Good end-of-life care in nursing home according to the family carers' perspective: A systematic review of qualitative findings

Title

Good end-of-life care in nursing home according to the family carers perspective: A systematic review of qualitative findings

Running head

Relatives' perspective on end-of-life care

Authors

Silvia Gonella[a,b], RN, MSc, PhD student; Ines Basso[c], RN, MSc; Maria Grazia De Marinis[d], RN, MSc, Professor of Nursing Science; Sara Campagna[c], RN, PhD; Paola Di Giulio[c], RN, MSc, Associate Professor of Nursing Science.

Authors affiliation

[a] Department of Biomedicine and Prevention, University of Roma Tor Vergata, Via Montpellier 1, 00133 *Roma*, Italy.

[b] Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino, Corso Bramante 88-90, 10126 Torino, Italy.

[c] Department of Public Health and Pediatrics, University of Torino, via Santena 5 bis, 10126 Torino, Italy.

[d] Nursing Research Unit. University Campus Bio Medico of Roma, via Alvaro del Portillo 200, 00128 Roma, Italy.

Corresponding author

Silvia Gonella, MSc, RN, PhD Student in Nursing Sciences and Public Health

Department of Biomedicine and Prevention, University of Roma Tor Vergata

Via Montpellier 1, 00133 *Roma,* Italy

Azienda Ospedaliero Universitario Città della Salute e della Scienza di Torino

Corso Bramante 88-90, 10126 Torino, Italy

Phone 39 011 0915831

Fax 39 011 2365831

Email silvia.gonella@unito.it

Abstract

BACKGROUND: Nursing homes are becoming a common site where delivering end-of-life care for older adults. They often represent the junction between the curative and the palliative phase.

AIMS: To identify the elements that nursing home residents' family carers perceive as good end-of-life care and develop a conceptual model of good end-of-life care according to the family perspective.

DESIGN: Systematic review (PROSPERO no. 95581) with meta-aggregation method.

DATA SOURCES: Five electronic databases were searched from inception between April and May 2018. Published qualitative studies (and mixed-method designs) of end-of-life care experience of nursing home family carers whose relative was dead or at the end-of-life were included. No language or temporal limits were applied.

RESULTS: In all, 18 studies met inclusion criteria. A "life crisis" often resulted in a changed need of care; the transition toward palliative care was sustained by a "patient-centered environment". Family carers described good end-of-life care as providing resident basic care and spiritual support; recognizing and treating symptoms; assuring continuity in care; respecting resident's end-of-life wishes; offering environmental, emotional and psychosocial support; keeping family informed; promoting family understanding; and establishing a partnership with family carers by involving and guiding them in a shared decision-making. These elements improved the quality of end-of-life of both residents and their family, thus suggesting a common ground between good end-of-life care and palliative care.

CONCLUSION: The findings provide a family-driven framework to guide a sensitive and compassionate transition toward palliative care in nursing home.

KEYWORDS: family, life change events, nursing homes, palliative care, qualitative research, systematic review, terminal care.

Introduction

An increasing number of elders will spend part of their remaining life in a nursing home (NH).[1-3] Compared to the past, residents' profile is changing: people enter these facilities with higher levels of dependency, advanced frailty and age-related dementia[4], and their death is usually expected in a shorter time.[5] Therefore, NHs are increasingly shifting toward a palliative-oriented care.[6]

The trajectories of decline commonly associated with death in old age are uncertain[7] and it can be difficult to determine when a resident is nearing death,[8] and whether to shift the goal of care from curative to palliative care.[9] Although the primary goal of care when death approaches is maximing comfort,[10] the quality of end-of-life care in NHs is usually poor and raises considerable concerns.[11-13] Only half of NH residents die peacefully,[14] while most suffer from uncontrolled symptoms.[15] Reports have identified deficiencies in pain and symptom management,[16, 17] and a number of inappropriate interventions (i.e., tube feeding, intravenous hydration) in the last days of life, particularly in cognitively-impaired residents.[13, 18]

Most family members often desire to remain involved in the lives of their relative following placement in NH[19] and should be given the opportunity to become an advocate of their relative's wishes and engaged in decisions concerning the transition toward palliative care.[20]

Although family members' perception of end-of-life care is acknowledged as an important quality indicator[21], it is rarely considered when planning care at the end-of-life.[22] This literature review aimed to identify the elements that families perceived as good end-of-life care. Secondarily, a derived conceptual model of the key aspects that family carers consider to define good end-of-life care in NH is proposed.

The central question driving this research was: what contributes to family's experience of good end-of-life care in NH?

Methods

Design

A systematic review of qualitative findings was performed according to the Joanna Briggs Institute (JBI) meta-aggregation method.[23] Meta-aggregation allows to be much closer to the reality than other qualitative approaches to synthetize with enhanced generalizability of the findings. Similarly to meta-analysis, aggregated findings are more than the sum of individual findings and can be used as a basis for evidence-based practice.[23] This review has been reported in accordance with the ENhancing TRansparency in REporting the synthesis of Qualitative research (ENTREQ) guidelines (Appendix 1).[24] The review protocol was registered on PROSPERO register of systematic review on May 29th

2018 (registration number CRD42018095581), available at http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018095581.

Search strategy

A three-step approach was adopted.[23] An initial limited search on CINAHL EBSCO and Pubmed was conducted between February and March 2018 followed by an analysis of title and abstract, to identify the most appropriate keywords. Then, five databases (PubMed, EBSCO CINAHL, EBSCO PsycINFO, Joanna Briggs Institute, and Scopus) were extensively searched from inception, between April and May 2018, employing both controlled vocabularies and free terms, without temporal or language limits. Finally, the references of included articles were screened manually.

Initial keywords were: family, caregivers, palliative care, end-of-life care, patient comfort, nursing homes, experience, qualitative research. The full search strategy is provided in Appendix 2.

Inclusion and exclusion criteria

Types of studies

Studies that focused on qualitative data, including designs such as phenomenology, grounded theory, ethnography, and action research that explored the end-of-life care experiences of NH residents' family carers were considered. Only the qualitative results of mixed-method studies were included.

Theses, dissertations, abstracts in proceedings and other papers published in non-peer-reviewed publications (e.g., government working papers) were excluded.

Types of participants

Studies were included if focused on family carers of NH residents dead or approaching death, regardless their underlying disease, since the end-of-life care does not depend on the disease leading to death.[10] Articles merging experiences of different populations (i.e., healthcare professionals, residents) were included only when the family carers' perspective was clearly recognizable. Family carers were defined as those people belonging to the family unit (e.g., spouse/partner, sibling, son/daughter, nieces/nephews, grandchildren).

Phenomena of interest

The phenomenon of interest was the end-of-life care experience of NH residents' family carers.

Context

Studies merging end-of-life care experiences across different settings (i.e., home, public hospital, hospice, private hospital, assisted living) were included only when the results related to the NHs were clearly distinguishable. NH was defined as a facility that provides room and board, as well as management of chronic medical conditions and 24-hour assistance with activities of daily living in patients who are physically and/or cognitively impaired.[25]

Screening and study selection

Two investigators (S.G. and I.B.) independently screened title and abstract and reviewed the full-texts of retrieved articles.

Assessment of methodological quality

The selected papers were independently assessed by S.G. and I.B. for methodological validity, using the JBI Quality Assement Review Instrument (JBI-QARI) for assessing the validity of interpretative and critical studies (Table 1).[26]

As the JBI-QARI does not recommend a cut off, studies were included only if they achieved a positive score (i.e., yes answer) in at least the following five criteria, out of 10:[27] congruity between research methodology and objective, data collection methods, data analysis, interpretation of the results, and the representation of the participants' voices (i.e., quotations).

Data extraction

Data including study aim, geographical context, participants, methodology, data collection methods, data analysis, and study findings were extracted by two independent reviewers (S.G. and I.B.) using the JBI-QARI data extraction tool.[23] For each study, the main end-of-life care domains (i.e., physical, psychosocial, and spiritual) according to the World Health Organization's definition of palliative care were identified (Table 2).[28]

Primary studies were read until reaching a full understanding of their findings. Findings were either labelled as theme or subtheme and were supported by data such as participants' direct quotations or the exact words of the authors.[23]

JBI-QARI levels of credibility were adopted to rate each extracted finding as: unequivocal (evidence beyond reasonable doubt); credible (plausible in light of the data and theoretical framework); or unsupported (no relationship between findings and data). Only findings unequivocal and credible were included in the synthesis (Table 3, Appendix 3). Each finding was identified by an alphanumeric code (e.g. A1, A2, B1, …). Each letter corresponded to a study and each number to a unique finding. The progressive numbers indicate the order of the findings in the original article (Table 3).

Any disagreement or uncertainty was solved by discussion.

Data synthesis

Research findings were pooled in accordance with the JBI meta-aggregation method:[23] first step) the findings of the primary qualitative studies, represented by categories, themes, metaphors or concepts, as reported by the study authors were identified; second step) findings with similar meanings were grouped into categories; third step) these categories were aggregated into a set of synthesised findings that could be used as a basis for evidence based-practice.[23]

S.G. and I.B independently clustered the findings and compared the generated categories, discussing discrepancies until reaching agreement. Finally, the same reviewers produced a comprehensive set of synthesised findings (Table 3).[23]

Development of the conceptual model

A conceptual framework can be defined as a visual presentation of key variables, factors or concepts and their relationship among each other.[29] Two reviewers (S.G. and I.B.) independently focused on the relationships of synthetized findings to determine their inter-relationships, using the problem statement (i.e., which are the elements that families of NH residents perceived as good end-of-life care?) as a reference. Agreement was reached by discussion. After all relationships in this initial model are fully tested, the model may change as a result of refinement and increased understanding of direct and indirect relationships.

Results

Review process

Over 570 articles identified, after duplicate removal (n=136) and screening for title and abstract (n=407), 27 entered the full text review process. Nine articles were further excluded according to the above-mentioned criteria and two[30, 31] for the poor methodological quality; two articles were included from the references lists of selected papers (Figure 1). Quality assessment is reported in Table 1 and Table 2.

Please, insert figure 1 here

Please, insert table 1 here

Characteristics of included studies

The included studies were conducted in seven countries: nine in the United States (1,642 family members), four in Europe (89 family members), three in Canada (122 family members), and two in New Zeland (31 family members). All except one[32] study were conducted after 2005. Studies involved a median of 6 NHs, from one[33-35] to 85[36]; four involved only NHs with more than 80 beds.[33, 35, 37, 38] NHs could be urban[37, 39, 40] or rural[36, 37], with a for-profit[32, 40, 41] or not for-profit[32, 40, 41] profile. NHs could benefit from hospice care (n=4),[41-44] palliative care services available on consultation basis (n=1),[40] or Liverpool care pathway (n=1).[39] Some NHs had beds for palliative [37] or dementia care[34, 35]. No information were provided about physician availability in the facilities while one study reported 24-hour registered nursing care.[33]

One study used an ethnographic methodology,[33] one an interpretive descriptive method,[45] and another phenomenological case studies,[46] while all the others used a qualitative descriptive method,[19, 32, 34-44, 47, 48] with thematic (n=16)[19, 32-35, 37-39, 41-48] or content analysis (n=2)[36, 40] (Table 2).

Please, insert table 2 here

Data were collected from face-to-face individual interviews (n=8),[32-35, 37, 39, 46, 48] telephone interviews (n=7),[36, 39, 42-44, 47] focus groups (n=3),[19, 40, 45] mailed surveys with open-ended questions (n=2)[38, 41] and field observations (n=1).[33] Interviews lasted on average one hour[36, 46] (range 20[39]-120 minutes[37, 47]) and were performed between two weeks[44] to 27 months[42, 43] after resident's death. One study considerably extended the time since death up to 100 months due to difficulties in accessing the sample.[48] In four studies, residents could be still alive.[19, 33, 45, 47] End-of-life care experience of family carers referred to different periods care: day of death,[46] last few days,[35-37] last week,[42, 43] last month,[38, 46] last three months,[48] or last year of life.[42, 43, 46]

Family carers were more often female (on average 74.2%, range 47.2%[39]-86%[40]), averagely older than 60 years[19, 34, 36, 38-41, 45, 47, 48], mostly adult children (range 40.7%[42, 43] to 94%[47]) or spouses (range 10%[38] to 100%[48]). Five studies involved dementia residents' carers.[19, 39, 46-48]

Meta-synthesis

Over 114 findings extracted, four were rated as unsupported and excluded from the synthesis. In all, 110 findings were included: 10 rated as credible and 100 as unequivoval. The level of credibility for each finding is reported in Table 3 and Appendix 3.

These findings were aggregated into 21 categories, then combined in the following five synthesised findings (Table 3):

1. Nursing home residents' family carers perceive life crisis and transitions in their relative's care

Life crisis are considered any trigger events that resulted in a changed need of care.[34, 46] The trigger may be functional such as "*stop eating*" and "*swallowing problems*", particularly in residents with advanced dementia,[34, 39] or social such as "*fear of leaving*" that prevented family carers to make any long distance trips since they "*keep expecting the call*".[36]

NH residents often experienced a "*burdensome transition*" with multiple hospitalizations in the last period of life that exacerbated family's distress.[46] Sometimes family realized that something was changing simply by the move from one table to another in the dining room because of the resident's new need to be fed:

> " *[…] He was sitting at another table. "Why did you move Herb?" She said, "Because he can't feed himself anymore." […]He wasn't feeding himself because he didn't want to eat. It was the beginning of the end*".[34]

2. Environmental and human factors influence the provision of a patient-centered care in nursing home

Several NH characteristics contribute to promote a patient-centered care: staffing, staff characteristics (knowledge and training), physical NH environment, and institutional policies.

Adequate staffing was a relevant concern for family carers.[38, 42] Staff restriction negatively affected the quality of care with delays or neglect in care:

> "*[…]they put feeding precautions that she needed to be sitting up to be fed, and it was difficult in the nursing home to get them to feed her the way she was supposed to be fed. . . . [T]hey were very inadequately staffed for the kind of patients they had.*''[42]

Some families were upset by the lack of physician availability:[38, 42]

> "*The doctor was supposed to have been in every day. I never saw the doctor. I don't even know his name!*".[42]

Other family members were dissatisfied with care provided by "*physician extenders*" such as nurse practitioners or physician assistants.[42]

Staff characteristics including knowledge and training were a pivotal aspect of the NH environment.[38, 42, 46, 48] Family carers suggested that staff needed more training to improve their ability to address resident's needs,[42, 48]

"*There has to be a lot more training and a lot more in-depth training – not just about the symptoms of dementia*",[48]

and to recognize the nearing death:

"And he was bruised from head to toe … But they so proud that they had given him a whirlpool bath".[42]

Physical environment with a comfortable spatial layout and home-like atmosphere was perceived as part of the resident's well-being:[19, 46]

"*[…] room with comfortable chairs, a TV, CD player, real furniture, a microwave, and refrigerator*".[46]

Instead, lack of privacy and excessive noise arose family concerns for their relative psychosocial and spiritual well-being.[38]

A person-centred care with caring attitudes of the NH staff inspired trust and relieved anxiety.[48]

3. Nursing home residents' family carers identify good end-of-life care at the resident level with dying in dignity

Providing good end-of-life care implies satisfying both basic and spiritual needs of the dying, managing symptoms, guaranteing collaboration between health care services, and respecting end-of-life wishes, thus promoting a dignified death.

Fulfilling basic needs was an essential ingredient:[35, 38, 43, 47]

"*They fed her. They dress her. They clean her, what can they do? […] They take care of her*".[47]

Managing symptoms was a further requirement judged essential;[36, 39, 41, 42, 44, 45, 48] its absence was perceived as a marker of poor expertise and knowledge and negatively affected family satisfaction with care.[40, 42] Families reported that

"[Staff] would not give [the resident] an injection of pain reliever an hour before the next one was due officially […] In a terminally ill, dying patient, it really seems silly to be told that [the resident] could become addicted to the drugs if given too soon".[38]

Instead, a considerable improvement in symptoms relief was reported after hospice involvement.[42]

A good end-of-life care should guarantee spiritual support to both families and residents,[32, 38]

"*The [spiritual caregivers] and volunteers brought sunshine and hope into [the resident]'s room every time. We cried, laughed, and prayed with them*",[38]

as well as continuity in care, intended as care provided in a familiar environment, by healthcare professionals that knew the resident:

"*And absolutely no different people taking turns in caring for him. That is confusing*",[19]

and it was valued more than specialized hospice care, particularly in people with dementia, since any transfer could impact on orientation and sense of place:

"*We have already decided, we are not going to move. No moving, no matter what. No way. As long as he is there. Because this is familiar!*".[19]

Also collaboration between different services was found to promote care continuity:

"*George was her [hospice] nurse, and he was just great … Anytime we needed him or if there was anything we needed communicated to him, all we had to do was leave a note with the nursing station, and he immediately got back*".[44]

Conversely, a poor collaboration between hospice and NH triggered family's concerns.[43]

Honouring the dying's wishes for a natural death without recurring to life-sustaining treatments enhanced the quality of the resident's remaining life, with the certainty of not being kept alive againt ones wishes[34, 45]:

"*I am sure that my mother often wishes to pass away*".[45]

4. Nursing home residents' family carers identify good end-of-life care at the family level with information, understanding and support

Family carers wanted to be kept informed and understand their relative's conditions and prognosis, and wished to be seen as bereaved persons in need of environmental, emotional and psychological support.

Family's information needs is a critical point.[19, 35-40, 43, 44, 46] Family carers valued good information and communication with healthcare professionals:[19, 37]

> "*What is very important is that in the last stage there is good communication between yourself and the nursing staff. That you know exactly, what is going on?*".[19]

Not knowing what was going to happen caused distress, concerns, and fearing the unknow;[36] families experienced feelings of anxiety and guilt concerning decisions perceived as outside their control.[39] Family members referred barriers when seeking information,[38, 40, 43] with staff that took for granted that they were already aware of the changes in their relative's condition, thus avoiding explicit discussion around prognosis,[39] and this "*missed opportunity*" prevented them from planning the last period with their relative.[39]

It was often difficult for families to understand the prognosis and the dying process.[32] The lack of congruence between family's expectations and resident's prognosis resulted in family's emotional unpreparedness to tackle with death.[34] In contrast, when both staff and family carers were aware of the decline, family felt supported from the mutuality of understanding and the recognition that healthcare professionals were caring for both the residents and their families.[34]

Family nurturance emerged as environmental, emotional and psychosocial support.[32, 35, 38] Family members appreciated caring activities such as staff bringing them coffee and sandwiches,[32] and being reassured that they would have been called immediatly if something had changed.[35] Family carers defined care as "*sensitive*":

> "*Staff even found a bed for [a family member] one night when things seemed precarious with [the resident]'s breathing....*".[38]

Aware families perceived their decision as right:

"*I didn't beat myself up too much for the fact that she was there because I was aware that there were really not anyway that she could have been with me in my home*".[47]

Family carers felt particularly supported when the hospice was involved:[42-44]

"*When the hospice came on board, it just soothed my worries*".[44]

5. Nursing home residents' family carers identify good end-of-life care with establishing a partnership with health care professionals

Creating a relationship with the staff implied having expectations about care acknowledged, being recognized as the resident's advocate, and having the opportunity to be involved in a shared decision-making with healthcare professionals' guidance.

Family members highlighted the importance of creating a sense of belonging and attachment between resident and staff and family and staff:[47, 48]

"*Well I felt like part of a family. And somehow or other they treated him like a member of the family you know [. . .]*."[48]

Relationships with staff engendered trust,[48] and their lack detachment[47] and distrustfulness.[39] When expectations for care were not met, they experienced frustation without developing a close relationship with staff.[36, 44]

Identification of a resident's advocate emerged as pivotal for good end-of-life care.[33, 42, 43] Family members were often more attuned than staff to a resident's changing condition and stated that their presence improved the quality of care:[42, 43]

''*I can remember having to speak with the staff about [his cough] and they were right on it. But I was right on them when I was there*".[42]

Family members deemed important to work in partnership for taking decisions in the best interest of the resident[48] and perceived benefits from being involved in care planning conferences[43]. Their satisfaction with end-of-life care increased when they could make end-of-life decisions consistent with their relative's preferences.[43, 47] However, they needed assistance from staff for taking decisions:[32, 36, 39]

"*I had him on full code status. No one ever explained to me what this meant. So I talked to the director of nurses. […] So she explained it to me. A couple other nurses talked to me about it too. So then I took him off the full code*".[32]

When this guidance was not offered, families lost confidence in the staff.[39]

Please, insert table 3 here

Conceptual model of good EOL care in nursing homes

Figure 2 shows a conceptual model of good end-of-life care according to family carers' perspective. As illustrated in Figure 2 Column A, functional triggers (i.e., stop eating), social triggers (i.e., family fears of leaving because one call might occur) and care transitions (i.e., hospitalization) impact on relatives' acknowledgement of the "not return point" of the situation and offer the opportunity to discuss the resident's conditions and the need to adjust the care plan. If a trigger event occurs and no one calls the question, the discussion does not take place (Column C) and the care provided does not change (Column D). Instead, whether the trigger event is recognized, the question is called, and care starts to shift toward a palliative approach, may depend in part on a patient-centered environment (Column B). This model identifies four elements influencing the care environment: 1) Staffing level; 2) Staff characteristics (knowledge and training in palliative care); 3) Comfortable physical environment (e.g., single clean and quiet room); and 4) Institutional policies. When there is a patient-centered environment, the provision of good end-of-life is more likely. Family carers identify elements of good end-of-life care at the resident and at family levels (Column D). These elements improve the quality of end-of-life of both residents and their family, thus suggesting a common ground between good end-of-life care and palliative care.

Please, insert figure 2 here

Discussion

The purpose of this systematic review of qualitative findings was to provide a comprehensive understanding of perceptions of good end-of-life care in NH according to family carers.

Our review suggested common elements between good end-of-life care and palliative care for terminally ill NH residents.[49, 50] In the health care arena, it is not infrequent to hear the terms end-of-life care and palliative care being used interchangeably. For a long time, palliative care has assumed the meaning of turning away from curative care when no other treatment is beneficial. However, this

thinking is now outdated particularly in chronically ill elderly patients that often need a mix of these kinds of care. Palliative care is a component of health care at any time, and may become predominant in the end-of-life care of chronically ill elderly patients.[51] However, rationing palliative care services according to patient expected survival unfortunately perpetuates the misperception of palliative care being appropriate only at the end-of-life when all curative treatments have failed.[52] Each person, at any stage of illness, should receive a care that maximises the quality of life with symptom control and support to their family carers;[49] alleviating family burden by addressing information and emotional needs, assume the connotations of a dignified, respectful and compassionate care since it's the last care provided to the dying and his/her family.[37]

Our findings identified functional or social triggers such as swallowing problems and family's fear of leaving for an out-of-town trip, as the key moment to realize that a change is taking place. Irrespective of the diagnosis, what matters is to consider that different triggers may indicate a worsening in residents' conditions and a further step in acknowledging the "not return point" of their situation.[8] Healthcare professionals should assume a sensitive and questioning attitude when facing these changes, that should be seen as opportunities to discuss, also with relatives, whether the care may benefit a change. Research relating to the triggers leading to the adoption of a palliative approach in NH is limited.[34, 36, 39, 46] However, a well-managed transition to a palliative approach is more likely when both family and staff are aware of the end stage decline, otherwise family may be emotionally unprepared and experience death as unexpected.[34] Although prognostication among older people may be complex and challenging,[53, 54] some clinical indicators such as the onset of eating problems, weight loss, or pneumonia have been largely associated with poor prognosis in people with dementia.[12, 16] Their prompt recognition and keeping family members updated on resident's health conditions, may allow a sensitive transition from curative to palliative care.

The role of the NH environment, with adequate staffing levels, staff characteristics, physical environment, and local policies that promote a resident/family centered care correlated more strongly with the quality of dying[55] and the adoption of a palliative care approach.[39] Deficits in staff knowledge and training emerged across studies, with lack of symptom control,[35, 38, 46] failure to recognize that treatments are becoming futile,[56] and misbeliefs such addiction to pain relievers if given too soon.[38] This suggests the need of improving education regarding palliative care.[57, 58] Our findings confirmed the importance of the environment, by providing privacy and promoting a home-like environment (e.g., inviting family carers to bring resident's belongings) to contribute to residents' dignity and well-being,[19, 46] as well as to family satisfaction with care.[48]

Family carers were more satisfied with the end-of-life care when they received physical, emotional, and psychosocial support and their relative died peacefully with physical and spiritual

needs addressed (these are the characteristics of palliative care[28]): higher support and quality of end-of-life care were experienced when the hospice team was involved.[42-44] Caring behaviours of staff to fulfill resident's basic care and spiritual needs,[35, 38, 39, 43] satisfy family's physical,[32, 37] psychosocial,[35, 38] and environmental needs[32] were considered important. Caregivering can be taxing on family members that may experience feelings of guilt and responsibility associated with decisions as treatment withdrawal.[39] Healthcare professionals should capture this discomfort using open-ended questions and offer them a tailored support to lessen the burden,[59] similar to that available to residents.[46] This suggests that end-of-life support should be simultaneously patient-focused and family-centered.[47, 60]

Staff should not take for granted that family is aware of the changes in their relative's health status.[39] Family members generally want to be informed about their resident's health conditions and need honest and updated communication to make decisions that allow them the best use of their remaining time with their relative.[61, 62]

A missed end-of-life planning[39] may result in complicated family grief and everlasting feeling of guilt.[63] NH residents whose family cares were informed of resident's conditions and involved in a shared decision-making, were 2-fold more likely to have a decision to limit or withdrawn aggressive treatments.[64]

Engaging family members in the care plan meeting is pivotal to establish a partnership between family and staff. Gaining insight into what is important for the resident[65] helps healthcare professionals to guide families across the end-of-life decision-making process.[66] However, previous authors found only one out of five family members were involved in the plan meetings[22] and only half of the decisions to withdraw or withhold treatments were routinely discussed.[19, 67] Further, most elders had never talked about their preferences about end-of-life care with their family or staff and trusted their preferences were known.[45]

The transition toward palliative care evolves as family' s awareness of the illness trajectory increases:[66, 68] if family members' advocacy role was not recognized and their expectations with care not discussed, they would assess palliative treatment as being inferior to life-prolonging therapy and fight to ensure all available treatments.[47, 69] The majority of family members expected to be guided throughout all the decision-making process in a timely and compassionate way[38] and felt abandoned and distressed when healthcare professionals failed to share information.[66]

Physical and psychosocial care were the prevalent domains addressed. However, our findings suggest that little attention is still paid to the spiritual issues (n=3,[32, 38, 45] *vs* physical n=13 *vs* psychosocial n=17), although they represent an essential element of end-of-life support and may benefit both residents and their family carers despite not actively religious.[31, 32] Spiritual and

existential problems were discussed with 3% of the NH residents and less than one fourth of their relatives.[70] Therefore, it is important for healthcare professionals to develop spiritual sensitivity and check the need for referrals to qualified professionals such as chaplains, priests, or rabbis.

Unfortunately, there is only partial overlap between families', healthcare professionals' and residents' perspective about end-of-life preferences: families desired end-of-life preferences honoured[34, 45] in addition to emotional, psychosocial and spiritual support[32, 38, 41] while healthcare professionals value less raising the dying preferences neither perceive the provision of spiritual care as a pivotal element.[71]

Although elements of good care (and palliative care) are acknowledged, providing good end-of-life care in NHs may be difficult due to several not easy to be overcome reasons: the poor staffing levels associated with time pressure and increased efficiency requirements that try to be contained by hiring temporary staff that, however, are often unskilled and threaten care continuity;[72] as well as the still too limited use of advanced care planning.[72] In addition, older people are less likely to access palliative care because symptoms and signs of approaching death are often blurred;[73] they often suffer from chronic illnesses such as dementia and heart failure that have not traditionally been the focus of palliative care.[73] Finally, some groups as those from minority ethnic communities, patients with nonmalignant conditions more often failed to receive timely palliative care.[74] Other barriers are represented by healthcare professionals' lack of knowledge and education to deliver at least basic palliative care, poor referral criteria to palliative care services, as well as regulation regarding the administration of medication, particularly the access to opioid.[52, 74]

Strengths and weaknesses

This study provides a conceptual model of good end-of-life care in NH by synthetizing the relevant qualitative literature of end-of-life care experiences according to family carers. Studies were mostly concentrated in the last decade, suggesting an increasing attention to end-of-life care in the NHs despite the facilities differed for type of care offered and hospice access. Most elements of good end-of-life care reported by family carers shared a common ground with palliative care.

Conclusions

Family carers desire a care aimed at early identifying and treating physical, psychological, and spiritual problems. These are the core elements of palliative care.[28] However, spiritual issues were poorly discussed.

According to our model, the adoption of a palliative approach starts from recognizing physical or social triggers and it is sustained by an environment characterized by adequate staffing, staff trained

in palliative care, supportive physical environmental and local policies directed at promoting patient-focused and family-centered care.

Family members have a central role in promoting the transition from usual care to palliative care, but they should be kept updated about their relative's condition, fully engaged in the decisions for the end-of-life treatments and emotionally supported to ensure a shared decision-making.

More efforts and resources should be invested on different fronts (e.g., staff training, physical environment, internal policies and regulations) to guarantee good end-of-life care in NH.

What is already known about this topic?

- Palliative care is a complex process aimed at early identification, assessment and treatment of physical, psychosocial, and spiritual problems.
- The transition from activities directed at promoting resident's quality of life to those promoting quality of death is usually gradual.
- Health staff often fails to recognize that a resident is dying, thus missing opportunities for discuss with and emotionally prepare families for the upcoming death.

What this paper adds?

- The end-of-life timeframe shifts the usual good care aimed at maximizing the quality of life into palliative care.
- Trigger events represent an opportunity for health staff to wonder whether the resident is likely to die in the coming weeks or months and the care plan needs an adjustment.
- Promoting family members understanding about their resident's disease trajectory favours a sensitive transition from curative to palliative care.
- Family members should be supported in a timely and compassionate way since the transition toward palliative care begins.

Implications for practice, theory and research

- Usual care team should have sufficient skills to anticipate and address needs for palliative care, including sensitivity towards spiritual and existential problems.
- Nursing home staff education in recognizing and managing symptoms should be improved in order to provide high quality end-of-life care.
- Nursing home facilities should pay attention to the environment design to favour a home-like atmosphere.

Acknowledgements

The Authors would thank Dr. Marco Clari for the methodological support with the Joanna Briggs Institute meta-aggregation method.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Declaration of conflicts of interest

The Authors declare that there is no conflict of interest.

References

1. Perrels AJ, Fleming J, Zhao J, et al. Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective analysis of a prospective population-based cohort aged 85 and over. *Palliat Med* 2014; 28: 220-233. DOI: 10.1177/0269216313510341.

2. Sleeman KE, Ho YK, Verne J, et al. Reversal of english trend towards hospital death in dementia: A population-based study of place of death and associated individual and regional factors, 2001-2010. *BMC Neurol* 2014; 14: 59. DOI: 10.1186/1471-2377-14-59

3. Bone AE, Gomes B, Etkind SN, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliat Med* 2018; 32: 329-336. DOI: 10.1177/0269216317734435

4. Gomez-Batiste X, Martinez-Munoz M, Blay C, et al. Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: A cross-sectional study. *Palliat Med* 2014; 28: 302-311. DOI: 10.1177/0269216313518266.

5. Currow DC and Hegarty M. Residential aged-care facility palliative care guidelines: Improving care. *Int J Palliat Nurs* 2006; 12: 231-233. DOI: 10.12968/ijpn.2006.12.5.21176

6. Froggatt KA. Palliative care and nursing homes: Where next? *Palliat Med* 2001; 15: 42-48. DOI: 10.1191/026921601671222652.

7. Barclay S, Froggatt K, Crang C, et al. Living in uncertain times: Trajectories to death in residential care homes. *Br J Gen Pract* 2014; 64: e576-583. DOI: 10.3399/bjgp14X681397

8. Bern-Klug M. Calling the question of "possible dying" among nursing home residents: Triggers, barriers, and facilitators. *J Soc Work End Life Palliat Care* 2006; 2: 61-85. DOI: 10.1300/J457v02n03_06.

9. van Riet Paap J, Mariani E, Chattat R, et al. Identification of the palliative phase in people with dementia: A variety of opinions between healthcare professionals. *BMC Palliat Care* 2015; 14: 56. DOI: 10.1186/s12904-015-0053-8.

10. van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: A delphi study and recommendations from the european association for palliative care. *Palliat Med* 2014; 28: 197-209. DOI: 10.1177/0269216313493685.

11. Andersson S, Lindqvist O, Furst CJ, et al. End-of-life care in residential care homes: A retrospective study of the perspectives of family members using the voices questionnaire. *Scand J Caring Sci* 2017; 31: 72-84. DOI: 10.1111/scs.12317

12. Sampson EL, Candy B, Davis S, et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliat Med* 2018; 32: 668-681. DOI: 10.1177/0269216317726443.

13. Di Giulio P, Toscani F, Villani D, et al. Dying with advanced dementia in long-term care geriatric institutions: A retrospective study. *J Palliat Med* 2008; 11: 1023-1028. DOI: 10.1089/jpm.2008.0020.

14. De Roo ML, Albers G, Deliens L, et al. Physical and psychological distress are related to dying peacefully in residents with dementia in long-term care facilities. *J Pain Symptom Manage* 2015; 50: 1-8. DOI: 10.1016/j.jpainsymman.2015.02.024

15. Fleming J, Calloway R, Perrels A, et al. Dying comfortably in very old age with or without dementia in different care settings - a representative "older old" population study. *BMC Geriatr* 2017; 17: 017-0605. DOI: 10.1186/s12877-017-0605-2.

16. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009; 361: 1529-1538. DOI: 10.1056/NEJMoa0902234.

17. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *J Am Med Assoc* 2004; 291: 88-93. Article. DOI: 10.1001/jama.291.1.88.

18. Mitchell SL, Kiely DK and Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med* 2004; 164: 321-326. Article. DOI: 10.1001/archinte.164.3.321.

19. Toscani F, van der Steen JT, Finetti S, et al. Critical decisions for older people with advanced dementia: A prospective study in long-term institutions and district home care. *J Am Med Dir Assoc* 2015; 16: 535 e513-520. DOI: 10.1016/j.jamda.2015.02.012.

20. Meier EA, Gallegos JV, Thomas LP, et al. Defining a good death (successful dying): Literature review and a call for research and public dialogue. *Am J Geriatr Psychiatry* 2016; 24: 261-271. DOI: 10.1016/j.jagp.2016.01.135.

21. Dy SM, Kiley KB, Ast K, et al. Measuring what matters: Top-ranked quality indicators for hospice and palliative care from the american academy of hospice and palliative medicine and hospice and palliative nurses association. *J Pain Symptom Manage* 2015; 49: 773-781. DOI: 10.1016/j.jpainsymman.2015.01.012

22. Reinhardt JP, Downes D, Cimarolli V, et al. End-of-life conversations and hospice placement: Association with less aggressive care desired in the nursing home. *J Soc Work End Life Palliat Care* 2017; 13: 61-81. Article. DOI: 10.1080/15524256.2017.1282919.

23. JBI. Reviewers' manual 2014 edition, Available at: http://joannabriggs. org/assets/docs/sumari/reviewersmanual-2014. pdf (accessed March 13th, 2018).

24. Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: Entreq. *BMC Med Res Methodol* 2012; 12: 181. DOI: 10.1186/1471-2288-12-181.

25. Sanford AM, Orrell M, Tolson D, et al. An international definition for "nursing home". *J Am Med Dir Assoc* 2015; 16: 181-184. DOI: 10.1016/j.jamda.2014.12.013.

26. Lockwood C, Munn Z and Porritt K. Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc* 2015; 13: 179-187. DOI: 10.1097/XEB.0000000000000062.

27. Petriwskyj A, Gibson A, Parker D, et al. A qualitative metasynthesis: Family involvement in decision making for people with dementia in residential aged care. *Int J Evid Based Healthc* 2014; 12: 87-104. DOI: 10.1097/XEB.0000000000000002.

28. WHO. Definition of palliative care, Retrieved on www.who.int/cancer/palliative/definition/en/ (2002, accessed May 24th, 2018).

29. Miles MB, Huberman AM, Huberman MA, et al. *Qualitative data analysis: An expanded sourcebook* 2nd ed. Beverley Hills: Sage, 1994.

30. Katz JS, Sidell M and Komaromy C. Dying in long-term care facilities: Support needs of other residents, relatives, and staff. *Am J Hosp Palliat Med* 2001; 18: 321-326. DOI: 10.1177/104990910101800507.

31. Jackson J, White P, Fiorini J, et al. Family perspectives on end-of-life care: A metasynthesis. *J Hosp Palliat Nurs* 2012; 14: 303-311. DOI: 10.1097/NJH.0b013e31824ea249.

32. Wilson SA and Daley BJ. Family perspectives on dying in long-term care settings. *J Gerontol Nurs* 1999; 25: 19-25.

33. Parker R, deVries K and Coombs MA. Redefining the patient-carer model at end of life. *Int J Palliat Nurs* 2016; 22: 272-277. DOI: 10.12968/ijpn.2016.22.6.272.

34. Waldrop DP and Kusmaul N. The living-dying interval in nursing home-based end-of-life care: Family caregivers' experiences. *J Gerontol Soc Work* 2011; 54: 768-787. DOI: 10.1080/01634372.2011.596918.

35. Goodridge D, Bond JB, Jr., Cameron C, et al. End-of-life care in a nursing home: A study of family, nurse and healthcare aide perspectives. *Int J Palliat Nurs* 2005; 11: 226-232. DOI: 10.12968/ijpn.2005.11.5.226.

36. Church LL, Schumacher KL and Thompson SA. Mixed-methods exploration of family caregiver strain in the nursing home. *J Hosp Palliat Nurs*; 18: 46-52. DOI: 10.1097/njh.0000000000000209.

37. Kaarbø¸ E. End-of-life care in two norwegian nursing homes: Family perceptions. *Journal of Clinical Nursing*; 20: 1125-1132. DOI: 10.1111/j.1365-2702.2009.03171.x.

38. Vohra JU, Brazil K and Szala-Meneok K. The last word: Family members' descriptions of end-of-life care in long-term care facilities. *J Palliat Care* 2006; 22: 33-39.

39. Frey R, Foster S, Boyd M, et al. Family experiences of the transition to palliative care in aged residential care (arc): A qualitative study. *Int J Palliat Nurs* 2017; 23: 238-247. DOI: 10.12968/ijpn.2017.23.5.238.

40. Thompson GN, Menec VH, Chochinov HM, et al. Family satisfaction with care of a dying loved one in nursing homes: What makes the difference? *J Gerontol Nurs* 2008; 34: 37-44. DOI: 10.3928/00989134-20081201-10.

41. Flock P and Terrien JM. A pilot study to explore next of kin's perspectives on end-of-life care in the nursing home. *J Am Med Dir Assoc* 2011; 12: 135-142. DOI: 10.1016/j.jamda.2010.07.017.

42. Wetle T, Shield R, Teno J, et al. Family perspectives on end-of-life care experiences in nursing homes. *Gerontologist* 2005; 45: 642-650. DOI: 10.1093/geront/45.5.642.

43. Shield RR, Wetle T, Teno J, et al. Vigilant at the end of life: Family advocacy in the nursing home. *J Palliat Med* 2010; 13: 573-579. DOI: 10.1089/jpm.2009.0398.

44. Oliver DP, Washington K, Kruse RL, et al. Hospice family members' perceptions of and experiences with end-of-life care in the nursing home. *J Am Med Dir Assoc*; 15: 744-750. DOI: 10.1016/j.jamda.2014.05.014.

45. Bollig G, Gjengedal E and Rosland JH. They know! - do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. *Palliat Med*; 30: 456-470. DOI: 10.1177/0269216315605753.

46. Glass AP. Family caregiving and the site of care: Four narratives about end-of-life care for individuals with dementia. *J Soc Work End Life Palliat Care* 12: 23-46. DOI: 10.1080/15524256.2016.1156605.

47. Palan Lopez R. Doing what's best: Decisions by families of acutely ill nursing home residents. *West J Nurs Res* 2009; 31: 613-626. DOI: 10.1177/0193945909332911.

48. Cahill S, Doran D and Watson M. Guidelines for nursing homes delivering end-of-life care to residents with dementia across the island of ireland. *Qual Ageing Older Adults* 2012; 13: 60-70. DOI: 10.1108/14717791211213625.

49. Johnson M and Fallon M. Just good care? The palliative care of those with non-malignant disease. *Palliat Med* 2013; 27: 803-804. DOI: 10.1177/0269216313504058.

50. Fosse A, Schaufel MA, Ruths S, et al. End-of-life expectations and experiences among nursing home patients and their relatives-a synthesis of qualitative studies. *Patient Educ Couns*; 97: 3-9. DOI: 10.1016/j.pec.2014.05.025.

51. Lynn J and Adamson DM. *Living well at the end of life. Adapting health care to serious chronic illness in old age*. Report no. 0-8330-3455-3, 2003. Santa Monica, CA.

52. Hawley P. Barriers to access to palliative care. *Palliat Care* 2017; 10: 1178224216688887. DOI: 10.1177/1178224216688887.

53. Mitchell SL, Kiely DK, Hamel MB, et al. Estimating prognosis for nursing home residents with advanced dementia. *JAMA* 2004; 291: 2734-2740. DOI: 10.1001/jama.291.22.2734.

54. Yourman LC, Lee SJ, Schonberg MA, et al. Prognostic indices for older adults: A systematic review. *JAMA* 2012; 307: 182-192. DOI: 10.1001/jama.2011.1966.

55. Thompson SA, Bott M, Gajewski B, et al. Quality of care and quality of dying in nursing homes: Two measurement models. *J Palliat Med* 2012; 15: 690-695. DOI: 10.1089/jpm.2011.0497.

56. Travis SS, Bernard M, Dixon S, et al. Obstacles to palliation and end-of-life care in a long-term care facility. *Gerontologist* 2002; 42: 342-349. DOI: 10.1093/geront/42.3.342.

57. Brazil K and Vohra JU. Identifying educational needs in end-of-life care for staff and families of residents in care facilities. *Int J Palliat Nurs* 2005; 11: 475-480. DOI: 10.12968/ijpn.2005.11.9.19782

58. Hanson LC, Henderson M and Menon M. As individual as death itself: A focus group study of terminal care in nursing homes. *J Palliat Med* 2002; 5: 117-125. DOI: 10.1089/10966210252785088.

59. Schofield P, Carey M, Love A, et al. 'Would you like to talk about your future treatment options'? Discussing the transition from curative cancer treatment to palliative care. *Palliat Med* 2006; 20: 397-406. DOI: 10.1191/0269216306pm1156oa.

60. Teno JM, Casey VA, Welch LC, et al. Patient-focused, family-centered end-of-life medical care: Views of the guidelines and bereaved family members. *J Pain Symptom Manage* 2001; 22: 738-751. DOI: 10.1016/s0885-3924(01)00335-9.

61. Romoren M, Pedersen R and Forde R. How do nursing home doctors involve patients and next of kin in end-of-life decisions? A qualitative study from norway. *BMC Med Ethics* 2016; 17: 5. DOI: 10.1186/s12910-016-0088-2.

62. Gjerberg E, Lillemoen L, Forde R, et al. End-of-life care communications and shared decision-making in norwegian nursing homes--experiences and perspectives of patients and relatives. *BMC Geriatr* 2015; 15: 103. DOI: 10.1186/s12877-015-0096-y.

63. Schulz R, Boerner K, Klinger J, et al. Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *J Palliat Med* 2015; 18: 127-133. DOI: 10.1089/jpm.2014.0309.

64. Gonella S, Basso I, Dimonte V, et al. Association between end-of-life conversations in nursing homes and end-of-life care outcomes: A systematic review and meta-analysis. *J Am Med Dir Assoc* 2018. Article in Press. DOI: 10.1016/j.jamda.2018.10.001.

65. Thoresen L and Lillemoen L. "I just think that we should be informed" a qualitative study of family involvement in advance care planning in nursing homes. *BMC Med Ethics* 2016; 17: 72. DOI: 10.1186/s12910-016-0156-7.

66. Caron CD, Griffith J and Arcand M. End-of-life decision making in dementia: The perspective of family caregivers. *Dementia* 2005; 4: 113-136.

67. van der Steen JT, Di Giulio P, Giunco F, et al. Pneumonia in nursing home patients with advanced dementia: Decisions, intravenous rehydration therapy, and discomfort. *Am J Hosp Palliat Care* 2018; 35: 423-430. DOI: 10.1177/1049909117709002.

68. Cable-Williams B and Wilson D. Awareness of impending death for residents of long-term care facilities. *Int J Older People Nurs* 2014; 9: 169-179. DOI: 10.1111/opn.12045

69. Dreyer A, Forde R and Nortvedt P. Autonomy at the end of life: Life-prolonging treatment in nursing homes-relatives' role in the decision-making process. *J Med Ethics* 2009; 35: 672-677. DOI: 10.1136/jme.2009.030668.

70. Morin L, Johnell K, Van den Block L, et al. Discussing end-of-life issues in nursing homes: A nationwide study in france. *Age Ageing* 2016; 45: 395-402. DOI: 10.1093/ageing/afw046.

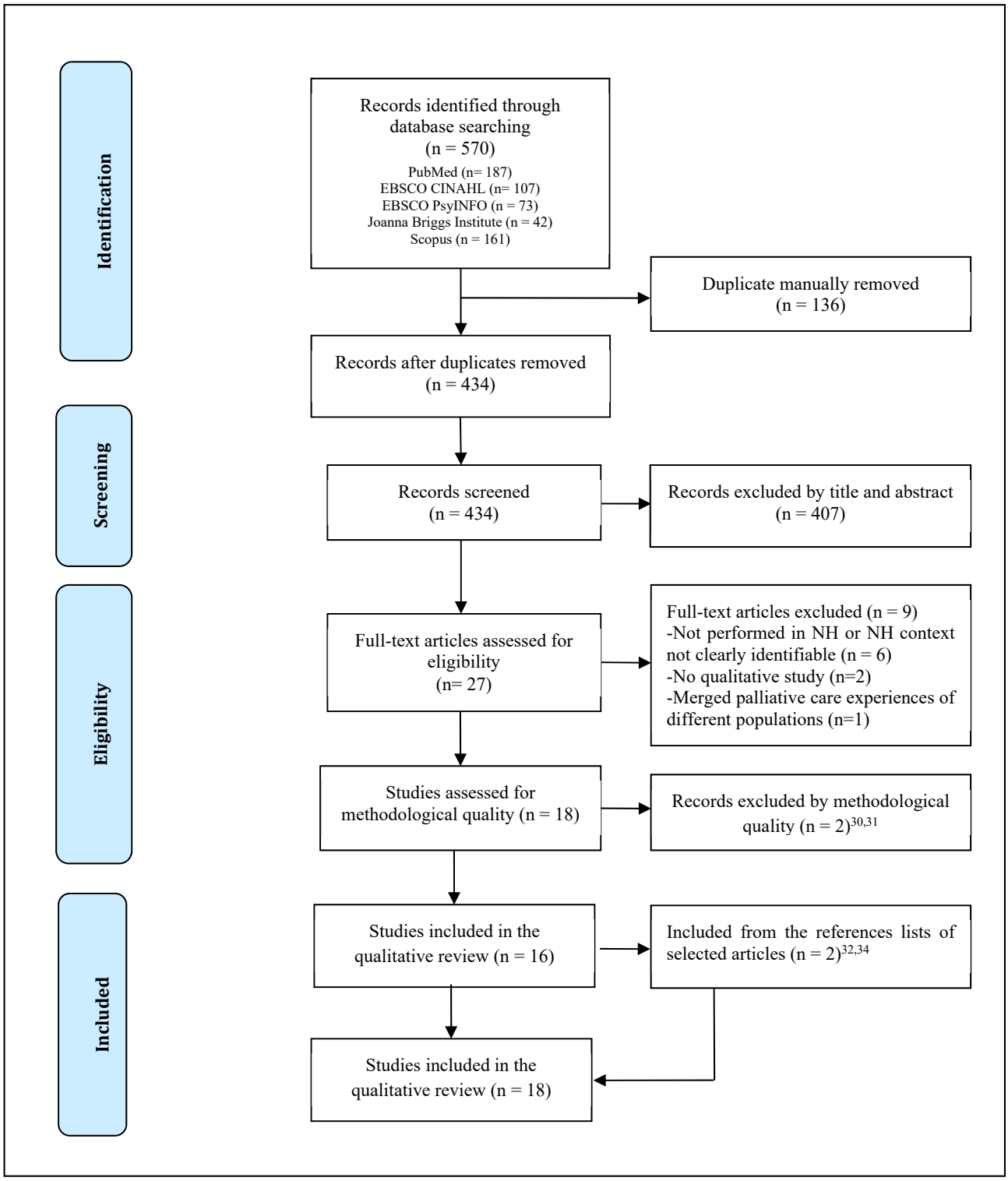
71. Lee RP, Bamford C, Poole M, et al. End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice. *PloS one* 2017; 12: e0179355. DOI: 10.1371/journal.pone.0179355.

72. Midtbust MH, Alnes RE, Gjengedal E, et al. Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals' experiences. *BMC Health Serv Res* 2018; 18: 709. DOI: 10.1186/s12913-018-3515-x.

73. Lloyd A, Kendall M, Carduff E, et al. Why do older people get less palliative care than younger people? *Eur J Palliat Care* 2016; 23: 132-137.

74. Ahmed N, Bestall JC, Ahmedzai SH, et al. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med* 2004; 18: 525-542. DOI: 10.1191/0269216304pm921oa.

Figure 1.PRISMA flow-chart depicting the main stages of the systematic review process.



Abbreviations: NH, Nursing home.

Figure 2. A conceptual model of good end-of-life care in the nursing home context according to family carers' perspective.

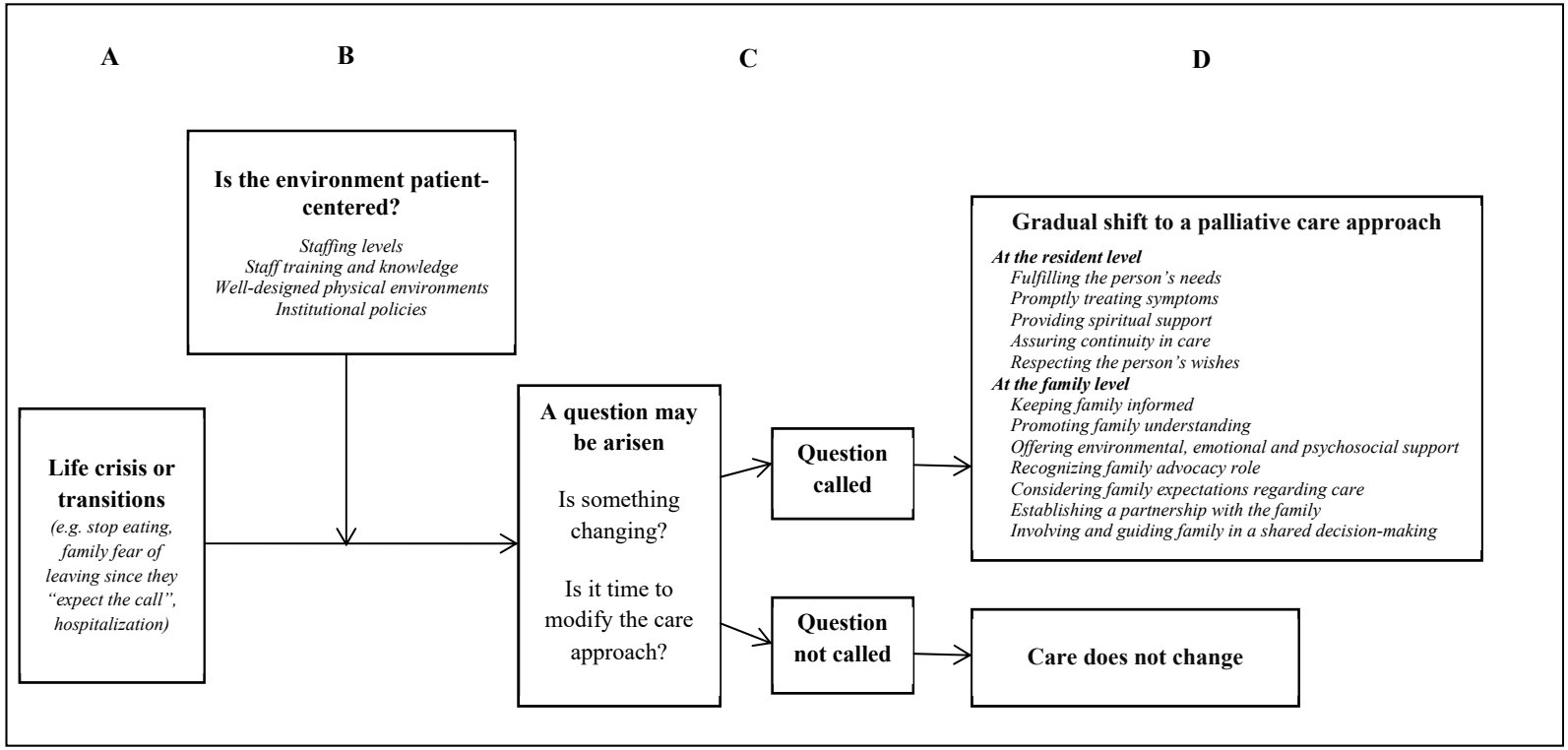


Table 1: Assessment of methodological quality[a]

Author(s), year (code)	C1. Congruity in philosophical perspective	**C2. Congruity in research objective**	**C3. Congruity in methods used to collect data**	**C4. Congruity in data analysis**	**C5. Congruity in interpretation of the results**	C6. Cultural or theoretical orientation of the researcher(s)	C7. Potential influence of the researcher on the research and vice-versa	**C8. Representativeness of the participants' voices**	C9. Ethical approval	C10. Conclusions drawn from the analysis	Included in the review	Quality appraisal[a]
Wetle, 2005 (A)[42]	N	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	8/10
Parker, 2016 (B)[33]	N	Y	Y	Y	Y	N	N	Y	Y	N	Y	6/10
Shield, 2010 (C)[43]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	8/10
Frey, 2017 (D)[39]	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/10
Katz, 2001 (E)[30]	Y	U	Y	U	N	N	N	Y	N	Y	N	-
Lopez, 2014 (F)[47]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	8/10
Waldrop, 2011 (G)[34]	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
Glass, 2016 (H)[46]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	8/10
Flock, 2011 (I)[41]	N	Y	Y	Y	Y	N	N	Y	Y	Y	Y	7/10
Thompson, 2008 (J)[40]	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
Kaarbø, 2010 (K)[37]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	8/10
Bollig, 2016 (L)[45]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Cahill, 2012 (M)[48]	N	Y	Y	Y	Y	N	N	Y	Y	Y	Y	7/10
Van der Steen, 2017 (N)[19]	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/10
Parker Oliver, 2014 (O)[44]	N	Y	Y	Y	Y	N	N	Y	Y	Y	Y	7/10

Jackson, 2012 (P)[31]	Y	Y	Y	U	Y	N	N	Y	Y	Y	N	-
Vohra, 2006 (Q)[38]	N	Y	Y	Y	Y	N	N	Y	Y	Y	Y	7/10
Goodridge, 2005 (R)[35]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	8/10
Wilson, 1999 (S)[32]	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	9/10
Church, 2015 (T)[36]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	8/10

Abbreviations: C, criteria; JBI-QARI, Joanna Briggs Institute - Quality Assessment Review Instrument; N, no; NA, not applicable; U, unclear; Y, yes.

Note. Studies were included in the review only if they achieved a positive score (i.e., yes answer) in at least the following five criteria (in bold): congruity between research methodology and research objective (C2), data collection methods (C3), data analysis (C4), and interpretation of the results (C5), and the representativeness of the participants' voices (C8).

[a] According to the JBI-QARI critical appraisal tool.

Table 2: Characteristics of the included studies

Auhtor(s), year (code)	Aim	Main EOL care domains[a]	Geographical context/ characteristics of NH	Participants	Methodology	Data collection	Data analysis	Methodological quality appraisal[b]
Wetle, 2005 (A)[42]	To expand the knowledge regarding EOL care in NHs according to family perspective.	Physical Psychosocial	USA/NR Hospice available	57 family members of died NH residents *Gender*: female 64.8% (n=37) *Education*: graduate or postgraduate 72.2% (n=41) *Kinship*: child (n=22, 40.7%) spouse/partner (n= 8, 14.8%) other (n=24, 44.5%)	Qualitative descriptive	- Semi-structured and open-ended telephone interviews lasting between 35 and 90 minutes each - Between 21-27 months after death -Referred period of EOL care experience: last year and last week of life	Thematic analysis Atlas.ti software	**8/10**
Parker, 2016 (B)[33]	To explore types of patient-carer models in use for those with advanced and progressive disease.	Psychosocial	New Zealand/ 1 NH (150 beds) providing 24-hour registered nursing care	5 family members (3 spouses, 2 children) of NH residents at high risk of dying in the next year *No sociodemographic data specified*	Ethnography	- 4 weeks of field observations - Face-to-face individual interviews (duration not reported) - Residents at their EOL but alive	Thematic analysis NVivo software	**6/10**
Shield, 2010 (C)[43]	To explore family members' perceptions of EOL care of their deceased family member	Physical Psychosocial	USA/NR Hospice available	54 family members of died NH residents *Gender*: female 64.8% (n=37) *Education*: graduate or postgraduate 72.2% (n=41) *Kinship*: child (n=22, 40.7%) spouse/partner (n= 8, 14.8%) other (n=24, 44.5%)	Qualitative descriptive	- Telephone interviews lasting from 35 to 90 minutes - Between 21-27 months after death - Referred period of EOL care experience: last year and last week of life	Thematic analysis Atlas.ti software	**8/10**
Frey, 2017 (D)[39]	To explore bereaved families' perceptions of the transition to care to incorporate a palliative approach for their relative	Physical Psychosocial	New Zealand/ 9 NHs (3 with 20-30 beds, 4 with 31-60 beds, 4 with ≥ 61 beds) All urban 2 NHs had Liverpool care pathway	26 family members of died NH residents *Gender*: female 47.2% (n=12) *Age*: 76.9% ≥ 55 y *Kinship*: child (n=16, 61.5%) spouse/partner (n=7, 26.9%) other (n=3, 7.6%)	Qualitative descriptive	- Face-to-face individual interviews or telephone interviews lasting from 20 to 60 minutes - Between 3-12 months after death - Referred period of EOL care experience: NR	Thematic analysis	**9/10**
Lopez, 2013 (F)[47]	To understand family members' perspective on person- and family-centered EOL care provided to NH residents with advanced dementia	Physical Psychosocial	USA/22 NHs (beds NR)	16 family members of NH residents with advanced dementia *Gender*: female 63% (n=10) *Mean age*: 62 y *Kinship*: 15 children 62% had resident alive at the time of interview	Qualitative descriptive	- Semi-structured, open-ended interviews via telephone lasting averagely 50 minutes (range 19-123 minutes) - Resident either at their EOL but alive or died in the prior year (referred period of EOL care experience: NR)	Thematic analysis NVivo software	**8/10**
Waldrop, 2011 (G)[34]	To explore family members'	Psychosocial	USA/1 NH (beds NR)	31 caregivers of died NH residents	Qualitative descriptive	- Face-to-face individual interviews lasting from 60 to 90 minutes	Thematic analysis	**9/10**

	experience during the end stage of a loved one's life and the living-dying interval in a NH		Dementia care unit available	*Median age*: 69 y (range 53-85) *Kinship*: child (n=20, 65%) spouse/partner (n= 5, 16%) other (n=6, 19%)		- Between 3-4.5 months after death - Referred period of EOL care experience: NR	Atlas.ti software	
Glass, 2016 (H)[46]	To understand families'perceptions of how individuals with dementia die	Psychosocial	USA/NR	2 family members (a wife and a daughter) of died NH residents *No sociodemographic data specified*	Phenomenological case studies	- Face-to-face individual interviews lasting an hour on average - Timing NR - Referred period of EOL care experience: case 1 death day; case 2 last year and last month of life	Thematic analysis	**8/10**
Flock, 2011 (I)[41]	To explore next of kin's perceptions of EOL care in the NH setting and to compare these perceptions for residents receiving hospice care plus usual care versus usual care only	Physical Psychosocial	USA/3 NHs (beds NR) 1 for-profit, 1 not for-profit, 1 affiliated with an academic medical center Hospice care available	100 family members of died NH *Gender*: female 69% (n=69) *Age*: 46% was 60-79 y *Education*: graduate or postgraduate 58% (n=58) *Kinship*: child (57%) spouse/partner (11%) other (32%)	Qualitative descriptive	- Mailed surveys with open-ended questions - Between 3-16 months after death - Referred period of EOL care experience: NR	Thematic analysis	**7/10**
Thompson, 2008 (J)[40]	To explore family member satisfaction and dissatisfaction with EOL care provided to NH residents	Physical Psychosocial	Canada/ 12 NHs (78 to 314 beds) 8 non-profit 7 nondenominational All urban Palliative care services available on a consultation basis through regional program	14 family members of died NH residents *Gender*: female 86% (n=12) *Mean age*: 56.6 y *Education*: graduate or postgraduate 79% (n=11) *Kinship*: child (n=9, 64%) other (n=5, 36%)	Qualitative descriptive	- Focus group interviews lasting 78 minutes on average - Timing NR - Referred period of EOL care experience: NR	Content analysis	**9/10**
Kaarbø, 2010 (K)[37]	To explore the experiences of relatives who had been present immediately prior to and after the death of a next of kin in a NH	Physical Psychosocial	Norway/ 2 NHs (93 to 188 beds) 1 urban, 1 rural with 5 palliative care unit beds	50 family members of died NH residents *Kinship*: child (n=33, 66%) spouse (n=11, 22%) other (n=6, 12%)	Qualitative descriptive	- Face-to-face individual interviews lasting between one-two hours - 8 weeks after death - Referred period of EOL care experience: last 72 hours of life	Thematic analysis	**8/10**
Bollig, 2016 (L)[45]	To explore the relatives' views of cognitive able NH residents on advance care planning, decision-making, and EOL care	Physical Spiritual	Norway/3 NHs (beds NR)	18 family members of NH residents *Gender*: female 72% (n=13) *Mean age*: 68 y (range 41-91 y) *Kinship*: child (n=10, 56%) spouse (n=6, 33%) other (n=2, 11%)	Interpretive descriptive	- Focus group interviews (duration not reported) - Resident alive	Thematic analysis QSR NVivo 9	**10/10**

Cahill, 2012 (M)[48]	To investigate the experiences of elderly spouses whose relatives died with end-stage dementia in NH	Physical Psychosocial	Northern Ireland and Republic of Ireland/9 NHs (beds NR)	16 bereaved spouses of relatives died wih end-stage dementia *Gender*: female 75% (n=12) *Mean age*: 77 y (range 62-88 y)	Qualitative descriptive	- Face-to-face individual interviews (duration not reported) - Averagely 34 months after death (range 8-100 months) - Referred period of EOL care experience: last 3 months of life	Thematic analysis	**7/10**
Van der Steen, 2017 (N)[19]	To understand what needs to be in place to develop optimal palliative care for people with dementia in the terminal phase	Psychosocial	The Netherlands/NR	4 wives of people with dementia *Age*: 60-75 y	Qualitative descriptive	- Focus group interviews (duration not reported) - 3 residents were alive, one resident has been died recently (referred period of EOL care experience NR)	Thematic analysis	**9/10**
Parker Oliver, 2014 (O)[44]	To explore the perceptions of family members regarding EOL care in the NH setting while their relative was enrolled in hospice	Physical Psychosocial	USA/NR Hospice available	86 family members of NH residents who received hospice care in NH *Sociodemographic data reported only for the whole group of subjects dead in NH (n=175)*	Qualitative descriptive	- Telephone interviews (duration not reported) - Two weeks after resident's death or hospice discharge - Referred period of EOL care experience: NR	Thematic analysis	**7/10**
Vohra, 2006 (Q)[38]	To explore family members' perceptions of EOL in NH	Physical Psychosocial Spiritual	Canada/ 6 NHs (84 to 370 beds) 3 religiously affiliated	104 family members of died NH residents *Gender*: female 78% (n=81) *Mean age*: 60.5 y (SD 11 y) *Kinship*: child (n=82, 79%) spouse (n=11, 10%) other (n=7, 11%)	Qualitative descriptive	- Mailed survey with one open ended question - Between 3-15 months after death - Referred period of EOL care experience: last month of life	Thematic analysis	**7/10**
Goodridge, 2005 (R)[35]	To explore the perspective of family members regarding the last 72 hours before a resident's death	Physical Psychosocial	Canada/ 1 NH (220 beds) 60 beds reserved for dementia care	4 family members of died NH residents *No sociodemographic data specified*	Qualitative descriptive	- Face-to-face semi-structured open-ended interviews (duration not reported) - Two months after death - Referred period of EOL care experience: last 3 days of life	Thematic analysis	**8/10**
Wilson, 1999 (S)[32]	To describe family perspective on death and dying in long-term facilities and to discuss ways staff may be helpful to families in coping with the loss of a family member	Psychosocial Spiritual	USA/ 11 NHs (beds NR) 5 for-profit 6 religiously affiliated	11 family members of died NH residents *No sociodemographic data specified*	Qualitative interpretive	- Face-to-face interviews lasting from 60 to 90 minutes - Timing NR - Referred period of EOL care experience: NR	Thematic analysis An electronic data management program not specified	**9/10**
Church, 2015 (T)[36]	To explore the strain experienced by family caregivers of NH residents who died in a NH	Physical Psychosocial	USA/ 85 NHs (39 to 254 beds) 62.4% rural 52.9% for-profit	1282 family members of died NH residents *Gender*: female 71% (n=910) *Mean age*: 63.6 y *Kinship*: child (n=1077, 84%)	Qualitative descriptive	- Telephone semi-structured interviews lasting approximately 1 hour - Six weeks after death - Referred period of EOL care experience: last few days of life	Content analysis	**8/10**

				spouse (n=167, 13%) other (n=38, 3%)				

[a] The main EOL care domains (i.e., physical, psychosocial, and spiritual) were identified according to the WHO definition of palliative care.[28]
[b]According to the JBI-QARI critical appraisal tool.
Abbreviations: AD, Alzheimer disease; EOL, End of life; JBI-QARI, Joanna Briggs Institute - Quality Assessment Review Instrument; NH, Nursing home; y, years; NR, Not reported; SD, Standard deviation; WHO, World Health Organization).
Studies code: A[42], B[33], C[43], D[39], F[47], G[34], H[46], I[41], J[40], K[37], L[45], M[48], N[19], O[44], Q[38], R[35], S[32], T[36].

Table 3: Synthesised findings, categories and findings extracted from the included studies

Synthesised findings	Categories	Study findings (alphanumeric code; level of credibility)
1. Nursing home residents' family carers perceive life crisis and transitions in their relative's care	1.1 Trigger	Dementia care (D2; U)
		Trigger event (G1; U)
		Beginning of the end (G7; U)
		Fear of leaving (T4; U)
	1.2 Transitions	Navigating the health care system (H2; C)
		Level of care crisis (G3; U)
		Hospitalization (G5; U)
		Hospital care (M4; U)
2. Environmental and human factors influence the provision of a patient-centered care in nursing home	2.1 Nursing home physical environment	Supportive environment (I2; U)
		Physical environment (Q9; U)
	2.2 Nursing home culture of care	Task-focused regulations add to resident and family burden (A9; U)
		Misinterpreted and misunderstood regulations (A10; U)
		Person-centred care (M2; U)
	2.3 Staffing	Physicians presence (A5; U)
		Physicians role (A6; U)
		Lack of staff (A7; U)
		Staffing levels (Q5; U)
		Physician availability (Q7; U)
	2.4 Staff knowledge and training	Failure to recognize symptoms or terminal phase (A2; U)
		Staff need better training (A8; U)
		Monitoring of resident's changing condition (C6; U)
		Challenges of caring for individuals with dementia (H1; U)
		Recognizing imminent dying (J1; U)
		Staff training (M5; U)
		Staff knowledge (Q6; U)
3. Nursing home residents' family carers identify good end-of-life care at the resident level with dying in dignity	3.1 Person's basic needs	Nutrition and personal care (C5; U)
		Providing basic care (F1; U)
		Physical care (Q4; U)
		Physical care (R3; U)
	3.2 Managing symptoms	Symptom management and palliative intervention (A1; U)
		Symptom management (D1; U)
		Decreased burden (I1; U)
		Pain and symptom-relief (L2; U)
		Pain and symptom control at the end of life (M3; U)
		Pain management (O5; U)
		Role of hospice (A13; U)

		Resident's symptom distress (T9; U)
	3.3 Spiritual support	Spiritual care (Q3; U)
		Provision of spiritual support (S5; U)
	3.4 Continuity in care	Concerns regarding hospice (C14; U)
		Communication and information sharing (J2; U)
		Familiarity (N2; U)
		Communication (O3; U)
		Positive experiences (O6; U)
	3.5 Preferences honored	Advance care planning (G4; U)
		Natural death or death as a wish (L1; U)
	3.6 Dignified death	The concept of good care (K1; U)
		Loss of dignity (T6; U)
4. Nursing home residents' family carers identify good end-of-life care at the family level with information, understanding and support	4.1 Family information needs	Getting basic information (C3; U)
		Assumptions (D3; U)
		Tick box exercise (D4; U)
		Planning (D5; U)
		Alternative sources (D10; U)
		Support and information (H4; U)
		Need for improvement (K3; C)
		Communication (N1; U)
		Communication (Q8; U)
		Education of the family (R4; U)
		Uncertainty (T5; U)
		Lack of communication (T7; U)
	4.2 Family understanding of the dying process	Awareness of dying (G8; U)
		Understanding the dying process (S3; U)
	4.3 Environmental, emotional and psychosocial support	Positive aspects of care in nursing home compared with hospital (A11; U)
		Negative experiences in the nursing home (C2; U)
		Time and effort expended (C8; U)
		Extra eyes and ears (C13; U)
		Anxiety and guilt (D7; U)
		Loss of control (D8; U)
		Coming to terms with the experience (F5; U)
		Accumulation of stressors (G2; U)
		Hospice use (H3; U)
		Respect and compassion (I3; U)
		Limitations of care (K2; U)
		Hospice collaboration in the nursing home (O1; U)
		Resident care issues (O4; U)

		Psychosocial support (Q1; U)
		Family care (Q2; U)
		Nurturance (R5; C)
		The resident's unique experience of dying (R6; U)
		Caring behaviors of staff (S1; U)
		Being present at the time of death (S4; U)
		Guilt (T3; U)
		Lack of quality care (T8; U)
5. Nursing home residents' family carers identify good end-of-life care with establishing a partnership with health care professionals	5.1 Relationship between family and staff	Adversarial relationships with staff (C7; U)
		Partnership with family members (C12; U)
		Distrust (D6; U)
		Creating a sense of belonging and attachment (F3; U)
		Relationships (M6; U)
		Trust (M8; U)
	5.2 Family expectations regarding care	Family expectations regarding care (A3; U)
		Referral to hospice (A12; C)
		Fears of poor quality of care (C1; U)
		Family expectations (O2; U)
		Hospice care not offered (T10; U)
	5.3 Family as resident's advocate	Advocacy (A4; U)
		Dependence on carer for provision of care and coordination of care (B1; U)
		Dependent on carer for coordination of care while in an organizational care settings for care provision (B2; U)
		Maintaining vigilance (C4; U)
		Obligation (T1; U)
	5.4 Involving family in end-of-life decisions	Collaboration with staff, informally and in care planning meetings (C11; U)
		End-stage decisions (G6; U)
		Decision-making (M6; U)
		Role reversal (T2; U)
	5.5 Family satisfaction with care	Improved care for loved one (C9; C)
		Personal gratification (C10; U)
		Fostering self-esteem and self-efficacy (F4; U)
		Satisfaction with care (M1, U)
	5.6 Offering family guidance in end-of-life decisions	Seeking guidance (D9; U)
		Being involved in decision-making (S2; U)

Abbreviations: C, credible; EOL, end of life; NH, nursing home; U, unequivocal.

Note. Each included finding was identified by an alphanumeric code (e.g. A1, A2, B1, …). Each letter corresponded to a selected study and each number to one unique finding of the study. The progressive numbers indicate the order in which the findings were presented in the original article.

Studies code: A[42], B[33], C[43], D[39], F[47], G[34], H[46], I[41], J[40], K[37], L[45], M[48], N[19], O[44], Q[38], R[35], S[32], T[36].