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Involvement, worries and loneliness of family caregivers of people with dementia during the COVID-19 visitor ban in long-term care facilities

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ABSTRACT

To prevent COVID-19 from spreading in long-term care facilities (LTCFs), the Dutch government took restrictive measures, including a visitor-ban in LTCFs. This study examined the relationship between involvement of family caregivers (FCs) of people with dementia (PwD) living in LTCFs and FCs mental health during the visitor-ban, and whether this relationship was moderated by the frequency of alternative contact with PwD during the visitor-ban and FC resilience. This cross-sectional study collected data from 958 FCs. FCs who visited PwD more frequently before, were more worried during the visitor-ban than those with lower visiting frequency. FCs who visited PwD daily before, but had minimal weekly contact during the visitor-ban, worried less. Resilient FCs who did social and task-related activities before, experienced less loneliness during the visitor-ban. It is advisable for healthcare professionals to reach out to these groups, to facilitate ongoing contact and help them overcome their loneliness.

Introduction

People with dementia living in long-term care facilities (LTCFs) are disproportionally at risk of becoming infected with COVID-19 because of their ageing immune system and comorbid diseases.1,2 Further, they have a decreased ability to comply with restrictive measures, e.g., social distancing and hand hygiene.3 The risk of COVID-19 outbreaks is especially high in LTCFs because residents often spend much of their time in communal spaces with other residents and have physical contact with care staff during the provision of care.4–6 A study on mortality associated with COVID-19 indicated that 46% of all people who died due to COVID-19 since the pandemic began until October 2020 lived in LTCFs.7

To protect people with dementia living in LTCFs from becoming infected with COVID-19, visitor bans have been implemented by governments worldwide.7,8 In the Netherlands, visitors were banned between mid-March and mid-May 2020, which meant that LTCFs closed their doors for visitors from outside as obligated by law.9,10 Similar measures taken within LTCFs prevented residents from going outside and halted social and group activities.10–12 These restrictions, together with the lack of social interaction and physical closeness (e.g., holding hands, hugging) with family and friends are thought to have had an adverse impact on the well-being of both residents and their family and friends. Indeed, research has demonstrated the effects of the visitor ban on the well-being and autonomy of LTCF residents.10,11,13 Although other, “innovative” means of contact, like video calls, were used to facilitate interaction with family and friends, some residents nonetheless felt socially isolated,9,10,13 with potentially negative consequences for their health and well-being.14,15 On the other hand, there are indications that the visitor ban did not have a negative impact on the mood of a small proportion of residents because they experienced more peace and quietude in the LTCF.10,17

Family caregivers, i.e., children, spouses, other family members, friends, neighbors, or legal guardians who have a personal relationship with the person with dementia and provide support, were presumably impacted by the visitor ban as well. This is because many family caregivers remain involved in the care and lives of people with dementia when they move to an LTCF.16,17 During the visitor ban, however, family caregivers were prohibited from such involvement. It remains unclear how this prohibition impacted family caregivers’ mental health.

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Before the pandemic, family caregivers contributed in different ways to the care of people with dementia. They provided task-related care (e.g., physical care tasks or helping with activities and meals), undertook pleasant personal or social activities, and gave psychosocial support.30–32 Also, family caregivers provided care staff with information about residents’ life history, background, and needs. Further, they monitored the provision of care and acted as a link to the outside world for people with dementia.23 Research has shown that the involvement of family caregivers in LTCFs contributes to improved quality of life of people with dementia as well as better quality of care.21,24

For family caregivers, involvement in the care for people with dementia living in LTCFs is also important because it can have positive outcomes of benefit to their own mental health, including relationship continuity and emotional rewards like feeling appreciated and personal growth.25,26 Previous research on visitor bans as a consequence of the SARS outbreak revealed a range of negative effects on the physical and mental health of family caregivers.27 In addition to missing the company of the person with dementia, family caregivers reported experiencing fear, worry, loss of control, frustration, and guilt.27

Based on these previous research findings, we assumed that the visitor ban imposed during the COVID-19 pandemic had adverse effects on family caregivers’ mental health.27,28 This is worrisome given the fact that their mental health is already under pressure. For example, research has shown that family caregivers experience ongoing feelings of guilt, burden and depression.29–31 There are individual differences in how family caregivers cope with caring for a person with dementia; these differences depend on various personal characteristics and circumstances. Resilience is one such characteristic, as it can serve as a protective barrier against developing certain psychological problems, including during the visitor ban.28,32 As such, resilience among family caregivers has been defined as a positive adaptation to adversity.33

In the current study, the relationship between the visiting frequency and types of activities performed by family caregivers of people with dementia in LTCFs before the visitor ban and their experiences of worrying and loneliness during the ban was examined. Two possible moderators in this relationship, i.e., the contact frequency during the visitor ban and the resilience of family caregivers, were studied as well.

Family caregivers might have experienced a loss of control and therefore increased worrying and loneliness during the visitor ban.7 because they were unable to monitor or be involved in the provision of care.27 Furthermore, family caregivers may have experienced more loneliness because they missed the company of the person with dementia27 and there was less continuity in their relationship.25,26 The relationship between the visiting frequency before and worrying and loneliness during the visitor ban might have been moderated by how much contact family caregivers still had with the person with dementia during the visitor ban (for example, by telephone or video calls). Having more frequent contact might have helped family caregivers stay informed about how the person with dementia was doing and how they were being cared for. This could have in turn reduced worrying and loneliness. Resilience was a potential moderator as well, as it could have helped family caregivers better adapt to the changed situation, thereby mitigating worrying and loneliness. Fig. 1 depicts the hypothesized relationships between the investigated variables.

**Methods**

**Design**

In this cross-sectional study, data were collected 6–10 weeks after the imposition of the national visitor ban, which lasted from April 30 until May 27, 2020, using a semi-open online survey administered to family caregivers of LTCF residents with dementia.13 This study was part of a larger study that aims to examine the impact of social isolation during the COVID-19 pandemic on socially vulnerable populations (www.coronatijden.nl). Medical ethical approval for the study

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**Fig. 1.** Models investigating the relationship between the involvement of family caregivers in LTCFs for people with dementia before the visitor ban and their worries (direct effect) and loneliness (direct effect), with moderators contact frequency during the visitor ban and the resilience of family caregivers (hypothesis 1 and 2).
was provided by the Medical Ethical Committee of Amsterdam’s Institute for Social Science Research.

**Sample and procedure**

A total of 357 care organizations, registered nationally as nursing home care providers, under the Chronic Care Act (WLZ), were invited by email to participate in the study. Information about the study and a link to the digital survey were provided. The care organizations were asked to distribute the information to the first contact persons of residents under their care, most of whom were family members, i.e., children, spouses or other family members, and a small number of friends, neighbors, or a legal guardian. In this paper they are referred to as family caregivers to stress the personal relationship with the person with dementia. No confirmation of participation was sought from the care organizations. All data was gathered anonymously, a distinction between care organizations cannot be made. Informed consent from participants was obtained digitally prior to the start of the online survey.

This study used data from a sub-sample of participants. Only data provided by family caregivers who indicated dementia or memory problems as the main reason for the admission of their relative to the LTCF were included in the analyses (N = 958). The participants provided information about the type of LTCF in which the person with dementia resided in. These data indicated that 53.6% of people with dementia lived in a nursing home, 44.0% lived in a residential care home, and 2.4% lived in another type of LTCF (e.g., care farm). Of the LTCFs, 36.2% were considered to be of small size (<40 residents), 37.2% of medium (40-100 residents), and 20.7% of large size (>100 residents). The size of the LTCF was not indicated for the remaining 5.9%. Most LTCFs were located in regions where the COVID-19 infection rate during data collection was high (64.4%), as opposed to low (14.8%) and medium (20.8%).

**Measures**

Demographic information about the participants was gathered, i.e., age, gender, relationship to the person with dementia, and gender of the person with dementia.

**Independent variables**

The frequency with which family caregivers visited the person with dementia before the visitor ban was measured with the following question: “How often did you visit your relative before the corona crisis in the LTCF?”. Answer options were “every day” (high frequency), “at least once a week” (moderate frequency), “at least once a month” (low frequency), and “never, less than once a year and once or multiple times a year”. Participants who did not visit or who visited only a few times per year were excluded from analyses, because they were considered to be incidental visitors.

Participants were asked to indicate, from a list of 11 activities, which activities they used to undertake with the person with dementia while visiting before the visitor ban. Participants had the option to add alternative activities to the list. As agreed upon by the researchers, the activities were categorized into social activities or task-related activities. Table 2 includes a list of these social and task-related activities.

**Moderators**

Contact frequency during the visitor ban was measured by asking participants “How often did you speak with your relative in the past four weeks?”. Answer options were “daily”, “multiple times a week”, “weekly”, “once in two weeks”, “once” and “never”. These options were combined into three categories for the purpose of readability, namely high frequency (daily or multiple times a week), moderate frequency (weekly), and low frequency (once in two weeks or once or never).

Two items of the translated version of the Brief Resilience Scale were used because they specifically measure resilience in stressful times: “I have a hard time making it through stressful events” (reverse-coded item) and “It does not take me long to recover from a stressful event”. The mean “resilience in stressful times” score was calculated from the two items. The scores ranged from 1 to 5. Higher scores indicated a higher resilience level.

**Dependent variables**

The extent to which family caregivers worried about the person with dementia in the past four weeks was assessed with nine items formulated by the research consortium and based on research on the impact of the COVID-19 pandemic on people with severe mental illnesses. The scores ranged from 0 (never) to 5 (almost always). A factor analysis was performed on these nine items. All but one item loaded on one factor; these eight items explained 48.5% of the variance. As the reliability of this eight-item scale, Cronbach’s alpha = 0.841, was sufficient, it was used to assess the extent to which family caregivers worried about the person with dementia. The topics included in the scale were worries about the physical health of the person with dementia, being unable to visit the person with dementia in the LTCF, loneliness and unrest of the person with dementia, whether care for the person with dementia was of high quality, the day structure of the person with dementia, the possibility of the person with dementia passing away before family caregivers were able to visit them again, and the person with dementia no longer recognizing their family caregivers after the visitor ban had been lifted.

Loneliness was measured with the loneliness scale developed by de Jong Gierveld. The scale consists of 11 items. Answer options are “no” (0), “more or less” (1) and “yes” (2). The total score, the sum of the dichotomized scores, ranged between 0 and 11. Higher scores indicated higher levels of loneliness.

**Data analysis**

Data were analyzed using SPSS version 27. Multiple regression analyses were performed to examine the relationship between the independent variables and the dependent variable. To create the interaction term, the independent and dependent variables were multiplied. The resilience score was centered to prevent multicollinearity. Statistical significance was determined at p < 0.05. For each outcome measurement, i.e., worrying and loneliness, a separate model was investigated.

**Results**

**Demographics**

The mean age of the family caregivers was 60.30 (SD = 8.95, range between 16 and 89), and 71.7% were female. Three quarters (75.7%) of family caregivers indicated that the person with dementia was their father or mother. Spouses or partners represented 10.3% of the sample, while 14.0% had another type of relationship with the person with dementia (for example, other family members, friends, neighbors or legal guardians). The mean age of the person with dementia to whom family caregivers were related was 85.67 (SD = 7.91, range between 46 and 105), and 73.5% were female. The demographics of the participants are presented in Table 1.

**Independent variables**

Of the family caregivers, 57.0% carried out social activities as well as task-related activities before the visitor ban, whereas 43.0% only engaged in social activities (Table 1). Table 2 shows the types of...
Respondents who paid no or few visits per year were excluded from the analyses. Before the ban, family caregivers had alternative means of contact, and were more resilient (moderating effect), they felt less lonely during the ban and the resilience of family caregivers.

The frequency with which the family caregivers contacted the person with dementia during the visitor ban was high for 45.4% of the caregivers, moderate for 23.1%, and low for 31.5% (Table 1). During the visitor ban, contact frequency increased for 17% of family caregivers and decreased for 25% as compared to visiting frequency before the ban. Family caregivers had alternative means of contact with the person with dementia via telephone (56.7%), video calls (53.2%), outside windows (29.5%), outside areas (23.7%), digital messages or social media (12.5%) or other ways (12.2%, for example, mail or hospital visits). Participants’ mean resilience score was 3.52 (SD=0.76), ranging from 1 to 5 (Table 1).

**Dependent variables**

The mean score on the worrying scale was 3.31 (SD = 0.79), ranging from 1 to 5, as presented in Table 1. On the loneliness scale, participants scored a mean of 6.84 (SD = 1.81), ranging between 2 and 11 (Table 1).

**Regression analyses**

The final models that best fit the data are presented in Table 3. The final model for worrying examined the relationship between the involvement of family caregivers before and their worrying during the visitor ban, as moderated by contact frequency during the ban (Fig. 1). The results indicated that family caregivers who visited at least weekly before the visitor ban, worried more during the ban than those who visited less than weekly before the ban (direct effect). When family caregivers visited daily before and had weekly or more contact with the person with dementia during the visitor ban, they worried less as compared to family caregivers that visited less than weekly before the visitor ban and had contact less than weekly during the visitor ban (moderating effect). The final model, presented in Table 3, explained 10.3% of the variance (R²).

The final model for loneliness examined the relationship between the involvement of family caregivers before and their loneliness during the visitor ban, as moderated by the resilience of family caregivers (Fig. 1). For the dependent variable, loneliness, no significant direct effects were found. However, when family caregivers performed social as well as task-related activities before the visitor ban and were more resilient (moderating effect), they felt less lonely during the ban. The final model, presented in Table 3 explained 9.0% of the variance (R²).

**Discussion/ conclusions**

In this study, we examined the relationship between the visiting frequency of and types of activities undertaken by family caregivers of people with dementia before and their worrying and loneliness during the COVID-19 visitor ban in LTCFs. Two possible moderators in this relationship were studied: contact frequency during the visitor ban and the resilience of family caregivers.

In line with hypothesis 1, we found that family caregivers who visited more than weekly before the visitor ban worried more during the ban than those who visited monthly but less than weekly. This is in line with the findings from McCleary et al., as they found that the most stressful aspect of the visitor ban for family caregivers during the SARS outbreak was their inability to fulfill their responsibilities while they felt that their relatives’ happiness and comfort depended on their presence. In addition, family caregivers in a study by McCleary et al. explained that their feelings during the visitor ban were similar to those they felt after the person with dementia moved into the LTCF, i.e., they experienced feelings of anger, worry, helplessness, grief, guilt, and failure. This is a possible explanation for the increased level of worrying we found in our study among family caregivers who visited the person with dementia more frequently before the visitor ban.

Further, this study revealed that family caregivers who visited the person with dementia more frequently before the visitor ban, worried less during the ban, when they had weekly or more contact. Family and professional caregivers were, however, compelled to find alternatives to physical visits during the visitor ban, e.g., telephone or video calls. When these methods allowed them to maintain frequent contact, they were likely better able to stay informed about the well-

**Table 1** Family caregivers’ and people with dementia demographics and scores on independent, dependent and moderator variables (N = 958).

| Characteristics                           | Family caregivers |
|------------------------------------------|-------------------|
| Mean age (SD)                            | 60.30 (8.95)      |
| Gender, n (%)                            |                   |
| Male                                     | 271 (28.3%)       |
| Female                                   | 687 (71.7%)       |
| Relationship to the resident, n (%)      |                   |
| Spouse/partner                           | 99 (10.3%)        |
| Son/daughter                             | 725 (75.7%)       |
| Other (e.g. other family member, friend, neighbor, legal guardian) | 134 (14.0%) |
| Visiting frequency before the visitor ban, n (%) |     |
| Low (monthly, less than weekly)*         | 98 (10.2%)        |
| Moderate (weekly, less than daily)       | 672 (70.1%)       |
| High (daily)                             | 188 (19.6%)       |
| Types of activities performed while visiting before the visitor ban, n (%) |         |
| Social activities                        | 412 (43.0%)       |
| Social and task related activities       | 546 (57.0%)       |
| Contact frequency during the visitor ban, n (%) |       |
| Low (less than weekly)                   | 302 (31.5%)       |
| Moderate (weekly)                        | 221 (23.1%)       |
| High (more than weekly)                  | 435 (45.4%)       |
| Mean resilience score (SD)               | 3.52 (0.76)       |
| Mean worrying score (SD)                | 3.31 (0.79)       |
| Mean loneliness score (SD)              | 6.84 (1.81)       |

* Respondents who paid no or few visits per year were excluded from the analyses.

**Table 2** Types of activities family caregivers did before the visitor ban, their categorization into social versus task-related activities and the number and percentage of family caregivers who undertook the aforementioned activities.

| Types of activities                          | Number of family caregivers that performed the activity (%) |
|---------------------------------------------|-----------------------------------------------------------|
| Social activities                           |                                                           |
| Talking                                     | 875 (91.3)                                                |
| Walking                                     | 570 (59.5)                                                |
| Eating/drinking together                    | 535 (55.8)                                                |
| Going somewhere together (e.g. shopping/outside/elsewhere) | 437 (45.6) |
| Television/radio                           | 254 (26.5)                                                |
| Playing games together                      | 197 (20.6)                                                |
| Enjoyable activities (e.g. looking at pictures, reading or being read to, singing/music, etc.) | 49 (5.1) |
| Religious activity                         | 3 (0.3)                                                   |
| Task-related activities                     |                                                           |
| Sorting out the laundry                     | 346 (36.1)                                                |
| Personal care (e.g. hair, shaving, hands, etc.) | 277 (28.9)    |
| Preparing clothes                           | 222 (23.2)                                                |
| Helping care staff                          | 121 (12.6)                                                |
| Helping with meals                          | 106 (11.1)                                                |
| Other (e.g. doing administration, organizing things) | 33 (3.4) |

**Table 3** Types of activities family caregivers did before the visitor ban, their categorization into social versus task-related activities, and the number and percentage of family caregivers who undertook the aforementioned activities.
It is possible that during the visitor ban, spouses who experienced loneliness or social isolation, especially when self-isolating, and older people are known to be more at risk of loneliness. Spouses of people with dementia are often older than the person with dementia, which means that they have less contact with the person with dementia. This might have impacted the frequency of interaction between family caregivers and people with dementia. It is possible that if this construct had been measured differently, we would have found that contact frequency declined more.

Although the models developed in this study explained a fair amount of variance, other factors, which we did not investigate, might also have had an effect on the worrying and loneliness experienced by family caregivers during the visitor ban. These factors include communication between family caregivers and care staff, as well as the provision of information. During the visitor ban, family caregivers depended on care staff to inform them about how the person with dementia was doing. Research has shown that informal communication between family caregivers and staff is essential for cultivating trust in staff and promoting family involvement. To keep family caregivers engaged, care staff need to be proactive and creative. However, in this study, the extent to which this occurred among LTCF staff members could have varied. COVID-19 outbreaks, for instance, could have influenced the degree to which care staff communicated with family caregivers. More specifically, such outbreaks could have made it more difficult for care staff to sufficiently inform family caregivers. The results indicate that regular contact between family caregivers and people with dementia is important and that such contact is often supported by care staff. Therefore, future research might explore the relationship between communication between family caregivers and care staff in times of crisis and the effects of this communication on the mental health of family caregivers.

The current study was unique in that we collected data during the COVID-19 visitor ban in the Netherlands. To our knowledge, very few studies collected data while the visitor ban was still active. Furthermore, we also collected retrospective data about the situation in LTCFs before the visitor ban, which made it possible to compare data about this situation before and during the visitor ban. Also, a substantial number of family caregivers who participated in the study lived in different regions in the Netherlands. Additionally, the explained variance of both investigated models (10.3% and 9.0%) was quite high considering the large scale of other factors that might contribute to loneliness, like dealing with uncertainty, having diminished social contacts in times of crisis, e.g., the COVID-19 lockdown, and unfamiliarity with digital tools for staying connected with the person with dementia.

In this study, we measured the visiting frequency before and contact frequency during the visitor ban differently. Concerning visiting frequency before the visitor ban, only physical visits were included, not contact in the form of, for example, telephone or video calls. This could mean that contact frequency before the visitor ban could have been higher if other types of contact were included. Regardless, during the visitor ban, family caregivers had less contact with the person with dementia. It is possible that if this construct had been measured differently, we would have found that contact frequency declined even more.

Further, we did not account for the way in which family caregivers had contact with the person with dementia during the visitor ban nor the duration of such interaction. For example, family caregivers might have depended on others to help them with video calls. This might also have been the case for people with dementia, who likely needed help from care staff, especially those with more advanced dementia. Time and tools must be made available to them as well. The duration of visits before and contact during the visitor ban also remains unclear. It was expected that experiences between family caregivers who visited the person with dementia before, on a daily basis and for hours, but who only spoke to them for five minutes at a time during the visitor ban via video calls might differ from family caregivers who

### Table 3

| Variables | Final Worrying Model ($\beta$) | Final Loneliness Model ($\beta$) |
|-----------|-------------------------------|-------------------------------|
| Visiting frequency before visitor ban |                           |                               |
| Low (reference) (monthly, less than weekly) |                           |                               |
| Moderate (weekly, less than daily) | 0.478*** | -0.047 |
| High (daily) | 0.914*** | -0.048 |
| Types of activities |                           |                               |
| Social activities only (reference) |                           |                               |
| Task related and social activities | 0.177 | 0.008 |
| Contact frequency during visitor ban |                           |                               |
| Low (reference) (less than weekly) |                           |                               |
| Moderate (weekly) | 0.222 |                               |
| High (more than weekly) | 0.251 |                               |
| Resilience | nm | -0.505 |
| Interaction effects (Visiting frequency before*contact during visitor ban) |                           |                               |
| Moderate before*moderate during | -0.448 | nm |
| Moderate before*high during | -0.409 | nm |
| High before*moderate during | -0.444* | nm |
| High before*high during | -0.674** | nm |
| Interaction effects (Type of activities before*contact during visitor ban) |                           |                               |
| Task related and social activities*moderate during | 0.006 | nm |
| Task related and social activities*high during | 0.069 | nm |
| Interaction effects (Visiting frequency before visitor ban*resilience) |                           |                               |
| Moderate before*resilience | nm | -0.009 |
| High before*resilience | nm | -0.209 |
| Interaction effects (Type of activities*resilience) |                           |                               |
| Task related and social activities*resilience | nm | -0.323* |

*p < 0.05, ** p < 0.01, *** p < 0.001.  
† in model  
‡ The confounders age and gender of the family caregiver and the relationship between the family caregiver and people with dementia have been taken into account in these analyses.
visited once a week for an hour before and called them for one hour per week during the visitor ban. Thus, more in-depth analyses are needed to investigate whether the type and duration of contact also influenced loneliness and worrying among family caregivers.

The extraordinary circumstances of the COVID-19 pandemic and the consequent LTCF visitor ban necessitated the development of a less traditional study design. This in turn imposed some limitations on the current study. To lower the threshold for participation as much as possible, LTCFs were permitted to participate fully anonymously and were not required to notify the research team about their participation. It seems that LTCFs in regions with high infection rates participated the most (64.4%), perhaps because they understood the urgency of contributing to research on the unique circumstances of the COVID-19 pandemic. Another consequence of the novel research design was that no response rates were available, and it is unclear how family caregivers were nested within LTCFs, i.e., multilevel analyses were not possible. This might have affected the research outcomes. Additionally, the policies and degrees of commitment of care staff to informing and involving family caregivers might also have differed between LTCFs. That said, as the visitor ban was imposed on the national level, the circumstances were likely the same in all participating LTCFs. In order to minimize the burden for participants during this stressful period, deliberate choices were made in the questionnaire to limit its length. In the case of the resilience measurements, this resulted in the inclusion of only two items of the Brief Resilience Scale that deemed most important for our study purposes.

The results of this work demonstrate that a visitor ban in LTCFs is undesirable not just for people with dementia but also for care staff and family caregivers. Although there is widespread agreement that national visitor bans in LTCFs should be avoided in the future, temporary and local bans might sometimes still be necessary. If and when this happens, adequate attention should be given to the mental health of not only people with dementia and care staff but also family caregivers as well. The results of this study suggest that reducing worrying among family caregivers, LTCFs should facilitate ongoing contact with people with dementia, specifically for highly involved family caregivers. Also, non-resilient family caregivers who generally only undertake social activities are more prone to loneliness. It is therefore advisable for healthcare and welfare professionals to reach out to this group to help them overcome their loneliness.

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