

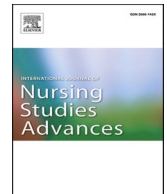


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International Journal of Nursing Studies Advances

journal homepage: www.sciencedirect.com/journal/international-journal-of-nursing-studies-advances

The impact of Covid-19-related distancing on the well-being of nursing home residents and their family members: a qualitative study

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ARTICLE INFO

Keywords:

Content analysis
Covid-19
Dementia care
Elderly care
Interaction
Isolation
Physical distancing
Social well-being
Qualitative study

ABSTRACT

Objectives: The aim of this study is to examine the consequences of Covid-19-related isolation and social restrictions on the well-being of nursing home residents and their family members, and to analyze how distancing has affected the relationships of family members with residents and the nursing home staff.

Design: The data consist of 41 thematic one-on-one interviews conducted during May–December 2020 with family members of nursing home residents. Convenience sampling was utilized by asking several nursing homes in different parts of Finland to relay a contact request from the researchers to the residents' family members. The main themes of the interviews were lockdown and visiting restrictions. Subthemes included the frequency of visits, other means of interaction, changes in the relationships of family members with their loved ones and with nursing home staff, and the feelings aroused by the situation. The interviews were audio recorded and transcribed verbatim, resulting in 794 pages of data.

Method: The qualitative study uses inductive content analysis. NVivo12 software facilitated the systematic coding of the data.

Results: According to the family members, distancing aggravated the residents' pre-existing conditions: they reported a sudden progression in memory disorders and significant deterioration in physical abilities, for example. Both residents and family members experienced anxiety, grief, and severe stress, and family members expressed concern that residents might die due to a lack of social contact and activity. Family members were also frustrated about not being able to touch their relatives or participate in their care, and therefore sometimes thought that their visits were useless. New forms of interaction with family members, introduced by the nursing homes, were appreciated. However, some family members perceived the interactional protocols as unfair and complained about insufficient information.

Conclusions: The findings underline the need for nursing homes to implement a good interactional protocol. Overall, the results show that the measures taken to protect residents' health during the Covid-19 outbreak were short-sighted in terms of the social dimension of well-being. It

Funding: This work was supported by the Academy of Finland [grant number 331555] and Kone Foundation [grant number 201901669].

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<https://doi.org/10.1016/j.ijnsa.2021.100031>

Received 25 March 2021; Received in revised form 4 May 2021; Accepted 21 May 2021

Available online 31 May 2021

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is therefore important to continue developing safe and humane solutions for interaction when social restrictions are in place.

Tweetable abstract: Covid-19-related distancing has caused anxiety, grief, and severe stress for nursing home residents and their family members.

What is already known about the topic?

- Visiting bans and other restrictions were introduced in nursing homes in Finland during the Covid-19 outbreak, thereby affecting the involvement of family members in care.
- Physical distancing has aggravated feelings of loneliness among residents of nursing homes.

What this paper adds

- Covid-19-related distancing in 2020 caused anxiety, grief, and severe stress to residents of nursing homes and their family members.
- Family members appreciated the new forms of co-operation and flexibility on the part of the nursing homes, but those who worried about the care that the residents received expressed frustration with the passivity in communication and complained about the lack of information and unfair interactional solutions.
- Family members were frustrated about not being able to participate in care, given the need to keep a physical distance, and could therefore perceive visiting as useless.

1. Introduction

The objective of this paper is to examine the consequences of Covid-19-related isolation and social restrictions on 1) the well-being of nursing home residents, 2) the well-being of the residents' family members (FMs), and 3) the FMs' relationships with the residents and the nursing home staff. The underlying purpose of the study was to shed light on the outcomes of chosen measures to fight the pandemic and to provide information on what needs to be considered when developing new, safe, and humane interaction solutions in times of social restriction. First, the multiple roles of FMs in nursing homes are briefly described on the basis of previous research (Section 1.1), and then the challenges related to measures introduced to control Covid-19 in nursing homes are viewed through initial reports (Section 1.2).

1.1. The role of family members in nursing homes for older adults

According to previous research, the involvement of FMs appears to improve the quality of individual care among older adults in nursing homes. FMs are sensitive to changes in the health status of their next of kin, which contributes to the timely deliverance of individually planned care. They may support professional care by providing valuable information, and are often able to reduce confusion and agitation among relatives with cognitive disorders (Fry et al., 2015; Alice Lau et al., 2008; Palmer, 2012). Inside the nursing homes they may participate in practical care and rehabilitative activities (Cohen et al., 2014; Looman et al., 2002; Hertzberg and Ekman, 2000; Ward-Griffin et al., 2003), and more importantly, they have an irreplaceable role in sustaining the previous relationships and personhood of residents (Alice Lau et al., 2008; Pirhonen and Pietilä, 2015).

In addition to the positive nursing outcomes for residents, collaboration between nursing home staff and FMs may reduce stress related to caregiving and increase their satisfaction with the care provided (Alice Lau et al., 2008; Maas et al., 2004). FMs highly value the interactional connection with the nursing home staff, particularly if residents are not able to discuss their own well-being (Haesler et al., 2006). They are also remarkably willing to be involved in care (Palmer, 2012; Holmgren et al., 2013), simultaneously monitoring the quality of care delivered by the nursing home staff (Vohra et al., 2004; Ben, 2009).

Current healthcare policy values holistic care and the inclusion of FMs (Finnish law 980/2012; World Health Organization (WHO) 2017). Indeed, interaction with FMs is considered vital in meeting the needs of nursing home residents (Kiljunen et al., 2017). However, in practice, this interactional connection has not always worked as well as it should, even before the Covid-19 pandemic (Cohen et al., 2014; Haesler et al., 2006; Heinrich et al., 2003; Puurveen et al., 2018).

1.2. The Covid-19 outbreak as a challenge to family members

Covid-19 spread rapidly worldwide in the spring of 2020, leading to social restrictions globally (Linka et al., 2020; Studdert and Hall, 2020; Douglas et al., 2020). The virus was known to be especially dangerous for older adults (D'Adamo et al., 2020), therefore visiting bans and other restrictions were introduced in nursing homes (Gardner et al., 2020; Hado and Friss Feinberg, 2020; Verbeek et al., 2020). The Emergency Powers Act (Finnish Government, 2020) came into force in Finland on 17 March 2020, banning anyone other than nursing home staff from entering care facilities. FMs and professionals who were not part of the regular staff, such as physiotherapists, were also barred (Dichter et al., 2020). As a consequence, FMs were unable to participate in the life and care of their

next of kin, and residents lacked the comfort and help of FMs.

When the total lockdown eased in Finland, nursing homes allowed visits in some form. People met outside during the summer but in autumn, when the weather became cooler, they moved indoors. Various infection-control measures have been adopted internationally (Fallon et al., 2020), such as using personal protective equipment and maintaining safe distances. National health authorities, namely the Ministry of Social Affairs and Health (Ministry of Social Affairs and Health, 2021) and the Finnish Institute for Health and Welfare (Finnish Institute for Health and Welfare, 2021), have instructed care providers to arrange visits according to the state of the pandemic. As the Finnish national supervisory authority (Saramaa and Kervinen, 2021) reports, only one percent of nursing homes still banned FMs in December 2020.

About 50,000 older adults reside in nursing homes in Finland (Finnish Institute for Health and Welfare 2021), which means that, FMs included, visiting restrictions affect hundreds of thousands of people nationally, and millions all over the world. The vast majority of residents have cognitive disorders (Helvik et al., 2015; Nuutinen et al., 2020) which are likely to affect their ability to comprehend the pandemic and the visiting restrictions. It is known that social isolation increases morbidity and mortality (Holt-Lunstad, 2018) and, as one might assume, the first studies on the lockdown have reported negative impacts on the well-being of older adults (e.g., Macdonald and Hülür, 2021; Kim and Jung, 2021; Wang et al., 2021). Brooks et al. (Brooks et al., 2020) identified post-traumatic stress symptoms, confusion, and anger in residents, whereas Lima et al. (Lima et al., 2020) found that separation from loved ones led to despair among residents, and the feeling that the world was ending. Concerns have also been expressed about the possible violation of the fundamental rights of nursing home residents during a pandemic (Amnesty International 2020), referring to their rights to family life, equality and humane treatment.

According to a survey organized by the Finnish Institute of Health and Welfare at the end of 2020 (Kehusmaa et al., 2021), one fifth of older adults in receipt of home care and in nursing homes had not been able to go outdoors at all since the imposition of social restrictions. Surprisingly, despite the lack of activities and the increased loneliness, the informants were satisfied with their quality of

Table 1
Interviews and informants.

Face-to-face/ Phone	Pseudonym	Gender	Resident's gender	Informant's relation to the resident	Duration in minutes	Pages (Calibri 12)
F2F	Esko	M	F	son	77	20
F2F	Risto	M	F	husband	61	21
F2F	Jukka	M	F	son	14	6
F2F	Aarne	M	F	husband	25	15
F2F	Pekka	M	F	husband	102	73
F2F	Marjukka	F	F	daughter	100	65
F2F	Tuija	F	F	daughter	55	35
F2F	Meri	F	F	daughter	27	18
F2F	Venla	F	M	wife	47	24
F2F	Annikki	F	F	daughter	61	30
F2F	Reetta	F	M	wife	62	34
F2F	Hilkka	F	M	wife	48	37
F2F	Laila	F	M	wife	62	31
F2F	Teija	F	M	wife	40	26
F2F	Seija	F	M	wife	44	33
F2F	Virpi	F	F	other	71	51
F2F	Heidi	F	M	daughter	59	37
F2F	Ritva	F	M	wife	50	21
Phone	Jouni	M	M	son	45	15
Phone	Raija	F	F	daughter	32	13
Phone	Tiina	F	F	sister	42	14
Phone	Tarja	F	F	daughter	11	6
Phone	Aija	F	F	daughter	107	25
Phone	Sirkka	F	M	daughter	43	13
Phone	Maire	F	M	wife	33	10
Phone	Teija	F	F	daughter	71	19
Phone	Anneli	F	F	daughter	37	11
Phone	Anna	F	F	granddaughter	30	9
Phone	Marja	F	F	daughter	24	7
Phone	Mirja	F	F	other family member	23	7
Phone	Mari	F	M	wife	28	6
Phone	Taina	F	F	daughter	21	9
Phone	Päivi	F	F	daughter	14	5
Phone	Ella	F	M	daughter	18	6
Phone	Krista	F	F	daughter	19	6
Phone	Sirpa	F	F	daughter	26	8
Phone	Tellervo	F	M	daughter	12	5
Phone	Kerttu	F	F	daughter	11	6
Phone	Pia	F	F	daughter	16	5
Phone	Eila	F	F	daughter	16	6
Phone	Elina	F	F	daughter	17	6
					1701	794

life during the pandemic. However, it should be pointed out that survey studies targeted at nursing home residents represent the voices of those who are in the best condition; residents with advanced memory disorders cannot respond to questionnaires. Therefore, there seems to be still more to uncover about the impact of the pandemic in nursing homes, especially from the point of view of FMs who actively monitor the well-being and care of their loved ones. The aim of this study was to shed light on the impact of visiting restrictions on the well-being of nursing home residents and their FMs, and to find out how distancing has affected the relationships of FMs with residents and the nursing home staff.

2. Material and methods

In line with criteria concerning the reporting of qualitative research, a 32-item COREQ checklist (Tong et al., 2007) was used in the planning and execution of the study. The data was collected by conducting individual thematic interviews (n=41, see Table 1) during May–December 2020. Representatives of the Alzheimer Society of Finland and the Memory Association of Finland were consulted for the interview design. Convenience sampling was utilized by asking nursing homes and Memory Associations in different parts of Finland to relay a contact request from the researchers to nursing home residents' FMs. Of those willing to participate in the study, the vast majority (35/41) were women, in most cases daughters of residents (see Table 1). This is in line with earlier findings concerning the role of female FMs in the lives of residents (Holmgren et al., 2013; Keefe and Fancey, 2000). The informants' ages varied from 40 to 83 years. Only a few of them had met the researchers before the interviews. According to the FMs, 34 of the 41 residents discussed in the interviews had a diagnosed memory disorder. The residents lived in 23 nursing homes in different parts of Finland.

Twenty-three one-on-one interviews were conducted on the phone and 18 were face-to-face (see Table 1). Only FMs who were willing to meet in person and who lived in the same cities as the researchers were invited to a face-to-face interview in order to avoid unnecessary travel during the Covid-19 pandemic. The interviews lasted between 11 and 107 minutes, reflecting the fact that some of the FMs tended to give short answers while others shared their experiences and thoughts more freely. More themes were covered in the face-to-face interviews than in the telephone interviews, which also reflects the relative durations. The interviews were audio recorded and transcribed verbatim, resulting in 794 pages of data (font Calibri, size 12). Pseudonyms are used to identify the participants in the extracts presented in this study.

The main themes discussed in the interviews were the lockdown and visiting restrictions, and the various sub-themes included visit frequency, other means of interaction, changes in relationships between the next of kin and the nursing home staff, and feelings aroused by the situation. The interviewees were also encouraged to raise other issues relating to their experiences in nursing homes. The focus in this study is on Covid-19-related data (206 pages). Some of the issues were sensitive, and many informants were emotional during the discussions. The researchers did their best to console and encourage them. At the end, these interviewees thanked the researchers for listening, which was indicative of the importance they attached to being heard. Within the team, the researchers shared their own feelings about the interviews.

The research was a collaborative effort between the universities of Turku and Helsinki. Ethical approval for the research was applied from ethics committees of both universities and the Finnish ethical guidelines for research (The Finnish National Board on Research Integrity (TENK) 2019) were followed accurately. FMs were provided with information about the research before the interviews, and they were given an opportunity to ask questions. They were assured that they had the right to terminate the interview at any time, and given information on data protection and anonymity. The FMs who had face-to-face interviews signed a written consent form and were given a handout containing contact information and data-protection guidelines. Safety instructions regarding Covid-19 were followed. Those who were interviewed by phone gave their oral consent, and they were told that the interview would be recorded. No additional material, such as residents' health records, was collected in this study.

The data were subjected to qualitative inductive content analysis (Neuendorf et al., 2017; Elo and Kyngäs, 2008). NVivo12 data-analysis software was used to label the Covid-19-related data in the interview transcripts. First, the impacts and consequences of pandemic-related distancing as perceived by the interviewees were coded. During the second round of the content analysis, the codes were arranged and assigned to five main categories: 1) Impacts on the well-being of the resident, 2) Impacts on the well-being of the FM, 3) Impacts on the relationship between the FM and the resident, 4) Impacts on the relationship between the FM and the nursing home, and 5) Other noteworthy remarks. Finally, the impacts were identified as negative or positive, and recurrent themes and connections between categories were identified. The codes and categories are presented in Table 3 in the Results section of this paper.

The research team varied in terms of educational background: the first author is specialized in linguistics and interaction studies, and the other three in nursing science and/or sociology. Three of the researchers have previous experience of nursing, and two have worked in nursing homes. This personal experience in the field of the study could be considered a bias, but at the same time it was advantageous when reflecting on the generalizability of the findings. In order to promote objectivity and to avoid subjective

Table 2
Positive and negative impacts of Covid-19-related distancing as perceived by family members.

Theme	Positive impacts	Negative impacts
Residents' well-being	2	72
Family members' well-being	13	124
Relationship between family members and nursing home residents	1	45
Relationship between family members and nursing home staff	19	104
Sum	35 (9%)	345 (91%)

interpretations, all four authors conducted the interviews and participated in the analysis process.

3. Results

3.1. Overview of the content analysis

Table 2 shows the distribution of the positive and negative impacts of Covid-19-related distancing on residents and FMs as perceived by the FMs. As was perhaps to be expected, most of the perceived impacts were negative (N=345/380, 91%). Only one of the FMs reported two positive changes in well-being (N=2), whereas there were 72 mentions of negative impacts in the data. Positive changes in the FMs' own well-being were somewhat more commonly disclosed (N=13), although there were more references to negative changes in the FM's well-being than in the well-being of the residents (N=124).

There was only one case in which the FM thought the relationship with their loved one had become closer during the pandemic, whereas there were 45 reports of negative impacts. With regard to the relationship between the FMs and the nursing homes, the coding revealed more factors that threatened it (N=104) than factors that could be interpreted as enhancing it (N=19).

Table 3 summarizes the codes used in the content analysis and the number of references. The results are analyzed in detail in the following subsections. The focus in subsection 3.2 is on the Covid-19-related impacts of distancing on the well-being of residents. In Section 3.3, the focus is on the impact on FMs. Finally, the impacts of the pandemic on the FMs' relationships with nursing home residents and staff are considered in Section 3.4.

3.2. Apathetic, lonely, and medicated residents

Seven of the interviewed FMs seemed to believe that the nursing home residents were not particularly affected by the distancing caused by the pandemic. This was often attributed to the nature of memory disorders, as Esko said.

I don't think people with dementia themselves really suffer from this. This is how I see it, at least, that they have their own world. Some of it is imagination, they live somewhere else, look out the window and see whatever they see, like my mother. They live in their own world, so it doesn't really matter much if there aren't many visitors. (Esko, son of a resident)

Table 3

An overview of the codes and references used in the analysis.

Theme	Impact	N	
Nursing home residents' well-being	Positive impact	2	
	Increased activity	2	
	Negative impact	72	
	Negative changes in physical state	25	
	Loneliness	18	
	Anxiety, depression, sorrow	13	
	Progression of memory disorder	12	
	Fear caused by protective measures	4	
	Family members' well-being	Positive impact	13
		Relief caused by distance	11
More time to rest		2	
Negative impact		124	
Anxiety, frustration, heartache		72	
Worrying about the residents' care		24	
Guilt over distancing		10	
Guilt over keeping in contact		8	
Strain caused by emotional work		5	
Loneliness		4	
Relationship between family members and nursing home residents	Negative changes in physical state	1	
	Positive impact	1	
	Closer relationship	1	
	Negative impact	45	
	Decrease of joint activities	16	
	FM distances from the resident	14	
	Resident misinterprets absence or new practices	12	
	Resident distances from FM	3	
	Relationship between family members and nursing home staff	Positive impact	19
		New ways of cooperation	19
Negative impact		104	
FMs' experiences of insufficient communication		32	
FMs' negative perceptions of the quality of care		30	
FMs' anger over unfair policy		23	
FMs perceptions that the staff is stressed		19	
Other remarks	FM believes that residents are unaffected	11	
	FM believes that residents are less affected than FMs	4	

Esko thought that his mother's inability to understand the situation or remember the last encounter with the family protected her from the negative impacts of distancing. However, most of the FMs interviewed in this study were convinced that their loved ones had been affected by the distancing. There was one resident who had become more active and independent during the pandemic, but all the other reported changes were negative. Many FMs referred to a deterioration in their relative's physical state.

The last time we saw her before the lockdown, she was walking, she walked and all. And the next time we saw she was completely bed-bound and, I mean I knew it, I had spoken with them, she had been put into a wheelchair, she could not stand up. (Meri, daughter of a resident)

Meri recalled how her mother had stopped walking during the lockdown. Several FMs were worried that not even physiotherapists could enter nursing homes. The distancing also resulted in other worries and concerns.

During the couple of weeks when we did not visit her, we kept getting bad news. Every time we called, they said mom hasn't eaten, mom hasn't done anything. I started to think, goddammit, she is going to die. (Päivi, daughter of a resident)

Päivi's mother stopped eating during the period when FMs were not allowed to visit nursing homes, which could have been a reaction to stress caused by the exceptional circumstances. Päivi was not alone in fearing the loss of her mother. Some of the FMs reported that the resident's memory disorder had progressed significantly. Marja explained that her mother had become more disoriented and for the first time started to have trouble distinguishing between dreams and reality.

Although the FMs acknowledged the possibility that the deterioration could have happened without the isolation and distancing, they saw a connection between the abruptness of the progression and the sudden changes in care, social contacts, and activities. Acute events, such as falls and other accidents that required a visit to the emergency room, could result in being quarantined to protect other residents from possible infection. In the case of Venla's husband Martti, this created a spiral: the quarantine aggravated his restlessness and aggressiveness, and he was sent back to the emergency room for a "sedation trip," as Venla called it.

And then they gave him so many sedatives and he was tied to the bed, and I got to visit him after midsummer, and we thought it was the end. But he was on that sedation trip for a couple of weeks. He has not walked since then... he has calmed down for sure. (Venla, wife of a resident)

Venla was not the only FM who was concerned about medication; some suspected that residents had been tranquilized to facilitate keeping them in their own rooms. In the next excerpt Heidi explains how her father, who had lived on his own until spring 2020 and exercised on a daily basis, lost his mobility and his ability to speak during his temporary residency in a care unit.

We noticed that they started to medicate him. At first, he lost his ability to speak. He had been quite fun to be around, he joked about things and everything, but it all started to disappear, and we saw it in his eyes. [...] And then he started to lose his mobility. He was completely, like apathetic and medicated. Like completely intoxicated. [...] It happened in such a short time. It was unbelievable. (Heidi, daughter of a resident)

Aside from the dramatic events described above, the FMs believed that distancing related to Covid-19 had strengthened the residents' feelings of loneliness. Many FMs reported that their loved ones were anxious and sad because of the restrictions. Teija told the interviewer that her husband became devastatingly depressed and did nothing but cry, and Marja had similar worries about her mother's psychological condition.

She says she will die of boredom; she will die because of the isolation. She says, do you not understand that there is not much value in this life. Because everything that means something to her, like seeing her family, her children, grandchildren, and great grandchildren is so important to her. (Marja, daughter of a resident)

Marja described her mother as having symptoms of serious depression (see Horwitz, 2011), as did Teija regarding her father. The personal protective equipment that was required during periods of contact with the nursing home staff and the visits of FMs also caused anxiety and fear among some of the residents, which made interaction challenging and stressful. Pekka recalled dealing with his wife's fear of face masks.

She had a mask, and I had a mask, and she was so scared because all she could see were these masked people. And our daughter was there as well. And we came up with the idea to just talk a lot. Like, even though she cannot see our faces but if we just talk, perhaps she recognizes our voices. And little by little, her shoulders dropped, she relaxed a bit. (Pekka, husband of a resident)

Pekka understood that his wife was afraid of the new visiting conditions, and fortunately he found a way to reassure her. In sum, in the view of most of the FMs the social restrictions had brought about a deterioration in both the physical and the mental well-being of their loved ones, namely by strengthening their feelings of loneliness and limiting their engagement in social activities and exercise.

3.3. Frustrated, heartbroken, and worried family members

As stated above, FMs also struggled to cope with the pandemic and the safety regulations. Worrying about their loved ones isolated in nursing homes, and witnessing their deteriorating state, was a distressing experience. Some, such as Taina, were deeply worried that they might miss their last chances of spending time with their loved ones, which highlights the relative nature of time as a concept: the meaning of "a couple of months" depends on the circumstances (see Gabriel et al., 2017). What is noteworthy is that feelings of loneliness also extended to some of the FMs.

I don't know how to cope with this. Or how my mother copes with this. That is what we fear the most, that we cannot be close to her in her last days. If I may say, I have a constant fear that my mother will die. And I always keep my cell phone close by, mhm. (Taina, daughter of a resident)

Some of the FMs were also afraid that residents might even die socially because of the isolation, in other words they acknowledged the risk of losing all interaction with other people. They therefore emphasized the quality of life, and they felt sorry for residents affected by the distancing at the end of life. Tellervo describes her father's life in isolation as *horrible*:

(Her voice breaking) If the last years in one's life are like this, it is horrible for those people, and also for us family members. (Tellervo, daughter of a resident)

FMs are sensitive to changes in the well-being of loved ones, and many of them consider the monitoring of care and participation in it part of their role (see [Section 1.1](#)). Because of the restrictions, FMs' access to care was minimal during the pandemic, which caused them discomfort. The challenges they faced in relation to the distancing are reflected in their expressions of guilt. Some of them felt guilty about their absence. Sometimes, too, the guilt derived from feelings of relief: the distancing was beneficial in terms of their own well-being, as it had given them time to take care of themselves and a chance to focus on other things in their lives.

I was relieved, I must confess [...] For a couple of weeks I was very happy that I didn't have to beat myself up because I had not allowed myself not to visit her. [...] It was peculiar, like a certain kind of relief, but after that, agony. That I still cannot go there, still cannot. And yet, I knew that she was there. [...] I felt that I had left her there on her own, even though I knew everything was alright. (Marjukka, daughter of a resident)

Marjukka's words "I felt that I *had left her there*" echo a common trait in the reasoning of relatives of people with a memory disorder: even though they *know* they have not abandoned them, but are merely following orders, they also *know* that their loved ones may not be able to see it that way—and this brings them pain. Nevertheless, the references to increased self-care represent the rare positive impacts of Covid-19-related distancing in the data.

Guilt feelings could also derive from keeping in contact with the residents, which some FMs thought was undesirable due to the risk of infection. They were thus balancing two conflicting demands of being a "good citizen": taking care of one's family and doing one's share to prevent the spread of the virus. In the next section, we explore what effect this had on the FMs' relationships and interaction with the nursing home residents and staff.

3.4. Increased cooperation, suppressed anger: the impact of distancing on the relationship of FMs with residents and staff

In the view of many of the FMs, one positive aspect of the Covid-19-related restrictions was an improvement in cooperation with the nursing home. Some reported that they had helped to develop new solutions for safe interaction, and some expressed gratitude to the staff for their flexibility. Sirpa was able to communicate with her mother from the other side of her window, for example: a nurse held up a phone with attached speakers for her mother in the home. Some FMs received updates and photos from the nursing homes, and one of the FMs, Laila, was picked up by staff members from her house so that she did not have to use public transport.

Then the head of the nursing home and one of the nurses picked me up and took me back home (laughs). And can you imagine, the nurse, she even cleared the snow for me before letting me walk to the car. Oh my. [...] I mean, I have nothing negative to say about them, they have done so very well with everything. (Laila, wife of a resident)

The experiences of cooperation built trust and, at best, forged friendships between FMs and staff members. However, many of the FMs had the opposite experience: their ideas and wishes were dismissed, and the connection was lost. Much of the frustration and worry described in [Section 3.3](#) was connected to anger over what the FMs perceived as unfair policy. Eila, for example, felt that FMs were considered a bigger risk to the residents than strangers.

My mother was sent to the ER, and they did not allow escorts but the taxi driver, who was not wearing a mask, was allowed in there with her. [...] I feel some kind of jealousy, and it drives me mad that complete strangers are allowed to be with her and near her. It is so stressful, why can't I be there? (Eila, daughter of a resident)

Some FMs questioned the isolating of adult residents without their consent, which they referred to as inhumane. Marja, daughter of a resident, likened the residents to prisoners, for example. The anger was largely directed at the governmental level, but sometimes it was also projected onto the nursing homes.

When we asked to meet our mother outside at the beginning of all this, they were always waiting for something, guidance from the government or whatever, orders. Why could they not use their own common sense? [...] they did not think much about these old people. (Krista, daughter of a resident)

Some FMs were, like Krista, frustrated because it took so long for the nursing homes to start seeking solutions to suit their own, particular circumstances. However, only a couple of them were in open conflict with the nursing home.

As stated above, some of the FMs were deeply worried about the care of their relatives, which possibly had a negative impact on their relationship with the staff. No longer being able to help was particularly challenging in that it distanced them from their loved one and from the staff. Moving from joint activities that included touching and moving around to mere chatting was devastating to FMs with next of kin who could not express themselves well in words. Some even felt that the interaction was no longer meaningful.

Me and my daughter, we went to see Martti a bit warily, and he came outside with a nurse and said, "I don't know that person" and walked right past us. So, we accepted the fact that it is entirely pointless to visit an old man who does not react when you look at him from a distance of two or three meters. (Venla, wife of a resident)

Some FMs also felt that they were somehow preventing the provision of mundane care by keeping in contact. Affected by the unstable circumstances and changing regulations, the staff sometimes seemed stressed and busy, which also inhibited the FMs from visiting and calling the nursing homes as often, as Krista relates.

When I called them again, they promised to call back soon, and it felt like I was distracting them from their work. They do not have that many nurses there. It was hard for me to call them, and so I stopped calling. (Krista, daughter of a resident)

Many FMs were uncertain about what was an appropriate time and way to make contact. They would have appreciated it if the staff had taken the initiative and contacted them, but at the same time they understood that this was difficult. Either way, in many cases the perceived insufficiency of communication and a lack of information caused mistrust of the nursing home staff among FMs.

Finally, the results imply that physical distancing weakened the connection between the FMs and their loved ones by aggravating their feelings of anticipatory grief and ambiguous loss (see [Alzheimer's Society, 2017](#)). The feeling of losing someone who is still alive is common among FMs caring for people with dementia and memory disorders. In an attempt to cope with these feelings, a couple of FMs had begun to distance themselves emotionally from their loved ones. Risto, husband of a resident, said that days could go by without his even remembering the existence of his wife, and Krista had started to pray for her mother's death.

This is a horrible thing to say but... every night I pray that my mother passes away. You know, it's awful. [...] But now that I know she will not see us a lot, we cannot visit her anymore. We used to wash her face and rub her feet. We made her comfortable. There is none of this left, so. I do pray the Lord will take her, end her suffering. (Krista, daughter of a resident)

These examples of how physical distancing has affected the relationships between FMs, residents and staff illustrate the meaning of social well-being, and they highlight the need for solutions that support safe but continual interaction.

4. Discussion

The study results reveal that, in the context of Finland, isolating nursing home residents from the surrounding society during the Covid-19 pandemic has caused significant negative changes in the well-being of the residents and their FMs. The FMs reported sudden progression in their relatives' memory disorders, and significant deterioration in their physical abilities. This is in line with initial reports on the situation of nursing home residents during the Covid-19 outbreak ([Douglas et al., 2020](#); [Brooks et al., 2020](#); [Lima et al., 2020](#); [Kehusmaa et al., 2021](#)). In fact, increased anxiety and the escalation of dementia symptoms attributable to COVID-19 public-health measures have also been reported among people living at home with caregivers ([Giebel et al., 2020](#); [Giebel et al., 2021](#)).

The FMs said that they and their loved ones had experienced anxiety, grief, and stress due to the social restrictions, which is in line with previous research findings ([Nelson and Bergeman, 2021](#); [Heid et al., 2021](#); [Whitehead and Torossian, 2021](#)). Loneliness and insufficient meaningful activity among nursing home residents was a concern before the pandemic ([Palacios-Ceña et al., 2016](#); [Pirhonen et al., 2018](#)), but the distancing seems to have emphasized the pre-existing challenges and worries (see also [Kehusmaa et al., 2021](#)). In the current study, several FMs expressed concern that their loved ones might die, socially at least, because of the lack of social contact and activities (see [Brannelly, 2011](#)). The findings imply that the measures taken to protect the life and health of residents during the Covid-19 outbreak were short-sighted in terms of the social dimension of well-being.

Unsurprisingly, the social restrictions affected the residents with memory disorders in complex ways. It has been reported that the role of FMs in nursing homes differs depending on whether or not the resident has a memory disorder. FMs of residents with no cognitive disorders participate more in activities related to life outside the nursing home, whereas in the case of residents with memory disorders FMs participate more in close-contact care activities, such as in tasks related to nutrition or mobility ([Cohen et al., 2014](#)). Touch is also known to be more significant for those with memory disorders. Touch and related emotions may promote well-being, facilitate social interaction, and alleviate behavioral symptoms ([Bush, 2001](#); [Wu et al., 2017](#)). The results of this study thus highlight the reciprocal meaning attached to the participation of FMs in care.

Although the Covid-19 safety measures have been distressing in many ways for the FMs of nursing home residents, the study also identified some positive effects. For example, some FMs reported that they had more time to rest and to take care of their own health and well-being, and they acknowledged that without the restrictions they would not have allowed themselves to do that. This kind of realization may be beneficial for FMs in that they might lower their threshold for self care in the future. In comparison, family caregivers of people with memory disorders experienced the opposite during the pandemic: due to the restrictions, they had very few opportunities to rest or to find support (see [Giebel et al., 2021](#); [Budnick et al., 2021](#)).

Another finding from this study is that new ways of cooperation and flexibility on the part of the nursing homes seemed to have a positive impact on the relationship with FMs, and to strengthen their trust in the care provided. The respondents were positive about the new means of communication, which is in line with findings reported by Heid ([Heid et al., 2021](#)) and Whitehead & Torossian ([Whitehead and Torossian, 2021](#)). According to Fuller & Huseth-Zosel ([Fuller and Huseth-Zosel, 2021](#)), contrary to popular belief, older people are also willing to use and learn about digital means of communication. However, many FMs who worried about the residents' care were frustrated with the nursing homes' passivity in terms of communication, and they complained about receiving insufficient information. This problem has now been highlighted, although there were difficulties, even before the Covid-19 pandemic ([Suhonen et al., 2015](#)). Experiences of insufficient communication and a lack of knowledge undermine the interpersonal trust between FMs and nursing home staff, and may lead to reciprocal misunderstandings and false assumptions (see [Looman et al., 2002](#); [Hertzberg and Ekman, 2000](#); [Ward-Griffin et al., 2003](#)). Barriers to interaction also affect the ability of nursing staff to meet residents' needs ([Kiljunen et al., 2017](#)).

It is likely that some health-security measures will remain in place. These findings highlight the need for nursing homes to develop a good interactional protocol. For example, taking the initiative in providing and obtaining information will facilitate the formation of

collaborative relationships with FMs (Alice Lau et al., 2008; Looman et al., 2002; Heinrich et al., 2003). Interventions promoting collaboration between FMs and nursing home staff have proved profitable for both parties, and for residents (Maas et al., 2004; Robison et al., 2007). Efforts to develop this collaboration are needed, not only in the current exceptional circumstances but also after the pandemic is over.

Although the quantity of data used here is sufficient for qualitative research, and the experiences of the FMs could be considered reliable, the study has certain limitations. First, due to the limitations caused by the pandemic, the study could only focus on the views of FMs. Therefore, observations on the well-being of residents must be treated as second-hand information and proxy reports of the residents' voices. Previous studies have revealed bias in various forms in the evaluations of FMs concerning the well-being of a person with dementia. For example, they tend to compare persons with dementia with how they used to be, whereas the persons themselves could make comparisons with their peers (Smith et al., 2005). FMs may also project part of their own health-related quality of life onto the person with dementia (Arons et al., 2013). On the other hand, even without the restrictions, some of the residents referred to in this study would not have been able to express themselves meaningfully in an interview due to their condition.

Second, given that some of the informants were recruited through the nursing homes, it is likely that those who volunteered represent FMs who visit nursing homes most actively. Previous studies have shown that the most active FMs tend to be the most worried about their loved ones' care (Vohra et al., 2004; Ben, 2009). For this reason, the participants in this study may express more critical attitudes to physical distancing than FMs on average might. On the other hand, nursing home staff may have avoided recruiting FMs with whom they were in conflict, thereby excluding some of the most critical voices from the study.

Third, the study could have benefited from more detailed background information on the informants. For example, it would have been useful to rate the FMs' involvement in care before and during the pandemic, such involvement being connected with caregiving stress and perceptions of the quality of care (Friedemann et al., 1997; Tornatore et al., 2002). It might also have been beneficial in the interviews to discuss the distance between the FM's home and the nursing home, which might affect experiences of distancing and distress (Stephens et al., 1991).

In terms of generalizing the results, it should be borne in mind that the current study concerns the situation in Finland during May–December 2020, and it does not represent a temporally complete or global view of the impact of Covid-19-related distancing. Respective guidelines, arrangements, and surveillance vary within Finland and between countries. In addition, both interaction and care are culturally colored concepts, which means that normal interaction in nursing homes may be understood somewhat differently in different parts of the world. However, one may assume that in essence, the impact of distancing will have similar qualities in different environments, as the need for social contact is indisputably human. It is therefore important that researchers around the world continue to work on capturing the zeitgeist and analyzing policies, so that future generations can learn from the past.

5. Conclusions

This study shows how good intentions may easily have poor consequences. Visiting bans and restrictions are imposed in nursing homes to protect the health and lives of the most vulnerable individuals. However, in that health, and especially well-being, are strongly related to the social fabric, social restrictions inevitably result in human suffering. The findings of this study indicate that restrictions designed to protect health cause anxiety, heartbreak, fear, and other negative outcomes among nursing home residents and their FMs. In addition, the weakening condition and autonomy of residents in nursing homes most likely contribute to lowering their quality of life and even to their premature death. Thus, the results highlight the need to promote a holistic understanding of well-being and agency in elderly care.

Now that the initial shock caused by the Covid-19 pandemic has passed, it is time to focus on minimizing the negative effects of the distancing (cf. Gallo and Wilber, 2021). First of all, to avoid extensive distrust and collateral damage in the future, policy makers should openly address the identified issues related to isolation (cf. Allen and Ayalon, 2021), and collaborate with researchers in developing safe solutions that enable social contact among nursing home residents. Those responsible for designing new interactional protocols in nursing homes should acknowledge the contribution of FMs to the residents' well-being should be acknowledged in changing circumstances (cf. Kemp, 2021). Because isolation from loved ones is one of the biggest causes of health problems related to Covid-19 actions (Birditt et al., Wang et al.), safety measures that allow the physical presence of FMs in nursing homes should be promoted alongside digital solutions, which are known to be challenging for people with late-stage memory disorders (Arpino et al., 2021; Seifert et al., 2021). A physical presence also allows touching and eye-contact, which are essential in dementia care (Bush, 2001; Wu et al., 2017).

The empowerment of nursing homes to develop safe visiting policies would help to safeguard the human rights of residents, as Amnesty International (Amnesty International, 2020) has pointed out. On the other hand, showing responsibility in the fight against Covid-19 would increase the sense of security and faith in the future (Kim and Jung, 2021). With regard to the well-being of FMs and their trust in care during exceptional times, nursing homes should take an active role in maintaining communication and volunteering information (Palmer, 2012). In circumstances in which all contact outside the nursing home must be avoided, it would be crucial to expand joint activities inside the homes to compensate for the sudden change (Nelson and Bergeman, 2021; Whitehead and Torossian, 2021; Fuller and Huseth-Zosel, 2021).

CRedit roles

Jenny Paananen: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Supervision; Validation; Visualization; Writing - original draft; Writing - review & editing. Johanna

Rannikko: Data curation; Writing - original draft; Writing - review & editing. Maija Harju: Data curation; Writing - original draft. Jari Pirhonen: Conceptualization; Data curation; Funding acquisition; Investigation; Methodology; Project administration; Resources; Supervision; Validation; Writing - original draft; Writing - review & editing. All authors have approved the final article and acknowledge that all those entitled to authorship are listed as authors.

Ethical approval

The research was a collaborative effort between University of Helsinki and University of Turku. Ethical approval for the research was applied for from both university ethics committees, and the Finnish ethical guidelines for research ([The Finnish National Board on Research Integrity](#)) were followed accurately.

Informed consent and patient details

Interviewees were provided with information about the research before the interviews and were given an opportunity to ask the researchers questions. They were told about their right to terminate the interview and given information on data protection and anonymity. In face-to-face interviews, interviewees signed a written consent form and were given a handout containing contact information and data protection guidelines. Safety instructions regarding Covid-19 were followed. In phone interviews, oral consent was recorded and informants were told that the interview would be recorded.

Data availability

Due to the sensitive nature of the questions asked in this study, survey respondents were assured raw data would remain confidential and would not be shared.

The anonymized transcripts of the interviews will be available for identified researchers at a later stage of the research project *Alongside Dementia*.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgments

Funding: This work was supported by the Academy of Finland [grant number 331555] and Kone Foundation [grant number 201901669].

We wish to thank all the interviewees for providing such rich data on the consequences of Covid-19. We also thank all the nursing homes involved in the data-collection process, as well as the Alzheimer Society of Finland and the Memory Association of Finland Proper for cooperation in the research design.

Supplementary materials

Supplementary data associated with this article can be found, in the online version, at doi:[10.1016/j.ijnnsa.2021.100031](https://doi.org/10.1016/j.ijnnsa.2021.100031).

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