Supplementary Materials for

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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Table 1
Report on accordance with the COREQ guidelines

No item	Description
Domain 1: research team and reflexivity	
Personal characteristics	
1. Interviewer/facilitator	S.G. ad I.B. conducted the interviews.
2. Credentials	S.G. was a PhD student, nurse, with post-graduate specialization in Bioethics and volunteering experience in NH; I.B. was a graduate student, nurse with a research scholarship at the University of Turin, Italy; M.C. was a postdoctoral researcher at the University of Turin, Italy; P.D.G. was a professor in Nursing Science at the University of Turin, Italy.
3. Occupation	S.G. was working both as a research nurse at the University of Turin, Italy and as a PhD student at University of Rome Tor Vergata.
4. Gender	S.G., I.B., and P.D.G. are female; M.C. is male.
5. Experience and training	The main investigator S.G. was a nurse trained in end-of-life care and with experience in research from different areas including quantitative and qualitative research.
Relationship with participants	
6. Relationship established	There was no relationship between the interviewers and the participants. No participants were recruited from the NH where S.G volunteered to avoid ethical problems and reporting bias.
7. Participant knowledge of the interviewer	The participants got information that S.G. and I.B. were research nurses from the University of Turin and that the aim of the research was to investigate family carers experience about end-of-life communication with HCPs in NH. When the participants asked, S.G. and I.B. told more about their background.
8. Interviewer characteristics	The article includes information about the professional background of the interviewers. The main interest of S.G. in the topic was grounded in her volunteering experience in NH since she witnessed challenges related to end-of-life communication between family carers and HCPs in NH.
Domain 2: study design	
Theoretical framework	
9. Methodological orientation	This study is underpinned by a social constructionist framework. The basis for the qualitative methods was qualitative description.
Participant selection	
10. Sampling	Fifty-two NHs were identified purposively for geographical area and different sizes. Twenty of the approached NHs agreed to participate.
11. Method of approach	Family carers were purposefully identified by the director of the NH with the help of the direct staff. 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 to provide permission for contact, 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 that families interested in the study had to re-call. Participants were recruited from bereaved family carers whose relative had spent the last 30 days of their life in NH and had died between 45 days to 9 months prior. This time frame was long enough to avoid the acute bereavement period, but still enabled participants to recall details of their relative's final days. The participants received written information about the study and had the opportunity to ask clarifying questions before the interview started.
12. Sample size	In total, 32 family carers from 13 NHs participated in the study. No family carer withdrew from the study.
13. Non-participation	Seven NHs did not find any family carers available to participate.

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Table 1
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Setting

14. Setting of data collection	The data were collected in 13 different North-west Italian NHs. Participants were interviewed at their preferred location (i.e., private home or NH). For those participants that chose the NH, interviews were conducted in private without participation of NH staff to open up for possible negative comments.
15. Presence of non-participants	No one else beyond the participants and the researcher was present at the interview.
16. Description of sample	The sample is described in the "Methods" section. The participants' characteristics are described in *Table 1*.

Data collection

17. Interview guide	Interview guide is shown in *Box 1*.
18. Repeat interviews	Due to the emotionally demanding issue as well as long distances between the researcher and the participants, no repeated interviews were carried out.
19. Audio/visual recordings	All interviews were digitally audio-recorded and stored on a computer according to the regulations of the Regional ethics committee.
20. Field notes	The researchers S.G. and I.B. made field notes during and after the interviews. These included personal impressions and other observations that were not recorded. S.G. and I.B. shared and commented the field notes shortly after the interview to pick up the main features that were later employed to prove findings.
21. Duration	The duration of the interviews varied from 20.54 to 57.20 min.
22. Data saturation	We adopted the "information power" approach that indicates that the more information the sample holds, the lower amount of participants is needed. Information power depends on the study aim (i.e., narrow vs broad), sample specificity (i.e., highly vs sparse), use of established theory (i.e., level of theoretical background), quality of dialogue (i.e., clear and focused interview vs ambiguous and unfocused interview), and strategy of analysis (in-depth analysis of narratives vs exploratory analysis) [1]. Although our study aim was narrow and sustained by a large amount of literature on end-of-life communication in NH and the interview guide was focused on the research question, the convenience sampling that enrolled participants who were available and the exploratory approach required more participants to offer sufficient information. Thus, we decided to recruit at least 30 participants to reach a good internal consistency and assure a reliable code frequency [2]. Finally, 32 family carers were recruited and saturation was reached. Due to space restriction, this has not been discussed in this article.
23. Transcripts returned	Participants were provided the option of reviewing transcripts for accuracy. Nine participants requested copies of transcripts. Seven transcripts were returned without any changes and two transcripts were returned with minor revisions (e.g., grammatical errors, syntax errors)

Domain 3: analysis and findings

Data analysis

24. Number of data coders	S.G. and M.C. participated in coding of the data.
25. Description of the coding tree	The analysis process consisted of two stages: 1) Data were analysed using a deductive content analysis [3] referring to a communication framework that had previously described the potential mechanisms by which end-of-life communication may influence palliative-oriented care in NH [4]; 2) Data not fitting this categorisation frame were analysed through inductive content analysis [3]. The method of analysis is described in the "Methods" section and in the *Supplementary Table 2*.
26. Derivation of themes	Themes were derived both from the original framework and from the data. Themes were discussed and agreed on by all the authors.

Table 1
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27. Software	Analysis and coding of the transcripts were aided by the software ATLAS.ti 6.2
28. Participant checking	Participants were provided the option of reviewing transcripts for accuracy (as explained above).
Reporting	
29. Quotations presented	Themes are illustrated by participant quotations that are identified by an alphanumeric code to ensure confidentiality (e.g., NH1, FC1; NH1, FC2; NH2, 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.
30. Data and findings consistent	The presented data and findings are consistent from our point of view.
31. Clarity of major themes	The major themes are presented in the results and illustrated in *Figure 1* and *Supplementary Table 3*.
32. Clarity of minor themes	The minor themes are presented in the results and illustrated in *Figure 1* and *Supplementary Table 3*.

COREQ, COnsolidated criteria for REporting Qualitative studies; FC, Family carer; HCP, Healthcare professional; NH, Nursing home.

Additional references:
[1] Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res. 2016;26(13):1753-60. doi: 10.1177/1049732315617444
[2] Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. Field methods. 2006;18(1):59-82. doi: 10.1177/1525822X05279903
[3] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today. 2004;24(2):105-12. doi:10.1016/j.nedt.2003.10.001 18.
[4] Gonella S, Campagna S, Basso I, De Marinis MG, Di Giulio P. Mechanisms by which end-of-life communication influences palliative-oriented care in nursing homes: A scoping review. Patient Educ Conuns. 2019;102(12):2134-44. doi:10.1016/j.pec.2019.06.018

Table 2
Details of the analysis process

1. S.G. and M.C. read the transcripts and familiarized with the data
2. S.G. and M.C. independently identified preliminary codes
3. S.G., I.B., M.C., and P.D.G. compared and discussed the preliminary codes and their fitting within the framework
4. S.G. coded all the material according to the preliminary codes and themes
5. S.G. revised the preliminary codes and themes and compared them to her field notes
6. S.G., I.B., M.C, and P.D.G. discussed the revised codes and their fitting within the framework, and the new themes emerged by data that supplemented the framework; they agreed on the final codes, themes and the modified framework
7. S.G. checked the transcripts to question the findings and identify illustrative quotations that proved the findings
8. S.G., I.B., M.C, and P.D.G. discussed the findings, themes and quotations, and agreed about the interpretation of the data and the final framework

Table 3
Codes, categories and themes from the interviews of nursing home residents' family carers

Themes	Categories	Codes
HCP-resident and HCP-family carers end-of-life communication	Delayed communication	Communication of worsening conditions during the last days of life
		Communication of worsening conditions one week before death
		Communication of worsening conditions 15 days before death
		Communication of worsening conditions one month before death
	Supportive communication	Clear verbal communication
		Clear non-spoken communication
		Constant information by phone
		Face to face communication
		Frequent communication (with nurses, with nurse aides)
		Honest communication
		Multiprofessional communication
	Absent or poor communication	Communication of death over the phone
		Desire for more frequent communication
		Missing the relative's death
		Fortuitous communication
		Looking for information
		No communication with the NH staff
		No discussion about preferences for end-of-life treatments
		No or only one meeting with the physician
		Poor communication (with nurses, physician)
		Unclear communication
	Communication barriers and facilitators	*Barriers*
		Different linguistic background
		Limited family asking
		Family desire not to inform the resident about his/her health conditions
		Facilitators
		Recognition of changes in the relative's health
		Bedside communication or environments closed to patient's room (e.g., corridor) to avoid family moving away
		Being provided information in a private environment (nursing office, detached room, NH director office)
	HCPs involved in communication	Nurse aides
		Nurses
		Head nurse
		Physician
		NH director
Gradual shift to palliative-oriented care	At the resident level	Psychosocial support
		Death without distressing symptoms
		Spiritual support
		Fulfillment of basic needs
		Changed via of drug administration
	At the family level	Feeling emotionally supported (by nurses, nurse aides, NH director, NH secretary)
		Being warned in time for spending the last days with the relative
		Perceiving a practical support
		Being reassured to be called if resident's conditions worsen

Table 3
Continued

Family carers understanding	Information received	Feeling constantly update
		Feeling informed about the resident's health conditions (by the NH director, NH staff, physician)
		Feeling informed about the resident's therapy (by the NH director, NH staff, physician, resident)
		Feeling informed as an indicator of involvement in end-of-life care decisions
		Feeling lack of information (by nurses, physician)
		Desire for more gradual information
	Acknowledgement of death as an expected event of human being	Awareness of old age-related death as an expected event
	Awareness/unawareness of impending death	Awareness of gradual decline
		Awareness of impending death
		Awareness of poor prognosis
		Being helped to develop clinical awareness
		Developing clinical awareness alone
		Expected death
		Previous exposures to death
		Acknowledgement of futile end-of-life treatments aimed at reassuring family
		Not perceiving ageing as a condition in need of communication about end-of-life care decisions
		Recognizing their own difficulty in accepting the impeding relative's death
		Delayed clinical awareness
		Differences in clinical awareness among family carers
		Unexpected death
		Awareness of impending death by both family, physician and NH staff
		Unexpected death by both family and NH staff
		Conflicting perceptions of impending death between family and NH staff
	Resident involvement in end-of-life care decisions	Resident's involvement in adjusting the analgesic therapy
		Resident's involvement in the decision to access the emergency department
Shared decision-making between HCPs and residents/family carers	Family involvement in end-of-life care decisions	Poor involvement in end-of-life care decisions
		Being informed about treatments after their starting
		Calling the emergency service before calling the family
		Limited relatives' involvement due to their perceived poor competence
		Not being called in time
		Not feeling involved in end-of-life care decisions
		Good involvement in end-of-life care decisions
		Coordination of care by family carers
		Explanation and proposal of therapies before their administration
		Feeling involved in the adjustment of analgesic therapy
		Feeling involved in the decision about hydration therapy
		Feeling involved in the decision to hospitalize the relative
		Feeling involved when a need emerged
		Feeling involved in signaling resident's changes
		Feeling involved in making decisions
		Feeling involved in the decision to reduce hypnotic drugs
		Feeling involved in arranging the resident's diet
	Family advocacy	Being asked what the resident would have wanted

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Table 3
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		Feeling the responsibility of some decisions
		Changing the visiting hours to control the quality of care
		Asking for relative's psychological support
		Asking for relative's spiritual support
		Asking for relative's pain management
		Asking for relative's oxygen therapy
	Family guidance	Looking for guidance for end-of-life decisions
		Need for staff's open or implicit support in withdrawing/withholding aggressive treatments
		Need for staff's guidance in withdrawing/withholding aggressive treatments
	Level of trust	Family trust NH staff and the physician about treatments to perform
		Distrust
		Mutual trust
	Relief from avoiding decisions	Being involved in decisions would be too burdensome
		Believing that HCPs are in charge to take decisions (NH staff, physician)
		Feeling end-of-life decisions difficult and burdensome
		Feeling relieved not to have to take decisions
		Giving carte blanche to HCPs
		Transferring responsibility of end-of-life decisions to the physician and nursing staff
		Trusting NH staff prevents families from feeling responsible for treatment decisions
	Shared decisions with HCPs and family unit	Feeling/not feeling the burden to take decisions alone for absence/presence of sharing
		Sharing decision how to treat pain
		Sharing decision to access/not access the emergency department
		Sharing decision to start hydration therapy
		Sharing decision about drug therapy (stop drug, dose reduction or drug change)
		Sharing how care should go on
		Sharing decision to avoid aggressive care (with the physician, the nurse and the NH director)
		Sharing decision to stop aggressive care with other family members
		Delayed discussion within the family unit about the desired intensity of end-of-life care
Resident's preferences known	Family carers' knowledge and assumptions	Assumptions about the relative's end-of-life wishes
		Knowing the resident's end-of-life wishes (to avoid meaningless life, life-prolonging treatments and desire for a natural death)
		Not knowing the relative's end-of-life wishes
		Desire to have written relative's end-of-life preferences
	Staff's knowledge	Knowing the resident's end-of-life wishes (staff)
		Not knowing the resident's end-of-life wishes (staff)
Family carers' preferences known	Low intensity of care	Avoiding aggressive care
		Avoiding hospitalization
		Not feeling the need to preassure for further care
	Priority for quality of life	Avoiding suffering was the priority
		Contribution or not to quality of life

HCP, Healthcare professional; NH, Nursing home.

Table 4
End-of-life communication and activation of the palliative care service stratified by nursing home

Nursing home	Discussions about the opportunity to activate the palliative care service for oncologic residents[†]	Discussions about the opportunity to activate the palliative care service for non oncologic residents[†]	Discussion about hospice referral[†]	Activation of the palliative care service for oncologic residents (N) in the previous 6 months	Activation of the palliative care service for non oncologic residents (N) in the previous 6 months
1	Often	Sometimes	Sometimes	-	-
2	Sometimes	Never	Rarely	-	-
3	Sometimes	Never	Never	1	-
4	Never	Never	Never	1	-
5	Never	Never	Never	-	-
6	Rarely	Often	Never	-	-
7	Never	Never	Never	-	-
8	Sometimes	Often	Rarely	2	2
9	Often	Often	Never	-	-
10	Never	Never	Rarely	1	-
11	Never	Rarely	Never	-	-
12	Always	Often	Rarely	6	4
13	Always	Often	Never	3	1
Overall				14	7

[†]On a 5-points Likert scale