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"I Didn't Meet My Mother; I Saw My Mother": The Challenges Facing Long-Term Care Residents and Their Families in the Age of COVID-19

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Abstract

The present research examines the effects of protective measures due to the coronavirus disease 2019 (COVID-19) pandemic within long-term care (LTC) settings on residents and their family members. Open-ended qualitative interviews were conducted with 14 family members of older adults who resided in LTC settings during the first wave of the pandemic in Israel. The first theme identified is Rupture, including the physical disconnect; the disruption in routine treatment to residents; and decline in the satisfaction with the setting. The second theme is Response, including sharing viewpoints and involvement in decision-making, as well as an intense ambivalence shared by family members. Our findings highlight the distress caused to residents and family members by the isolation and restrictions in LTC settings during the pandemic and underscore values and priorities that are central to them and their family members, including maintaining continuity, transparency, and working in unison with their families, staff, and management.

Keywords

COVID-19, long-term care settings, qualitative research, informal caregivers

Introduction

Ever since the outbreak of the new severe acute respiratory coronavirus 2 (SARS-CoV-2) and the declaration of the coronavirus disease 2019 (COVID-19) a pandemic by the World Health Organization (2020), societies worldwide have experienced its ongoing impact. It is estimated that even after the dissemination of vaccinations it will take time to curb the pandemic, and thus, the strategy for controlling the spread of the virus involves measures such as lockdown of communities, social isolation, face masks, and quarantines, greatly impacting and disrupting routines (e.g., Palgi et al., 2020). The higher risk posed to those who are older and more susceptible to the effects of COVID-19, coupled with these restrictions, can have detrimental outcomes for the mental health of older adults (e.g., Montauk & Kuhl, 2020; Shrira et al., 2020). Indeed, preliminary studies have shown that older adults experience high levels of stress and low mental health due to the COVID-19 pandemic, findings that need to be further explored (e.g., Krendl & Perry, 2021). This study, therefore, aims to examine these effects among the group that is most susceptible to the effects of the virus (Pillemer et al., 2020), older adults who live in long-term care (LTC) settings.

The characteristics of LTC settings and LTC residents result in high levels of COVID-19 infections and death worldwide (Ayalon et al., 2020). As a result, LTC settings have received a substantial amount of attention and there has been a great effort to protect LTC residents. In the initial wave of the virus, governments in different countries responded by adopting drastic measures with the goal of attenuating the spread of the virus and reducing the number of hospitalizations and deaths (Balmford et al., 2020). In Israel, government guidelines regarding older adults in LTC settings prohibited residents from leaving the settings, and visitors were not allowed entry. These severe restrictions began before the first national lockdown took place in Israel and continued after it was lifted (Ayalon & Avidor, 2021).

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Table 1. Characteristics of the Study Sample.

N = 14	Participants	LTC residents
Gender	Female: 10 (71%)	Female: 11 (79%)
Family status	Married: 11 (79%) Divorced: 3 (21%)	Widowed: 9 (64%) Divorced: 4 (29%) Married: 1 (7%)
Age (range, *M*, *SD*)	46–72, 61.23 (7.89)	68–100, 87 (8.87)
Relation to resident	Offspring: 12 (86%) Spouse: 1 (7%) Grandchild: 1 (7%)	
Institution of resident	Nursing unit in nursing home: 2 (14%) Assisted living with live-in help: 5 (36%) Assisted living, independent: 5 (36%)	
Length of time in institution (range, *M*, *SD*)	6 months to 20 years, 6.2 years (5.94)	

To date, several studies have demonstrated the effects of the lockdown and the ensuing isolation on older adults living in LTC settings (Simard & Volicer, 2020; Van der Roest et al., 2020). While caregivers of older adults have also been impacted (Park, 2020; Sun et al., 2020), there has been no particular focus on caregivers of older adults in LTC settings, despite having likely been dramatically affected by the various measures taken to protect LTC residents and by the sense of threat surrounding these settings. Thus, the present research is part of a larger study which aimed to examine the experiences of residents and their family members during the pandemic. To that end, we conducted open-ended qualitative interviews with 14 family members of older adults who resided in LTC settings during the first wave of the coronavirus pandemic in Israel. We aimed to obtain information on their personal experiences and their views regarding the experiences and care of their loved ones during the pandemic.

Methods

The study was approved by the ethics committees of the first author's institution (IRB protocol number: L/gcp, 50-2020). We approached the sample via word of mouth and advertisements in social media. All participants provided verbal informed consent prior to participation, as approved by the ethics committee of the institution of the first author, due to the fact that all interviews were held over the phone. Thus, participants were explicitly asked to state that they were aware of the requirements and that they consented to participate. This was documented in writing by the interviewer. In total, 14 family members were interviewed. The LTC residents to whom participants were related varied in terms of the amount of time in the setting and their age range. Residents came from different settings and from diverse regions of the country (see Table 1 for further descriptive information on the sample). Interviews were conducted between April 22 and June 9, 2020, corresponding with the transition from a full state of lockdown in the entire country to a partial reopening for most people in Israel.

Procedure. All interviews were recorded and transcribed verbatim. Interviews were conducted over the phone and lasted 45 min on average. Respondents were initially asked about their family member's decision to enter the residential setting and experiences in the setting prior to the pandemic. They subsequently were asked about their experiences during lockdown, including challenges and coping mechanisms. Respondents were also asked to reflect about ways in which the staff and management could improve the care of residents during the pandemic.

Analysis. We employed a bottom-up approach to the data, relying on open coding (Burnard, 1991). Authors read each of the interviews several times, noting major themes and impressions. Next, texts were segmented into smaller units of meaning and assigned descriptive codes, which were not conceived a priori (Burnard, 1991). These were collapsed into more interpretative themes. For instance, family members' reports which expressed disappointment, resentment, anger, or dissatisfaction were all grouped under a single category of a rupture in satisfaction and trust. As several possible directions emerged from the data, we employed selective coding to create a coherent storyline of the findings by focusing on two themes as described below (Holton, 2007).

Trustworthiness. We documented our analysis process to maintain an audit trail (Rodgers & Cowles, 1993). All themes are accompanied by thick descriptions from the interviews to ensure that the findings can be interpreted by the reader (Ponterotto, 2006). Finally, we obtained the point of view of LTC residents as well, and although not incorporated in this study, it does appear to corroborate the current findings (Ayalon & Avidor, 2021).

Findings. Two general themes emerged from the interviews with family members: The substantial rupture experienced by family members of LTC residents, including the physical disconnect between family members and residents brought on by the lockdown; the disruption in routine treatment to residents; and an abrupt decline in the satisfaction with and trust in the setting. The second theme was that of response, which included an active attempt to share viewpoints and to become involved in decision-making and care. In addition, family members reported an intense ambivalence both in relation to keeping their loved ones in an institution during these troubling times and in relation to the best response in light of the extreme situation faced by LTC settings.

Rupture. The pandemic and the lockdowns that were almost immediately placed in LTC settings caused a sense of abrupt rupture, or breach, as was expressed in several configurations by family members. The first one was a sudden separation from one's family member in the LTC setting. The second form of rupture concerned a discontinuation of the routine treatments and care received by the residents. As a result, a third form of rupture was described as the previous sense of satisfaction turning into dissatisfaction and distrust in the system.

Separation From Family

Family members discussed the separation from their loved ones as emotionally painful, as exemplified in this brief account of the rupture the pandemic has caused (all names and identifying information were changed to protect the privacy of participants). Eden, whose father is in a nursing home, said, "Wow! It's sad! So many things changed—we used to come and visit, the whole family, so he could see everyone. All of a sudden it's BOOM! You can't do anything! It's very hard." The next quote from Beatrice, whose mother resides in a dementia care unit, also describes a sudden shutdown. It alludes to the effects of this restriction not only on family members, but also on older residents, who often were left with no proper understanding of the new situation:

> Honestly, what happened was, they suddenly stopped the visits, and it was in one fell swoop. It was sudden without me having the possibility of saying goodbye or explaining to her that I won't be able to come in any longer.

Rupture was hardly eased by means of communication that were available throughout this time. This is because many of the residents experienced cognitive and/or physical impairments that prevented them from fully participating in phone conversations, as Beatrice describes:

> Phone calls are a very poor replacement for visits, everyone says that. And even when there's visits, it's so hard without touch. Sitting across from someone wearing a mask, two meters from you, doesn't feel like a visit at all.

Once the first lockdown was lifted, LTC settings were forced to allow family visits, but under very restricted conditions. The following quote describes the unsatisfactory experience this created. Orit, whose mother is in a dementia care unit, shared,

> from that distance (two meters) she didn't really see me. I kind of knew that for her it wouldn't be of any use . . . I didn't meet my mother, I saw my mother. They placed tables there, I think they're three meters long, with ropes on each side—they made sure there would be no contact between the family members and the residents.

Discontinuation of Care

Family members also reported a discontinuation of care, which impacted the health of LTC residents, which was already deteriorated even prior to the pandemic. Galit, whose mother lives in an assisted living facility, said, "Everything was put on freeze, not all the therapists who normally came could come in anymore, and suddenly there's this situation where older adults couldn't move, their bedsheets couldn't be changed, they couldn't be showered, it was rough."

In addition to physical care, social care also stopped as this was considered non-essential. Nonetheless, it was clear that the impact of discontinuing all social activities was tremendous.

David, whose spouse lives in a dementia care unit, said,

> There was this situation where little by little all of this cultural and human activity stopped . . . A few months back, my wife started to lose her mobility. I didn't give up, I brought a private physical therapist . . . and my wife was walking again. But when I went there after two months, obviously she deteriorated. The therapists that I paid for personally, they wouldn't let them come in.

A Rupture in Satisfaction and Trust

Some participants experienced a deep decline in their trust and satisfaction with their relatives' LTC setting. Eden, who described having been previously satisfied with her father's nursing home, now abruptly found herself questioning and critiquing the care that her father received:

> We brought our own private doctor to examine Dad, because we began to worry so much, and he immediately saw that he was dehydrated, and asked for testing. And the manager of the home said that she couldn't do it. I had to fight with them to have it done. And now he has bedsores, which means that they not only don't move him, they're also giving him improper food.

She continued, "I'm looking into transferring him to another facility. That's how bad it is."

A similar experience was echoed by Limore, who describes that her satisfaction was never positive with her grandmother's institution, but that it deteriorated so steeply during the pandemic, that she described a sense of relief when her Grandmother was hospitalized due to an exacerbation of her frailty: "We felt—Wow! How great it is that she is in a hospital! She was given proper medical and emotional attention by the staff, and we were able to visit her at last . . . It's sad to say, but yes."

Some, however, expressed faith in the home that their family member was in, in spite of everything. Orit explained, "for me, I have to say that other than the difficulty and unease due to the pandemic, it only strengthened the confidence I had in that place." Furthermore, some family members maintained the trust that they still had on some levels, such as the staff, but disclosed distrust at other echelons, such as management. Maayan, whose mother resides in an independent living facility with live-in help, said,

> I don't have one negative thing to say about the staff! I think that the mishandling came from above them. Management just didn't talk to us and didn't explain what was happening and they didn't apply enough pressure so that they would get everyone tested.

David, for instance, blamed the ministry of health:

> They didn't let anyone in . . . because there were no guidelines then . . . this isn't about the institution, it's about the dumb directives given by the health ministry. We were practically bleeding by the time their guidelines regarding retirement homes came out.

Response. Another common reaction among the family members of residents was related to an active struggle and involvement in the decision-making process during the peak of the pandemic. The second one was a deep sense of ambivalence regarding the proper way to respond to the pandemic, as well as with regard to the general notion of placing their family member in an LTC institution.

Perspective and Involvement in Decision-Making

Nora, whose father lives in an assisted living facility, stated,

> I think that for my father being locked up is really hard. I think there should be more physical exercise, they should really make it a priority. And they didn't. I think that being sedentary for two weeks, at that age, it can finish you. I think they should enable them to move around—in the inside spaces, keep the 2-meter distance between them and all that, but let them move.

Some had further recommendations. Eden stressed the importance of psychologically assisting those working inside the setting: "I think they should have first gotten some form of therapy or assistance. I think that if they had been given proper tools, they could have functioned differently with the residents." She also recommends increasing transparency to improve trust in the setting:

> When I try to help them out, you can see the door being slammed—'leave us alone, we know how to deal with this!' They *don't* know how to deal. If they'd really wanted to know how to get other tools, everything could have looked different there. It's about transparency towards the family. Open a group chat . . . share with us . . . No hiding, no being scared. I want to see where my dad sits all day.

Tying all of this together, Galit recommends,

> I think there should be mental support . . . physical and mental support—it goes together—bring in teams who are experts in crisis management, emergency situations—with social workers, psychologists, psychogeriatricians, so that they can give the residents and the staff some sort of ventilation, a break, and so that they could locate people who need therapy.

Involvement in Active Struggle

Perhaps due to the decline in trust in the system during the pandemic, many family members reported their involvement in actively attempting to change the handling of the coronavirus pandemic among older residents. Maayan relates participating in demonstrations outside her mother's home following a growing feeling of mishandling of the crisis there:

> Why did we demonstrate? We were just demanding that they get everyone tested—the residents and the staff and everyone. And it took so so so much time! And it just made its way into the newspapers, and we started coming to the gate to demonstrate.

Galit describes feeling as though she was compelled into this situation:

> I entered this whirlwind and this need, without wanting to. I was in touch with family members of other residents, whom I did not know prior to this. I was very concerned about my mother, who was living across from someone who tested positive for the virus. Why did I have to intervene to the point of almost involving the police and even involving a lawyer??

Eden, who also described actively demanding testing in her father's institute, connects this active involvement to a wider view of filial loyalty:

> My father needs me today, this is his time today that he gets me. And that woman (the manager) is afraid of it (laughs). What am I going to do? He taught us to take care of our dear ones. If someone is important to you, you fight for them tooth and nail.

Ambivalence

In the face of the many hardships that arose due to the pandemic for residents in LTC settings and their families, the last form of response to emerge is that of ambivalence. Many participants described a sense of worry and distress, alongside a rather contradictory one of satisfaction or composure. This was mostly expressed in regard to coping with the current crisis, but also with regard to placing one's parent, spouse, or grandparent in an LTC facility in the first place. Furthermore, this was also expressed in a difficulty to find straightforward or unequivocal answers in a time of crisis.

David described an inner conflict stemming from his deep ambivalence about his wife staying in an institution during the crisis:

> Normally I'd spend about 20 hours a week with her. So I then felt that I had given her the best. But when COVID-19 began, I kept feeling guilty about whether or not I should bring her home somehow and find some help. It was always . . . how should I describe it . . . till now, its agonizing, yes.

Maayan describes a similar inner debate:

> At some point we thought about pulling her out of there, we thought about bringing her to my place. But I don't have the possibility at my house—I don't have all the means that it would require. And the institute also said that if you pull them out, you can't bring them back in. So what do I do?? So we thought and thought and thought about it and we said: OK, we'll keep her there, and she also doesn't want to leave either, because you know, in spite of all the difficulty, and the fact that she was inside there this whole time, she said: this is my home!

Many reported an ambivalence given their wish to physically protect their loved ones on the one hand and the realization that this has come at a significant price on the other hand. Alexandra relayed her experience regarding the first family gathering after the lockdown at her mother's institute:

> We brought some chairs, and she was on one side of the fence, and the whole family was on the other side . . . she was holding her great-grandchildren's hands . . . To tell you that is was a lovely sight? No! But it made her happy. I don't know how it can be otherwise.

Hence, she too admits to the fact that she does not know what the best course of action would be and how to best protect her loved one while also fulfilling her own emotional needs for true physical contact.

Finally, Beatrice's words enfold an attempt to reconcile a sense of perturbance, alongside one of complacency in the face of an ambiguous future:

> There's no end in sight—you can't say when this is going to end, it could go on like this for a year. Do I know if she'll be alive in a year? And there's always this fear that she'll pass, not because of COVID, just old age, without me having had the chance to say goodbye . . .

Regarding the handling of the virus in her mother's institute, she adds,

> In my humble opinion, they're handling it well. At least that's how they've been describing it over the phone to me. And of course, I don't really know for sure what's going on in there . . . well, look, between parentheses let me say that if I had the option I would take her out . . . But I live in a single bedroom apartment—I don't have the option! You know what? I don't know what to think, because I'm quite confused about the whole thing.

Hence, this argument underscores her ambivalence both with regard to the institutional placement and with regard to the best measures in the light of this extreme situation.

Discussion

This study examined the experiences of family caregivers during the COVID-19 pandemic with a particular focus on the effects of continuous lockdown. Our findings show a severe rupture between the experiences of family members prior to the pandemic and afterward. We classified this rupture into three aspects, based on respondents' accounts. First and most obvious is the physical and emotional rupture that took place due to the requirement to physically distance, particularly from older adults. Although technological means to maintain contact between people who are forced to be physically distanced from each other exist, these means appear to be inadequate in the case of many older people, especially those who experience cognitive decline (Seifert et al., 2020). Family members explicitly argued that the absence of physical contact resulted in severe emotional consequences both for them and for their loved ones. This finding adds to research conducted elsewhere (Shrader et al., 2021), which stresses the important emotional bond between family members and older persons, even in the context of LTC settings during the pandemic (Verbeek et al., 2020). It also stresses the fact that technology does not provide an adequate replacement to actual physical and emotional contact.

In addition, older residents experienced a rupture in their care, as all nonessential medical and social care was discontinued. Older LTC residents often experience multiple ailments and a substantial reduction in their physical functioning even prior to entering the setting, and the disruption of their routine care can be detrimental to their functioning and emotional state, especially in a deprived physical environment (i.e., Millán-Calenti et al., 2013). Although family members described their experiences during the pandemic as a rupture, an in-depth reading of their arguments suggests that problems in the LTC settings existed prior to the pandemic. More specifically, family members described how the lack of manpower to provide older people with personal care was

compounded during the pandemic, with detrimental effects on the well-being of older residents. Hence, the pandemic highlights the vulnerabilities not only of older residents but also of the settings they live in (Wagner, 2020).

Family members also discussed the impact social distancing from LTC residents had on themselves. Reportedly, family members experienced high levels of anxiety and fear for their loved ones, which resulted in a disillusion with the LTC setting. Whereas many reported high levels of satisfaction with the setting prior to the pandemic, following the pandemic and the lockdown of LTC settings, some family members reported a rupture in their relationships with the setting. For these family members, the trust and satisfaction previously experienced in their relationship with management and staff transformed into distrust and disappointment.

These sentiments were reflected in the second theme, that of the response of the family members, who were eager to share their viewpoints and to be more involved in the decision-making process that impacted the residents of the LTC. The pandemic represents an unfamiliar and stressful situation for most of the public. This is intensified by the fact that many of the LTC settings have turned into total institutions (Goffman, 1961), enclosing the residents within them for a significant amount of time during the pandemic. In an attempt to protect the lives of their residents, many settings have deprived older people of their free will and imposed an extended period of lockdown on the residents. This was shown to be quite detrimental for the residents (Ayalon & Avidor, 2021). However, it also had a negative impact on their family members, who were removed from the everyday life of the setting with no physical access to their loved ones, while a threatening pandemic spread throughout the world. Frustrated family members described the totalistic features of LTC institutes as being characterized by limited transparency. Hence, not only did many of the settings isolate their residents, but many of the settings also did not openly share information about the pandemic and its impact on residents, resulting in high levels of frustration and distrust among family members. This sense of concealment and limited transparency with regard to LTC settings is not unique to Israel as a recent study conducted in the United States has reported a similar sentiment (Allen & Ayalon, 2020). Their active involvement through banding together to protest against the restrictions and the rupture from the residents speaks to the importance of maintaining an open dialogue between the staff and the family members, and of working in collaboration with them to ensure that the priorities and personal values of the residents, who could not speak up for themselves during the lockdown, are heard and taken into account.

Finally, ambivalence was a common emotional reaction shared by many of the family caregivers. This gives emphasis to the fact that there is no single optimal way to cope with the current situation. Providing in-home care to older people with substantial care needs is not an option for many individuals for a variety of reasons (Pillemer et al., 2019). This is in line with previous literature on the nature of caregiving, and its associations with burden and burnout, which have increased among informal caregivers during the pandemic (e.g., Sheth et al., 2021). When older persons enter an LTC facility, family members usually continue to stay involved (Courbage et al., 2020; Eika et al., 2014), yet the transition may result in reduced levels of burden and burnout and in a gained sense of freedom (Cottrell et al., 2020). Our initial findings, however, suggest a profound sense of ambivalence on the part of the family members during the lockdown. Reportedly, the well-being of family caregivers, and perhaps their satisfaction with the LTC, was replaced with a sense of distress during the COVID-19 pandemic. In many cases, the lockdown prevented family members from continuing to remain involved in the care of their loved ones in the LTC, which came at a cost for their own well-being while also impacting the health care and health outcomes of the residents. Thus, the distress of family members and caregivers must be taken into consideration when making decisions regarding restriction of visitations to LTCs, as a comprehensive lockdown can be replaced with more moderate limitations, that would enable the maintenance of the connection between residents and family members.

The unfamiliar situation brought by the pandemic also stressed the fact that no clear guidance concerning the best care practices during the pandemic exist, further contributing to the sense of ambivalence. While active attempts to physically protect LTC residents are commendable and understandable, these have been taken to the extreme during the pandemic and have compromised the mental and physical health of residents (Avidor & Ayalon, 2020; Chu et al., 2020) as well as the well-being of their family members. Thus, it is essential that any measures that are introduced in the future balance between protecting residents from infectious diseases with other, equally important needs, including their mental health, through retaining interpersonal ties and support, and allowing for continuous and significant contact with loved ones, caregivers, and the rest of the outside world.

This study does not go without limitations. Our small, nonrepresentative sample provides a preliminary glimpse of the experiences of family members of LTC residents. Despite their depth, interviews did not include the viewpoint of the older residents. This is unfortunate given the outsize emphasis on the views of family members which are often proxies for views of the residents themselves (Allen & Ayalon, 2020). Nevertheless, our findings point to several important lessons for the care of LTC residents. First, the findings stress the importance of continued physical contact with family members as technological means appear to be insufficient in replacing human contact, especially for older people with cognitive impairments. Second, older people in LTC settings with substantial medical and social care needs require ongoing routine care. Even during regular times, this care is often absent or inadequate due to an underfunded LTC system,

worldwide. During extreme times brought by the pandemic, the shortage of LTC staff is even more pronounced and the importance of continuous medical and social care cannot be overestimated. Third, our findings stress the importance of ensuring transparency and involvement in decision-making both for older LTC residents and for their family members. Finally, our findings underscore the importance of in-depth interviews as a means for gleaning important information regarding the experiences and needs of LTC residents and their family members. Coping with the first wave of the coronavirus was a novel situation for everyone involved in the LTC system, and open-ended questions enabled a dialogue that brought to the fore central themes that might not have been known otherwise (Phoenix, 2018).

In the decades since Goffman coined the term total institution (Goffman, 1961), LTC settings have drawn away from the totalistic features, allowing for greater autonomy and person-centered care for their residents (Koren, 2010), with positive outcomes for family members. This study raises a highly acute dilemma concerning the appropriate ways to protect older people during the pandemic. This dilemma is intensified in LTC settings as family members may feel helpless and deprived of influence to adequately impact the care of their loved ones, while staff and management face an unclear future for which only ad hoc guidelines can be offered. Addressing family members' ambivalence can ease their experiences during the current pandemic, but also subsequently, as all stakeholders involved will be obliged to deal with its aftermath (Inzitari et al., 2020).

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Author Contributions

S.A. designed the study, supervised the data collection, analyzed the data, and co-wrote the paper. L.A, also supervised the data collection, analyzed the data, and co-wrote the paper.

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