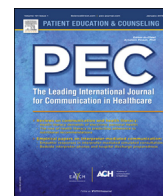




Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Review Article

Mechanisms by which end-of-life communication influences palliative-oriented care in nursing homes: A scoping review

Silvia Gonella^{a,b,*}, Sara Campagna^c, Ines Basso^c, Maria Grazia De Marinis^d, Paola Di Giulio^c^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

ARTICLE INFO

Article history:

Received 28 December 2018

Received in revised form 5 June 2019

Accepted 18 June 2019

Keywords:

Communication

Conversation

End of life care

Family carers

Palliative care

Nursing home

ABSTRACT

Objective: End-of-life communication has been largely recognized to promote quality end-of-life care in nursing home (NHs) by increasing residents' likelihood of receiving comfort-oriented care. This scoping review summarizes what is known about the potential mechanisms by which end-of-life communication may contribute to palliative-oriented care in NHs.

Methods: Using the framework proposed by Arksey and O'Malley and refined by the Joanna Briggs Institute methodology, five literature databases were searched. We extracted 2159 articles, 11 of which met the inclusion criteria: seven quantitative, three qualitative, and one mixed-methods study.

Results: Three mechanisms were identified: a) promotion of family carers' understanding about their family member's health condition, prognosis, and treatments available; b) fostering of shared decision-making between health care professionals (HCPs) and residents/family carers; and c) using and improving knowledge about residents' preferences.

Conclusion: Family carers' understanding, shared decision-making, and knowledge of residents' preferences contribute to palliative-oriented care in NHs.

Practice implications: Discussions about end-of-life should take place early in a resident's disease trajectory to allow time for family carers to understand the condition and participate in subsequent, mindful, shared decision-making. HCPs should conduct systematic and thorough discussions about end-of-life treatment options with all cognitively competent residents to promote informed advance directives.

© 2019 Elsevier B.V. All rights reserved.

Contents

1.	Introduction	2135
2.	Methods	2135
2.1.	Research design	2135
2.2.	Identifying the research question	2135
2.3.	Identifying relevant articles	2135
2.3.1.	Search strategy	2135
2.3.2.	Inclusion and exclusion criteria	2135
2.4.	Screening and study selection	2136
2.5.	Charting the data	2136
2.6.	Collating, summarizing, and reporting of results	2136
3.	Results	2136
3.1.	Review process	2136

* Corresponding author at: Department of Biomedicine and Prevention, University of Roma Tor Vergata, Via Montpellier 1, 00133, Roma, Italy.
E-mail address: silvia.gonella@unito.it (S. Gonella).

3.2.	Characteristics of included studies	2137
3.3.	EOL communication mechanisms	2137
3.3.1.	Methods to ascertain EOL communication mechanisms	2137
3.3.2.	Family carers' understanding	2137
3.3.3.	NH residents' and/or family carers' perception of decision-making as a shared process	2137
3.3.4.	Knowledge of residents' preferences regarding EOL care	2140
4.	Discussion and conclusion	2141
4.1.	Discussion	2141
4.1.1.	Family carers' understanding	2141
4.1.2.	Shared decision-making between HCPs and NH residents/family carers	2141
4.1.3.	Knowledge of resident's preferences	2141
4.1.4.	Strengths and limitations	2141
5.	Conclusion	2142
6.	Practice implications	2142
	Funding	2142
	Author contributions	2142
	Declaration of Competing Interest	2142
	References	2142

1. Introduction

Communication with residents and their family carers is of central importance to quality end-of-life (EOL) care in nursing homes (NHs) [1], which are becoming the most common place of death [2,3]. It is estimated that the number of deaths that occur in NHs will increase by almost 110% by 2040 [2]. This has huge implications for palliative-oriented care in older people, who account for more than two out of three people referred to palliative care services in high-income countries [3].

When asked about what constitutes quality EOL care, family carers of deceased NH residents identified communication as an essential component [4–6]. A recent meta-analysis found that EOL communication between healthcare professionals (HCPs) and family carers had a pivotal role in the promotion of palliative-oriented care among NH residents. It reduced aggressive care at EOL, with a two-fold increase in the likelihood of a decision to limit or withdraw life-sustaining treatments [7]. Similarly, discussing preferences for EOL care with older adults was associated with less in-hospital death and an increased use of hospice [8].

HCPs are often conflicted about whether to place the ultimate value on life or to maximize residents' comfort in order to allow a good quality of dying [9]. Therefore, it should not be taken for granted that all NH residents at EOL receive palliative-oriented care. Indeed, the literature documents poor EOL care in NHs, with residents receiving burdensome treatments such as intravenous therapy, tube feeding, emergency room visits, and many transitions from NHs to hospitals that are of limited clinical benefit [10,11]. Burdensome interventions are even more frequent among residents with dementia, due to their limited or absent decisional capacity to express treatment preferences [12–14]. Moreover, NH residents at EOL often suffer bothersome and distressing symptoms (e.g., pain, breathlessness) [15] and are offered little psychological support or spiritual care [16].

EOL communication, in addition to other factors such as staffing, NH policy, and culture of care, influences the extent to which a palliative-oriented approach is adopted [7]. Improving EOL communication appears to be a promising way to improve palliative-oriented care among older NH residents. The effectiveness of EOL communication in promoting the adoption of a palliative-oriented approach may depend on the timing and depth of communication, with early, frequent, and structured conversations being associated with the highest improvement in resident- and family carer-related care outcomes [17–19]. Therefore, we conducted a scoping review of the literature to examine and summarize what is known about the potential mechanisms by

which EOL communication may contribute to the promotion of palliative-oriented care in NHs. This scoping review may help map key concepts that underpin the research on EOL communication in NHs and its conceptual boundaries [20].

2. Methods

2.1. Research design

A scoping review adopting the methodological framework proposed by Arksey and O'Malley [20] and refined by the Joanna Briggs Institute methodology [21] was performed. The following steps were followed:

2.2. Identifying the research question

Our research question was: What is known from the existing literature about the potential mechanisms by which EOL communication between HCPs and NH residents and/or HCPs and family carers contributes to the promotion of palliative-oriented care in NHs?

2.3. Identifying relevant articles

2.3.1. Search strategy

A three-step approach was adopted [21]: 1) An initial limited search on Pubmed and EBSCO CINAHL was conducted between April and May 2018, followed by an analysis of the articles' title, abstract, and index terms (communication, conversation, palliative care, EOL care, patient comfort, and nursing homes). 2) Extensive literature searches were conducted in June 2018 in five databases (PubMed, EBSCO CINAHL, EBSCO PsycINFO, Joanna Briggs Institute, and Scopus) using the identified index terms. Each database was searched from its inception, employing both controlled vocabularies (e.g., MeSH terms, CINAHL headings) and free terms, without temporal or language limits. 3) Finally, the reference lists of included articles were screened manually. The full search strategy is provided in Appendix A.

2.3.2. Inclusion and exclusion criteria

2.3.2.1. Type of sources. Only original research articles published in peer-reviewed journals that provided sufficient detail regarding the methods and results were included. Gray literature, opinion papers, letters, theses, dissertations, and abstracts in proceedings were excluded.

2.3.2.2. Types of participants. Articles were included if they focused on NH residents at their EOL or on family carers of residents who were at EOL or who had passed away, regardless their underlying disease. All races, ethnicities, and cultural groups were included. Articles merging different populations were included only when the residents' or their family carers' perspective was clearly recognizable.

2.3.2.3. Concept. The phenomenon of interest was the association of EOL communication between HCPs and NH residents and/or family carers with transition towards palliative-oriented care. Palliative-oriented care was defined as care aimed at improving the quality of life among residents at EOL and their family carers by means of early identification, assessment, and treatment of physical, psychosocial, spiritual, and emotional problems [22].

2.3.2.4. Context. Only studies conducted in NHs were included. Studies that merged different settings (i.e., home, public hospital, hospice, private hospital, assisted living) were included only when the results related to NHs were clearly distinguishable.

2.4. Screening and study selection

Two investigators (S.G. and I.B.) independently screened the title and abstract of retrieved articles and reviewed the full texts. In accordance with the standard approach to conducting scoping reviews, a quality appraisal was not performed [20,23].

2.5. Charting the data

The research team developed a data charting form to collect the following data: author(s), country of origin, year of publication,

study type (i.e., quantitative, qualitative, mixed-methods), study aim(s), number of NHs involved and their size, study population (i.e., NH residents, family carers, HCPs) and sample size, EOL communication mechanism(s) investigated and data collecting tools used, method(s) employed by the authors of the selected studies to ascertain the EOL communication mechanism(s), and main findings.

Two investigators (S.G. and I.B.) independently extracted data from the selected articles using the predefined data charting form [23]. Discrepancies and uncertainties were resolved by consensus with a third researcher (S.C.).

2.6. Collating, summarizing, and reporting of results

The country of origin of the study was categorized as the country in which the study was conducted. Thematic analysis [24] was applied by two independent researchers (S.G. and I.B.) to identify the EOL communication mechanism(s). Disagreements were resolved by discussion with a third researcher (S.C.). The EOL communication mechanism(s) became the primary unit of analysis, and the present report was organized around the mechanisms identified.

3. Results

3.1. Review process

A total of 2159 articles were identified. After removal of duplicates and screening, 19 articles were included in the full-text review, and 10 finally met our inclusion criteria. Following a manual screening of the reference lists of these articles, one additional article was included (Fig. 1).

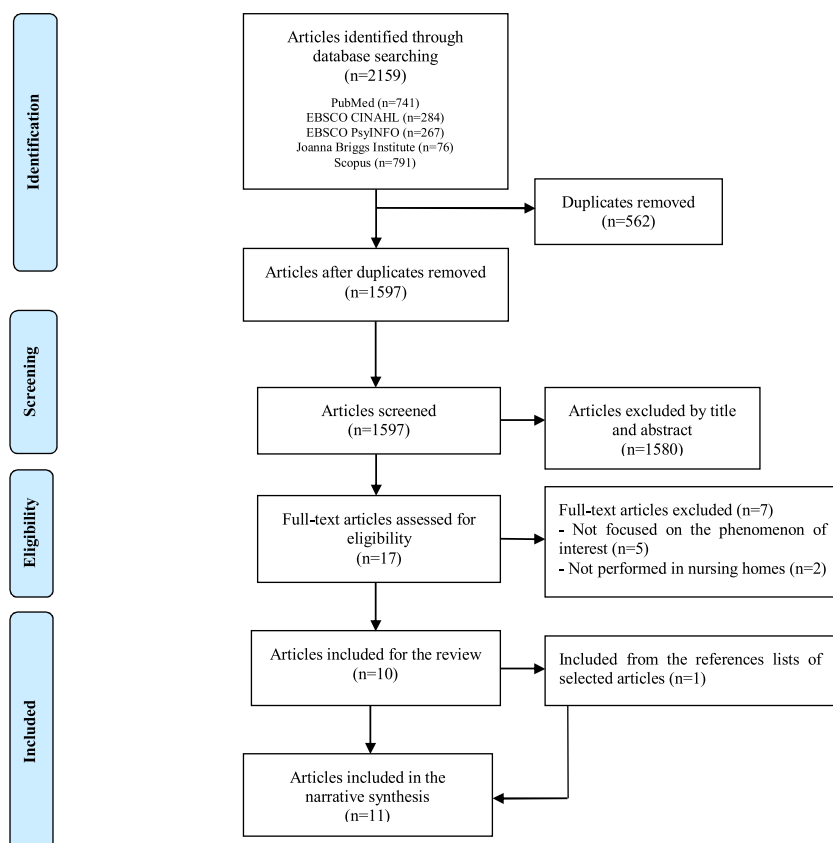


Fig. 1. PRISMA flow-chart depicting the main stages of the review process.

3.2. Characteristics of included studies

Six studies were conducted in the United States (323 family carers in [13], 402 family carers in [25], 190 family carers in [26], 24 family carers in [27], 413 NH residents in [28], and 1812 NH residents in [14]), three in Europe (161 family carers in [29], 18 family carers and 25 NH residents in [30], and 101 NH residents in [31]), one in Canada [32] (12 family carers) and one in New Zealand [33] (26 family carers). All but one study [28] were conducted after 2005 (Table 1). Studies involved a median of 20 NHs (range 1 [26] to 69 [31]). Seven studies were quantitative [13,14,25,26,28,29,31], three were qualitative [27,30,33] and one was a mixed-methods study [32] (Table 1).

Most studies involved only family carers [13,25–27,29,32,33], two studies included both NH residents and their family carers [30,31], and two included only NH residents [14,28]. Five studies focused on residents with dementia or their family carers [13,14,25,27,29]. Some studies involved physicians [28,29], nurses [31], or other HCPs [26,32]. Data were collected from NH residents' medical chart (n = 4 [25,28,31,32]), interviews with family carers (n = 4 [25,27,32,33]), focus groups with family carers (n = 2 [30,32]), a family carers questionnaire (n = 2 [13,29]), interviews with NH residents (n = 2 [28,30]), and health care databases (n = 2 [14,26]), (Table 1).

3.3. EOL communication mechanisms

The thematic analysis identified three potential mechanisms by which EOL communication contributed to the promotion of palliative-oriented care in NHs: a) promotion of family carers' understanding about their family member's health condition, prognosis, and treatments available; b) fostering of shared decision-making between HCPs and residents/family carers; and c) using and improving knowledge about residents' preferences regarding EOL care.

Four studies explored family carers' understanding about their family member's health condition and prognosis [13,25,29,32]; four studies assessed to what extent family carers' perceived decision-making to be a shared process [25–27,33], and one study assessed this same perception among NH residents [30]; four studies described NH resident's treatment preferences [14,28,30,31]; and a further study reported NH residents' treatment preferences as reported by family carers [30] (Table 1). The three identified EOL communication mechanisms and their relationships are graphically summarized in Fig. 2.

3.3.1. Methods to ascertain EOL communication mechanisms

The method employed to ascertain EOL communication mechanisms differed across articles. Family carers' understanding of their family member's health condition was investigated as awareness of poor prognosis [25,32], awareness of clinical complications and/or prognosis [13], or perception that their NH resident family member was affected by a terminal disease [29].

Family carers' perception of whether decision-making was a shared process was explored as decisions made about care [27] and any communication that led to the care provided [33]. Two studies used a combined modality: shared decision-making required "having the opportunity to share opinions about goals of care and/or participation in treatment decisions for the resident" [25], or "family attendance at the care plan meeting and/or documented discussion with any HCPs about treatments or goals of care" [26]. NH residents' involvement in decision-making was investigated as their participation in planning for care in critical medical situations or at EOL [30].

NH residents' preferences were identified by written advance directives [14,28,31], or residents were asked about their

preferences for EOL care [30]. One study asked family carers if they knew which type of care or treatment their family member would want to receive at EOL [30].

3.3.2. Family carers' understanding

Family carers' awareness that their family member was approaching EOL was important to the promotion of palliative-oriented care; however, family carers often had little cognizance that residents were at this stage [32]. The adoption of a palliative-oriented approach was therefore promoted by a two-stage, layered awareness: 1) the acknowledgement that death was a reality of the human condition, particularly for those who are aged and in advanced ill health; and 2) the clinical awareness of impending death, which was gained through discussions with HCPs [32]. However, the former was not enough to promote palliative-oriented care; only the latter led to the modification of the care plan [32].

Family carers' understanding that dementia is "a disease one can die from" predicted higher comfort among NH residents when dying [29], whereas mere information on health problems and how long the resident could live were unrelated to resident's comfort during the dying process [29] or family carers' preference for palliative-oriented care [25]. Similarly, when family carers believed that their family member had a poor prognosis or understood the clinical course of advanced dementia, NH residents were less likely to undergo burdensome interventions during the last 3 months of life [13]. Family carers' understanding of poor prognosis was associated with a greater family carer preference for palliative-oriented care [25]. When HCPs took for granted family carers' awareness of changes in their family member's conditions, discussion around prognosis and the need for a shift in care goals were neglected [33].

However, time was a critical element: some authors found no relationship, or even a negative relationship, between EOL communication and the quality of dying [31]. They attributed this unexpected finding to EOL conversations that took place only when residents were experiencing clinical complications.

3.3.3. NH residents' and/or family carers' perception of decision-making as a shared process

The involvement of cognitively able residents in their own advance care planning is an extremely useful, although not always easy, way to promote palliative-oriented care. Indeed, most residents said they did not want "to become a vegetable" and desired "a smooth passage without pain and suffering" [30]. The qualitative studies in this scoping review highlighted the fact that family carers wanted to be involved in EOL decisions [27,33] but often felt ill-equipped for their decision-making role. They did not know what was expected of them and experienced a substantial burden [27]. Family carers needed to be guided by HCPs in the decision-making process, and they reported feeling abandoned when this guidance was lacking [33]. Most of them wanted to be involved in decision-making with HCPs and appreciated regular meetings [30].

Caron and colleagues identified different dimensions associated with decision-making at EOL, including the quality of interaction with HCPs, the nature and intensity of potential treatments, and the quality of life of the resident, which was of central importance to family carers [27]. They identified four phases of EOL decision-making (i.e., transition, curative, uncertainty, and palliative) according to the family carers' perception of the quality of life of the resident. When acceptable quality of life was present, family carers usually supported curative treatments; when they acknowledged that their family member's condition had declined, a gradual decrease in the intensity of treatments occurred, and the primary goal of care was to control symptoms without unnecessarily extending their family member's suffering.

Table 1
Summary of the selected articles.

Author(s) (country, year)	Study type	Study aim (s)	Nursing homes (N) / size	Study population (N)	End-of-life communication mechanism(s) investigated (data collecting tool used)	Method(s) to ascertain end-of-life communication mechanisms	Main findings
Cable-Williams & Wilson (Canada, 2014) [32]	Mixed methods	To explore awareness of impending death for very old persons in long-term care facilities	3/172 to 256 beds	Family carers of residents aged >85 years (n = 12) Any healthcare professionals (n = 29)	Family carers understanding of the potential death of their family member (interview, focus group, resident's chart)	Family carers were asked what made them think that their family member would have died	(i) A two-stage layered awareness of impending death was identified: first generalized and then clinical awareness. (ii) Positive association between family carers clinical awareness of impending death and information gained through discussions with staff members; (iii) Care changed to palliative in nature when clinical awareness of impending death was acknowledged.
Van der Steen et al. (The Netherlands, 2013) [29]	Quantitative	To assess if family carers understanding of progressive and terminal nature of dementia predicts resident comfort while dying	28/11 to 210 beds	Family carers of dementia residents (n = 161) Physicians (n = 73)	Family carers understanding of the nature of dementia (questionnaire)	Family carers were asked if they perceived dementia as a disease you can die from	(i) Family carers understanding of complications, prognosis and having received information on health problems or prognosis were unrelated to NH resident's quality of dying; (ii) Family carers baseline understanding of dementia as a disease you can die from after the first meeting with the physician predicted better NH resident's quality of dying (adjusted coefficient = -0.8, 95% CI -1.5 to -0.06).
Mitchell et al. (USA, 2009) [13]	Quantitative	To assess family carers' understanding of their family member's prognosis and the clinical complications expected in residents with advanced dementia.	22/>60 beds	Family carers of dementia residents (n = 323)	Family carers understanding of clinical complications and prognosis expected in advanced dementia (questionnaire)	Family carers were asked whether they understood the clinical complications expected in advanced dementia and whether they thought their family member had less than 6 months to live	(i) Positive association between family carers understanding of expected clinical complications and poor prognosis and less likelihood for residents to receive burdensome interventions in the last 3 months of life (aOR, 0.12, 95% CI 0.04 to 0.37); (ii) Positive association between either believing their family member had less than 6 months to live or understanding expected clinical complications and less likelihood for residents to receive burdensome interventions in the last 3 months of life (aOR 0.25, 95% CI 0.13 to 0.49).
Mitchell et al. (USA, 2017) [25]	Quantitative	To describe and identify factors associated with level of care preferences among family carers of NH residents with advanced dementia	62/NR	Family carers of dementia patients (n = 402)	Family carers involvement in shared decision-making (interview, medical chart) Family carers understanding of their family member's prognosis (interview)	Family carers were asked if any health care provider had asked their opinion regarding: 1. the goals of care since NH admission, 2. whether they had ever participated in treatment decisions for their family member, and 3. whether they expected their family member to die within 6 months.	(i) Positive association between family carers preference for comfort-focused care and 1. family carers perceiving their family member had less than 6 months to live (aOR 12.25, 95% CI 4.04 to 37.08); and 2. the family carers having been asked about goals of care (aOR 1.71, 95% CI 1.07, 2.74); (ii) No association between family carers preference for comfort-focused care and 1. receiving information about health problems in advanced dementia; and 2. participation in prior treatment decisions; (iii) No association between family carers preference for comfort-focused care and a documented goals of care discussion in their family member's medical chart during the prior 3 months.
Frey et al. (New Zealand, 2017) [33]	Qualitative	To explore bereaved family carers perceptions of the transition to care to incorporate a palliative approach for their family member	9/20 to over 60 beds	Family carers (n = 26)	Family carers involvement in decision-making (interview)	Family carers were asked about the communication with the staff leading to their experience of the palliative care provided.	(i) Family carers stated that staff took for granted their awareness about the changes in their family member's condition, thus preventing discussions about prognosis and the need for a shift in care goals; (ii) Not being kept up-to-date on their family member's declining health impacted the family carers in several ways, including the hindrance of

Reinhardt et al. (USA, 2017) [26]	Quantitative	To identify specific care indicators that are significantly associated with having Do Not Orders in place	1/NR	Family carers (n = 190) Physician, nurse, social worker (n = 296)	Family carers involvement in decision-making (health care databases)	Family carers attendance at a care plan meeting and/or documented discussion with any healthcare professionals about six treatments (resuscitation, intubation, hospitalization, feeding tube, hydration, and antibiotics), or resident-centered goals	planning for a transition to a palliative approach, the fostering of distrust and the experience of anxiety and guilt concerning decisions; (iii) Family carers looked for guidance to make decisions and felt abandoned in the decision-making process when guidance was not forthcoming. (i) Negative association between family carers attendance at the care plan meeting and DNH order (aOR 0.37, 95% CI 0.20 to 0.69); (ii) No association between family carers attendance at the care plan meeting and DNR order, DNI order, no artificial hydration order, no feeding tube order, no antibiotics order; (iii) Positive association between discussion about resident-centered goals for care with family carers and DNH order (aOR 1.96, 95% CI 1.10 to 3.50); (iv) No association between discussion about resident-centered goals for care with family carers and DNR order, DNI order, no artificial hydration order, no feeding tube order, no antibiotics order; (v) Positive association between discussion with family carers and 4/6 orders (DNH, no artificial hydration, no feeding tube, no antibiotics).
Caron et al. (USA, 2005) [27]	Qualitative	To describe family carers' role as decision makers and their experience with regards to the decision-making process at the EOL of a family member with dementia	NR/NR	Family carers of dementia residents (n = 24)	Family carers perceived involvement in decision-making (interview)	Family carers were asked about the decisions that they had to make about the care of their family member and how these decisions were made	(i) Resident's quality of life as perceived by family carers determined the treatment intensity family carers considered justifiable; (ii) Most family carers expressed the need to take part in the decisions or at least understand the treatments being proposed by the medical team; (iii) Family carers did not know what was expected of them and felt ill-equipped to make decisions about the care of their family member.
Bollig et al. (Norway, 2016) [30]	Qualitative	To study the views of cognitively able residents and family carers on Advance Care Planning, EOL care, and decision-making in NH	9/NR	Residents (n = 25) Family carers (n = 18)	Resident's preferences (interview) Resident's involvement in decision-making (interview) Resident's preferences according to family carers perspective (focus group)	Residents were asked about their preferences for EOL care and if they were involved in planning for care in critical medical situations or the EOL Family carers were asked if they knew which type of care or treatment their family member would have wanted at EOL	(i) Many residents did not want life-prolonging treatments but desired a natural death; (ii) A few residents discussed their wishes for EOL with their family carers or the staff; (iii) Family carers were insecure about their family member's wishes; if they talked about their family member's preferences in advance the level of certainty increased.
Levin et al. (USA, 1999) [28]	Quantitative	To explore the relationship between discussions about life-sustaining care and the completion of advance directives and/or orders to limit therapy in the NH	20/NR	Residents (n = 413) Physicians (n = NR)	Resident's preferences (interview, medical chart)	Presence or absence of advance directives (i.e., Durable Powers of Attorney for Health Care or Living Wills) in the medical record	(i) 29% of residents reported discussions about life-sustaining treatments; (ii) The likelihood of physician-resident communication decreased with age (aOR 0.93 per year, 95% CI 0.89 to 0.97) and increased with the number of medical diagnosis (aOR 1.22 per additional diagnosis, 95% CI, 10.5 to 1.42); (iii) 32% of residents had an advance directive; (iv) Positive association between advance directive in medical chart and DNR order (aOR 5.22, 95% CI 2.59 to 10.5).
Nicholas et al. (USA, 2014) [14]	Quantitative	To investigate the interactions of NH stays, dementia, and the use of advance directives with the cost and aggressiveness of EOL care.	NR/NR	Residents (n = 1812 out of which 68.4% were cognitively impaired)	Resident's preferences (health care databases)	Written advance directive in the form of a living will that expressed a desire to limit care in certain situations	(i) Positive association between written advance directive and lower rates of in-hospital death for cognitively able residents and residents with severe dementia; (ii) No association between written advance directive and the use of Intensive Care Unit or life-sustaining treatments in the last 6 months of life regardless the cognitive status.

Table 1 (Continued)

Author(s) (country, year)	Study type	Study aim (s)	Nursing homes (N) / size	Study population (N)	End-of-life communication mechanism(s) investigated (data collecting tool used)	Method(s) to ascertain end-of-life communication mechanisms	Main findings
Vandervoort et al. (Flanders - Belgium, 2014) [31]	Quantitative	To investigate to what extent Advance Care Planning in the form of written advance directives and spoken advance communication with resident and/or family carers relate to the quality of dying in residents with dementia	69/average of 101 beds	Residents (n = 101) Family carers/friends (n = 101) Nurses (n = 101)	Resident's preferences (medical chart)	Presence of written advance directives	(i) 17.5% of the residents had a written advance directives and 17.1% verbally expressed their wishes concerning EOL medical treatments to nurse; (ii) Positive association between written advance directives and lower levels of emotional distress when dying (aOR 2.99, 95% CI 1.1 to 8.3); (iii) No association between nurse-resident verbal communications concerning the desired direction of care in the last phase of life and the quality of dying; (iv) Negative association between nurse-carer/friend verbal communication concerning the desired direction of care and the quality of dying (aOR 0.28, 95% CI 0.08 to 0.98 and aOR 0.26, 95% CI 0.1 to 0.6 for physical distress and dying symptoms, respectively).

Abbreviations: aOR, Adjusted Odd Ratio; CI, Confidence Interval; DNH, Do Not Hospitalize; DNI, Do Not Intubate; DNR, Do Not Resuscitate; EOL, End-Of-Life; NH, Nursing Home; NR, Not Reported.

Any shared decision-making process needed to be sustained by family carers' understanding, which was achieved through in-depth, resident-centered discussions about the goals of care [33]. When family carers were involved in discussions about the goals of care, they were more likely to prefer palliative-oriented care for their family member [25,26]. Simply being involved in decisions did not automatically promote a transition towards palliative-oriented care [26]. Family carers reported that they felt it was essential they were updated about and involved in the decisions regarding the care being provided to their family member. These updates and the shared decision-making role helped reassure family carers and promoted a gradual move towards a palliative-oriented approach [27]. In contrast, a lack of updating hindered family carers' involvement in planning a transition to a palliative-oriented approach, fostered distrust, and led family carers to experience anxiety and guilt concerning decisions for their family member's EOL care that they had to take [33]. However, no association or negative association was found between palliative-oriented care and family carers' attendance at care plan meetings [26] or participation in prior treatment decisions [25], which were indicators of shared decision-making. Only when family carers were aware of their family member's precarious conditions and their progressive worsening quality of life did they gradually perceive the need to move from curative-oriented to palliative-oriented care [27]. This prompted a complex relationship between EOL communication, family carers' understanding, and shared decision-making (Fig. 2). Shared decision-making between HCPs and residents/family carers was strictly associated with the knowledge of the resident's preferences regarding EOL care, the third identified mechanism by which EOL communication contributed to the promotion of palliative-oriented care in NHs.

3.3.4. Knowledge of residents' preferences regarding EOL care

The qualitative studies in this review showed that many residents did not want life-prolonging treatments such as artificial nutrition or hydration at EOL [30]. However, only a few cognitively competent residents were involved in discussions about the desired direction of EOL care [30], with the likelihood of such discussion decreasing with age [28]. Moreover, other authors found that the quality of dying only improved when there was a clear formulation of the resident's wishes in writing [31]. Verbal communication about resident's wishes, medical treatment at EOL, or the desired direction of care was not associated with a better quality of dying as judged by family carers [31]. Conversely, having a written advance directive was associated with lower levels of emotional distress when dying [31], an increase in Do-Not-Resuscitate orders [28], and lower rates of in-hospital death [14]. A written advance directive decreased residents' chance of experiencing fear in the last week of life compared with not having a written advance directive [31]. Thus, advance directives might embody a psychological process during which residents can feel involved in a thorough communication about their preferred EOL care, and going through that process may result in dying with a better emotional status. Indeed, the effectiveness of advanced directives is dependent on EOL communication that improves the knowledge and implementation of residents' preferences, but these directives may not always be the result of EOL communication.

Although many residents had concrete wishes for their EOL, they had not shared them with anyone, neither their family carers nor HCPs [30]. Thus, family carers' opinions of their family member's preferences were mainly based on assumptions. Several family carers were unsure about their family member's wishes; thus they experienced decision-making as a burden and hampered the transition towards palliative-oriented care [30]. Speaking about EOL preferences in advance gave family carers certainty about their family member's wishes [30].

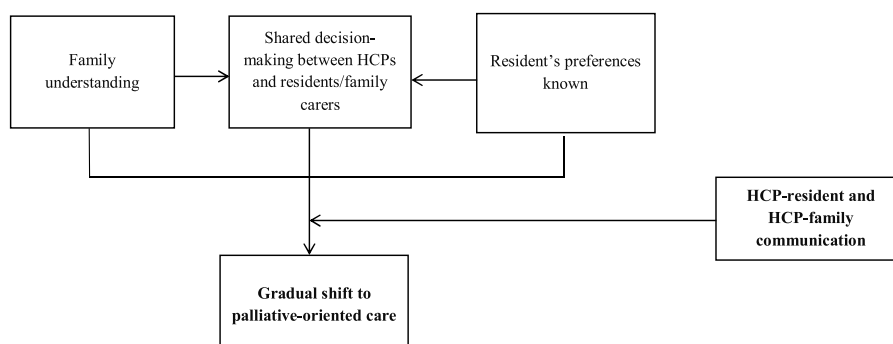


Fig. 2. A first framework attempting to describe the mechanisms by which end-of-life communication contributes to palliative-oriented care in nursing home with available knowledge.

Note. End-of-life communication contributes to palliative-oriented care acting through three mechanisms, including a) promotion of family understanding about their family member's health condition, prognosis and treatments available; b) fostering of shared decision making between HCPs and resident/family careres; and c) using and improving knowledge about resident's preferences for end-of-life care.

HCP, health care professional.

4. Discussion and conclusion

4.1. Discussion

This scoping review suggests three potential mechanisms by which EOL communication may contribute to the promotion of palliative-oriented care among NH residents at EOL. EOL communication seems to a) promote family cares' understanding about their family member's health condition, prognosis, and treatments available, b) foster shared decision-making, and c) use and improve knowledge about resident's preferences regarding EOL care.

4.1.1. Family carers' understanding

Our findings suggest that informing family carers about disease trajectory and the understanding that a family member was coming to the end of his/her lifespan in advanced old age was not automatically associated with a better quality of dying [29,31] nor with family carers' preference for palliative-oriented care [25]. Such information needs to be interiorized, and it only results in changes in care once family carers understand the progressive and terminal nature of the disease [29,32]. Our results support the need to start EOL conversations very early in a NH resident's disease trajectory, because family carers need time to understand and accept EOL, after which a palliative oriented-approach can be adopted based on a shared decision-making process.

Clear information and communication between HCPs and family carers promotes family carers' understanding, which is an essential requirement for aware, informed, and emotionally-prepared shared decision-making [34]. A thorough and in-depth understanding is achieved only when family carers are regularly updated about the general health conditions of their family member, the treatments available, the progression of disease, and the care provided, and when family carers can express their fears and doubts and receive emotional support [35].

4.1.2. Shared decision-making between HCPs and NH residents/family carers

Although shared decision-making is the preferred model of communication when optimal treatment is uncertain (as in chronically ill NH residents) to ensure that treatments are consistent with the resident's and family carers' values [36], we found only five studies [25–27,30,33] that identified shared decision-making as a key component in orienting the type of care. This limited application of shared decision-making to daily practice may be due to HCPs' perception of shared decision-making as a lengthy [37] or emotionally challenging process [38].

Few residents are mentally competent enough to be involved in the planning of their EOL care [30]. When cognitive decline occurs and residents are no longer able to communicate their preferences about EOL treatments [39,40], family carers become their substitute decision-makers [41] and face the decision of whether to provide aggressive treatments [42]. Although family carers usually want to be involved in EOL decisions [1,27], for the most part they are informed only after medical decisions have already been implemented [39,40]. Only 38% of family carers of persons with advanced dementia recalled being involved in EOL decisions [43], and about 90% of the decisions concerning the treatment of pneumonia in advanced dementia residents were communicated to family carers after the fact, but only half were discussed before they were implemented [39]. Similarly, a previous study on critical decisions for NH residents with severe cognitive impairments found that only half of decisions were discussed with family carers before being implemented [40]. These findings suggest the tendency of HCPs to adopt communication with the intent only to inform, rather than to promote true shared decision-making.

4.1.3. Knowledge of resident's preferences

The literature has shown a relatively low prevalence of advance directives among NH residents (range 0–32%) [7], suggesting the tendency to delay communication about EOL care options. This hesitancy means that residents are not involved in choosing their EOL treatments. Improving the knowledge regarding a resident's values and EOL care preferences facilitates his/her involvement in the decision-making process and in advance care planning [44], during which anticipatory decisions are derived through open discussions between HCPs, residents, and/or family carers [45].

Communication helps HCPs align medical decisions with residents' values: when the resident is unable to express him/herself, as frequently happens in cases of cognitive impairment, family carers should be included in discussions to identify the resident's preferences. Residents usually desired to die as naturally as possible; they stated that life-sustaining treatments were in contrast to that wish and that HCPs should not prolong a life without meaning [30]. However, a recent observational multicenter study aimed at assessing treatment decisions and discomfort in residents with advanced dementia and pneumonia found that final decisions were never guided by residents' wishes, and that their family carers were generally informed of care decisions post-facto [39].

4.1.4. Strengths and limitations

This study provides a conceptual model of how EOL communication in NHs may contribute to palliative-oriented care by

synthesizing the relevant quantitative and qualitative literature on the topic. A Systematic Literature Review method could have revealed further studies; however, the scoping review method provides a comprehensive identification of relevant studies and allowed us to incorporate a wide range of study designs to clarify complex concepts such as the one under study. Secondly, we did not assess the NH environment, including staffing levels, staff training and knowledge, institutional policies and beliefs, or religious attitudes that may influence the adoption of a palliative-oriented approach. We could not identify NH environments that may facilitate (e.g., adequate staffing, culture of care that sustains the presence of written procedures to manage pain and promotes palliative-oriented care services and advance care planning) or hinder (e.g., staff shortages, deficits in knowledge) the shift towards a palliative-oriented approach, and our findings should be interpreted in the light of this fact. However, although the NH environment may affect the timing and frequency of communication, it's unlikely to impact the three EOL communication mechanisms we identified.

5. Conclusion

This review points to the complex and dynamic interactions among the EOL communication mechanisms that potentially contribute to the promotion of palliative-oriented care in NH. Family carers' understanding is pivotal to promote the transition from curative-oriented care to palliative-oriented care. Family carers' awareness of their family members' health conditions and the treatments available, in addition to knowing what to expect in the coming months, encourage family carers to avoid burdensome interventions and pursue care that is aimed at controlling their family member's symptoms. Family carers who are aware of their family member's condition are more likely to actively participate in shared decision-making on behalf of their incapacitated family member, and this involvement increases the likelihood that residents' preferences about EOL care will be respected. Involving cognitively competent residents in their care plan is also likely to further align medical decisions with a palliative-oriented approach rather than a curative one. Knowledge of resident's preferences obtained through open discussions between HCPs, residents, and/or family carers facilitates the arrangement of a care plan that is consistent with the resident's wishes for EOL care, with most residents desiring to die as naturally as possible and not to receive meaningless, life-prolonging treatments.

6. Practice implications

EOL discussions should take place early in the disease trajectory, while residents' health conditions are stable. These discussions should guide residents and their family carers in reflecting about EOL care options [46]. Postponing these conversations until times of crisis impacts residents' ability to express their preferences and leaves no time for family carers to process information, achieve true understanding, and become an active decision-making partner.

Although it may be challenging, HCPs should promote family carers' understanding about what to expect in the months before death by arranging structured conversations around a predefined set of topics, such as resident's health condition, clinical course and prognosis of the resident's disease, and family carers' goals of care for the resident [18]. Family carers can only advocate for a sensitive transition towards a palliative-oriented approach when they are aware of their family member's progressive decline and are emotionally prepared [41]. When family carers realize that their family member's health conditions are not going to improve, they accept the stance of "dying allowed" care, which is aimed at

comfort and symptom relief. Indeed, when death is expected, family carers want to avoid burdensome care, and comfort becomes of primary relevance [47]. Therefore, investments in the training of HCPs and interpersonal communication interventions aimed at developing communication skills to share prognostic information are needed.

Residents, or at least their family carers, should be involved early in the adjustment of care plans through a shared decision-making process. Establishing a partnership with family carers and recognizing them as advocates of their family member's wishes are pivotal to ensure shared decision-making and the adoption of palliative-oriented care [48]. Residents and family carers may refuse decision-making authority, thus handing over the final decision to HCPs [1]. However, if the shared decision-making steps have taken place (i.e., information that a decision needs to be made, explanation of the care options and their pros and cons, and discussion of the resident's preferences [37]), HCPs will know what the resident's wishes are, and the care approach will be proposed accordingly.

Knowledge of resident's wishes for EOL care may play an essential role in guaranteeing that EOL decisions are consistent with the resident's preferences and relieve the decision-making burden experienced by family carers [30]. Systematic and thorough discussions about EOL treatment options should be offered to all cognitively competent NH residents to promote informed advance directives. Care consistency with documented preferences is indeed one of the top-ranked quality indicators for hospice and palliative-oriented care identified by the Measuring What Matter project [49].

Future research should explore new strategies, such as decision aids, to ameliorate the quality of EOL communication and palliative-oriented care. A recent randomized controlled trial demonstrated the effectiveness of a goal of care video decision aid in improving the quality of EOL communication as perceived by family carers, the concordance between family carers and HCPs with regard to the primary goal of care, and the palliative care content in the treatment plans, while reducing hospital transfers by half [50]. Finally, residents' participation in EOL discussions is still extremely limited, and strategies to improve their participation need to be further investigated.

Funding

None.

Author contributions

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

Declaration of Competing Interest

None.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2019.06.018>.

References

- [1] E. Gjerberg, L. Lillemoen, R. Forde, R. Pedersen, End-of-life care communications and shared decision-making in Norwegian nursing homes—experiences and

- perspectives of patients and relatives, *BMC Geriatr.* 15 (2015) 103, doi:<http://dx.doi.org/10.1186/s12877-015-0096-y>.
- [2] A.E. Bone, B. Gomes, S.N. Etkind, J. Verne, F.E. Murtagh, C.J. Evans, I.J. Higginson, 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.* 32 (2018) 329–336, doi:<http://dx.doi.org/10.1177/0269216317734435>.
 - [3] D.C. Currow, J. Phillips, M. Agar, Population-based models of planning for palliative care in older people, *Curr. Opin. Support. Palliat. Care* 11 (2017) 310–314, doi:<http://dx.doi.org/10.1097/spc.0000000000000304>.
 - [4] G.N. Thompson, V.H. Menec, H.M. Chochinov, S.E. McClement, Family satisfaction with care of a dying loved one in nursing homes: what makes the difference? *J. Gerontol. Nurs.* 34 (2008) 37–44.
 - [5] R.R. Shield, T. Wetle, J. Teno, S.C. Miller, L.C. Welch, Vigilant at the end of life: family advocacy in the nursing home, *J. Palliat. Med.* 13 (2010) 573–579, doi:<http://dx.doi.org/10.1089/jpm.2009.0398>.
 - [6] E. Kaarbo, End-of-life care in two Norwegian nursing homes: family perceptions, *J. Clin. Nurs.* 20 (2011) 1125–1132, doi:<http://dx.doi.org/10.1111/j.1365-2702.2009.03171.x>.
 - [7] S. Gonella, I. Basso, V. Dimonte, B. Martin, P. Berchiolla, S. Campagna, P. Di Giulio, 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.* 20 (2019) 249–261, doi:<http://dx.doi.org/10.1016/j.jamda.2018.10.001>.
 - [8] K.E. Bischoff, R. Sudore, Y. Miao, W.J. Boscardin, A.K. Smith, Advance care planning and the quality of end-of-life care in older adults, *J. Am. Geriatr. Soc.* 61 (2013) 209–214, doi:<http://dx.doi.org/10.1111/jgs.12105>.
 - [9] J. Hughes, J. Common, Ethical issues in caring for patients with dementia, *Nurs Stand.* 29 (2015) 42–47, doi:<http://dx.doi.org/10.7748/ns.29.49.42.e9206>.
 - [10] P. Gozalo, J.M. Teno, S.L. Mitchell, J. Skinner, J. Bynum, D. Tyler, V. Mor, End-of-life transitions among nursing home residents with cognitive issues, *N. Engl. J. Med.* 365 (2011) 1212–1221, doi:<http://dx.doi.org/10.1056/NEJMsa1100347>.
 - [11] S.C. Miller, J.C. Lima, J. Looze, S.L. Mitchell, Dying in U.S. Nursing homes with advanced dementia: how does health care use differ for residents with, versus without, end-of-life Medicare skilled nursing facility care? *J. Palliat. Med.* 15 (2012) 43–50, doi:<http://dx.doi.org/10.1089/jpm.2011.0210>.
 - [12] S.L. Mitchell, D.K. Kiely, M.B. Hamel, Dying with advanced dementia in the nursing home, *Arch. Intern. Med.* 164 (2004) 321–326, doi:<http://dx.doi.org/10.1001/archinte.164.3.321>.
 - [13] S.L. Mitchell, J.M. Teno, D.K. Kiely, M.L. Shaffer, R.N. Jones, H.G. Prigerson, L. Volicer, J.L. Givens, M.B. Hamel, The clinical course of advanced dementia, *N. Engl. J. Med.* 361 (2009) 1529–1538, doi:<http://dx.doi.org/10.1056/NEJMoa0902234>.
 - [14] L.H. Nicholas, J.P. Bynum, T.J. Iwashyna, D.R. Weir, K.M. Langa, Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia, *Health Aff (Millwood)*, 33 (2014) 667–674, doi:<http://dx.doi.org/10.1377/hlthaff.2013.1258>.
 - [15] S. Andersson, O. Lindqvist, C.J. Furst, M. Brannstrom, 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.* 31 (2017) 72–84, doi:<http://dx.doi.org/10.1111/scs.12317>.
 - [16] L. Morin, K. Johnell, L. Van den Block, R. Aubry, Discussing end-of-life issues in nursing homes: a nationwide study in France, *Age Ageing* 45 (2016) 395–402, doi:<http://dx.doi.org/10.1093/ageing/afw046>.
 - [17] S.E. Engel, D.K. Kiely, S.L. Mitchell, Satisfaction with end-of-life care for nursing home residents with advanced dementia, *J. Am. Geriatr. Soc.* 54 (2006) 1567–1572.
 - [18] J.P. Reinhardt, E. Chichin, L. Posner, S. Kassabian, Vital conversations with family in the nursing home: preparation for end-stage dementia care, *J. Soc. Work End. Palliat. Care* 10 (2014) 112–126, doi:<http://dx.doi.org/10.1080/15524256.2014.906371>.
 - [19] J.P. Reinhardt, K. Boerner, D. Downes, The positive association of end-of-life treatment discussions and care satisfaction in the nursing home, *J. Soc. Work End. Palliat. Care* 11 (2015) 307–322, doi:<http://dx.doi.org/10.1080/15524256.2015.1107805>.
 - [20] H. Arksey, L. O'Malley, Scoping studies: towards a methodological framework, *Int. J. Soc. Res. Methodol.* 8 (2005) 19–32, doi:<http://dx.doi.org/10.1080/1364557032000119616>.
 - [21] M. Peters, C. Godfrey, P. McInerney, C. Soares, H. Khalil, D. Parker, The Joanna Briggs Institute Reviewers' Manual 2015: Methodology for JBI Scoping Reviews, Joanna Briggs Institute, North Adelaide, Australia, 2015.
 - [22] WHO, Definition of Palliative Care, (2002) . . . (Accessed October 4th, 2018) <http://www.who.int/cancer/palliative/definition/en/>.
 - [23] D. Levac, H. Colquhoun, K.K. O'Brien, Scoping studies: advancing the methodology, *Implement. Sci.* 5 (2010) 69, doi:<http://dx.doi.org/10.1186/1748-5908-5-69>.
 - [24] M. Vaismoradi, H. Turunen, T. Bondas, Content analysis and thematic analysis: implications for conducting a qualitative descriptive study, *Nurs. Health Sci.* 15 (2013) 398–405.
 - [25] S.L. Mitchell, J.A. Palmer, A.E. Volandes, L.C. Hanson, D. Habtemariam, M.L. Shaffer, Level of care preferences among nursing home residents with advanced dementia, *J. Pain Symp. Manage.* 54 (2017) 340–345, doi:<http://dx.doi.org/10.1016/j.jpainsymman.2017.04.020>.
 - [26] J.P. Reinhardt, D. Downes, V. Cimarolli, P. Bomba, End-of-life conversations and hospice placement: association with less aggressive care desired in the nursing home, *J. Soc. Work End. Palliat. Care* 13 (2017) 61–81, doi:<http://dx.doi.org/10.1080/15524256.2017.1282919>.
 - [27] C.D. Caron, J. Griffith, M. Arcand, End-of-life decision making in dementia: the perspective of family caregivers, *Dementia* 4 (2005) 113–136.
 - [28] J.R. Levin, N.S. Wenger, J.G. Ouslander, G. Zellman, J.F. Schnelle, J.L. Buchanan, S. H. Hirsch, D.B. Reuben, Life-sustaining treatment decisions for nursing home residents: who discusses, who decides and what is decided? *J. Am. Geriatr. Soc.* 47 (1999) 82–87.
 - [29] J.T. van der Steen, B.D. Onwuteaka-Philipsen, D.L. Knol, M.W. Ribbe, L. Deliens, Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study, *BMC Med.* 11 (2013) 1741–1705, doi:<http://dx.doi.org/10.1186/1741-7015-11-105>.
 - [30] G. Bollig, E. Gjevedal, J.H. Rosland, 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 (2016) 456–470, doi:<http://dx.doi.org/10.1177/0269216315605753>.
 - [31] A. Vandervoort, D. Houttekier, R. Vander Stichele, J.T. van der Steen, L. Van den Block, Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study, *PLoS One* 9 (2014) e91130, doi:<http://dx.doi.org/10.1371/journal.pone.0091130>.
 - [32] B. Cable-Williams, D. Wilson, Awareness of impending death for residents of long-term care facilities, *Int. J. Older People Nurs.* 9 (2014) 169–179, doi:<http://dx.doi.org/10.1111/opn.12045>.
 - [33] R. Frey, S. Foster, M. Boyd, J. Robinson, M. Gott, Family experiences of the transition to palliative care in aged residential care (ARC): a qualitative study, *Int. J. Palliat. Nurs.* 23 (2017) 238–247, doi:<http://dx.doi.org/10.12968/ijpn.2017.23.5.238>.
 - [34] A. Petriwskyj, A. Gibson, D. Parker, S. Banks, S. Andrews, A. Robinson, A qualitative metasynthesis: family involvement in decision making for people with dementia in residential aged care, *Int. J. Evid. Healthc.* 12 (2014) 87–104, doi:<http://dx.doi.org/10.1097/XEB.0000000000000022>.
 - [35] A. Fosse, M.A. Schaufel, S. Ruths, K. Malterud, End-of-life expectations and experiences among nursing home patients and their relatives—a synthesis of qualitative studies, *Patient Educ. Couns.* 97 (2014) 3–9, doi:<http://dx.doi.org/10.1016/j.pec.2014.05.025>.
 - [36] L.C. Hanson, G. Winzelberg, Research priorities for geriatric palliative care: goals, values, and preferences, *J. Palliat. Med.* 16 (2013) 1175–1179, doi:<http://dx.doi.org/10.1089/jpm.2013.9475>.
 - [37] A.M. Stiggelbout, A.H. Pieterse, J.C. De Haes, Shared decision making: concepts, evidence, and practice, *Patient Educ. Couns.* 98 (2015) 1172–1179, doi:<http://dx.doi.org/10.1016/j.pec.2015.06.022>.
 - [38] J.A. Soodalter, G.J. Siegle, M. Klein-Fedyshin, R. Arnold, Y. Schenker, Affective science and avoidant end-of-life communication: can the science of emotion help physicians talk with their patients about the end of life? *Patient Educ. Couns.* 101 (2018) 960–967, doi:<http://dx.doi.org/10.1016/j.pec.2017.12.008>.
 - [39] J.T. van der Steen, P. Di Giulio, F. Giunco, M. Monti, S. Gentile, D. Villani, S. Finetti, F. Pettenati, L. Charrier, F. Toscani, D.P.C.R.G. End of Life Observatory-Prospective Study on, Pneumonia in nursing home patients with advanced dementia: decisions, intravenous rehydration therapy, and discomfort, *Am. J. Hosp. Palliat. Care* 35 (2018) 423–430, doi:<http://dx.doi.org/10.1177/1049909117709002>.
 - [40] F. Toscani, J.T. van der Steen, S. Finetti, F. Giunco, F. Pettenati, D. Villani, M. Monti, S. Gentile, L. Charrier, P. Di Giulio, D.P.C.R.G. End of Life Observatory-Prospective Study on, D.P.C.E.-P.R.G. End of Life Observatory-Prospective Study on, Critical decisions for older people with advanced dementia: a prospective study in long-term institutions and district home care, *J. Am. Med. Dir. Assoc.* 16 (2015), doi:<http://dx.doi.org/10.1016/j.jamda.2015.02.012> 535 e513–520.
 - [41] D.P. Waldrop, N. Kusmaul, The living-dying interval in nursing home-based end-of-life care: family caregivers' experiences, *J. Gerontol. Soc. Work* 54 (2011) 768–787, doi:<http://dx.doi.org/10.1080/01634372.2011.596918>.
 - [42] D.T. Maust, D.M. Blass, B.S. Black, P.V. Rabins, Treatment decisions regarding hospitalization and surgery for nursing home residents with advanced dementia: the CareAD Study, *Int. Psychogeriatr.* 20 (2008) 406–418.
 - [43] J.L. Givens, D.K. Kiely, K. Carey, S.L. Mitchell, Healthcare proxies of nursing home residents with advanced dementia: decisions they confront and their satisfaction with decision-making, *J. Am. Geriatr. Soc.* 57 (2009) 1149–1155, doi:<http://dx.doi.org/10.1111/j.1532-5415.2009.02304.x>.
 - [44] B.S. Black, L.A. Fogarty, H. Phillips, T. Finucane, D.J. Loreck, A. Baker, D.M. Blass, P.V. Rabins, Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care, *J. Aging Health* 21 (2009) 627–650, doi:<http://dx.doi.org/10.1177/0898264309333316>.
 - [45] F. Stewart, C. Goddard, R. Schiff, S. Hall, Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families, *Age Ageing* 40 (2011) 330–335, doi:<http://dx.doi.org/10.1093/ageing/afq006>.
 - [46] H. Biola, P.D. Sloane, C.S. Williams, T.P. Daaleman, S.W. Williams, S. Zimmerman, Physician communication with family caregivers of long-term care residents at the end of life, *J. Am. Geriatr. Soc.* 55 (2007) 846–856.
 - [47] M. Bern-Klug, A conceptual model of family surrogate end-of-life decision-making process in the nursing home setting: goals of care as guiding stars, *J. Soc. Work End. Palliat. Care* 10 (2014) 59–79, doi:<http://dx.doi.org/10.1080/15524256.2013.877863>.
 - [48] S. Gonella, I. Basso, M.G. De Marinis, S. Campagna, P. Di Giulio, Good end-of-life care in nursing home according to the family carers' perspective: a systematic

- review of qualitative findings, *Palliat. Med.* (2019), doi:<http://dx.doi.org/10.1177/0269216319840275> [Epub ahead of print].
- [49] S.M. Dy, K.B. Kiley, K. Ast, D. Lupu, S.A. Norton, S.C. McMillan, K. Herr, J.D. Rotella, D.J. Casarett, 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 Symp. Manage.* 49 (2015) 773–781, doi:<http://dx.doi.org/10.1016/j.jpainsymman.2015.01.012>.
- [50] L.C. Hanson, S. Zimmerman, M.K. Song, F.C. Lin, C. Rosemond, T.S. Carey, S.L. Mitchell, Effect of the goals of care intervention for advanced dementia: a randomized clinical trial, *JAMA Intern. Med.* 177 (2017) 24–31, doi:<http://dx.doi.org/10.1001/jamainternmed.2016.7031>.