

Pandemic Preparedness and Beyond: Person-Centred Care for Older Adults Living in Long-Term Care during the COVID-19 Pandemic

Préparation à la pandémie et au-delà : des soins axés sur la personne pour les personnes âgées dans les établissements de soins de longue durée pendant la pandémie de COVID-19

Amy T. Hsu, Geetha Mukerji, Anne-Marie Levy and Andrea Iaboni

Key Takeaways

- Transformative changes and innovative integrative care models that aim to build capacity within long-term care are required to address the ongoing and complex care needs of residents who receive care in this setting.
- The pandemic has offered an opportunity to create innovative approaches to how person-centred care can be provided in an under-resourced healthcare setting. The partnership with research teams has accelerated the development of context- and environment-specific tools and resources for LTC.
- Solutions designed to support person-centred care must be flexible and adaptable to the environment. Allowing LTC providers to articulate the needs and goals of their own homes has been essential for motivating change.

Abstract

The increasing complexity of residents' needs, emphasis on social distancing and limited access to high-quality support presented challenges to patient-centred care during the pandemic. Yet the pandemic created an opportunity to explore novel approaches to achieving person-centred care within long-term care (LTC). We share three projects designed to enhance care delivery in the context of the pandemic:

to address personhood needs during outbreaks, to improve the quality of medical care and to deliver personalized palliative and end-of-life care using a prediction algorithm. These projects enabled better care during the pandemic and will continue to advance person-centred care beyond the pandemic.

Résumé

La complexité croissante des besoins des résidents, l'accent mis sur la distanciation sociale et l'accès limité à un soutien de haute qualité ont posé des défis en matière de soins axés sur le patient pendant la pandémie. Pourtant, la pandémie a créé une occasion d'explorer de nouvelles approches pour obtenir ce type de soins dans le cadre des soins de longue durée (SLD). Nous faisons état de trois projets conçus pour améliorer la prestation des soins dans le contexte de la

pandémie : répondre aux besoins de la personne pendant les épidémies, améliorer la qualité des soins médicaux et offrir des soins palliatifs et de fin de vie personnalisés à l'aide d'un algorithme de prédiction. Ces projets ont donné lieu à de meilleurs soins pendant la pandémie et continueront de faire progresser les soins axés sur la personne au-delà de la pandémie.

The Context and Challenges of Person-Centred Long-Term Care

Even before the pandemic, long-term care (LTC) homes struggled to meet the complex care needs of their residents. Across the sector, homes were under-resourced, with low staff-to-resident ratios and inadequate access to high-quality medical services and support. Many residents, given their advanced age, have limited life expectancy, experience severe physical and cognitive deficits and can benefit from a palliative approach to care. Yet discussions about prognosis, advance care planning and palliative care are not always prioritized. These gaps left LTC homes woefully unprepared for the pandemic in March 2020, with catastrophic results, including unnecessary suffering and death. We need to learn from these failures to be prepared for the future and support the transformation of this sector.

For this transformation to take place, there needs to be a common value underlying our efforts. Person-centred care is ubiquitous in discussions of quality of care within LTC homes. However, the understanding and application of this principle in real-world settings vary enormously (Godfrey et al. 2018). At its core, person-centred care is care that is respectful of an individual's personhood, values them as social beings and understands their psychosocial needs (Hanley 2017). It prioritizes approaches to care that ensure that residents' needs for attachment, inclusion, identity, occupation and comfort are met (Flicker 1999; Hanley 2017). Beyond theory, person-centred care is, in fact, a highly practical and evidence-based approach to improving care (Kim and Park 2017). It is an approach to care that is of importance throughout a resident's care journey – from the day-to-day nursing care and personal support they receive in the LTC home, to the care that they receive in the home or in the hospital, to their end-of-life care.

Achieving person-centred care within LTC has been challenging, with time constraints, lack of staffing, cost, educational gaps, poor teamwork and lack of management support as the usual culprits (Griffiths et al. 2019; Kloos et al. 2020; Kong et al. 2021; McArthur et al. 2021). During the pandemic, the frequently changing care practices and public health measures

were additional obstacles to achieving person-centred care. We witnessed how these measures negatively impacted attachment bonds and meaningful occupation in LTC. Visitors were barred, recreational activities for residents were curtailed and high staff turnover resulted in a loss of knowledge about who the residents were and the life they lived. We lost sight of the need to provide holistic and comfort care, even as residents approached end of life, with restrictions resulting in many family members being unable to say their final goodbyes or hold the hands of a loved one before they died.

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Despite these challenges, the COVID-19 pandemic has provided the opportunity to create innovative approaches to how we provide person-centred care in an under-resourced healthcare setting. In this article, we share insights and stories on promising practices related to the planning of COVID-19 and non-COVID-19 care. Specifically, we focus on the theme and examples of person-centred integrated care to meet the unique and complex needs of frail residents in Canada's LTC homes. These insights have come from three projects funded through the Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care Program (HEC 2022), which examined the implementation of tools and interventions designed to improve the quality of care in LTC homes during the pandemic:

- The first project is the Dementia Isolation Toolkit (DIT) (www.dementiaisolationtoolkit.com) that includes a person-centred isolation care planning tool designed to bring personhood needs to the forefront during an outbreak.
- The second project is a collaborative program that aims to provide rapid access to a suite of virtual and in-person clinical and diagnostic services for all LTC home residents.

- The third project is a personalized mortality risk communication tool, called Risk Evaluation for Support: Predictions for Elder-life in the Community Tool in Long-Term Care (RESPECT-LTC), which supports discussions about goals of care as the resident declines in health and the early identification of palliative care needs.

We synthesized the main themes across the three studies into evidence-informed strategies for delivering high-quality, person-centred care in LTC settings during the pandemic and beyond.

Promising Practices and Policies for Person-Centred Care

Dementia Isolation Toolkit

The DIT was designed and developed with people working in LTC homes to support the delivery of person-centred care during infectious disease outbreaks. At the foundation of the DIT is the idea that while many infection-control interventions (such as quarantine/isolation) conflict with the principles of person-centred care, it is still possible to deliver these interventions in a way that is compassionate and respects the personhood of the resident. The most popular tool is a Person-Centred Isolation Care Plan worksheet (Iaboni et al. 2020), which is a supplement to a resident's care plan, addressing the fact that usual care is disrupted by an outbreak and that an individual's needs may be different under outbreak conditions or when isolated in their room. Some learnings from this project are outlined here under the themes of motivating change, flexibility of process and innovating in partnership.

Motivating change

Allowing the local team to articulate the needs and goals of their own home was essential for motivating change. The uptake of COVID-19 vaccines was high among residents of LTC homes in Ontario by March 2021, and COVID-19 cases and outbreaks had become rare. With wishful thinking that the pandemic was behind us, motivation was low: the focus had shifted to staffing challenges in the wake of vaccine mandates and to re-opening the homes to visitors and essential care partners. By working with the local implementation teams to identify gaps and opportunities, the implementation goals shifted to proactive planning for isolation care, preparedness for future waves and the need to integrate more person-centred information into the process for new admissions.

Flexibility of process

Each home required an individualized and flexible approach to implementation. When faced with a choice between using

the DIT exactly as designed or integrating it sustainably within existing processes, the implementation team chose the latter option. This required a good understanding of the local work processes and a recognition of their strengths and limitations. An example is the homes' varying approaches to care planning: the extent to which these care plans were living, accessible documents used to guide care versus a document that was inaccessible to front-line staff providing care. One adaptation was to reduce the care planning tool to a one-page document as the implementation teams were wary of the original two-page version and the administrative burden it may impose on staff. At two of the implementation sites, they tried to avoid redundancies in the process by replacing the "Personhood" and "Isolation" sections of the paper-based tool with existing electronic care plan documents and developing processes for collecting more personhood information about residents.

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Innovating in partnership

The largest challenge is ensuring that these process changes translate into genuine practice and culture changes so that we are outbreak-ready at all times. It became clear that the biggest strides in the project were facilitated by the enthusiasm and energy of champion staff members. The individuals who had a large impact were those who saw the value of the intervention and the parallels between the principles guiding the toolkit and the homes' culture-change journey, and those who knew the home well enough to identify the gaps and opportunities to advance the DIT and its principles. To leverage this important enabler, we innovated using the huddle model developed in the patient safety field to bring together the team for a 10-minute stand-up meeting facilitated by a colleague who would introduce and apply the Person-Centred Isolation Care Plan tool to a single resident known to the staff. While we are still evaluating and refining these DIT huddles, they have advantages: they create a non-judgmental, safe space for staff to reflect on and communicate about care and for facilitators to model a person-centred frame.

A novel model for integrated COVID-19 and non-COVID-19 care

Preventing avoidable emergency department transfers of LTC home residents has been an important focus for quality improvement efforts even before the pandemic (Andrea 2013). Prior research suggests that nearly 50% of LTC home transfers to acute

care facilities are considered potentially avoidable (Gruneir et al. 2010), and one approach to reducing such transfers is to provide access to high-quality medical and diagnostic services within the homes (Razak et al. 2020). Meeting the medical care needs within the LTC setting (i.e., providing care in place) has intrinsic value as it reduces the need for unnecessary and, often burdensome, transfers. It is also person-centred in its alignment with residents' goals of care and their preferences. As frailty increases, most residents and their substitute decision makers report preferring comfort-focused rather than aggressive care (Mitchell et al. 2017). In addition, it minimizes risks of delirium, care discontinuity and functional decline associated with transfer to acute care settings (Creditor 1993; Walsh et al. 2012).

Developing the capacity to provide high-quality specialized person-centred care through partnerships

In the first wave of the COVID-19 pandemic, we developed and rapidly implemented a multi-institutional specialized integrated virtual care model that provides LTC homes in the Greater Toronto Area (GTA) with rapid access to specialists and diagnostic services (Wong et al. 2022). Our program, GTA-LTC+ (<https://ltcplus.ca/about-ltc/>), focused on preventing avoidable hospital transfers and wrapping high-quality healthcare services around LTC homes, reflecting the perceived priority at the time of the pandemic. While the need for more coordinated access to specialist care and rapid access to diagnostic imaging and services existed pre-pandemic, the urgency of the pandemic accelerated the implementation of this integrated care program.

Early results of the GTA-LTC+ program's implementation have been published (Wong et al. 2022). Briefly, from April 2020 to June 2021, the GTA-LTC+ program provided 381 general internal medicine (GIM) consultations and 65 nurse navigator calls. The perceived emergency department avoidance rate by GIM consultants and nurse navigators was approximately 46%, where the consults had sufficiently addressed care needs to potentially avoid the need for acute care transfer. All 36 primary care physicians who consulted the GTA-LTC+ program reported satisfaction with the advice provided. Robust evaluation is under way and will assess the impact of the GTA-LTC+ program and inform strategies for improving, scaling and sustaining this model for enhancing care for residents in LTC homes. The GTA-LTC+ program can enable timely access to high-quality care and ensure that residents receive more person-centred specialized care in this setting, which is useful in pandemic and non-pandemic contexts.

Earlier identification of palliative care needs using RESPECT

Without reliable prognostic information (e.g., an estimate of the survival of residents based on their present health and frailty status), clinicians in LTC may find it difficult to identify which residents are the most frail and at the highest risk of death from both COVID-19 and non-COVID-19 causes.

RESPECT is a mortality-risk communication tool originally developed for application in the home and community settings (Hsu et al. 2021). It accurately predicts an older adult's six-month mortality risk, reports their life expectancy and can inform care providers, residents and their families when the resident may be approaching end of life by estimating their survival in days, weeks and months – a metric that has been shown to be patient-oriented and meaningful for care planning (Kirk et al. 2004; Parker et al. 2007). It was designed to inform health and social service providers' decision making regarding initiating palliative and/or end-of-life care. RESPECT is one of the tools recommended by the Ontario Palliative Care Network for the early identification of palliative care needs in the homecare setting and is publicly accessible from ProjectBigLife.ca.

At the onset of the pandemic, the high mortality rate within LTC homes expedited the need to assess, review and document frail residents' goals and values as their health declined. By recognizing the value in providing personalized risk estimates during goals-of-care discussions, our research team rapidly adapted the community-based version of RESPECT for use in LTC.

RESPECT-LTC was developed and validated in over 2.5 million health assessments performed in Ontario's LTC homes between 2010 and 2017. The algorithm stratifies patients into 37 distinct risk groups to support the operationalization of frailty; each risk group represents an actionable time frame – ranging from 28 days to more than eight years – to empower providers to determine if and when the resident will benefit from a palliative care approach, which may be initiated as early as 18 months prior to death, or whether and when the resident will need end-of-life care.

The implementation of RESPECT-LTC involved a needs assessment, appraisal of technological readiness and motivation for a palliative approach to care within the LTC homes.

Appraisal of technological readiness

Most LTC homes do not have access to technology support or an in-house information technology (IT) team. To enable the tool's implementation, the research team provided technical support, from a web developer and an implementation

coordinator; they helped with installation and troubleshooting and further modified our web-based RESPECT–LTC application to support seamless integration with the electronic medical record systems that the homes were using.

Motivation and readiness for a palliative approach to care

While the partner LTC homes were highly motivated to implement a palliative approach to care, most did not have access to all the resources or tools to enable them to achieve this culture change. To support behavioural change across the decision-making and care hierarchy within the LTC homes, the research team provided training on:

- how to use RESPECT–LTC and how prognostic information from RESPECT–LTC can facilitate discussions regarding goals of care to physicians on staff, as well as nursing and other front-line unit workers;
- how to conduct serious illness conversations with residents and care partners; and
- how to action or use or clinical pathways that precipitate the identification of a resident’s morality risk and palliative care needs.

Each of these learning modules was co-developed with representatives from partner LTC homes as homes and staff within each home varied greatly in skills and competencies as well as in their comfort in communicating about palliative care and the end of life. The implementation and training also had to be flexible to accommodate the sporadic outbreaks that affected the availability of staff to participate in training.

The evaluation is still ongoing. But early findings indicate that the education provided (especially the training on conducting serious illness conversations) significantly improved physicians’ and nurses’ confidence and comfort in discussing goals, values and wishes with residents and care partners to support a more person-centred approach to care toward the end of life.

A Call for Dynamic and Multi-Dimensional Approaches to Person-Centred Care

Achieving person-centred care within LTC has been a challenging but not an insurmountable task. However, there is no one-size-fits-all solution, and allowing the LTC providers to articulate the needs and goals within their homes was essential for motivating change. Findings from the three implementation projects featured here suggest that person-centred care in under-resourced settings is not only achievable in a

pandemic context, but the tools developed over the course of the pandemic can be leveraged to support more person-centred care in this environment in the future.

Prior to the pandemic, the lack of person-centred care may be attributable to low staffing levels, time constraints, cost, educational gaps, poor teamwork and a lack of management support. While not all of these barriers have been removed, the partnership with research teams accelerated the development of context- and environment-specific tools and resources for LTC. We must also recognize that each LTC home needs to find its own motivations for bringing about change in practice and may have to overcome unique challenges in their implementation of a new tool, technology or program. Accordingly, solutions that are designed to support person-centred care must be flexible and adaptable to the environment – be it a lack of technological and IT support, staffing shortages and time constraints or the culture within the home. This includes, as shown by all three projects, adapting existing evidence-based tools at no or very low costs to the LTC providers, as well as the provision of education to fill existing knowledge and practice gaps.

While many of these tools and programs have shown promising advancement toward greater internal capacity within LTC to provide more person-centred care, they can still benefit from being part of a network of service providers that includes hospitals, home care and other community-based organizations. As most LTC homes receive limited access to specialist and diagnostic services that could aid their decision making and capacity to treat in place, the provision of coordinated support and forming a network of providers are crucial for reducing unnecessary transfers to hospitals while improving access to timely assessment and diagnosis. Similarly, while the provision of training in serious illness conversations has boosted providers’ confidence in leading these discussions, many admitted that they could benefit from access to palliative care expertise that may exist outside the LTC home. With the education, as well as the partnership with other providers within the same geography, we were able to augment the LTC homes’ internal capacity for providing person-centred dementia, medical and palliative care.

Finally, an often-overlooked aspect of the implementation of new tools, technology and programs in low-resource settings is ongoing and robust monitoring and evaluation to inform scale and spread. For example, in a systematic review on the effectiveness of person-centred care for dementia patients, the authors only identified 17 interventional studies within LTC (Kim and Park 2017). As part of these implementation projects, the research teams brought content and methodological

expertise to these partnerships to support the evaluation of the interventions that can inform scale and spread, as well as the sustainability of these tools or programs. This exemplifies the importance of such partnerships; however, as researchers we have learned to appreciate the context, needs and resource constraints that LTC providers face before engaging them in research projects.

Summary and Conclusion

Transformative changes and innovative integrative care models that aim to build capacity within LTC are required to address the ongoing and complex care needs of residents who receive care in this setting. Using frameworks and methods from the field of implementation science, we examined barriers to and facilitators of the systematic uptake of evidence-based practices into routine care to support person-centred care in LTC. Learnings from the three projects highlighted in this article demonstrated that there is a need for flexibility when introducing and adapting promising solutions to the varied

needs and environments within this sector. To be successful, new interventions should be supplemented (at least initially) with external support and education and ideally with training material that is co-designed with LTC providers. Researchers can bring valuable knowledge and expertise to these partnerships; however, thoughtful planning and consideration for the constraints that LTC providers face will ensure that their engagement in the research project adds value rather than increasing the workload of an already overextended sector.

Our experience through the pandemic highlighted the existing needs and gaps within the LTC sector. At the same time, it has created an opportunity for the accelerated implementation and evaluation of innovations to support more person-centred care to meet the needs of a highly frail and vulnerable population. Our learning from the failures of the past will not only prepare us for a possible future pandemic but also support the transformation of this sector beyond this current one. **HQ**

Declaration

RESPECT-LTC

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About the Authors

Amy T. Hsu, PhD, is an investigator at the Bruyère Research Institute and a lecturer in the Department of Family Medicine at the University of Ottawa in Ottawa, ON. She holds the University of Ottawa Brain and Mind-Bruyère Research Institute Chair in Primary Health Care in Dementia. Her research uses population-level health administrative data at ICES to examine older adults' health and healthcare needs, especially those living with Alzheimer's disease and dementia. She can be reached by e-mail at ahsu@bruyere.org.

Geetha Mukerji, MD, MSc, FRCPC, is a clinician in Quality and Innovation at the Women's College Hospital Institute of Health Systems Solutions and Virtual Care and an associate professor in the Department of Medicine at the University of Toronto in Toronto, ON. Her research interests include the development and evaluation of innovative models of care delivery including virtual models.

Anne-Marie Levy, PhD, is a research associate in the Lazaridis School of Business & Economics at Wilfrid Laurier University in Waterloo, ON, and a clinical research coordinator in the Geriatric Psychiatry Department, University Health Network in Toronto, ON. Her research centres on the use of technologies and interventions to improve the quality of life for people living with cognitive impairments.

Andrea Iaboni, MD, DPhil, FRCPC, is a geriatric psychiatrist based at the Toronto Rehabilitation Institute, University Health Network, and an associate professor in the Department of Psychiatry, University of Toronto, in Toronto, ON. Her research focuses on developing new models of dementia care by making use of physiological and behavioural data from environmental sensors, work around mobility and falls prevention, the treatment of neuropsychiatric symptoms of dementia and the prevention of injury through rational use of psychotropic medications in frail older adults.