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Title page

Title

Association between end-of-life conversations in nursing homes and end-of-life care outcomes: a systematic review and meta-analysis

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Abstract

OBJECTIVE: Less aggressive end-of-life (EOL) care has been observed when healthcare professionals discuss approaching EOL and preferences about life-sustaining treatments with nursing home (NH) residents or their families. We performed a comprehensive systematic review to evaluate the association between healthcare professionals-residents and healthcare professionals-family EOL conversations and EOL care outcomes.

DESIGN: Systematic review with meta-analysis.

SETTING AND PARTICIPANTS: Seven databases were searched in December 2017 to find studies that focused on healthcare professionals-residents (without oncologic disease) and healthcare professionals-family EOL conversations and aimed to explore the impact of EOL conversations on resident's or family's EOL care outcomes.

MEASURES: Random effects meta-analyses with subsequent quality sensitivity analysis and meta-regression were performed to assess the effects of EOL conversations on the decision to limit or withdraw life-sustaining treatments. A funnel plot and Eagger test were used to assess publication bias.

RESULTS: 16 studies were included in the qualitative and 7 in the quantitative synthesis.

Healthcare professionals-family EOL conversations were positively associated with the family's decision to limit or withdraw life-sustaining treatments (odds ratio=2.23, 95% confidence interval: 1.58-3.14).

The overall effect of healthcare professionals-family EOL conversations on the family's decision to limit or withdraw life-sustaining treatments remained stable in the quality sensitivity analysis. In the meta-regression, family members with a higher level of education were less influenced by EOL conversations with healthcare professionals when making decisions about limiting or withdrawing life-sustaining treatments. No publication bias was detected (p=0.4483)

CONCLUSIONS/IMPLICATIONS: This systematic review shows that EOL conversations promote palliative care. Structured conversations aimed at exploring NH resident preferences about

EOL treatment should become routine. NH administrators should offer healthcare professionals regular training on EOL conversations, and resident-centered care that involves residents and their families in a shared decision-making process at EOL needs to be promoted.

Keywords: Communication; Conversation; End of life; Life-sustaining treatment; Meta-analysis; Nursing home; Systematic review.

INTRODUCTION

The increasing number of nursing home (NH) residents and their chronic, progressive decline in the end-stages of disease[1] have led to growing interest in NH end-of-life (EOL) care. Research has revealed a relatively poor quality of EOL care in NHs, with aggressive treatments often being employed, a non optimal management of symptoms and lack of psychological and spiritual care.[2-4] About one-third of NH residents are hospitalized in the last 30 days of life, 60% of whom experience in-hospital death.[5,6]

Discussing EOL issues (treatment goals, advanced care planning, and preferences about life-sustaining treatments) with NH residents and their families is important to ensure patient-centered care.[6,7] EOL conversations enable healthcare professionals to align decisions with NH residents' values, and NH residents whose healthcare professionals are informed of these values and preferences are four times more likely to die in their preferred place.[8] However, healthcare professionals' decision making can be influenced by several factors such as societal values and constraints, training, regional laws, and the policies of the nursing home.[9] Even cultures that favour disclosure and discussion of EOL issues as those of Australia and United States, may have different approaches[10] Sustaining EOL conversations is even more challenging when a common ethno-cultural background lacks.[11]

Because many NH residents experience cognitive decline,[1,12] healthcare professionals depend on family or a designated proxy (surrogate) to guide EOL care. Over 90% of NH residents with late-stage dementia have a surrogate,[3] and around 80% of surrogates must make decisions on aggressive treatments.[13] Indeed, up to 90% of Do-Not-Resuscitate (DNR) directives are put in place by surrogates.[14] Although healthcare professionals recognize the importance of planning a care consistent with the shared goals of NH residents and their families,[15] EOL conversations usually occur only after NH residents' health conditions have worsened,[16] which limits the provision of palliative care and hospice referral.[3,17,18]

Family involvement in EOL conversations results in decreased provision of aggressive care,[4,19] increased families'satisfaction,[2,20] and reduced in-hospital deaths.[4] EOL conversations were

positively associated with Do-Not orders (no feeding tube, no artificial hydration, no hospitalization).[21] EOL hospitalizations are judged especially inappropriate when care can be provided with equal benefit in the NH,[22] and are often inconsistent with residents' preferred EOL treatment and place of death.[23]

No systematic review exists on the impact of EOL conversations on EOL care outcomes. Since social, geographical and cultural contexts may affect sensitivities towards EOL conversations, this systematic review aimed to offer a comprehensive overview on the association between healthcare professionals-NH resident or healthcare professionals-family EOL conversations and EOL care outcomes.

METHODS

Design

We conducted a systematic literature review according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Table A1, Appendix 1).

Search Strategy

Searches were conducted in seven databases (PubMed, EBSCO CINAHL, EBSCO PsyINFO, Joanna Briggs Institute, Cochrane Database of Systematic Reviews, Scopus, and ISI Web of Knowledge) by an expert librarian (B.M.) for relevant articles published from the databases' inception until 31 December 2017. Searches employed both controlled vocabularies and key words, without temporal or language limits. Search strategies were adapted for each database (Appendix 2). The reference lists of included articles were screened manually to identify potentially relevant publications.

Eligibility Criteria

Original studies were included if published in peer reviewed journals, focused on healthcare professionals-NH non oncologic resident or family EOL conversations and aimed to explore the

impact of EOL conversations on NH resident's or family's EOL care outcomes. Studies that included multiple settings (i.e., home, public hospital, hospice, private hospital, NH) or different populations (i.e., healthcare professionals, NH residents, families) were excluded when it was not possibile to identify the impact of EOL conversations on NH resident or family outcomesin the NH context. Studies using other interventions that promoted less intensive EOL care (e.g., decision aid video) were excluded.

Article Screening and Study Selection

The title and abstract were screened independently by S.G. and I.B. and duplicates were removed. The same investigators then reviewed the full text of the potentially relevant articles. Any disagreement or uncertainty regarding eligibility was addressed through consensus with a third investigator (S.C.).

Quality Assessment of Studies

Study quality was assessed by S.G. and I.B., using an adapted version of Moilanen and collegues' appraisal criteria.[24] This tool has three sets of questions: general, for quantitative and for qualitative papers. We applied general questions (n=13) and questions for quantitative papers (n=8) (Table A2 in Appendix 1). Response options (yes=1, no=0, not relevant=1) were summed to determine the mean quality score (range 0-21), and classified as high (≥19), moderate (16-18), low (13-15), or very low (<13); values with decimals were rounded to the lower integer. Agreement between the investigators was tested using Cohen's Kappa analysis in R v 3.3.3 statistical software[25] and classified as poor (<0.20), fair (0.21-0.40), moderate (0.41-0.60), substantial (0.61-0.8), or almost perfect (>0.8).[26]

Data Collection

Data were entered into a standardized spreadsheet under the following headlines: study characteristics (author, country, year, design, definition of life-sustaining treatments and EOL conversation, subjects

involved and duration of EOL conversation, outcome(s) investigated and assessment tools, data source and time of data collection, number and size of NHs); sample characteristics (number, sex, age, cognitive deficit, nursing home length-of-stay, and advanced directive of NH residents; number, kinship, sex, age, education of family members); narrative summary of findings; and quantitative results (number and proportion of individuals exposed to at least one decision to limit or withdraw life-sustaining treatments).

S.G. and I.B. independently extracted all the data. Disagreements and uncertainties were resolved by consensus with a third researcher (S.C.).

Data Synthesis

Prevalence of decision to limit or withdraw life-sustaining treatments was considered the main EOL outcome. Prevalence was calculated as the proportion of NH residents exposed to at least one decision to limit or withdraw a life-sustaining treatment.

We performed a meta-analysis to assess the association between healthcare professionals-family EOL conversations and the main EOL outcome (only one study[27] assessed healthcare professionals-NH resident EOL conversations), using odd ratios (ORs) with 95% confidence intervals (CIs). We used a random-effects model with unrestricted maximum likelihood using the sample size as a weighting factor. Heterogeneity, assessed using the Cochran Q test via a Mantel-Haenszel test based on the pooled OR, was suggested if Q>degrees of freedom and confirmed if $p \leq 0.10$, and by means of the I^2 statistic as proposed by Higgins and Thompson. I^2 values of 0-24.9%, 25-49.9%, 50-74.9%, and >75% were considered as none, low, moderate, and high heterogeneity, respectively.[28] A funnel plot and Eagger test were used to assess publication bias. ORs were plotted on a logarithmic scale against the corresponding standard error for each study. In the absence of publication bias, one would expect studies of all sizes to be scattered equally to the right and left of the line, showing the pooled estimate of natural log OR.[29]

Additional data were requested from authors. Two[21,30] did not answer: one study[30] was excluded since no explicit data on the decision to limit or withdraw life-sustaining treatments after EOL conversation was available; the second study[21] provided individual figures for each life-sustaining treatment, thus the most frequent DNR decision (90%) was used.

We performed a sensitivity analysis based on study quality according to Moilanen's appraisal criteria[24] and a meta-regression in case of heterogeneity. We combined the data regarding family member's kinship (child *vs* others), sex (male *vs* female), age, education (graduate or postgraduate *vs* lower education), and multi-healthcare professionals EOL conversation (yes *vs* no) in a meta-regression to identify factors associated with the decision to limit or withdraw life-sustaining treatments. Results were considered statistically significant at 2-tail $p<0.05$. All analyses were carried out in R v 3.3.3 statistical software.[25]

Results

Review Process

A total of 1,958 articles were identified. After removal of duplicates and screening, of the 19 articles included in the full-text review, 14 met our inclusion criteria. Two additional articles were included from the reference lists of selected articles (Figure 1).

Please, insert figure 1 here

Characteristics of Included Studies

Ten studies were conducted in the United States (54,149 NH residents; 1,910 family members), four in Europe (1,141 NH residents; 275 family members), one in Canada (208 NH residents; 208 family members), and one in Asia (201 NH residents; 201 family members). All but one study[27] were conducted after 2000 (Table 1). The main aim of each study is reported in Table A3 (Appendix 1).

Studies involved a median of 20 NHs (range 1[19-21]-1,201[31]). Eleven studies were cross-sectional,[2,13,14,27,30-36] four prospective,[4,19,20,37] and one retrospective[21] (Table 1).

Please, insert here table 1.

Most studies assessed the decision to limit or withdraw life-sustaining treatments:[4,13,14,19,21,27,30,36] six explored the prevalence of in-hospital death,[2,4,16,21,31,33] five assessed family satisfaction with EOL care,[2,19,20,32,35] two described the quality of dying,[33,37] and one assessed family well-being[34] (Table 1). Data were collected from medical records (n=9),[4,13,14,19-21,27,34,35] family interviews (n=8),[2,13,19,20,27,34-36] family questionnaires (n=5),[14,30,32,33,37] healthcare professionals questionnaires (n=4),[30,31,33,37] healthcare databases (n=2),[21,31] or NH resident interviews.[27] Data from healthcare professionals were collected between <5 [4] and 82 days after the resident's death.[33] Data collection from families ranged from the time of the resident's EOL[13,14,19,20,27,34,35] to 23.8 month after the resident's death[36] (Table 1).

Ten studies were classified as high quality, two as moderate quality and four as low quality (Table A2, Appendix 1).

Subjects Involved in End-of-Life Conversations

Families were always involved in EOL conversations, while NH residents only in six studies.[4,21,27,30,31,33] Family members were mostly adult children (range 55.2%-75.5%),[2,14,19,20,32,34-37] nieces/nephews (range 9.2%-14.4%),[20,21,32,34,35] and spouses (range 3.9%-19%)[2,19-21,32,34-37] (Table 1). EOL conversations were managed exclusively by the physician[4,14,27,34,37] or nurse,[32] or by multiple healthcare professionals (i.e., physician, nurse, healthcare aide, social worker, physical therapist).[2,19-21,30,33,35] Three studies did not specify the healthcare professionals qualification.[13,31,36] The mean duration of EOL conversations varied from 47 minutes (range 20-75 minutes),[19] to a range from <5 to >15 minutes,[34,35] up to >1 hour[36] (Table 1).

Definition of End-of-Life Conversations

The definition of EOL conversations differed (Table 1): eight studies defined it as a "discussion" about life-sustaining treatments or care goals,[21,27,35] advanced directives,[14,34] the risks and benefits of invasive treatments such as feeding tubes[36] or other treatments,[31] the prognosis, the possibility to withdraw treatments, palliative care options, or care for psychological, spiritual, and existential problems.[4] Three studies defined EOL conversations as "speaking" about life-sustaining treatments and symptom management[20] or future care;[30,33] one defined it as "talks" about how the NH resident was doing[13] or as "receiving information" about the NH resident's health problems or what to expect.[37] Three studies used a combined definition: EOL conversations required "receiving information and speaking about NH resident's condition and medical treatment"[2] or "receiving/providing information, discussing and understanding what to expect and medical treatment options".[19,32] Only one study[19] explicitly adopted "structured" conversations that systematically addressed the NH resident's health condition, clinical course and prognosis, the family's care goals and how to achieve them while explaining the risks and benefits of potential treatments. However, the majority of the studies did not report the characteristics nor the structure of EOL conversations. In one study, family attendance at care plan meetings was an indicator of EOL conversation.[21]

Definition of Life-Sustaining Treatments

The definition of life-sustaining treatments changed across the studies (Table 2). Some authors explored one medical intervention, such as resuscitation[14] or tube feeding,[36] while others[13] only hospitalizations and surgery. Four studies defined life-sustaining treatments as resuscitation, hospitalization, artificial feeding, hydration, intubation, antibiotic use, only comfort care, terminal sedation, or euthanasia.[19,21,27,30] One study did not define life-sustaining treatments.[4]

Please, insert here table 2.

End-of-Life Conversations and Life-Sustaining Treatments

Seven studies reported the prevalence of decisions to limit or withdraw life-sustaining treatments and were included in the quantitative synthesis (Table 2);[4,13,14,19,21,27,36] the risk of bias is presented for each study in Table A2, Appendix 1 and by a funnel plot of ORs by the size of the study sample (Figure A1). No publication bias was detected (Eagger test p=0.4483).

As shown in Figure 2, healthcare professionals-family EOL conversations were positively associated with the family's decision to limit or withdraw life-sustaining treatments (OR=2.23, 95% CI 1.58-3.14). Although there was relatively low heterogeneity (I^2=40.9%), a quality sensitivity analysis and a meta-regression were performed. The overall effect remained stable after removing low- and medium-quality studies (OR=2.51, 95% CI 1.96-3.22 I^2=0%, Figure A2). Family member's kinship, sex, age, and multi-healthcare professional EOL conversations, were not associated with such decision. Instead, education explained all the observed heterogeneity, with family members with higher education being less influenced by EOL conversations (Figure A3).

End-of-Life Conversations and Quality of Dying

Six studies[2,4,21,31,33,36] reported the prevalence of in-hospital death (6%[33]-22[31]). Discussing EOL issues was associated with fewer in-hospital deaths[4,31] and increased odds of receiving strong opioid analgesics in the last 24 hours of life.[4] Unplanned hospital admission and length of hospital stay in the last month of life also decreased, although not significantly.[4] However, healthcare professionals-family EOL conversations on prognosis and health complications were unrelated to NH resident's comfort during the dying process.[37] Similarly, nurse-family EOL conversations were negatively associated with residents' physical distress and dying symptoms,[33] nor were they a predictor for hospice use.[31]

End-of-Life Conversations and Family Satisfaction with End-of-Life Care

Five studies (764 family members) investigated the association between healthcare professionals-family EOL conversations and family satisfaction with EOL care.[2,19,20,32,35] Families that received scarce or confusing information were up to 6-fold more dissatisfied with EOL care than those who felt adequately informed,[2] while satisfaction with nurse communication was associated with higher satisfaction with EOL care.[32] EOL care satisfaction increased with the duration[35] and the frequency[20] of EOL conversations.

Discussion

This systematic review suggests that healthcare professionals-family EOL conversations may promote a palliative care approach in NH residents, with less aggressive treatments regardless the social, geographical and cultural contexts. Families involvement in EOL conversations increased 2-fold more the likelyhood to limit or withdraw life-sustaining treatments, with an average of 56% of residents receiving limited or no life-sustaining treatments (16.4%[14]-94.3%[19]).

In the cancer literature, discussing EOL issues has been shown to increase patients' and families' acceptance of the illness as terminal, their preference for comfort treatments aimed at relieving pain and discomfort, and receiving more as needed drugs without increasing pain or anxiety.[38,39] However, it should not be taken for granted that these conversations occur, particularly in Latin countries where non-disclosure appears as a way to maintain hope and continuity of social life.[40] In Latin countries, less than 65% of cancer patients are aware of their diagnosis and usually information about prognosis is even poorer than about diagnosis.[41]

EOL conversations generally involved family. According to Flemish physicians, only 22% of NH residents were involved in such conversations, although more than 60% were capable or partly capable of medical decision making at admission.[30] This poor involvement, in addition to the low prevalence of advanced directives (0-32%), which were reported in only six of 16 studies (USA,[13,27,35] Flanders,[30,33] and Canada[2]), suggests a tendency to avoid or delay EOL conversations until the

resident's health has deteriorated.[42,43] In fact, previous literature showed that 75% of direct care staff would talk to families about death, dying, and treatment options only when the NH resident became terminal.[44] Shifting the focus to comfort care would facilitate timely interventions aimed at promoting quality of living and dying[45] but requires healthcare professionals to confront the issue of how residents want to die and to care for their spiritual needs.[46] Spiritual care is a milestone of palliative care, but only one study assessed it in EOL.[4] Meeting the spiritual needs, in addition to symptom control, limiting or withdrawing aggressive care, and avoiding hospital admissions, are considered quality indicators for EOL care, particularly in severely cognitively impaired patients[1] (the majority of our sample). In patients with advanced dementia, treatments such as terminal hospitalization and tube feeding are considered aggressive[1,47] and perceived as poor EOL care by families .[36]

Confronting EOL issues may be emotionally challenging for healthcare professionals.[48] However, timely, sensible communication with staff is necessary to ensure quality care[47,49] and does not worsen predeath grief in families:[34] a clear explanation of treatment choices by the physician was associated with a dignified death according to families,[50] and up to 91% of DNR decisions were made by family members.[14] The presence of the family at care plan meetings favors a shared decision; however, family members were present in only one of five such meetings,[21] in spite of their wish to be involved in discussions on NH resident's treatment[51] and health condition.[44] No discussion occurred in over one-third of the cases,[4] and only half of the decisions to withdraw/withold life-sustaining treatments were discussed.[4,52] Similarly, only 41% of competent NH residents were involved in discussions about starting life-sustaining treatments.[12]

EOL conversations were often brief (<5 minutes)[16,35] and infrequent (>60% of physician-family EOL conversations occurred less than once a month).[13] However, some conversation was offered to the families of all terminal residents and their effect was measured mostly in observational studies, that differently from trials, reflect the actual routine care. Our findings show an emerging positive change, but much work is still to be done to make this palliative approach routine care. Moreover, this positive trend was mainly limited to North America (n=11)[2,13,19-21,27,31,32,34-36] and Northern

Europe (n=3);[30,33,37] while examples from other countries are few.[4,14] Differences in the definition of palliative care[53] and NH[54] exist across countries. Culture may influence healthcare professionals' involvement in and the structure of EOL conversations, however, our findings suggest that any family involvement in EOL conversations has a positive effect regardless the lack of cohesive definitions and differences across countries.

EOL conversations need improvement. Families often reported dissatisfaction with the provision of information about what to expect during the dying process,[2,4,18,55] the clarity of the information,[2] and the opportunity to share the preferences and wishes of the dying person.[2] Qualitative studies reported that families wanted more information about the condition of their loved ones and were upset by the lack of contact.[43] Families may feel overwhelmed by their EOL decision-making role if they feel ill-equipped to make such decisions,[56] exposing them to undue burden.[57] This raises the issue of balance between family autonomy and medical paternalism. [58] This balance is largely influenced by the societal context, as suggested by a qualitative study involving NH American and Dutch physicians: the former informed families about appropriate care and let them make choices supporting autonomy, while the latter took the final decision although keeping families involved in the decision-making process (paternalistic approach).[9] Patients and families need guidance about life-and-death decisions.[58] Experts recommend the involvement of patients and their families in "expectation conversation" to make them aware that critical decisions (e.g., hospitalization, artificial feeding) may be required in the coming weeks.[57,59] Families tend to choose comfort care when they acknowledge that the NH resident's health is not expected to improve. For example, surrogates of dementia patients without a full understanding of the situation scored their relative's quality of life as worse when active treatment was not provided.[13]

EOL conversations might not be associated with a better quality of dying.[33,37] Only residents whose surrogates understood the poor prognosis were less likely to receive aggressive therapeutic or diagnostic interventions.[17,60] Highly-educated family members were less influenced by EOL conversations, likely because skilled enough to refer to other information sources (i.e., the Internet).

However, quality of dying is difficult to measure, and distressing symptoms such as dyspnea may be uncontrollable. This may explain the apparent lack of association between EOL conversations and dying symptoms.[33,37] This issue should be better explored in future studies.

Our systematic review suggests that EOL conversations shape families' satisfaction with EOL care, and satisfaction increased with the duration[35] and frequency of discussion,[20] suggesting that in-depth, scheduled EOL conversations promote family members' gradual involvement and awareness with a positive effect on their satisfaction with EOL care.[61]

Limitations

The results of this review should be considered in light of several limitations. First, although we used a systematic search strategy, eligible studies may have been missed. Second, one valuable study[30] was not included in the meta-analysis, because the authors did not provide additional information. Third, characteristics of EOL conversations were largely unreported, thus we could not explore whether the different definitions (e.g., speaking, discussion, talk) implied differences in the structure of conversation. Finally, unmeasured confounders like medical or NH culture or religious attitudes may have accounted for the association between EOL conversations and the decision to limit or withdraw life-sustaining treatments. However, our findings remained consistent despite differences in context, interventions, or nursing home culture, suggesting that EOL conversations may play a positive role in promoting a palliative approach.

Conclusions/Relevance

This systematic review provides the first comprehensive evaluation of the role of EOL conversations on EOL care outcomes, and particularly on the decision to limit or withdraw life-sustaining treatments. EOL conversations influence adoption of a palliative approach, thus reducing aggressive interventions, possibly by making NH residents and families better understand their lack of benefit. Our findings suggest that EOL conversations should not be confined to the final days of life but

offered from an early stage with NH administrators offering healthcare professionals regular training on EOL conversations. This is the first step to more meaningful participation and shared decision making, which improves EOL care outcomes including families' satisfaction. Future research should explore whether and how differences in the structure of conversations affect EOL care outcomes.

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None.

Conflict of interest

The authors have no conflicts of interest to declare.

Table 1. Summary of the selected articles.

Author(s) (Country, year) Quality score*	Study characteristics						Study sample characteristics							Main findings
							Residents				Family members			
	Design	Definition of EOL conversation	Subjects involved in and duration of EOL conversation	Outcome (s) investigated (assessment tool used if applicable)	Data source (time of data collection)	Nursing homes (N)/size	(N) Males (%) Age, years[a]	Cognitive deficit (%)	Nursing home length of stay, years[†]	Advanced directive (%)	N/ kinship (%)	Males (%) Age, years	Education (%)	
Levin et al.[27] (USA, 1999) High	XS	Discussion about life-sustaining treatments	NH resident, family member, physician Duration NR	- Decision to limit life-sustaining treatments - Completion of advanced directive	Record review/ structured resident and family member interview (residents at their EOL but still alive)	20/NR	N=413 192 (46.5%) were interviewed M: 25 Age: 84 (39 to 107)	78	Mean 2.7 (6 weeks to 21 years)	32	N=363/NR	M: NR Age: NR	NR	(i) 54/192 (28.1%) and 197/363 (54.3%) of residents and families discussed life-sustaining treatments, respectively; (ii) 305/413 (74%) had at least one order to limit life-sustaining treatments (range 0-6); 298/305 (98%) had an order restricting CPR; (iii) Significant association between healthcare professionals- family EOL conversation and DNR orders (aOR=2.90, 95% CI 1.61-5.22); (iv) No association between healthcare professionals-NH resident EOL conversation and DNR orders (aOR=0.54, 95% CI 0.25-1.18); (v) No association between healthcare professionals-NH resident (aOR=1.15, 95% CI 0.56-2.34) or healthcare professionals-family (aOR=1.44, 95% CI 0.83-2.51) EOL conversations and advanced directive completion.
Engel et al.[35] (USA, 2006) Moderate	XS	Discussing advance care planning for life-sustaining treatments	Family member, physician, nurse, social worker, nurse administrator or other administrator,	Family satisfaction with EOL care (SWC-EOLD)	Record review/surrogate telephone interview with structured questionnaire	13/>60 beds	N=148 M: 12.2 Age: 85 (60 to 103)	All	Mean 3.8 (8 weeks to 15 years)	12.8	N=148 Child (73) Spouse (10.1)	M: 38.5 Age: 59.1 (32-92)	77.7% > high school	(i) Mean score on SWC-EOLD was 31.0 (4.2, range 10-40; higher scores indicate greater satisfaction); (ii) Positive association between discussing advanced directives >15 minutes with a healthcare professional at nursing home

			physical therapist, ombudsman Duration: 14.9% did not discuss, 14.9% spent 1-5 minutes, 17.5% spent 6-15 minutes, 52.7% spent >15 minutes in conversation at nursing home admission		(residents at their EOL but still alive)						Others (16.9)			admission and family member satisfaction with EOL care (parameter estimate=2.39, 95% CI 1.16-3.61).
Kiely et al.[34] (USA, 2008) High	XS	Discussing the NH resident's advanced directives and being counseled on the NH resident's prognosis	Family member, physician Duration: 49% of family members spent >15 minutes discussing advanced directives	Family predeath grief symptoms (PDG)	Record review/surrogate telephone interview with structured questionnaire (residents at their EOL but still alive)	22/>60 beds	N=315 M: 15 Age: 85.2 (7.6)	All	3.8 (3.3)	NR	N=315 Child (70) Spouse (10) Others (20)	M: 37 Age: 59.9 (11.5)	75% > high school	(i) No association between spending >15 minutes discussing NH resident's advanced directive with the physician at the time of nursing home admission and family member pre-death grief symptoms; (ii) No association between being counseled by the physician about NH resident's prognosis and family member pre-death grief symptoms.
Maust et al.[13] (USA, 2008) Low	XS	Talking to healthcare professionals about how the resident is doing	Family member, healthcare professional Contact with healthcare professional:	Decision to limit life-sustaining treatments	Record review/ surrogate interview with structured questionnaire (every 3 months and one after resident's death)	3/NR	N=100 M: 41 Age: 81.2 (7.2)	NR	NR	0	N=100/NR	M: 25 Age: 59.3 (11.6)	63% graduate or postgraduate	(i) No association between EOL discussion and family member's decision to withhold life-sustaining treatments (p=0.999); (ii) No association between frequent contact with physicians and withholding life-sustaining treatments (p=0.891); (iii) Frequent contact with nurses was associated with not providing life-sustaining treatments (p=0.031);

			<once/month (62% for MD, 33% for RN) ≥once/month (38% for MD, 67% for RN)											(iv) No association between meetings to discuss treatment options and family member's decision to withhold life-sustaining treatments (p=0.999).
Lo et al.[14] (Taiwan, 2010) High	XS	Discussing DNR decision	Family member, physician Duration NR	Decision to limit life-sustaining treatments (DNR)	Record review/family questionnaire (residents at their EOL but still alive)	7/60 to 170 beds	N=201 M: 38.8 Age: 80 (10.5)	Mean MMSE score‡ 8.57 (9.15)	Mean 2.1 (2.07)	NR	N=201 Child (75.2) Spouse or others (24.8)	M: 51.2 Age: 52.2 (10.8)	44% graduate or postgraduate	(i) Positive association between surrogates' discussion of DNR with physicians and presence of a DNR directive (aOR=4.09, 95% CI 1.53-10.96).
Teno et al.[36] (USA, 2011) Moderate	XS	Discussion of feeding tube insertion explaining options, risks and benefits	Family member, healthcare professional Duration of conversations ranged from <5 minutes to >1 hour	- Decision to limit life-sustaining treatments - Quality of EOL care (5-point Likert scale)	Surrogate telephone interview (23.8 months after resident's death)	NR/NR	N=486 M: 28.5 Age: 87.9 (NR)	All	NR	NR	N=486 Child (66.6) Spouse (8.4) Others (25)	M: 33.4 Age: NR	67.1% up to 4 years college or postgraduate	(i) No difference in the decision for no feeding tube insertion when risks to placing feeding tubes were explained (45.5%, 95% CI 34.2-57.2 vs 50.8%, 95% CI 39.3-62.2); (ii) No difference in the decision for no feeding tube insertion when benefits to placing feeding tubes were explained (50.4%, 95% CI 39.0-61.8 vs 47.2%, 95% CI 35.9-58.7); (iii) No difference in the decision for no feeding tube insertion when option of hand feeding was explained; (iv) Family members were less likely to report an excellent quality of EOL care when their loved one died with a feeding tube (aOR=0.42, 95% CI 0.18-0.97); (v) 15.6% died in a hospital.
Liu et al.[32] (USA, 2012) Low	XS	Receiving information about what to expect, discussing wishes for medical treatment, having the opportunity	Family member, nurse Duration NR	Family satisfaction with EOL care (SWC-EOLD)	Mailed questionnaire to family members (dead residents - timing not specified)	NR	N=131 M: NR Age: NR	All	NR	NR	N=131 Child (65.4) Spouse (3.9) Others (30.7)	M: 29 Age: 65 (9.75)	44.3% graduate or postgraduate	(i) Mean score on FPPFC was 17.24 (SD=4.77; range 0-21; higher scores indicate greater satisfaction with communication); (ii) Mean score on SWC-EOLD was 34.4 (5.569, range 10-40; higher scores indicate greater satisfaction);

		to ask questions, feeling listened to and understanding what was said												(iii) Positive association between family satisfaction with EOL and nurse-family communication (β=0.33, p<0.001).
Thompson et al.[2] (Canada, 2012) High	XS	Receiving information about NH resident's care or condition, speaking about his/her wishes concerning medical treatment, consistency of NH resident's wishes with medical treatments	Family member, physician, nurse, health care aide Duration NR	Family dissatisfaction with EOL care (4-point Likert scale)	Telephone or face-to-face family member interview (mean 7 months [range 2-16] after NH resident's death)	21/NR	N=208 M: 40.4 Age: 87.5 (56 to 104)	58.2	Mean 2.7 (2 weeks to 15 years)	29.2	N=208 Child (75.5) Spouse/ partner (12) Others (12.5)	M: 29.8 Age: 62.5 (30-97)	51% graduate or postgraduate	(i) Association between family's acquisition of inadequate information from nursing staff and family's dissatisfaction with EOL care (aOR=4.88, 95% CI 1.4-16.9); (ii) Association between provision of confusing information by nursing staff regarding the NH resident's care or treatments and family dissatisfaction with EOL care (aOR=6.4, 95% CI 1.8-22.7); (iii) 9.6% died in a hospital.
Van der Steen et al.[37] (The Netherlands, 2013) High	P	Receiving information on health problems patients may experience in later stages of dementia and on survival	Family member, physician Duration NR	Quality of dying (CAD-EOLD according to healthcare professional)	Physician (within 2 weeks) and family member (2 months after NH resident's death) questionnaire	28/11 to 210 beds	N=161 M: 31 Age: 86.0 (6.3)	All	Mean 1.0 (0.7)	NR	N=73 Child (59) Spouse (19) Others (22)	M: 36 Age: 60.3 (11.7)	28% graduate	(i) Families' baseline understanding of poor prognosis 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); (ii) Families having being counseled on health complications was unrelated to NH resident's quality of dying (aMD= -0.9, 95% CI -2.8 to 1.1); (iii) Families having being counseled on prognosis was unrelated to NH resident's quality of dying (aMD= -0.6, 95% CI -2.8 to 1.6).
Vandervoort et al.[30]	XS	Speaking about a NH resident's future care (medical	Nurse, general practitioner, NH resident,	Decision to limit life-sustaining treatments	Structured questionnaire to family member, nurse and general practitioner	69/101 beds	N=205 M: 38.9	All	NR	9, 13.6 and 18.4 according to the	N=101/NR	M: 35.4 Age: 60.6 (11.0)	NR	(i) Professional caregivers more often discussed EOL treatments with the relative than with the NH resident (70.6% *vs* 22% for the general

(Flanders Belgium, 2014) High		treatment and desired direction of care)	family member or friend Duration NR		(median 134 days, IQR 45-104; 65 days, IQR 37-91; and 82 days, IQR 48-137, respectively after NH residents death)		Age: 34.8%>90 years			general practitioner, nurse and relative, respectively				practitioner and 59.5% *vs* 9.7% for the nurse); (ii) According to the relative, professional caregivers spoke with the NH resident (35.6%) and with a family member/friend (61.4%); (iii) The decision to limit or withdraw life-sustaining treatments was documented in medical records in 58.1% of cases according to the nurse and 77.3% of cases according to the general practitioner; (iv) Professional caregivers more frequently discussed the decision to limit or withdraw life-sustaining treatments with the relative than with the NH resident (79.3% *vs* 13% for the general practitioner and 80.8% *vs* 4% for the nurse).
Vandervoort et al.[33] (Flanders, Belgium, 2014) High	XS	Speaking about a NH resident's future care (medical treatment and desired direction of care)	Nurse, general practitioner, resident, family member or friend Duration NR	Quality of dying (CAD-EOLD according to family member)	Structured questionnaire to family member, nurse and general practitioner (median 134 days, IQR 45-104; 65 days, IQR 37-91; and 82 days, IQR 48-137), respectively after resident's death)	69/NR	N=101 M: 42 Age: 36% <85 y 27% 85-89 y 36% ≥90 y	All	Median 2.1 (1.0 to 3.7)	17.5	N=101/NR	M: NR Age: NR	NR	(i) No association between nurse-NH resident EOL conversation and quality of dying; (ii) Nurse-family member/friend EOL conversation was negatively associated with physical distress (aOR=0.28, 95% CI 0.08-0.98) and dying symptoms (aOR=0.26. 95% CI 0.1-0.6); (iii) No association between discussion of general practitioner orders and quality of dying; (iii) 6% died in a hospital.
Reinhardt et al.[19] (USA, 2014) Low	P (RCT)	Providing information about risks and benefits of potential treatments, discussing family's goal of care for the NH resident and	Physician, social worker, family member Mean duration 47 minutes	- Decision to limit life-sustaining treatments - Family satisfaction with EOL care (SWC-EOLD)	Record review/ telephone interview to family members at study enrollment, 3 and 6 months after enrollment (or 4-6 weeks after NH resident's death if it occurred)	1/large	Intervention N=47 M:14.9 Age: 85.7 (6.2)	All	Intervention 3.8 (3.3) Control 4.8 (3.9)	NR	Intervention N=47 Child (42.5) Spouse (6.4) Others (51)	Intervention M: 21.3 Age: 59.6 (12.3)	Intervention 55.3% graduate or postgraduate	(i) Significant increase in limiting life-sustaining treatments in the intervention group (pre 78.7%, post 100%, p<0.01) compared to the control group (pre 77.5%, post 87.5%); (ii) Satisfaction with EOL care increased from T1 to T2 in both groups; at T3 remained unchanged in

		how to achieve those goals, and assessing the understanding of NH resident's current health condition, clinical course of the disease, and prognosis	(range 20 to 75 minutes)	- Family perception of resident's symptom control (SM-EOLD) -Family members' well-being (PHQ-9) -Family members' life satisfaction (SWLS)	(residents at their EOL but still alive)		Control N=40 M: 22.5 Age: 85.2 (8.5)				Control N=40 Child (70) Spouse (7.5) Others (22.5)	Control M: 20 Age: 58.9 (11.9)	Control 65% graduate or postgraduate	the intervention group and decreased in the control group; (iii) No significant difference between groups or over time in the perception of NH resident's symptom control, family members' own well-being and life satisfaction.
Reinhardt et al.[20] (USA, 2015) Low	P	Speaking about pain and symptom management or about 6 life-sustaining treatments (resuscitation, hospitalization, artificial feeding and hydration, antibiotics, diagnostic procedures)	Physician, nurse, social worker, family member Duration NR	Family members satisfaction with EOL care (SWC-EOLD)	Record review/ telephone interview to family members at study enrollment, 3 and 6 months after enrollment (NH residents at their EOL but still alive)	1/large	N=90 M: 20 Age: 85.5 (NR)	All	NR	NR	N=90 Child (56) Spouse (7) Others (37)	M: 31 Age: 59.2 (11.7)	60% graduate or postgraduate	(i) Positive association between greater frequency of discussion of artificial hydration and care satisfaction at 6 months (β=0.32, p<0.05); trend for discussion about hospitalization and diagnostic procedures (β =0.27, β=0.24, respectively, both p<0.10); (ii) Positive association between greater frequency of discussion of artificial hydration and change in 6-month care satisfaction (β=0.32, p<0.01); trend for discussion about hospitalization and diagnostic procedures (β =0.21, p<0.10).
Morin et al.[4] (France, 2016) High	P	Discussion about the course of the disease and the prognosis, the approaching EOL, the possibility to withdraw treatments, palliative care, the psychological, spiritual	Physician, resident or family member Duration NR	-Unplanned hospital admission -Total hospital LOS -Death in hospital -Designation of a surrogate -Withdrawal of life-	Record review (within 5 days after resident's death)	78/NR	N=674 M: 31.2 Age: 74.8% ≥ 85 years	70.9 23.1% MMSE ≥10 47.8% MMSE ≤ 9	24.3% <1 year 26.7% from 1 to 3 years 49% >3 years	NR	NR/NR	M: NR Age: NR	NR	Association between discussing >3 EOL issues and (i) unplanned hospital admission or total length of stay: no association; (ii) decreased likelihood of dying in hospital (aOR=0.51. 95% CI 0.33-0.79); (iii) designation of a surrogate (aOR=2.36, 95% CI 1.9-3.66) or withdrawal of life-sustaining treatments (aOR=2.37, 95% CI 1.72-3.29);

		and existential problems over the last month before death		sustaining treatments -Medication use										(iv) decreased likelihood of no opioid therapy during the last month (aOR=0.60, 95% CI 0.44-0.82), the last week (aOR=0.53, 95% CI 1.72-3.29) and the last 24 hours (aOR=0.69, 95% CI 0.50-0.94). (v) decreased likelihood of prescribed treatments for chronic conditions during the last 24 hours (aOR=0.63, 95% CI 0.43-0.92); (vi) 15.9% died in a hospital.
Temkin-Greener et al.[31] (USA, 2016) High	XS	Discussion about prognosis and the risk/benefit of treatments	Healthcare professional, NH resident or family member Duration NR	In-hospital death, hospice use (EOL care processes tool)[§]	Health care databases/ Director of Nursing questionnaire (dead residents – timing not specified)	1201/> 50 beds	N=41,586 for in-hospital death N=52,079 for hospice use M: 37.4 Age: 85.2 (8.0)	33.3	NR	NR	NA	M: NR Age: NR	NR	(i) Mean healthcare professional-NH resident/family communication score was 2.67 (range 1-5); (ii) Better healthcare professional-NH resident/family member communication was associated with fewer in-hospital deaths (coefficient -0.010, p=0.015); (iii) healthcare professional-NH resident/family member communication was not predictor for hospice use (coefficient -0.003, p=0.697); (iv) 22.03% died in hospital; 44.5% used hospice.
Reinhardt et al.[21] (USA, 2017) High	R	Documented discussion in the medical record about NH resident-centered goals for care or 6 life-sustaining treatments (resuscitation, intubation, hospitalization, feeding tube, hydration	Physician, nurse, social worker, resident, family member Duration NR	- Decision to limit life-sustaining treatments - Discussion of goals of care	Health care databases	1/large	N=300 M: 32 Age: 87 (NR)	82	2.8 (NR)	NR	N=190[‖] Child (71.8) Family (27.6) Spouse (9) Others (26.1)	M: NR Age: NR	NR	(i) Positive association between discussion relevant to the medical order in question and 4/6 life-sustaining treatments: DNH order (aOR=2.23, 95% CI 1.28-3.90), no artificial hydration order (aOR=2.97, 95% CI 1.51-5.85), no feeding tube order (aOR=2.23, 95% CI 1.18-4.23), no antibiotics order (aOR=2.67, 95% CI 1.08-6.64); (ii) Goals of care were discussed in 66% of cases; (iii) Positive association between care goal discussion and for 1/6 life-

		and antibiotics) or family attendance at a care plan meeting												sustaining treatments, i.e. DNH order (aOR=1.96, 95% CI 1.10-3.50); (iv) 21% of family members participated at the care plan meeting; (v) 8% died in a hospital.

Note. Any healthcare professionals means physician, nurse, social worker.

[*] According to Moilanen criteria.[24]

[†] Age and length of stay are expressed as mean (range), mean (SD), or median (IQR).

[‡] Score ranges from 0 to 30, with severe impairment <16, moderate impairment 17-20, mild impairment 21-24; intact cognition ≥25.

[§] Higher score indicates a more positive appraisal to communication.

[‖] More family members could be involved simultaneously.

Abbreviations: aMD, Adjusted Mean Difference; aOR, Adjusted Odd Ratio; CAD-EOLD, Comfort Assessment in Dying with Dementia; CI, Confidence Interval; CPR, Cardio-Pulmonary Resuscitation; DNH, Do-Not-Hospitalize; DNI, Do-Not-Intubate; DNR, Do-Not-Resuscitate; EOL, End-Of-Life; HPC, Healthcare Provider; FPPFC, Family Perception of Physician-Family Caregiver Communication; IQR, Interquatile Range; IVs, Intravenous lines; MD, Medical Director; MMSE, Mini Mental State Examination; NA, Not Applicable; NR, Not Reported; P, Prospective; PHQ-9, Patient Health Questionnaire; R, Retrospective; RCT, Randomized Controlled Trial; RN, Registered Nurse; SD, Standard Deviation; SM, Symptom Management at the End of Life in Dementia; SWC-EOLD, Satisfaction with Care at End-of-Life in Dementia Scale; SWLS, Satisfaction With Life Scale; XS, Cross-sectional.

Table 2: Prevalence of Decision to Limit or Withdraw Life-Sustaining Treatments in Nursing Homes Residents

Study (Country, Year)	**Sample Size** (No of residents)	**Definition of Life-Sustaining Treatments**	**Decision to Limit or Withdraw Life-Sustaining Treatments** No (%)	**Family Member Participants with Graduate or Postgraduate Education** (%)
Levin et al.[27] (USA, 1999)	413	DNR, no tube feeding, no hospitalization, DNI, no intravenous fluids, or palliative care only	305 (74)	NA
Maust et al.[13] (USA, 2008)	100	No hospitalization, no surgery	36 (36)	63
Lo et al.[14] (Taiwan, 2010)	201	DNR	33 (16.4)	44
Teno et al.[36] (USA, 2011)	486	No feeding tube insertion	82 (16.9)	67.1
Vandervoort et al.[30] (Flanders, Belgium, 2014)	205	DNH, DNR, DNI, withholding or withdrawing antibiotics or administration of artificial food and/or fluids or other treatment, euthanasia, terminal sedation	NA*	NA
Morin et al.[4] (France, 2016)	674	Not specified†	417 (61)	NA
Reinhardt et al.[19] (USA, 2014)	87	DNR, DNI, DNH, no artificial feeding, no intravenous lines, no antibiotics, or only comfort care	82 (94.3)	40.2
Reinhardt et al.[21] (USA, 2017)	300	DNR, DNI, DNH, no artificial hydration, no artificial feeding, no antibiotic use	271 (90%)‡	NA

Abbreviations: DNH, Do-Not-Hospitalize; DNI, Do-Not-Intubate; DNR, Do-Not-Resuscitate; NA, Not Available.

* This study was not included in the meta-analysis since data were not available.

† These authors only reported the figure of life-sustaining treatments withdrawal without reporting what they meant for life-sustaining treatments.

‡Authors provided individual figures for each life-sustaining treatments rather than a combined figure including all the explored life-sustaining treatments. Prevalence data of the most frequent decision (i.e., DNR) were entered the meta-analysis.

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

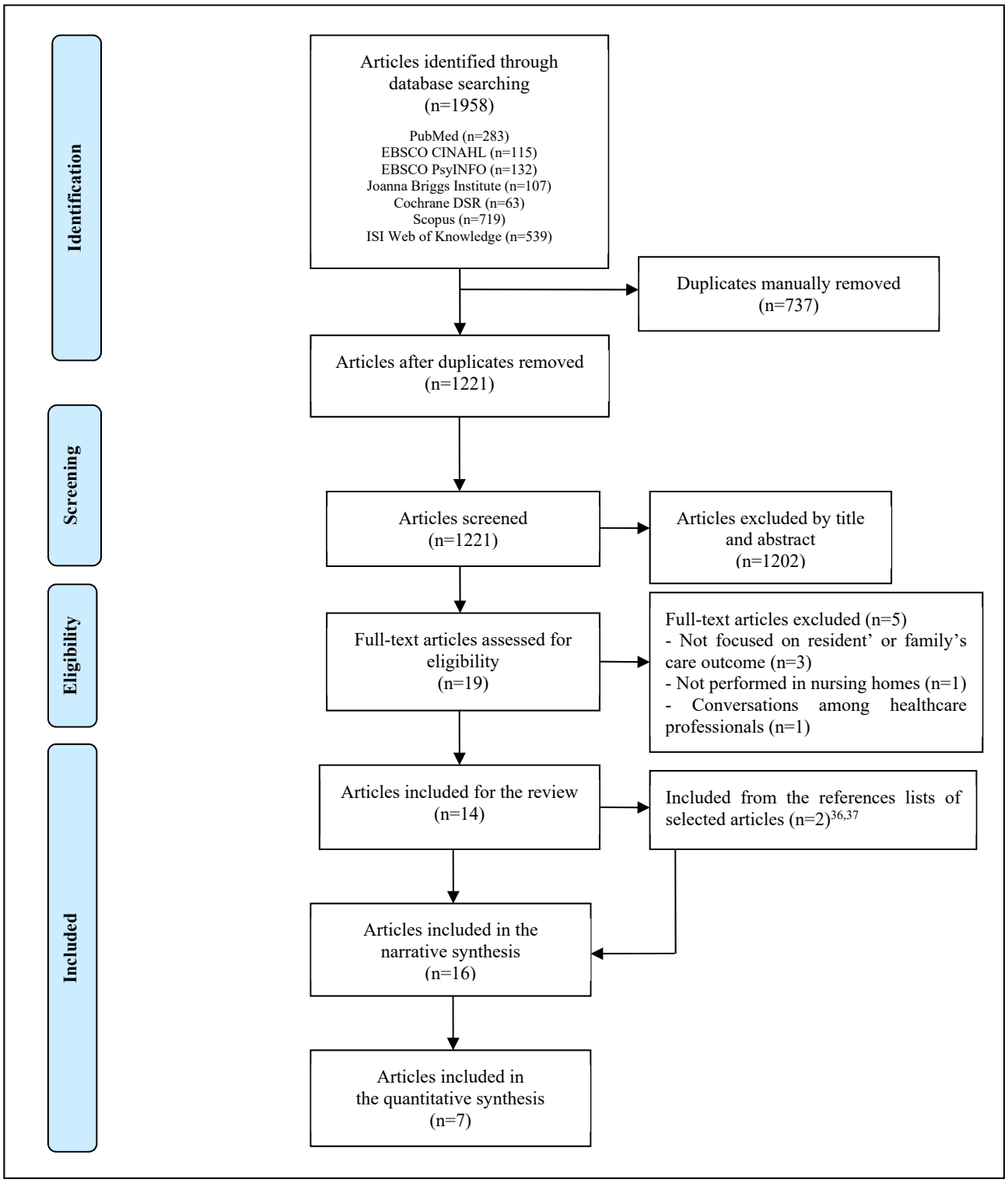
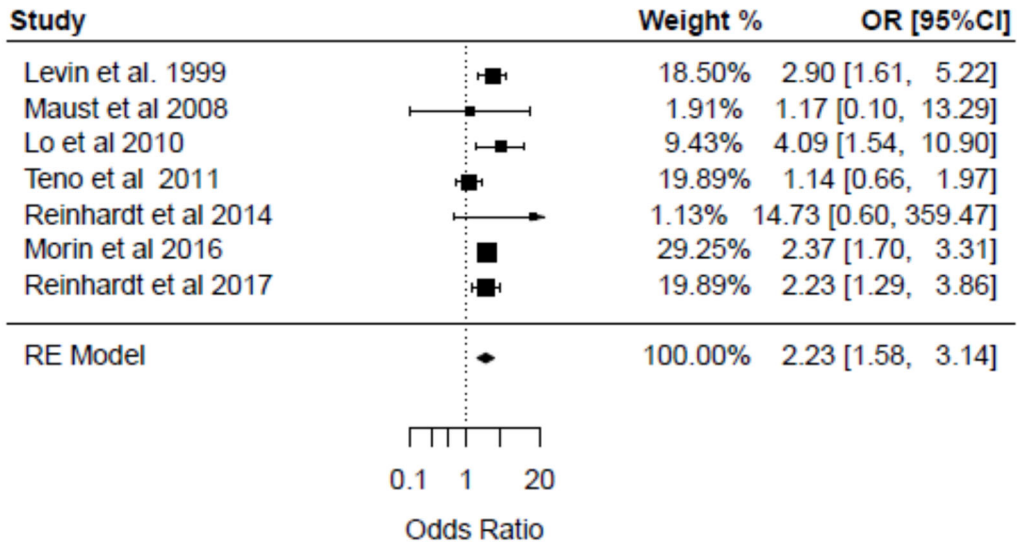


Figure 2: Meta-analysis of family members-health care professionals EOL conversations and the decision to limit or withdraw life-sustaining treatments



Random-Effects Model (k = 7; tau^2 estimator: REML)
tau^2 (estimated amount of total heterogeneity): 0.0763 (SE=0.1102)
tau (square root of estimated tau^2 value): 0.2761
I^2 (total heterogeneity / total variability): 40.90%
H^2 (total variability / sampling variability): 1.69
Test for Heterogeneity: Q(df = 6) = 9.7124, p-val = 0.1373
Abbreviations: CI, confidence interval; df, degrees of freedom; OR, odds ratio; REML, restricted maximum likelihood; SE, standard error.

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