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# Narratives of Personhood and Caregiving in Ontario Long-Term Care Homes During COVID-19

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## Abstract

Drawing on narratives recorded from family members of residents in long-term care homes in Ontario, Canada, during the 2020 COVID-19 lockdown, in this paper, I present a two-pronged argument. First, following Taylor (2008) and Seaman (2018, 2020) I suggest that family caregiving for residents of long-term care homes helps to sustain residents' personhood: the recognition of their identity as an ongoing participant in their social universe. The second part of my argument is that caregiving is a multifaceted and paradoxical endeavour. While caregiving can be a transformative and reciprocal practice of self-actualization (cf. Kleinman 2012; Kleinman and van der Geest 2009), at times it can also be troubled, ambivalent, and stressful (Cook and Trumble 2020). At its best, caregiving is a two-way street, enabling the maintenance of personhood for the care recipient, and validating the caregiver's sense of 'moral agency,' or what medical anthropologist Neely Myers (2015, 13) defines as the capacity to be recognized in one's local sphere as a good person who can make intimate connections to others. When caregiving goes awry, however, it leads to frustration, despair, and a sense of moral failure for the caregiver. For the care recipient, non-recognition and the loss of personhood can lead to social death and may also hasten physical decline. I conclude that for both professional and family caregivers of long-term care residents, systemic improvement of social and material support is needed to mitigate the challenges inherent in the recognition of personhood in caregiving relationships.

***Keywords:*** *COVID-19 pandemic; Family caregiving; Elder care*

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## Introduction

Drawing on narratives recorded from family members of residents in long-term care homes in Ontario, Canada, during the 2020 COVID-19 lockdown, in this paper, I present a two-pronged argument. First, following anthropologists Janelle Taylor (2008) and Aaron Seaman (2018, 2020), I suggest that family caregiving for residents of long-term care homes helps to sustain residents' personhood: the recognition of their identity as an ongoing participant in their social universe. The second part of my argument is that caregiving is a multifaceted and paradoxical endeavour. While caregiving can be a transformative and reciprocal practice of self-actualization (cf. Kleinman 2012; Kleinman and van der Geest 2009), at times it can also be troubled, ambivalent, and stressful (Cook and Trumble 2020; see also Cubellis 2020; Murphy 2015). At its best, caregiving is a two-way street, enabling the maintenance of personhood for the care recipient, and validating the caregiver's sense of 'moral agency,' or what medical anthropologist Neely Myers (2015, 13) defines as the capacity to be recognized in one's local sphere as a good person who can make intimate connections to others. When caregiving goes awry, however, it leads to frustration, despair, and a sense of moral failure for the caregiver. For the care recipient, non-recognition and the loss of personhood can lead to social death and may also hasten physical decline. I conclude that for both professional and family caregivers of long-term care residents, systemic improvement of social and material supports is needed to mitigate the challenges inherent in the recognition of personhood in caregiving relationships.

Throughout Europe and North America, residential facilities for elderly persons with chronic care needs were devastated by high mortality rates during the first wave of COVID-19 in early 2020 (Aalcevich et al. 2021; Badone 2021; Cohen 2020; Freidus, Shenk, and Wolf 2021; Freidus and Shenk, 2020, 2024; Leibing 2020; Mas Romero et al. 2020). In Canada, the first wave of COVID marked a crisis in long-term care with 80% of COVID deaths occurring in long-term care homes, the highest proportion in any OECD country (Estabrooks et al. 2020, 5; Stall et al. 2021; see Figure 2). The province of Ontario was particularly affected, with five long-term care homes sufficiently impacted by staffing shortages and outbreaks that military personnel were deployed to take over management of these facilities (Mialkowski 2020). As in many other jurisdictions, Ontario long-term care homes were locked down to visitors starting in mid-March 2020, in an effort to prevent the spread of contagion. As a result of the lockdown, family caregivers who had previously been providing significant levels of assistance in activities of daily living for long-term care residents were no longer able to offer this support.

When the pandemic erupted, the long-term care system in Ontario was already suffering from chronic staff shortages. According to a December 2019 report on personal support worker (PSW) shortages in Ontario, "in virtually every long-term care home, on virtually every shift, long-term care homes are working short staffed" (Unifor 2019). Prior to the pandemic, staff shortages in long-term care homes were offset to some extent by family involvement in caregiving. In 2018, throughout Canada, 4.5 million people reported providing care to parents or spouses. Of these family caregivers, 13% were providing care for relatives living in care facilities, in many cases upwards of ten hours weekly (Long-Term Care Staffing Advisory Group 2020, 15-16; Hunter, Ward, and Purveen 2023).

Prior to the COVID pandemic, Ontario's long-term care system had been impacted by decades of neoliberal policies that promoted for-profit corporate ownership of long-term care homes and decreased comprehensive inspections (Badone 2021). In this context, the "intimate labor" of physical care for residents is not economically valued (Boris and Salazar Parreñas 2010). PSWs in Ontario are poorly compensated, and often lack full-time employment with benefits, making it necessary for them to work more than one part-time job. Significantly, 90% of Ontario's PSWs are women, and 41% are people of color (Stall et al. 2021). The family caregiving that offsets inadequate staffing is also predominantly provided by women, who are not remunerated, and may be forgoing earning opportunities in order to provide care (see CCCE 2022, 13 and 16). Under neoliberal conditions, provision of care beyond what the institution offers is frequently perceived as necessary, and family members can feel responsible for engaging in this effort. High levels of family caregiver involvement have also been reported for nursing homes in the US, with family members reporting that they are involved in monitoring and filling gaps in institutionally provided care, as well as "helping the resident maintain his or her sense of identity through the continuation of loving relationships and helping staff to get to know the resident as an individual" (National Academy of Sciences 2022, 266).

## Theoretical Framework

My research began in response to the crisis in Ontario's long-term care system at the start of the COVID-19 pandemic, and involved interviews by Zoom or telephone with almost 100 family members of residents in Ontario long-term care homes. For the majority of my interlocuters, the quotidian activities of attention to parents, partners, siblings, or spouses in long-term care prior to the COVID lockdown closely resembled Arthur Kleinman's idealization of care as the "essence of being human" and a requirement of a morally good individual (Kleinman and van der Geest 2009, 160). Contrasting care with market models of biomedicine that emphasize cost efficiency and technical competence, Kleinman claims:

> Acknowledgment of the personhood of sufferers and affirmation of their condition and struggle have long been recognised as the most basic and sustaining of moral acts, whether among the friendship and kin network or in patient-physician and other professional relationships. (2012, 1550-1)

From Kleinman's perspective, care involves both practical actions that sustain physical well-being and emotional support, including simply being present with one who is suffering (Kleinman and van der Geest 2009, 161). Drawing upon his own experience of caring for his wife during her struggle with a severe neuro-degenerative disorder, he conceives of caregiving as a form of reciprocity between carer and cared-for, that changes both parties: "What is exchanged is the moral responsibility, emotional sensibility, and social capital of the relationship" (Kleinman 2012, 1551; see also Kleinman 2019).

Significantly, however, research attention has also focused on the emotional ambivalences involved in caregiving. Caregiving potentially involves conflicting desires and needs of the care recipient and caregiver and can therefore be a site of frustration and mixed feelings. Accordingly, anthropologists Joanna Cook and Catherine Trundle (2020, 178) describe caregiving as "unsettled," and claim that it includes "morally ambiguous practices" that can generate ambivalence on the part of the caregiver. As these researchers suggest, “Caring for another and being cared for is often messy, both emotionally and physically… mundane, long-term care relationships may involve daily labor and aspirations toward the ‘good life,’ but they are rarely, if ever, settled” (Cook and Trundle 2020, 180). Moreover, as Taylor (2008) points out, failure to recognize the personhood of care recipients can generate social death, a condition in which their ongoing existence as participants in the world of the living is denied. Social death can also have impacts on physical health. The caregiver narratives that I quote below emphasize the complexities of caregiving, including its potential to either sustain or negate the personhood of the care recipient and the caregiver’s moral agency or sense of identity as an ethical actor within their social domain (Myers 2015). It is also important to recognize that scholars in critical feminist science studies have advocated “unsettling” ideas about care in order to question larger historical processes of social and economic reproduction. They argue that the positive affect sometimes associated with care can work within capitalist structures to disenfranchise caregivers, often women, people of color, and unwaged family members (Fraser 2016; Murphy 2015; Nadasen 2023; Puig de la Bellacasa 2012). Accordingly, I suggest that when caregiving breaks down, the structural circumstances in which it is embedded must be taken into account rather than simply the individual moral and affective character of the caregiver.

## Methodology

Although I would have liked to interview long-term care residents themselves, I was unable to do so in person because of the lockdown. Further, I was hesitant to approach already overworked long-term care staff to facilitate the consent process and technology for online or phone interviews with residents. Instead, I sought to connect with family members of long-term care residents to gain insight into their perspectives on the lockdown and its impact on their relatives. Since most long-term care homes in Ontario have a Family Council, a group of family members and friends of residents that provides peer support, education, and advocacy, I circulated a description of my research together with my contact information through the Facebook page and newsletter of Family Councils Ontario, a non-profit umbrella organization that supports and distributes information to individual Family Councils throughout the province. I was contacted by over 100 people between June and September 2020, and carried out Zoom or phone interviews with 94 participants. The majority of those with whom I spoke were family members of long-term care residents, and this article reflects their lived experience, not the actual experience of long-term care residents themselves. Additionally, although I interviewed several long-term care staff members, including nurses, recreation therapists, personal support workers, and directors of long-term care homes, my materials are too scant to adequately convey their experience of the pandemic. The experience of staff members is, however, richly documented for the United States context by Freidus and Shenk (2024, 2020; see also Freidus, Shenk, and Wolf 2021), and by Hung et al. (2022) for British Columbia, Canada.

Ethics approval for the study was received through the McMaster Research Ethics Board (Project ID 4887), and I personally received informed consent and conducted each interview. Most interviews were audio-recorded, although if participants preferred, I made hand-written notes during our conversation. Audio-recordings were transcribed using NVivo’s automated transcription software. Some transcriptions were subsequently corrected and re-typed by a research assistant. All participants were assigned a pseudonym and some identifying details in the interviews were altered to protect confidentiality. Place names are also pseudonyms. I analyzed the interviews thematically. Those that are presented in this article were selected because participants were especially articulate in voicing themes that recurred throughout the larger body of material. The texts quoted below are not composites or amalgams pieced together from different sources.

Before the lockdown in March 2020, the family members I interviewed had been extensively involved in providing assistance in activities of daily living for their relatives in long-term care such as feeding, dressing, washing, grooming, toileting, exercise, and social stimulation. This type of daily assistance ceased abruptly with the lockdown. The caregiver narratives I present in this paper demonstrate both the caregivers' level of involvement prior to COVID, and the impact of the rupture created by COVID. Research conducted in other Canadian provinces indicates similarly high levels of family involvement in caregiving for residents of long-term care homes, and similar expressions of concern by family caregivers when COVID restrictions prevented them from entering residences and engaging in care (Hindmarch et al. 2021; Hung et al. 2022; see also Freidus and Shenk 2024, 45, 87, 165–166, for US examples).

While the narratives presented in this paper only touch obliquely on the impact of the COVID-19 lockdown on long-term care residents, their situation has been described by health science researchers. According to the Ontario COVID-19 Science Advisory Table, as a result of confinement in their rooms, together with the absence of visitors, group activities, communal dining, and outings,

> countless LTC home residents experienced severe and potentially irreversible harm, with many sustaining physical, cognitive, psychological and functional declines. This constellation of resident clinical issues associated with restrictive IPAC [infection prevention and control] measures in LTC homes has been termed 'confinement syndrome,' a term appropriated from the medical literature describing the symptoms experienced by persons placed in solitary confinement from intense anxiety and sensory deprivation. (Stall et al. 2021, 17)

Furthermore, in many cases, these symptoms were managed through medication, as evidenced by increases in prescriptions for psychoactive drugs to long-term care residents in Ontario that were "out of proportion to expected trends over time, and distinct from observed prescribing changes in other drugs during the pandemic" (Stall et al. 2021, 17; CIHI 2022). In sum, the absence of family caregivers and group activities in long-term care homes during the lockdown led to the isolation of residents, impeded the recognition of their personhood and contributed to their social, psychological and physical decline, the symptoms of which were frequently managed through psychoactive medications.

## Caregiver Narratives

At this point, I turn to the lived experience of my interlocuters during the COVID-19 lockdown. I am particularly concerned to honor the narratives of my participants in their own words as they were recounted to me. These are powerful stories, and I hope to do them justice in their own right, while also using them to illustrate my arguments about caregiving, personhood, moral agency, and public policy.

### *Tom*

At the time of our interview, Tom was in his early 70s. His 80-year-old wife was in the late stages of dementia and had been living in a long-term care home for the past four years. Tom's narrative illustrates how a caregiver can sustain the personhood of a care recipient and in so doing experience a sense of moral agency.

> My wife, Ann, she's in Pleasant View. I'm her second husband. And we've been married 36 years this August. And, you know, we met in grad school. … She's eight years older than I. Just absolutely fell for each other and it started off there. … Prior to the lockdown, I saw her every day. I would go in the mornings and help her with breakfast.

> And the weekends, I would be there for all her meals. For the other two meals a day and during in-between times, when I didn't always get a chance to show back up, I hired sitters. And they were expensive. I felt badly having to do it, but, you know, the level of care was, you know, I felt she needed more than they could deliver or were delivering. And so, I spent, last year $25,000 on sitters. And almost the same amount the previous year. 25 bucks an hour. … She only has in the last few years been on fluids. So, Resource and Carnation Instant Breakfast. Has not been able to take any solid food for the last 2 ½ years and she insists on feeding herself. And it's slow and … she needs prompting. She needs prompting to drink. Sometimes she'll pause or she'll get thrown off. So, you know, we used to work hard to make sure she got a sufficient amount of nourishment at every meal. … Since March 13th, the last day [before the lockdown], nobody has been back in, of course. So, I haven't been able to do this. I see her once a week with a 15 to 20-minute iPad visit. That started up once they [the long-term care staff] got it together. Kinda two or three weeks after lockdown. … She didn't, doesn't relate well to the iPad. It was difficult. And, you know, pretty unsatisfying. Sometimes I can get her engaged a little bit if she hears my voice, maybe see my face. But I talk to her. And tell her I love her and how pretty she looked today. You know, some pet names. We'd try to have a conversation. And we'd have those conversations when I could see her [before the lockdown]. I would say things and she would talk back to me. You know, it was completely incomprehensible most of the time. But it had her phrasings. It had her nuances. And she was telling me stuff. So that I would go, "Oh that's very interesting." And I would come back, and we'd sit. You know, at least when I was there, I could accept she was there. I could go see her. I can sit with her. Just sit and – just sit and hold hands. I'd spend two or three hours with her you know. Or more. Just to be with her. So very difficult with iPad visits. I couldn't – not a lot of information coming out of Pleasant View on a granular level. People are very busy trying, you know, to carry on. I finally- she looked to me like she was losing weight. Because I suspect- just- they don't have anybody to really supervise her meals.

Tom's concern for Ann's physical state was justified: she lost 10 pounds during the first weeks of the pandemic. He continued,

> And she was always a social, bright- social, brilliant person. She was just a big star … and she- I think now she's like many people in there, just parked with the TV on. I think she's retreated into herself even further. Because what would one do anyway? They sling her from the bed to a wheelchair and from her wheelchair back into the bed.

In addition to calling Pleasant View for news of Ann, and participating in the iPad visits during lockdown, Tom bought clothes and sent them to Ann during COVID, to reaffirm her status as a unique individual whose identity is expressed through what she wears. He laments that even when he was allowed to do a socially distanced, masked, in-person visit, no physical contact was permitted:

> I saw her on Monday afternoon. I had my mask; socially distanced. It was wonderful to be in her presence. I had my mask. I was allowed to pull it down at the very beginning to say hi. Put it back up right away. There could be no physical touch. You know, kind of anything that might suggest to her that she was a real person that was loved.

Again, Tom emphasizes the importance of recognizing Ann's ongoing personhood. He observes that the PSWs are "caring people," but that "they had no time to care. … They have to keep moving, there weren't enough of them on the wing or the floor. There's no time – no time in these ladies' lives to nurture their people."

### *Amanda*

Like Tom, other family caregivers I interviewed had, prior to COVID, been participating daily in feeding relatives in long-term care, and sought ways to maintain connections with them during the lockdown. My second caregiver narrative, recounted by Amanda, also illustrates how the personhood of a family member in long-term care was sustained throughout the pandemic, and how engaging in care enhanced the moral agency of the caregiver. At the start of the pandemic, Amanda's 84 year old mother had dementia and congestive heart failure, and had been confined to a wheelchair since falling and breaking her hip. Prior to COVID, Amanda would visit daily, sometimes multiple times a day when she was not working. Amanda's visits were timed for supper because although her mother could feed herself, she ate too quickly:

> I didn't help her. But I would just try and slow her down. Because she would try and put everything in her mouth. For me, it was her issue of choking with too much food. And that's why I went at supper every time because there is less staff on in the building so you don't have the coverage. And I would sit with her and just slow her down from eating. Redirect or just say "Small bites" or, you know, like she could feed herself, but just "Take a little bit less because you don't want to drop it on yourself," or sort of things like that.

Here again, the issue of staff shortages is apparent. Amanda noted that like many people with dementia, her mother would get anxious at the end of the day, so Amanda would help her get ready for bed:

> So as soon as she was done I would take her to her room and I'd change her into, as much as I could, being in the wheelchair. Change in [her] nightgown, have her brush her teeth and wash her face. And sometimes I would do her hair... We would go talk for a bit and then I would get her ready and then the ladies would transfer her into bed … because I wasn't allowed to help transfer, because she's a two-person transfer. So uh, I was told, no, I wasn't allowed to do that, but definitely I would help get her ready and I would support her feeding. But I also did the cognitive support too, and in activities and that with her. And … she had physiotherapy three times a week before COVID. So we would do exercises, like daily exercises so that she could take a few steps.

Since Amanda lives very close to her mother's long-term care residence, visiting was relatively convenient. At the beginning of the COVID lockdown, Amanda was able to work out an arrangement with staff so that each morning at 10:30 a.m., a staff member would bring her mother with her cell phone to a first floor window. Amanda, outside, would call her mother's phone, and the staff member would answer, putting the phone on speaker. In this way, Amanda could have a conversation with her mother and they could see each other:

> And I generally I start off with singing "You Are My Sunshine." And I've done that for eons now. And then- I just converse with her and they come back and check. And some days, well some days if she's sleeping, they just take her back after a few minutes and then other days the conversation, if I'm just doing all the talking, then they'll come in

> and I'll just say, “That's fine. You can take her.” If she's having a good day and I can just talk a little longer, then I'll just stay a little longer. I am there ten to fifteen minutes. I don't like to do it much shorter. But there are days when there's no communication so, I'd like to at least give her that. And on a good day when I can see a brightness in her eyes or whatever, I stay, you know, twenty-five minutes on average.

In addition to conversation, Amanda organized a snack for her mother during their window visit. Each week, she dropped off a pack of small cakes or puddings to the residence, marked with her mother’s name. The staff member would bring one of the food items, along with a cup of tea, for her mother during the window visit. Amanda herself would bring her own tea, so they could share this morning ritual. Arguably, this daily window visit and shared snack was equally, if not more, important for Amanda than for her mother. Not only did it serve to sustain their relationship, it also confirmed for Amanda her sense of identity as an ethical social actor. Here we see how the caregiving relationship involves reciprocal exchange that impacts both carer and cared-for (cf. Kleinman 2012, 1551; see also Kleinman 2019).

As the lockdown wore on, Amanda noticed, during her window visits, that her mother was becoming less capable of feeding herself. At first, she could open the package and take out the cake and drink her tea unaided. But,

> as time went on, we had to switch the cake to a pudding and the tea to a straw. … So, she needs to drink her tea down with a straw and now it is a lot more coaching to get her, when she's done her pudding…to put it on her table and just switch it for her tea. … She has definitely declined. … And physically she just does not have any strength. She was initially able to hold the phone up to her ear. But now what we do is put it on a pillow and they put it on speaker, and I just talk to her.

Over the course of the lockdown, Amanda observed cognitive and physical decline in her mother. Many of my interlocuters made similar observations. Brenda, for example, commented that after several months of the lockdown her husband, who is blind and has dementia and Parkinson’s, had been refusing to eat or take his medications for two days. He became dehydrated, and told staff, “It’s time to go to heaven.” For Brenda, “The refusal to eat and the refusal to take his medications and basically the wish to die was because nobody was there. His family wasn’t there. I wasn’t there. He couldn’t see his dogs. There was nothing going on in the home. And he just gave up.” In the absence of the recognition of their personhood through regular interaction in a familiar social setting, long-term care residents experienced social death, which precipitated a diminution of physical well-being

### *Dora*

Most of the family members I interviewed attempted to maintain the personhood of relatives in LTC by means of ongoing communication during the lockdown through phone calls, window visits, and iPad visits. However, there was one instance in which a family member made the decision to remove her mother from long-term care at the beginning of April 2020 and care for her at home. Dora lives alone, and although she has a PhD in a humanities field, works in retail. Her elderly mother with dementia was living in a four-bed ward in an older long-term care home, one of the types of accommodation where it was most difficult to prevent the spread of infection since four people shared a room (see Stall et al. 2020; 2021, 13). Following reports of COVID deaths at other Ontario residences at the end of March 2020 and when she learned that someone in her mother’s residence had tested positive, Dora made the difficult decision to bring her mother home. Dora had barely a day to prepare a bedroom in her home for her mother. Within an hour of informing the director of her decision, Dora had to be at the residence to pick up her mother with all her belongings. Dora describes her mother's discharge from long-term care as "one of the more terrifying moments in my life." She had to inform her boss that she would take time off work, since she had nobody else at home to help care for her mother.

Although her mother has dementia, she is able to follow the TV news and carry on a conversation. One evening, Dora and her mother were watching news coverage of long-term care and the deaths due to COVID. In a vignette that echoes Kleinman's (2012, 1551; 2019) observations about reciprocity in caregiving, Dora recalls:

> We were watching it on TV and I said, "Look, mom, look. This is the long term care, the deaths." And she said, "Yes." She says, "Is that why I'm here?" And I said, "Yes." And then she said, "You saved me." And she said, "Thank you." And I can't think of that without wanting to cry.

It turned out that the residence where Dora's mother had been living was one of the long-term care homes hardest hit by COVID in Ontario, with over 50 deaths.

When I interviewed Dora, she freely admitted that she had been "terrified" by the challenge of caring for her mother alone at home. Moreover, she was uncertain about the future, concerned about the possibility of being unable to return to her job after the pandemic, and unsure about how long she could keep her mother at home. Nonetheless, Dora persisted in this "moral experiment" seeking to do what she felt the circumstances demanded in order to construct a good life for herself and her mother (Mattingly 2019, 116).

While Dora expresses some of the emotional ambivalences involved in caregiving, my next caregiver narrative goes further, illustrating the struggles and despair emanating from care, the difficulties of sustaining a care recipient's personhood over time, and ultimately the decision to curtail care. In other words, Phil's story reflects the experience of caregiver burnout, and underscores the need for public policy implementing structural supports for family caregivers in Ontario's long-term care system.

### *Phil*

Phil has been on a 15 year journey of caring for his wife, Patty, now 70, who started to have memory problems at age 55. Patty had been "the pillar of health." She rarely drank, never smoked, and enjoyed long-distance cycling. Phil recalled that it was on a cycling trip in 2007, during a conversation with Patty that she "looked at me and asked me to repeat myself again. And I guess I looked at her and I was just kind of, I was annoyed, when she started crying and she had no idea what I had said…So I said, you know, 'Something's not right here. I think we need to be checked out.'"

In 2008, a specialist suggested that Patty likely had early-onset Alzheimer's, which was formally diagnosed two years later. Phil continued:

> She then underwent a series, a battery of tests and started a clinical trial of a new drug … and nothing changed whatsoever. And she went downhill pretty quickly from 2010 to 2014 and … our case worker from Social Services…essentially looked at me and says, "You need to declare an emergency. … And I said, "Well, I'm still trying to look after Patty." And she said it wasn't as much for Patty as it was for me. She said, "No, you're going downhill fast as well from an emotional stress point of view."

Phil described his state at the time as "having a nervous breakdown." As he explained, "Because of the stress, I am not a born caregiver." Although he tried to take breaks by putting Patty into temporary respite care,

> Patty absolutely hated it, just detested it. And she pleaded, pleaded with me to stay home and then pleaded with me not to put her in a long term care. And I tried my, I tried my best, but I'm not a natural born caregiver. Well, I couldn't, I couldn't handle it.

Patty was placed in a locked unit in long-term care in May 2014. Over the seven years between the onset of her Alzheimer's and her admission to long-term care, the relationship of care between Phil and Patty evolved and shifted, from one in which Phil could meet her needs and his own to one in which Phil himself began to require care.

By the end of 2014, Patty had ceased communicating through speech. Inability to move her legs followed in 2015, and she lost the use of her arms in 2018. She is now totally confined to a wheelchair. Phil explains that although she can still swallow, "her eyes haven't opened in probably a year, year and a half. She is in, for all intents and purposes, a complete vegetative state." Phil and his two daughters feel guilty, but dislike visiting Patty in long-term care. As he puts it, "My kids and I don't want to go in because we don't like the environment, we don't like to see our loved one in that particular state." He is satisfied that, although numbers of PSWs seem low, the long-term care staff are "doing their best" and the care that Patty is receiving is better than what he could provide at home.

Phil regrets that Patty's "quality of life left a long time ago, years ago." Owing to the lockdown, many months had elapsed since he had last seen Patty. Yet he explains, "Even if I went in to see her, if I could, there's no reaction. The person that's there in that wheelchair is not the person I know anymore." Here, Phil expresses his inability to recognize Patty's personhood. Her incapacity to respond means that she has crossed over into the category of social death. As Phil states, "She looks familiar, but there's just no life left in her." For Phil, it would "almost be a blessing" if Patty caught COVID "because there's not a chance in hell she would want to be living in the state that she is in."

Phil is not a caregiver who views the other as an extension of the self, with needs that are inseparable from his own (cf. Kleinman and van der Geest 2009, 160). Rather, he has mentally separated himself from caring for Patty, spending six months of the year in Florida. As he told me, "You know, I've actually started saying, 'OK, well, there's nothing I can do. I'm going to do what I can to live my life and, you know, enjoy finding another companion.'" This decision was not made without moral anguish, however. Phil acknowledged that several former friends, including Patty's sister, no longer speak to him because of his decision to put Patty into long-term care and "live his life." However, he claims that he is inadequate to the task of continuing to support her: he is not a "natural born caregiver."

## Conclusion

The narratives presented above reflect the paradoxical and many-sided character of caregiving. Tom, Amanda and Dora experienced caregiving as an emotionally rewarding endeavour that reinforced their sense of identity as moral agents, while also affirming the personhood of their relatives in long-term care homes. Kleinman's claim that caring is the essence of being human resonates in these caregiver narratives (Kleinman and van der Geest 2009, 160). In contrast, for Phil, over the course of his wife's illness the caregiving experience became meaningless, leaving him depressed in the face of perceived moral failure and negative judgements from friends and family. As Cook and Trundle argue, in many cases the work of care "challenges the valorization of caregiving (as 'natural,' 'good,' or 'rewarding') by revealing the unsettled nature of lived experience, replete with uncomfortable and changeable affective relations" (Cook and Trundle 2020, 191). Importantly, however, Phil's experience cannot be read in isolation as a case of personal inadequacy. Indeed, from an anthropological perspective the very notion of a "natural-born caregiver" that he posits is problematic. Caregiving always exists within the context of social, political and economic structures. By way of a conclusion, I move here to a consideration of these structures.

As Béland and Marier suggest, COVID-19 served as a "focusing event" highlighting the policy challenges facing long-term care in Canada. As such, the pandemic created the possibility for the opening of a "policy window" for systemic reform (Béland and Marier 2020; see also Picard 2021). In the wake of the devastation wrought by COVID-19 on long-term care in Ontario, in 2021 the Ontario legislature passed the "Fixing Long-Term Care Act." Among its provisions, the act stipulates that by March 2025, an average of four hours of direct care must be provided to each resident per day (Ontario 2021). At the federal level, the government is also taking steps to develop national standards for long-term care (Government of Canada 2021). These developments encourage the hope that going forward, long-term care institutions will recognize and prioritize levels of care that can help to maintain the personhood of their elderly residents. Yet, as in the healthcare system more generally, a staffing crisis continues to undermine such efforts to reform long-term care. In part, the roots of this crisis lie in the low wages, precarious employment, and difficult working conditions that characterize the long-term care sector.

The goal of recognizing the frail elderly in long-term care as persons can only be achieved if long-term staff too are treated with dignity. Their personhood and the expertise involved in their work of caregiving for those with dementia and chronic disabilities must be recognized. Adequate levels of staffing in long-term care need to be prioritized in the aftermath of the COVID-19 crisis (Flanagan et al. 2023, 31-35). In this connection, it is important to emphasize that long-term care nurses and PSWs deserve salaries, benefits, and working conditions commensurate with their vital role of ministering to some of the most vulnerable members of society (Connelly et al. 2023; Freidus and Shenk 2024, 169-170; Hung et al. 2022; Picard 2021, 164). Moreover, the role of family caregivers needs to be supported, and practical measures instituted to enable them to work together with long-term care staff as active members of the caregiving team (Flanagan et al. 2023, 38). Greater government support for home and community care would also enable more individuals to age in their own homes while cutting costs relative to residential long-term care (Kokorelias and Flanagan 2023; Flanagan et al. 2023, 25-6; Freidus and Shenk 2024, 168). Additionally, a 2023 report by the National Institute on Ageing at Toronto Metropolitan University identifies eight challenges in the current state of long-term care in Canada, of which the seventh is "Canada's Perilous Overreliance on Unpaid Caregivers Amidst a Lack of Support for Them" (Flanagan et al. 2023). More systemic assistance for family caregivers, including financial, respite, and mental health supports could decrease caregiver stress and prevent people like Phil from having to face the agonizing alternative of personal burnout or institutional care for a family member.

Finally, both family and professional caregivers must acknowledge the ambivalent, multifaceted character of caregiving. Caregiving is challenging in the best of circumstances, and becomes more arduous in crisis situations like the COVID-19 pandemic, requiring creative policies and resources to support resilience (Connelly et al. 2023, 4368). Caregiving can be physically arduous and can bring the caregiver into close proximity with bodily substances and states that may induce revulsion and serve as reminders of the inevitability of death for all beings. The goals, needs, and desires of caregivers and care recipients can be at odds with one another, generating frustration, and despair. Yet caregiving also holds the potential to reinforce humanity and personhood, both for carers and those for whom they care.

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