

Improving Family Presence in Long-Term Care during the COVID-19 Pandemic

Améliorer la présence de la famille dans les établissements de soins de longue durée pendant la pandémie de COVID-19

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Key Takeaways

- Partnerships between long-term care (LTC) homes and family caregivers should allow for active engagement in policy development and implementation of programs that improve residents' quality of life.
- Technological and virtual innovations are promising avenues for promoting stronger family presence within LTC homes.
- Public health policies coupled with under-resourcing in the LTC sector impacts family visitation due to a lack of staffing and infrastructure.

Abstract

Family caregivers play a vital role in supporting the physical and mental health of long-term care (LTC) residents. Due to LTC visitor restrictions during the COVID-19 pandemic, residents (as well as family caregivers) showed significant adverse health outcomes due to a lack of family presence. To respond to these outcomes, eight implementation science teams led research projects in conjunction with Canadian LTC homes to promote the implementation of interventions to improve family presence. Overall, technological and virtual innovations, increased funding to the sector and partnerships with family caregivers were deemed effective methods to promote stronger family presence within LTC.

Résumé

Les proches aidants jouent un rôle essentiel pour la santé physique et mentale des résidents des établissements de soins de longue durée (SLD). En raison des restrictions imposées aux visiteurs pendant la pandémie de COVID-19, les résidents (ainsi que les proches aidants) ont vécu d'importants effets néfastes sur la santé en raison d'un manque de présence familiale. En réaction à ces résultats, huit équipes en science de la mise en œuvre ont mené des projets de recherche en collaboration avec des établissements de SLD canadiens dans le but de promouvoir la mise en œuvre d'interventions qui visent à favoriser la présence familiale. Dans l'ensemble, les innovations technologiques et virtuelles, l'augmentation du financement du secteur et les partenariats avec les proches aidants sont considérés comme des méthodes efficaces pour favoriser une présence familiale plus soutenue au sein des SLD.

Importance of Family Presence

Impact of the COVID-19 pandemic on the presence of family in long-term care

Across Canadian provinces and territories, long-term care (LTC) homes saw an unprecedented number of COVID-19 infections and deaths. During the first wave of the COVID-19 pandemic, for example, almost 80% of COVID-19 deaths across the country were among LTC residents (CIHI 2020). Compared to Canada, the average number of COVID-19 deaths in LTC homes across all other countries belonging to the Organisation for Economic Co-operation and Development was only 42% (CIHI 2020). To prevent the spread of COVID-19 within LTC homes, Canadian authorities put in place several public health measures, including restrictive visitation policies (Stall et al. 2020).

Although well-intentioned, restrictive visitation policies within Canadian LTC homes led to increased feelings of loneliness and social isolation among residents, which themselves are risk factors for the development of depression, cognitive impairment, physical frailty, recurrent stroke, obesity, elevated blood pressure and mortality (Cacioppo et al. 2015; Choi et al. 2015; McArthur et al. 2021; Read et al. 2020; Simard and Volicer 2020). Moreover, these policies resulted in increased worry among family caregivers as they were unable to engage with residents, monitor their well-being or provide comfort to them (Mitchell et al. 2022). Even before the pandemic, family presence was known to improve residents' quality of life and reduce mortality (Verloo et al. 2018). According to the most recent survey on family caregiving in Canada, 7.8 million Canadians over the age of 15 years provided care to relatives with a long-term health condition, a disability or problems associated with aging (Statistics Canada 2020).

Restrictive visitor policies put in place during the COVID-19 pandemic highlighted the essential role of family presence within LTC homes, and several policy and practice recommendations have emerged that challenge us to rethink the ways in which family caregivers are part of care planning (Gaugler and Mitchell 2022). As a group of researchers, we have worked in partnership with family caregivers and LTC homes to identify how to improve family presence during the COVID-19 pandemic and beyond. In this article, we discuss the purpose of our work and the recommendations that stem from these findings.

Purpose of This Work

The Implementation Science Teams (ISTs) (Table 1) partnered with LTC homes across several provinces – including homes in Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia and Prince Edward Island – to support the

successful implementation and sustainability of promising practices and interventions to maintain family presence within LTC homes. Within these homes, the total number of participants across ISTs included over 100 residents, 250 family and other informal caregivers and 150 staff members. Interventions varied greatly across the teams, but they were primarily focused on strengthening connections between residents and family caregivers through policy analysis, digital interventions and adaptations of established programs and resources.

Policy analysis

A couple of teams took a policy analysis approach to their intervention. Janice Keefe and Annie Robitaille each looked at the current policies in their respective jurisdictions and conducted interviews with key stakeholders – including family caregivers, LTC staff members and government policy makers. Following this policy analysis, both teams provided recommendations on current LTC policies so that visitation policies could be more inclusive and recognize the important role of family caregivers.

Digital interventions

Marie-Soleil Hardy and Idrissa Beogo each led a team of researchers and knowledge users to equip LTC staff members with the necessary technological tools to preserve communication between residents and family caregivers during the COVID-19 pandemic. Both teams used digital platforms (e.g., Zoom) to interview residents, family caregivers and LTC staff members on their thoughts on these technological tools before and after they were implemented. Sharon Kaasalainen and her team focused on providing opportunities for reflective debriefing using digital platforms, as well as access to a virtual course to roll out the Strengthening a Palliative Approach in Long-Term Care toolkit (SPA-LTC 2020). Natasha Gallant's team also created a virtual course, but this virtual course was focused on infection prevention and control procedures for family caregivers so that they can protect LTC residents from COVID-19 or other infections.

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Adaptations of established programs and resources

A few teams adapted established programs and resources to better fit the context of the COVID-19 pandemic. James Conklin's team, under his leadership, implemented the

TABLE 1.
Implementation Science Teams improving family presence in long-term care homes

Team lead	Study design	Participants (N)	Location (N)	Intervention
Natasha Gallant	Mixed-method (checklists, interviews, surveys)	Residents (11) Family (6) Staff (9)	SK (1) ON (1) NB (1)	A virtual course on infection prevention and control procedures for family caregivers and inclusive satisfaction surveys for residents and family caregivers
Marie-Soleil Hardy	Mixed-method (checklists, interviews, surveys)	Residents (27) Family (27) Staff (16)	QC (4)	Virtual meetings between residents and their family caregivers using tablets
Idrissa Beogo	Mixed-method (interviews, surveys)	Residents (45) Family (11) Staff (25)	MB (2) QC (2) NB (2)	A digital platform to strengthen the connection between residents and their family caregivers
James Conklin	Mixed-method (interviews, surveys)	Residents (39) Family (117) Staff (78)	ON (3)	An adapted version of the Caregiver ID Program that includes supportive tools and creating a learning collaborative
Denise Connelly	Mixed-method (focus groups, interviews, surveys)	Residents (12) Family (6) Research partners (4) Staff (9) PIECES mentors (3)	ON (2)	Virtual delivery of the PIECES intervention along with virtual team huddles
Sharon Kaasalainen	Mixed-method (interviews, surveys)	Residents (2) Family (5)	ON (2)	Palliative care pamphlets and booklets for family caregivers, as well as a virtual course and reflective debriefing for staff
Janice Keefe	Mixed-method (document review, interviews, surveys)	Family (57) Staff (54) Key informants (10)	NS (4) PEI (2)	Policy analysis of family visitation programs from the point of view of various stakeholders
Annie Robitaille	Qualitative (interviews)	Residents (ongoing) Family (59) Staff (ongoing) Volunteers (9)	ON (7) NS (1)	Interviews with stakeholders to discuss new ideas or changes to existing policies and practices

MB = Manitoba; NB = New Brunswick; NS = Nova Scotia; ON = Ontario; PEI = Prince Edward island; PIECES = Physical, Intellectual, Emotional health, Capabilities for quality of life, Environment, Social; QC = Quebec; SK = Saskatchewan.

supportive tools and collaborative aspects of the Caregiver ID Program (Sault Area Hospital 2022) created by The Change Foundation (<https://changefoundation.ca/>) and The Ontario Caregiver Organization (OCO n.d.). In collaboration with three Ontario-based LTC homes, Conklin's team adapted the Caregiver ID Program to fit the individual needs of each LTC home. To do so, Conklin and his colleagues used developmental evaluation. Developmental evaluation is a highly participatory process that involves the program's team members in all the design and decision processes.

One of the other teams – led by Denise Connelly – used the Physical, Intellectual, Emotional health, Capabilities for quality of life, Environment, Social (PIECES) model (Pieces Canada n.d.) to implement better supports for residents, family caregivers and LTC staff members during the COVID-19 pandemic. Similar to Conklin's adaptation of the Caregiver ID Program, Connelly adapted the PIECES model to include virtual team huddles. Although not a traditional part of the PIECES model, the virtual team huddles were aimed at providing an opportunity for the interdisciplinary health

professional care teams to come together to discuss the care of residents. Virtual team huddles allowed care teams to problem-solve ways of addressing the residents' behavioural expressions and engaging family caregivers within the context of restrictive visitation policies.

What Was Learned?

ISTs conducted varied research in LTC homes to improve family presence but a few common observations emerged. We asked each team to reflect on their experiences to improve family presence in LTC during the COVID-19 pandemic. We outline some of these reflections below.

Digital innovations show promise for promoting stronger family presence in long-term care homes

One promising avenue for the involvement of caregivers was the introduction of digital innovations. These innovations can provide a way of maintaining communication between residents and their caregivers while also enabling caregivers to remain informed and advocate for their loved ones even if they are not physically present in the home. For example, Beogo and Hardy noted the importance of digital platforms, mainly through videoconferencing software, in preserving communication. Beogo explained how digital platforms could help keep residents connected to their family caregivers:

Digital applications have become a promising avenue to reduce social isolation and loneliness by providing a way to maintain communication between LTC residents and their families and will certainly remain in the post-COVID-19 pandemic world.

Meanwhile Hardy explored how the use of tablets in LTC homes would help residents, especially cognitively impaired older adults, connect with their caregivers:

Videoconferencing can be complementary to face-to-face visits in LTC homes in an effort to provide residents with cognitive stimulation. In this way, electronic tablets offered residents and their family caregivers an opportunity to increase and maintain communication regardless of visitation restrictions that were in place and other challenges, such as geographical distance.

The introduction of this innovation in LTC homes has created more opportunities to increase social connections by simply increasing the frequency of contact for caregivers who already had face-to-face visits or by providing the opportunity

to potential caregivers living far away from the residents' home to have more visits with their loved ones. As Hardy explained:

When we started this project, caregivers who were living in different cities and provinces were delighted and excited to be able to check on their relative[s] whom they hadn't seen for a long time. Others appreciated the availability of this option to talk to residents when they didn't have enough time to travel to the LTC homes.

The potential to use technology to enable family presence is substantial and a learning that can be taken forward to improve care beyond our COVID-19 pandemic response.

Interventions need to be designed with equity and inclusion at front of mind

While digital innovations are a promising avenue for LTC homes, we still need to address barriers for residents and their caregivers so that they can equitably access and meaningfully engage with these innovations. For example, throughout the COVID-19 pandemic, gaps have been identified in the linguistic obligations (i.e., bilingualism) of public institutions and governments in various jurisdictions in Canada (Chouinard and Normand 2020). Beogo noted that some residents and family caregivers required further support to engage with digital innovations:

For better inclusivity and accessibility to health services, older adults in LTC homes and, especially, in the context of linguistic minority, deserve special attention in health crises such as the COVID-19 pandemic.

As a numerical minority, few LTC homes across Canada are devoted to Francophones in anglophone settings and vice versa. Older adults in linguistic-minority LTC homes often live far away from their families, so improving interactive virtual conversations with the help of technology is of utmost importance.

Similarly, Hardy highlighted the necessity of equity-based and person-centred approaches to adapt interventions for vulnerable populations – such as residents with cognitive impairments – to counter the negative outcomes of social isolation this population usually suffers from:

It is important to prioritize the emotional well-being and quality of life of residents and implement more equitable standards to family caregiver presence as they play an essential role on the care and quality of life of residents.

Gallant and her team also spent some time working with LTC knowledge users to outline several recommendations for equitable and inclusive intervention development and implementation within LTC settings (Finnegan et al. 2022).

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A lack of staffing and physical infrastructure adversely impacts family visitation policies

While individual barriers are important to address, the greatest barriers to accessible and inclusive family visitation policies are a lack of staffing and physical infrastructure within an underfunded LTC sector. For example, Hardy explained the importance of having the resources to support digital innovations: “LTC homes need to be equipped with the necessary resources – mainly staffing and technological resources – to preserve communication between residents and their family caregivers.” Kaasalainen, who led the implementation of the palliative care toolkit for residents and their family caregivers, echoed this need for resources:

The COVID-19 pandemic highlighted the lack of available resources in LTC homes – including staff and money – that negatively impacts the care of LTC residents and impedes the implementation of a palliative care toolkit.

Through Kaasalainen’s work, it became evident that LTC staff were pulled in multiple directions, impeding staff members’ ability to focus on developing and implementing policies that promoted the inclusion of family caregivers. Relationships between family caregivers and LTC staff members suffer when staff members struggle to meet government priorities in a health emergency, such as the COVID-19 pandemic.

Including and partnering with family caregivers leads to better outcomes for residents

Encouraging partnerships between LTC homes and residents’ family and other informal caregivers can improve resident outcomes. As Connelly noted, for example, “implementing a new process for care planning requires partnerships between researchers and stakeholders in LTC.” In fact, for the PIECES program, involving key LTC stakeholders, researchers and PIECES program experts during all stages of the project – from

conception to implementation – was the most important ingredient for success. Connelly went on to explain the benefits of such partnerships:

These partnerships ensure that the priorities, needs and experiences of residents, families and staff members are used to inform care planning processes that reflect the realities of LTC during COVID-19 and beyond.

Partnerships between stakeholders and researchers in LTC work by ensuring that LTC homes continue to have access to evidence-based solutions. With the effect of the COVID-19 pandemic on the LTC sector engrained in everyone’s minds, Conklin explained:

There is growing recognition that the care provided by family members is essential, and conditions are favourable to strengthening the natural partnership that exists between family and frontline care providers to bolster the wellbeing and health of residents.

These findings suggest that LTC staff appreciate and value the role of family caregivers, that family caregivers appreciate LTC staff members’ good intentions and that both parties find the existing situation regarding family presence in LTC to be unacceptable.

Family caregivers can also be engaged in policy development and implementation to ensure that new and ongoing policies – especially, visitation policies – enrich and add meaning to residents’ lives. As noted by Keefe, “family caregivers need to be engaged throughout policy development and implementation to ensure [that] they can play a meaningful and vital role in their relatives’ lives.” Keefe also explained that a bottom-up approach allowed for flexibility in the development and implementation of these visitation policies to facilitate better accessibility and inclusivity within LTC homes.

Recommendations

Based on our collective learnings, we have outlined recommendations to improve family presence within the LTC sector in Canada:

- Create opportunities and partnership programs to promote family caregivers’ and residents’ roles in decision making within LTC homes.
- Tailor inclusive and patient-centred approaches so that they are adapted to the different characteristics of LTC homes, including the specific characteristics of residents and their family caregivers.

- Support the use of digital innovations and improve digital literacy for residents, family caregivers and LTC staff members by providing training opportunities and the resources needed to use these innovations.
- Build capacity among LTC staff to implement interventions prioritizing family presence and person-centred care approaches during a health emergency.
- Integrate research efforts and program evaluations within the LTC sector so that policy makers and decision makers can be provided with evidence-based information.

Conclusion

The evidence that we have collectively gathered has revealed the importance of the presence of family on the well-being

and quality of life of LTC residents. This is especially true in the context of the pandemic, but it is also essential beyond it. We recommend that researchers, LTC managers and policy makers collaborate and create partnerships with family caregivers that facilitate the successful development and implementation of evidence-based strategies to support family presence in LTC homes. Within these partnerships, LTC residents and family caregivers need to be centred in the work. Whether interventions focus on the use of technological innovations, educational materials or feedback mechanisms, the voices of residents and their family caregivers must be considered and reflected in the interventions and policies that are developed and implemented. **HQ**

Disclaimer

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