**Appendix**

This supplementary material is provided by the authors to give readers additional information about the study process.

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**Appendix 1.** Report on accordance with the COREQ guidelines

|  |  |
| --- | --- |
| **No item** | **Description** |
|  |  |
| ***Domain 1: research team and reflexivity*** |  |
| **Personal characteristics** |  |
| 1. Interviewer/ facilitator | A.A. ad S.T. conducted the interviews. |
|  |  |
| 2. Credentials | A.A. and S.T. were both master students in nursing sciences; S.G. had PhD in end-of-life communication, post-graduate specialization in Bioethics and volunteering experience in NH; N.C. had PhD and experience in end-of-life care; P.M. had PhD and was an expert in end-of-life communication; P.D.G. had MScN and experience in dementia care and end-of-life care; V.D. had MScN and experience in qualitative methodology. |
|  |  |
| 3. Occupation | A.A. and S.T worked as nurses in two Italian hospitals; S.G. worked as research nurse at the University of Turin, Italy; N.C. was a senior lecturer at the University College Cork, Ireland; P.M. was a professor of clinical communication and end of life care at Deakin University’s School of Medicine, Australia; P.D.G. and V.D. were professors in Nursing Science at the University of Turin, Italy. |
|  |  |
| 4. Gender | A.A., N.C., S.G., S.T., and P.D.G. are female; P.M. and V.D. are 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 A.A. and S.T were master students in nursing from the University of Turin and that the aim of the research was to investigate family caregivers’ experience of communication with NH staff during COVID-19 pandemic from admission to end of life. When the participants asked, A.A. and S.T. told more about their background. |
|  |  |
| 8. Interviewer characteristics | The main interest of S.G. in the topic was grounded in the well-known challenging communication between family caregivers of NH residents and staff during COVID-19 pandemic due to visitation restrictions. |
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| ***Domain 2: study design*** |  |
| **Theoretical framework** |  |
| 9. Methodological orientation | A qualitative descriptive study with content analysis was performed. |
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| **Participant selection** |  |
| 10. Sampling | Forty-four NHs were identified purposively for geographical area and different sizes. Eight of the approached NHs agreed to participate. |
|  |  |
| 11. Method of approach | Family caregivers 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;  Deterioration-in-condition phase: change in care needs after trigger events such as hospitalization or overall disease progression had been identified;  End-of-life phase: death is expected within the next weeks or a few months.  Using these criteria, NH managers with the support of direct staff identified the family caregivers and sent them a preliminary invitation. Twenty-five family caregivers agreed to participate and their names were given to the research team, who verified that the family caregivers met the criteria for one of the phases of care and then contacted them by phone to arrange an interview.  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, 25 family caregivers (8 in the transitional phase, 10 in the deterioration-in-condition phase, and 7 in the end-of-life phase) from 7 NHs participated in the study. No family caregivers withdrew from the study. |
|  |  |
| 13. Non-participation | One NH did not find any family caregivers available to participate. |
| **Setting** |  |
| 14. Setting of data collection | The data were collected in 7 different North-west Italian NHs. Interviews took place in the modality (i.e., in-person, remote) and setting (i.e., interviewee’s home, park) preferred by the family caregiver. |
|  |  |
| 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 | The interview guide was tailored to each phase and all guides were refined after the first two interviews. |
| 18. Repeat interviews | No repeated interviews were carried out. |
|  |  |
| 19. Audio/visual recordings | All interviews were digitally audio-recorded and stored on a password-protected computer according to the regulations of the Regional ethics committee. |
|  |  |
| 20. Field notes | A.A. and S.T. made field notes during and after the interviews. The field notes were shared and commented within the research team shortly after each interview to pick up the main features. |
|  |  |
| 21. Duration | Mean duration of interviews was 23 minutes (range 11-24), 41 minutes (range 20-71) and 40 minutes (range 32-52), for the transitional, deterioration-in-condition and end-of-life phase, respectively. No relevant differences in duration emerged between interviews done face-to-face and video call. |
|  |  |
| 22. Data saturation | It was estimated to enroll at least 6 family caregivers for each phase of the NH stay because basic elements for meta-themes arise as early as six interviews.1 Finally, 25 family caregivers (8 in the transitional phase, 10 in the deterioration-in-condition phase, and 7 in the end-of-life phase) were recruited and saturation was reached. |
|  |  |
| 23. Transcripts returned | Participants could review their interview transcript for accuracy. Four participants requested copies of transcripts which were returned with no changes. |
|  |  |
| ***Domain 3: analysis and findings*** |  |
| **Data analysis** |  |
| 24. Number of data coders | A.A., S.T., and S.G. participated in coding of the data. |
|  |  |
| 25. Description of the coding tree | The detailed coding three for the transitional phase, deterioration-in-condition phase, and end-of-life phase is provided in Appendix, 4, 5, and 6, respectively. Table 2 and figure 1 show an overview of all coding trees. |
|  |  |
| 26. Derivation of themes | Themes were derived from the data. Themes were discussed and agreed on by all the authors. |
|  |  |
| 27. Software | Analysis and coding of the transcripts were aided by the software ATLAS.ti 9.1 |
|  |  |
| 28. Participant checking | Participants were provided the option of reviewing their interview transcript 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, 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 are consistent with findings. |
|  |  |
| 31. Clarity of major themes | The major themes are presented in the results and illustrated in Figure 1, Table 2, and Appendix 4, Appendix 5, and Appendix 6. |
|  |  |
| 32. Clarity of minor themes | The minor themes are presented in the results and illustrated in Figure 1, Table2, and Appendix 4, Appendix 5, and Appendix 6. |

COREQ, COnsolidated criteria for REporting Qualitative studies; FC, Family caregivers; NH, Nursing home.

Additional references:

1. 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

# Appendix 2. Interview guides

|  |  |  |
| --- | --- | --- |
| **Appendix 2a.** Interview guide for the transitional period | **Appendix 2b.** Interview guide for the deterioration-in-condition period | **Appendix 2a.** Interview guide for the end-of-life period |
| 1. Could you tell me the decision-making process to institutionalize your …..?  2. How do you feel when you think back to the decision to institutionalize your …..? Why?  3. Thinking back to the preliminarily contacts with the facility during the selection process until the admission of your ….:  a. How did you feel? What impression did you get?  b. Have you had the opportunity to share with someone the routine/habits of your ...? Could you give me some examples?  c. Which information have you been told during preliminarily contatcs? Would you have wanted more information? If so, which ones? Could you give me some examples?  d. Which communication modalities were employed? Do you believe that the modality of communication influenced your understanding? Why?  4. Thinking back to the communication modalities in the last two months:  a. Which modalities have been adopted by the staff to update you on the clinical conditions of your …?  b. How did you feel during these communications?  c. Are you satisfied with the communication with the staff? Why?  d. Would you have desired different communication? If so, different how and with whom?  e. Due to the current pandemic, often the only possible way to communicate with the staff is remote communication which may entail some challenges. In your opinion, how could remote communication be improved?  Feel free to add anything you consider important. | 1. Looking back to the communication with the staff in the last two weeks, did you have the opportunity to talk about the changed clinical conditions of your …? Please, can you tell me?  2. Looking back to the communication with the staff in the last two weeks:  a. have you been informed about the care received by your ……? What have you been told?  b. would you have wanted more information to understand what was happening? If so, which? Would you have wanted more information to make care decisions for your…?  c. would you have preferred not to be informed about your … ’s worsening or informed at a different time?  3. Looking back to the communication with the staff in the last two weeks:  a. Did you feel listened to and encouraged? If so, how or by whom? If not, why?  b. Did you feel guided and supported in making decisions for the care of your …? If so, how or by whom? If not, why?  c. Have you been told about the worsening of your …’s health conditions openly, gradually, or indirectly? Please, can you tell me?  4. Thinking about the modalities of communication in the last months:  a. How have you been informed about your …’s health conditions and treatment provided?  b. Overall, are you satisfied with the communication with the staff? Why?  c. Would you have desired different communication? If so, different how and with whom?  d. Due to the current pandemic, often the only possible way to communicate with the staff is remote communication which may entail some challenges. In your opinion, how could remote communication be improved?  Feel free to add anything you consider important. | 1. Looking back to the communication with the staff in the last two weeks, did you have the opportunity to talk about the worsening of your …’s health conditions? Please, can you tell me?  2. Looking back to the communication with the staff in the last two weeks:  a. have you been informed about your …’s symptom management such as pain or difficulty in breathing, if any? What have you been told?  b. would you have desired more information to understand the situation? If so, which? Would you have desired more information to make care decisions for your …? If so, which?  c. would you have preferred not to be informed of the severity of your …’s situation or informed at a different time? Why?  3. Looking back to the communication of the last two weeks:  a. Did you feel listened to and encouraged? If so, how or by whom? If not, why?  b. Did you feel guided and supported in making decisions for the care of your …? If so, how or by whom? If not, why?  c. Have you been told about the worsening of your …’s health conditions openly, gradually, or indirectly? Please, can you tell me?  4. Thinking about the modalities of communication in the last months:  a. How have you been informed about your …’s health conditions and treatment provided?  b. Overall, are you satisfied with the communication with the staff? Why?  c. Would you have desired different communication? If so, different how and with whom?  d. Due to the current pandemic, often the only possible way to communicate with the staff is remote communication which may entail some challenges. In your opinion, how could remote communication be improved?  Feel free to add anything you consider important. |

# Appendix 3. Details of the analysis process

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| --- |
| 1. A.A., S.G. and S.T. read the transcripts and familiarized with the data  2. A.A., S.G. and S.T. independently identified preliminary codes and developed one coding sheet for each set of interviews (i.e., transitional period, deterioration-in-condition period, and end-of-life period)  3. A.A., N.C, P.D.G., P.M, S.G., S.T., and V.D. discussed and finalized the coding sheets |
| 4. A.A., S.G. and S.T. coded all the material by employing the coding sheet specific for each phase of family caregiving |
| 5. A.A., N.C, P.D.G., P.M, S.G., S.T., and V.D. discussed the gathering of similar codes into categories, and then of similar categories into themes; they agreed on the final codes and themes  6. S.G. checked the transcripts to question the findings and identify illustrative quotations that proved the findings  7. A.A., N.C, P.D.G., P.M, S.G., S.T., and V.D. discussed the findings, themes and quotations, and agreed about the interpretation of the data |

# Appendix 4. Codes, categories and themes related to the transitional phase

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| --- | --- | --- |
| **Transitional phase** | | |
| **Themes** | **Categories** | **Codes** |
| **Deciding to institutionalize** | Awareness of the impossibility to care for their relative at home | Challenges in sustaining working careers  Family carers’ physical and emotional burden  Supporting more than one older adult at the same time  Parenting  Greater relative’s needs |
| Complex and turbulent emotions | Feeling guilty  Feeling to have abandoned their relative  Feeling to have cheated their relative  Feeling lonely in making the decision  Agonizing decision  Decision not shared with the relative  Fear of abuse portrayed by media |
| Factors relieving the burden of decision | Decision to institutionalize shared with the physician  Decision to institutionalize shared within the familial network  Decision to institutionalize based on known relative’s preferences |
| Striving to find the right place for their relative | Easy access to thorough information on the website or in the charter of services  Availability and friendliness of the staff  Previous knowledge of the facility  Structural and organizational characteristics  Facility perceived to have adequate services to satisfy the relative’s care needs  Proximity to home  Rushed decision with limited choice |
| **Establishing a partnership between family caregivers and the facility** | Preference for traditional communication strategies | In-person communication  Face-to-face communication with the NH manager  Face-to-face communication with NH staff |
| Moving towards new technology-based modalities of communication | Awareness of communication challenges due to COVID 19 pandemic-related restrictions  By text message  By email  By pictures  By telephone  By video-calls with the relative  By video-calls with the staff  Personalized communication modalities tailored on family caregivers’ preferences  No perceived difference between telephone or video-call communication  Greater opportunity of interaction between the resident and family caregivers who work at long distance or are physically impaired  Perceived need of further investments in technology-based modalities  Proposed development of a resident’s personal digital profile with videos and clinical updates |
| Healthcare professionals’ competence and attitudes | Empathy  Humanity  Kindness  Availability  Sensitivity  Attention  Professionalism and clinical competence  Bothered staff  Annoyed staff |
| Supportive communication | Simple  Complete  Transparent  Regular  Bidirectional  Addressing non-verbal features of communication  Incomplete  Delayed |
| Sharing care preferences and relative’s routine | Sharing relative’s routine with the staff  Sharing care preferences for the relative with the staff  Desire to be involved in care decisions  Satisfaction with the communication established |
| Level of trust | Opportunity to directly accessing the facility before institutionalization  Perception of residents receiving good care  Satisfaction with relationships established with the staff since the admission  Complaint of no open access to the facility |

# Appendix 5. Codes, categories and themes related to the deterioration-in-condition phase

|  |  |  |
| --- | --- | --- |
| **Deterioration-in-condition phase** | | |
| **Themes** | **Categories** | **Codes** |
| **Family caregivers’ understanding of their relative’s worsening conditions** | Trigger events | Difficulties in swallowing  Increased dependency in activities of daily living  Stop walking  Stop eating  Stop sitting and being bedridden  Stop speaking  Losing weight  Missed second dose of vaccine for clinical deterioration  Phoning daily to check the relative’s conditions  Sharing opinions about the relative’s health status within the familiar network |
| Information received | Feeling informed  Feeling to have enough information  Being given the opportunity to question  Being informed about important clinical problems (e.g., neurological signs)  Being timely informed about the relative’s conditions  Unmet need of information about prognosis and disease trajectory |
| Family caregivers’ awareness of their relative’s worsening conditions | Awareness of a disease with fluctuating pattern  Awareness of an advanced disease  Awareness of a progressive disease  Recognizing the relative’s changed conditions on their own  Sharing feelings between family caregivers and healthcare professionals when the relative’s conditions worsen |
| Family caregivers’ preparedness for their relative’s worsening conditions | Not feeling prepared for the relative’s worsening conditions  Difficulties to accept the relative’s worsening conditions  Usefulness of regular communication to get prepared for death |
| **Communicating deterioration** | Preference for traditional communication strategies | In-person communication  Traditional communication outweighing long-distance communication does not equal |
| Moving towards new technology-based modalities of communication | By mail  By phone  By video-call  By whatapp  By vocal messages  By text-messages  No perceived changes in the content of communication when using remote modalities  No perceived difference between in-person and over the phone communication  No perceived difference between over the phone communication and video-calls  Proposal to develop an app to facilitate updating  Appreciation for alternative forms of communication  Desire to be informed regardless the modality |
| Absent, poor or delayed communication | Brief update  Communication left to chance  Paternalistic communication  Delayed communication  Lack of communication  Lack of multi-professional communication  Looking for information  Desiring more information  Asking to be regularly updated  Reaching information in a roundabout way  Triangulated communication  Feeling large room of improvement for communication |
| Supportive communication | Bidirectional  Clear  Constant  Direct  Informal  Frequent  Timely  Peaceful  Consistent among healthcare professionals  Receiving the desired communication  Communication started by healthcare professionals  Open  Soft  Indirect  Tailored  Difficulties to identify the right time for starting communication |
| Healthcare professionals involved in communication | Nursing home manager  Nurses  Chief medical officer  Psychologist |
| Healthcare professionals competence and attitudes | Tenderness  Availability  Honesty  Attentiveness  kindness  Humanity  Closeness  Being present  Respect  Sensitivity  Clinical competence  Professionalism  Inflexibility  Indifference  Commanding attitudes  Unpreparedness  Finicky |
| **Impact of COVID-19 pandemic on caregiving** | Strategies to safeguard family caregivers-resident relationship despite visiting restrictions | In-person visits  Visits through plexiglass  Window visits  Hug room  Video-calls  Regular telephone calls  Poor strategies to facilitate resident-family caregivers communication |
| Complex and turbolent emotions | Feeling lonely for not being allowed to spend time with the relative  Feeling worried about what happens in the NH  Feeling upset  Feeling distressed  Feeling angry |
| Increased family caregivers’ support needs | Need for more staff attentiveness  Need of a point of contact to communicate with  Need to be prepared about the relative's worsened conditions before in-person visit  Need to be reassured  Need of exclusive time for communication  Emotional support threatened by COVID-19-related staffing shortage  Clinical details not useful  Reassurance not improved by increased frequency of communication over telephone  Perceived benefit from psychological support  Use of technology to reassure family caregivers |
| Increased family caregivers’ information needs | Need to know  Need to be regularly updated  Need of comprehensive communication within the agreed timelines |
| **Shared decision-making between family caregivers and healthcare professionals** | Resident’s preferences for end-of-life care known/unknown | Resident’s living will  Guessing the relative's preferences for end-of-life care  Not knowing relative's preferences for end-of-life care |
| Family caregivers’ preferences for end-of-life care known/unknown | Desire to avoid aggressive care  Explored family preferences for end of life |
| Family caregivers involvement in end-of-life care decisions | Feeling involved in decisions  Feeling involved in the decision to make cortisone infiltration  Being informed before interventions take place  Being informed post facto  Being the reference person of the familar network  Coordination of the relative’s care  Mutual exchange of information |
| Shared decisions with healthcare professionals and family unit | Feeling that important decisions are shared  Sharing decisions about daily care  Sharing decisions to avoid cortisone infiltration  Sharing the decision to avoid intensive care  Sharing the decision to hospitalize  Feeling in line with staff about care decisions that need to be made |
| Supportive family caregivers-healthcare professionals relationships | Collaborative  Familiar  Friendly  Good  Informal  Satisfying  Sharing worries with nurses  Nurses as link between the physician and family caregivers  Staff taking the time to hear family caregivers  Feeling safe  Feeling supported  Feeling/not feeling reassured  Feeling own needs being considered by staff  Feeling understood  Not feeling listened to |
| Level of trust | Trust promoted by supportive communication  Feeling to be told the truth  Trusting the staff  Trusting the NH  Not feeling the necessity to act as a sentinel  Not feeling the need of daily updates  Looking for sources of information external to the NH |
| Transferring responsibility of decisions | Transferring decisions to the physician  Feeling right that staff could act without sharing decisions with family caregivers  Giving charte blanche to the staff in taking decisions |
| Family guidance | Feeling adviced about what to do when problems arise  Looking for nurses to solve problems |
| Family advocacy | Asking for change the weelchair strap  Asking for changes in relative’s daily care activities  Residents’ preferences advocated by their family caregivers  Need to verify |
| Nursing home environment | Collaborative atmosphere  Welcoming atmosphere  Familiar atmosphere  Engaging atmosphere |

# Appendix 6. Codes, categories and themes related to the end-of-life phase

|  |  |  |
| --- | --- | --- |
| **End-of-life phase** | | |
| **Themes** | **Categories** | **Codes** |
| **Communicating at the end of life** | Preference for traditional communication strategies | In-person communication  Limits of long-distance communication (e.g., partial lack of non-verbal communication, inability to understand the context, missed knowledge of the speaker) |
| Moving towards new technology-based modalities of communication | By telephone  By text message  By email  No or poor perceived difference between in-person communication, communication over the phone or video calls |
| Supportive communication | Transparent  Complete  Honest  Open  Human  Kind  Personalized  Bidirectional  Regular  Increased in frequency with worsening conditions  Consistent among healthcare professionals  In-person meetings involving all family members in charge of making decisions |
| **Communicating the impending death** | Family caregivers’ awareness of upcoming death | Awareness promoted by trigger events such as stop eating and walking  Awareness of a progressive disease  Awareness of no therapeutic opportunity to recover |
| Healthcare professionals involved in communication | Chief medical officer  Physician  Nurse  Psychologist |
| Healthcare professionals’ competence and attitudes | Clinical competence  Sensitivity  Kindness  Availability  Empathy  Humanity  Relational skills as important as technical skills |
| Content of communication | High likelihood of impending death  Emotional support  Dying process |
| **Impact of COVID-19 pandemic on caregiving** | Family caregivers’ need to stay in contact with their relative | Desiring in-person contacts with the relative  Desiring to spend time with the relative  Need to let the relative know that family is present |
| Strategies to safeguard family caregivers-resident relationship despite visiting restrictions | Visits allowed also during the pandemic by employing safety measures (e.g., family caregivers’ negative swab)  Outdoor visits  Visits in special rooms with personal protective equipment  Visits through plexiglass  Window visits  Video calls  Visits moved up due to the relative’s clinical deterioration |
| Complex and turbulent emotions | Shocked by the sudden and unexpected detachment  Fear of relative’s worsening health conditions due to interruption of family caregivers’ visits  Frustration for the impossibility to actively participate in the relative’s basic care  Bitterness for leaving one's relative alone at death |
| Increased family caregivers’ support needs | Reassurance that they were not abandoning their relative  Need of a reference person for communicating with  Need of exclusive time without interruptions due to tight working schedule  Need of psychological support |
| **Shared decision-making between family caregivers and healthcare professionals** | Resident’s preferences for end-of-life care known/unknown | Resident’s care preferences known by the staff  Preferences shared in multi-professional meetings |
| Family caregivers’ preferences for end-of-life care known/unknown | Sharing care preferences with the staff  Desire to avoid suffering  Desire to avoid hospitalization |
| Family caregivers involvement in end-of-life care decisions | Feeling involved in the decision to hospitalize  Feeling involved in the decision to access emergency services  Feeling involved in how to control pain  Feeling active partners in the relative’s care  Receiving information before care decisions had been taken  Post-hoc information |
| Supportive family caregivers-healthcare professionals relationships | Feeling welcomed  Feeling listened to  Feeling supported  Feeling connected with healthcare professionals  Feeling disoriented due to staff turnover |
| Level of trust | Family caregivers trust healthcare professionals’ competence  Satisfaction with the care provided |
| Relief from avoiding decisions | Feeling relieved not to have to take decisions  Feeling poor clinical competence |
| Family guidance | Need for staff’s guidance in the decision-making process  Need for staff’s support in the decision-making process |
| Family advocacy | Family caregivers as witness of their relative’s care preferences  Asking for changes in pain management  Telephoning the facility to check the relative's telling |