Original Article

Family caregivers' experience of communication with nursing home staff from admission to end of life during the COVID-19 pandemic: A qualitative study employing a transitional perspective

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Abstract

Objectives. Family caregivers' (FCs) caregiving in nursing home (NH) moves across 3 main phases: transitioning relatives to long-term care, worsening of a relative's conditions, and end of life; each phase brings specific challenges that FCs must confront. Moreover, during the COVID-19 pandemic, strict mandatory visitor restrictions affected communication modalities. This study explored FCs' experience of communication with NH staff during the COVID-19 pandemic from admission to end of life.

Methods. A descriptive qualitative study with inductive content analysis was performed in 7 Italian NHs from May to June 2021. NH managers purposively identified 25 FCs at different phases of their caregiving trajectory: transitional (i.e., admission in the previous 8 weeks, $n = 8$), deterioration-in-condition (i.e., acknowledged changes in care needs of their relative after trigger events, $n = 10$), and end-of-life phase (i.e., death expected in the next weeks or a few months, $n = 7$), who were interviewed.

Results. Regardless the phase of caregiving trajectory, what mattered most to FCs was the opportunity to have regular and sensitive discussions with health-care professionals. The need of in-person communication increased nearing death. The COVID-19 pandemic enhanced FCs' need to interact with health-care professionals they trusted. Knowledge of residents' preferences mitigated FCs' turbulent emotions throughout the overall caregiving trajectory.

Significance of results. Findings suggest that in-person contacts should be prioritized and facilitated when possible, particularly at the end of life; nonetheless, meaningful communication can occur also through remote modalities. Investments in training health-care professionals about effective long-distance communication and supportive skills can help trusting relationships to be established. Open discussions about residents' care preferences should be encouraged.

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Introduction

Caregiving for older adults follows a relatively linear trajectory driven by the progressive functional and often also the cognitive decline of the care recipient (Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division, National Academies of Sciences Engineering, and Medicine 2016). This trajectory may begin with family caregivers (FCs) developing awareness of a relative's progressing illness, evolve into increasing care needs punctuated by episodic events such as falls and hospitalization, and finally involve placement into a nursing home (NH) (Caldwell et al. 2014).

FCs' caregiving in NH moves across 3 main transition phases: transitioning relatives to long-term care, worsening of a relative's clinical conditions, and end of life; each phase brings with its specific challenges that the FCs must confront (Committee on Family Caregiving for Older Adults; Board on Health Care Services, Health and Medicine Division, National Academies of Sciences Engineering, and Medicine 2016).

Transitioning into a NH is stressful for most FCs and includes the decision about NH placement (i.e., pre-transition phase), the choice of the facility (i.e., active transition), and the adaptation to a new role (i.e., post-transition) (Konietzny et al. 2018; Merla et al. 2018). Pre-transition has been described as a period of ambivalence, guilt, powerless, and a sense of

oss, encompassing the time prior to the decision to place the relative into NH. Active transition includes the process of accessing information and choosing the best facility to address a relative's needs. Finally, the post-transition phase is a time of emotional and role adjustments for FCs (Koplow et al. 2015; Merla et al. 2018; Strang et al. 2006). Following this transition phase, families potentially face a series of further care priority transitions (e.g. deterioration-in-condition and end-of-life phase).

FCs experience further challenging times as death approaches, usually after trigger events such as stopping eating/walking or swallowing problems. When this happens, they are more urgently pushed to reflect upon the need to adjust care and the desired end-of-life care (Gonella et al. 2021).

Nearing the end of life, most FCs have to take difficult decisions about treatment options on behalf of their relative who lacks decision-making capacity (Daneau et al. 2020), and this may be challenging even when FCs know prior relative's wishes (Fetherstonhaugh et al. 2017). FCs are often unprepared to make end-of-life decisions and often suffer significant distress and pre-death grief (Sarabia-Cobo et al. 2016).

Clear and supportive communication benefits FCs over the entire institutionalization. It reassures FCs when they make decisions about NH placement, thus resulting in smoother transitions and an improved transitioning experience (Teng et al. 2020).

When facing sudden changes in relative's conditions, open communication is pivotal to promote FCs' understanding of impending death and contributes to early conversations about a palliative-oriented approach (Gonella et al. 2019c; van der Steen et al. 2013). Instead, ineffective communication is often responsible for dissatisfaction with the care provided (Thompson et al. 2012). End-of-life conversations may offer guidance and support and foster FCs' awareness about critical decisions (e.g., artificial feeding and hospitalization) that may deliver more goal-concordant care avoiding non-beneficial treatment (Gonella et al. 2019a, 2019b).

During the COVID-19 pandemic, strict visitation restrictions (Miralles et al. 2021) have forced a shift from in-person visits to remote communication (Ersek et al. 2021), with a negative impact on FCs' psychological well-being (O'Caoimh et al. 2020). However, aside the COVID-19 experience, an increasing number of FCs who act as long-distance caregivers to aged relatives may benefit from remote communication, with easier access to information and enhanced communication with health-care professionals (HCPs) (Williamson et al. 2014). Literature shows that bereaved NH FCs who reported effective remote communication with the health-care team had a better overall experience of end-of-life care (Ersek et al. 2021).

The majority of research on communication in NH is cross-sectional, focuses on the advanced end-of-life phase, and involves FCs of people with dementia. Whether and how communication patterns change over time according to FCs' needs is relatively unknown. Adopting a transitional perspective may capture more dynamic patterns and provide greater insight into the process of communication in NH, throughout the entire resident journey. Moreover, exploring the perspective of FCs regardless of the underlying disease of their relative could offer a more thorough and comprehensive overview. Finally, doubts about the inherent motivation and abilities of FCs for the adoption of remote communication have been risen (Arthanat et al. 2019). Therefore, this study aimed to explore the FCs' experience of communication with NH staff during the COVID-19 pandemic from admission to end of life by employing a transitional perspective.

Methods

Study design

A qualitative study design based on descriptive methodology as described by Sandelowski was performed from May to June 2021. The qualitative descriptive study provides a comprehensive summary of events in their everyday terms and is the method of choice when a straight description of phenomena is desired. Researchers stay close to the data and the surface of words and events (Sandelowski 2000).

The Consolidated Criteria for Reporting Qualitative studies (COREQ) guidelines were followed to report the methodological aspects (Tong et al. 2007) (Supplementary Appendix 1).

Setting and sample selection

Forty-four Italian NHs were purposively sampled for geographical area and size to ensure the greatest variation of data and 8 expressed interest in partaking in the study on a voluntary basis.

NH managers were approached by telephone and mailed the study protocol. Eight of 44 NH managers with a background in medicine ($n = 4$), nursing ($n = 2$), philosophy ($n = 1$), and educational science ($n = 1$) joined the study.

FCs were deemed eligible to participate if their relative was at one of the following phases of care:

Transitional phase: (a) dependent on the activities of daily living; (b) admitted to the NH in the previous 8 weeks; and (c) with a life expectancy >6 months (Merla et al. 2018).

Deterioration-in-condition phase: change in care needs after trigger events such as hospitalization or overall disease progression had been identified (Gonella et al. 2021).

End-of-life phase: death is expected within the next weeks or a few months (White et al. 2017).

Using these criteria, NH managers with the support of direct staff identified the FCs and sent them a preliminary invitation. Twenty-five FCs agreed to participate, and their names were given to the research team, who verified that the FCs met the criteria for one of the phases of care and then contacted them by phone to arrange an interview.

It was estimated to enroll at least 6 FCs for each phase of the NH stay as basic elements for meta-themes arise as early as 6 interviews (Guest et al. 2006).

Participants

In all, 25 FCs (transitional phase [$n = 8$], deterioration-in-condition phase [$n = 10$], and end-of-life phase [n = 7]) across 7 of 8 adhering NHs voluntarily participated in the study. No FCs were available in one NH. Table 1 shows participants' characteristics.

Twenty-one FCs had face-to-face interviews and 4 were interviewed utilizing a video call. The mean duration of interviews was 23 min (range 11–24), 41 min (range 20–71), and 40 min (range 32–52) for the transitional, deterioration-in-condition, and end-of-life phase, respectively. No relevant differences in duration or number of interruptions emerged between interviews done face-to-face and using a video call.

NHs were mostly private ($n = 6/7$). FCs' rationale for selecting the NH for their relative was based on previous friends' or relatives' positive experiences, closeness to home, structural characteristics, vacancy, or economic reasons (Table 1).

Table 1. Participants' characteristics

Family caregivers	Transitional phase (*n* = 8), *N*	Deterioration-in-condition phase (*n* = 10), *N*	End-of-life phase (*n* = 7), *N*
Female gender	5	7	4
Age, years, mean [range]	59 [49–73]	57 [38–72]	63 [51–82]
Education			
Middle	2	1	–
Secondary/ university	6	9	7
Marital status			
Married/cohabitant	6	7	5
Single	1	1	2
Divorced/separated	1	2	–
Employment			
Full-time	3	5	3
Retired	3	5	3
Part-time/freelance	2	–	1
Relationship to the resident			
Adult child	6	8	4
Nice/nephew	–	–	2
Daughter-in-law/ son-in-law	1	1	–
Other[a]	1	1	1
Frequency of visiting before COVID-19 pandemic[b]			
Daily	–	2	2
Two times a week	–	3	1
Once a week	–	3	–
Every 2 weeks	–	2	–
Frequency of visiting after COVID-19 pandemic			
Once a week	7	8	7
Every 2 weeks	1	1	–
Once a month	–	1	–
Reasons for choosing the facility[c]			
Previous friends' or relatives' positive experience	3	5	6
Closeness to home	3	5	3
Structural characteristics (e.g., garden and new building)	4	2	2

(Continued)

Table 1. *(Continued.)*

Family caregivers	Transitional phase (*n* = 8), *N*	Deterioration-in-condition phase (*n* = 10), *N*	End-of-life phase (*n* = 7), *N*
Vacancy	1	2	1
Economic reasons (i.e., lower costs)	1	3	–

COVID-19, Coronavirus disease 19.
[a]Wife in the transitional phase (1), sister in the deterioration-in-condition phase (1), and sister-in-law in the end-of-life phase (1).
[b]All residents in the transitional phase and 4 residents in the end-of-life phase were admitted to the nursing home after the first wave of the COVID-19 pandemic.
[c]More options were possible.

Data collection

Two trained researchers conducted semi-structured in-depth interviews with open-ended and follow-up questions based on the participants' answers. The interview guides were tailored to each phase and refined after the first 2 interviews (Castillo-Montoya 2016). An overview of all final interview guides is provided in Supplementary Appendix 2.

Interviews took place in the modality and setting preferred by the FC and were digitally audio-recorded.

Additional data were collected about FCs' profiles (e.g., gender, age, education, and relationship to the resident).

Transcription and qualitative data analysis

Two researchers transcribed interview recordings verbatim. Another researcher checked transcripts for accuracy. Participants could also review transcripts. Four participants requested copies of transcripts, which were returned with no changes. The full research team was involved in analyzing anonymized interview transcripts shortly after each interview. Transcripts were analyzed using inductive content analysis (Graneheim and Lundman 2004) with the aid of ATLAS.ti 6.2 software. A coding sheet was developed for transcripts of each phase following an iterative process of discussion among the research team (i.e., 3 separate processes of analysis). Transcripts were read carefully several times, and a summary of excerpts was generated and coded. All transcripts were reread as new codes were developed. Similar codes were gathered into categories and similar categories in themes. Themes are illustrated by interviewees' quotations, which are identified by an alphanumeric code indicating the NH and the FC (e.g. NH1/FC1, NH2/FC7, etc.).

The progressive numbers indicate the order in which NHs and FC participants were recruited.

Details of the analysis process are provided in Supplementary Appendix 3.

Trustworthiness

Credibility was pursued by repeated discussion within the research team and member-checking. Dependability was established by having members of the research team review the coding process and agree on categories and themes. An audit trail was maintained. Confirmability was addressed through constant dialogue between the researchers, using audit trails, and excerpts from the

participants. Transferability was enhanced by describing the data collection process and sample characteristics and seeking data saturation. Authenticity was ensured by establishing a trusting relationship with the interviewees and putting them at ease using their preferred modality and setting for the interview (Holloway and Galvin 2016). Further strategies to improve trustworthiness are detailed in Supplementary Appendices 1 and 3.

Quantitative data analysis

Demographic variables and NH-related variables were summarized using quantitative data analysis. Descriptive statistics was performed by computing frequencies, percentages, and mean with standard deviation or range (Table 1).

Results

Overall, 11 themes were identified: 3 related to the transitional phase, 4 to the deterioration-in-condition phase, and 4 to the end-of-life phase (Figure 1 and Table 2).

Transitional phase

Deciding to institutionalize

FCs' awareness that caring for their relative at home was no longer sustainable triggered the transition to the NH. They recognized that their relative's health was deteriorating with increased care needs, and their physical and mental health status had worsened. The burden of caregiving further increased when they had to look after grandchildren, support more than one older adult at the same time, or their caring responsibilities interfered with employment (daughter, 60 years).

The transitional phase was an emotionally turbulent time: the fear of elder abuse portrayed by the media made the challenging decision to institutionalize their relative even harder (daughter, 55 years). FCs often felt lonely in taking this decision, mostly not shared with their relative; they felt guilty for breaking promises that they would always care for their relative and for abandoning their relative. Instead, they felt relieved when the decision was shared with the physician or with other family members or was based on known relative's preferences (daughter, 56 years).

FCs strove to find the right place and based their decision on several factors. Thorough information available through the website or the charter of services as well as the staff's friendliness during preliminary phone contacts were pivotal factors guiding the choice (daughter, 55 years). They also relied on previous knowledge, structural and organizational characteristics of the NH, perception of facilities having adequate services to satisfy their relative's care needs, and proximity to home.

Some FCs had to weigh preferences for a facility with the urgent need to institutionalize and felt pressured to make rushed decisions with limited choice and information (daughter, 60 years).

Establishing a partnership between family caregivers and the facility

All interviewees desired supportive communication: simple, complete, transparent, frequent, and that the staff picked up on their cues and emotions. Bidirectional communication was particularly appreciated with FCs asking for clinical updates and staff keeping them posted on their initiative (daughter, 56 years). In addition to professionalism and clinical competence, they valued compassionate care. Most interviewees perceived that thorough communication is still possible despite visiting restrictions when HCPs are emphatic, kind, available, sensitive, and attentive. Instead, annoyed or bothered behaviors made FCs doubt the quality of care provided to residents (son, 67 years); absent, incomplete, or delayed information caused anxiety and dissatisfaction (daughter, 55 years).

FCs reported being updated about their relative's health conditions in different ways, including email, text messages, photos, phone, and video calls. Despite traditional in-person communication being preferred by most, FCs did highlight the need to move toward new technology-based modalities. Beyond overcoming restrictions due to the COVID-19 pandemic, remote communication was perceived as having great potential to enhance interactions in cases of limited access to the facility (son, 49 years). Thus, they suggested investing in these new communication modalities, even aware of the challenges of making important decisions with remote communication (son, 57 years).

Most FCs desired to play an active role in their relative's care and were satisfied when they were involved in care decisions. Having the opportunity to visit the facility before their relative moved in promoted trust and satisfying interactions. Trust increased when they perceived that their relative received professional and compassionate care. Instead, no open access led to distrust (daughter, 60 years).

Deterioration-in-condition phase

Family caregivers' understanding of their relative's worsening conditions

FCs reported several trigger events, which made them doubt that their relative would recover. Physical deterioration trigger events, such as stopping eating/walking or swallowing problems, were most frequently reported or confirmation trigger events such as the need to call the NH daily or sharing worries with other family members (sister, 67 years; daughter, 66 years).

Most interviewees felt informed and valued the opportunity to ask additional questions. This helped them to become aware of their relative's deterioration. Regular communication about their relative's conditions helped to get prepared for death (daughter, 61 years).

Communicating deterioration

Remote communication was predominant at times of clinical deterioration since quick updates were usually needed. It was largely perceived as a partial substitute for in-person communication; however, FCs appreciated the efforts of NH to find alternative forms of communication to provide clinical updates (daughter, 38 years).

Most interviewees felt that communication about deterioration required significant improvements. This communication was often reported as poor quality, delayed, or absent, with unsatisfying brief updates and often left to chance (daughter, 51 years). Instead, they would prefer frequent and timely updates. Preferred timing and features ranged across interviewees; therefore, tailoring on interviewees' preferences was needed to make communication supportive.

Communicating deterioration required clinical communication competence, professionalism, and compassionate attitudes (e.g., availability, kindness, and sensitivity). Interviewees did not feel supported when the staff were unkind and unprepared (son, 60 years; daughter, 66 years).
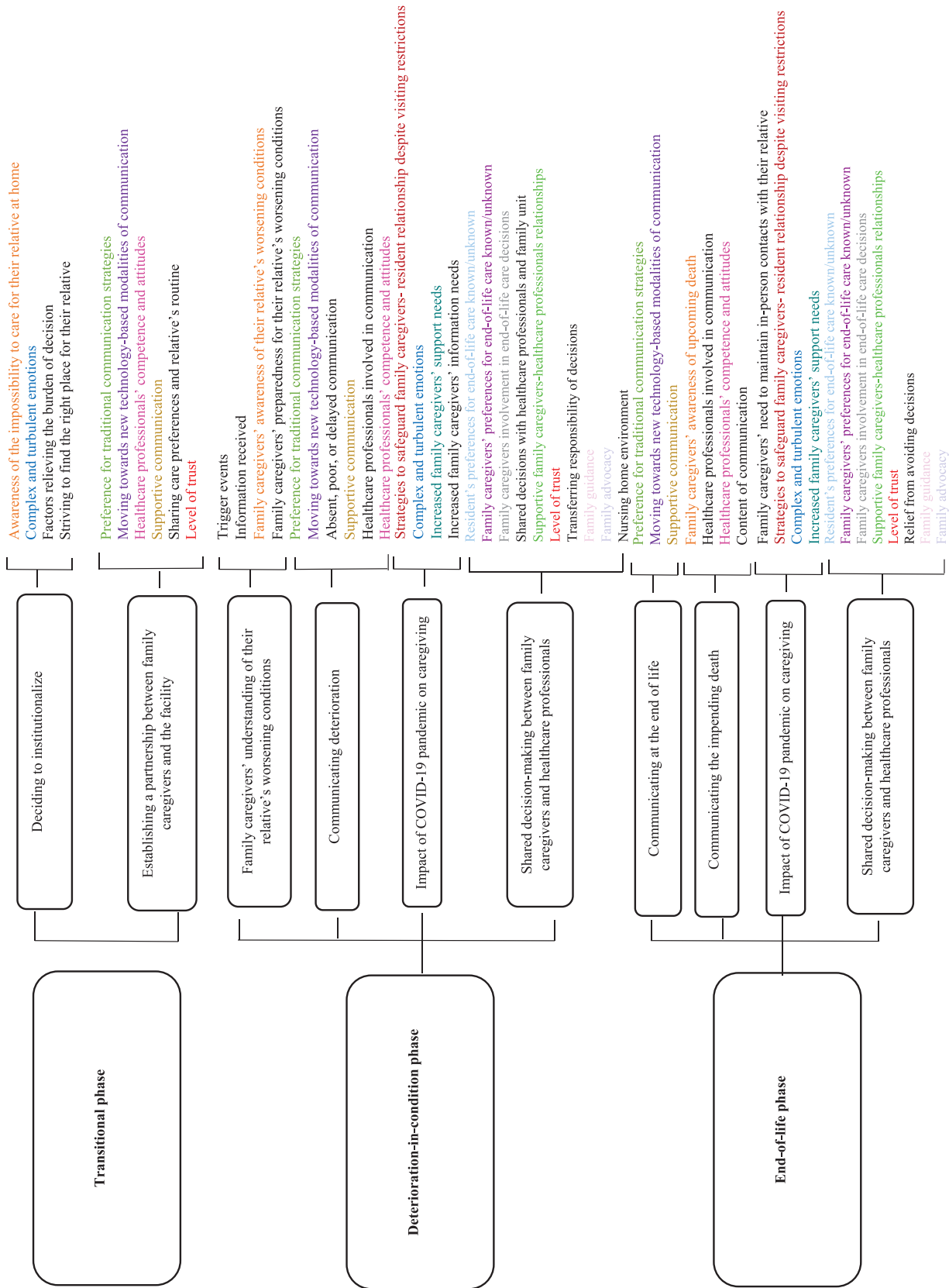
Fig. 1. Categories and themes. Recurrent categories are reported in the same color. COVID-19, Coronavirus disease 19.

Table 2. Participants' illustrative quotations

Phase	Themes	Quotations (alphanumeric code)
Transitional phase	Deciding to institutionalize	"Life was becoming really unbearable, also because I had to look after my mum who suffers from severe heart failure … she is extremely sick and could not live with my dad anymore since his physical and mental conditions were severely worsening." (daughter, 60 years)
		"It was a challenging decision … I feel guilty for taking such a decision […] with what you hear on television about these facilities, cameras are off and doors closed, you don't know how [residents] are cared for." (daughter, 55 years)
		"The decision was taken peacefully because when my mom was still cognitively competent, she expressed the desire to transition to a residential home … […] It was my mum's choice in her times of clarity." (daughter, 56 years)
		"The charter of services and the manager were lived up to my expectations." (daughter, 55 years)
		"Time was running out, I was under pressure, I had to decide quickly and find a solution for this situation by choosing a facility I only knew from outside." (daughter, 55 years)
	Establishing a partnership between family caregivers and the facility	"It's a mutual approach … At least once every 2 days, either they call me or I call them." (daughter, 56 years)
		"Being bothered or annoyed in answering the phone doesn't look well […], one thinks 'if those who have to look after my mum behave in this way' […] the doubt comes." (son, 67 years)
		"I didn't even know if my mum had been vaccinated or not, in my opinion this is extremely serious." (daughter, 55 years)
		"It would be nice to have a gallery with 2 or 3 videos of daily activities as breakfast, launch, or extra-activities […], even only 5 seconds in length. They can be uploaded to a portal with a password for families, so you can get an idea of your relative's life inside the structure." (son, 49 years)
		"Among my peers, I don't think there are several people used to video calls and if one has to make an important decision by this modality … most would be disoriented." (son, 57 years)
		"It's a great thing to be able to see … […] now you come in by appointment. Then they accompany the guest to the living room, briefly, you only see what they want you to see." (daughter, 60 years)
Deterioration-in-condition phase	Family caregivers' understanding of their relative's worsening conditions	"My brother has let himself go, the situation is quite serious because if he doesn't start eating again he can't go on for a long." (sister,67 years)
		"I called the ward or the nurse almost every day to know if he had eaten, drunk, or even just tasted a small dessert or something." (daughter, 66 years)
		"When they regularly tell you how your family member is doing, one realizes the deterioration and get ready." (daughter, 61 years)
	Communicating deterioration	"Whether it is by phone, text messages, in-person, or any other way, I do not care … I want clear communication that makes me take aware decisions for my mom." (daughter, 38 years)
		"I did not get any information spontaneously … I had to insist through my husband who is the medical director of another facility and has contacts to understand why my mom had lost so much weight." (daughter, 51 years)
		"They have been always available to take time to welcome our impressions and discuss them together." (son, 60 years)
		"I would just like to be a little reassured, instead she [member of the NH staff] is very strict, very dictatorial in her attitudes." (daughter, 66 years)
	Impact of COVID-19 pandemic on caregiving	"I think they should have made the situation easier […]. Sometimes, we couldn't even see him through the glass because sun rays reflected in the glass." (daughter, 66 years)
		"It would have been better if I had been warned that I would have seen her in a wheelchair, I would have come to meeting more prepared." (daughter, 50 years)

(Continued)

Table 2. (Continued.)

Phase	Themes	Quotations (alphanumeric code)
		"It would be nice if every guest had a person who knows their whole story, so you can interface with that person who gives you thorough and truthful answers." (daughter, 51 years)
	Shared decision-making between family caregivers and health-care professionals	"I talked to the physiatrist about the pelvic fracture … then I also talked to his general practitioner and the geriatrician. I had a bit of communication with everyone and then I sent all the medical reports via email to the NH manager who acted accordingly." (daughter, 50 years)
		"Beyond the communication of each individual, there is a context that communicates as a whole … an approach that activates collaboration and works with all limitations of this period […]. This is a context that activates, engages in communication, makes people feel part. (daughter,61 years)
		"We called a geriatrician who increased one dose of medicine and removed another […]. Then, I also inquired from some nurse friends to understand how the disease goes, whether there may be need of invasive interventions and what decisions to make." (daughter, 51 years)
		"Already in 2005, my mum had drawn her living will up and I provided a copy to the NH. […] As requested by the facility, I put in writing that I completely agreed with what my mother wrote. That is, I considered adequate those interventions aimed to control pain but nothing more." (son, 60 years)
End-of-life phase	Communicating at the end of life	"You can better realize the context and staff availability when in-person, you may not get it over the phone." (daughter, 67 years)
		"I've never had the impression of being faced with a standard communication, but communication is tailored to me." (son, 55 years)
	Communicating the impending death	"There was no longer way to make her swallow anything. That was worrying because a person who no longer eats […], cannot go on." (nephew, 51 years)
		"Once I burst into tears, [the chief medical officer and the NH manager] comforted me, they were very present." (daughter, 60 years)
	Impact of COVID-19 pandemic on caregiving	"They were afraid of losing her in the night. Thus, our visit has been anticipated to yesterday and my sister will go tomorrow, […], we saw her." (daughter, 60 years)
		"Loneliness, we suffered loneliness, they [residents] suffered loneliness. […] I'd have liked to be there." (daughter, 67 years)
		"It would take a person with an in-depth knowledge of each resident just to take care of communication with family caregivers." (son, 55 years)
		"They [NH] should establish a specific time to phone. […] Currently, they are really busy and sometimes can't answer, thus you have the feeling of being abandoned." (daughter, 60 years)
	Shared decision-making between family caregivers and health-care professionals	"We strongly recommended them to not make her suffer. It doesn't make sense to live 2 more hours in pain." (niece, 70 years)
		"They look after her very well and tell us all the things they do … They even tell us before, so we feel quite calm." (son, 55 years)
		"Sometimes they tell me 'we have changed the treatment,' […] I feel updated, involvement is something different." (daughter, 67 years)
		"Staff instability makes you feel confused for a while when you loose your contact person." (son, 55 years)
		"The decision to hospitalize was taken unilaterally by the staff, and I am very happy about this. Their competence is not comparable to mine. I believe that things should be done this way." (nephew, 51 years)

NH, nursing home.

Impact of the COVID-19 pandemic on caregiving

During the COVID-19 lockdown, FCs experienced a set of unpleasant emotions. They felt lonely, upset, distressed, and angry for not being allowed to stay with their relative in times of need, in addition to be worried about what was happening in the NH. Most NHs implemented strategies to safeguard FCs–resident relationships; besides phone and video calls, hug-room visits and visits through plexiglass were organized, and in some cases, in-person

visits were maintained. Nonetheless, some interviewees perceived the strategies adopted as inadequate and thought that the NH could do more (daughter, 66 years).

The COVID-19 lockdown increased FCs' information and support needs. They needed comprehensive and regular updates to understand their relative's situation: clinical details were mostly not useful and more frequent calls alone were not enough to reassure interviewees. They needed more staff attentiveness, a single point of contact to communicate, exclusive time to share their doubts, and psychological preparation before in-person visits (daughter, 50 years; daughter, 51 years). Emotional support was often limited by a staffing shortage.

Shared decision-making between family caregivers and health-care professionals

FCs generally felt in line with staff and involved in important decisions such as hospitalization and desired care intensity, while they were usually informed post facto for daily care interventions (daughter, 50 years).

When collaborative relationships were established, interviewees felt safe and looked for staff's guidance in taking decisions or transferred responsibility for decisions to HCPs (daughter, 61 years). Instead, distrust directed families to search for alternative sources of information external to the NH to adjust the care plan (daughter, 51 years).

FCs' preferences for end-of-life care were usually comfort-oriented, but poorly known by staff; residents' preferences were poorly known also by their FCs. When known, FCs advocated for their relative's care preferences (son, 60 years).

End-of-life phase

Communicating at the end of life

At the end of life, remote communication was largely employed, while in-person communication was limited even if preferred. Some limits of remote communication, such as missed knowledge of the speaker and the inability to assess HCPs' non-verbal cues, were identified (daughter, 67 years). However, 3 interviewees did not find any difference between in-person and remote communication.

FCs desired transparent, open, human, personalized, and consistent communication among HCPs (son, 55 years). They appreciated increased updates, proactive information, and meetings involving all FCs involved in making decisions.

Communicating the impending death

Awareness of nearing death was mostly promoted by trigger events (e.g., stop eating). Some FCs acknowledged a progressive disease with no therapeutic opportunity to recover (nephew, 51 years).

End-of-life communication aimed to explain that death was likely in a short time and provide emotional support. It was usually provided by the chief medical officer, rarely by nurses or psychologists. FCs valued the staff's caring attitudes as equally important to clinical competence when providing this sensitive communication (daughter, 60 years).

Impact of COVID-19 pandemic on caregiving

All interviewees felt a compelling need to stay in contact with their relative at the end of life and appreciated when NHs provided several alternatives beyond video calls, including outdoor visits, visits through plexiglass, and window visits, in addition to moving up the visit when doubt of impending death arose (daughter, 60 years).

The pandemic increased FCs' turbulent emotions due to sudden and unexpected detachment. FCs perceived the interruption of regular visits to speed the clinical deterioration of their relative, felt frustrated with the inability of actively participating in basic care activities, and were devastated for leaving one's relative alone at death (daughter, 67 years). Their support needs dramatically increased during the pandemic: FCs needed to be reassured that they were not abandoning their relative and their relative did not feel abandoned. Most highlighted the need for a key contact person for communicating with, exclusive time for communication without interruptions, and the ability to provide psychological support (son, 55 years; daughter, 60 years).

Shared decision-making between family caregivers and health-care professionals

Nearing the end of life, several FCs reported that staff knew FCs' care preferences aimed at relieving pain and improving the quality of remaining life (niece, 70 years). Instead, the resident's preferences remained poorly known by both FCs and staff.

Decisions about pain management, accessing emergency services, and hospitalization were usually shared. The timing of information was pivotal to perceive involvement in care decisions; receiving information before taking care decisions positively impacted perceived involvement (son, 55 years), while post hoc information was associated with the perception of poor involvement (daughter, 67 years).

FCs reported needing guidance and support by HCPs in navigating difficult care decisions at the end of life. Most of them felt listened to and connected with staff, despite staff turnover sometimes threatening trusting relationships being developed (son, 55 years).

Others transferred the responsibility of decisions to the staff and felt relieved when they did not have to decide due to their limited clinical knowledge (nephew, 51 years). Trust and supportive relationships promoted the sharing of decisions and ability to trust HCPs' clinical guidance.

Discussion

This study explored FCs' experience of communication with NH staff during the COVID-19 pandemic from admission to end of life by employing a transitional perspective.

Our findings confirm that FCs experience significant transitions during their caregiving trajectory, including (a) moving from home care to long-term care, (b) acknowledging their relative's deteriorating clinical condition with no opportunity for recovery, and (c) entering the end-of-life phase. However, boundaries between these 3 phases are often blurred and it is difficult to determine when the end of life begins. New residents are older and with a high burden of comorbidity often combined with impaired physical and cognitive functioning (Ng et al. 2020). Their death is usually expected within 3 years of the transfer to a NH (Joling et al. 2020). This suggests that transitioning from home to NH may overlap with the clinical deterioration phase or even the end-of-life phase. Our findings show the recurrence of some issues, such as FCs' awareness that changes are occurring, the multitude of complex and turbulent emotions, the need for supportive person-centered communication, staff's caring attitudes and trusting relationships with HCPs, and the knowledge of the residents' care preferences. This overlap became even more evident across the final 2 phases; however, the time frame contributed to the FCs' communication experience with unique nuances that mostly concerned the emotional sphere and the knowledge of their care preferences. Indeed,

as death approaches, FCs' need to stay in contact with their relative and be emotionally supported became more urgent, and their care preferences were increasingly disclosed to HCPs.

FCs' awareness that something is changing is a recurring issue throughout the caregiving trajectory and involves critical turning points or events. During the transitional phase, FCs realize that home care has become impossible due to their relative's increased basic needs and declining cognitive status, which make the caregiving burden unbearable (Konietzny et al. 2018). During the deterioration-in-condition phase, FCs acknowledge that their relative's conditions are getting worse through physical deterioration events (e.g., stopping eating/walking) or confirmation events (e.g., daily phoning to check the relative's conditions) (Gonella et al. 2021). Finally, during the end-of-life phase, FCs recognize that their relative's death is close and their evaluation of the quality of life guides choices for treatment intensity (Caron et al. 2005).

FCs experienced turbulent emotions throughout the entire care period in NH, and the COVID-19 pandemic heavily influenced their caregiving experience. Consistently with the literature, guilt and uncertainty with the difficult decision to institutionalize were predominant during the transitional phase (Konietzny et al. 2018; Merla et al. 2018). Moreover, during the COVID-19 time, they had to choose the NH without having the opportunity of direct access due to visitation guidelines. At times of deterioration, they felt upset, distressed, and angry for not being allowed to take care of their relative in need; and at the end of life, they felt frustrated and distressed about leaving their relative alone close to death. At the end of life, the COVID-19 pandemic makes FCs' emotions even more turbulent: FCs complained of not staying close to their relative as they would like, despite NHs best efforts to provide in-person contacts.

Person-centered communication appears a worthy resource to support FCs through all the transition phases. Open communication can assist FCs in weighing the pros and cons of transitioning to long-term care and mitigate the anxiety and guilt of making placement decisions (Teng et al. 2020). When residents' conditions worsen, supportive communication helps FCs to understand trigger events and the potential disease trajectory and prepare for death (Gonella et al. 2021; Hebert et al. 2009). At the end of life, person-centered communication facilitates the provision of palliative-oriented care while providing FCs emotional support (Gonella et al. 2019a, 2022a). During a period of visiting restriction, it becomes even more important to facilitate regular communication between HCPs and FCs to satisfy FCs' increased information and supportive needs (Hartigan et al. 2021; Morris et al. 2020; Wammes et al. 2020). However, these relationships may be particularly challenging at times of strict visitation restrictions and necessitate strengthening new communication channels (Hado and Friss Feinberg 2020). Our findings suggest the potential usefulness of remote communication with new technology-based modalities helps maintain regular communication across the overall NH stay and reduce loneliness (Cormi et al. 2020; O'Caoimh et al. 2020). What mattered most across all interviews was the opportunity for sensitive and personalized communication rather than the modality employed. Consistently with previous literature (Ersek et al. 2021; van der Steen et al. 2017; Zmora et al. 2021), NH environment and interpersonal relationships were integral to FCs' experience of communication and care: our FCs felt supported when perceiving a familiar atmosphere and HCPs who used a collaborative approach, listened to them, and took initiative in keeping them informed. As previously highlighted, FCs appreciated when HCPs tried to facilitate alternative contact possibilities

apart from telephone and video calls to stay in contact with their relative; instead, they had less confidence in the care of their relatives when staff tended to be annoyed and inattentive (Morris et al. 2020; Wammes et al. 2020). Particularly, at the end of life, good communication, clear and reliable information, as well as relationship-centered care and HCPs' caring attitudes were valued as much as clinical competence and professionalism. The need for in-person communication and meetings involving all FCs in charge of making decisions increased nearing death. To satisfy this need, the NHs maintained FCs' visits for "compassionate care situations" (Bergman et al. 2020). When health conditions deteriorated or death was close, FCs preferred to have a single point of contact they trusted and exclusive time slots to share concerns. Not knowing which staff member to contact for concern may be a frustration (Hart et al. 2020; Wammes et al. 2020; Zmora et al. 2021). Trusting and supportive relationships may mitigate FCs' unpleasant emotions and their burden in navigating care decisions. Overall, our findings highlight that meaningful and comforting communication can occur also at distance and mitigate the distress experienced by FCs if it is led by competent, sensitive, and trusted HCPs.

Trusting relationships between FCs and HCPs can take time to develop and be negatively impacted by events such as a confusing phone call or frequent staff turnover. This may lead to a sense of overall disorientation for FCs (Zmora et al. 2021). Therefore, it is important to establish a partnership following the transitional phase. Our FCs started to develop trust toward the NH and the staff during the selection process of the facility, which was usually a stressful and time-consuming search. Open access to the NH before institutionalization as well as HCPs taking the time to explore routines that new residents had at home promoted trust. Frequent updates about residents' clinical condition strengthened FCs' trust in the competence of HCPs. High levels of trust make FCs feel emotionally supported (Lopez et al. 2013) and are associated with positive experiences of communication (Boogaard et al. 2017). When our interviewees trusted HCPs, they were more likely to rely on their guidance to navigate difficult care decisions and sometimes may decide to hand decisions over to HCPs, thus confirming previous works (Frey et al. 2017; Gonella et al. 2020). In fact, if the shared decision-making steps had taken place (i.e., information that a decision needs to be made, explanation of the care options and their pros and cons, and discussion of the resident's preferences) (Stiggelbout et al. 2015), FCs were sure that the HCPs would take the best decision for their relative and felt relieved to avoid the burden of deciding.

Knowing residents' preferences played a pivotal role for FCs at all time points in mitigating difficult emotions and facilitate good palliative care (Goodman et al. 2013). When residents had previously considered being admitted to a NH, their FCs perceived the decision to institutionalize as less burdensome. Being aware of their relative's preferences for comfort-oriented care at the end of life reduced FCs' uncertainty to make the right choice when opting for symptom control and promote a focus on quality of life. This confirmed that known relative's preferences reduce burdensome care at the end of life (Bischoff et al. 2013). When residents suffer from advanced dementia and their preferences have not been previously explored or when their preferences did not align with FCs' ones (Cohen et al. 2019), FCs could experience a challenging advocacy role (Fetherstonhaugh et al. 2017).

In summary, our findings suggest the need to co-design and trial educational materials for FCs that prepare them for each of the 3 phases of transition. FCs require tailored resources to meet their information needs as they and their relative transition from

admission to the end of life. Moreover, our data suggest that NHs would benefit from investments in communication skills training targeted at all HCPs, to improve their confidence in sustaining challenging conversations, and improve the quality of communication. Finally, future studies should evaluate which remote communication techniques and support systems may be most effective to meet the needs of FCs when they could not have frequent in-presence meetings with HCPs. There is a strong consensus in the paper that FCs require regular and consistent updates: an electronic tracking system that assists HCPs with updates of FCs may be useful to manage the communication pipeline and ensure a systematic approach to communication with FCs.

Limitations

This study took place in Italy and mainly involved the residents' adult children, consistently with literature that shows around 70% of adult children being responsible for caregiving activity after institutionalization (Gonella et al. 2019b). Anyway, in Italy, filial obligation toward older parents is more deeply rooted compared to other cultures (Albertini and Mantovani 2021). This sense of responsibility has likely influenced FCs' desire to be involved in the care of their relative and increased their frustration during the COVID-19 pandemic when they could not freely enter the NH. FCs' unmet expectations to fulfill this social obligation boosted anger and aggressive behaviors toward HCPs, particularly as death approaches (Gonella et al. 2022b).

We looked at the family caregiving trajectory by employing a transitional perspective to identify changes in the pattern of communication during the NH stay. We are aware that a longitudinal design may have been more valuable to capture the dynamics of individuals; however, it would not have been possible to frame the phenomenon within the COVID-19 experience. Moreover, data about the length of residents' stay in NH were not collected. Time is pivotal in establishing trusting relationships between FCs and HCPs, and this information would have provided greater insight into the FCs' shared decision-making and caregiving experience.

While qualitative research is not usually aimed at generalizability (Mills and Birks 2014), we believe that our findings could be transferrable to other FCs of NH residents who experienced visitation restrictions due to COVID-19. Indeed, all countries worldwide restricted visits to minimize infection transmission, thus preventing FCs from in-person contacts with both their relative and HCPs and threatening FCs' well-being and their relationships with the NH staff (O'Caoimh et al. 2020; Wammes et al. 2020).

Conclusion

Our findings suggest that the challenging transitions experienced by FCs during their caregiving are strictly intertwined and may overlap, including shifting from home care to long-term care, when acknowledging that their relative cannot recover anymore, and when recognizing that death is close. These transitions and subsequent FCs' role changes, along with the functional and cognitive decline of their relative, affect the social, physical, and emotional health of FCs over time.

Person-centered communication and trusting relationships between FCs and HCPs become even more important given the increased FCs' distress due to COVID-19 pandemic-related visitation restrictions, particularly nearing death. What matters most to FCs is the opportunity to have regular and sensitive contacts with HCPs even with remote communication. However, technology alone is not enough and requires HCPs to have caring attitudes combined with skilled communication to instill confidence in FCs that their relative is receiving quality care.

The knowledge of residents' care preferences partially mitigates FCs' decision-making burden. Therefore, open discussions between HCPs, residents, and/or FCs should take place from the time of admission and regularly over the NH stay to explore the resident's preferences. Also, people with dementia should be actively involved in discussions as long as they maintain a good decision capacity to make their care preferences clear.

Technology-based modalities of communication can be useful beyond the pandemic to promote meaningful interactions when FCs cannot regularly access the facility in person. Therefore, NH managers should promote frequent and multiple alternative contact opportunities for FCs to stay in contact with their relative and HCPs, when their presence at the bedside is not possible. Moreover, government and local leaders should invest in training HCPs to promote the development of effective remote communication and supportive skills.

Identification of a single point of contact for FCs, if possible, is worthy to promote consistent communication and the development of trusting relationships, particularly in times of in-person visitation restrictions. Finally, open discussions about residents' preferences between HCPs, residents, and/or FCs should take place at the time of admission and regularly over the NH stay to mitigate FCs' decision-making burden.

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