentially force more delays in securing supports:

> On se dit que si qu'on se met à ne pas vouloir d'elle, elle va-tu être fâchée? Est-ce qu'elle va dire à ses collègues qu'on n'est pas faciles ou … tu sais, on ne sait pas trop quoi faire. Ça va-tu prendre du temps? Va-t-il falloir qu'on recommence? Elle est vraiment, vraiment terrible cette travailleuse sociale. [We tell ourselves that if we start not wanting her, will she be angry? Is she going to tell her colleagues that we're not easy or ... you know, we don't really know what to do. Will it take time? Will we have to start over? She is really, really terrible this social worker.] (France)

Several participants also talked about holding their tongues with homecare workers. Tracy described multiple instances of poor care (including the homecare worker leaving her mother alone for hours and providing poor physical care), but she was too afraid of retribution if she complained every time. She said: "You have to treat these homecare workers with kid gloves because if you offend them, then, they hold that against you." Like Tracy, Jennifer lived rurally and pointed to this geographic isolation as compounding the need to remain silent. She said: "You're scared to say anything because there's no other option anyway." She elaborated by comparing her situation to that of people in city centres:

> If you're not happy with the one [homecare worker] you have, you can move on to another one! When you're rural, you don't have that choice! You can't burst into their office freaking out at them because it's not going to do you any good! If I do that, it's going to reflect in Mum's care. (Jennifer)

Being in the Know and Relying on Whomever You Know

Several participants had professional experience in the home and health care systems as nurses, nursing home staff, and personal support workers. While they also struggled in many ways, they acknowledged their advantage. For instance, Denise described how her insider knowledge enabled her to arrange for her mother to move into a nursing home quickly: "I moved fast because I knew who to call, what to get, what was needed. I knew the list. I knew the website. I knew the social worker." Such expertise not only enabled these participants to navigate the systems more efficiently, but it also provided them with a better understanding of what is involved in care at home. As Donna said:

> I had worked with Extra-Mural for twenty years in the community as a hands-on nurse, so I worked with all the professionals. I saw people living in their own homes and I saw what it takes to make that happen. I saw that the rehab needed to be involved. All of those things. I had that knowledge. (Donna)

Monique also spoke to the high degree of training required to provide care at home. She emphasized that most people are ill-equipped to take on this extensive work: "Ce n'est pas les gens ordinaires qui peuvent faire ça; ça, je peux vous le dire. C'est très difficile, c'est demandant. Puis, que le gouvernement n'essaye pas de faire passer ça à tout le monde parce qu'ils vont avoir des abus encore pires que dans les foyers." [Ordinary people can't do that; that, I can tell you. It's very difficult, it's demanding. Then, that the government does not try to pass this on to everyone because they are going to have even worse abuse than in LTC.] She elaborated by giving an example: "Admettons que je n'ai aucune notion en *nursing* et que je veux prendre soin de ma sœur, je ne peux pas! Puis ce ne serait pas recommandable à tout l'monde non plus parce que psychologiquement, physiquement c'est dur. Moi, je ne recommanderais pas ça à personne." [Let's say I have no knowledge of nursing and want to take care of my sister, I can't! Then it wouldn't be advisable to everyone either because psychologically, physically it's hard. I wouldn't recommend this to anyone.] Although all participants described care work as stressful, those with professional training were at a distinct advantage, and several described being called on to share their knowledge with other caregivers. For example, Diane said, "I don't know how many of my friends call me up and say, 'Look my mom's got to go in a nursing home' or 'My father fell and broke his leg. Where can we get this? What can we do?'"

Participants without professional care backgrounds frequently recounted relying on the advice of friends and family members who were knowledgeable in that area. Angela noted that there were several health professionals in her family who offered invaluable support in her mother's care. Continuing the battle metaphor described earlier, she said that having this well-educated team enabled her to be "better armed going against the health care system." David also spoke about needing to harness his professional connections to advocate for his wife who had early-onset dementia. He lamented: "That's the sad thing in New Brunswick, that you continuously have to fall back on who you know and […] your personal contacts, who you know. That's very sad, I think." Speaking to this sadness, many participants, like Carolyn and Marilyn, described fearing for New Brunswickers who have no insider resources to draw upon: "I pity these poor families that have no starting point at all" (Carolyn); "I worry about all the other families that don't know how to navigate the system" (Marilyn). In essence, these participants described how New Brunswick's care services are organized into a two-tiered care system, in which better services are available to those with more resources.

Care via Crisis

As a result of being unable to navigate the system and secure proper support, many informal caregivers and their families end up in a state of crisis ("on était rendus en crise là; on ne savait plus quoi faire" [we had reached a crisis there; we did not know what to do] (France). As a result, several resorted to going to the emergency room for help. For instance, when Denise could no longer manage her mother's care, she said calling the ambulance was her last resort: "That's enough. So, I called the ambulance. It was the only way." Similarly, Barbara said: "I said, 'Call an ambulance, we'll take her to the hospital.' Because that was the only answer I had at that point when you can't manage it anymore." However, as Stephanie asserted, "It shouldn't take a crisis to get timely access to service."

Chris's mother, who had advanced dementia, did not have a family physician and this significantly exacerbated the challenge of managing her care. Chris described lacking direction and having to rely on the emergency room throughout the course of her decline: "I just went in. I said, 'My family's falling apart. I don't know what to do.'" However, despite going to the emergency room repeatedly, he could not find the help he so desperately needed:

> Whenever you go into the emergency and you go in so many times looking for help and nobody is giving you direction coming out and you're expecting them to do something for you and they're not, then all of a sudden, it's just like you don't know where to start, right? And then you're almost in there crying. (Chris)

Notably, several of Chris's friends suggested that he should leave his mother at the hospital to secure services. He said: "A lot of people were saying, 'If you don't hear back from the government, drop her off, and then you'll force the government's hand to do something.'" Although no one in the study resorted to this coping strategy, it was a theme articulated across the interviews and the appearance of this common knowledge strategy reflects the level of crisis in senior care in the province. In the final section, we explore central recommendations that participants articulated for fixing this broken system.

Participant Recommendation #1: Navigation Support

Participants expressed the need for help navigating the disjointed, opaque, and confusing systems. Betty said, "I don't know if it's only New Brunswick, but you really are on your own to find out what's out there." Participants repeatedly asked for professional navigation services to help them find their way through the process. Susan reported that her "biggest need is [for] an adviser." Similarly, Isabella stated that having a phone line for informal caregivers would be a great help: "Avoir une ligne directe, ça nous aiderait énormément." Marilyn echoed this sentiment, recommending: "The government could think about having like telecare for 'How do I navigate the system?'"

There are three initiatives in the province under the Department of Social Development that appear to meet this demand: (1) a website (https://socialsupportsnb.ca/en/); (2) a 1-800 phone line; and (3) the "Home First" program, which offers a one-time visit with seniors to provide information. Notably, participants had either not heard of these services or not found them useful (the website was not available at the time of the interviews). What is lacking from current offerings is extensive and ongoing personalized navigational support. Gérard cautioned that any such service would have to distinguish between government supports that are *real* and those that are merely *window dressing*:

> Le gouvernement pourrait dire: "Voici les services qu'on offre." Puis, il pourrait énumérer une belle liste de services. Sauf que les vrais services, dans la réalité, ceux-là, ils s'auto-détruisent: celui-là ne marche pas, celui-là en pratique ne se fait pas, celui-là c'est impossible. Tu sais, c'est de la *bullshit*. [The government might say, "Here are the services we provide. Then it could provide a nice list of services. Except that the real services, in reality, these, they are self-destructing: this one does not work, this one in practice is not done, this one is impossible. You know, it's bullshit.] (Gérard)

In line with Gérard's comment, it is important to note that many participants needed ongoing "counselling" (Chris) that could respond to their evolving needs. As Jennifer said, one-time consultation is insufficient, as people need help at every step of the way given that conditions and needs change: "There is no one person that you can pick up the phone and say, 'This is where we are, what's my next step?' […] I think there needs to be some administrative body that helps these people go through the system." Jennifer went on to describe how she also needed someone who could advocate for her, so that she didn't have to remain silent when her mother received poor-quality care. She specified:

> The communication between the social workers and the homecare agencies isn't adequate either. Like there needs to be somebody that if you're getting the lack of care that mom got, then I could pick up the phone and call and say, "Can you please on my behalf rattle their chains?" Because oh there were times that I really wanted to go to that [homecare agency] office! But, [I] just didn't dare. (Jennifer)

In sum, participants wanted a knowledgeable, available, and officially designated person who understood their situation, would help make arrangements for the next steps, and could advocate on their behalf through the duration of their care journey. Having someone who could advocate for their loved one's care could make a tremendous difference for an informal caregiver's health and well-being. A quotation from Stephanie's interview sums up what such a publicly funded position could mean: "If we had a system where I could call someone and they took that one little piece off of me? Like maybe I could breathe, maybe I could sleep a whole night through."

Participant Recommendation #2: Governmental Investment in Quality Care

Participants emphasized that, contrary to current conceptualizations and pay structures, care work requires skill, training, and education. For example, David outlined the high level of skill and understanding required to provide proper care for a person with dementia:

> There's the washing, the changing, the medicating, the getting them into bed and then being content to go to sleep. Well, to me that takes a pretty skilled person to pull off that continuum of activities in a way that gives you the outcome you're looking for. And with a person whose mood can change from day to day, and from minute to minute. Obviously, they [homecare agencies] have gifted people, but they also have people who are just looking for a job. It's pretty high-risk, I think.

Here, David rejects the myth that care work is low-skill work. His account goes on to highlight the significant "risk" involved in relegating the critically important work of care to low-paying positions. This concern was shared by several participants, including Cantin: "Si tu n'es pas payé [assez], ce n'est pas le meilleur qui va être engagé. Ça va être celui qui n'a pas d'emploi." [If you are not paid (enough), it's not the best person who is going to be hired. It's going to be the one who does not have a job.] And, as Chris said, most people will avoid the demanding work of providing care when they can make more money at "a call centre." As Janet explained, the fundamental problem, then, is that care work is undervalued and underpaid: "There are a lot of problems with the homecare providers. And it's not a highly educated job. Some people just do it because they can't get anything else. There are only a few people that are really doing it because that's what they want to do." Janet further explained, "The problem is you're putting people in there that have no background in gerontology, no background on how to deal with the elderly." Accordingly, participants' accounts suggests that the solution is to re-envision the personal care worker role in a way that it reflects the following: (1) it acknowledges the skill and effort required; (2) it requires specialized training and education; and (3) it compensates appropriately for the work provided.

Participant Recommendation #3: Restructuring the System Toward a Continuum of Care

The central challenge underlining participants' experiences of caregiving was the disjointed and confusing system. Accordingly, participants pointed to the need to streamline the system in a way that mirrored people's changing care needs (as opposed to organizing it around power structures). Denise described the bureaucratic nightmare she faced in supporting her mother through several hospitalizations (under the purview of the Department of Health), homecare (Department of Health or Social Development, depending on the situation), and nursing home care (Department of Social Development):

> Another problem is that Social Development is [located] over here. Department of Health is over here. And they're both in their silos and nobody wants to give anything up! […] It's not a matter of "Oh we're moving you to Health. Oh, now we're moving you back to Social Development." We've been bounced around so many times! Nobody wants us cause it's such a big challenge! And when we'd go to the hospital, they're Health. Then they go to nursing home, they're Social Development. See! There's no continuity at all! (Denise)

David also spoke eloquently about the system's fragmentation and its consequences for his wife who had early-onset dementia:

> Having Social Development […] and Health, under different ministries, I don't understand that […] because there's a continuum of care. So [my wife] is a good example. She received a ton of medical care for seven years. And then what she needed was much more homecare, support care, then assessment for long-term care. But it was a continuum, it was the same disease. […] Why should she go from one system to another system? There's no logic to it at all. (David)

To highlight the lack of logic of the current system, David offered an analogy: "You wouldn't have roads under one department and bridges under another, would you?" He then elaborated:

> At the base of it are two systems that aren't under the same umbrella! I don't understand it, except if you think, OK, hospitals have a certain amount of political power, nursing homes have a certain amount of political power. […] I have no idea what the rationale is but, it's unfortunate in my view. We're a small province, and I don't see why it isn't a continuum of administration under Health. And that impacts on us! If you're really serious about homecare, then, let's go beyond just having a bunch of, somewhat approved, homecare companies. But really have something that gives you the sense of OK, this is where [my wife] is, this is what she needs.

David's account points to the problems inherent to an organizational structure that extends across different governmental departments and a host of private homecare companies. Although navigation challenges exist in other provinces in which all senior care falls under the same department, participants made clear that the extra bureaucracy of two departments presented additional and unnecessary challenges in their daily lives. While it is no panacea, having one continuum of administration could help reduce gaps in care and accountability that we heard across participants' interviews.

Discussion

The findings outlined here will be sadly familiar to many. Warnings about the inadequacies of our system in meeting the needs of an aging population have been sounded for years, including in the Romanow Report twenty years ago, and at least seventeen reports in New Brunswick alone since then (Hull 105). In 2017, the Council on Aging, co-chaired by Ken McGeorge and Suzanne Dupuis-Blanchard, released an extensive "Aging Strategy" for the province. However, the government's own auditor general recently reported that the Department of Social Development produced "limited and inaccurate public reporting on progress" and an overall "lack of implementation plan" for the Aging Strategy (133). The New Brunswick Nurses Union has also sounded urgent calls for reform, releasing a damning report on the state of long-term care, but this appears to have also fallen on deaf ears. In the throes of the devastating effects of COVID-19 on our elders, surely the chorus of voices calling for change will finally be heard. As Donald Savoie implored in the title of his commentary on New Brunswick's political economy, "Let's not waste a crisis" (see Works Cited).

In order to begin to address the fractured state of our health and homecare systems, many have called for the modernization of the *Canada Health Act* to include senior care (including long-term care and homecare, which are both currently excluded) (Armstrong et al., "Privatization and Covid-19…," 450; Hull 158; NIA 17). The National Institute on Aging makes it clear that the problem is not our aging demographic, but our failure to meet it with appropriate policy:

> Canada's health care system was designed and built more than 50 years ago with the passage of its Medical Care Act in 1966 when the median age of Canadians was 25.5 years of age and when most Canadians didn't live beyond their late 60s or early 70s. In that context, the universal health care system Canada implemented at that time for its much younger population was appropriately focused on providing physician services and acute hospital-based health care. What is clear, is that Canada's health care system was not built to focus on the needs of Canadians living into their late 70s and 80s with chronic health issues and greater levels of social isolation, which are now established and growing realities. (6)

Strengthening the *Canada Health Act* would not only streamline the system but ensure uniformity in standards of care across the country and the province. This would also have immediate and positive consequences for caregivers and those they support by reducing administrative and navigational burdens. For instance, the first step in applying for long-term care or subsidy for homecare in New Brunswick is to go through an extensive financial assessment through the Department of Social Development. This process determines how much patients pay for homecare or long-term care. The application requires submitting an extensive financial package including: Notice of Assessments and tax information slips (T4) for the past two years; proof of cost of private health insurance premiums; power-of-attorney documents; and proof of income from current private pension amounts, pensions from any other country, long-term disability payments, Veterans Affairs Canada, rental properties, and employment in the form of pay stubs (last month's pay stubs if employed) (Department of Social Development). This supporting documentation must be provided within thirty days of application and is often done in the midst of family crisis. Many participants reported that this process was overwhelmingly difficult, especially in the context of dementia care where personal finances have often been neglected for years. Indeed, many caregivers reported only coming to appreciate the level of decline after discovering the state of their loved one's financial records.

Several participants also suggested that provincial oversight of homecare and long-term care be moved from the Department of Social Development to the Department of Health. A proposal supported by the New Brunswick Nurses Union highlighted that "New Brunswick remains the only province in Canada where the care of seniors in nursing homes is overseen by something other than a Department of Health" (Hull 161). They argued that:

> The Department of Social Development can no longer be counted on to police New Brunswick's Long-Term Care sector. Lack of departmental capacity has led to countless problems with nursing home staffing levels, record keeping, oversight and quality of care. Most of the sector's stakeholders agree that it is long past time for these responsibilities to be transferred to the Department of Health. (Hull 43)

Retired CEO of Horizon Health John McGarry has also championed this recommendation. In a 2021 interview with *The Daily Gleaner*, he stated: "I was saying years ago the assessment of seniors should be made by those in the hospital system not people in the Department of Social Development" (Chilibeck). He reported that seniors can wait in hospital for up to ninety days, by which time they have deteriorated so much they must be placed in a higher level of care (Chilibeck). Despite repeated calls for change, the minister of Social Development, Bruce Fitch, has thus far declined to pursue this transfer of power (MacKinnon).

Improvements to the quality of senior care are also urgently needed, and to do this, we must look to working conditions, including staff shortages, as well as high rates of turnover and burnout. As Pat Armstrong and colleagues have recently articulated in "Re-imagining Long-Term Residential Care in the COVID-19 Crisis," "The conditions of work are the conditions of care" (7). Associated with women's work and undervalued, care work is notorious for unmanageable workloads and poor compensation. It is thus no surprise that recruitment and retention of qualified personnel have become even more challenging: "The sector which was in crisis long before the pandemic is facing challenges in recruitment and retention of caregivers given their low wages and poor working conditions, such as little to no paid sick days" (New Brunswick Coalition for Pay Equity, "Caregivers Cannot Live on Recognition Alone"). Moreover, employers are increasingly relying on precarious part-time and casual positions so that they do not have to pay benefits (Armstrong et al., "Re-imagining Long-Term Residential Care in the COVID-19 Crisis," 6; Malek). As Hull noted, "In early 2020, it was learned that New Brunswick nursing homes were making offers of casual employment at a far higher rate than offers of full-time employment. For RNs this ratio was 5:1 or higher" (167). Under such conditions it is no wonder that turnover rates are so high. In 2017, 147 of the 543 (i.e., 27%) RNs working in nursing homes in New Brunswick left their positions (Hull 85). Turnover rates are even higher amongst poorer paid personal support staff who work in both long-term care and homecare (Zeytinoglu et al. 266; New Brunswick Coalition for Pay Equity, "Value of Care…"). Although the government recently increased these care workers' wages to a range of $15.50 to $16.80/hour, these rates continue to fall well below the $22 to $25 rates that the New Brunswick Coalition for Pay Equity calculated they should earn to be on par with wages of male-dominated jobs of comparable value ("Equity Is Decades Away").

In the forward to the New Brunswick Nurses Union report, *The Forgotten Generation: An Urgent Call for Reform in New Brunswick's Long-Term Care Sector*, Dr. Deborah van den Hoonaard underscored the importance of investing in the caregiving sector as follows:

> It is essential that these precarious and underpaid jobs be replaced with full-time, well-paid, secure jobs that allow the nurses and other workers to provide real care (that includes real relationships) with residents and recognize the skill involved in the work. The discourse around long-term care and homecare has always framed the money involved as an expense that we cannot afford. I would suggest that it would be more profitable to think about staffing as an investment and as job creation. (Hull 5)

Both van den Hoonaard and the province's Nurses Union go on to argue against the continued privatization of long-term care—a warning that has been heard across the nation as COVID-19 brought public attention to the conditions of those facilities classified as such. In fact, for-profit homes have had larger outbreaks and higher death tolls than not-for-profit homes (Stall et al. 946). In Ontario, for-profit nursing homes had 78% more COVID-19 deaths than not-for-profit homes (Ferguson). Older design standards, chain ownership, crowding, and failing to provide workers with sick time have all been implicated. In their review of the COVID-19 crisis in long-term care, Armstrong and colleagues argued strongly against privatization in the care sector:

> Private, for-profit services are necessarily more fragmented, more prone to closure and focused on making a profit. The research demonstrates that homes run on a for-profit basis tend to have lower staffing levels, more verified complaints, and more transfers to hospitals, as well as higher rates for both ulcers and morbidity. Moreover, managerial practices taken from the business sector are designed for just enough labour and for making a profit, rather than for providing good care. ("Re-imagining Long-Term Residential Care in the COVID-19 Crisis," 6)

Dr. Samir Sinha, lead of the National Senior Strategy, argues that the issue is not necessarily privatization but Canada's overall poor investment in senior care. Tragically, Canada leads amongst OECD nations in having the highest percentages of COVID-19–related deaths in long-term care settings. In an interview with Brent Bambury on CBC Radio, Dr. Sinha explained: "We spend one third less than other OECD countries on what we provide in long-term care, and that translates into less staffing, and it also translates into outdated facilities, and that becomes the perfect storm for a COVID-19 outbreak to claim lives pretty quickly" (S. Sinha 2021). In conclusion, privatization appears to simply make the dire situation in long-term care worse – it is "like pouring gasoline on a fire" (Hull 69).

The Auditor General of New Brunswick reports that the waitlist for nursing home beds in New Brunswick comprises over seven hundred individuals with over half waiting in the hospital. The waitlist is projected to reach 2,500 within five years, and 4,100 in ten years (New Brunswick Department of Health 13). At the same time, Premier Higgs has indicated that the province cannot afford to build as many nursing homes as needed, noting that this would leave too many such establishments unused after the baby boomers generation dies (Chilibeck). However, Penny Ericson argued that this is a short-sighted vision, given the unprecedentedly high rates of chronic health conditions among younger generations. (39)

In the absence of enough nursing home beds, increasing numbers of seniors are awaiting placement in hospital. Indeed, New Brunswick has the highest proportion of "alternate-level-of-care" patients in the country—those who do not need acute hospital care but are awaiting residential care (Chilibeck). A significant number of them have some cognitive decline (New Brunswick Department of Health 13). This is not only an incredibly expensive solution but also one that leads to quick cognitive and physical decline among patients (McGeorge and Bateman 27). In a particularly telling discursive turn, these patients are often called "bed blockers" by staff, a pejorative term that positions blame on their shoulders (as though anyone would want to live in a hospital) and deflects away from pervasive problems in the system.

In the context of the COVID-19 crisis in long-term care, public and political attention has turned toward homecare and *aging in place*, which, according to Armstrong and colleagues, "primarily means looking after yourself (i.e., *responsibilization*) or having—usually female—relatives look after you" ("Privatization and COVID-19…," 450). Results from our study counter romanticized notions of homecare and highlight a reality of difficult and stressful, unpaid and unacknowledged work. Indeed, many participants with professional care backgrounds emphasized that the provision of homecare is simply impossible for many New Brunswickers without such training. Without sufficient long-term care beds in the province, the government is ignoring demographic trends and relying on informal caregivers, who are already overstretched and in short supply. *Homes* do not care for people; *people* do, and often at a tremendous cost to themselves. Moreover, our analysis highlights that the way in which care is (dis)organized in New Brunswick directly and negatively effects the lives of caregivers and those they support. Our fragmented, opaque, and confusing system itself impedes care and causes harm. Accordingly, any attempt at policy reform must attend carefully to the needs and challenges of informal caregivers. It is imperative that the government invest in innovative ways to recognize, compensate, and support the essential and skilled work that informal caregivers undertake.

What is clear is that change is needed—now. Luckily, extensive and reliable research in this area has already been conducted. There are multiple reports to guide reform, and New Brunswickers have proposed innovative solutions such as the "Nursing Home Without Walls" initiative in which nursing homes act as community hubs for outreach services (Dupuis-Blanchard and Gould 447). We already have extensive plans for change as outlined in the Aging Strategy (2017). What is needed now is the political will to do the right thing. The COVID-19 pandemic has brought the harsh realities of senior care into the national spotlight, and we cannot look away. We must move forward from this tragic lesson with bold, innovative, person-centred, and respectful approaches to care.

To comment on this article, please write to editorjnbs@stu.ca. Veuillez transmettre vos commentaires sur cet article à editorjnbs@stu.ca.

Michelle Lafrance is a professor of Psychology at St. Thomas University. Her academic interests centre on the social and political determinants of health and distress.

Lynne Gouliquer is an associate professor at Laurentian University. She is a Banting and O'Brien fellow. Her research focuses on the sociology of institutions and marginalization.

Carmen Poulin is Associate Dean of Arts (Research and Graduate Studies) and professor in Psychology and Gender and Women Studies, University of New Brunswick. She co-developed the P-SEC methodology.

Cassandra Swift, **Valérie Godin**, **Lauren McWilliams**, and **Moira Kinney** graduated with honours in Psychology from St. Thomas University.

Acknowledgement

Funding for this research was provided by the Social Sciences and Humanities Research Council of Canada.

Note

[1] Transcript notation: [...] short section of text omitted; … discernible pause; - sharp cut-off in speech; pseudonyms are used to protect participants' anonymity.

Works Cited

Armstrong, Pat, and Ruth Lowndes. *Negotiating Tensions in Long-Term Residential Care: Ideas Worth Sharing*. Ottawa: Canadian Centre for Policy Alternatives, 2018.

Armstrong, Pat, et al. "Privatization and COVID-19: A Deadly Combination for Nursing Homes." In *Vulnerable: The Law, Policy and Ethics of COVID-19*, edited by Colleen M. Flood et al. Ottawa: University of Ottawa Press, 2020, pp. 448–62.

Armstrong, Pat, et al. "Re-imagining Long-Term Residential Care in the COVID-19 Crisis." Ottawa: Canadian Centre for Policy Alternatives, April 2020.

Atlantic Provinces Economic Council. "Looking Ahead: Atlantic Canada's Aging Population." 21 January 2021. https://www.apec-econ.ca/publications/view/?do-load=1&publication.id=411, accessed 15 May 2022.

Auditor General of New Brunswick. *Volume II: Performance Audit*. New Brunswick Department of Social Development, February 2021, pp. 41–62.

Banerjee, Albert. *An Overview of Long-Term Care in Canada and Selected Provinces and Territories*. Toronto: Women and Health Care Reform Group, October 2020.

Beals, Diane E. "Reappropriating Schema: Conceptions of Development from Bartlett and Bakhtin." *Mind, Culture, and Activity*, vol. 5, no. 1, 10 June 1998, pp. 3–24.

Bem Lipsitz, Sandra. "Gender Schema Theory: A Cognitive Account of Sex Typing." *Psychological Review*, vol. 88, no. 4, 1981, pp. 354–64. DOI:10.1037/0033-295X.88.4.354.

Braun, Virginia, and Victoria Clarke. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology*, vol. 3, no. 2, 2006, pp. 77–101. DOI: 10.1191/1478088706qp063oa.

Braun, Virginia, and Victoria Clarke. *Successful Qualitative Research: A Practical Guide for Beginners*. London: SAGE, 2013. https://unb.on.worldcat.org/oclc/811733656, accessed 15 May 2022.

Burdett, Freda, et al. "Culture of Corrections: The Experiences of Women Correctional Officers." *Feminist Criminology*, vol. 13, no. 3, pp. 329–49, 22 March 2018. DOI: https://doi.org/10.1177/1557085118767974.

Canadian Healthcare Association. "Home Care in Canada: From the Margins to the Mainstream." Ottawa: Canadian Healthcare Association, 2009. https://www.healthcarecan.ca/wp-content/themes/camyno/assets/document/PolicyDocs/2009/External/EN/HomeCareCanada_MarginsMainstream_EN.pdf, accessed 15 May 2022.

Chilibeck, John. “Special-Care Beds Could Ease Crunch: Experts.” *The Daily Gleaner*, 5 May 2021.

Department of Social Development. *Long-Term Care Program*. 28 May 2021. https://socialsupportsnb.ca/en/program/long-term-care-program, accessed 15 May 2022.

Dupuis-Blanchard, Suzanne, and Odette N Gould. “Nursing Homes Without Walls for Aging in Place.” *Canadian Journal on Aging / La Revue canadienne du vieillissement*, vol. 37, no. 4, 2018, pp. 442–49.

Ericson, Penny. “Opening the Door: A Much-Needed Dialogue on Current Health Care Delivery.” *Journal of New Brunswick Studies / Revue d’études sur le Nouveau-Brunswick*, vol. 8, 23 November 2017, pp. 33–40.

Ferguson, Rob. “Ontario’s For-Profit Nursing Homes Have 78% More COVID-19 Deaths Than Non-Profits, Report Finds.” *Cambridge Times*, 20 January 2021.

Funk, Laura. *Relieving the Burden of Navigating Health and Social Services for Older Adults and Caregivers*. Institute for Research on Public Policy, no. 73, November 2019.

Garner, Rochelle, et al. “Transitions to Long-Term and Residential Care Among Older Canadians.” *Statistics Canada Health Reports*, vol. 29, no. 5, 2018, pp. 13–23. www150.statcan.gc.ca/n1/en/pub/82-003-x/2018005/article/54966-eng.pdf?st=MSWBOZmd, accessed 15 May 2022.

Gouliquer, Lynne, and Carmen Poulin. “For Better and for Worse: Psychological Demands and Structural Impacts of the Military on Gay Servicewomen and their Partners in Long-Term Relationships.” In *Doing Ethnography: Studying Everyday Life*, ed. Dorothy Pawluch, William Shaffir, and Charlene Miall. Toronto: Canadian Scholars’ Press, 2005, pp. 323–35.

Gouliquer, Lynne, Carmen Poulin, and Maryani Lesmana. “Mobility Boundaries Between Home, Community and Beyond: Experiences of the Exceptionally Old Living in a Canadian Province.” *Qualitative Sociology Review*, vol. 11, no. 3, 2015, pp. 124–150.

Harding, Sandra, ed. *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*. New York: Routledge, 2004.

Hull, Jeff. *The Forgotten Generation: An Urgent Call for Reform in New Brunswick’s Long-Term Care Sector*, First Edition. New Brunswick Nurses Union, Taylor Printing, October 2020.

Keefe, Janice. *Supporting Caregivers and Caregiving in an Aging Canada*. Montreal: Institute for Research on Public Policy, 2011.

Lee, Christina. “Health, Stress and Coping Among Women Caregivers: A Review.” *Journal of Health Psychology*, vol. 4, no. 1, January 1999, pp. 27–40. DOI:10.1177/135910539900400104.

Mackinnon, Bobbi-Jean. “Nurses’ Union Calls for Independent Inquiry into Long-Term Care Sector.” *CBC News*, 15 October 2020.

Macarov, David. *What the Market Does to People: Privatization, Globalization, and Poverty*. London: Zed Books, 2003.

Malek, Jan. "Urgent Action Needed Now for People in Long-Term Care." *The Council of Canadians*, November 2020.

McGeorge, Ken., and Thomas M.J. Bateman. "Settling for Mediocrity: Aging and Health Care in New Brunswick." *Journal of New Brunswick Studies / Revue d'études sur le Nouveau-Brunswick*, vol. 8, Fall 2017, pp. 15–31.

Molinari, Nicole, and Geraldine Pratt. "Seniors' Long-Term Care in Canada: A Continuum of Soft to Brutal Privatisation." *Antipode*, online early view, 14 February 2021, pp. 1–21. *Wiley Online Library*, doi:10.1111/anti.12711.

National Institute on Aging. *An Evidence Informed National Seniors Strategy for Canada – Third Edition*. 2020, pp. 5–19.

New Brunswick Coalition for Pay Equity. "Caregivers Cannot Live on Recognition Alone." 15 March 2021. https://equite-equity.com/en/news/caregivers-cannot-live-recognition-alone, accessed 15 May 2022.

New Brunswick Coalition for Pay Equity. "Equity Is Decades Away." 19 March 2021. https://equite-equity.com/en/news/equity-decades-away, accessed 15 May 2022.

New Brunswick Coalition for Pay Equity. "The Value of Care: Pay Equity in Special Care Homes, ESSP Agencies, and Family Support Agencies." 12 May 2021. https://equite-equity.com/en/news/value-care-pay-equity-special-care-homes-essp-agencies-and-family-support-agencies, accessed 15 May 2022.

New Brunswick Council on Aging. *We Are All in This Together: An Aging Strategy for New Brunswick*. Fredericton: Province of New Brunswick, 2017.

New Brunswick Department of Health. *Striving for Dependable Public Health Care: A Discussion on the Future of Health Care in New Brunswick*. January 2021. https://www2.gnb.ca/content/dam/gnb/Departments/h-s/pdf/en/Publications/HealthCare/DependablePublicHealthCare-DiscussionPaper.pdf, accessed 15 May 2022.

Poulin, Carmen, Lynne Gouliquer, and Alissa Moore. "Pompières: la passion du feu et le prix à payer." In *Enjeux humains et psychosociaux du travail*, ed. Jacinthe Douesnard. Québec: Presses de l'Université du Québec, 2018, pp. 209–47.

Poulin, Carmen, Lynne Gouliquer, and Jessica McCutcheon. "Violating Gender Norms in the Canadian Military: The Experiences of Gay and Lesbian Soldiers." *Sexuality Research and Social Policy*, vol. 15, 2018, pp. 60–73. https://doi.org/10.1007/s13178-017-0304-y, accessed 15 May 2022.

Roth, David L, Lisa Fredman, and William E. Haley. "Informal Caregiving and Its Impact on Health: A Reappraisal from Population-Based Studies." *The Gerontologist*, vol. 55, no. 2, April 2015, pp. 309–19. DOI:10.1093/geront/gnu177.

Savoie, Donald J. "New Brunswick: Let's Not Waste a Crisis." *Journal of New Brunswick Studies / Revue d'études sur le Nouveau-Brunswick*, vol. 1, January 2010, pp. 54–63.

Schulz, Richard, and Scott R. Beach. "Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study." *JAMA*, vol. 282, no. 23, December 1999, pp. 2215–19. DOI: 10.1001/jama.282.23.2215.

Sinha, Maire. "Portrait of Caregivers, 2012." Statistics Canada, Government of Canada, September 2013. https://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf, accessed 15 May 2022.

Sinha, Samir. "Kicking Out For-Profit Operators Won't Be Enough to Fix Long-Term Care." *Day 6 with Brent Bambury*, CBC Listen, 30 January 2021.

Smith, Dorothy E. *The Everyday World as Problematic: A Feminist Sociology*. Boston: Northeastern University Press, 1987.

Smith, Dorothy E. *Institutional Ethnography: A Sociology for People*. Walnut Creek, CA: AltaMira Press, 2005.

Stall, Nathan M., Aaron Jones, Kevin A. Brown, Paula A. Rochon, and Andrew P. Costa. "For-Profit Long-Term Care Homes and the Risk of COVID-19 Outbreaks and Resident Deaths." *CMAJ: Canadian Medical Association Journal*, vol. 192, no. 33, August 2020, pp. 946–55.

Statistics Canada. *Annual Demographic Estimates: Canada, Provinces, and Territories*. 25 January 2019. www150.statcan.gc.ca/n1/en/pub/91-215-x/91-215-x2018002-eng.pdf?st=bzRFzrrJ, accessed 15 May 2022.

Statistics Canada. *Portrait of the Canadian Population in 2006, by Age and Sex, 2006 Census*. July 2007. https://www12.statcan.gc.ca/census-recensement/2006/as-sa/97-551/index-eng.cfm, accessed 15 May 2022.

Turcotte, Martin. "Family Caregiving: What Are the Consequences?" Statistics Canada, September 2013. https://www150.statcan.gc.ca/n1/pub/75-006-x/2013001/article/11858-eng.pdf, accessed 15 May 2022.

Wiles, Janine. "Informal Caregivers' Experiences of Formal Support in a Changing Context." *Health & Social Care in the Community*, vol. 11, no. 3, May 2003, pp. 189–207. DOI:10.1046/j.1365-2524.2003.00419.x.

Williams Allison M., and Valorie Crooks. "Introduction: Space, Place and the Geographies of Women's Caregiving Work." *Gender, Place and Culture*, vol. 15, no. 3, June 2008, pp. 243–47. DOI:10.1080/09663690801996254.

Zeytinoglu, Isik U., Margaret Denton, Sharon Davies, Andrea Baumann, et al. "Deteriorated External Work Environment, Heavy Workload and Nurses' Job Satisfaction and Turnover Intention." *Canadian Public Policy*, vol. 33, 2007, pp. 31–48. DOI:10.3138/0560-6GV2-G326-76PT.

Zimmerman, Lillian. "The Caregiving Crunch." *Herizons: Women's News and Feminist Views*, vol. 26, no. 3, Winter 2011, pp. 28–31.