

LETTER TO THE EDITOR

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People with young-onset dementia and their families experience distinctive impacts of the COVID-19 pandemic and associated restrictions

Evidence is emerging to describe the impacts of the COVID-19 pandemic and associated restrictions for older people with dementia, who are at high risk of contracting the virus (Hariyanto *et al.*, 2021) and experience rapid worsening of behavioral and psychological symptoms (Cagnin *et al.*, 2020). People with dementia report reduced psychological wellbeing and increased anxiety associated with COVID-related social service closures (Giebel *et al.*, 2021). Family members of people with dementia have reported increased levels of stress and caregiving load during lockdown measures (Cohen *et al.*, 2020), especially where they reported anxiety about the virus itself (Savla *et al.*, 2020) and where they withdrew from support services for the safety of the person with dementia (Giebel *et al.*, 2020).

Research has yet to specifically examine the COVID-related experiences of those with young-onset dementia (YOD) (with symptom onset prior to 65 years), which represents 8% of all dementias and 5 million cases in the US, 42,000 in the UK, and 27,000 in Australia (Brown *et al.*, 2017). People with YOD report higher rates of distress and carer burden than their older counterparts, partly related to their higher financial, familial, and occupational responsibilities (Cations *et al.*, 2017; Ryan *et al.*, 2021). In Australia, YOD care is funded and delivered in the disability system (rather than aged care). People with YOD and their families may therefore have distinct experiences with COVID-19 and support needs that require a tailored response.

We invited Australians living with YOD or providing informal care to a person with YOD to complete a cross-sectional, mixed-methods survey about how the COVID-19 pandemic and associated restrictions have impacted their care. Participants were diagnosed with YOD or currently providing informal support to a person with YOD and were re-contacted after participating in an earlier survey study (Cations *et al.*, 2021). Surveys were completed in May–June 2020, 3 months after the first recorded Australian case of COVID-19. Strict lockdown restrictions, including the closure of non-essential services, were gradually being eased across the country (Lupton, 2020).

The survey was granted ethical approval by the Flinders University Social and Behavioural Research Ethics Committee (Project 8331).

Participants were 12 people living with YOD and 41 unpaid carers of a person with YOD. Most respondents (or those they care for) were diagnosed with Alzheimer's disease ($n=29$) or frontotemporal dementia ($n=11$), with median onset age of 56 years. Twenty-five percent of informal carers provided care for a person living in residential care. Quantitative data were summarised using descriptive statistics (e.g. means and percentages), and open-ended qualitative responses were transcribed verbatim and examined for themes using a thematic analysis approach with open coding to generate themes (Cavanagh, 1997). Particular attention was paid to data indicating unique impacts for young people with dementia (i.e. those that may be less relevant for older people with dementia or those without dementia). Illustrative quotations are included here as representative examples of the themes identified.

Most participants reported that the pandemic negatively impacted on their care in some way (Table 1). Many reported similar barriers to service access as have been reported by older people with dementia (Giebel *et al.*, 2021), including service shutdowns and restrictions on visitation to residential care. However responses were marked by a sense of urgency about access to physical and social activity for maintaining otherwise good physical health. As one survey respondent living with YOD noted, *"My body is healthy and regular social interaction helps to regulate my symptoms, so lack of contact is making things terrible for me."* Many noted difficulties managing the behavioral and psychological responses to the stress, isolation, and boredom caused by COVID-19 restrictions, especially for those with frontotemporal dementias.

Carers noted that their already high caring responsibilities for the person with YOD, young children, and sometimes also aging parents were each simultaneously increased by the pandemic. Carers with young children affected by school closures were faced with what one described as *"an excruciating caring load"* with little opportunity for respite. Residual impacts of working from home, losing work, and/or interrupting work to suit strict facility visitation times were noted to reduce tolerance and empathy such that the quality of care was negatively affected.

Table 1. Summary of survey responses with illustrative quotations

STATEMENT	N (%) ENDORSED	EXAMPLE RESPONSE
I/We have been unable to access one or more support services	33 (80.5)	<i>“Even when visitors are allowed, most support workers are mums and can’t work when their kids are at home.”</i>
I/We have been unable to access one or more health service	16 (40.0)	<i>“Because of the lockdown [the nurse] was unable to keep an eye on her oedema - now she has very red, painful and swollen legs.”</i>
I/We have felt concerned about our risk for contracting COVID-19 from support or healthcare workers	18 (43.9)	<i>“Support workers did not seem to be using any PPE. Not all support providers had a plan or policy for handling COVID-19 contact.”</i>
I/We have been satisfied with measures taken by support or healthcare workers to reduce the risk of transmission	35 (85.4)	<i>“There has been a quick response in development and communication of policies and practices at the group home.”</i>
I/We have cancelled or reduced use of services because of concerns about contracting COVID-19	15 (36.6)	<i>“We cancelled our Saturday service largely because the worker said she was still going to a lot of other homes . . .”</i>
Managing my/the person I support’s dementia symptoms has been more difficult because of the COVID-19 pandemic	36 (87.8)	<i>“[The person with YOD I support] relies heavily on predictable routine, and they depend on the regular presence of close family members but that has suddenly been removed. They don’t really understand and so become easily distressed.”</i> <i>“I am working from home, trying to home school my kids, and trying to keep my husband engaged and busy. I am drowning.” (Care partner survey respondent)</i> <i>“Without me there a few times a week, it takes forever to get anything done.”</i>

COVID-19: Coronavirus 2019; PPE: personal protective equipment; YOD: young-onset dementia.

About 15% of participants reported dissatisfaction with disability support workers’ insufficient use of personal protective equipment (PPE). One respondent noted that *“the carers go from house to house and don’t wear protective gear or use hand sanitiser.”* One care partner respondent noted concerns that the disability workforce providing in-home support may lack health expertise: *“There are no nurses, and I don’t know how much training in infection control these people get.”*

This small study provides early insight into the impacts of the COVID-19 pandemic for people with YOD and their families. Our sample reported similar experiences and concerns with care related to the pandemic and associated restrictions as those reported by older people with dementia and their families in international studies, including social isolation, boredom, and loneliness (Hanna *et al.*, 2021), an associated increase in challenging behavioral responses (Cagnin *et al.*, 2020), and anxiety both about contracting the virus and the ongoing impacts of restricted access to supports (Hariyanto *et al.*, 2021).

International studies have demonstrated that retaining their often good physical health is a priority for people with YOD (Bakker *et al.*, 2010), and in this context the loss of access to

allied health and other services has been devastating. For care partners, service restrictions were often paired with school closures and work stressors that combined to further amplify their already high caring load (Lockeridge and Simpson, 2013). Dissatisfaction with PPE use and other risk reduction strategies among the dementia care workforce has been reported among family carers of people with dementia (Giebel *et al.*, 2020). These concerns were echoed here and, on a local level, continue to raise questions about the ability of the disability workforce in Australia to adequately limit the risk of COVID-19 transmission (Kavanagh *et al.*, 2020). Disability and healthcare services are poorly integrated in Australia, and disability professionals often do not have health training. Outbreaks of COVID-19 in disability settings in the months following our study support the suggestion that additional resources are required to prevent further harm (Kavanagh *et al.*, 2020).

Conflicts of interest

MC has been employed in the past 5 years to assist with data collection for Alzheimer’s disease drug trials funded by Janssen and Merck. All other authors declare no conflicts of interest.

Description of authors' roles

MC obtained funding for this study, analyzed the data, and drafted and edited the manuscript. SD conducted recruitment and data collection. KL, AW, and BD provided oversight for the study and assisted with manuscript editing.

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