RESEARCH TOPICS & THEMES

FOR LONG-TERM CARE DEVELOPED IN PARTNERSHIP WITH RESIDENTS AND FAMILIES

Building Capacity for Long-Term Care Stakeholders in COVID-Related Patient-Centered Outcomes Research/Comparative Effectiveness Research (PCOR/CER)

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INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®
Transforming health care through partnerships

INTRODUCTION

During the height of the COVID-19 pandemic, federal, state, and provincial government recommendations and policies at the local level restricted the presence of families and friends in long-term care communities to prevent the spread of infection. In addition, most residents were confined to their rooms, and social activities were extremely limited. Implementation of these restrictions led to profound social isolation and loneliness among residents, resulting in an adverse impact on resident and family mental health and well-being. This occurred despite evidence from the previous SARS pandemic of serious harm caused by family presence restrictions.

The universal commitment to the concept of surplus safety—the practice of reducing risk at all costs—in long-term-care settings compounded this situation by attempting to eliminate all risk. This practice resulted in harm to residents' mental health and well-being by further preventing them from assuming any level of personal risk. Thus, this continued the longstanding practice within long-term care of reinforcing residents' lack of self-determination. Moreover, because of these severe restrictions on visitation, existing Resident and Family Councils were hindered in partnering with staff and leaders to mitigate the impact of social isolation and loneliness. This lack of engagement contributed to feelings of powerlessness for both residents and families who were trying to advocate for them.

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Available from https://ipfcc.org/long-term-care-partnerships

ROOT CAUSES OF SOCIAL ISOLATION AND LONELINESS WITH AN ADVERSE IMPACT ON MENTAL HEALTH AND WELL-BEING

Multiple contributing factors to social isolation and loneliness were identified through Small Group Conversations with residents and families from four long-term care communities in different regions of the United States and Canada. A fishbone diagram was then used to analyze what was learned, and the following root causes were determined:

- Enforcement of no visitation policies for families and friends
- Lack of resident self-determination
- No opportunity for resident and family participation as partners in planning pandemic responses
- Lack of sufficient and consistent staffing

RESEARCH TOPICS & THEMES

Building on the root causes of social isolation and loneliness, two stakeholder meetings were convened with selected long-term care residents, families, staff and leaders, and researchers to identify topics and themes for long-term care research. A National Advisory Committee of industry and research leaders as well as resident and family leaders participated in the review process. The priorities for research related to the residents and families' experiences during the COVID-19 pandemic were organized into six categories:

- **Government/Policy**
- **Partnerships**
- **Communication**
- **Physical Spaces**
- **Risk**
- **Staffing**

This resource presents specific topics and themes with context from meetings held with residents and families. These meetings provided a forum for them to share insights and perspectives about their experiences during the COVID-19 pandemic.

Government/Policy

During the COVID-19 pandemic, federal, state, and provincial governments issued edicts that placed severe restrictions on residents and families without their input, resulting in a profound adverse impact on their mental health and well-being. Families were viewed only as "visitors;" there was almost no acknowledgement of families as "essential care partners," especially in the United States.

"...When people say we can't have visitors, we can't have visitors. I don't feel like a visitor."

"So most of his [difficulty] coping had to do with why I couldn't come there. 'You are my wife, I'm your husband...'"

"I can't see anybody, I might as well just give up."

Recommendations for research:

- **Compare various ways to inform/educate government and public health policy makers about the essential roles of families in long-term care.**
  - **Create and evaluate opportunities for residents, families, staff, and leaders to discuss the importance of safe family presence with local and state/provincial public health authorities to prevent harm to mental health and well-being.**
  - **Compare a variety of formats, including in-person and/or virtual meetings, and different approaches (e.g., a collaborative policy lab or town hall meetings).**
- **Compare different approaches to the implementation of policies and processes for preparing families as essential care partners for both physical care and social support at both regional and organizational levels.**

Partnerships

There appeared to be almost no opportunities for residents and families to serve as true partners with long-term care community leaders and staff in pandemic planning over the last 2 1⁄2 years. Structures were not in place to support effective partnerships.

Recommendations for research:

- **Compare various approaches to inform/educate long-term care community leaders about the value of partnerships with residents and families in safety and quality improvement, and how to develop effective partnerships that can be sustained during a future pandemic, outbreak, or disaster.**
- **Compare different ways to establish an effective infrastructure to support partnering with residents and families in:**
  - **Current and future pandemic planning and response as well as other emergencies that may occur in the future.**
  - **Safety and quality improvement and physical design of long-term care community.**

Communication

Residents could identify some positive aspects of communication during the pandemic. Technology was helpful to some families to maintain a level of connection. To this end, one resident described getting closer to family members living in another country by texting more frequently. But for some families, technology was not helpful.

"My grandma would hit the mute button [and] wouldn't unmute herself...So no one would come and notice that she was muted the whole time until that the whole hour was over."

Recommendations for research:

- **To promote effective connections with families and others, develop and evaluate a range of technology/devices that are easy for residents to use as well as the necessary supports for residents to facilitate their use.**
  - **Compare programs to ensure Internet access for long-term care communities and the individual rooms and households within the community.**

Some residents described various ways their organization communicated information about COVID-19 with residents and their families, including a newsletter, the PA system, and emails, while others expressed frustration about the lack of news. Further transparency was needed, showing respect for residents and families as adults.

Communication continued

Several families appreciated getting emails or texts with information about changes in protocols and policy and recognized that the long-term care communities were sometimes limited in their ability to be transparent. Other families expressed frustration about the lack of information. As examples, they reported phone messages going unanswered, policy changes not being communicated, and lack of information about COVID-19 cases within their long-term care community.

"There was like an unspoken rule where you just didn't...until this day...know what the real numbers were, [or] how many patients passed away. ...We don't know so many things."

Recommendations for research:

- **Explore the most effective ways to improve systems of communication and the sharing of ideas among residents, families, Resident and Family Councils, and senior leaders.**
  - **Test and compare innovative approaches developed by schools, national and international long-term care communities, and others for disseminating current and important information efficiently (e.g., listservs, etc.).**
  - **Evaluate the effectiveness of a pandemic reporting dashboard with information important to residents and families that is also time efficient for staff to maintain.**

One family member wished that there had been more transparency about the scarcity of supplies. When she learned about the issue, she reached out for donations for the long-term care community. This is an example of a missed opportunity to partner with families in ensuring the quality of life and safety in the long-term care community. This partnership would have benefited residents, families, and staff.

Physical Spaces

Isolation in a room with or without roommate(s) and moving to new floors contributed significantly to feelings of loneliness, depression, loss of connection with staff and friends, and the lack of self-determination. The isolation and restriction to their rooms for long periods of time evoked strong emotional responses among residents.

"Being inside a room for such a long time, I was a prisoner."

Families perceived that the required isolation caused harm to their loved ones.

"The isolation almost did her in. She was just way too quiet. She wasn't smiling...it has left a lasting effect on her and her level of depression."

Dealing with restrictions was sometimes exacerbated when a resident had a roommate with cognitive impairment. Moreover, the death of a roommate contributed to anxiety.

"When my roommate passed away, to me I was gonna be the next one. I was kind of expecting that. Anytime, it will happen to me."

Being in the room for an extended period of time also meant that residents were watching a lot of television and a significant amount of TV coverage at the time was: *"1,000's of people dying, going to hospitals."*

Physical Spaces continued

The isolation in a room was often mitigated by creative approaches. Open doorways were used to reduce feelings of isolation. Residents communicated across their doorways. They appreciated an approach like having a music therapist who would walk down the hallways singing songs.

Recommendations for research:

- **Create and evaluate accessible and safe spaces indoors that reduce the risk of infection for recreation, visits from families and community volunteers, library and music programs, and typical activities such as haircuts, etc.**
- **Building on previous studies, compare the impact of total isolation (residents restricted to their rooms) to modified isolation that includes social activities but not group dining.**

During the lockdown, access to the outdoors was possible for some residents who had a patio outside their room and "enjoyed the plants and the flowers." However, for the majority of residents, it was inaccessible.

"I couldn't go outdoors. I couldn't see nobody. Be with nobody...I was by myself. I was isolated."

Recommendation for research:

- **Create and evaluate accessible, climate-controlled outdoor spaces that reduce the risk of infection with safe access for residents.**

Risk

Pandemic restrictions were a dramatic change in the everyday lives of residents, often with negative consequences. Restrictions denied residents and families the opportunity to take any level of personal risk.

"It was shocking...to have them come in and say we are under this and you can't do this. You're restricted to this..."
"They locked the doors."

Recommendations for research:

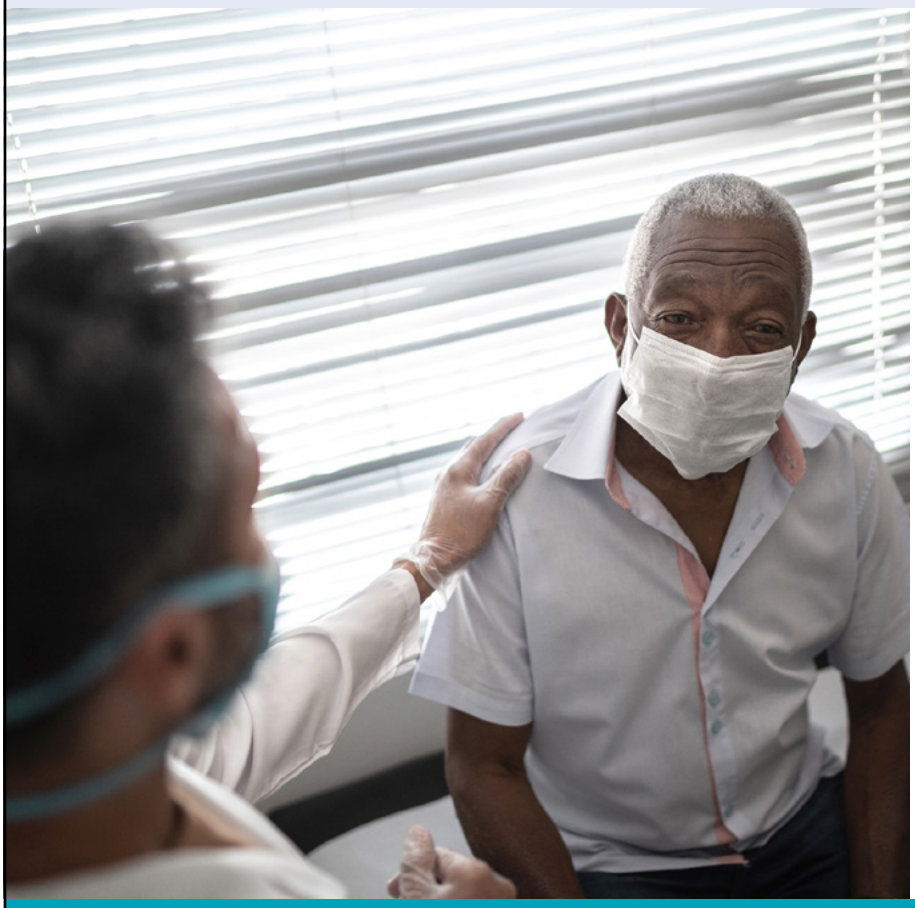
- **Develop and evaluate a risk assessment protocol to determine a family member's or resident's risk of transmitting infection to enable safe family presence and social interaction within the long-term care community.**
- **Identify and evaluate the most effective approaches that support residents in assuming personal risks in ways that minimize the risks to others in long-term care communities.**
  - **Compare various ways to educate staff in supporting residents in assuming personal risks.**
- **Evaluate approaches to engaging residents and families in addressing risk concerns related to family presence at end-of-life.**

Staffing

Both residents and families praised staff and recognized the difficult working conditions created by the pandemic. However, staff shortages contributed to limited activities, ineffective communication, and impacted residents who now did not know their caregivers as they had previously. Similarly, these new caregivers were unfamiliar with residents and families.

"The staff changed during the pandemic, you may see your favorite nurse on a Monday and then come Friday, she's left...or she's got COVID."

"...We have definitely seen a huge change in overall staffing...[I] feel like I don't know who anyone is anymore...I feel like a lot of people don't know my mom, and don't know what her needs are..."



Recommendations for research:

- **Compare various programs to provide proactive support and mental health services to staff working in long-term care that enhance their health and well-being.**
- **Identify and evaluate various ways to address staffing shortages.**
- **Compare various approaches for safe volunteering in long-term care settings.**

Conclusion

This resource has been developed to encourage future research that addresses the concerns and priorities of residents and families about social isolation and loneliness due to the severe restrictions imposed by long-term care communities and government guidance and policies. These restrictions had an adverse impact on the mental health and well-being on residents, families, and staff. While residents and families participated in early planning for this research, it is the intent that they will be involved as meaningful partners in all phases of future research. The companion resource, *A Guide for Promising Practices in Engaging Long-Term Care Communities in Planning for Future Research,* may be helpful in developing authentic partnerships with residents and families.

Resources

ORGANIZATIONAL RESOURCES

Institute for Patient- and Family-Centered Care (IPFCC) Website

Long-Term Care Partnerships: https://ipfcc.org/long-term-care-partnerships
Research Partnerships: https://ipfcc.org/research-partnerships.

PCORI Resources

Research Fundamentals: Preparing You to Successfully Contribute to Research
www.pcori.org/engagement/research-fundamentals

Building Effective Multi-Stakeholder Research Teams
www.pcori.org/events/2020/building-effective-multi-stakeholder-research-teams

AARP Policy Institute. Long-Term Services and Supports and Family Caregiving, *AARP Nursing Home COVID-19 Dashboard*. www.aarp.org/ppi/issues/caregiving/info-2020/nursing-home-covid-dashboard.html

Altarum. https://altarum.org/populations/eldercare

Americans for Financial Reform Education Fund (AFREF). *The Deadly Combination of Private Equity and Nursing Homes During a Pandemic — New Jersey Case Study of Coronavirus at Private Equity Nursing Homes,* August 2020. https://ourfinancialsecurity.org/2020/08/report-3-private-equity-nursing-homes-coronavirus/

American Institute of Architects (AIA). *Strategies for Safer Senior Living Communities,* May 2020. https://www.aia.org/resources/6307024-strategies-for-safer-senior-living-communi

Canadian Centre for Caregiving Excellence (CCCE). *An Approach to a Better Caregiving Landscape in Canada,* November, 2022. https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE_Giving-Care.pdf

Caregivers for Compromise. A coalition of leaders across the U.S. working to establish legislation that eliminates the isolation of residents in long term care facilities like that experienced in response to COVID-19. https://caregivers4compromise.com

Center for Advance Design Research and Evaluation (CADRE). *Resilient Access to Social Connection for Lower-Income Older Adults: Tapping the Potential of the Built Environment*. www.cadreresearch.org/resilient-social-connection

Resources

Centers for Disease Control. www.cdc.gov/longtermcare/index.html

CJE Senior Life. *Bureau of Sages* – Research Advisory Board comprised of long-term care community members and stay-at-home elders. www.cje.net/bureauofsages

Facilities Guideline Institute (FGI). *Guidance for Designing Health and Residential Care Facilities that Respond and Adapt to Emergency Conditions*, March 2021. https://fgiguidelines.org/resource/guidance-for-designing-health-and-residential-care-facilities-that-respond-and-adapt-to-emergency-conditions/

FrameWorks. *How to Share the NASEM Report, The National Imperative to Improve Nursing Home Quality, with Public Audiences*, April 2022. www.frameworksinstitute.org/wp-content/uploads/2022/04/Nursing-Homes-Framing-Guidance_2022.pdf.

Healthcare Excellence Canada (HEC). LTC+ Resources and Promising Practices for Those Living and Working in Long-Term Care. www.healthcareexcellence.ca/en/what-we-do/all-programs/ltc-acting-on-pandemic-learning-together/ltc-resources-and-promising-practices-for-those-living-and-working-in-long-term-care/

- *Practices of Interest to Support In-Person Family Presence and Communication with Families.* www.healthcareexcellence.ca/media/jamgqx4q/20211015_supportfamilypresenceandcommunication_en.pdf.
- *LTC+ – Mental Health and Resiliency Resources for Healthcare Providers, Staff and Leaders*. www.healthcareexcellence.ca/en/what-we-do/all-programs/ltc-acting-on-pandemic-learning-together/ltc-mental-health-and-resiliency-resources-for-healthcare-providers-staff-and-leaders/
- *Promising Practices for Supporting Long-Term Care Provider Resilience*. https://www.healthcareexcellence.ca/media/amycqp4n/20211004_promisingpracticesforsupportingltcproviderresilience.pdf
- *Safely Re-entering Long-Term Care Homes During COVID-19: A Resource for Essential Care Partners*. https://www.healthcareexcellence.ca/en/what-we-do/all-programs/ltc-acting-on-pandemic-learning-together/safely-re-entering-long-term-care-homes-during-covid-19/
- *Essential Together Tool: Identifying Strengths and Improvements to Reintegrate Essential Care Partners.* www.healthcareexcellence.ca/media/eudefits/20211222_essentialtogethertool_en.pdf

Resources

Innovation in Aging. *Does Living in a Higher Proportion Minority Facility Improve Quality of Life for Racial/Ethnic Minority Residents in Nursing Homes?* June 2020. https://academic.oup.com/innovateage/article/4/3/igaa014/5851608

Institute for Healthcare Improvement (IHI). *COVID-19 Resources: Care of Older Adults.* www. ihi.org/Topics/COVID-19/Pages/COVID-19-Care-of-Older-Adults.aspx

- *Might the COVID-19 Pandemic Lead to Better Practices in Long Term Care.* https://www.ihi.org/about/news/Pages/Might-the-COVID-19-Pandemic-Lead-to-Better-Practices-in-Long-Term-Care.aspx
- *COVID-19 Rapid Response Network for Nursing Homes.* https://www.ihi.org/Engage/Initiatives/COVID-19-Rapid-Response-Network-for-Nursing-Homes/Pages/default.aspx
- *Leveraging National Nursing Home Huddles for Rapid COVID-19 Response.* https://www.mdpi.com/2308-3417/6/2/62

National Academies of Sciences, Engineering, and Medicine (NASEM). *The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff,* 2022. https://nap.nationalacademies.org/catalog/26526/the-national-imperative-to-improve-nursing-home-quality-honoring-our

Ontario Association of Residents' Councils (OARC). *Communicating with Residents During Outbreaks: OARC Tips and Template*. www.ontarc.com/tools/20210719ComTipsTemplate.pdf

- *Residents' Council: Considerations and Strategies for Long-Term Care Homes During Outbreaks*: https://www.ontarc.com/education-support/tools.html#outbreaks

Ontario Centres for Learning, Research and Innovation in Long-Term Care (CLRI). Resources: https://clri-ltc.ca/resource/essential-care-partner/

- *Essential Care Partners Are Essential: Infographic Resource.* https://clri-ltc.ca/files/2022/10/Infographic-Report_V5_Final_FINAL-s-2.pdf
- *Program Implementation Guide*. https://clri-ltc.ca/files/2022/10/Essential_Care_Partner_Implementation_Guide_V5_Final_FINAL-s-1.pdf

Resources

Pioneer Network. https://www.pioneernetwork.net/

- *Honoring Preferences When the Choice Involves a Risk: A Process for Shared Decision Making and Care Planning*, August 2018. www.pioneernetwork.net/wp-content/uploads/2021/02/Honoring-preferences-when-the-choice-involves-risk.pdf

Planetree. Guidelines on Family Presence During a Pandemic. https://planetree.org/wp-content/uploads/2020/08/Published-Guidelines-on-Family-Presence-During-a-Pandemic-Final-8.13.20v5.pdf.

- *Family Presence Policy Decision-Making Toolkit.* https://planetree.org/wp-content/uploads/2021/05/Family-Presence-Policy-Decision-Making-Toolkit.pdf

The Green House® Project. https://thegreenhouseproject.org

- *Elevate Eldercare Podcast.* "Rethinking "Surplus Safety" in Long-Term Care," October 26, 2022.

JOURNAL ARTICLES AND BOOKS

Healthcare Quarterly. "Lessons from Long-Term Care Home Partners during the COVID-19 Pandemic." *December 2022.* https://www.longwoods.com/content/26981/lessons-from-long-term-care-home-partners-during-the-covid-19-pandemic

International Journal of Health Policy and Management (IJHPM). "Structural and Managerial Risk Factors for COVID-19 Occurrence in French Nursing Homes." February, 2022. www.ijhpm.com/article_4207.html

JAMA Internal Medicine. "Association Between Nursing Home Crowding and COVID-19 Infection and Mortality in Ontario, Canada." February, 2021. https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2772335

Journal of Alzheimer's Disease. "Dementia-Friendly 'Design': Impact on COVID-19 Death Rates in Long-Term Care Facilities Around the World." 2021 www.j-alz.com/content/dementia-friendly-design-impact-covid-19-death-rates-long-term-care-facilities-around-world

Resources

Journal of the American Medical Directors Association (JAMDA)

- "Allowing Visitors Back in the Nursing Home During the COVID-19 Crisis: A Dutch National Study Into First Experiences and Impact on Well-Being." June 2020. www.jamda.com/article/S1525-8610(20)30526-0/fulltext
- "Caring for a Relative With Dementia in Long-Term Care During COVID-19." December 2021. www.jamda.com/article/S1525-8610(21)01013-6/fulltext
- *Dementia*. "Family members' reasoning in relation to pleasant environments in nursing homes." January 2023. https://journals.sagepub.com/doi/epub/10.1177/14713012221142474
- "Essential Family Caregivers in Long-Term Care During the COVID-19 Pandemic." May 2021. www.jamda.com/article/S1525-8610(20)30430-8/fulltext
- "Nontraditional Small House Nursing Homes Have Fewer COVID-19 Cases and Deaths." March 2021. www.jamda.com/article/S1525-8610(21)00120-1/fulltext
- "Nursing Home Design and COVID-19: Balancing Infection Control, Quality of Life, and Resilience." November 2020. www.jamda.com/article/S1525-8610(20)30788-X/fulltext
- "Nursing Home Design and COVID-19: Implications for Guidelines and Regulation." January 2021. https://www.jamda.com/article/S1525-8610(21)00120-1/fulltext
- "Predicting Mortality Risk in Older Hospitalized Persons With COVID-19: A Comparison of the COVID-19 Mortality Risk Score with Frailty and Disability." July 2021. www.jamda.com/article/S1525-8610(21)00512-0/fulltext
- "Reimagining Long-Term Care." February 2022. www.jamda.com/issue/S1525-8610(21)X0011-4
- "The Adverse Events of the COVID-19 Pandemic on Nursing Home Resident Well-Being" *May* 2021. www.jamda.com/article/S1525-8610(21)00306-6/pdf
- "The Inevitability of Reimaging Long-Term Care." February 2022. www.jamda.com/article/S1525-8610(21)01106-3/pdf

Neglected No More: The Urgent Need to Improve the Lives of Canada's Elders in the Wake of the Pandemic. André Picard, Random House Canada, 2021. www.penguinrandomhouse.ca/books/669793/neglected-no-more-by-andre-picard/9780735282247