

# “A brutal disadvantage for my wife [living with dementia] That has set us back years”: Results of a quantitative survey of caring relatives of people living with dementia during the Covid-19 pandemic in Germany

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#### Abstract

**Background:** The Covid-19 pandemic poses a major challenge to the entire population. People living with dementia and their caring relatives, mostly older people, are considered a high risk group for infection with Covid-19. As people living with dementia have a particular need for consistent daily routines and care, the restrictions during the pandemic presented relatives with new burden. Here, we investigated how caring relatives experienced the time during the Covid-19 pandemic.

**Method:** We planned to conduct focus groups with different stakeholders in dementia care. Due to contact restrictions, we carried out a quantitative survey with a semi-structured questionnaire as an alternative method of data collection. Questionnaires (n = 45) including open and closed questions were sent by post to the leaders of four self-help groups for relatives of people living with dementia and then distributed to the members by the group leaders. We asked about the current health status of the respondents, the limitations during the Covid-19 pandemic and changes in the care of people living with dementia.

**Result:** A total of 23 questionnaires were completed and returned to us. Participants had a mean age of 70.4 years (range 51 to 88 years). The majority of participants were female (69.6%). More than half of the participants assessed their health status as less good or bad (56.5%). Compared to the health status before the Covid-19 pandemic, more than one third of respondents felt their own health was deteriorating (39.1%). Feelings of isolation and social exclusion increased in 39.1% of the participants during Covid-19 pandemic. Most participants suffered from limitations of social contacts and leisure activities. The temporary closure of day care facilities for people living with dementia was a particular burden for caring relatives.

**Conclusion:** The majority of respondents experienced the Covid-19 pandemic as burdensome with regard to their health and their care responsibilities. The statements of relatives underline the importance of maintaining clear structures in everyday life and in care of people living with dementia even in periods of crisis.