

## **Giving a voice to the care partners of older people living in a long-term care home during the COVID-19 pandemic: A critical ethnography of their experience and recommendations**

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Full report (in French): [https://www.chairepersonneagee.umontreal.ca/fileadmin/documents/Rapport-projet\\_Voix.pdf](https://www.chairepersonneagee.umontreal.ca/fileadmin/documents/Rapport-projet_Voix.pdf)

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### **ABSTRACT**

**Problem.** The COVID-19 pandemic is having a major impact on older people living in long-term care homes (LTCH). They are more at risk of contracting the disease and dying from it. They suffer significant health impacts because of the sanitary measures put in place to control contagion by the virus (e.g., lockdown, physical distancing). Many older people living in LTCHs are regularly visited by a family member or friend. These people play important roles in LTCHs that have been greatly disrupted by the pandemic. Although previous studies have described the burden of these care partners and interventions to alleviate it in a normal context, COVID-19 brought significant changes for them. However, the specific nature of their experience and support needs in this context is poorly documented. Scientific knowledge on this subject should guide actions during the current pandemic as well as for future ones.

**Purpose.** To describe the experience of being a family care partner of an older person living in a LTCH during the COVID-19 pandemic and their recommendations for supportive actions to promote their health and that of older people.

**Method.** As part of a critical ethnography, we recruited 24 care partners of older people living in LTCHs. These care partners were caring or had cared for an older person living in a LTCH in Quebec (Canada) during the COVID-19 pandemic between March 14 and July 31, 2020. They were recruited from a pool of 65 participants from previous research projects. We collected data using a sociodemographic questionnaire, semi-structured interviews, and field notes. The data set was analyzed using Spradley's method. Iterations of this analysis were conducted and discussed within the research team to identify themes and subthemes.

**Results.** Five themes describe the experience of care partners. The care partner-older person dyad had a difficult time with their forced separation when visiting was denied. This had an impact on their respective health. Care partners found that care was sometimes inhumane, or they doubted the quality of the care. Exceptionally, some care partners were satisfied with the care. For care partners whose older person had died, distressing processes were reported during the post-mortem period. Communication opportunities between care partners and the older person, as well as with the LTCH staff, were uneven, with some settings showing inertia and other creativity. This variability was also noted in the organization of visits between LTCHs and sometimes within the same LTCH, even after public health directives allowed such visits. Care partners consider that a LTCH is a community, but that it has been neglected even though older people deserve better. For the five themes, recommendations for supportive actions or practices were made by the care partners.

**Conclusion.** The results show that care partners play an essential role for older people living in LTCH and that the pandemic has caused great distress for care partners and older people. Eighty-eight (88) support or practical actions were proposed by care partners. Additional recommendations resulted from the discussion considering the scientific literature. All these actions and recommendations must be a catalyst for change towards humane care that promotes the well-being of older people and their care partners, as well as for the community that each LTCH represents.