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“Let me touch him”: Perceptions and experiences of family caregivers of nursing home residents during the COVID-19 outbreak in Israel

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ABSTRACT

Older adults in nursing homes were particularly vulnerable to COVID-19 morbidity and mortality worldwide. Due to the COVID-19 pandemic, visitations in nursing homes were restricted. The present study examined the perceptions and experiences of family caregivers of nursing home residents during the COVID-19 crisis in Israel and their coping strategies. Online focus group interviews were held with 16 family caregivers of nursing home residents. Three main categories were identified through Grounded Theory techniques: (a) Anger and decreased trust in nursing homes; (b) Perception of the residents as victims of the nursing home policy; (c) Coping strategies at different levels. The outbreak redefined family caregivers' understanding of their role. Practical implications include making the voice of the family caregivers heard, identifying effective coping strategies, and creating a dialogue between family caregivers, nursing home managements, and staff.

Introduction

Following the outbreak of the COVID-19 pandemic, residents of nursing homes became one of the populations most vulnerable to morbidity and mortality of the virus (Barnett & Grabowski, 2020; Su, McDonnell, & Li, 2021). The strict instructions to close nursing homes to visitors during the COVID-19 pandemic forced family caregivers to relinquish visits, at the risk of disconnection from their loved ones and inability to monitor the care they received. This state was bound to affect family caregivers, who are committed to their family members living in institutions (Bauer, Fetherstonhaugh, Tarzia, & Chenco, 2014; Bern-Klug, 2008; Davies & Nolan, 2006) and see their care role as significant (Bern-Klug & Forbes-Thompson, 2008; Davies & Nolan, 2006). Understanding how family caregivers of nursing home residents perceived and experienced the COVID-19 crisis in Israel may help shed light on how to avoid family disconnection in future scenarios.

Family caregivers of older adults in nursing homes

Older adults usually prefer to age in place for as long as possible and avoid institutionalization (Fernández-Carro, 2016). For most families, nursing home care becomes an option when people experience increasing infirmity, cognitive impairment, and palliative care needs,

because of perceived improved access to skilled care and strategies for symptom relief, and reduced burden on family caregivers (Chau et al., 2010; Milte, Ratcliffe, Chen, & Crotty, 2018), especially when the carer is an older adult or a person with other obligations preventing them from providing optimal full-time care (Gilbert, Amella, Edlund, & Nemeth, 2015).

Nursing homes, as facilities of prolonged care, share many characteristics with total institutions (Lang, Löger, & Amann, 2007), namely an organizational need to achieve conformity, obedience (Solomon, 2004) and functional efficiency. These aims are reflected in a rigid daily routine, a lack of privacy and autonomy, and limited choice opportunities (Angelelli, 2006; Harnett, 2010). These features could potentially weaken the power of the residents when facing the staff (Nelson, 2000). Awareness of client-oriented models, which emphasize quality of life and encourage autonomy and empowerment of residents, has increased in recent decades (Duan, Mueller, Yu, & Talley, 2020; McCabe et al., 2021). Yet, scholars still emphasize the “total” features of nursing homes (Tremain, 2021; Zbyrad, 2021), and the process of “othering” that nursing homes residents experience (Verbruggen, Howell, & Simmons, 2020).

The transition to a nursing home requires the older adults' relatives to redefine their role as caregivers, while their former roles as providing instrumental assistance and basic care in daily activities (Roth,

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Fredman, & Haley, 2015) are transferred to the nursing home. Thus, the family caregivers' ability to supervise, control, and be involved in care diminishing upon move to a nursing home (Hennings & Froggatt, 2019). This experience includes relief and stress (Bern-Klug, 2008) alongside confusion and guilt for having placed their relative in a nursing home (Hennings & Froggatt, 2019; Majerovitz, Mollott, & Rudder, 2009).

Yet, family caregivers often continue to be involved in their relatives' lives in the nursing home. Indeed, they spend about as much time with their relatives as do those caring for older adults in the community (Port et al., 2005), and have a significant role in maintaining their relatives' well-being (Bauer et al., 2014; Bern-Klug, 2008; Davies & Nolan, 2006). They monitor the care received, provide feedback to staff, and fill gaps in care (Hennings & Froggatt, 2019; Hoek et al., 2021). Families' roles also include representation of the resident's perspective, maintaining continuity and sense of identity through the continuation of family relationships and by helping staff to get to know the resident as an individual (Bern-Klug & Forbes-Thompson, 2008; Davies & Nolan, 2006). Another role is contributing to the nursing home community, by interacting with other residents, relatives, and staff, taking part in social events, and generally providing a link with the outside world (Davies & Nolan, 2006). Many family members perceive themselves as strongly committed to their role as caregiver; they feel that they have the information, perspectives, time, and commitment to help improve the experience of residents living in a nursing home (Bern-Klug, 2008).

However, family caregivers lack the ability to provide direct care, and the dependence on the nursing home staff might intensify feelings of lack of control and suspicion toward the staff (Hennings & Froggatt, 2019; Hoek et al., 2021). High involvement of family caregivers in nursing homes may create tensions between them and the formal care staff (Bauer et al., 2014; Bern-Klug, 2008; Wilson, Davies, & Nolan, 2009). Family caregivers who are thought to overstep an unspoken line and become too demanding or critical are perceived as difficult by staff, and sometimes even as a disturbance (Bauer et al., 2014). In such cases, family caregivers may feel criticized, a feeling that may exacerbate existing feelings of guilt and distress (Majerovitz et al., 2009).

Family caregivers of older adults in nursing homes during the COVID-19 crisis

Older adults in long-term care facilities are at greater risk for severe illness or death from COVID-19 (Barnett & Grabowski, 2020; Su et al., 2021). In order to control the virus outbreaks, visitations in nursing homes were restricted or temporarily ceased (Barnett & Grabowski, 2020; Boucher, 2021). Along with the necessity for life-saving limitations (Barnett & Grabowski, 2020; da Silva, Mafra, e Sousa, Mayers, & do Carmo Cupertino, 2020), these restrictions had major effects on residents' quality of life, including negative effects on mental health (Boucher, 2021; Chu, Donato-Woodger, & Dainton, 2020) as well as cognitive and physical decline (da Silva et al., 2020). This was particularly the case for residents with dementia (O'Caomh et al., 2020).

Families have attempted to adjust their support strategies to various remote care modalities, for example, using technology, arranging delivery of essential items, thanking nursing home staff (Lightfoot & Moone, 2020), and contact behind glass or outside, maintaining physical distance. Although these strategies mitigated the negative effects of social distancing (Wammes et al., 2020), they were not sufficient, especially for residents with cognitive decline or with hearing and vision impairments (Barnett & Grabowski, 2020; Fearn et al., 2021). Furthermore, family caregivers have understood that in a situation where visits are curtailed and staff absenteeism rises, the quality of care might decline (Gardner, States, & Bagley, 2020). This reality has been associated with distress and a sense of helplessness at their lack of ability to monitor their relative's care (Lightfoot & Moone, 2020).

Thus, in addition to threats to residents' quality of life, family caregivers also experienced low psychological and emotional well-being during the pandemic. Well-being was significantly lower among those

whose relative resident had cognitive impairment (O'Caomh et al., 2020). The greatest concerns of family caregivers of nursing home residents during COVID-19 were social isolation, decline in mental health, decline in physical and cognitive functioning, keeping their family members safe from COVID-19, lack of caregiving support, and caregiving stress (Avidor & Ayalon, 2022; Lightfoot et al., 2021).

Restrictions on nursing home visits were criticized in the literature, which views families not only as visitors but as essential care partners who are crucial to one's physical and emotional well-being (Hado & Friss Feinberg, 2020; Kemp, 2021; Verbeek et al., 2020). Even if physical visits are not possible, the guidelines should not interfere with relationships between residents and their family caregivers (Hado & Friss Feinberg, 2020). Scholars have called for a policy that supports the involvement of family caregivers in the care of their relatives (Kemp, 2021) and suggested various proactive solutions to meet the challenge. For example, one suggestion included infection prevention strategies such as personal hygiene measures, optional outdoor visits, and COVID-19 detection tests (Bergman et al., 2020; Stall et al., 2020; Verbeek et al., 2020). Another suggestion was mobilizing social work students and trainees to assist long-term care staff in maintaining communication with families and providing social support (Hado & Friss Feinberg, 2020). Activating family councils was also suggested: in the US, federal regulations give family caregivers of residents living in long term care facilities the right to advocate for residents and partner with staff (Hado & Friss Feinberg, 2020). Strengthening nursing home-family caregiver communication channels was mentioned as well, for example by assigning staff members as primary contacts for families (Hado & Friss Feinberg, 2020).

Nursing homes in Israel

Nursing homes in Israel are at the far end of the spectrum of long-term care services for the older population (Brodsky, Shnoor, & Be'er, 2012). They are designated for older adults who need assistance with activities of daily living due to functional and mental impairment, complex health needs, and increased vulnerability requiring 24-h nursing care (Ministry of Health, State of Israel, 2023; Sanford et al., 2015). Nursing homes in Israel are partially privatized, where 58% of them are privately owned, 38% are owned by civil society associations, and the rest are under government ownership (Shnoor & Cohen, 2020). However, privatization is partial: the Israeli Ministry of Health is responsible for defining the services to be given, eligibility criteria, regulation of services, partial financing, and supervision (Ministry of Health, State of Israel, 2023).

The convoys of care model

The tension between family caregivers and nursing homes can be understood according to the convoys of care model (Kemp, Ball, & Perkins, 2013). According to this model, care recipients and their formal and informal care providers are located in dynamic care convoys (networks) of formal and informal care. Convoys of care are "the evolving collection of individuals who may or may not have close personal connections to the recipient or to one another, but who provide care, including help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), socio-emotional care, skilled health care, monitoring, and advocacy" (Kemp et al., 2013, p. 18). Care convoys are shaped by different ecological levels, from the individual through care networks to community and societal levels. Each individual's care convoy is unique, and the division of care work changes with time through negotiation processes.

Convoy members have different power or control in negotiation processes, since power is fluid and may be contextual, depending on an individual's position and setting. Typically, as consumers, families and residents have the most power, yet depending on staff for care, makes them vulnerable, especially residents (Kemp et al., 2013). The outbreak

of the COVID-19 pandemic led to a rapid change in the care convoys of nursing home residents, and the balance of power in the nursing home residents' convoys changed radically (Kemp, 2021).

The present study

Although the caregiving roles of families in nursing homes are more limited than in the community, they often see themselves as responsible for their relative's well-being and as overseers of care (Bern-Klug & Forbes-Thompson, 2008; Davies & Nolan, 2006). The already existing gap between the comprehensive responsibility and the limited ability to intervene in their relatives' care might be associated with feelings of frustration and tension between family caregivers and the nursing home staff. The visitation ban during the COVID-19 outbreak potentially intensified this tension.

The purpose of the present study was to examine how family caregivers of nursing home residents perceived and experienced the COVID-19 crisis, and what strategies they used to cope with the situation imposed on their families. Despite the accumulated body of knowledge indicating the impact of the COVID-19 pandemic on family caregivers of nursing home residents, empirical qualitative studies that explore family members of nursing home residents during the critical periods of lockdown are limited. The present study, which was conducted before COVID-19 vaccines were available, allows a unique look at one of the most difficult and complex periods for family caregivers of nursing home residents.

Method

This is a qualitative study, based on in-depth online focus group interviews with family caregivers of nursing home residents during the height of the COVID-19 crisis in Israel. A focus group is a technique for gathering qualitative data, based on in-depth group interviews, focused on a given topic. Focus groups are guided by a skilled moderator and usually include 6–10 participants (Morgan, 1998). The potential safe atmosphere provided in a small group and the interactions within it may provide rich and deep data, even compared to information generated in personal interviews (Lederman, 1995). Additional advantages of focus groups include raising different opinions over a short period of time (Lederman, 1995; Morgan, 1998). Focus groups were regarded as a method that captures context and nuances and can be empowering for participants. Individuals who may be reluctant to discuss sensitive topics in a one-on-one interview with a researcher, may open up when participating in a focus group with others who share similar experiences, so some of the pressures or discomfort associated with the topic can be shared and, therefore, diluted. Thus, using focus groups can be particularly useful when discussing a sensitive or difficult topic (Cyr, 2019). Furthermore, focus groups can be useful in studies where little is known about the subject (Kidd & Parshall, 2000), because the researcher can rely upon focus group participants to reveal what might be noteworthy about a new topic of interest (Cyr, 2019). The drawbacks of the method are that dominant participants might control the discussion, and a consensus might be reached, rather than having diverse opinions expressed. The present study attempted to mitigate these potential risks by using experienced moderators and working with small groups, to allow voicing multiple opinions (Morgan, 1998).

Online focus groups

The current study began in September 2020, a period in which COVID-19 morbidity in Israel increased and a second lockdown was imposed, in accordance with the social distancing approach employed to halt the spread of disease. The current research utilized the Zoom videoconferencing platform (<https://zoom.us>), which supports real-time audio and video, with a user-friendly interface (Lobe, Morgan, & Hoffman, 2020). This research design enabled the recruitment of

participants from a wide geographic spread. Being convenient, efficient, cost effective, and flexible (Archibald, Ambagtsheer, Casey, & Lawless, 2019), online focus groups allow the potential for greater diversity among participants sampled, and provide them enough convenience and anonymity to speak about sensitive topics (Reisner et al., 2018). However, virtual settings in online research might have technical issues (Archibald et al., 2019), limit nonverbal signals, and negatively affect group dynamics (Reisner et al., 2018). Ethical issues of privacy should also be considered in online studies (Archibald et al., 2019; Lobe et al., 2020).

Participants

Participants were 16 Jewish Israeli family caregivers (15 women, one man) of 17 residents of nursing homes (one participant was a daughter of a couple living in a nursing home). Thirteen participants were daughters of residents, two were spouses, and one was a sister of a resident. Participants' age ranged from 43 to 72. Participants were diverse in terms of family status (12 married, two single, one divorced, and one widowed); religiosity level (nine secular, six traditional, and one ultra-orthodox); and education (four were high school graduates, five had non-academic professional training, three had a bachelor's degree, and four had a master's degree). The duration of participants' relatives' residence in the nursing homes ranged from seven months to eight years ($M = 3.34$ years, $SD = 2.30$). The allocation of participants to groups was according to the dates on which they could participate.

Recruitment of participants

Participants were approached directly by the researchers, either personally, through professional relationships, or by social network posts in Facebook and WhatsApp groups of family caregivers, or by personally contacting relevant post writers. Access to internet and ability to participate in a Zoom meeting were required. Participants included in the study were those whose family member lived in a nursing home for older adults during the study period. Fourteen potential participants who were directly approached decided not to participate, and three more waived their participation after initial consent. Eventually, most study participants (except one) were located in groups on social media. Of note, the participants did not know each other before the participation in the study and their family members lived in different institutions. The research was approved by the institutional review board of Ruppin Academic Center. All participants signed an online informed consent form prior to joining the research and were explained in writing and orally about the aims of the research and its procedure.

Research procedure

The participants were allocated to four focus groups, and each group met once for 1.5 h. Three meetings were held during September 2020 and one in January 2021, two periods in which Israel was under a full lockdown. The groups were relatively small, with 3–5 participants each. Group meetings began with presenting research objectives and procedures. The researchers, experienced with group guidance and with Zoom, were the moderators. Each group had two moderators. Commitment to anonymity and confidentiality was clarified, including participants' commitment to each other. The moderators requested that the participants introduce themselves, and then presented guiding questions. All group sessions were recorded and transcribed verbatim.

The focus groups were given a number of common guiding questions: "Tell us about your relationship with your relatives who live in a nursing home since the COVID-19 crisis has started," "Tell us about the difficulties you experienced in this context during the crisis," "How do you deal with these difficulties?" "How do you think your relatives living in a nursing home experience the crisis?" "How do you think the

management of the nursing home is coping with the crisis?" Some of the questions were answered during discussion before they were asked, as is common with focus groups (Lederman, 1995).

In addition, self-report online questionnaires were used to gather demographic information, including respondent's age, gender, family status, education, country of birth, religion, religiosity, and the respondent's relative's age, gender, duration of residence in a nursing home, and family relation of the respondent to the relative.

Analysis of the findings

Each focus group interview was analyzed by two of the researchers separately. The analysis was encoded in stages in accordance with the principles of the Grounded Theory (Strauss & Corbin, 1998): First, the transcribed text of each group interview was coded thematically, where each topic unit raised in a focus group was given a code name. For example, in the first focus group interview, 78 codes were found by one researcher and 64 codes by the other. Next, each researcher grouped the codes into initial themes according to their content and context. For example, in the first group, 18 initial themes were grouped by one researcher and 10 by the other researcher. An example of an initial theme in this group is "perceptions of exaggeration and irrationality in the conduct of nursing homes," which included the following codes (topic units): The sweeping "no entry" policy of nursing homes in situations where caregivers' entry could have been beneficial to the residents (e.g., a private caregiver, a daughter who wanted to fix her father's computer to communicate with him); Exaggerated restrictions on the residents (e.g., a grandmother who was not allowed to see her grandchildren even from a distance in the yard, a participant whose mother was required to stay in her room and was not allowed to go out on the patio next door).

Next, discussions were held regarding the initial themes researchers found, and second-order themes were grouped. For example, the first focus group interview included the following second-order themes: (1) Residents' physical and mental deterioration during the COVID-19 period; (2) Families' feelings that the residents are "prisoners" of the institutions/staff: helplessness, anger, and the need to maintain a normal relationship with the staff; (3) Ambivalence toward the institutions' conduct: criticism and understanding their work complexities; (4) Demands/proposals/actions for change: demand for commitment to residents' quality of life, for regulation and supervision, proposals to raise awareness of the situation, actions against the procedures.

Following second-order theme groupings, similarities and differences between the interviews were evaluated, and themes were grouped to create broader structures (Strauss & Corbin, 1998). This approach guarantees that the findings are encoded openly in a way that creates categories based on the content of the interviews (Cresswell, 2013). Thus, the second-order themes were grouped into 12 interpretive themes based on analyses of all group interviews. During analysis, comparisons were repeated between individual participants, within groups, and between researchers (Strauss & Corbin, 1998). Finally, the researchers assembled the data (the interpretive themes) in a structured approach that presented a logic paradigm that consisted of causal conditions ("Anger and decreased trust in nursing homes"), a central phenomenon ("Perception of the residents as victims of the nursing home policy"), and the strategies to cope with the phenomenon ("Coping strategies at different levels") (Cresswell, 2013). Each of these categories lists the themes found.

Rigor and trustworthiness

The following strategies were used to increase the trustworthiness and credibility of data analysis: intercoder agreement (Cresswell, 2013) by three researchers who analyzed the findings separately and independently. In writing this article, the findings were presented using quotes from the interviews, which allows the reader to judge the proposed interpretations (Cresswell, 2013).

Findings

The thematic analysis of the data led to the identification of three main categories: (a) Anger and decreased trust in nursing homes; (b) Perception of the residents as victims of the nursing home policy; (c) Coping strategies at different levels.

Anger and decreased trust in nursing homes

In order to protect residents, the nursing homes and Israeli Ministry of Health ordered to reduce visits and prevent physical contact in nursing homes. This policy led to four themes expressing perceptions among family caregivers.

Perceptions of nursing home performance as preserving life at the expense of quality of life

One of the dominant opinions that emerged in the various groups expressed the pain and anger of family caregivers, who were prevented from approaching and touching their relatives in the nursing homes. For example, a daughter whose mother was a nursing home resident said:

They [the nursing home staff] constantly prowl to make sure we keep a distance of two meters, [and] let us meet with our parents only for half an hour, once a week, in the yard outside ... There is a separation fence, a very unpleasant feeling. (Group 1, Daughter 2).

In the next quote, it is evident how the pain and helplessness of the daughter echoes the pain and helplessness of her father:

It was impossible to get inside [the nursing home] to see him. My father has very severe dementia ... when he does not see us, he seems to forget us, he is angry with us: "You are not here! You left me!" ... He does not understand what is happening to him ... There is total disconnect ... He [her father] cries and says, "Why don't you touch me?" ... He reaches out to me, and he cries. (Group 3, Daughter 1).

The interviewee in the following quote described her attempts of negotiation with the management about the possibility of touching her spouse. The spouse's experience of helplessness and anger mirrors the interviewee's experience when her negotiation attempts failed:

I said [to the staff], "I am willing to wear protection – wear gloves, buy robes, whatever you want, [just] let me touch him!" ... He [her spouse] held out his hand. I was not allowed to hold it. He saw me crying. He became terribly upset and so did I. I shouted [at the staff]. (Group 2, Spouse 1).

Family caregivers' feelings of exclusion from care work in nursing homes

Some of the family caregivers said that before the COVID-19 pandemic, they used to stay for hours in the nursing home and took a major part in caring for their relatives. The loss of the role caused caregivers frustration and concern, as reflected in the following quote:

Our presence [in the nursing home] also helped the department, the staff. I used to bring him [her father] food. He does not like the food there ... I used to ... shave him, clip his nails, cut his hair, everything. But they do not let us [visit]. (Group 3, Daughter 2).

The following excerpt shows that the assistance by the family caregivers was in some cases provided not only to their family members, but also to other residents:

I used to bring all kinds of [recreational] activities to the residents, and we would work with stickers and paint. I used to let them call their family members using my cell phone, and that made them [the residents] feel so good. Then they [nursing home staff] told me, "You cannot come in anymore." ... It did not matter that I was the same person who had come to see my sister, while providing [activities] for thirty additional residents there every day. (Group 4, Sister 1).

Lack of transparency and absurd procedures

The limited visits reduced the ability of family caregivers to monitor the quality of care their relatives received in the nursing homes. As a result, some of the interviewees raised concerns that the nursing home did not fully share information about the condition of their relative, and suspected that the restrictions were convenient for the nursing home, as expressed in the following quote:

I was there every day before the COVID-19 [pandemic], and I knew exactly what was going on and when she [her mother] went to bed and what pills were being given to her. Today I don't know anything ... I want full transparency in what is happening with my mother. There is no transparency. And I think it is pretty convenient for them, or it is impossible [to provide transparency], or, I don't know. We need to know exactly what is going on with our parents. When my mother comes for a half hour meeting [with me], she is dressed and tidy, but I don't know if she has any pressure sores, ... anything [wrong] with her body. I want to know all these things. (Group 3, Daughter 3).

The difficulty of family caregivers to accept the limitations of physical contact and visits intensified when they perceived the nursing homes instructions as inconsistent and sometimes even absurd. Perceptions of absurdity arose when family caregivers discovered that the strict nursing homes restrictions did not apply during older adults' hospitalizations (outside the nursing home). Thus, some of the family caregivers reported actually enjoying their relatives' hospitalization, because they could touch their relatives and be close to them, as reflected in the following quote:

[At the nursing home] I was allowed to come once a week ... She started having gallbladder problems ... and had to be taken to a hospital ... With all the pain and suffering, as absurd as it may sound, ... these were her happiest days, and ours, of course. We came to the hospital every day on the days she was hospitalized there, and we could have the privilege of touching her and stroking her, and the same goes for her – touching, stroking. The touch is something any person needs, especially people with dementia. I felt it was a kind of treatment, in addition to the treatment she received at the hospital. It is a treatment for the soul – the touch, the hug ... (Group 4, Daughter 3).

Criticism of the nursing homes' instructions alongside appreciation for the functioning of the staff

Participants distinguished between criticism of the nursing homes' policy, that was related to management, and appreciation for the staff. In some cases, participants expressed empathy and understanding regarding the many challenges and difficulties faced by staff in nursing homes during the pandemic. They appreciated their ability to care for their relatives despite these complex challenges, as reflected in the following quotes:

It is very difficult for her [the head nurse at the institution] to cope with it. The problem of human resources is extremely difficult. I see how she maneuvers between the nurses to make work arrangements. The issues of visits and lockdowns are also very difficult. She told me today, "We are entering a lockdown again. I cannot take it anymore." (Group 2, Spouse 1).

The staff, I take my hat off to them. They really do and have done the maximum possible, and I have no complaints. (Group 4, Daughter 1).

Perception of the residents as victims of the nursing home policy

Many interviewees emphasized the negative consequences of nursing home policy on their relatives' health and well-being. These contents usually involved expressing feelings of pain and anger, as reflected in the following three themes.

Self-neglect and neglect on the part of the nursing home staff

According to some participants, the reduction in visits of the nursing homes' residents was associated with residents' self-neglect, without intervention by the nursing home staff:

When COVID-19 started ... he [her father] would wear the same shirt for a whole week ... he would tell me, "I have not showered for two weeks...I don't want to." It really causes a regression, because when they meet people from outside, they have to put on a facade: they have to get dressed, they have to come showered... and now when [they are] closed up, they might rot in bed. (Group 1, Daughter 1).

Cognitive, physical, and mental deterioration of the relatives in the nursing homes

Many participants emphasized that the nursing home performance (management and staff) during the pandemic led to a major deterioration in the cognitive, physical, and mental status of their relatives, as reflected in the following quote:

[During the COVID-19 period I saw that] her condition really declines ... her words disappear, she barely communicates, she repeats the same words. Her hand, which was already twisted, became even more twisted. I also see that they tend to give her ground food, which I did not want ... She has lost a lot of weight. Maybe it is because of the ground food ... I don't know how much she is fed. When we were visiting ... I used to sit and feed her lunch. (Group 2, Daughter 1).

Family caregivers believed that the reduction of contact with family and the outside world had a major effect on the mental health and well-being of the nursing home residents, as expressed in the following quote:

He [her father] told me that he wants to die. He kept saying every time that he can no longer live with this isolation, ... he just wants to die ... He says, "What is this life? What for?" ... He doesn't want to live ... He wants to commit suicide. (Group 2, Daughter 2).

Perception of relatives in nursing homes as detached or "Prisoners"

The detachment of the nursing home residents from the outside world has often created prison associations among the participants and, as shown in the following quote, among some of their relatives:

The older adults suffer greatly from loneliness, from the whole situation, like a prison ... My father says, "I am like in solitary confinement." (Group 1, Daughter 1).

Interviewees also emphasized the residents' dependence on the nursing home staff, which intensified the experience of helplessness of both the residents and their family caregivers. Family caregivers expressed their fears that any harm to their relationship with the staff may harm the well-being and safety of their relatives, as expressed in the following quote:

At the end of the day they [the staff] are the ones who take care of my mother ... It is like when I used to maintain a relationship with the children's kindergarten teacher. [Like my children,] my mother is also at their [the staff's] mercy. The children could somehow tell [me] something. My mother is helpless, she cannot tell me what is happening. (Group 1, Daughter 2).

Coping strategies at different levels

The family caregivers' limited contact with their relatives in the nursing homes, as well as the relatives' deterioration, which was perceived as related to this limited contact, led the family caregivers to use a range of coping strategies. Three main coping levels were found: the individual level, the level of dealing with the institutions and their procedures, and the broader social level.

Coping at the individual level

The interviewees reported periods of difficulty and frustration, and feelings of helplessness, despair, and guilt as a result of understanding that they cannot help their relatives. For example:

I am exhausted, and I have no strength to fight anymore ... I feel helpless ... I comfort myself that it is not because of me, I cannot do more than I have done ... He [her father] spent his early life in Auschwitz, and spends the end of his life in lockdown, and I cannot give him something better. It feels terrible. (Group 4, Daughter 2).

In light of these strong feelings, participants indicated diverse sources of support and self-care, such as hobbies, art, relationships with grandchildren, and psychotherapy.

Conflict with the nursing homes and knowingly violating their guidelines

Many interviewees used the terms “war” and “struggle” to describe their relationship with the nursing home management and staff. Struggle was often perceived by family caregivers as the only way to ensure the rights of their relatives, as expressed in the following quote:

I had to constantly fight ... for this [visiting her father] with the manager [of the nursing home]. I understand them ... They indeed did not have COVID-19 in the nursing home ... but I could not tolerate... not seeing him when he needed us so much. (Group 4, Daughter 2).

Of note, the quote demonstrates the participant’s ambivalence: despite her appreciation for the nursing home for being able to prevent an outbreak of COVID-19, her need to be with her father led her to a conflict with the nursing home manager for preventing her from doing so.

Additionally, some of the participants felt that the nursing home staff responded to the families’ war with their own war:

When I complained for the first time, my sister and I were summoned for a meeting ... She [the nursing home manager] told me, “If you don’t stop complaining, you can take your father and get out.” ... The nursing home manager, a social worker, and a senior doctor simply threatened me. (Group 3, Daughter 1).

In some cases, family caregivers consciously chose to violate the nursing home guidelines, when the rules were perceived as contrary to the needs of their relatives. This violation was sometimes accompanied by ambivalence and justification. Thus, the daughter in the following quote indicates her commitment to adhere to the guidelines, and on the other hand, her commitment to her father as overriding these guidelines:

I bring him food, take off his mask and feed him, and I have no choice. I want to pamper him – he is my father. How much time do I have left with him? What else is there for him in life? ... I do try to adhere [to the guidelines], but it is hard for me (laughs). He is my father! (Group 3, Daughter 4).

Sometimes, the violation of the guidelines was more blatant and unequivocal:

I went back with him [from the hospital] in the ambulance to the institution. I went inside to change his diaper, get him settled, and feed him. They [the staff] told me, “Oh boy, if she [the nurse] finds out you are inside.” I said, “I don’t care about her or any of you, and I will do what I want,” and I went in. (Group 2, Spouse 1).

Activism

Understanding that family caregivers often do not have sufficient power to protect their relatives in nursing homes, some of the participants contacted the authorities and the media. In the following quote, a daughter of a nursing home resident describes how she personally approached ministers and senior officials whom she thought could help:

I corresponded with the Ministers of Health and Welfare. I text with Prof. ... and Prof. ... [Head of the COVID-19 program in Israel and Head of the program to address the COVID-19 crisis in nursing homes in Israel] ... But no one does anything ... When the COVID-19 crisis started, we immediately wrote a letter to the Minister of Health, and I immediately wrote to our mayor ... I brought the TV [to the nursing home]. The following day they had the [COVID-19] tests in the nursing home. (Group 3, Daughter 2).

Some of the participants joined a new organization, which was founded during the COVID-19 crisis, one established by family members of nursing home residents in Israel, aimed to protect the residents’ rights. They talked about the great help they received and of feelings of sharing, partnership, and empowerment:

There is a group of families of nursing home residents ... The group manager ... knows the rules perfectly, and if there is a problem with any institution, he makes sure they [the institution] know what happens if they do not follow the rules ... I think that it is also a support group: people talk, share, pour out their hearts. (Group 2, Daughter 2).

Discussion

The present study examined how family caregivers of nursing home residents perceived and experienced the COVID-19 pandemic crisis in nursing homes in Israel, and what strategies they used to cope with the situation. Three main categories were found. First, family caregivers perceived nursing homes’ policy and performance as aimed to preserve life at the expense of quality of life, excluding family caregivers from care, as not transparent, inconsistent, and leading to family caregivers’ decreased trust in nursing homes’ staff and management. Second, family caregivers’ perceptions regarding the residents’ experience emphasized the negative implications for the residents’ health and well-being, in terms of severe cognitive, physical, and mental deterioration. These perceptions led to a third category, regarding family caregivers’ reactions and coping strategies at the individual level, at the institutions and their procedures, and at the broader social level. Family caregivers’ reactions were at times extreme, to the point of violating the guidelines, and their coping strategies were usually emotional and personal.

The family caregivers’ claims against the nursing homes were harsh. Accordingly, nursing homes’ neglect of residents’ emotional and social needs during the COVID-19 crisis led to residents’ cognitive, physical, and mental deterioration. These findings support similar findings from various countries (e.g., Boucher, 2021; Chu et al., 2020; da Silva et al., 2020; O’Caoimh et al., 2020), and were particularly prominent among residents with cognitive impairment, whose communication abilities were limited. Family caregivers described with great pain and anger their loved ones’ severe mental condition, to the point of self-neglect. A prisoner-like emotional state of their family member in nursing homes was frequently reported by participants, as also found in other studies conducted in Israel, among various long term care facilities’ residents and family members (Avidor & Ayalon, 2022; Ayalon & Avidor, 2021). These findings relate to a paternalistic conception that favors the preservation of life even at the cost of a major decrease in quality of life, loss of autonomy, and social and emotional deprivation.

Moreover, a substantial recurring notion in the findings criticized the policy of restricting family visits in order to lower the risk of infection with COVID-19. Of note, participants accepted the need to be careful about the risk of infection. Yet, nursing homes’ policy and performance were described by family caregivers as rigid, inconsistent, and sometimes illogical or even absurd. The professional community has criticized the visiting restrictions in nursing homes, and objected to the disruption of relationships between residents and their family caregivers (Hado & Friss Feinberg, 2020; Kemp, 2021; Verbeek et al., 2020). The present findings emphasize the importance of addressing the residents’

emotional and social needs, and from the perspective of some of the family caregivers, even at the cost of health risks.

The significance of the family caregiving role in nursing homes in general and during the COVID-19 pandemic in particular can be explained through the convoys of care model (Kemp et al., 2013). According to the model, the outbreak of the COVID-19 pandemic led to a rapid change in the care convoys (networks) of nursing home residents (Kemp, 2021), and the balance of power in the nursing home residents' convoys changed radically and quickly. Thus, according to our respondents, the family caregivers and the residents became more vulnerable during the pandemic.

The vulnerability of nursing homes residents during the COVID-19 crisis is linked to three main factors. One factor is residents' limited functional and cognitive resources, which are major reasons for moving to a nursing home (Chau et al., 2010; Milte et al., 2018). Another factor is nursing homes' characteristics of total institutions that aspire to achieve conformity and obedience (Solomon, 2004) with rigid daily routines, and limited privacy, autonomy, and choice opportunities (Angelelli, 2006; Harnett, 2010; Lang et al., 2007). These totalling features have intensified during the COVID-19 pandemic, while the residents' autonomy was limited due to fear of infection (Avidor & Ayalon, 2022; Ayalon & Avidor, 2021). Third, family caregivers routinely serve as their relatives' representatives in dealing with institution staff (Bern-Klug & Forbes-Thompson, 2008; Davies & Nolan, 2006) and monitor the care they receive (Hennings & Froggatt, 2019; Hoek et al., 2021). Under the conditions created during the pandemic, care networks were reduced without an adequate replacement (Kemp, 2021). Family caregivers felt excluded from care work and could not fill their caregiving roles.

Family caregivers typically have power as consumers within the care convoys. However, the convoys of care model emphasizes how decisions at the organizational or governmental levels affect care convoys (Kemp et al., 2013). In the present case, decisions made at the government level and implemented in the nursing homes resulted in a sharp decrease in the power of the family caregivers within their loved one's care convoys. Study participants expressed feelings of helplessness and despair in light of this. In parallel, many participants chose to cope with the situation by constantly battling with the nursing homes, demanding change, knowingly disobeying regulations, contacting policymakers, officials or the media, and joining an organization of family caregivers of nursing home residents. Participants reported that activism helped: media attention led to changes (even if small), and joining groups helped answer questions and empower participants.

The findings indicate that the a priori complex situation of the family caregivers of nursing home residents has become markedly more complex due to the nursing homes' policies during the COVID-19 outbreak. Specifically, these policies aggravated family caregivers' pre-existing feelings of guilt, distress, and confusion (Hennings & Froggatt, 2019; Majerovitz et al., 2009). Additionally, these policies exacerbated existing tensions between family caregivers and the nursing homes' staff and management (Bauer et al., 2014; Bern-Klug, 2008; Wilson et al., 2009). Of note, despite the tensions with staff and management in the nursing homes, there were family caregivers who appreciated their work, especially in light of the complexities during the COVID-19 period.

Along with our research participants' strong desire to enter nursing homes and stay with their loved ones, a significant issue that did not come up in the focus group discussions is the risk it entails for other residents, beyond their family members. Our findings emphasize the paramount importance that family caregivers ascribed to their relatives' emotional and social needs. They expressed a clear position about the importance of personal encounters with relatives who reside in nursing homes. However, they did not talk about the practical aspects of planning visits at minimum risk, nor about the implications of this option. We suggest considering these findings within the context in which they took place: a period of prolonged lockdowns, weeks in which they were prevented from seeing their relatives, a major change in their care

convoys, and a period of crisis. In situations of crisis, individuals tend to be task-oriented and focus on themselves and their loved ones (Everly & Lating, 2019; McBride & Johnson, 2005). Perhaps the participants were in crisis mode and thus were not emotionally available to assess the broader consequences of their desires and actions, and therefore focused only on their "convoy".

The findings also demonstrate the way in which family caregivers of nursing home residents see themselves: not just as visitors, relatives, or family members of the residents, but as *caregivers*. As such, their roles include maintaining their relatives' well-being, monitoring the care received, and representing them (Bauer et al., 2014; Bern-Klug, 2008; Davies & Nolan, 2006; Hennings & Froggatt, 2019; Hoek et al., 2021). However, the literature points to the role of the informal caregiver as "transparent," with inadequate formal recognition, credited with poor social rights, if any (Charles, Brémault-Phillips, Parmar, Johnson, & Sacrey, 2017). The role of family caregivers of nursing homes' residents seem even more "transparent." Our findings corroborate previous studies conducted during the COVID-19 outbreak that stated that family members are care partners who are crucial for nursing home residents' physical and emotional well-being (Kemp, 2021). We further argue that the extreme situation created by the COVID-19 outbreak highlighted that family caregivers' perceive of themselves as essential caregivers, yet nursing homes and policymakers do not see them that way. Thus, the role status of family caregivers was threatened.

The limitations of the present study include a small sample. The study included family caregivers whose relatives were alive during the study period. Further research is needed with family caregivers whose relatives died as a result of COVID-19 infections or during lockdowns. Another limitation is that the study addresses specific points in time, full lockdowns, which were characterized by a global state of emergency, chaos, and uncertainty. Under such circumstances, role definitions and statuses (as family caregivers) may not reflect their routine meaning. Further research that will follow the perceptions of the family caregivers is recommended.

The study raises several important findings, which have practical implications. First, generally, the study illustrates the complex position of family caregivers of older adults who reside in nursing homes, which was significantly exacerbated during the COVID-19 period. Thus, based on the convoys of care model (Kemp et al., 2013), decision-making processes regarding family caregivers' visits in nursing homes during the pandemic should consider the damage to the older adults' convoys of care and take action to minimize it. Second, the findings indicate family caregivers' frustration at being excluded from their relatives' care. The findings emphasize the importance of perceiving family caregivers as an essential component in the care convoys of older adults in nursing homes, as providers of the older adults' emotional, social, and belonging needs. Hence, the study implications emphasize the need to make the voice of family caregivers of nursing home residents heard, and to socially recognize them as caregivers. This can be done on the individual and group levels through support groups, and on the social level – by presenting policy change recommendations to policy makers. Third, in light of the findings regarding the personal and emotional coping strategies of the family caregivers, guidance and personal counseling can be offered to identify effective coping strategies, in the context of the role of family caregivers in general and during the COVID-19 crisis, or others like it, in particular. Fourth, regarding the family caregivers' claims and reactions directed at the management and staff of the nursing homes, a guided structured dialogue between the parties may help alleviate conflicts and identify cooperative ways to care for the residents in periods of routine and emergency. This can be done through dialogue groups, in a professional setting that respects both sides and allows them to listen to each other, and should help alleviate fears that family caregivers and nursing home residents themselves have after experiencing the forced disconnect of pandemic lockdowns.

To conclude, this study presented the consequences of the isolation policy of nursing homes residents during the global COVID-19 pandemic

crisis, as experienced by the residents' family caregivers. Although the pandemic's peak seems to be behind us, its events illustrate the harsh consequences of the imbalance within the residents' care convoys, and specifically of excluding families from care. The experience gained in this crisis can contribute to preparing for future scenarios in a way that considers the residents' needs and the role of family caregivers.

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Declaration of Competing Interest

None.

Data availability

Data will be made available on request.

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