

Everyday lives of community-dwelling older people with dementia during the COVID-19 pandemic in Japan

The coronavirus disease 2019 (COVID-19) outbreak severely impacted the everyday lives of people with dementia. For example, this group may have difficulty understanding and adapting to abrupt changes in everyday behaviours, such as social distancing, washing hands and wearing masks. In Japan, outpatients with Alzheimer's disease¹ and frontotemporal dementia² were reported to have difficulty taking preventive measures against COVID-19. However, the everyday lives of community-dwelling older people with dementia during this pandemic have not been fully explored.

The person-centred approach highlights that the experiences of individuals with dementia are important. However, the nature of cognitive impairment and the need for physical distancing means accessing these experiences is challenging. We believe that archiving the voices of people with dementia is essential in combating future zoonotic disease pandemics, which is an important global public health issue.³

In 2020, we reported a quantitative analysis of our telephone outreach project for people with cognitive impairment during the COVID-19 pandemic. We compared those with cognitive impairment with healthy controls and found the former had a severe risk of being homebound.⁴

Here, we report a qualitative analysis from the same project, focusing on people with dementia that were diagnosed by a visiting psychiatrist before the pandemic. Details of the project have been described elsewhere.⁴ In summary, we conducted a large-scale epidemiological survey⁴ and community action approach⁵ in parallel under a community-based participatory framework. Two public health nurses who were central to the action research telephoned potential participants during Japan's declaration of a national state of emergency in April and May 2020. Because a simple information-gathering method was preferable during the pandemic, we allowed cases in which only family members wished to respond. A limitation of this study was that we were unable to collect descriptions for the same participant from both people with dementia and their family members. In addition to collecting qualitative data, we gathered data for Mini-Mental State Examination responses (obtained from October 2020 to February of 2021, just before pandemic), and subjective anxiety (selected from the three potential answers: "no anxiety," "moderate anxiety," and "severe anxiety"). The Ethics Committee of the Tokyo Metropolitan Institute of Gerontology approved the study protocol.

Table 1 compares records of everyday life described by people with dementia ($n = 9$) and family members ($n = 8$) who were unrelated to those people with dementia. The latter showed a high frequency of anxiety (7/8) compared with the former (5/9). The narratives of people with dementia showed that they cared more about others than themselves. Furthermore, narratives of three people with severe anxiety included breaking relationships: not seeing their sister (No. 2), visiting dentist stopped coming (No. 6), and quitting their club (No. 8). In contrast, the narratives of four people with no anxiety included maintaining relationships: stable relationships with family (Nos. 1 and 4) and continuing day-care services (Nos. 3 and 9).

Family members' reported observing advancing dementia, decreasing appetites (and subsequent death), and severe behavioural symptoms, such as making threats and getting lost. However, those with dementia did not report such events. Interestingly, increasing behavioural and psychological symptoms of dementia during the pandemic were reported in Canada.⁶

We drew the following conclusions from our explorative project. (1) Because information concerning behavioural symptoms was only included in the narratives of family members, behavioural symptoms of people living with dementia who are living alone may be difficult to find. (2) Maintaining relationships may be central to stable everyday lives. (3) More support is essential for the family member who often manage behavioural symptoms. (4) Because our telephone outreach project in the community-based participatory framework revealed voices that are usually overlooked, more social outreach to vulnerable populations such as people with dementia is essential, especially in challenging situations such as pandemics.

A strength of our study was that despite substantial societal disruption, we could access people with dementia because of long-term relationships with residents. Our study also had some limitations. First, the number of participants was small. Second, telephone interviews with people with dementia might have been a source of bias. Third, as noted, we were unable to collect descriptions for the same participant by both people with dementia and their family members.

KEYWORDS

community, COVID-19, dementia

TABLE 1 Everyday lives described by people with dementia (n = 9) and family members (n = 8) during the pandemic

No	Sex	Age	MMSE	Anxiety	Living status	Life during the pandemic (subjective view) in spring 2020
1	F	83	14	(-)	Living alone. Her son lives in neighbourhood	I can sleep well after bathing and drinking spirits. My son takes care of me. He says I have dementia. But we seem to get along well
2	F	78	22	(++)	Living alone	My fear is...my sister is living in a geriatric institution. Because of COVID-19, I can't visit her
3	F	90	18	(-)	Living alone	I continue going to day-care service
4	F	96	16	(-)	Living with her daughter	I am living with my daughter and I don't go out
5	F	81	18	(+)	Living with her son	My fear is...my sister will die when she is taking a bath
6	F	82	7	(++)	Living with spouse	I have a toothache. The visiting dentist has stopped coming
7	F	87	20	(+)	Living alone. Her son lives in neighbour	I go to day-care service. My sons often come to my house
8	M	85	23	(++)	Living with spouse	I quit my sports club
9	F	85	24	(-)	Living with spouse	I go to day-care service, but I don't tell my neighbours
						Life during the pandemic (description by family) in spring 2020
F1	M	85	13	(+)	Living with spouse	The participant got lost during the pandemic. The police found him. His wife worries that he may get lost again
F2	F	87	13	(++)	Living with her son	The participant's son manages the care services. He worries about her being alone when he works at night
F3	F	90	22	(++)	Living alone. Her daughter lives next to her	The participant's daughters worry that her dementia is advancing
F4	M	80	8	(++)	Living with spouse	The participant told his wife, 'I want to die. I want to die. I want to kill you.' When his wife came back from shopping, he said 'Where have you been? You've been playing around every day.' Although his wife knows dementia is causing his behaviour, she is very depressed and she goes to a psychiatric clinic
F5	M	86	16	(++)	Living with spouse	The participant's wife worried that the participant was losing his appetite. A month later, she called us and said he had died of gastric cancer
F6	M	85	21	(++)	Living with spouse	The participant's wife is a retired nurse, so she is always calm
F7	F	80	20	(-)	Living with spouse	The participant's wife said the participant's speech was decreasing. He was awake at night and sleep during the day. He didn't know anything about COVID-19
F8	M	82	10	(++)	Living with spouse	The male participant doesn't usually go out. But when the female family member was not paying attention, the participant left the house and suffered a facial injury. This shocked her


Note: (-) = no anxiety, (+) = moderate anxiety, (++) = severe anxiety.


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CONFLICT OF INTEREST

The authors declare no conflict of interest.

Tsuyoshi Okamura 

Chiaki Ura 

Mika Sugiyama

Yukiko Kugimiya

Mutsuko Okamura

Shuichi Awata

Tokyo Metropolitan Institute of Gerontology, Tokyo, Japan

Correspondence

Tsuyoshi Okamura, Tokyo Metropolitan Institute of Gerontology, 35-2 Sakae-cho, Itabashi-ku, Tokyo 173-0015, Japan.
Email: t.okamura.jp@gmail.com

ORCID

Tsuyoshi Okamura  <https://orcid.org/0000-0002-5879-6051>

Chiaki Ura  <https://orcid.org/0000-0001-7228-6632>

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