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A qualitative study of family carers views on how end-of-life communication contributes to palliative-oriented care in nursing home

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Abstract

Background. Although family-centered communication about end-of-life care has been recognized to promote palliative-oriented care in nursing home (NH), how this communication may work is still unknown. Therefore, we explored the mechanisms by which end-of-life communication may contribute to palliative-oriented care in NH from the perspective of bereaved family carers.

Methods. A descriptive qualitative design was performed. Interviews were conducted with 32 bereaved family carers whose relative had died between 45 days to 9 months prior from 13 different NHs. A two-steps analysis process firstly with deductive and then with inductive content analysis was adopted.

Results. Four mechanisms by which end-of-life communication contributed to palliative-oriented care were identified: a) promoting family carers understanding about their relative's health conditions, prognosis, and treatments available; b) fostering shared decision-making between healthcare professionals and residents/family carers; c) improving knowledge of residents' preferences; and d) improving knowledge of family carers' preferences.

Conclusion. Clear and in-depth communication provides insight into residents' and family carers' preferences for care and treatment at the end-of-life, and increases understanding and shared decision-making.

Key words
- family
- nursing homes
- palliative care
- communication
- decision-making
- qualitative research

INTRODUCTION

An increasing proportion of residents living in nursing home (NH) requires adjustments of the care plan at the end-of-life with care aimed at improving comfort and quality of life – as in palliative care – becoming more appropriate, due to the shift in the epidemiology of dying from acute deaths to chronic progressive illnesses-related deaths [1].

Family carers of NH residents are more satisfied with end-of-life care when a shared comfort goal is established with healthcare professionals (HCPs) [2] and play a pivotal role in the transition from curative- to palliative-oriented care [3, 4].

Clear communication between HCPs and family carers should develop over time in relation to the resident's changing conditions, to allow each person to actively participate in the decision-making process, and pay attention to the resident's physical needs and to the psychological and social needs of residents and their family carers [5].

Since family-centered communication about end-of-life care improves the quality of dying [6], literature stresses the importance of continuous communication with family carers about care and prognosis, involvement of family carers in care, assessment of their needs, and acknowledgment of their care role [7]. HCPs taking the time to discuss and establish a partnership with family carers facilitated the provision of palliative-oriented care [8] and residents whose family carers were satisfied with physician communication were more likely to have a comfort care goal [6]. Unfortunately, the opportunity to establish communication about end-of-life care plans is often missed [9] and its quality is poor [10]. Previous authors [11] found family carers to report negative perceptions about clarity of information and about what to expect during the dying process.

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Poor communication negatively influenced family carers experience with end-of-life care and was associated with poor resident outcomes [12].

Although end-of-life communication has been recognized to promote palliative-oriented care in NH [13], how communication may work is still unknown. Hence, this study aimed at exploring the mechanisms by which end-of-life communication contributes to palliative-oriented care in NH from the perspective of bereaved family carers.

METHODS

Study design

A descriptive qualitative study was carried out.

The COnsolidated criteria for REporting Qualitative studies (COREQ) guidelines were followed to report the methodological aspects [14] *(Supplementary Table 1, available online)*.

Setting, participants and sample selection

Fifty-two NHs were purposively sampled for geographical area and different size in Piedmont – northwest Italy – to ensure the greatest possible variation of data and 20 adhered to the study on a voluntary basis.

Family carers were eligible if a) they were willing to participate, and their relative b) spent the last 30 days of their life in NH and c) had died in NH from 45 days to 9 months prior the study started. The NH director with the help of the direct staff purposefully identified bereaved family carers to include information-rich cases related to the phenomenon under study (i.e., end-of-life communication). Family carers were then contacted according to the NH preferences: i.e. a) by phone call with preliminary contact by the director to inform of the study and request permission for contact by the research team, b) interview directly scheduled by the director, or c) a personalized letter of condolence with a brief presentation of the project and the researchers' phone number.

In all, 32 family carers across 13/20 adhering NHs participated in the study.

Most family carers were female (n = 20) and the mean age was 58 years [range 35-71]. The relation with the resident was adult child (n = 19), nice/nephew (n = 7), daughter-in-law (n = 3), others (n = 3) (sister-in-law, cousin, and wife), and the majority visited their relative daily (n = 12) *(Table 1)*.

Family carers' interview was recorded after a median of 106 days (interquartile range 68-175) after their relative's death. Two family carers had their interview over telephone and three interviews were in double (two interviews with child and daughter-in-law, and one interview with two nieces). Mean duration of interviews was 38 minutes (SD 22.6).

Data collection

Semi-structured in-depth interviews [15] with bereaved family carers of NH residents were conducted by two researchers (S.G. and I.B.). An open-ended interview technique with follow-up questions related to the participants' answers was employed. The interview guide was refined after the first 10 interviews to better explore emerging topics [16]. *Box 1* provides an overview of the final interview guide.

Table 1

Demographics of family carers of nursing home residents (n = 32)

Family carers	**N (%)**
Female gender	20 (62.5)
Age, years, mean [range]	58 [35-71]
Education	
Middle	5 (15.6)
Secondary/university	27 (84.4)
Marital status	
Married/cohabitant	22 (68.8)
Widowed/single	6 (18.7)
Divorced/separated	4 (12.5)
Employment	
Full-time	14 (43.8)
Retired	11 (34.4)
Housewife	4 (12.5)
Part-time/freelance	3 (9.3)
Relationship to the resident	
Adult child	19 (59.4)
Nice/nephew	7 (21.9)
Daughter-in-law	3 (9.4)
Other†	3 (9.4)
Frequency of visiting	
Daily	12 (37.5)
Three/four times a week	5 (15.6)
Two/three times a week	13 (40.6)
Less than once a month‡	2 (6.2)
Main contact person	
Interviewee and one or more family carers	20 (62.5)
Interviewee only	11 (34.4)
Interviewee and social worker	1 (3.1)

†Sister-in-law (1), cousin (1), wife (1)
‡Every 45 days (1); every 3 months (1)

All interviews were digitally audio-recorded.

Additional data were collected about:

a) residents' demographics and clinical information (clinical records, *Table 2*).
b) NHs' profile and their working processes. NH directors filled in a semi-structured questionnaire that explored: i) NH organizational features (e.g., public or private profile, bed size, *Table 3*); ii) frequency of end-of-life communication between NH staff and family carers during the last 6 months on a 5-points Likert scale (never to always); and iii) activation of the palliative care service during the last 6 months (i.e., number of and reasons for activations).

Data were collected from December 2018 to May 2019.

Transcription and analysis

S.G. and I.B. transcribed the interviews verbatim. M.C. checked a random sample of transcripts for accuracy. Analysis of the interview transcripts started shortly after each interview.

The analysis process consisted of two stages:

1. data were analysed using a deductive content analysis [17] (i.e., theory-driven approach where codes derived from data are organized in an a-priori framework) referring to a communication framework that

Box 1
Interview guide

1. Please, can you tell me how your relative died? Have her/his health conditions gradually or suddenly worsened?
2. Have you talked about the care provided to your relative with the nursing home staff or the physician during her/his last week of life? Can you tell me a positive episode and a negative episode about communication with the nursing home staff or the physician?
3. The week before your relative's death, have you thought that she/he would be died within 7 days? Why?
4. Have you felt involved in planning for care during the last week of life of your relative? How the nursing home staff/physician promoted your involvement?
5. Have you talked about preferences for care at the end-of-life with your relative when she/he was at home or during her/his nursing home stay?
6. Do you know whether your relative talked about her/his preferences for care at the end-of-life with the nursing home staff/physician? Have any meetings about preferences for care and treatments at the end-of-life taken place between HCPs and the resident or HCPs, resident and family carers?
7. Have the nursing home staff or the physician asked you which type of care or treatment you would have desired at the end-of-life for your relative?
8. Did your relative suffer from distressing symptoms (e.g, pain, difficulty in breathing) during her/his last week of life? Are you satisfied with the management of symptoms?
9. Feel free to add whatever.

HCPs, Healthcare professionals

Table 2
Demographics of nursing home residents (n = 32)

Residents	**N (%)**
Female gender	23 (71.9)
Age, years, mean [range]	88.8 [75-99]
Length of residence, months, median [IQR]	18 [5-36]
Treatments in the last week of life (n = 133)	
Antibiotics	12 (9.0)
Curative-oriented treatments	71 (53.4)
Intravenous hydration	24 (18.0)
Blood test	12 (9.0)
Peripheral cannulation	11 (8.3)
Call to the emergency services	6 (4.5)
Bladder catheter	6 (4.5)
Access to emergency department	5 (3.8)
Other[†]	7 (5.3)
Palliative-oriented treatments	50 (37.6)
Oxygen therapy	15 (11.3)
Assessment of pain/discomfort	13 (9.8)
Hypodermic hydration	11 (8.3)
Oral therapy withdrawal	4 (3.0)
Opioid analgesics	4 (3.0)
Other[‡]	3 (2.3)
Cause of worsening conditions (n = 46)	
Pulmonary infection	11 (23.9)
Severe dehydration	10 (21.7)
Worsening of dementia	7 (15.2)
Urinary infection	6 (13.0)
Worsening of neurodegenerative disease	4 (8.7)
Other[§]	8 (17.4)
Cause of death	
Cardiac arrest	17 (53.1)
Cachexia	6 (18.7)
Dementia	3 (9.4)
Sepsis	3 (9.4)
Other organ failure	3 (9.4)

[†] Glycemic monitoring (2), parenteral nutrition (2), enteral nutrition (1), cardiopulmonary resuscitation (1), hospitalization (1)
[‡] Oral aspiration (2), palliative sedation (1)
[§] Fall (two with trauma and one without complications), ab ingestis (2), worsening of respiratory disease (2), pressure ulcer infection (1)
IQR, interquartile range

Table 3
Nursing home characteristics (n = 13)

Characteristics	**N**
Profile	
Private	11
Public	2
Bed size, mean (SD)	78 (34)
≤ 60	4
61-119	6
≥ 120	3
Beds for functionally independent residents, mean (SD)	25 (16)
Beds for functionally dependent residents, mean (SD)	53 (29)
Number of death per year, mean (SD)	20 (9)
Beds for hospice care in the structure, mean (SD)	0
Alzheimer unit	2

SD, Standard deviation.

had previously described the potential mechanisms by which end-of-life communication may contribute to palliative-oriented care in NH [18];

2. data not fitting this categorisation frame were analysed through inductive content analysis (i.e., new categories and themes emerging by data supplemented the original framework) [17].

Analysis was aided by the software ATLAS.ti 6.2.

Themes are illustrated by participants' quotations that are identified by an alphanumeric code to ensure confidentialy (e.g., NH1, FC1). NH refers to the facility where the participant's relative died, FC refers to the interviewee. The progressive numbers indicate the order in which facilities and participants were recruited.

Details of the analysis process are provided in *Supplementary Table 2* (available online).

Trustworthiness

The process of continuous self-reflection known as reflexivity which was aimed at improving transparency in the researcher's subjective role [19], was sought through repeated discussions within the team about alternative interpretations of the results. Repeated reading of the interview transcripts and repeated discussions with coauthors of emerging categories, themes and illustrative extracts were undertaken to validate the findings. An audit trail was kept throughout all the analysis process. Further strategies to improve trustworthiness are detailed in *Supplementary Table 1 and 2* (available online).

Ethics

The study was approved by the Ethics Committee of the University of Torino (Italy, reference 457626/10.12.2018). All participants gave their written informed consent after receiving oral and written information about the aim of the study. All participants could stop the interview at any time and for any reasons, and a protocol to manage the onset of emotional distress was available.

The timeframe of family carers' recruitment was consistent with previous research [20], to reduce the emotional burden on participants while avoiding recall bias.

Data collections forms about residents' demographics and clinical information were anonymous with residents identified with a progressive number, which was paired with their family carer's interview. Data collection forms as well as the transcribed interviews were stored in the archive of the University of Torino and could be accessed only by the research team.

RESULTS

Family carers' experience

The original communication framework [18] was updated and finally consisted of six themes and 21 categories that describe family carers' perspective about the mechanisms by which end-of-life communication may contribute to palliative-oriented care in NH *(Figure 1, Supplementary Table 3 available online)*. Specifically, (1) HCP-resident and HCP-family carers end-of-life communication may promote or hinder a (2) gradual shift to palliative-oriented care by acting on (3) family carers understanding about their relative's health conditions, prognosis, and treatments available, (4) shared decision-making between HCPs and residents/family carers, (5) knowledge of residents' preferences, and (6) knowledge of family carers' preferences.

Theme 1. Healthcare professional-resident and healthcare professional-family carers end-of-life communication

Several HCPs were involved in end-of-life communications, including nurses, head nurses, nurse aides, physicians and NH directors, although few family carers where engaged in multiprofessional communications.

Communication was both verbal and non-spoken, generally face-to-face even if communication over phone was largely employed when compelling issues needed to be discussed with family carers or when family carers lived far.

End-of-life communication was often described as clear, honest and constant, but often occurring late in the dying process (usually one week before death, range one month to few days). Moreover, while communication with nurses and nurse aides was generally frequent, many interviewees were dissatisfied that the physician was rarely or never seen in the NH. Communication with the physician was fortuitous and often family carers had to look for information by phone or going to the physician's office to be updated. No interviewee was asked about what they would have desired for their relative's end-of-life care by any HCPs:

- "The communication was direct, open, clear and got to the point" (NH4, FC9);
- "I never talked to the physician, I saw him only the day of my mother-in-law's death" (NH11, FC28).

Family carers reported both barriers and facilitators of end-of-life communication. Among the former, different linguistic and cultural background and limited family desire to ask were frequently reported; among the latter, family carers reported their recognition of changes in their relative's health and the characteristics of the setting where communication took place. They appreciated being provided information in a private environment (e.g., nursing office, NH director office) or in places closed to the relative's room (e.g., bedside, corridor):

- "I didn't ask, I didn't go too far in asking" (NH10, FC24);
- "I noticed that my uncle had some difficulties in breathing, therefore I asked the nurse to measure his vital signs … thus I recognized the problem and activated the process that led to his physician's visit [...]. Then, talking to the physician, we started to personalize my uncle's therapy" (NH5, FC12).

Theme 2. Gradual shift to palliative-oriented care

Most family carers reported that end-of-life care was palliative-oriented rather than curative-oriented, with oral therapy usually stopped and their relative sustained by hypodermic hydration. Many interviewees stated that their relative received psychological support, spiritual support, had basic needs fully fulfilled and died without distressing symptoms:

- "During the last week she was hydrated subcutaneously" (NH1, FC3);
- "I don't think she was in pain because she never complained, she went out just like a candle". (NH3, FC7).

A large proportion of family carers felt emotionally supported by all those working in the NH and were relaxed when coming back home to rest since they were sure to be called if their relative conditions should have worsened. They appreciated to be called in time for sharing the last moments with their relative:

- "Here I had a practical and moral support, especially moral" (NH2, FC5);
- "It has been very important for us to spend some moments more with our father when he was still lucid, above all because we lived far […]. They allowed us, they warned us in time, they let us ... they gave us the time, they allowed us to say him goodbye" (NH1, FC3).

However, those family carers that perceived poor information and involvement in end-of-life, they also complained of having missed their relative's death since they were not called in time:

- "They called me 3 minutes before she died… my work

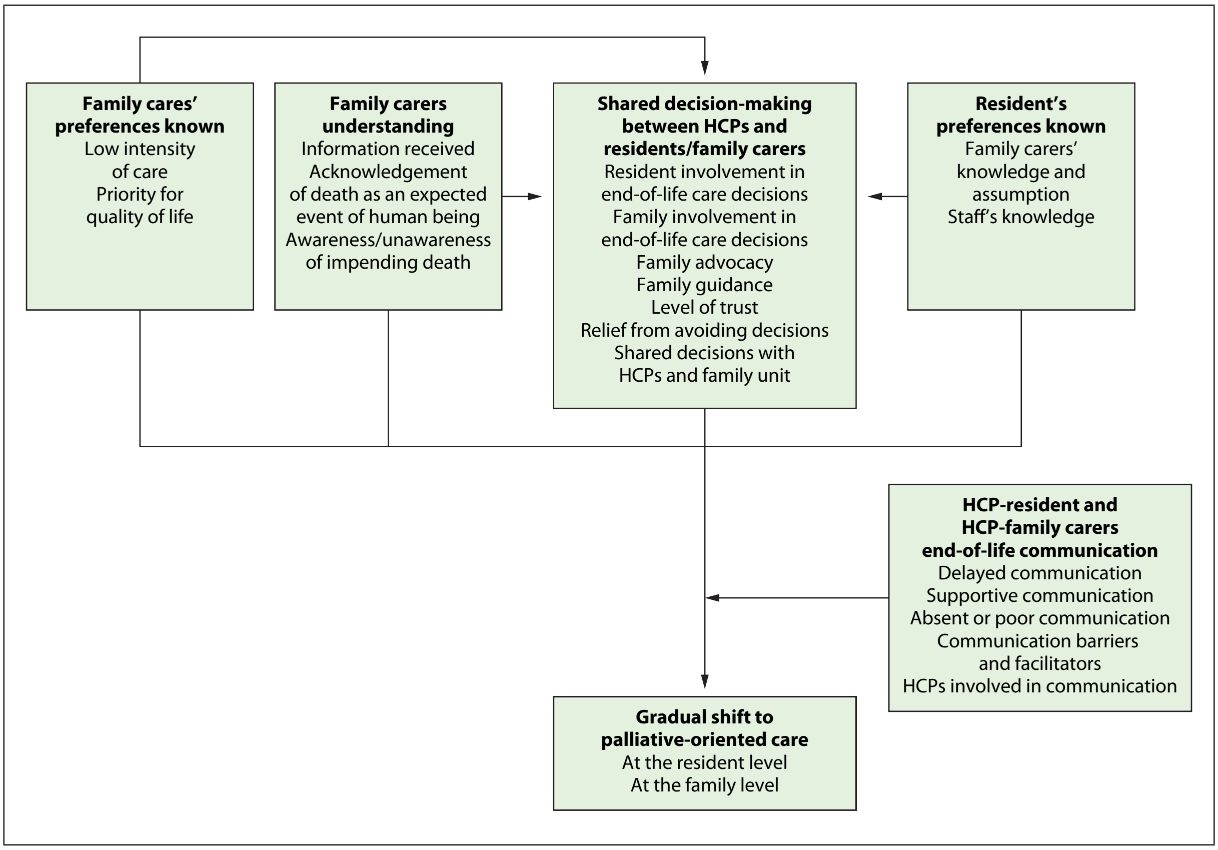

Figure 1
Mechanisms by which end-of-life communication contributes to palliative-oriented care in nursing home according to family carers perspective.
HCP, Healthcare professional

place is 3 minutes far from the NH, I would have wanted to be there. Five minutes before would have been enough… I'm still suffering…" (NH12, FC31).

Pathways of successful end-of-life communication

Four pathways by which end-of-life communication may contribute to palliative-oriented care emerged:

Theme 3. Family carers understanding

Most family carers reported being constantly updated about their relative's health conditions and therapy. They were informed by several HCPs, including the NH director, the NH staff, and the physician:

- "I've never had any problems to know what was happening to my mom ... whatever persons I talked to, in the office, nurses or nurse aides, all of them informed me about how she was going on" (NH2, FC5).

Most interviewees understood that their relative was coming to the end of his/her lifespan in advanced old age, but this understanding was not always associated with the awareness of impending death. Three scenarios concerning awareness emerged: i) family carers were aware of the changes but perceived HCPs did not share it with them; ii) both family carers and HCPs were aware; and iii) neither were aware.

- "Her conditions were severely deteriorated … when the nurse told me 'Do not worry, she will recover', I answered 'Please, don't joke about these things!" (NH11, FC25);
- "All of us, family carers, nurses and nurses' aides, understood that my mother was going to pass away" (NH13, FC32);
- "No one here expected my mother's death, if you'll talk to the nurses, they'll tell you that we are still all shocked" (NH12, FC29).

Family carers' awareness was characterized by the expectation that their relative's death would occur in a short time due to worsening conditions. Some interviewees reported to find peace when they acknowledged the upcoming death:

- "My mom's health conditions got worse in the last three months before death, it was a slow process that lasted two years" (NH10, FC24);
- "I felt relieved after deciding to let her go and told my children 'Tomorrow I'm shopping new clothes for grandma, thus she will be nicely dressed when meeting my [dead] dad" (NH6, FC15).

Family carers could become aware very late (i.e., few days before death) with differences among family members:

- "On Monday, I would have never said that Sunday all

would have been over, I was aware that some symptoms got worse but I thought that he could go on a little bit more" (NH8, FC19);
- "My sister took longer than me to accept that ... I know she kept on asking 'what can be done" (NH1, FC3).

Nurses were the HCPs that more frequently supported family carers in developing awareness of impending death:
- "The nurse explained me that it was not phlegm but a rattle that came from inside: the kidneys were blocked, she did not pee anymore and water was rising, thus provoking this rattle" (NH6, FC14).

Theme 4. Shared decision-making between healthcare professionals and residents/family carers

Family carers reported that their relative was rarely involved in decisions concerning end-of-life treatments, such as adjustments of the analgesic therapy or the decision to access the emergency department. However, this usually was a family carers' desire:
- "My mom was cognitively competent, we couldn't say 'Mommy, you are going towards the end of your life', she was 86 years and would have felt bad if hearing these things" (NH11, FC27).

Particularly in the case of dementia, family carers took decisions for their relative, but reported to need guidance in deciding to withdraw or withhold aggressive treatments, and needed a confirmation by HCPs that the decision was right:
- "The physician told us 'You should not forget that the aim is not to heal him but accompany him, you should accept that he does not want to eat anymore" (NH1, FC3).
- "When I said 'I don't want aggressive treatments', the nurse looked at me and nodded. I felt supported" (NH2, FC5).

Others believed that HCPs were in charge to take decisions, tended to hand over the responsibility to decide and felt relieved when they did not have to decide. Trusting NH staff was recognized as a way to hand over treatment decisions; family carers usually trusted both the NH staff and the physician about treatments their relative was in need of and did not feel the need to look for alternative source of information:
- "I think that in these structures, they [NH staff] must tell me what needs to be done" (NH7, FC17);
- "I trusted them [NH staff], what they said and what they did and therefore I didn't feel responsible for taking decisions for my mother-in-law" (NH6, FC13).

Decisions concerning hydration therapy, drug therapy, pain management and above all hospitalization were usually shared between family carers and HCPs, although few family carers felt active partners in their relative's care due to their perceived poor medical competence that made them feel informed rather than involved:
- "We decided with them [NH staff] to allow him to pass away quietly, little by little, and avoid hospitalization [...] we felt supported in the decision" (NH5, FC11);
- "I'm not a physician, I don't have any medical competence, so I trusted what they advised me" (NH9, FC22).

When decisions were shared with HCPs, family carers felt supported, whereas absence of sharing foster a feeling of loneliness and the burden of responsibility:
- "I would have shared with the physician the decision to hospitalize my father, because sometimes we uselessly accessed the Emergency Department ... I felt quite alone and responsible for decisions" (NH8, FC19).

The timing of information was a pivotal element to perceive involvement in care decisions; receiving information before care decisions had been taken, positively impacted on perceived involvement, while post hoc information were associated with the perception of poor involvement:
- "They never did anything without they told it me before" (NH13, FC32);
- "They told me about the change after it was already implemented" (NH10, FC24).

Sharing decisions to withdraw or withhold aggressive treatments among family carers was also common, even if discussions about the desired intensity of care usually took place too late:
- "I never asked my brother what he thought about it ... that day [the day before death], I said 'I would be of this idea', and my brother also stated 'you are right, these treatments are too aggressive and without any meaning" (NH6, FC15).

Theme 5. Resident's preferences known

Many family carers reported that their relative was reluctant to talk about her/his desired end-of-life care and treatments, thus, they had to make assumptions; instead, they felt released if the relative had left written preferences:
- "I would have preferred something written, I did it, because it seems to me to relieve my loved ones from any kind of choice" (NH10, FC23).

According to the family carers' perspective it was unlikely that their relative had shared her/his preferences for end-of-life care with HCPs. Few interviewees were sure that HCPs were aware of their relative's end-of-life wishes:
- "They [NH staff] were absolutely informed, they were well aware… we still talked about it even if, it can look ugly, we even smiled each other" (NH10, FC23).

Theme 6. Family carers' preferences known

A substantial number of family carers stated that they preferred not aggressive care for their relative and shared their opinion with the NH staff, particularly nurses. The priority was to avoid suffering, to improve the quality of their relative's remaining life:

- "I told them [nurses] 'My mother could not continue to be bombed with antibiotics ... Thus, why persisting in therapies? Let her to go …" (NH2, FC5);
- "The most important thing is that she does not suffer. I shared my opinion with the NH staff" (NH11, FC25).

End-of-life communication and activation of the palliative care service

During the last 6 months, 9/13 NHs discussed with family carers the opportunity to activate the palliative care service while the others did not offer this opportunity *(Supplementary Table 4 available online)*. The NH director reported that resident's health conditions unresponsive to curative treatments, uncontrolled pain, and the desire to provide good end-of-life were the reasons that led to the activation of palliative care service, which was the result of family carers' choice, physician's choice, a shared decision between family carers and physician or due to the resident's denial of any curative treatments.

Hospice referral was discussed less frequently than the activation of the palliative care service *(Supplementary Table 4 available online)*.

DISCUSSION

This study found that end-of-life communication may contribute to palliative-oriented care in NH according to the family carers perspective by: a) promoting family carers understanding, b) fostering shared decision-making between HCPs and resident/family carers, c) improving knowledge of resident's preferences, and d) improving knowledge of family carers' preferences.

Family understanding was mainly sustained by the amount of information received and the awareness for impending death. Particularly, our findings suggest that residents were more likely to receive palliative-oriented care at their end-of-life when family carers understood the prognosis and clinical course of the disease [21-23]. Consistently with previous quantitative studies [24], most family carers were prepared for their relative's death. However, the acknowledgement that the old relative was going to the end-of-life was often not sufficient to promote understanding [25]. We found awareness to have both a cognitive dimension (i.e., need of clinical information) and an affective dimension (i.e., emotional preparation) [26]: one could be very knowledgeable about medical aspects but not emotionally prepared. This multidimensional nature of awareness in addition to the unpredictable trajectory of the illness [27] may explain why understanding was often delayed and why some family carers were unprepared for their relative's death. No or poor understanding poses a serious problem to provide optimal end-of-life care, since it may lead to an unaware decision-making and hinder optimal care planning. Indeed, failure to implement a timely plan of care was identified as an obstacle to palliation and end-of-life care [8].

In accordance with previous literature [26, 28, 29], our inteviewees expressed the need to be constantly updated about their relative's health conditions and treatments to develop understanding. Clear, frequent, and honest communication is essential to prepare for death [26]. Instead, poor or ambiguous communication could make understanding more difficult and increase the risk of short awareness time [30]. Although end-of-life communication plays the most prominent role in promoting family carers understanding, it is one of the most neglected aspect of end-of-life care with poor or fortuitous communication and no or rare meetings with the physician being not uncommon [24, 28, 29]. This is unfortunate since the link between end-of-life communication and improved end-of-life care quality has been demonstrated [13]. Our findings suggest that communication should be a dynamic process and start as early as possibile in the disease trajectory, rather than being an isolated or occasional event limited to the last days of life. Therefore, HCPs should provide family carers timely information about their relative's clinical course and prognosis to promote understanding and to offer emotional support, since high-quality palliative care should be both resident-centered and family-focused [31].

Several elements of a shared decision-making emerged: family carers judged particularly worthy to feel involved in end-of-life care decisions and greater the amount of information received, higher the perception of involvement. Our family carers generally desired to remain involved in care planning and decision-making [5], and were an important partner in establishing the care goal particularly in the case of dementia [32]. Thus, encouragement to be part of the caring team reinforced their role as contributors to residents' care. Several family carers were involved in their relative's care through a constant monitoring of the basic care provided and by asking for physical, psychological and spiritual support for their relative. This suggests that family advocacy may improve the quality of end-of-life care [29], although family carers needed HCPs guidance towards the best care options for their relative [28]. However, most interviewees felt informed rather than involved and received information about changes in their relative's treatment after they were already implemented. This confirmed previous literature that highlighted poor family involvement with little substantive communication regarding end-of-life care planning [33], only one out of five family carers involved in the plan meetings [34] and only half of the decisions to withdraw or withhold treatments routinely discussed [35].

Supportive end-of-life communication promotes trust and partnership between family carers and HCPs [3], that is valued as much if not more than care activities of daily living [36]. High levels of trust make family carers to feel emotionally supported [31] and are associated with positive experiences of HCPs-family communication [37], while lack of trust could be one of the reasons family carers may not accept prognostic information about their relative [38]. Therefore, improving communication may increase family carers' trust in HCPs and provide a good basis to activate palliative care, also avoiding the burden of decisions by handing over the final decision to HCPs [39]. In fact, if the shared decision-making steps have taken place, HCPs will know what the resident's wishes are, and the care approach will be proposed accordingly [40]. In contrast, delayed or poor communication both between family carers and HCPs or within the family unit hinders shared decision making [8]. Therefore, educational initiatives aimed at improving communication skills should be regularly offered to HCPs.

Our study confirmed that resident's involvement in decisions was extremely limited, thus further increasing family carers perceived burden because of taking decisions on behalf of their relative [41]. Instead, literature suggests that when residents were engaged in advance care planning, their family carers reported to feel more prepared for death [24].

Although exploration of resident's wishes has been identified as key feature for good palliative care [42] because of knowing the relative's preferences reduces aggressive care at the end-of-life [43], the majority of our interviewees reported that their relative did not share her/his wishes for end-of-life care neither with HCPs nor with family. This is consistent with previous research [41] and explains why several interviewees stated to desire written relative's preferences for end-of-life care to avoid assumptions and the burden of decision. Anyway, all cognitively competent NH residents should be engaged in discussions about pros and cons of end-of-life treatment options as early as possible to promote informed decisions and allow HCPs planning end-of-life care accordingly. However, these dialogues are not easy and HCPs are not always prepared to start such discussions. When residents' wishes are not available, HCPs should explore family carers' desired goal of end-of-life care for their relative and engage them in decisions [6].

Our family carers usually did not desire treatments to sustain their relative's life, while the quality of life became a central element of the decision-making process [32]. They generally preferred to avoid burdensome hospitalizations and leave their relative to die quietly in NH, being reassured that the NH could provide care with equal benefit as compared to hospital [44].

Our study suffered from two main limitations. Firstly, recruitment was affected by the emotionally challenging topic and ethical considerations [45]. However, although the non-random sample that may have introduced a selection bias, family carers were drawn from several NHs across a large geographical area and data saturation was reached. Secondly, interviews with other family carers and friends could have provided greater understanding of the communication experience of the interviewees; however, three interviews were in double and all participants were engaged carers, thus providing an in-depth picture of end-of-life communication experience in NH [46].

CONCLUSIONS

Clear communication between HCPs and residents/family carers is essential to provide quality care, particularly at the end-of-life. In-depth and thorough communication that promotes family carers understanding about their relative's health condition, prognosis and treatments available, fosters shared decision-making between HCPs and residents/family carers, and improves knowledge about residents' and family carers' preferences for end-of-life care, may contribute to a timely transition towards palliative-oriented care.

Planning of end-of-life care requires ongoing communication with information about prognosis and problems that are likely to occur during the disease trajectory to achieve shared decisions. Because end-of-life is often a protracted and unpredictable process that occurs during the NH stay, communication about prognosis and residents' and family carers' preferences for care and treatments at the end-of-life should start as early as possible to promote establishing palliative-oriented care.

Author's contribution statement

SG, IB and PDG were responsible for the concept and design of the research. SG and IB collected the data. SG, IB and MC conducted the data screening and analysis. SG and PDG wrote the manuscript while IB and MC revised it critically. All authors gave final approval of the submitted manuscript.

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Conflict of interest statement

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