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Interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes: A mixed-methods systematic review

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Abstract

Background: Most people with dementia transition into nursing homes as their disease progresses. Their family caregivers often continue to be involved in their relative's care and experience high level of strain at the end of life.

Aim: To gather and synthesize information on interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes and provide a set of recommendations for practice.

Design: Mixed-Methods Systematic Review (PROSPERO no. CRD42020217854) with convergent integrated approach.

Data sources: Five electronic databases were searched from inception in November 2020. Published qualitative, quantitative, and mixed-method studies of interventions to support family caregivers of people with advanced dementia at the end of life in nursing home were included. No language or temporal limits were applied.

Results: In all, 11 studies met the inclusion criteria. Data synthesis resulted in three integrated findings: (i) healthcare professionals should engage family caregivers in ongoing dialog and provide adequate time and space for sensitive discussions; (ii) end-of-life discussions should be face-to-face and supported by written information whose timing of supply may vary according to family caregivers' preferences and the organizational policies and cultural context; and (iii) family caregivers should be provided structured psychoeducational programs tailored to their specific needs and/or regular family meetings about dementia care at the end of life.

Conclusion: The findings provide useful information on which interventions may benefit family caregivers of people with advanced dementia at the end of life and where, when, and how they should be provided.

Keywords

Education, dementia, family, health communication, nursing homes, systematic review, palliative care, terminal care

What is already known about the topic?

- Several people with advancing dementia move permanently into nursing homes due to increasing disability and dependence.
- Family caregivers of people with dementia experience the highest level of strain when their relative's death is nearing and they often live in nursing homes.

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- Family caregivers of people with dementia at the end of life have specific information and support needs related to the emotional impact of dementia and their decision-making role.
- Supporting family caregivers during the end-of-life stage prepares them emotionally for their relative's death and helps them cope with their caregiving role.

What this paper adds?

- This paper focuses on support for family caregivers of people with dementia at end of life in nursing homes while most literature addresses family caregivers of people living in the community or during the transition to the nursing home.
- Ongoing discussions between family caregivers and healthcare professionals facilitates partnership, promotes informed and shared decisions, is a source of emotional support, and essential to family caregivers' empowerment.
- Preferred timing of information provision about care options in advanced dementia is highly influenced by individual preferences and context.
- Psychoeducational programs and regular meetings with trusted healthcare professionals tailored to family caregivers' specific and changing emotional and information needs can promote self-care and empowerment.
- Interacting with peers and healthcare professionals independent from the nursing home or experienced in psychological care may help family caregivers to identify their dementia education needs, manage distress and develop problem-solving skills.

Implications for practice, theory, or policy

- Interventions to support family caregivers of people with advanced dementia at the end of life should include timely and ongoing face-to-face discussions complemented by written information and structured psychoeducational programs which provide targeted socio-emotional care in addition to tailored information, while involving a multiprofessional team and possibly peers.
- Governments must acknowledge support of family caregivers of people with advanced dementia as a public health priority and invest resources in programs to provide them evidence-based support.
- Optimal support for family caregivers of people with advanced dementia at the end of life can promote their empowerment resulting in improved self-care attitudes and greater engagement in shared decisions for their relative's end-of-life care.
- Further research could assess how peer support and professional support for family caregivers of people with dementia in the nursing home may complement each other.

Introduction

Dementia is a cluster of terminal neurodegenerative disorders characterized by progressive and irreversible cognitive and functional decline, particularly among older adults.[1] It is estimated that around 50 million people currently have dementia worldwide, and there are nearly 10 million new cases every year.[2] The total number of people with dementia is projected to reach 82 million in 2030 and 152 in 2050.[2,3] Most people with dementia and their family caregivers desire that they remain at home for as long as possible[4] and there is growing research about interventions which aim to postpone transition to nursing homes.[5,6] These facilities are also known as aged-care or long-term care homes and provide nursing care and assistance in activities of daily living in addition to room and board.[7] However, about 75% of people with dementia move permanently into nursing homes at some point of the disease trajectory due to increasing disability and dependence.[4,8] This means that healthcare professionals working in nursing homes increasingly care for people living with dementia and their family caregivers.[9]

Family caregivers of people with dementia are at increased risk of burden, stress, and depression.[10,11] Despite literature shows that some family caregivers experience less clinically significant burden and depressive symptoms once their relative moves to a nursing home, particularly for those who lived with the person with advanced dementia in the community as their caregiving responsibilities decrease,[12] often the burden of caregiving persists after a relative moves to a nursing home[13,14] and levels of strain increase near the end of life.[15] Indeed, most family caregivers continue to occupy a pivotal position in the decision-making process as surrogate decision-maker after their relative's move to the nursing home.[16,17] This suggests that entering a nursing home does not necessarily signal the end of caregiving but rather identifies a new phase of the caregiving trajectory, which may be as challenging as or even more than caregiving at home.[18] Therefore, family caregivers of people with dementia need continuous support, from a relative's move to a nursing home to realign their role[19] until death since high level of family caregivers' anticipatory grief was suggested to be associated with worse well-being outcomes post-death.[20,21]

The World Health Organization recognizes support for family caregivers of people with advanced dementia as a

public health priority.[2] Particularly, family caregivers need both guidance in taking decisions for their relative's end-of-life care[22] and social and emotional support.[23]

Supporting family caregivers during the end-of-life stage may be particularly worthy not only with respect to offering them resources to tackle their strain thus avoiding prolonged or complicated grief,[20,24] but also to help them cope with their caregiving role as a best interest decision-maker on behalf of their relative who may lack capacity.[23] Caring for family caregivers by providing information about the course of dementia and treatment options as well as attending to their emotional, psychosocial, and spiritual needs should be planned for throughout the overall disease trajectory.[23] However, literature mainly focuses on the support that family caregivers of people with dementia receive when they are still at home[25] and during the transition toward the nursing home,[26,27] while knowledge about the support in taking challenging decisions about goals of care and treatments during the final weeks or a few months of their relative's life (hereafter end of life) is poor and fragmented. Therefore, this literature review aims to gather and synthesize information on interventions to support family caregivers of people with advanced dementia at the end of their relative's life in nursing homes and provide a set of recommendations for practice.

The central question driving this research is: what interventions support family caregivers of people with advanced dementia at end of life in nursing homes?

Methods

Design

A systematic review according to the Joanna Briggs Institute methodology for Mixed-Methods Systematic Review was performed.[28]

This review has been reported in accordance with the Synthesis Without Meta-analysis (SWiM) guidelines[29] (Supplemental Appendix 1) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[30] (Figure 1) to enhance the quality and transparency of reporting. The review protocol was registered on PROSPERO register of systematic reviews on 5 November 2020 (registration number CRD42020217854), available at https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020217854.

Search strategy

A three-step search strategy was employed: (1) an explorative search on PubMed and CINAHL EBSCO was conducted in October 2020 followed by an analysis of title, abstract, and the index terms to identify the most appropriate keywords; (2) five databases (PubMed, CINAHL EBSCO, PsychInfo EBSCO, Joanna Briggs Institute, and Scopus) were searched from inception on November 5th 2020. Searches employed both controlled vocabularies and free terms, without temporal or language limits. Search strategies were adapted for each database (Supplemental Appendix 2); and (3) the references of included articles were screened to identify further relevant publications.

Inclusion and exclusion criteria

Population. Studies were included if they focused on any type of interventions aimed at supporting family caregivers of people with advanced dementia at the end of life in nursing homes by promoting their awareness and resilience. End of life was defined as the final weeks or a few months of a relative's life.[31]

Interventions delivered at the organizational level (e.g. care coordination program, respite program) or at the societal/policy level (e.g. payment rules, waiver programs, direct services to caregivers of people with dementia, policies regarding unpaid or paid leave for caregivers) as well as resident-oriented support interventions were excluded. Interventions at the organizational level were excluded since they are usually delivered in community settings and aimed at relieving caregiving responsibilities on a temporary or periodic basis during the disease trajectory, rather than promoting family caregivers' awareness and resilience, thus not providing an ongoing support for the end-of-life phase. Interventions at the societal/policy level were excluded since public support may widely vary across jurisdictions, thus preventing from providing generalizable recommendations. Caregiver-oriented support interventions as part of multi-faceted programs were included only when caregiver-oriented support interventions were clearly recognizable and assessable.

Family caregivers of people with advanced dementia were defined as the relative, partner, close friend, or neighbor who provides assistance in activities of daily living, or social or emotional support to the person with dementia, or assumes an advocacy role.[32]

Phenomena of interest. The review considered studies that investigated all forms of interventions delivered at the caregiver level (e.g. educational, psychosocial, and psychological interventions) which are employed to support family caregivers of people with advanced dementia at the end of life in nursing homes.

Context. Studies merging caregiver-oriented support interventions across different settings (i.e. home, public hospital, hospice, private hospital, and assisted living) were included only when the results related to the nursing homes were clearly distinguishable. Nursing home was defined as a facility that provides room and board, as

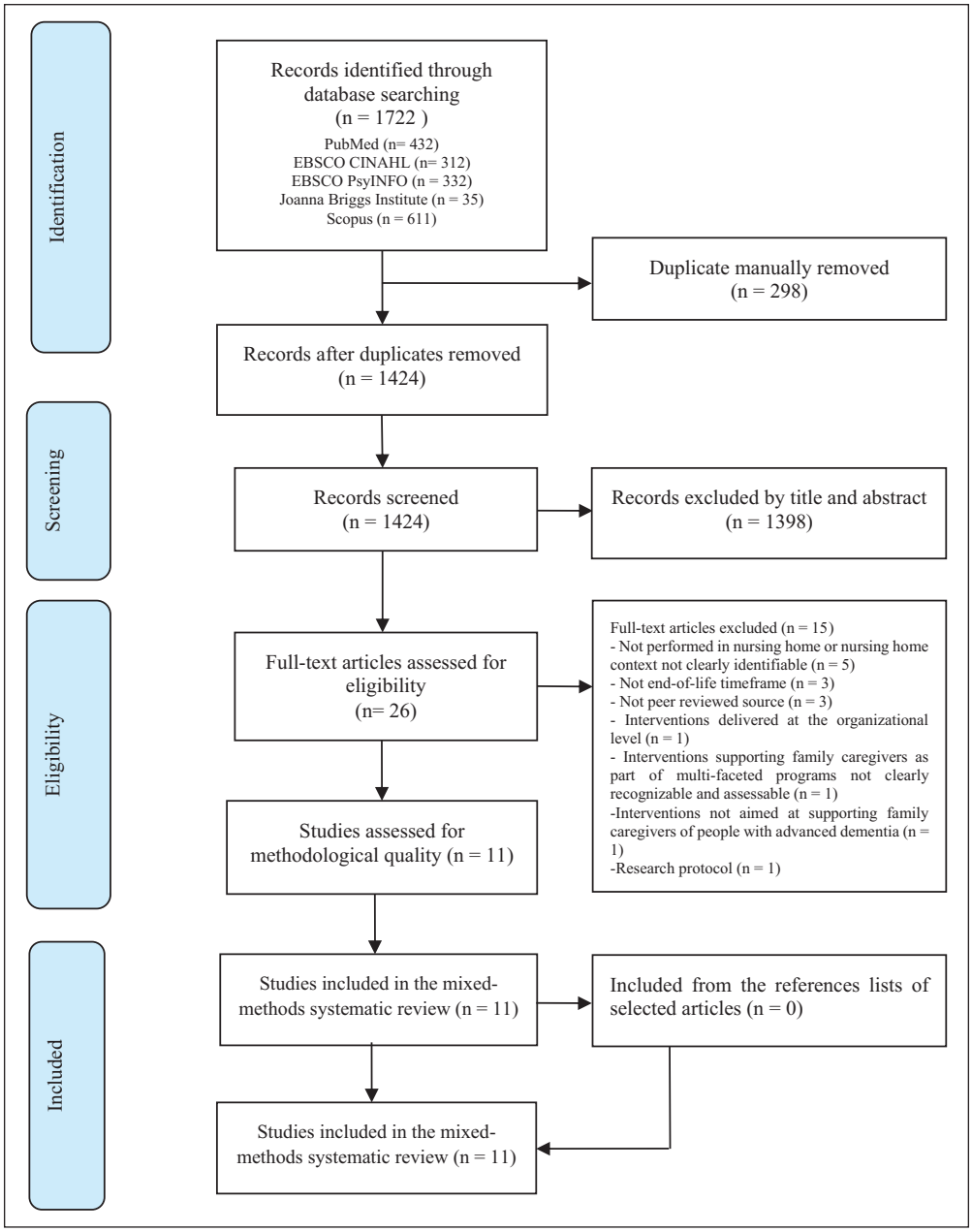

Figure 1. PRISMA flow-chart depicting the main stages of the systematic review process.

well as management of chronic medical conditions and nursing care and interventions with activities of daily living for patients who are physically and/or cognitively impaired.[7]

Types of studies. Quantitative, qualitative, and mixed methods studies were considered. Quantitative studies included cross-sectional studies, pre-post studies, clinical trials, controlled clinical trials, and randomized controlled trials; qualitative studies included qualitative descriptive, phenomenology, grounded theory, ethnography, case study, and action research design. Mixed methods studies were considered if data from the quantitative or qualitative components were clearly recognizable. When studies were quantitative according to the study authors but also reported qualitative data, the study was considered "quantitative" but both qualitative and quantitative data were included.

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

Screening and study selection

All identified articles were loaded into EndNote X9 (Clarivate Analytics, PA, USA) and duplicates removed. Titles, abstracts, and finally full texts, were screened by two independent reviewers for assessment against the inclusion and exclusion criteria.

Assessment of methodological quality. The selected papers were independently assessed by two reviewers for methodological validity using Joanna Briggs Institute critical appraisal tools for survey designs reporting frequencies/proportions,[33] randomized controlled trials,[34] qualitative studies,[35] and case reports.[36] Details of the items contained in each critical appraisal tool are reported in Supplemental Appendix 3. No studies were excluded on the basis of methodological quality.

Data extraction. Two independent reviewers extracted data including author(s), year, type of study (i.e. quantitative, qualitative, and mixed methods), methodology (e.g. cohort, phenomenology), geographical context and other context-related information, number and characteristics of participants, phenomena of interest, data collection, data analysis, and main findings according to the Joanna Briggs Institute mixed methods data extraction form following a convergent integrated approach.[28] Moreover, details regarding the interventions delivered to support family caregivers were extracted, when available.

Quantitative data comprised of averages or percentages that profiled the sample as well as all relationships between study variables and outcome. Qualitative data comprised of themes or subthemes relevant to the review question with corresponding illustrations (i.e. participants' direct quotations or the exact words of the authors), which were assigned a level of credibility based on the congruency of the finding with supporting data: unequivocal (evidence beyond reasonable doubt); credible (plausible in light of the data and theoretical framework); or unsupported (no relationship between findings and data).[37] Only findings unequivocal and credible were included in the synthesis. Each finding was identified by an alphanumeric code (e.g. A1, A2, B1, . . .). Each letter corresponded to a study and each number to a unique finding. The progressive letters indicate the order of study inclusion in the review, while the progressive numbers indicate the order of findings in the original article (Tables 1–3).

Data transformation. The quantitative data was converted into "qualitized data" because codifying quantitative data is less error-prone than attributing numerical values to qualitative data.[28] Qualitized data comprised textual descriptions or narrative interpretation of the quantitative results (e.g. "Undergoing some type of educational program as a significant factor in predicting less role overload, less stress related to the caregiving situation, more frequent use of reframing, and greater competence dealing with healthcare professionals" is the transformation identified from a three-arm randomized study aimed at testing the efficacy of a psychoeducational program compared to a comparison program or no program in enhancing mental health of women caregivers of a relative with dementia living in a long-term care setting that used prediction analysis).[38]

Data synthesis and integration. The convergent integrated approach to synthesis according to the Joanna Briggs Institute methodology for Mixed-Methods Systematic Review,[28] based on previous work of Sandelowski et al.[39] and Hong et al.[40] was adopted. Qualitized data were assembled with the qualitative data directly extracted from qualitative studies. Assembled data were categorized and pooled together based on similarity in meaning (i.e. a category may integrate two or more types of data: qualitative data, qualitized data or a combination of both). Categories were aggregated to produce a set of integrated findings in the form of a set of recommendations or conclusions.

Appraisal of level of evidence. The level of evidence was assessed at the study level. The level of evidence for quantitative studies was assessed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system,[41] that ranks evidence as very low, low, moderate, and high. According to this approach, all randomized controlled trials start with a ranking of "high" while all other study designs start with "low." This a-priori rank can then be adjusted (i.e. downgraded or upgraded) after considering eight assessment criteria and making a judgement about quality based on these.

The ConQual system was used to establish the confidence for qualitative evidence which included qualitative studies and integrated findings.[42] According to the ConQual approach, all qualitative studies start with a ranking of "high" on a scale of very low, low, moderate, and high. This ranking system then allows the findings of individual studies to be downgraded based on their dependability (i.e. appropriateness of the conduct of the research with research aims and purpose) and credibility (i.e. findings classified as unequivocal, credible, or unsupported).[37] The integrated finding may then be downgraded based on the aggregate level of dependability from across the included findings. Downgrading for credibility may occur when not all the findings included in an integrated finding are considered unequivocal.[42]

Any disagreements during the selection process, quality assessment, data extraction, transformation, synthesis and integration, and appraisal of the level of evidence was resolved by involving a third reviewer.

Results

Review process

Of the 1722 articles identified, after duplicate removal (n = 298) and screening for title and abstract (n = 1398), 26 entered the full text review process. Fifteen articles were further excluded according to the above-mentioned criteria; no articles were included from the reference lists of selected papers. Finally, eight quantitative studies and three qualitative studies were included in the review (Figure 1).

Quality assessment is reported in Table 1 and Supplemental Appendix 3.

Characteristics of included studies

The included studies were conducted in seven countries: two in the United Kingdom,[43,44] two in the United States,[45,46] two in Canada,[38,47] one in Australia,[48] one in the Netherlands,[49] and three were transnational studies.[50–52]

All except two studies[38,47] on the same cohort of patients were conducted after 2010.

Studies involved a median of 12 nursing homes, from 1[45,46] to 44[43]; only two studies reported the nursing home size which ranged from 40 to 99 beds.[43,44] Nursing homes had a main for-profit[43] or not for-profit[38,47,50] profile. No information was provided about physician availability in the facilities.

The qualitative studies employed an ethnographic,[44] qualitative descriptive,[48] or longitudinal case study[46] methodology. The quantitative studies adopted randomized controlled[38,45,47] and cross-sectional[43,49–52] designs.

Qualitative data were collected from face-to-face semi-structured individual interviews with family caregivers (n = 2)[38,44] and healthcare professionals (n = 2),[44,48] healthcare professionals' reflective diary (n = 1),[44] and email letters (n = 1).[46] Quantitative data were collected from postal questionnaires (n = 4),[49–52] family caregivers' structured face-to-face interviews with the questionnaire format (n = 3),[38,47,51] telephone questionnaires (n = 1),[45] and online surveys (n = 1).[43]

Sample sizes ranged from 1[46] to 188,[50] with the qualitative studies having smaller samples. A total of 443 healthcare professionals, 437 family caregivers, and 49 nursing home directors are represented in the review findings.

Studies explored the views of family caregivers,[38,45–47,51] healthcare professionals,[50,52] and nursing home managers,[43] with two studies[48,49] including both family caregivers and healthcare professionals and one study[44] family caregivers, healthcare professionals and nursing home managers (Table 1).

Interventions to support family caregivers in included studies

In all, seven unique interventions across 11 studies were identified. A booklet about comfort care in advanced dementia[49–52] and a psychoeducational program[38,47] were evaluated in multiple studies. Interventions were gathered into three main categories including (a) provision of information (n = 5)[43,49–52]; (b) psychoeducational programs (n = 2)[38,47]; and (c) family meetings associated with written information,[48] psychosocial support,[45] education,[44] or all these three aspects simultaneously[46] (Table 2). Specifically, included studies explored practices adopted to inform family caregivers of people with dementia about end of life[43]; acceptability and usefulness of written information alone[49–52] or in association with family meetings[48] to improve end-of-life discussions about dementia care; benefits of psychoeducational programs for family caregivers' psychological health and competence in dealing with healthcare professionals[38,47]; and benefits of family meetings associated with psychosocial support,[45] educational programs,[44] or written information and education[46] (Table 1).

Data synthesis

Of the 46 findings extracted, 23 were qualitative and 23 quantitative (Tables 1 and 3). All qualitative findings were rated as unequivocal and thus included in the synthesis in addition to the qualitized data. The level of credibility for each qualitative finding with participants' direct quotations is reported in Table 1.

Qualitative and qualitized data were assembled into seven categories, then combined in the following three integrated findings (Table 3, Figure 2):

> Integrated finding 1. End-of-life dialogue should be ongoing and provide adequate time and space for sensitive discussion to establish a family caregivers-healthcare professionals partnership, promote shared decision-making and improve the quality of family caregivers' remaining time with their relative while offering emotional support

Twelve qualitative findings from four studies[38,44,46,48] formed two categories which constituted the first integrated finding. This integrated finding revealed that end-of-life discussions should start as early as possible in the disease trajectory when the first cognitive problems arise and be ongoing: this provides family caregivers emotional support and enough time to process information, thus establishing a partnership between family caregivers and healthcare professionals and promoting shared decisions about end-of-life care.

> *Category 1: Ongoing discussion between healthcare professionals and family caregivers is pivotal to promote informed decisions, establish a partnership, provide emotional support and improve the relationship between family caregivers and their relative at the end of life*

Ongoing dialog helped building trusting relationships between family caregivers and healthcare professionals, provided reassurance, and allowed time for family

Table 1. Characteristics of the included studies.

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest	Data collection	Data analysis	Findings	Methodological quality appraisal	Level of evidence
Arcand et al. (H)	Quantitative	Cross-sectional	(*n* = 2), French Canada English Canada (*n* = 3), France (*n* = 4), Japan (*n* = 3)/all non-for-profit NHs; Catholic affiliation for one NH	188 nurses *Gender* = female 156 (83%) *Age* = 36.8–49.1 (10.8–12.7)	Nurses' perception of acceptability and usefulness of a family booklet about comfort care in advanced dementia aimed to educate and reassure family	Postal questionnaire	Descriptive and inferential analyses	1. The booklet was generally well accepted with some variations among countries; 2. The majority of nurses felt the booklet could be useful for the majority of families to provide education about end-of-life care in advanced dementia; 3. About three quarters or more of the nurses indicated that the best moment to provide the booklet was when there are discussions about a medical problem for which comfort care is an option.	7/9	●●○○ Low
Ducharme et al. (G)	Quantitative	Randomized controlled trial	Canada/27 public NHs (NR)	137 daughters Experimental psychoeducational program entitled "Taking care of myself" (*n* = 45) *Age* = 57 (6.5) Comparison program (*n* = 51) *Age* = 54.5 (7.0) No program (*n* = 41) *Age* = 51.5 (8.4)	Family caregivers' psychological distress, role overload, stress appraisal, coping strategies, and competence dealing with HCPs 3 months after a psychoeducational program	Structured face-to-face interview with the questionnaire format 2 weeks prior to the start of the program, at the end of the program, and 3 months later	Descriptive and inferential analyses	1. At the 3-month follow up, a higher proportion of family caregivers undergoing some type of educational program reported less stress related to their caregiving situation, more frequent use of coping strategies, and greater competence dealing with HCPs compared to those family caregivers who did not receive any educational program; instead, the perception of less role overload was not maintained; 2. Outcomes non-significant at the end of the program failed to reach significance at the 3-month follow up as well.	6/12	●●●○ Moderate
Ducharme et al. (F)	Quantitative	Randomized controlled trial	Canada/27 public NHs (NR)	137 daughters Experimental psychoeducational program entitled "Taking care of myself" (*n* = 45) *Age* = 57 (6.5) Comparison program (*n* = 51) *Age* = 54.5 (7.0) No program (*n* = 41) *Age* = 51.5 (8.4)	Family caregivers' psychological distress, role overload, stress appraisal, coping strategies (i.e. problem solving, reframing, and stress management), and competence dealing with HCPs following a psychoeducational program Family caregivers' perception of the psychoeducational program relevance in producing changes in their daily life	Structured face-to-face interview with the questionnaire format 2 weeks prior to the start of the program and at the end of the program Semi-structured open-ended interview at the end of the program	Descriptive and inferential analyses Undefined qualitative data analysis	1. A higher proportion of family caregivers undergoing some type of educational program reported less role overload, less stress related to their caregiving situation, more frequent use of reframing, and greater competence dealing with HCPs compared to those family caregivers who did not receive any educational program; no improvement in psychological distress, problem solving skills, and stress management; 2. To communicate better with their relative and to render their visits more pleasant—"*I'm more patient during the visits. I can follow what my mother says instead of frustrating her*" (U); 3. To express their point of view to the nursing staff—"*I managed calmly to let my dissatisfaction with my mother's diet be known. We managed to find ways of correcting the situation*" (U); 4. To practice reframing—"*The program allowed me to step back from my situation*" (U); 5. To reflect upon the acceptance of loss—"*I became aware of how I responded to loss and of my resources for dealing with it*" (U); 6. To take care of myself—"*Everything having to do with guilt . . . it helped me a lot to change things in that regard and to try to dedicate more time to me and my husband*" (U); 7. To become aware of their strengths (empowerment)—"*I tell myself that I'm able and I feel less impotent*" (U).	6/12	●●●○ Moderate

(Continued)

Table 1. (Continued)

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest	Data collection	Data analysis	Findings	Methodological quality appraisal	Level of evidence
Moore et al. (E)	Quantitative	Cross-sectional	UK/44 NHs, 86% Gold Standard Framework accredited, 77% privately owned, 66% with between 40 and 99 beds	44 NH managers/deputy managers *Gender* = female 38 (86.4%) *Age* = NR	Practices adopted to inform family caregivers of people with dementia about end of life	Online survey	Descriptive analyses	1. 68.2% (*n* = 30) of survey participants reported that family meetings were offered to support family caregivers; 2. Only three NHs offered family education sessions; 3. Survey participants provided family caregivers verbal discussions and information about (i) dementia as a progressive illness (68.2%), a life-shortening illness (61.4%), a disease you can die from (59.1%), and a terminal illness (56.8%); (ii) spirituality or interpretation of the meaning of death (59.1%); (iii) importance of support for family caregivers from their social network (63.6%); (iv) meaning and implications of loss of mental capacity (72.7%); (v) Advance Care Planning discussions about patient's wishes for the future (77.3%); (vi) legal health care arrangements (52.3%); and legal financial arrangements (38.6%); 4. The provision of information in leaflet form ranged according to the topic: from 20.5% for the importance of support for family caregivers from their social network to 68.2% for Advance Care Planning discussions about patient's wishes for the future.	9/9	●●○○ Low
Reinhardt et al. (C)	Quantitative	Randomized controlled trial with 6-month follow-up	USA/1 large skilled NH (NR)	87 family caregivers Intervention group (*n* = 47) *Gender* = female 37 (78.7%) *Age* = 59.6 (12.3) *Kinship* = child (*n* = 20), spouse (*n* = 3), friend (*n* = 4), other (*n* = 20) Control group (*n* = 40) *Gender* = female 32 (80.0%) *Age* = 58.9 (11.9) *Kinship* = child (*n* = 28), spouse (*n* = 3), friend (*n* = 1), other (*n* = 8)	Family caregivers' depressive symptoms and life satisfaction following a face-to-face, structured conversation about end-of-life care options for their relative in addition to 2-month interval follow-up calls	Questionnaires via telephone at study entry, 3- and 6-months after	Descriptive and inferential analyses	1. Structured conversations with follow-up calls hold by palliative care physicians and social workers did not have any significant effects on family caregivers' depressive symptoms and life satisfaction neither no significant effect by time.	8/11	●●●○ Moderate
Sabat (J)	Qualitative	Longitudinal 3-year case study	USA/1 NH (NR)	1 wife *Age* = NR	Dynamic experience of a spousal caregiver receiving education, counseling and psychosocial support by email and in-person meetings	Email letters	Undefined qualitative data analysis	1. Understanding that she cannot fix everything—"*Accepting the fact that you cannot fix some things is a huge, but necessary, step to take. Not to accept what cannot be changed is just not healthy or helpful in any way to anyone. To work as best you can to make things as good as they can be within the limits that exist is a very, very important thing to do*" (U); 2. Understanding and reducing her emotional reactivity—"*You also told me to stop resenting what was happening in my life. That wasn't easy either. However, though there are . . . times I do still resent what has happened to [my husband], they are less frequent, and on some days I can almost believe there is a reason*" (U);	7/7	●●●● High

(Continued)

Table 1. (Continued)

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest	Data collection	Data analysis	Findings	Methodological quality appraisal	Level of evidence
								3. Reflections—"*With your help, I stopped and thought about what I was going to say and made sure I wanted to respond in that way*" (U); 4. Flourishing—"*It is like I found another person inside of me. I like the person I found*" (U).		
Saini et al. (A)	Qualitative	Ethnografic	UK/2 NHs (99 and 77 beds, respectively)	4 family caregivers (two daughters, a husband, and a son, between the ages of 54 and 76) 19 HCPs [healthcare assistants (*n* = 6), deputy managers (n = 3), managers (n = 2), activity co-ordinators (n = 2), general practitioner (n = 2), nurses (n = 2), palliative care nurse (n = 1), and geriatrician (n = 1)]	Practices relating to end-of-life discussions with family caregivers of NH residents with advanced dementia Strategies for improving practice of end-of-life discussions	Reflective diary reporting fieldwork notes and observation by an interdisciplinary care leader HCP Semi-structured and open-ended interviews with family caregivers (10 to 25 min in length) and HCPs (5 to 35 min in length)	Thematic analysis	1. Discussions with family appear to increase their capacity to make informed decisions – "*I started telling her why this (cardiopulmonary resuscitation) can be inappropriate for someone in the advanced stages of dementia. . .the likelihood of it being successful was very low. She said that when you put it that way it made more sense. . .*" (U); 2. Family sessions generated much discussion and appeared a good avenue for education—"*There was a lot of discussion. . . about dementia. . . diagnosis process. . .acceptance of dementia amongst family and. . .society. . .how this hindered the diagnosis process. . . early part about dementia identification, diagnosis, symptoms. . .family inheritance*" (U); 3. Usefulness of written information to support discussions—"*She [ICL] was the one who spoke to me and gave me a very good leaflet to read, the stages she would go through and that did make. . . it a lot clearer. . . So in that sense that was excellent and . . .she was very caring and she was the one that explained it all to me*" (U); 4. Importance of ongoing dialog with family to build relationships, provide reassurance and allow time for family to process information—"*When I have plenty of time and sometimes talk to family members for well over an hour, we don't usually get to a point where they are ready to complete an Advance Care Planning or change goals of care. . .requires ongoing discussions. . . reflections. . . perhaps some involvement from the GP*" (U); 5. Importance of addressing family member's current issues and concerns before discussing future plans—"*in the first scenario. . . the nurse was trying to talk about end-of-life care and DNRs while the 'family member' was talking about (as per the scenario) her concerns about the care at the care home. . .the nurse did not pick up and try to alleviate the family member's concerns about the quality of care. . . We talked about how if she had talked more about comfort care . . .what was happening to the resident today and that that would have addressed the concerns that the family member was raising*" (U);	10/10	●●●● High

(Continued)

Table 1. (Continued)

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest	Data collection	Data analysis	Findings	Methodological quality appraisal	Level of evidence
								6. Need to acknowledge family members' grief and guilt—"*She cried at one stage. . . She felt that dementia was a horrible disease and hated what it did to her loving gentle husband who was now aggressive and agitated*" (U); 7. Importance of information provided in a sensitive way—"*I find that the nurses tend to feel they don't really know how to start the conversation. It is often a very difficult conversation for them to initiate and then even if they can initiate it is then the depth of that discussion is often lacking*" (U); 8. Not suitable having sensitive conversations with family in communal areas such as lounge or dining room—"*It is very difficult having a conversation in the main lounge with all the other residents. . . family members and staff in the room*" (U); 9. Spending sufficient time with family to address their questions and explore their concerns, including follow-up sessions/ongoing dialog—"*I think takes time; because it's not one that you can do in one sitting. That often you need to build the relationship and then go it step by step. And I think that's where [ICL] role is quite unique in that she can come back and have a second conversation, a third conversation and a fourth if that is required*" (U); 10. Having an independent healthcare professional or team with responsibility for end-of-life discussions—"*We feel it's helpful because she has got a different way of looking at the situation. The areas where we don't normally see. . . it will help and improve in the care of these service users*" (U).		
van der Steen et al. (I)	Quantitative	Cross-sectional	Italy/4 NHs (NR) Netherlands/29 NHs (NR) Canada/5 NHs	138 bereaved family caregivers *Gender* = female 98 (71%) *Age* = 58.7–61.1 (7.7–12)	Family caregivers' perception of acceptability and usefulness of a booklet about comfort care in advanced dementia aimed at their education and reassurement	Face-to-face interview with the questionnaire format Postal questionnaire	Descriptive analyses (SPSS version 15.0.1)	1. The booklet was found highly acceptable by Canadian and Dutch family caregivers and acceptable by Italian family caregivers; 2. Almost all family caregivers (94%) perceived the booklet as useful; 3. Those family caregivers not finding the booklet useful stated that they preferred talking over reading; 4. There was large variation in preference of when to obtain the booklet, but the dying phase was the least preferred time; 5. Almost all family caregivers (96%–100%) accepted any HCPs to have a role in providing the booklet and about half (42%–58%) endorsed availability not through practitioners.	9/9	●●●● High

(Continued)

Table 1. (Continued)

Author(s) (code)	Type of study	Methodology	Geographical context/ characteristics of NH	Participants (number and characteristics)	Phenomena of interest	Data collection	Data analysis	Findings	Methodological quality appraisal	Level of evidence
van der Steen et al. (K)	Quantitative	Cross-sectional	Netherlands/NHs (NR)	30 physicians *Gender* = female 19 (63%) *Age* = 48 (9) 38 nurses *Gender* = female 36 (95%) *Age* = 39 (9) 59 bereaved family caregivers *Gender* = female 66% *Age* = 60 (10) *Kinship* = child (*n* = 41), spouse (*n* = 8), other (*n* = 10)	Physicians', nurses' and family caregivers' perception of the need, acceptability and usefulness of a family booklet about comfort care in advanced dementia aimed to educate and reassure family caregivers	Postal questionnaire	Descriptive (SPSS 15.0)	1. All respondents reported a need of written information about comfort care and end-of-life issues for family caregivers; 2. High acceptability of the booklet for nurses and family caregivers, moderate to high acceptability for physicians; 3. The booklet was found useful by all respondents; 4. Variability in the preferred timing of receiving the booklet among all respondents with discrepancy between family caregivers and physicians; 5. All respondents agreed that HCPs such as the attending physician or nurse should have a role in providing the booklet, and half favored availability also not through practitioners.	7/9	●●○○ Low
van der Steen et al. (D)	Quantitative	Cross-sectional	Italy/14 NHs (NR) Netherlands/21 NHs (NR)	87 physicians *Gender* = female 54 (62.1%) *Age* = 46.3–48.3 (6.8–10) 81 nurses *Gender* = female 75 (92.6%) *Age* = 38.6–42 (9.0–11.3)	Physicians' and nurses' perception of acceptability and usefulness of a family booklet about comfort care in advanced dementia aimed to educate and reassure family caregivers	Postal questionnaire	Descriptive analyses (SPSS version 15.0.1)	1. Both Italian and Dutch HCPs found the booklet acceptable with high acceptability by Dutch nurses; 2. HCPs' perception that a family booklet about comfort care in advanced dementia would be useful for most families to make them understand the risks and benefits of care options and reassure those who opt for comfort care that this is an acceptable option and probably the most appropriate one in advanced dementia.	9/9	●●●● High
Stirling et al. (B)	Qualitative	Descriptive	Australia/4 NHs (NR)	5 dementia care nurses 11 family caregivers	Need for and usefulness of a booklet aimed to aid talking about dementia and dying during family meeting	Open-ended interviews with family caregivers (about one hour in length) and dementia nurses	Thematic analysis	1. Moving to engaged dialog—"*I found it [dementia dialog] beneficial because it enabled me to ask a few questions and speak on a more one to one basis than perhaps we would otherwise. . .than we do in the [traditional] care plan meetings*" (U); 2. Providing a format for discussion of future care needs—"*. . .we did talk about palliative care and I said, 'yes, here. There's no need to go the [hospital]*" (U).	8/10	●●●○ Moderate

HCP: healthcare professional; NH: nursing home; SD: standard deviation.
The progressive letters next to author(s)' name indicate the order of study inclusion in the review, while the progressive numbers within the column of findings indicate the order of findings in the original article.
Age is reported as mean (SD).
Studies code: A,[44] B,[50] C,[45] D,[48] E,[43] F,[38] G,[49] H,[51] I,[52] J,[46] K[47].

Table 2. Description of interventions provided to family caregivers of people with advanced dementia at the end of life in nursing home and their contribution to integrated findings.

Author(s) (code)	Intervention	Contribution to integrated finding(s)
Provision of information (*n* = 5)		
Arcand et al. (H)	Nurses working in long-term care settings were asked to rate the acceptability and usefulness of a **booklet** which informed on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief.	2
Moore et al. (E)	Online survey among a random sample of nursing homes with Gold Standards Framework in Care Homes accreditation. The survey explored the current practice regarding **information provided by the service** (e.g. dementia progression, the terminal nature of dementia, spirituality, mental capacity, end-of-life preferences, and legal arrangements) **and the format of this information** (in direct discussion with the person with dementia or carer, in a group setting or in written format).	2 and 3
van der Steen et al. (I)	Family caregivers were asked to rate the acceptability and usefulness of a **booklet** which informed on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief.	2
van der Steen et al. (K)	Family caregivers, physicians, and nurses were asked to rate the need, acceptability and usefulness of a **booklet** which informed on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief.	2
van der Steen et al. (D)	Physicians and nurses were asked to rate the acceptability and usefulness of a **booklet** which informed on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief.	2
Psychoeducational programs (*n* = 2)		
Ducharme et al. (G)[a]	Family caregivers participated in a **psychoeducational group program** called "Taking Care of Myself." This program consists of 10 90-min weekly sessions for groups of six to eight caregivers. It covers the following six themes: (1) how to feel at ease with my relative; (2) how to express my point of view to health care staff; (3) how to avoid emotional torment; (4) how to deal with small daily losses and prepare myself for the ultimate loss of my relative; (5) how to identify and call upon my support network and community services; and (6) how to reorganize my life after my relative moves to a nursing home and take care of myself. A participatory approach is used (e.g. discussions, written exercises between sessions, role playing), centered on the actual concerns of caregivers in order to foster transfer of the strategies learned.	1 and 3
Ducharme et al. (F)[a]	Family caregivers underwent a **psychoeducational group program** called "Taking Care of Myself." For details see Ducharme Levesque et al. (G).	3
Family meetings associated with written information (*n* = 1)		
Stirling et al. (B)	Family caregivers of people living with dementia were invited to a **family meeting** held by the resource nurse of the facility. A **booklet** was employed as a meeting guide to facilitate discussion about a resident's dementia and disease trajectory. The booklet included information about the need for a palliative approach in dementia, guidance for communicating with families about death and a palliative approach, and advice to support the "real world" situations faced by nursing home staff.	1 and 2

(Continued)

Table 2. (Continued)

Author(s) (code)	Intervention	Contribution to integrated finding(s)
Family meetings associated with psychosocial support (n = 1)		
Reinhardt et al. (C)	The intervention was delivered by a palliative care team which included two certified palliative medicine physicians and a palliative care social worker. A **structured, face-to-face meeting** with an "ask-tell-ask" model was employed. Family members were asked what they understood about dementia, where they think their relative is in the disease process, and what they expect as the disease progresses. Further, the physician shared the assessment of the resident's condition, and the palliative care team discussed the family's goals of care for the resident, made recommendations of how to achieve those goals, and provided **psychosocial support**, such as empathic and active listening and rephrasing. These meetings took an average of 47 min (range 20–75 min) and included the following topics: (a) resuscitation, (b) hospitalization, (c) artificial nutrition and hydration, and (d) pain and symptom management. As part of the intervention, the palliative care social worker delivered a **telephone follow-up** every 2 months for 6 months to address family caregivers' potential concerns about their relative. Each of these three telephone calls lasted an average of 10 min.	3
Family meetings associated with educational programs (*n* = 1)		
Saini et al. (A)	An interdisciplinary care leader with social science background and experienced in working with people with severe dementia delivered the intervention, which has two core components: (i) facilitation of integrated care for people with advanced dementia and (ii) training and support for those working with and caring for people with advanced dementia. To facilitate integrated care, the leader attended weekly meetings with nursing home nurses and when possible the general practitioner. In these meetings residents' care needs were discussed, the need for external referral reviewed and end-of-life plans agreed. Wider multidisciplinary team meetings were conducted on a monthly basis. **Discussions with family** covered concerns raised by the family, common symptoms in advanced dementia, end-of-life care and whether the family member was coping or needed more support. The leader ran **formal training sessions** for staff and family and informal on-the-job advice and support. Staff training sessions covered behavioral symptoms, pain management and end of life, and family sessions covered the trajectory of dementia, common end-of-life symptoms and the personal experiences of care.	1, 2, and 3
Family meetings associated with written information, psychological support, and education (*n* = 1)		
Sabat (J)	Email communication over a 3-year period with a total of 1276 letters, averaging approximately 38 per month, between the wife of a man with dementia and a psychologist. Letters informed the spousal caregiver about a variety of issues, including aspects of her husband's memory and selfhood, how she could interact with him to their mutual advantage, her husband's subjective experience of, and his reactions to, the losses he was experiencing, and how his responses affected her. **Frequent email communication constituted the main source of education, counseling and psychosocial support.** This information was associated with **in-person meetings** which occurred every 3 to 4 months to help the spousal caregiver to understand her husband's condition more clearly, interact with him more effectively, and gain a measure of control over what was happening in their lives.	

The progressive letters next to author(s)' name indicate the order of study inclusion in the review.
Studies code: A,[44] B,[50] C,[45] D,[48] E,[43] F,[38] G,[49] H,[51] I,[52] J,[46] K[47].
[a]Data collected on the same cohort of patients.

Table 3. Integrated findings, categories and qualitized and qualitative findings extracted from the included studies.

Qualitized (QZ) and qualitative (QT) findings (alphanumeric code)	Categories	Integrated findings	Level of evidence
QT. Discussions with family appear to increase their capacity to make informed decisions (A1) QT. Importance of ongoing dialog with family to build relationships, provide reassurance and allow time for family to process information (A4) QT. Moving to engaged dialog (B1) QT. To communicate better with their relative and to render their visits more pleasant (F2) QT. Understanding and reducing her emotional reactivity (J2) QT. Spending sufficient time with family to address their questions and explore their concerns, including follow-up sessions/ongoing dialog (A9) QT. To express their point of view to the nursing staff (F3)	1. Ongoing discussion between healthcare professionals and family caregivers is pivotal to promote informed decisions, establish a partnership, provide emotional support and improve the relationship between family caregivers and their relative at the end-of-life	1. End-of-life dialog should be ongoing and provide adequate time and space for sensitive discussion to establish a family caregivers-healthcare professionals partnership, promote shared decision-making and improve the quality of family caregivers' remaining time with their relative while offering emotional support	●●●○ Moderate
QT. Importance of information provided in a sensitive way (A7) QT. Not suitable having sensitive conversations with family in communal areas such as lounge or dining room (A8) QT. Need to acknowledge family members' grief and guilt (A6) QT. Importance of addressing family member's current issues and concerns before discussing future plans (A5) QT. Having an independent healthcare professional or team with responsibility for EOL discussions (A10)	2. Consideration of the manner and location when discussing with family caregivers about their relative's end-of-life care preferences is important		
QT. Usefulness of written information to support discussions (A3) QT. Providing a format for discussion of future care needs (B2) QZ. HCPs find a booklet about comfort care in advanced dementia acceptable (D1) QZ. HCPs perceive that a family booklet about comfort care in advanced dementia would be useful for most families (D2) QZ. Difference in the provision of information in leaflet form according to the topic (E4) QZ. A booklet about comfort care in advanced dementia is well accepted among countries (H1) QZ. The majority of nurses feel a booklet about comfort care in advanced dementia could be useful for the majority of families to provide education about EOL care in advanced dementia (H2) QZ. Family caregivers find a booklet about comfort care in advanced dementia acceptable to highly acceptable (I1) QZ. Almost all family caregivers perceive the booklet about comfort care in advanced dementia as useful (I2) QZ. Most NHs provide family caregivers verbal discussions and informations (E3) QZ. All physicians, nurses and family caregivers report family caregivers' need of written information about comfort care and EOL issues (K1)	3. End-of-life discussions should be face-to-face, structured around a set of pre-defined topics and supported by written information to educate and reassure family caregivers about care options at the end of life	2. End-of-life discussions should be face-to-face and guided by supporting written information whose provision may vary in timing and way according to family caregivers' preferences and the context	●●●○ Moderate

(Continued)

Table 3. (Continued)

Qualitized (QZ) and qualitative (QT) findings (alphanumeric code)	Categories	Integrated findings	Level of evidence
QZ. High acceptability of the booklet for nurses and family caregivers, moderate to high acceptability for physicians (K2) QZ. Physicians, nurses and family caregivers find the booklet about comfort care in advanced dementia as useful (K3) QZ. Family caregivers not finding useful a booklet about comfort care in advanced dementia prefer talking over reading (I3) QZ. Most nurses indicate that the best moment to provide the booklet is when there are discussions about a medical problem for which comfort care is an option (H3) QZ. There is large variation among family caregivers in preference of when to obtain a booklet about comfort care in advanced dementia, but the dying phase is the least preferred time (I4) QZ. Variability in the preferred timing of receiving the booklet about comfort care in advanced dementia among physicians, nurses and family caregivers with discrepancy between family caregivers and physicians (K4) QZ. Almost all family caregivers accept any HCPs in providing the booklet and about half endorse availability not through practitioners (I5) QZ. Physicians, nurses and family caregivers agree that HCPs such as the attending physician or nurse should have a role in providing the booklet, and half favor availability also not through practitioners (K5)	4. Consideration of when to provide written information about care options at the end of life and how to make them available to family caregivers is essential		
QZ. Structured conversations with follow-up calls hold by palliative care physicians and social workers did not have any significant effects on family caregivers' depressive symptoms and life satisfaction neither no significant effect by time (C1) QZ. Family caregivers undergoing some type of educational program report less role overload, less stress related to their caregiving situation, more frequent use of reframing, and greater competence dealing with HCPs; no improvement in psychological distress, problem solving skills, and stress management (F1) QZ. Some months after some type of educational program, family caregivers continue to report less stress related to their caregiving situation, more frequent use of coping strategies, and greater competence dealing with HCPs, while the perception of less role overload is not maintained (G1) QZ. Outcomes non-significant at the end of the educational program do not improve in the following months (G2) QT. Flourishing (J4) QZ. Most NHs offer family meetings to support family caregivers (E1) QZ. A few NHs offer family education sessions (E2)	5. Psychoeducational programs and/or regular family meetings are needed to effectively relieve family caregivers' strain while just one meeting or simply providing information is not enough; involvement of professionals experienced in psychological care may be required to help family caregivers manage their psychological distress and develop problem solving skills	3. Family caregivers should be offered tailored psychoeducational programs and/or regular family meetings about dementia care at the end of life according to their specific information and emotional needs to promote understanding about their relative's health conditions, acceptance of the upcoming loss, and empowerment in facing challenging end-of-life-related issues	●●●○ Moderate

(Continued)

Table 3. (Continued)

Qualitized (QZ) and qualitative (QT) findings (alphanumeric code)	Categories	Integrated findings	Level of evidence
QT. Family sessions generated much discussion and appeared a good avenue for education (A2) QT. Having an independent healthcare professional or team with responsibility for EOL discussions (A10)	6. Interaction with peers and healthcare professionals independent from the staff of the nursing home is useful to bring out family caregivers' needs of education and can be a source of emotional support		
QT. To practise reframing (F4) QT. Reflections (J3) QT. Understanding that she cannot fix everything (J1) QT. To take care of myself (F6) QT. To become aware of their strengths (empowerment) (F7) QT. To reflect upon the acceptance of loss (F5)	7. Family caregivers should be helped to take care of themselves by promoting reflection, reframing, acceptance, and finally empowerment		

HCP: healthcare professional; NH: nursing home.
The progressive letters indicate the order of study inclusion in the review, while the progressive numbers indicate the order of findings in the original article.
Studies code: A,[44] B,[50] C,[45] D,[48] E,[43] F,[38] G,[49] H,[51] I,[52] J,[46] K[47].

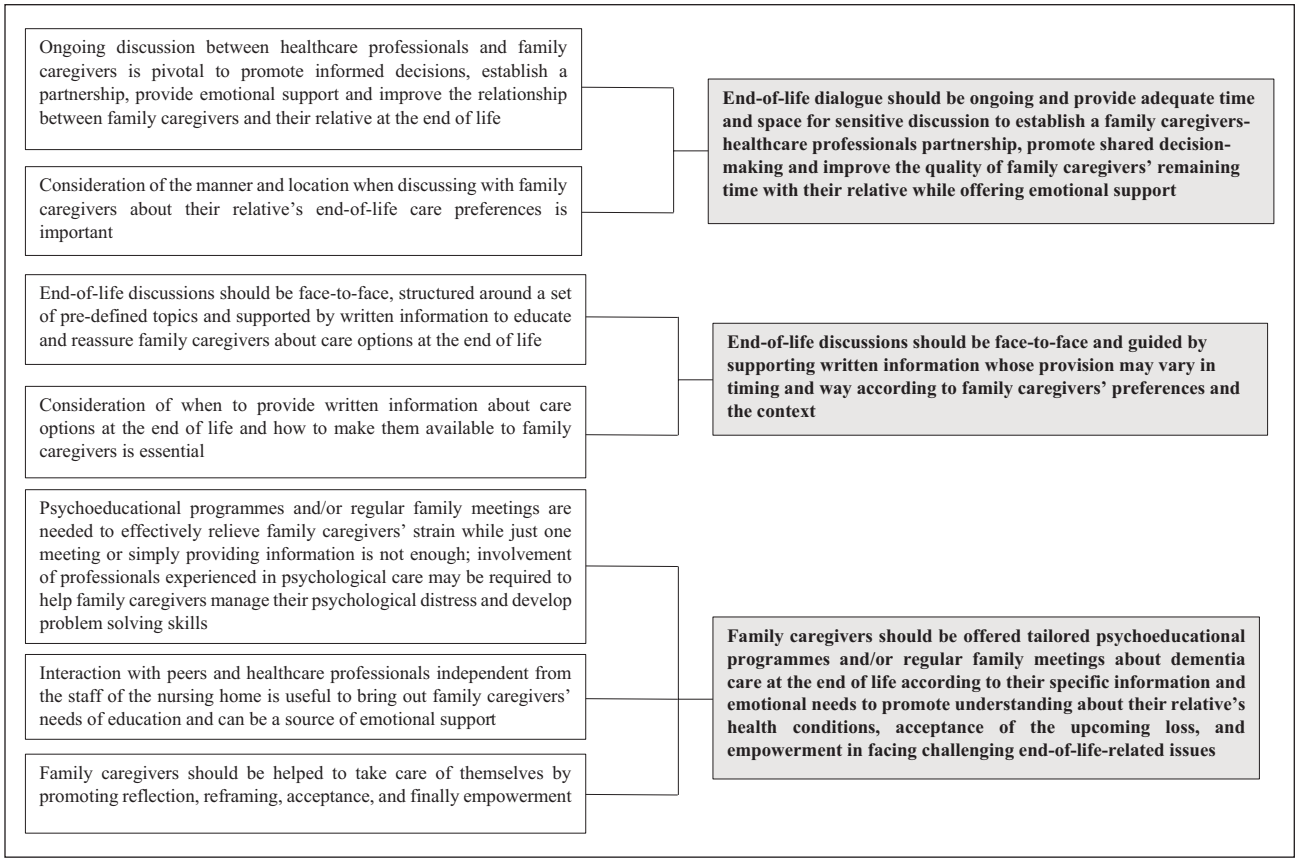

Figure 2. Categories and integrated findings.

caregivers to process information about their relative's health conditions.[44,46] Ongoing discussions appeared to increase family caregivers' awareness about their relative's worsening conditions and prognosis and increased their capacity to make informed decisions,[44,46] in addition to helping them feel less emotionally unsettled.[46,48]

Family caregivers usually desired to be engaged in discussions rather than "being told,"[48] and when this happened they felt able to successfully express their dissatisfaction with their relative's care to the healthcare professionals and to collaborate together to find solutions.[38] Moreover, family caregivers described the benefits of the dialog process for the relationship with their relative, reporting better communication and more pleasant visits.[38]

Category 2: Consideration of the manner and location when discussing with family caregivers about their relative's end-of-life care preferences is important

The physical environment where end-of-life discussions took place as well as how healthcare professionals sustained such discussions were key aspects. Communal areas such as a dining room or lounge were deemed unsuitable for sensitive discussions with family caregivers, and privacy and intimacy emerged as essential aspects to be considered.[44] Moreover, great emphasis was put on the importance of providing information in a sensitive way, while addressing family caregivers' grief and guilt and their current issues and concerns before discussing future plans of care.[44]

Integrated finding 2. End-of-life discussions should be face-to-face and guided by supporting written information whose provision may vary in timing and way according to family caregivers' preferences and the context

Nineteen findings (17 qualitized and 2 qualitative) from eight studies[38,43,44,48–52] formed two categories which constituted the second integrated finding. This integrated finding showed that end-of-life discussions about dementia care with family caregivers should be face-to-face and supported by written information; the timing and way to provide written information may be influenced by family caregivers' preferences and the organizational policies and cultural context.

Category 3: End-of-life discussions should be face-to-face, structured around a set of pre-defined topics and supported by written information to educate and reassure family caregivers about care options at the end of life

Most nursing homes provided family caregivers face-to-face information and rates of discussing depended on the topic: 77.3% of discussions explored advance care planning about resident's wishes for the future care while only 38.6% focused on legal financial arrangements.[43] Moreover, both healthcare professionals and family caregivers reported the need[48,49] and value[44] of providing written information about care options at the end of life for people with dementia to support discussion. All findings relating to written information to support face-to-face discussion highlighted the acceptability and usefulness of a booklet to provide information and reassure family caregivers about care options in advanced dementia at the end of life, according to both the healthcare professionals'[49,50,52] and family caregivers' perspective.[49,51] Family caregivers reported that they gained confidence as decision makers and felt better able to engage in discussion when a discussion tool structured around a set of pre-defined topics was available.[48] Witten information emerged as useful regardless of the organizational and cultural context.[50]

Category 4: Consideration of when to provide written information about care options at the end of life and how to make them available to family caregivers is essential

Variability in the preferred timing of information provision about care options in advanced dementia emerged among healthcare professionals and family caregivers.[49] However, preference of timing was highly variable also across individuals and countries.[50,51] Most nurses indicated that the best moment to provide written information was when there are discussions about a medical problem for which comfort care is an option, however, the proportion of nurses who thought an informational booklet could be provided at the time of dementia diagnosis or before moving to a nursing home was higher in Japan and English Canada than in French Canada.[50] The dying phase was the least preferred time among family caregivers, however, the proportion of Italian family caregivers who would have wanted to receive an informational booklet at the time of dementia diagnosis or shortly afterwards was higher than among Canadian and Dutch family caregivers.[51]

Both family caregivers and healthcare professionals agreed that the attending physician or nurse should have a role in providing written information.[49,51]

Integrated finding 3. Family caregivers should be offered tailored psychoeducational programs and/or regular family meetings about dementia care at the end of life according to their specific information and emotional needs to promote understanding about their relative's health conditions, acceptance of the upcoming loss, and empowerment in facing challenging end-of-life-related issues

Fifteen findings (six qualitized and nine qualitative) from six studies[38,43–47] formed three categories which constituted the third integrated finding. This integrated finding highlighted that psychoeducational programs should be tailored to family caregivers' needs to empower them when confronted with end-of-life issues and promote their understanding about their relative's prognosis and proximity to dying.

Category 5: Psychoeducational programs and/or regular family meetings are needed to effectively relieve family caregivers' strain while just one meeting or simply providing information is not enough; involvement of professionals experienced in psychological care may be required to help family caregivers manage their psychological distress and develop problem solving skills

Most nursing homes offered family meetings to support family caregivers, while only a few offered family education sessions.[43] When family caregivers were involved in regular in-person meetings with a psychologist and provided with personalized information and advice in step with the evolution of the disease, they perceived education, counseling and psychosocial support, thus flourishing and feeling happy with themselves most of the time, while deepening their relationship with and becoming an advocate for their relative.[46] Also, psychoeducational programs structured in up to 10 weekly sessions for small groups (i.e. 6–8) of family caregivers which employed a participatory approach (e.g. discussions, written exercises between sessions, role playing) and were centered on their actual concerns emerged as beneficial; family caregivers reported less role overload, less caregiving-related stress, more frequent use of reframing, and greater competence in dealing with healthcare professionals,[38] and most benefits appeared to be retained in the months following the educational intervention.[47] However, no effects on psychological distress, problem solving skills and stress management were identified.[38] Moreover, just one in-person meeting delivered by palliative care physicians or social workers did not have any significant effects on family caregivers' depressive symptoms and life satisfaction, despite providing structured information about the pros and cons of treatment decisions and follow-up psychosocial support via telephone.[45] Furthermore, regardless the type of intervention, when improvement was not reached at the end of the intervention, no significant benefit emerged over time.[45,47]

Category 6: Interaction with peers and healthcare professionals independent from the staff of the nursing home is useful to bring out family caregivers' needs of education and can be a source of emotional support

Two qualitative findings from one study[44] contributed to this category. Eliciting family caregivers' needs for dementia education may be challenging. Strategies such as interacting with other family caregivers in structured family sessions and with healthcare professionals or

teams independent from the nursing home eased talking and generating questions about dementia and its progression, as well as provided an alternative view of the residents' needs and how to improve their care.[44]

Category 7: Family caregivers should be helped to take care of themselves by promoting reflection, reframing, acceptance, and finally empowerment

Family caregivers reported that educational programs helped them to take care of themselves, they learned to dedicate more time to themselves without feeling guilt.[38] According to family caregivers' perspective, educational programs worked at two levels by (1) promoting the development of coping strategies such as reflection, reframing, and acceptance of unchangeable negative events such as their relative's loss to counteract stressors[38,46] and (2) by making them aware of their strengths.[38] Educational programs allowed family caregivers to stop, step back from their current situation, take time to think and change their way of looking at things.[38,46] The more family caregivers understood including the fact that they could not fix some things[46] and not to accept what could not be changed was just not healthy or helpful in any way to anyone,[38] the less anxious and the more empathetic they felt. Moreover, educational programs seemed to help family caregivers to exercise control through an increased belief in their potential.[38]

Level of evidence

Among quantitative evidence ($n = 8$), three studies received a ranking of low,[43,49,50] three studies of moderate,[38,45,47] and two studies of high[51,52] (Table 1). Main reasons to downgrade and upgrade the a-priori ranking of quality were the risk of bias and large magnitude of effect, respectively (Supplemental Appendix 4a).

Two qualitative studies[44,46] were ranked as providing high evidence and one study[48] received moderate evidence due to the downgrading of the dependability criterion by one level (Table 1, Supplemental Appendix 4b).

The quality of evidence for the three synthesized findings received moderate ranking due to the downgrading of the dependability criterion by one level (Table 3, Supplemental Appendix 4c).

Discussion

The purpose of this Mixed-Methods Systematic Review was to gather and synthesize knowledge about interventions employed to support family caregivers of people with advanced dementia at the end of life in nursing homes in the form of recommendations for daily practice. We found that the evidence which sustains recommendations was of moderate quality and comprehensively advises (i) ongoing dialog between healthcare professionals and family caregivers and adequate time and space for sensitive discussions, (ii) face-to-face discussions supported by written information whose timing of supply may vary according to family caregivers' preferences and the organizational policies and cultural context; and (iii) structured psychoeducational programs and/or regular family meetings about dementia care at the end of life tailored to family caregivers' specific needs. Overall, the small number of included empirical studies suggests large room of improvement for evidence-based interventions to support family caregivers of people with advanced dementia at the end of life living in a nursing home. Moreover, studies were mostly concentrated in the last decade, suggesting increasing attention to the need to educate and reassure family caregivers about care options for their relative with advanced dementia at the end of life, despite facilities differing in organizational policies and cultural context.

Recommendation 1

A regular open dialog is essential to facilitate partnerships between family caregivers and healthcare professionals and promote both the provision of preference-based care and family empowerment.[38,44,46,48] Moreover, quality communication provides emotional support to family caregivers, builds trusting relationships and informs good decision-making processes.[53,54] When family caregivers trust healthcare professionals, they are usually satisfied with their decision-making experience and the care provided aligns with family caregivers' and residents' wishes.[55] Instead, when a sense of belonging and attachment lacks, family caregivers experience detachment and isolation.[56] Good relationships with the nursing home staff is a source of emotional support for family caregivers[57] and essential to provide good quality end-of-life care.[54]

Establishing a dedicated space for sensitive end-of-life communication can provide family caregivers both privacy and proximity at end of life.[58] Environmental design which improves social interaction and a home-like atmosphere has been found to positively impact end-of-life care.[58,59] However, even when attention is paid to the environment, end-of-life communication remains emotionally challenging for both healthcare professionals and family caregivers.[57,60] Family caregivers usually expect that healthcare professionals start communication about end-of-life care,[60] while healthcare professionals may struggle to initiate and sustain such sensitive discussions.[61] Therefore, it is important that healthcare professionals support each other[62] to engage family caregivers in decision making which may reduce the uncertainty of choices taken at times of crisis and promote palliative-oriented care.[63] How/when to engage family

caregivers is highly variable and requires a personalized approach, as discussed below in Recommendation 2.

Recommendation 2

The Covid-19 pandemic has further challenged end-of-life communication due to visiting restrictions which prevented family caregivers' in-person presence.[64,65] However, also during pandemic times, family caregivers need to be involved in the decision making process, in a timely manner, to provide care consistent with their relative' wishes[66] and avoid their caregiving role to be disrupted with negative impact on their psychosocial and emotional well-being.[67] This has forced a change in the way of communication between family caregivers and healthcare professionals by necessitating the use of remote Information and Communication Technologies.[68,69] Worthy examples of remote communication in the nursing home setting showed that bereaved family caregivers who reported effective remote communication with healthcare professionals had a better overall experience of end-of-life care.[68] This suggests that despite in-person discussions remain the first choice for end-of-life communication, Information and Communication Technologies-based discussions may be a valuable alternative when family caregivers' presence in nursing homes is not possible (e.g. visitation restrictions, long distance family caregivers).

Complementing end-of-life communication with written information may facilitate shared decision-making and help family caregivers to make an informed choice about their relative's end-of-life care.[43,44,48–52] Written information promotes family caregivers' understanding of disease progression, prognosis and care options, while providing family caregivers the opportunity to go through information several times and process information at their own pace.[70,71] In addition, written information may help healthcare professionals to introduce the issue of end-of-life care and guide family caregivers to reflect on their relative's values and preferences for future care.[72] This suggests that end-of-life communication may be supported through a hybrid model of face-to-face communication, either in-person or using Information and Communication Technologies, complemented by written materials. A transnational ongoing study, known as mySupport, that involves a consortium of six countries is exploring the benefits of structured in-person or Information and Communication Technologies-based family care conferences associated with written information, as perceived by family caregivers of residents with advanced dementia and healthcare professionals.[73] This study will inform about the feasibility to implement such a structured hybrid educational intervention and its impact on family caregivers and nursing home staff.

Consistent with previous authors,[60,70] our findings suggest a great variability in the preferred timing of information despite the dying phase was the least preferred and most family caregivers desired discussions when medical problems arise or at the time of admission to a nursing home.[49–51] Similarly, the responsibility for end-of-life discussions appears to vary across care settings, professional scope of practice and countries, and has been described as a "hot potato,"[74] whereby everyone and no one is taking ownership. Our review confirms Dixon and Knapp's[75] suggestion that the optimum approach both from an economic and quality effectiveness standpoint is a multi-disciplinary one. When a team-based approach is employed, family caregivers report higher quality communication and feel more involved in care planning that allows for a better-perceived death for their relative.[76] Therefore, it is the role of all healthcare professionals to create an environment of openness so that patients and their family caregivers feel comfortable to voice their concerns regarding end-of-life issues and can be involved in planning end-of-life care.

Recommendation 3

Consistently with previous literature,[77] our findings advocate that healthcare professionals should support family caregivers-centered care at the end of life through the provision of targeted information and socio-emotional care. Family caregivers of people with advanced dementia have unique disease-specific information and support needs[78] and experience significant stress during the transition from curative-oriented to palliative-oriented care.[79,80] Therefore, educational interventions should be preceded by in-depth assessment of family caregivers' positionality[81] and incorporate strategies to promote their wellbeing during this transitioning period and beyond, in addition to providing tailored education.

Our review suggests that psychoeducational programs, which involve weekly small groups of family caregivers for up to 10 weeks, reduce their role overload and caregiving-related stress, and improve use of reframing and competence in dealing with healthcare professionals despite not significantly affecting psychological distress.[38,47] Moreover, we found that just one family meeting with palliative care physicians or social workers does not improve family caregivers' depressive symptoms and life satisfaction.[45] Instead, when family caregivers are involved in regular meetings with a psychologist and receive personalized information and advice as the disease evolves, they are more aware about their relative's disease trajectory, perceive better relationships with healthcare professionals and are more engaged in a shared decision-making process at the end of life.[46] Also, regular meetings with healthcare professionals having a social science background and experienced in working with people with dementia increased family caregivers' perceived capacity to make informed decisions and provided reassurance.[44] Thus, our findings highlight that psychoeducational programs and regular meetings with healthcare professionals

experienced in dementia care tailored to family caregivers' specific and changing emotional and information needs can promote self-care and empowerment. This is noteworthy since empowered family caregivers are more prone to understanding the nature of dementia and being engaged in shared decisions, and feel more prepared to advocate for their relative's dignity.[82–85]

This review also suggests that family sessions may be an important means for education and emotional support.[43,44] A study involving family caregivers of community dwelling people with dementia showed that the majority of their unmet needs related to their mental health and caregiver support groups.[86] Similarly, findings from an European cross-country evaluation of a meeting centers support program highlighted that peer support can help to increase the capacity to deal with the challenges caused by dementia and can promote emotional balance.[87] Those family caregivers who were most satisfied with the discussion groups offered in such program, had experienced strong emotional support.[87] It may be postulated that family caregivers find comfort and support with each other in sharing and discussing matters related to the emotional impact of dementia. Structured family sessions facilitated by professionals experienced in psychological care may thus be a promising avenue to be considered when planning interventions to support family caregivers of nursing home residents with advanced dementia. In the community setting, professionally facilitated peer support has already shown positive effects on mental health outcomes of family caregivers of people with dementia.[88]

Strengths and weaknesses

This study provides a set of recommendations about interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes by synthetizing the relevant qualitative and quantitative literature of interventions delivered at the caregiver level. A strength of this study is the convergent integrated approach[28] which minimizes methodological differences between qualitative and quantitative studies and allows to present results together because both are viewed as addressing the same research question. Our recommendations are limited by not considering organizational and policy level interventions and may suffer from bounded transferability to Eastern cultures since they are mainly based on studies conducted in Western countries. Moreover, the limited available literature prevented from making recommendations more actionable. Further methodologically sound studies are needed to clearly point out which, how, when and by whom interventions to support family caregivers of people with advanced dementia at the end of life in nursing home should be delivered to maximize their effectiveness.

Conclusions

Despite interventions that may benefit family caregivers of people with advanced dementia at the end of life in nursing home and where, how, when and by whom they should be provided is a topic which has been gaining increasing interest in the recent years, available evidence is still limited.

Our findings are supported by evidence of moderate quality and advise healthcare professionals to establish ongoing and sensitive discussion with family caregivers to promote partnership, informed and shared decisions around their relative's end-of-life care and provide emotional support. Discussions should be face-to-face, structured around a set of pre-defined topics and supported by written information to reinforce messages. Discussions should take place in a private environment avoiding communal areas and preference of timing may be variable across individuals and contexts.

This review also suggests that family caregivers may benefit from structured psychoeducational programs and/or regular family meetings tailored to their specific information and emotional needs to promote understanding about their relative's prognosis, acceptance of the approaching death, and enhance belief in their inner strengths and potential. Interacting with peers and healthcare professionals independent from the nursing home or experienced in psychological care may help family caregivers to identify their dementia education needs, manage distress and develop problem solving skills.

Future research should explore the potential benefit of structured hybrid psychoeducational interventions which complement face-to-face discussion with written materials as well as professionally facilitated peer support to promote the psychosocial and emotional well-being of family caregivers of people with advanced dementia at the end of life.

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Author contributions

GM, IB, and SG contributed to the conception and design of the work; IB, GM, LB, MV, and SG extracted and analyzed the data. All authors contributed to interpret data and draft the manuscript. All authors critically revised the manuscript, agree to be fully accountable for ensuring the integrity and accuracy of the work, and read and approved the final manuscript.

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Supplemental material

Supplemental material for this article is available online.

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