

Survey uncovers pandemic's complex impact on people living with dementia and their families

March 24 2021, by Kerry Blackadar



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COVID-19 has been especially challenging for people living with dementia, their families and caregivers, confirms a new study published

in the *Journal of Alzheimer's Disease*.

The study uncovers the complex effects of the pandemic on more than 400 people in this community in B.C., and identifies their unique needs.

Dr. Julie Robillard, the study's senior author and assistant professor of neurology at UBC's faculty of medicine, discusses the biggest challenges being faced by people living with [dementia](#) and their caregivers, and shares how this work is already being used to inform services and resources in B.C.

How has the pandemic impacted the physical and emotional health of people living with dementia?

With the social distancing regulations and other prevention measures, we found that people living with dementia were more restricted and confined within the home, some without opportunities to step out and get groceries, attend regular health care services, receive home care support or access community networks—all of which have negative impacts on health.

We also heard from this community that they are experiencing high levels of stress and loneliness. When compared to before the pandemic, most (83 percent) reported feeling more isolated. And while participants reported engaging in a number of activities to manage their stress, from walking around the neighborhood to talking to friends and family, fewer than half felt that these activities had been sufficient to manage their stress.

What were the main concerns of families and caregivers?

Nearly all the caregivers we surveyed indicated that not being able to visit the person they cared for in long-term or [palliative care](#) was a major concern.

We also heard that changing levels of care were challenging. Many caregivers experienced reduced home care support and worried about the possibility of outside care staff bringing the virus into their homes.

What improvements are needed to help people living with dementia, their families and caregivers during this time?

First and foremost, we need to ensure that people living with dementia and their caregivers are receiving up-to-date, clear and useful resources about the pandemic and how to manage the challenges it is raising for this community.

As many care and support services have transitioned to online formats, it is also important to ensure that those living with dementia and their caregivers are empowered to make the most of what technology can offer. A majority of participants in our study indicated that they already use technologies like cell phones and tablets to connect with others, but many experienced technical issues, so raising awareness about dementia-friendly solutions could be beneficial.

Finally, involving persons living with dementia and their caregivers in the broader discussion about how to manage the pandemic as a society would ensure their specific needs and concerns are addressed.

How are the survey findings being used?

The Alzheimer Society of British Columbia, our partner for this study, is

already implementing the findings in the content and delivery of their services.

Based on survey feedback capturing the lived experiences of people living with dementia and their caregivers, the society is now offering programs for the dementia community online, and in a way that is as user-friendly as possible. They're making it easier for people to access programs with confidence and have increased the frequency of communication to people affected by dementia.

The society has also developed online resources and webinars to address topics our survey confirmed to be of most concern to people living with dementia and their caregivers: navigating long-term care visitation, providing at-home activities and managing [caregiver](#) stress.

More information: Mallorie T. Tam et al. The Impact of a Global Pandemic on People Living with Dementia and Their Care Partners: Analysis of 417 Lived Experience Reports, *Journal of Alzheimer's Disease* (2021). [DOI: 10.3233/JAD-201114](https://doi.org/10.3233/JAD-201114)

Provided by University of British Columbia

Citation: Survey uncovers pandemic's complex impact on people living with dementia and their families (2021, March 24) retrieved 25 June 2024 from <https://medicalxpress.com/news/2021-03-survey-uncovers-pandemic-complex-impact.html>

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