Trust as a key measure of quality and safety after the restriction of family contact in Canadian long-term care settings during the COVID-19 pandemic☆

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ABSTRACT

Family caregivers in Canadian long-term care homes are estimated to provide 10 h per week of direct care to approximately 30% of residents through roles including mobility support, mealtime assistance, personal care, social interaction, psychological care, care coordination, and advocacy. Despite these contributions, they continue to be viewed as visitors rather than as key participants in the interdependent relationships that support the long-term care sector. Their marginalization was evident during the COVID-19 pandemic, as Canadian public health policy focused on preventing them from entering long-term care, rather than supporting personal risk management, symptom screening, personal protective equipment, and other mechanisms for safe involvement in care. Several iatrogenic resident outcomes have been attributed to this, including decreased cognitive function, decreased mobility, increased incontinence, weight loss, increased depression and anxiety, increased responsive behaviours amongst those living with dementia, and increased delirium. In this commentary article, we argue that family caregiver presence was conflated as a risk when instead, it contributed to unintended harm. We identify nine well-known human social cognitive predispositions that may have contributed to this. We then examine their implications for trust in long-term care, and consider how quality and safety can be further fostered in long-term care by working in partnership with family caregivers to rebuild trust through enquiry and collaboration. We advocate incorporating trust as an essential measure of quality health service.

1. Introduction

Family caregivers in Canadian long-term care (LTC) homes are estimated to provide 10 h per week of *direct* care to approximately 30% of residents [1]. Continuing a role that began long before admission to LTC, family caregivers help residents mobilize; assist with meals, personal care, grooming, and bathing; and provide social interaction, psychological care, care coordination, and advocacy [1,2]. In LTC, active family caregiver involvement can decrease staff workload and reduce mortality, infection and hospitalization rates [2]. Family caregivers contribute significantly to the physical and psychosocial wellbeing of their own relatives while also supporting other residents, and this addresses practical needs, decreases experiences of loneliness and isolation, and fosters a sense of community and belonging [1–3].

Family caregiver contributions are fundamental to supporting the fourth age of life. While the third age of life is a time when people age relatively independently, during the fourth age, encompassed by late older adulthood, people experience physical and cognitive changes that increase reliance on others [4]. This stage, marked by the intersection of older age and disability – including frailty, complex multisystem disease, and advanced dementia – poses an existential threat to others outside it who have not yet made peace with their need for others, the temporariness of their able-bodiedness, and the impermanence of life itself. Fears associated with these perceived threats render people in the fourth age particularly vulnerable to stigmatization [4].

Yet the fourth age is also a natural part of life; a stage that most of us will ultimately experience and adjust to. Rather than a stage evoking fear, sympathy, or charity, it can be stage during which a collaborative or partnered approach to health, safety, and quality of life, set in the context of relationships with family and community, becomes increasingly and mutually valuable. The natural and necessary interdependence manifested in the fourth age calls for a relationship-centred approach to care in LTC homes that is flexible enough to accommodate and extend interdependent care partnerships between people with disabilities and their families, friends, and communities.

Grounded in relational ethics, *relationship-centred care* is an approach to improving care quality and safety by recognizing and extending the natural reciprocity amongst residents, family caregivers, and health care

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professionals [5,6]. The central tenets of relationship-centred care are that the personhood of everyone involved matters; affect and emotion are important components of relationships in healthcare; all healthcare relationships occur in the context of reciprocal influence; and forming and maintaining genuine relationships is morally valuable [5,6]. The implication of these principles for LTC is that the healthcare experience is co-constructed by *all* participants, including residents, family caregivers, employees, and leaders. Relationship-centred care is not superfluous in LTC; on the contrary, mattering to others affects health, survival, and employee wellbeing [7]. Moreover, capacity for relationship-centred healthcare cannot be taken for granted, since "relational labour is skilled and complex" [8].

Within the network of interdependent relationships supporting long-term care, family carework has been named the "bedrock" ([9], p. 116). It is distinguished from systematized carework in its emphasis on permanent, personal, relations characterized by positive and deep affect, task flexibility, and longstanding commitment without need for personal gain [10,11]. In short, it is a relationship-centred approach. In contrast, paid health carework tends to emphasize impersonal and hierarchical relationships, task specialization, and instrumental, timebound commitments [10,11]; deprioritizing relationships to achieve economies of scale. Although this conceptualization is not without criticism (e.g., for oversimplifying family and staff caregiving roles, failing to recognize the technical expertise of family caregivers, and failing to account for diversity in the care orientation`s of staff and family members; Dupuis & Norris [12]) it continues to be referenced in relation to historical tensions between the health system and family caregivers.

Consistent with Litwak's account, current healthcare policy positions family caregivers as different than health care employees; for instance, as having low technical expertise and acting out of moral or personal obligation. Consequently, rather than being perceived as co-creators of care quality who are integral to residents' social engagement, quality of life, sense of home and community, and even, in some instances, survival ('essential'), at the outset of the pandemic, family members were identified as mere 'visitors' ('non-essential'). As policies adopted during the pandemic capitalized on the notion of families as visitors, LTC homes closed their doors on family members who were otherwise instrumental to the health and wellbeing of their relatives [13]. Family caregiver visitation restrictions began in March 2020, at the outset of the pandemic, often without warning, and were prolonged [13]. These restrictions disrupted the functions of the LTC community by removing family caregivers from resident quality of life and care and as a resource in the pandemic response [13–15]. This choice reinforced LTC as a healthcare institution rather than an interdependent community of residents, families, and interprofessional staff, all of whom are partners in co-producing safety, quality of life, quality of care, and a quality work environment for employees [16].

This policy choice had unforeseen consequences. Staff workload and movement between residents increased, requiring additional infection control work [17]. Compounded by staff shortages, this increase in workload decreased time for direct resident care, increased residents' social isolation, and is hypothesized to have increased COVID-19 transmission [17]. Further, a cascade of iatrogenic resident outcomes attributed to visitor restrictions was observed, including: decline in cognitive function, decreased mobility, increased incontinence, weight loss, increased depression and anxiety, increased responsive behaviours amongst those living with dementia, and increased delirium [14,16,18]. A preliminary study from Ontario evaluated excess mortality due to social isolation during the early stage of the pandemic [19]. The 2.3% of LTC residents with the least personal contact with family or friends (including phone calls or virtual visits) had 34.8% greater excess mortality. Ultimately, visitor restrictions caused unintended harm, including social isolation, loss of support for functions, excess morbidity and excess mortality [13,15,19,20].

Additionally, during the first year of the pandemic, research examining the effects of limited relief of visitor restrictions did not suggest an increase in COVID-19 risk attributable to family involvement [15,20–23]. For instance, Horikoshi et al. [24] found that permitting sibling visits in neonatal intensive care units did not increase infection rate amongst admitted neonates. Similarly, in the context of a previous epidemic, a Canadian paediatric hospital found no connection between broad visiting hours and SARS infection [25]. Although one explanation for these findings is that there may be fewer visitors than staff, other tenable hypotheses ought to be explored (e.g., whether family caregiver risk sensitivity is associated with taking additional precautions to avoid transmission and whether risk-associated demographic factors systematically differ between staff and families; see [26]). Overall, there continues to be insufficient evidence that prolonged visiting restrictions are effective [14,20,27–31]. There also continues to be insufficient evidence that the benefit outweighs the harm [32,33].

Public health policy begins with the harm principle; in this case, taking rapid action to minimize widespread harm that could occur from an outbreak [34]. Initial strict visitor restrictions occurred because of the unknown, yet foreseeably harmful, impact of the pandemic [13]. The immediate public health response to a then poorly defined viral threat was a standardized response of limiting the frequency of individual interactions as a means of decreasing potential transmission [13]. Yet, the policy choice to achieve this by keeping families out was illogical from the outset, conflating *families* rather than specific behaviours and conditions (e.g., *adherence to infection control training, total number of contacts, or duration of contacts*) with the risk of infection. This policy choice failed to acknowledge the extent of family caregivers' contributions to long-term care, instead reprioritizing the understanding of healthcare work as paid, instrumental labour. This choice also disregarded prior evidence that this policy choice might be ineffective [35, 36] and demonstrated a lack of attention to the level of resources currently available to facilitate quality care in the long-term care sector. Furthermore, it violated the human right of integrity of the family [37].

Over time, visitor restrictions eased with the introduction of new policy concepts such as *essential family caregiver,* recognizing that some family caregivers had previously provided direct care (paralleling staff work), and *palliative care* or *compassionate care*, recognizing moral reasons to acknowledge the interdependent relationships within families at the time proximal to death. In practical terms, these were policy loopholes; ideas so compelling that they begged forgiveness of the general standard. Yet, these are also very serious policy complications that must be properly addressed. From a human rights perspective, family relationships are considered essential, period, and it is important to protect the integrity of the family whenever possible [38]. From a palliative care perspective, family relationships are prioritized in two ways, with family caregivers recognized both as part of the unit of care and as an integral part of the care team, engaged from the time of diagnosis to the end of life – the window during which palliative care is intended to be applied [31]. Yet, in Canada, many caregivers were unable to touch or even so much as stand in the same room as their family member for more than 12 months – a period during which one third of LTC residents in Canada could be expected to have died, even apart from the pandemic. Outside of LTC, such severe conditions would not have been tolerated.

Despite growing evidence of the unintended harms associated with the application of visitor restriction policies in long-term care, the harm principle of the public health framework has not yet been applied within a policy response that unequivocally upholds human rights and supports family caregivers to resume their caregiving roles and partner in current and future pandemic responses. This delayed response to recognizing the harms associated with excluding family caregivers from the pandemic response suggests the possibility of a serious gap in policy-makers' recognition of the nature of family carework in LTC. This gap exists despite a moral and evidentiary foundation for the value of family carework in healthcare. We now turn to potential reasons for this gap. We begin by examining why the way we think about family caregiving matters.

1.1. How we think about family caregiving matters

During the COVID-19 pandemic, two of the authors (Hunter & Ward) took part in a weekly exchange between family caregivers, community members, students, and clinical researchers in the province of Saskatchewan, Canada. During this exchange, family caregivers clearly articulated their experiences and reactions (for a highly resonant account, see [39]). For example, two family caregivers who had previously delivered 20 h per week of direct care assistance to spouses, including mealtime assistance, bathing, and walking, were prohibited from entering the same facility for over four months, despite using every available channel (except media) to express concern and request that their role be restored. Both ultimately coordinated a move to another home, where, as policy restrictions eased, they were able to be designated 'essential' – despite believing their essentialness, and that of other family caregivers, should have been obvious from the beginning. Even then, they noticed that the rules that applied to employees were often different for them. Some family caregivers described having the sense that the health authority now *owned* their family member, having practically assumed all rights, since family caregivers, even if legally positioned as decision-makers, were clearly barred from making some kinds of decisions (e.g., the decision to visit), and now lacked appropriate information and context to support other decisions (e.g., healthcare decisions they were legally responsible for). There was also a general sense that somehow, despite an initial media focus on the situation in long-term care, the plight of families relying on long-term care had been mislabeled as a moderately concerning ethical dilemma rather than a serious human rights issue [39]. The collective and longstanding tolerance of this situation provoked consideration of the metaphor of the boiling frog and prompted reflection on a fuller range of potential social and cognitive biases that might be contributing to a miscalculation of the risk-benefit ratio of involving family caregivers in the pandemic response, and a serious regression in progress toward relationship-centred care in LTC. As we reflected on these dynamics, we referred to the work of the third author (Puurveen), who had, prior to the pandemic, observed the significant challenges family members faced in translating their perspectives, their expertise, and their value as care partners in long-term care [3,40].

Such conditions suggest the possibility that implicit bias [41] influenced perspectives on family caregiving both prior to and during the pandemic. Implicit bias contributes to discrimination in healthcare [42]; yet, psychologists perceive it as a natural feature of human cognition, and as part of a larger set of cognitive and relational predispositions [43]. This is not a resigned acknowledgement of a sometimes maladaptive human tendency; rather, it is a bold line of enquiry about who we do or do not prioritize, why, and what to do about it. Encompassing the study of implicit bias, the broader tradition of *social cognition* explores "how people think about themselves, the people they know, and the social world more generally" [44]. It is recognized as integrally linked to the study of relationship-centred care [6].

2. Social cognitive predispositions that informed family caregiving policy during the pandemic

Borrowing from the social cognitive tradition, we now identify nine predispositions that may have contributed to family caregivers being specially identified as a safety concern in the LTC sector during the COVID-19 pandemic, and to their tolerance of this situation. We begin with the role of family caregivers' *perceived behavioural control*, or perceived influence over the situation, to account for the 'boiling frog' metaphor. We then explore the potential contribution of social perception (*social categorization, ingroup-outgroup bias*) to the positioning of family caregivers. Finally, we explore the role of cognitive heuristics (the *contagion heuristic, representativeness and the distinctiveness heuristic, oversimplification,* and *sunk-cost fallacy*), and other social cognitive phenomena, including *cognitive dissonance*, and *majority influence*, or

group belonging.

2.1. Perceived behavioural control

Early in the pandemic, in the context of uncertainty, aggressive measures were introduced to halt virus spread as the most effective mitigating actions were awaited [45]. When contact between long-term care residents and their families was interrupted as a precautionary measure, family caregivers were troubled, yet tolerated this as a short-term emergency measure [46–48]. However, as this practice continued, people seemed to grow accustomed to a situation that would normally have been intolerable, seemingly like the fox in Aesop's fable (see Fig. 1). Icek Ajzen [49] believes that many social situations that appear at first glance to be instances of habituation actually more accurately reflect *perceived behavioural control*, or whether we believe it is in our power to change an outcome. According to Ajzen [49], perceived behavioural control has to do with self-efficacy (whether we believe our actions will be effectual) and freedom (whether we are actually allowed to perform the actions). During the pandemic, in an environment of high uncertainty and government control, perceived behavioural control was very low. Family caregivers had neither authority nor access to ask pandemic decision-makers to consider whether family contact measures needed to be re-evaluated as the balance of potential risks and benefits began to shift (cf. [50]).

2.2. Social categorization

Social categorization, or the tendency to group people based on their personal characteristics, and stereotyping, or the tendency to make attributions or assumptions about people based on these characteristics, are robustly documented human tendencies [51]. These tendencies can be very adaptive, as when you know just what kind of toy a six-year-old child might like to receive for their birthday. But they can also be harmful, as when a sixty-year-old adult is given a package of adult incontinence products as a 'humorous' birthday gift. Discrimination – the tendency to act on negative stereotypes – is at the root of serious social problems, and contributes to intergroup conflict [51].

Dissatisfied with the way overuse of the term 'ageism' masks particularities that, if discovered and discussed, might help to address age-based discrimination, British sociologists Paul Higgs and Chris Gilleard (2021) distinguished between the *third age* and *fourth age* of life. Whereas the third age is a time when we will age relatively independently, the fourth age is marked by the intersection of age and disability [4]. Further, their term *fourth ageism* emphasizes that ageism is primarily directed toward those in the fourth age, a stage of increased reliance on others that is seen by modern societies as unwanted and distasteful [4]. In other words, fourth ageism is the intersection of ageism and ableism, directed toward people with intersectional identities as older adults with disabilities (Fig. 2).

About one in three Canadian older adults age 85+ live in LTC [52]. While this represents 3% of all older adults [52], it also represents the group at greatest risk of experiencing fourth ageism. Fourth ageism was pronounced in the pandemic response. Although globally, there was immediate recognition of the potential adverse effects of COVID-19 on older people (i.e., those in the third age), the potential impact on people living in LTC homes (i.e., those in the fourth age) did not capture attention until after devastating outbreaks occurred [4]. In Canada, although gerontologists immediately began to refer to LTC as a "tinderbox" of pandemic risk, LTC homes were not supported to make rapid adaptations to address these issues [53].

Beyond the likely contribution of fourth ageism to the inadequate pandemic response in LTC, another outcropping of social categorization is prominent in healthcare settings. *Paternalism* is widely defined as a limitation of autonomy or freedom imposed with benevolent intentions by an agent of the state. It is associated with the presumption "we know better" and is commonplace in healthcare settings despite evidence that

"A fox who had never yet seen a lion, when he fell in with him for the first time in the forest was so frightened that he was near dying with fear. On his meeting with him for the second time, he was still much alarmed, but not to the same extent as at first. On seeing him the third time, he so increased in boldness that he went up to him and commenced a familiar conversation with him."

(Æsop's Fables, as cited in Thompson 2009)

Fig. 1. Habituation.

Reflect on how people speak about growing very old, becoming frail, acquiring disabilities, or living in LTC. Have you ever heard people say, "I would never want to live like that" or "I want euthanasia if it ever gets to that point"? How many times have you heard alternative points of view, such as, "We all rely on the support of other people", or "They need extra support now, just as one day I will need it, too", or "They have done so much for us in our lives, and now it is our turn to serve them"? What does this suggest about our attitudes toward the oldest adults in our society, or toward persons living with disability?

Fig. 2. Social categorization and fourth ageism.

its opposite (active patient and family participation) is associated with reduced problems or improved outcomes [27,54]. Paternalism was a significant factor in the taken-for-granted assumption that it was in LTC residents' best interests for healthcare providers to assume sole responsibility for their care during the pandemic (see Fig. 3).

2.3. Ingroup-outgroup bias

In 1982, Robert Hogan theorized that as social animals, humans are driven by two basic social motivations: *getting along*, or being accepted by others, and *getting ahead*, or having social status. These tendencies were well illustrated by a psychology experiment conducted at a summer camp. In the experiment, 22 school-age boys were divided into two groups. Within each group, the boys got to know each other. The groups were then brought together and offered prizes for wining competitions like tug-of-war. Before long, each group began to call the other names, and after some time, the situation escalated into physical aggression. Additional intervention led to a hopeful ending to the story, but the study became part of a tradition of research that showed clearly how easily people sort themselves into "us" and "them", adopting in-group affiliations and outgroup biases in a bid to attain status and belonging [55,56].

As life and livelihood were threatened by the pandemic, in-group favouritism increased. In North America, this was visible in increased ethnic intergroup conflict; for instance, anti-Asian attitudes increased when China was specified as country from which COVID-19 originated [57]. Ingroup-outgroup dynamics also operated in vaccine and mask use hesitancy as dialogue about "maskers and vaxers" or "anti-maskers and anti-vaxers" emerged – calling to mind the juvenile name-calling in Sherif's experiment. In one pandemic-era online gaming experiment, when information about the virtual game partner's choice to wear a mask or not became available, cooperation significantly decreased [58]. Arguably, ingroup-outgroup dynamics were also observed in LTC. Families were almost immediately identified as an outgroup (non-essential "visitors") when they might more logically have been seen as an ingroup; people integral to residents' lives and essential members of residents' caregiving teams [13–16].

Have you lived, worked, or spent time in a LTC home? Did you ever hear the words, "this is how we do things here" or "this is just how the system works"? How was it decided that this is how we do things? Who is responsible for the functioning of 'the system' if not the people within it?

Fig. 3. Paternalism.

2.4. Contagion heuristic

Cognitive heuristics are often referred to as "mental shortcuts", or tendencies that facilitate quick judgments and decisions yet also predispose us to error. One such tendency is the *contagion heuristic*. When people rely on this heuristic, they automatically avoid contact with people or objects they associate with contamination. According to psychologist Mark Schaller [59], other behavioural tendencies are also activated on exposure to stimuli signalling the possible presence of pathogens. These tendencies are part of what Schaller terms the *behavioural immune system*, potentially including strong emotions (including fear or disgust), reduced extraversion, and increased ingroup affiliation and outgroup bias [60]. This theory has been used to account for ingroup-outgroup bias during the pandemic [61].

In Canada, based on prior policy, it was taken for granted that allowing family caregivers into LTC facilities would increase COVID-19 transmission. This led to the implementation of prolonged and severe restrictions on family presence in healthcare [13,16,18]. For many, these policies reinforced assumptions that family members elevated risk and that family members would not follow infection control protocols [14,20]. Family members were increasingly seen as contagious outsiders prone to infectious spread [26,28], while healthcare employees were accepted as members of a less contagious ingroup.

2.5. Representativeness and distinctiveness heuristics

When people rely on a cognitive heuristic called the *representativeness heuristic,* they rely on the examples that first come to mind for estimating probability [62]. In a classic example of the representativeness heuristic, if people are asked whether the most common cause of death is a car accident or a heart disease, they often choose 'car accident' because of vivid examples from local news stories, even though heart disease is actually the leading cause of death. Of course, just because an example easily comes to mind does not mean it is statistically reliable. During the pandemic, health care workers easily called to mind examples of family members who disrespected public health policies. Even though the majority of family members were conscious of the high stakes and took safety precautions [20], these few distinctive departures became vivid (albeit inaccurate) representations of the risks associated with increasing family caregiver involvement.

2.6. Oversimplification

Problem oversimplification is the undesirable end result of using cognitive heuristics in complex decision-making. At all levels of government and healthcare, pandemic decision-makers were operating under conditions of constant change and time pressure, with diverse interests to take into account. Many decisions represented true practical and ethical dilemmas, with significant potential for each option to have unwanted consequences. Cognitive scientists have observed that as decisional demands increase, energy wanes and *decision fatigue* ensues

[63]. One response to decision fatigue is to employ the *take-the-best heuristic*, which involves focusing mainly on one aspect of a problem to avoid having to think about all of the other complex variables [64] (see Fig. 4).

Under conditions of high cognitive load, decision-makers over-relied on heuristic strategies as they selected measures to minimize the chance of an outbreak in LTC [65,66]. These measures included previously used outbreak management strategies that largely fell into two categories; first, social precautions (physical distancing and limiting contact with family and friends) and secondly, traditional infection control measures (screening, contact tracing, sanitization, and masking).

While many of the infection control strategies implemented early in the pandemic (e.g., screening and masking) were supported by incoming evidence throughout the pandemic, the evidence supporting others was not adequately revisited as it came in under conditions of choice overload and decision fatigue. For example, although the potential for compromised mental health and excess mortality associated with the involuntary separation of family members was raised early in the pandemic, this was considered an ethical dilemma rather than an evidence dilemma. Even with emerging evidence that including family caregivers on healthcare teams did not significantly elevate infection control risk, conditions were not favourable to integrate this new information [15,20–23].

2.7. Sunk cost fallacy

When we make a decision, even if not ideal, we tend to commit. It's not difficult to imagine how this strategy of accepting imperfection often serves us well in life; in fact, some psychotherapies are actually geared toward helping people to make choices and commit to them, even if positive results cannot be guaranteed [67]. But it's also easy to imagine this tendency serving us poorly; in the words of one American country song, "You've got to know when to hold 'em and know when to fold 'em". The tendency to cling to previous choices even when they are poor ones is called the *sunk cost fallacy*. It seems to result from reluctance to acknowledge associated losses, or accept associated social costs [68]. When the evidence is not perfectly clear, *confirmation bias* causes us to look for information that aligns with our current perspective rather than seeking out the most accurate information.

One policy comparison done after the first quarter of the pandemic showed that countries that emphasized policies reducing community contact with LTC residents over providing infection control supplies and coaching experienced proportionally more deaths in LTC [69]. Canada was the worst performer. Although this policy and evidence summary should have prompted some revisiting of pandemic strategy for LTC, it did not. Family contact with LTC residents was ultimately suspended for a full 15 months with few exceptions (e.g., when a family member was dying) and very limited relief (e.g., summer, outdoor, and distanced visits).

You go to a new grocery store and find that the eggs you usually buy are not available. A panorama of new choices is available. Will you decide by price, size, number of eggs, condition of the eggs, colour, brand, or how the chickens were raised? When the array of choices is complex, many people will ultimately choose just one main thing to focus on (perhaps low price or familiar brand) even when this strategy does not maximize their advantages.

Fig. 4. Choice overload bias and taking the best.

2.8. Cognitive dissonance (Moral distress)

The subject of moral distress in healthcare began to attract a great deal of attention during the pandemic. An older term for moral distress comes from a research tradition in psychology on the topic of *cognitive dissonance,* the intense anxiety people feel when there is sustained discord between their values and actions [70]. While modern research focuses on the consequences of sustained moral distress, studies from the older tradition showed that people are highly motivated to reduce the distress associated with unresolved misgivings. The sum of these observations is that when people are in a difficult situation, they often choose the path of least resistance. Rather than acting in a way that aligns with their values, they adjust their values to align with their actions [70] (see Fig. 5).

During the pandemic, moral distress intensified. For example, in the LTC context, many healthcare employees experienced moral distress about the absence of family members from LTC during the pandemic [71]. Others felt distress at the thought that many LTC residents would die without ever seeing their family members again. Rather than maintaining moral distress, some healthcare providers are likely to have moved toward the view, "This is the way it has to be to protect the residents".

2.9. Majority influence

In a series of surprising experiments, social psychologists found that people are motivated to do very illogical things to align with the groups they belong to. In one demonstration, a number of university students sat around a table, comparing the length of a stimulus line to a selection of other lines –one equal, and the others either shorter or longer [72]. Most of the students were stooges, planted to say they believed the stimulus line matched best to a line that was *not* the obvious choice. Participants caved to the pressure of the staged group, apparently experiencing the "need to be liked" (belonging) as a much more powerful source of motivation than the "need to be right" (accuracy) [73]. This elegant social experiment demonstrated the intense social pressure faced by those who wish to express a minority perspective.

In Canada, Ontario premier Doug Ford's call for "an iron ring of protection" around LTC became a powerful metaphor for the introduction of strong precautions to prevent outbreaks, and intensified pressure on LTC providers. It was implied that LTC could be safely shielded if the proper measures were put in place to keep the virus out. In truth, because LTC is integrally linked to the community, the number of COVID-19 outbreaks in long-term settings was directly related to the level of community spread [13,17]. Thus, the compelling but inaccurate metaphor of an iron ring established an impossible standard. The fact of having a COVID-19 outbreak became a reflection on LTC organizations' abilities to care for residents, and keeping families out became a part of

the arsenal of precautions to forge the mythical iron ring [13,17].

2.10. Summary

We have identified nine social cognitive predispositions that may have operated as blind spots reinforcing the supremacy of the health system's approach to pandemic carework, while simultaneously underestimating the value of family carework. In line with the prediction of Litwak [10,11], when health system and family caregiving roles were not held in balance, the fundamental experience was a trust 'cleavage' [74], seriously impeding progress toward relationship-centred care [75]. We now examine implications for family caregiver trust in LTC.

3. Trust

Trust has been identified as an essential foundation for both individual and group relationships [76] and for partnerships in disability care [77]. Trust begins in infancy, as children learn to rely on their parents to meet basic needs [78]. As we develop the capacity to trust, we learn that "[*t*]he entire fabric of our day-to-day living, of our social world, rests on trust – buying gasoline, paying taxes, going to the dentist, flying to a convention – almost all our decisions involve trusting someone else" ([79], p. 443). Trust is fundamentally a risk; a chance we take in exposing our vulnerability in order to receive support from another person [80].

Most of the scientific literature on trust assumes that trust operates in a context of choice. We decide who to trust, and when. But sometimes, we are compelled to rely on other people. Trusting in these circumstances is an enormous risk, and negotiating this successfully relies on an implicit social understanding that we must signal trust, regardless whether we truly possess it, in the hope that our signals will be reciprocated with needed support. Nowhere is this risk more prominent than in disability care, where it is keenly felt by people who rely directly on caregiving support, by their family caregivers, and even by the employees who provide care, who often experience a lack of support for their work [81]. When a person depends on others for their basic needs to be met, it is very difficult to speak up when something is wrong. They know that if reciprocal trust is permitted to further devolve, it will contribute to additional unmet need, and to risk. Many LTC residents and families will confide, "I never said anything because I was afraid of how they would be treated"; choosing, instead, to mask their emotions and signal agreeableness – a trust-building strategy [80]. During the pandemic, many residents and family caregivers resigned themselves to the situation rather than speaking up, perceiving they could not afford to further compromise their interests (see Fig. 6).

> You trained for 4 years to do the job you love, and you've been doing your job for 10 years now.
>
> In your jurisdiction, there is one employer for the kind of the work you do. You are asked to integrate into your job something that makes you wonder if you are doing more harm than good.
>
> Will you leave? If so, how will it affect your income and your family? Or, will you stay? If so, how long could you keep negotiating these worries? Could you ever imagine beginning to rationalize what you have been asked to do, shifting your focus away from your concern?

Fig. 5. Cognitive dissonance.

According to Eva Kittay (2011), those of us living without disabilities would do well consider ourselves as "temporarily abled". Adopting this perspective, imagine that one day you become profoundly physically disabled, and have no choice but to rely on or trust unknown others to meet your most basic needs – to feed you, to cleanse your body, to ensure that you have adequate rest. How do you imagine you might feel? Considering the full range of people you interact with every day, who would you trust? Why? Who wouldn't you? How might you feel if, at least sometimes, you had to rely on someone you did not fully trust?

Fig. 6. Trust.

3.1. Family caregiver trust in long-term care

Trusting relationships develop both at an interpersonal level and at a structural level [82]. At the interpersonal level, trust rests on emotional bonds between individuals and is shaped by direct interaction. It manifests as a belief in the intentions and motivations of healthcare providers to act in the best interest of patients and families [82]. For most families, reliance on the health care system is an act of concern; a reflection of a long-debated moral dilemma about options that will provide the best safety and support for their family member. Central to this moral deliberation the hope that healthcare providers will have the motivation, commitment, and moral integrity to provide optimal support for their relative: "trusting another requires the belief that the goals and values of the one we trust are similar to our own" ([83], p. 122).

Trust at the structural level is manifested as a trust in the competence of the institution itself. Ideally, Canadians would have a generalized trust in the Canadian healthcare system to be efficient, effective and use public funds equitably [74]. Yet, trust in LTC has been on tenuous grounds for decades, as past breaches in trust, including governments' failures to bring about prevailing change in LTC, fuelled scepticism that anything would change even with increased scrutiny [84]. In one recent economic study, approximately 70% of Canadians expressed an increased intention to avoid relying on LTC, a phenomenon referenced as "nursing home aversion" [85]. Ross argues that three things influence trusting relationships: threat, powerlessness, and scarce resources [86]. As the pandemic threatened the lives and the quality of life of LTC residents, LTC residents and their family members were left powerless to express their interests [16,18]. Meanwhile, resident and family interests were compromised within a system that had already been asked to make do with less; a system not structured or staffed to effectively support resident wellbeing [87].

The implementation of policies to restrict resident and family contact during the pandemic provide a powerful illustration of the structural deficiencies that currently undermine trust in LTC [82,84]. These policies were implemented quickly without full appreciation of the impact and roles of family in LTC and the evidence supporting family caregiver presence. While these policies outlined the responsibilities of families, they were not created in consultation with families and lacked an examination of the social context in which families participate in the life of LTC [16,18]. This monocentric policy solution 'assigned' rather than 'negotiated' responsibilities and signalled distrust in family capacity to support the wellbeing of long-term care residents – which, in turn, fuelled mistrust in the LTC sector. This is not to say that policy makers were not highly motivated to secure good outcomes for LTC residents. Yet, it does reflect a wider problem of hierarchical, top-down approaches to developing policy in LTC [16,18,84]. The result of this approach was the removal of valuable members of the care team within an already fractured and undersupported environment, contributing to unintended harm to residents, families, and staff [16,18]. The consequence, a deep rupture in trust, remains in need of repair.

3.2. Repairing trust at the interpersonal level within long-term care homes

If trust is at the heart of relationship-centred care, then repairing trust must take precedence. At the interpersonal level in long-term care, such repair, at very least, involves the recognition and integration of family carework into the daily routines of the care home, including psychosocial support, symptom assessment, assistance with eating and drinking, hygienic care, and advocacy [16,18]. Family caregivers' knowledge and expertise must be brought to bear in relation to decision-making, such as advance care planning, and they must have a seat at the table in care conferences and other avenues for information sharing [40].

To effect real change, family caregiver involvement must extend beyond forums to socialize with each other, to meaningfully informing how LTC homes will enact their fiduciary responsibility to residents [16, 18]. Family caregivers must be included, in meaningful ways, in the determination of solutions that are ultimately aimed at enhancing resident and family experience of care. These forums could foster an environment of allyship – a community of practice wherein leaders in positions of power actively support an environment of collaboration and inclusion, where staff, families, and community members strengthen relationships, dare to discuss difficult issues, and learn from each other's perspectives, using their collective knowledge to contribute to change. Families would have access to opportunities and resources to empower them to participate in long-term care quality beyond being a mere 'visitor' or a temporary resource to support care staff.

Adopting models of care that support such an environment is vital. For example, within a palliative approach to care, which is well-matched to most LTC contexts, family members are considered as care partners [31]. This approach emphasizes that residents, families and healthcare workers *belong* to the same team and have similar goals and values, all seeking to support and promote residents' quality of life. Family caregivers are not just an extra set of hands to provide mealtime assistance (for example), but are integral to relational continuity and resident wellbeing. Similarly, a compassionate community approach emphasizes collaboration between caring community members, families, and the healthcare system to enhance the quality of life of those with life limiting illnesses [88]. This movement reminds us that LTC need not function as a system for the segregation of older people, but rather, can maintain vibrant, reciprocal relationships with the wider community.

3.3. Repairing trust at the structural level or healthcare system

We must be prepared to identify the difficult issues in LTC in order to shift the current of balance of trust and mistrust in the sector, and while solutions at the interpersonal level can help shift this balance, without change at the structural level, such shifts are likely not sustainable.

How can trust in the long-term care system be repaired? O'Neill [89] suggests that trust relies on active enquiry – in this case, between the health system or health providers and family caregivers. One way to address this is to adopt a "polycentric approach" [16,18,90] which entails viewing policy responses as "emergent and cooperative phenomena" with government being far from the "only relevant actor" (p. 10) in policy development. Along these lines, Schwartz [30] proposes an 'agent-centred model' to policy development that places the expert in the role of "equal negotiating partner rather than in the role of authority" holding "one source of knowledge amongst many" (p. 127). As one form of active enquiry, co-production of pandemic policies on family presence with family caregivers could have enabled a more egalitarian way of making these difficult decisions. This does not mean that family groups unilaterally decide on the responsibilities. Rather, responsibilities would be negotiated in dialogue with all stakeholders in intentional and meaningful ways to co-develop policy to ensure a more comprehensive and balanced approach [91]. This does require however, that all stakeholders trust one another, believing that each other is working in good faith and that goals align. This requires a conceptual shift in valuing families as inherently belonging in LTC spaces and having important knowledge and expertise to contribute [16,18].

3.4. Measuring trust in the long-term care sector

The relationship of trust to some of the most serious pitfalls of Canada's pandemic response, including excess mortality [92] and concern about family caregiver exclusion in LTC, positions trust as a key quality and safety measure for future pandemic planning. Low trust is an indicator of the need to address a widening gap in relationship [82]. While trust may seem too ethereal to be measured, increasingly, it is viewed as an important measure of health system functioning, incorporated into international comparisons of health system quality and safety. It is fundamental to human experience, essential to the concept of relationship-centred care, and measurable at every level of the healthcare system as an indicator of quality and safety [82].

Within direct care relationships, trust can be conceptualized an outcropping of relationships in which the health provider has the patient's best interests at heart and aims are congruent with the patient's wishes [93]. At this level, a useful way for health providers to assess trust is to ask if patients and families felt heard and understood and are satisfied with the outcomes of their interactions [94]. In the aftermath of the ongoing pandemic, trust could also be assessed by family and residents' appraisals about appropriate care (e.g., their satisfaction with adequate pain management and timely end of life care) and support offered to them (e.g., satisfaction with lines of communication).

At a systems level, trust can be conceptualized as the adequate availability of healthcare services and the competent delivery of those services (cf. [82,95]). At this level, measures of trust frequently assess humanism (listening to, accurately comprehending, and acting on patient/family concerns); information-sharing; adequacy of service, knowledge of providers, reliability or competence of providers, and functioning of healthcare teams [95–97]. Trust at a systems level could also be measured as the degree and quality of efforts undertaken to include patient and family perspectives in the development of policy and protocols, and measures of their perceptions of the level of meaningful involvement in such practices [16,18,91,98].

4. Conclusion

In the age of relational care, bringing family caregiver voices to the policy table is critical, and this cannot be mere happenstance or one-off occurrences in response to emergent crises. Formalizing family caregiver involvement vis-à-vis policies that promote participation in care, decision-making, organizational development, and policy development repositions family caregivers from outgroup to ingroup and recalibrates their perceived behavioural control, engaging their commitment to care, and in so doing, relieving the cognitive dissonance of both family caregivers and healthcare providers. Such actions would help to inform more robust, informed, and contemporary long-term care policy, and would counter ageism, ableism, and paternalism by signalling to residents, families, and the public a valuing of those who rely on long-term care and those who support them. Low trust during a pandemic became a harbinger of problems that compromised public health and safety. We must now move to rebuild trust, and conceptualize it as the most important indicator of the resilience of our long-term care system. Addressing gaps in trust will foster better outcomes for health system recovery and future pandemic responses.

CRediT authorship contribution statement

P.V. Hunter: Conceptualization, Writing – original draft, Writing – review & editing. **H.A. Ward:** Conceptualization, Writing – original draft, Writing – review & editing. **G. Puurveen:** Conceptualization, Writing – original draft, Writing – review & editing.

Declarations of Competing Interest

None.

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