Palliative Care in Early Dementia: A Scoping Review

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Title: Palliative Care in Early Dementia: A Scoping Review

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- Advance care planning

ABSTRACT

Background: Palliative care is recommended for all people with dementia from diagnosis through end-of-life. However, palliative care needs and effective elements of palliative care are not well-defined for the earlier stages of dementia.

Objective: To systematically map current research on palliative care early in the disease trajectory of dementia.

Design: Scoping review of scientific literature.

Data sources: PubMed, CINAHL, EMBASE, Cochrane, PsycINFO, Web of Science

Review Methods: We included studies published in English over the last decade (through March 2022) that focused on palliative care in early stages of dementia and targeted outcomes in palliative care domains. Two authors independently screened abstracts and full texts and scored the quality of included studies using tools by the Joanna Briggs Institute.

Results: Among the 77 papers reviewed, few addressed early stages of dementia specifically. We found that: 1) While “early” palliative care was not well-defined in the literature, evidence indicated that palliative care needs were present at or before diagnosis and across the trajectory. Notable opportunities for palliative care arise at ‘tipping points’ (i.e., when symptoms, functional status, or caregiving needs change). 2) Palliative care needs in early dementia include advocacy for goal-aligned care in the future, reassurance against the threat of negligence and abandonment by caregivers, planning for future scenarios of care (practical, individual, and relational needs), and establishing of long-term relationships with providers entrusted for care later in disease. 3) Elements of effective palliative care in early dementia could include dementia-specific

ACP and goals of care discussions, navigation for building a network of support, provision of tools and resources for family, tailored care and knowledge of the person, and well-prepared dementia-care providers. The scarcity of palliative care studies aimed at early disease indicates a gap in the evidence in dementia care.

Conclusion:

The literature on palliative care in early dementia is sparse. Future studies should focus on assessment tools for optimizing timing of palliative care in early dementia, gaining better understanding of patient and family needs during early phases of disease, and providing training for providers and families in long-term relationships and communication around goals of care and future planning.

INTRODUCTION

Dementia affects approximately forty-seven million individuals worldwide.[1] Population trends predict a three-fold increase in dementia prevalence by the year 2050.[1] As in other serious illnesses, those with dementia may benefit from palliative care for symptom management, quality of life support, and planning for future care.[2,3] Palliative care focuses on promoting quality of life in seriously ill individuals and their families.[4] Ensuring timely access to palliative care has been found to improve quality of life, illness coping, symptom management and bereavement in serious illness.[5-9] However, referrals to palliative care often occur when death is imminent. For people with dementia, access to palliative care early in the disease trajectory is complicated by uncertain prognosis and delayed diagnosis.[10] Moreover, optimal timing of palliative care initiation or integration for dementia is not well defined in the literature, nor is it clear what interventions specific to early dementia are likely to meet palliative care needs for persons with dementia and their family caregivers.[3,11,12] With the advent of disease-modifying monoclonal antibodies such as Lecanumab, the role of palliative care early in the disease trajectory is even more critical. Given that these drugs are expensive, invasive, and controversy persists over their effectiveness, patients and families could benefit from palliative care supports that help them weigh costs and benefits and consider how use of these drugs may or may not align with their goals of care.[13]

Little consensus exists about what aspects of palliative care are important in early dementia versus later stages beyond a widespread acceptance that advanced care planning (ACP) is a key component of palliative care. ACP, considered an essential component of palliative care and serious illness communication,[14-16] is a common endpoint of studies of appropriate palliative care in dementia.[17-19] However, few studies of advance care planning in dementia capture nuances around maintained versus diminished capacity, or include documenting wishes for a lengthy phase of diminished capacity, making traditional ACP ill-suited for a long horizon of future care planning concerns in early dementia.[20-22]

To fill gaps in knowledge about the palliative care needs in early dementia and components of effective palliative care in this population, we conducted a scoping review of academic literature. In view of the many controversies surrounding palliative care in dementia, [11] we aimed to provide a general overview of research regarding timing of palliative care in mild to moderate dementia, to examine needs for palliative care in early dementia, identify key components of palliative care relevant earlier in the disease trajectory, and describe the role of ACP as an early palliative intervention.

METHODS

Search Strategy

Given the lack of clear definition of what constitutes ‘early palliative care’ or ‘palliative care earlier in the disease trajectory,’ we conducted a scoping review consistent with the methodological framework proposed by Arksey and O’Malley, refined by Levac et al.[11] We searched MEDLINE (PubMed), Cochrane Library, CINAHL, PSYCINFO, EMBASE and Web of Science (Table 1). The full search strategy and inclusion criteria are presented in detail in the study protocol, published elsewhere.[11] A first search was conducted in November 2019; an updated search was performed in March 2022.

Study selection process

We included peer-reviewed articles published in English that focused on all dementia types (e.g. Alzheimer’s disease, frontotemporal dementia, etc.) early in the disease trajectory. Our inclusion criteria were general with respect to design, domain of palliative care considered (i.e.: symptom management, psychosocial distress, spiritual care, care coordination, decision support, care planning), and setting of care. We excluded studies that focused exclusively on end-of-life care and terminal stages of dementia, except where studies captured reflections on experiences earlier in the disease. One author (JG) screened titles and abstracts and excluded records not fulfilling the inclusion criteria. A random list of 10% of studies to be included for full-text screening was then sent to two additional authors (LH/IM), as well as studies with uncertainty. All full texts were independently screened by two authors (JG & IM/LH). Consensus was reached by discussion between the first and second screener, and if necessary, with consultation from an arbiter. JG then hand-searched reference lists of all included studies. Finally, a list of included and excluded studies were sent to the other authors (LVDB, JVDS & CR) who independently screened the full texts of a random sample (10% each).

Quality appraisal

We used the Joanna Briggs Institute (JBI) Critical Appraisal Tools for systematic reviews for all designs included, and the MMAT (Mixed Methods Appraisal Tool) screening tool for mixed methods studies.[23,24] Two authors (JG & LH) independently assessed the quality of all qualitative studies and reviews included. For the other designs, a random sample of 20% of each design was independently screened by another author. If both independent raters' scores differed more than 4 points, a third independent rater was involved, and his/her assessment was included in the mean (this was the case for only four studies). Inter-rater reliability (weighted kappa) was 0.49 (standard error: 0.056).

Synthesis, thematic analysis, and conceptualization

We used both deductive and inductive approaches to analyzing and synthesizing the data. Reflexive thematic analysis using Braun and Clarke's paradigm[25] was used to initially code for a priori categories, and then inductively for emergent themes. First, we considered preliminary questions proposed in the study protocol, assigning discrete codes for each in nVivo,[26] and abstracts were reviewed against these questions. In the process of analyzing, we adapted a refined set of research questions inductively. A hierarchy of themes was agreed upon by consensus among three authors (Kd, JG, LH). Codes were collapsed into broader categories to capture overlapping and recurrent themes. The lead author constructed an original codebook and reviewed all included papers. Codes and themes were discussed between Kd and LH, with regular consultation by a third author, JG. The resulting broad topics included two a priori research questions that were well represented in included papers and two that emerged inductively from the literature: a) defining "early" and optimal timing of early palliative care for this population; b) advance care planning and its role in early palliative care for this population; c) identifying palliative care needs in early dementia; and d) qualifying components of effective palliative care in early dementia.

RESULTS

We identified 2,547 unduplicated records from our initial search. Of those, 356 were selected for full-text screening and 107 were selected for initial inclusion. After consideration, we excluded reviews and focused on primary studies, for a total 77 articles included in the scoping review (Figure 1). Descriptions of the articles, including authors, year, objectives, design, setting, participants, and whether they focused on ACP are shown in Table 3.

Quality review of included studies

Scores for qualitative studies range from 1-10, RCTs: 1-13, quasi-experimental 1-9, prevalence studies: 1-9, cohort studies:1-11, cross-sectional survey studies: 1-8 (higher scores indicate higher quality. Average quality scores using the MMAT of two independent and quality ratings of studies are shown in Table 2.

Results by theme

Timing of "Early" Palliative Care for Dementia

Studies discussing optimal time for initiating palliative care in dementia reported a range of definitions, perspectives, and practices regarding what constitutes "early." Several studies report a preference among persons with dementia, family caregivers and providers for "early," but most described the time of diagnosis as too early and potentially overwhelming and acknowledge a lack of clarity about when the right time is.[27-34] Four studies investigating the timeliness of palliative care delivery operationalized time as days or weeks prior to death, [21,35-37] though Beernaert et al. found that palliative care is most beneficial prior to a terminal phase of illness,[2] and Wang et al. suggested that prognostic accuracy could support earlier delivery of palliative care.[38] Beernaert et al. found, with respect to timing, supportive care needs are a feature of serious illness throughout its trajectory, suggesting that while nearer to diagnosis may be better, opportunities to intervene are present from diagnosis to death.[2,38]

When an early palliative care intervention was explicitly discussed, it was overwhelmingly ACP.[2,12,27-34,39-43] Generally, studies either directly or indirectly endorsed "early" as a good time to initiate advance care planning; however, only Mulqueen & Coffey identified a specific moment (upon admission to long-term care) that palliative care (including ACP discussions) would be most beneficial.[2,21,27,29,35,37,39,44-47] Ryan & McKeown describe "tipping points," at which time couples felt revisiting ACP would be helpful, such as when persons with dementia experienced cognitive or physical health changes, when family caregiver health declined or failed, and when children or others raised the need for planning.[43] Three studies describe ACP as an unfolding process that supports personal knowledge of the person with dementia, [29,43,48] while another six endorse ongoing, informal "everyday" conversations as opportune for goals of care discussions.[12,21,41,47-49] Mulqueen & Coffey also find that the initial ACP should be augmented by ongoing conversations with the person with dementia.[47]

Palliative Care Needs in Early Dementia

We grouped palliative care needs into several major areas: care continuity and coordination, communication, individualized care, and relationship care, including family caregiver involvement and support. Nearly half of reviewed studies described palliative care needs to some degree in early disease, but only two were *specifically* aimed at describing experiences of care in early dementia.[29,50] Few studies focused on spiritual care,[2,41] functional support,[34] and practical (non-medical) preparation for serious illness.[29,51]

Care Continuity and Coordination

The need for longitudinal, continuous relationships with providers and caregivers emerged as a common theme. Continuity of caring relationships was characterized as a hedge against both poor or insufficient future care and as assurance that, when decisions needed to be made, those who knew the person with dementia best would be equipped to act with fidelity as proxy.[12,21,28,41,47,49,52] Additionally, Ryan et al. and Hill et al. describe navigational support at diagnosis as meeting a need for protection against stigma and a sense of abandonment by primary care providers.[43,53]

Communication Needs

Communication needs included in studies encompassed ACP, goals of care discussions, and end-of-life care preferences,[2,21,28,29,32,40,41,47,48,54-65] anticipatory guidance and disease information,[29,32,41,45,50,54,55,61,66] the need for compassionate communication from providers,[32,40,47,58] for frank and realistic communication,[67] and for transparent shared decision-making.[59,61]

Individualized Care and Identity Preservation

Several studies discussed vulnerability to what Davies et al. termed “loss of self,” and McLeary named the danger of the lost, forgotten, annihilated self in dementia,[49] signaling the need for the person with dementia to be known as a person, or a dyad to be known as a couple.[12,29,32,37,41,43,47,48,52,68] Being known by both families and providers gave an assurance of future advocacy, protection from isolation and neglect, and the guarantee of sufficient care, rather than limiting care intensity during the lengthy palliative phase.[29,41,47,48,50,68] [12,21,28,29,40,41,47,49,52,58,59,61,68,69] The assurance of future care that acknowledges human dignity also emerged as a distinct need in early experiences of dementia.[29,34,40,41,47,49,58,68-70]

Relationship-Focused Care, Family Caregiver Involvement and Support

Twenty studies identified relationship-focused and family caregiver needs in early disease.[28,29,31,32,34,47,48,58,61,63,64,66-69,71-74] Caregivers and couple dyads noted the need for space for conversations and to engage care as a family, to protect enduring relationship identity early apart from support for the newer caregiver role.[32,34,47,48,50,61,68,74] In one study, couples reflected that an extended ACP process enabled assertion of their "couple-hood," strengthening the couple in the context of sparse social resources and the threat of loss of intimacy.[43] Other studies highlight the need for family caregivers to have easy access to disease information, practical assistance, and a network of social supports and resources to cope with relationship loss, caregiving, care coordination, task and problem-solving support, unexpected changes, and preparation for end of life.[67] Family caregivers across several studies reported a need for support in their role as decision-maker and proxy for the person with dementia. [28,29,32,34,47,48,50,61,64,66-68,73]

Components of Effective Palliative Care in Early Dementia

Forty-five of 77 papers offered information about elements of effective palliative care in early dementia, falling under the general domains of communication, individualized care, and well-prepared providers. Other core palliative care components as defined in consensus by the European Association for Palliative Care, [3] i.e., shared decision-making and symptom management, were rarely discussed as part of effective care in early dementia.[27,49,52,75]

Communication in Palliative Care Delivery

Including persons with dementia in discussions emerged as an important element of care. While some studies report including those with cognitive difficulties as a barrier to palliative care delivery,[12,20,53] those that included persons with dementia report successfully eliciting care preferences, establishing trusting relationships, offering disease information and facilitating decision-making discussions with family caregivers.[2,29,32,34,41,43,50,52,55,61,68,74] Huang et al. mention that including visual aids in their intervention significantly improved communication outcomes among participants with dementia, suggesting that modifying modes of communication for sensory and learning needs may facilitate discussions.[50] Seven studies describe the usefulness of specific disease trajectory information, including the terminal nature of dementia and what to expect at end of life both in symptoms and treatment options.[29,49,54,58,61,64,76]

Individualized Care

Longitudinal relationships with providers helped meet the need for those with dementia to be known as individuals, enabling what Ryan et al. describe as “the long view” of the person.[12,21,48,49,77] Care experiences are improved by limiting transitions of care and limiting staff turnover in long-term care.[49] Similarly, “up-skilling,” or task-shifting of primary palliative interventions to those in closest and most frequent proximity to the person with dementia and family members (i.e., nursing home staff, primary care providers in community and long-term care) was preferable to episodic support by specialists.[27,39,73,77,78] Personalizing living environments and adaptations for sensory needs (for hearing and visual loss) were mentioned as effective support for and protection of identity.[27,52,69] Skillful management of cognitive and behavioral symptoms was perceived as effective (or desired) individualized support.[12,31,43,48,49,67,77]

Well-prepared Providers

Ten studies identified the need among providers for training to be able to identify palliative needs, address difficult topics (including diagnosis), and facilitate referrals to specialty palliative care.[12,28,35,47,56,59,61,77,79,80] Regarding organization of care, while Harrison et al. suggest that neurologists are well positioned to initiate palliative care at diagnosis or points of disease progression, others noted that front-line providers, such as nurses and nursing aides frequently engage in effective communication and support, and an interdisciplinary team was noted to provide higher value, holistic care.[12,39,63,73,78]

Advance Care Planning (ACP)

Three-quarters of papers reviewed discussed or investigated ACP, many as a primary aim of study. [3,12,21,27-35,37-39,41,42,44-52,54,55,59-62,64-69,72-76,79-94] Naming or studying ACP as an early palliative care intervention was rare in papers reviewed. However, distinct dementia-specific features of ACP were described, often in qualitative studies. ACP was used by those with dementia to identify preferences for decisional control as well as articulating specific medical decisions, [29,48,78] to describe preferences for enough (rather than too much) care, [12,37,47] to affirm relational intimacy, [43] to protect quality of life over a long period of decline, [29,43,48,67] and to assert parts of the self whose voice may be lost in future.[47,48,67] Finally, ACP conversations were used by stakeholders as a means to build trust in those who would provide care later in disease, rarely represented in one document or occurring at just one point in time.[43,47,48] Ayalon et al. suggest that, given frequently low dyadic concordance in couples regarding ACP in early dementia, it is ethically important to continue to respond to autonomy, preferences, values, wishes of the person while there is still voice, even if voice has already changed from mild cognitive impairment.[55]

Discussion

The incidence of dementia globally is growing rapidly and the need for palliative care interventions in early dementia has never been greater. This review highlights how sparse the literature is focusing on palliative care in early stages of dementia. The limited evidence identified in this review highlighted several palliative care needs in early dementia, including care continuity, personhood preservation, and relationship-focused care. To address these needs, key components of high-quality palliative care in early dementia include systems to support care coordination and continuity and well-trained providers who can engage in ongoing and empathetic communication.

One goal of this scoping review was to bracket “early” and begin to inform debates about timing of palliative care interventions in dementia. While “early” is an accepted feature of palliative care overall, generally measured by proximity to diagnosis of serious illness, defining early for dementia is complicated by its lengthy course from diagnosis to death, the under-recognition of dementia as a terminal illness, and its co-occurrence with other illnesses.[95] Several papers discussed prognostic uncertainty as a barrier to adequately prepare patients and families for end-of-life, or for making specialty palliative care referrals.[61,65,79] The literature reviewed here did not fully settle the “when” question, but instead put forward multiple opportunities for timing of palliative care interventions. One obstacle to provision of early palliative care is that more than 50% of dementia cases have missed or delayed diagnoses in primary care settings.[96] Diagnosing early stage dementia and equipping providers (i.e., primary care providers and neurologists) with palliative care skills has been suggested as a reasonable and necessary approach to initiating timely palliative care for this population.[97-100]

Our findings suggest several elements of high-quality palliative care in early dementia, including personalized care, longitudinal relationships with providers, and a well-prepared dementia workforce familiar with dementia trajectories and symptom management. Though referral to specialist palliative care occurs later and less regularly than recommended across serious illnesses, referrals to palliative care are much more likely for those with dementia in the setting of a co-occurring diagnosis of cancer.[36] Because the suffering associated with dementia is distinct from that of other life-limiting illness, a dementia-specific approach is more likely to limit preventable suffering, for example by better recognition of pain, psychosocial and spiritual distress among those whose ability to communicate is compromised. [12,21,36,37,42,58,77,101,102] Improving the preparedness of a multidisciplinary geriatric workforce to recognize early palliative care needs in this population is a fundamental step toward effective palliative care.

A fulsome discussion of advance care planning is underway across specialties, with recognition that ACP, both as a process and a document has fallen short of its promise to protect the values and preferences of individuals at end of life.[103] Some have suggested that a wider frame, for example Serious Illness Communication, be adopted to hold the purpose but modify the process of ACP.[17,104] Studies in this review demonstrate how some have engaged with future care planning creatively.[21,32,43,67] In a recent review, Barnato and Khayal state that our current ways of studying palliative care interventions may overlook what they term “wild type” palliative care, i.e.: interventions with palliative effect that are not labeled “palliative” to fill gaps in care for unmet needs.[105] In studies reviewed here, such “wild type” ACP that is co-created by health care providers, persons with dementia, and family caregivers is used to address unmet needs such as threat of loss of future self, abandonment, and loss of intimate relationships, and also used as a conversation space for decisional, practical, and social support for caregivers. [21,32,43,67]

A creative approach to timing and documenting ACP surfaced as well, in which plans were rarely encompassed by a single document composed at a particular point in time but were instead emergent and part of daily communication. Some moments were identified as having special relevance, such as at time of diagnosis, caregiving needs intensify, or at admission to long-term care. ACP for early dementia, therefore, might be better considered as part of every patient encounter to revisit goals of care and decisional control preferences, and as a guide to providers for what supports are needed as cognitive and functional status decline.

Limitations

Few of the studies reviewed were targeted at early dementia palliative care; most generally considered experiences of patients and families in retrospect during or after end of life (e.g., asking caregivers to reflect on what they wish they had known). Little distinction was drawn between different dementia etiologies (i.e., Alzheimer’s versus vascular dementia), despite significant diversity of experiences from different dementia disease types. Also, very few articles discussed the overlap of dementia with race/ethnicity or any social determinant of health. Therefore, we are unable to summarize findings pertaining to issues of diversity, except to call attention to this critical gap in the literature. Many studies included discussion of barriers and facilitators of palliative care delivery in dementia; because this topic is well discussed elsewhere, we have not discussed those findings. Further, the quality of the studies varied, making results difficult to generalize.

CONCLUSIONS

This scoping review highlights the lack of evidence defining both needs and components of palliative care in early dementia. We give a general overview of the current evidence concerning palliative care in the early stages of dementia and provides a basis for expanding the field. Future studies should focus on assessment tools for optimizing timing of palliative care in early dementia, gaining better understanding of patient and family needs during early phases of disease, and developing holistic and integrated care models and providing training in long-term relationships and communication around goals of care and future planning for this population.

Disclosure/Conflict of Interest

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Figure 1. Scoping review flow chart.

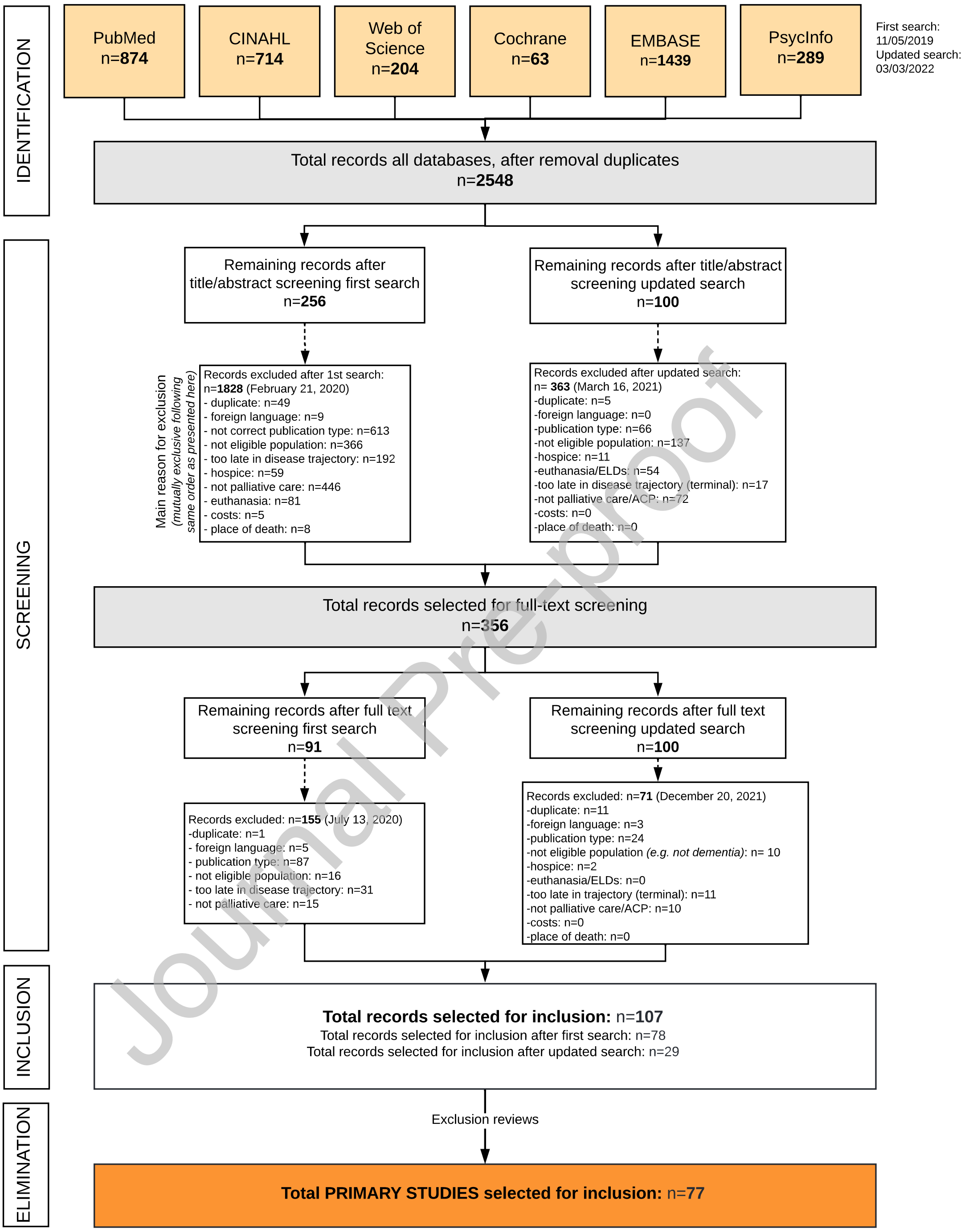

Table 1. Search String

Database	Search Strategy	Limits
PubMed	(dementia OR "Dementia"[mesh]) AND (((early OR earlier OR timely) AND "Palliative Care"[Mesh]) OR "early palliative care" OR "earlier palliative care" OR "Hospice Care"[Mesh] OR “hospice care” [tiab] OR "Terminal Care"[Mesh] OR “terminal care”[tiab])	2009-2022
Web of Science	TOPIC: (dementia OR alzheimer OR “alzheimer’s”) AND TOPIC: ("early palliative care" OR "earlier palliative care" OR "timely palliative care" OR "hospice care" OR "terminal care")	2009-2022
Embase	('dementia'/exp OR dementia OR 'alzheimer disease'/exp OR 'alzheimer disease') AND (('palliative care'/exp OR 'palliative care') AND (early OR earlier OR timely) OR 'early palliative care' OR 'earlier palliative care' OR 'timely palliative care' OR 'hospice care'/exp OR 'hospice care' OR 'terminal care'/exp OR 'terminal care')	2009-2022; human
CINAHL	(dementia or alzheimer or alzheimer's) AND ("early palliative care" OR "earlier palliative care" OR "timely palliative care" OR "hospice care" OR "terminal care")	2009-2022; academic journals
PsycINFO	(dementia or alzheimer or alzheimer's) AND ("early palliative care" OR "earlier palliative care" OR "timely palliative care" OR "hospice care" OR "terminal care")	2009-2022; peer-reviewed journals
Cochrane Library	Dementia "early palliative care" OR Dementia "earlier palliative care" OR Dementia “timely palliative care” OR Dementia “hospice care” OR Dementia "terminal care" OR Alzheimer "early palliative care" OR Alzheimer "earlier palliative care" OR Alzheimer "timely palliative care" OR Alzheimer "hospice care" OR Alzheimer "terminal care" OR Alzheimer’s “early palliative care” OR Alzheimer’s "earlier palliative care" OR Alzheimer’s "timely palliative care" OR Alzheimer’s "hospice care" OR Alzheimer’s "terminal care"	No limits

Table 2: Quality Assessment of Included Articles

Scores for qualitative studies range from 1-10, RCTs: 1-13, quasi-experimental 1-9, prevalence studies: 1-9, cohort studies:1-11, cross-sectional survey studies: 1-8 (higher scores indicate higher quality).

#	First author	Year	Design	Quality score 1	Quality score 2	Average quality score	Match
1	Ampe et al.	2015	Cross-sectional	4	5	4.5	0
2	Armstrong et al.	2019	Cross-sectional	2	4	3	0

3	Ayalon et al.	2012	Cross-sectional	3	6	4.5	0
4	Bamford et al.	2018	Qualitative	8	8	8	1
5	Beernaert et al.	2015	Qualitative	9	8	8.5	0
6	Beernaert et al.	2014	Qualitative	8	8	8	1
7	Beernaert et al.	2015	Prevalence study	7	8	7.5	0
8	Beernaert et al.	2015	Qualitative	8	8	8	1
9	Bolt et al.	2019	Qualitative	8	8	8	1
10	Brazil et al.	2015	Cross-sectional	1	3	2	0
11	Coffey	2016	Qualitative	6	7	6.5	0
12	Crowther	2013	Qualitative	6	7	6.5	0
13	Davies et al.	2014	Qualitative	8	8	8	1
14	Davies et al.	2017	Qualitative	8	8	8	1
15	Davies et al.	2018	Qualitative	8	8	8	1
16	De Gendt et al.	2013	Cross-sectional	4	4	4	1
17	de Vries et al.	2018	Qualitative	6	7	6.5	0
18	Durepos et al.	2019	Qualitative	8	8	8	1
19	Goodman et al.	2013	Qualitative	8	7	7.5	0
20	Goodman et al.	2015	Mixed methods	3	2	2.5	0
21	Harrison Dening et al.	2012	Qualitative	7	7	7	1
22	Harrison Dening et al.	2012	Qualitative	8	8	8	1
23	Hill et al.	2018	Qualitative	7	8	7.5	0
24	Hong et al.	2019	Cross-sectional	2	6	4	0
25	Huang et al.	2018	Cross-sectional	4	5	4.5	0
26	Illiffe et al.	2013	Mixed methods	2	0	1	0
27	Lamahewa et al.	2017	Qualitative	8	8	8	1
28	Lawrence et al.	2011	Qualitative	8	8	8	1
29	Lee et al.	2015	Qualitative	7	8	7.5	0

30	Livingston et al.	2013	Quasi-experimental	6	3	4.5	0
31	Livingston et al.	2017	Qualitative	7	8	7.5	0
32	McCleary et al.	2018	Qualitative	7	8	7.5	0
33	McInerney et al.	2014	Qualitative	7	6	6.5	0
34	Noh et al.	2016	Qualitative	7	7	7	1
35	Perri et al.	2020	Mixed methods	1	1	1	1
36	Pettigrew et al.	2019	Cross-sectional	7	4	5.5	0
37	Poole et al.	2018	Qualitative	8	8	8	1
38	Poppe et al.	2013	Qualitative	7	8	7.5	0
39	Robinson et al.	2012	Qualitative	8	8	8	1
40	Ryan et al.	2011	Qualitative	8	8	8	1
41	Sampson et al.	2015	Qualitative	5	5	5	1
42	Torke et al.	2010	Cross-sectional	3	3	3	1
43	van der Steen et al.	2016	Cross-sectional	5	7	6	0
44	van der Steen et al.	2016	Mixed methods	4	4	4	1
45	van der Steen et al.	2014	Mixed methods	4	4	4	1
46	van Riet Raap et al.	2015	Qualitative	7	7	7	1
47	Van soest-Poortvliet et al.	2014	Cohort study	3	7	5	0
48	Vandervoort et al.	2014	Prevalence study	5	5	5	1
49	Vandervoort et al.	2012	Prevalence study	6	6	6	1
50	Wang et al.	2019	Cohort	8	8	8	1
51	Armstrong MJ et al	2020	Qualitative	7	8	7.5	0
52	Tapsfield J et al	2019	Qualitative	7	7	7	1
53	Ryan & McKeown	2018	Qualitative	8	7	7.5	0
54	Bolt et al	2020	Cross-sectional	3	3	3	1
55	Davies et al		Qualitative	8	7	7.5	0
56	Fried T.R., et al	2020	Qualitative	7	7	7	1

57	Harrison K.L., et al	2020	Cohort study	5	5	5	1
58	Huang et al	2020	Quasi-experimental	7	4	5.5	0
59	Moore et al	2020	Cross-sectional	8	5	6.5	0
60	Tilburgs B., et al	2020	Rct	9	8	8.5	0
61	Courtright K.R., et al	2020	Qualitative	6	6	6	1
62	Fleming R., et al	2015	Qualitative	7	8	7.5	0
63	Ernecoff et al	2020	Cross-sectional	5	6	5.5	0
64	Sharda et al	2020	Cross-sectional	5	8	6.5	0
65	Van Rickstal et al	2020	Qualitative	8	8	8	1
66	Moore et al	2020	Cross-sectional	3	2	2.5	0
67	Goossens et al	2020	RCT	3	3	3	1
68	Sævareid et al	2019	Rct	9	9	9	1
69	Song et al	2019	Mixed methods	3	5	4	0
70	Lackraj	2021	Cohort	9	9	9	1
71	Leniz	2021	Cohort	9	9	9	1
72	Malhotra	2021	Qualitative	7	6	6.5	0
73	Miranda	2021	RCT	8	9	8.5	0
74	Moon	2021	Qualitative	8	7	7.5	0
75	Quinn	2021	Cohort	8	8	8	1
76	Sussman	2021	Qualitative	8	8	8	1
77	Ten Koppel	2019	Cross-sectional	5	7	6	0
							0.49

Table 3. Characteristics of included primary studies (N=77)

#	**First author**	**Year**	**Study objective(s)***	**Analytic Method**	**Study design**	**Country**	**Setting (sample size)**	**Participants /unit of analysis (sample size)**
1	Ampe	2015	To evaluate the ACP policy for nursing homes	Quantitative	Observational cross-sectional study	Belgium	Dementia care units in nursing homes (n=20)	Nursing home staff of various disciplines (no n)

2	Armstrong	2019	To investigate the natural history, cause of death, and end-of-life experiences of individuals diagnosed with dementia with Lewy bodies	Qualitative	Online survey study	USA	Not specified	Caregivers, family members, or friends of an individual who had died with a diagnosis of Lewy bodies in the past 5 years (n=658)
3	Armstrong	2020	To explore barriers to quality EOL care with caregivers and families of individuals who died with DLB	Qualitative	Interviews	USA	Not setting specific	caregivers and family members of individuals who died with DLB (n=30)
4	Ayalon	2012	To evaluate concordance in end-of-life preferences between patients with mild cognitive impairment (MCI) or dementia and their spouses	Quantitative	Cross-sectional survey study	Israel	Psychogeriatric clinics (n=2)	All consecutive new referrals for cognitive evaluation who were married, over the age of 65, and had a cognitive diagnosis of either MCI or dementia at the time of initial evaluation (n=106 respondents; 53 couples)
5	Bamford	2018	To find key factors required for the delivery of good end-of-life care for persons with dementia	Qualitative	Interviews (n=116), focus groups (n=12) and observations of routine data (n=256)	UK	Not setting specific	national experts, service managers, frontline staff, persons with dementia and family carers (n=259)

6	Beernaert	2015	To understand the primary care needs of patients for whom palliative care (not necessarily specialized palliative care) could be beneficial	Qualitative	Interviews (n=18)	USA	Community/ home	Patients (18 years old or older living at home with cancer, COPD, heart failure or dementia (MMSE score of 10–26, that is, everyone with the clinical diagnosis of mild to moderate dementia capable of doing an interview) (n=18)
7	Beernaert	2014	To explore the barriers to and facilitators of the early identification by family physicians of the palliative care needs	Qualitative	Focus groups (n=6) and Interviews (n=18)	Belgium	Community/ home	1) Patients with cancer, COPD, heart failure or dementia (n=18) 2) GPs (n=20) and nurses (n=12)
8	Beernaert	2015	To examine the use of these services and the reasons for not using them in a population in potential need of palliative care	Quantitative	Population based survey study	Belgium	Primary care	Physicians responding for deceased patients (n=1917)
9	Beernaert	2015	To explore the views of GPs, nurses and patients about the tasks of the GP in palliative care for people with a life-limiting illness from	Qualitative	Semi-structured interviews (n=19) and focus groups (n=6)	Belgium	Community/ home	1) Patients with cancer, COPD, heart failure or dementia (n=18) 2) GPs (n=20) and nurses (n=12)

			diagnosis onwards					
10	Bolt	2019	To investigate relatives' experiences with end-of-life care for persons with dementia, comparing the nursing home and home setting	Qualitative	In-depth interviews	the Netherlands	Nursing home and home setting	Individuals who were bereaved of someone with dementia (n=32)
11	Bolt	2020	To evaluate what types and forms of support nursing staff need in providing palliative care for persons with dementia	Quantitative	Cross-sectional survey	Netherlands	Home care or nursing home setting (n not known)	nursing staff (n=416)
12	Brazil	2015	To assess optimal timing of ACP discussions among GPs and dementia patients	Quantitative	Cross-sectional survey study	Ireland	Primary care	Primary care physicians (n=133)
13	Courtright	2020	To describe hospitalists' decision-making regarding palliative care consultation for patients with dementia	Qualitative	Interviews	USA	Seven hospitals within a national nonprofit health system	Hospitalist physicians (n=171)
14	Crowther	2013	To explore what are determinants of palliative care for people with dementia and their family carers	Qualitative	In-depth interviews	UK	Not setting specific	Bereaved carers (n=40)

15	Davies	2014	To explore perceived barriers to the delivery of high-quality palliative care for persons with dementia	Qualitative	Individual and group interviews	UK	Not setting specific	Professionals, researchers and managers from backgrounds in palliative care and dementia (n=26)
16	Davies	2017	To explore views of family caregivers about quality end-of-life care for persons with dementia	Qualitative	In-depth interviews	UK	Community/ home	Family caregivers of someone who had recently received a diagnosis of dementia, currently caring for someone with dementia or bereaved (n=47)
17	Davies	2018	To test the usability and acceptability of a set of heuristics which could be used by practitioners providing end-of-life care for persons with dementia in a variety of clinical and care settings	Qualitative	1) synthesis evidence 2) testing 3) individual and group interviews	UK	Complex care acute hospital ward (n=1), General practice (n=1), Community nursing team (n=1), Palliative care community teams (n=2)	Family carers and practitioners (n not provided)
18	Davies	2020	To explore the challenges older family carers of persons with dementia face towards the end of life and their support needs which could be addressed by	Qualitative	Interviews	UK	Not setting specific	current and former family carers (over 65 years) of persons with dementia (n=23)

			online support					
19	De Gendt	2013	To investigate the prevalence and characteristics of documented advance directives and physicians' orders for end-of-life car, and the authorization of a legal representative in relation to the residents' demographic and clinical characteristics and care received	Quantitative	Retrospective cross-sectional study	Belgium	Nursing homes (n=318)	Nursing home administrators (n=318)
20	de Vries	2019	To explore experiences of preparedness and support for family members of persons with dementia, before, during and following the death of the person with dementia	Qualitative	Interviews	New Zealand	Community/ home	People who had been carers or provided support for a family member with dementia who had died (n=23)
21	Harrison Dening	2012	To identify perceived and real barriers that prevent persons with dementia and their carers receiving end-of-life care of	Qualitative	Semi structured interviews and focus groups	UK	Not setting specific	Recently bereaved family carers of a persons with dementia and a wide range of health and social care staff (n=50)

			acceptable quality					
22	Dening	2013	(1) To explore whether persons with dementia and their carers were able to generate and prioritize preferences for end-of-life care; and (2) To examine whether carers influenced the choices made by the persons with dementia	Qualitative	Nominal group technique	UK	Memory assessment services (n not known)	People with dementia (n=6), carers (n=5) and dyads of persons with dementia and carers (n=6)
23	Durepos	2019	To explore perceived benefits and challenges of a unique psychoeducation program provided at end of life for current and bereaved caregivers of persons with dementia	Qualitative	Semi-structured interviews (n=16)	Canada	Hospital Specialized Care Unit (n=1)	Healthcare professionals (n=5) Caregivers (n=11)
24	Ernecoff	2020	To evaluate palliative care services of a CBSC program.	Quantitative	Retrospective chart review	USA	CBSC program	Patients enrolled in program (n=159)
25	Fleming	2015	To explore the views of persons with dementia, family carers and professionals on what aspects of the physical environment would be important to support a	Qualitative	Focus groups	Australia	Not setting specific	(bereaved) family carers of persons with dementia, and practitioners caring for persons with dementia nearing or at the end of their lives (n=18)

			good quality of life to the very end					
26	Fried	2021	To elicit the perspectives of older adults with early cognitive impairment and their caregivers on traditional and dementia-specific ACP	Qualitative	Focus groups	USA	Memory disorder clinics	persons aged 65+ with mild cognitive impairment or early dementia (n=28) and caregivers (n=19)
27	Goodman	2013	To explore how older persons with dementia discuss their priorities and preferences for end-of-life care	Qualitative	Interviews	UK	Care homes (n=6)	People with dementia (n=18)
28	Goodman	2015	To develop a framework for understanding the essential dimensions of end-of-life care delivery in long-term care settings for persons with dementia	Mixed-methods	Secondary data analysis from three mixed methods studies	UK	Care homes (n=29)	Residents (n=528), care home staff (n=205), and visiting health care professionals (n=44)
29	Goossens	2020	To examine the effects of an ACP educational intervention	Quantitative	Rct	Belgium	Nursing homes (n=65)	Nursing home staff members (n=311)
30	Harrison	2020	To examine demographic and clinical characteristics of persons with dementia versus nondementia serious illnesses receiving	Quantitative	Cohort study	USA	Large not-for-profit organization that provides community-based hospice and palliative care services (n=1)	people 65+ receiving an initial consultation from a community-based palliative care practice (n=3883)

			community-based palliative care					
31	Hill	2018	To investigate the experiences of long-term care staff delivering palliative care to persons with dementia to determine how care was delivered, to learn which guidelines were used, and whether policies affected the delivery of palliative care	Qualitative	Interviews	UK	Long-term care homes (n=8)	Multidisciplinary professional staff (n=22)
32	Hong	2019	To examine intention to discuss ACP for a family member with Alzheimer's disease	Qualitative	Cross-sectional survey study	USA	Community	Participants were 40 years of age or older and self-identified Korean Americans (n=68)
33	Huang	2018	To explore the factors related to the end-of-life care discussions of registered nurses, social workers, and physicians with residents with dementia and their families	Quantitative	Cross-sectional & correlational study	Taiwan	Long-term care facilities (n=48)	Registered nurses, social workers and physicians (n=478)

34	Huang	2020	To explore the effects of a family-centered ACP information intervention among persons with dementia and family caregivers	Quantitative	Quasi-experimental	Taiwan	Outpatient clinics	dyads consisting of persons diagnosed with mild cognitive impairment or mild dementia and their family caregivers (n=40)
35	Illiffe	2013	To develop a model of palliative care for persons with dementia that captures commonalities and differences across Europe	Qualitative	Literature review, interviews, nominal groups, consensus meeting	5 countries (UK, DE, IT, NO, NL)	Not setting specific	number of experts recruited at each site depended on reaching saturation (no n provided)
36	Lackraj	2021	examine associations between hospital-based palliative care and treatment intensity (discharge to hospice) for hospitalized patients with dementia	Quantitative	retrospective cohort study	USA	51 hospitals in NY State; hospitals either without a pc program or implementing pc program during study period	n=82,118 patients with dementia with acute hospitalization, 2008-2014
37	Lamahewa	2017	To explore difficulties in decision making for practitioners and family carers at the end of life for persons with dementia	Qualitative	Focus groups and semi-structured interviews	England	English dementia voluntary group	Former (n=4) and current (n=6) family carers from an English dementia voluntary group; Health and care professionals with expertise and experience in dementia

								end of life care (n=28)
38	Lawrence	2011	To define good end-of-life care for persons with dementia and identify how it can be delivered across care settings	Qualitative	In-depth interviews	UK	Community, care homes, general hospitals, and continuing care units	Bereaved family carers (n=27) and care professionals (n=23)
39	Lee et al.	2015	To determine expert views on the key factors influencing good practice in end-of-life care for persons with dementia	Qualitative	Cross-sectional survey study	England	Not setting specific	Experts in dementia care and/or palliative care (n=30)
40	Leniz	2021	examine association between identification of palliative care needs and acute care utilization in last 90 days of life among decedents with dementia	Quantitative	retrospective secondary analysis of Discover administrative dataset	UK (Northwest London)	n=5804	decedents with dementia, utiliation in last 90 days of life per public registry data 2016-2019
41	Livingston	2013	To compare advance care wishes documentation and implementation, place of death for residents who died, and themes from staff and family carers' after-death interviews pre- and post-intervention	Mixed methods	Intervention study: pre-post design	UK	Nursing home (n=1)	Nursing home residents (n=98; pre n=56 post n=42)

42	Livingston	2012	To examine barriers and facilitators to care home staff delivering improved end-of-life care for persons with dementia	Qualitative	Individual interviews	UK	Nursing home (n=1)	Nursing home staff (n=58)
43	Malhotra	2021	examine discordance between end of life goals and treatment preferences among family caregivers of those with severe dementia	Qualitative	semi-structured in-depth interviews (n=26); reflexive thematic analysis	Singapore	family caregivers of community dwelling older adults with severe dementia	n=26 family caregivers
44	McCleary	2018	To explore family and staff experiences of end of life and end of life care for persons with dementia in LTC homes	Qualitative	Focus groups (n=18)	Canada	Long-term care homes (n=4)	Staff members (n=77) and relatives of persons with dementia (n=19)
45	McInerney	2014	To explore participants' understanding of the concept of palliative care in the context of dementia	Qualitative	Analysis of open-ended survey data	Tasmania	Not setting specific	Caregivers, caring formally or informally for someone living with dementia as well as those with a general interest in dementia (n=1330)
46	Miranda	2021	investigate effects of training program (PACE) on end of life experiences for those with and without dementia	Qualitative	sub-group analysis of cluster-randomized controlled trial	Belgium, England, Finland, Italy, the Netherlands, Poland, Switzerland	78 nursing homes randomized; participants within clusters included those with a) advanced dementia,	n= 811 control arm: n=460, treatment arm n=351, in dementia subgroups

							b)non-advanced dementia; c)156 without dementia	
47	Moon	2021	systems-theory based examination of clinicians' and families' understanding of dementia as terminal illness.	Qualitative	semi-structured interviews (n=20 clinicians; n=12 family members of deceased patients with dementia)	Australia	n=20 clinicians n=10 bereaved family members	clinicians: social work, medine, nursing family members of deceased patients with dementia 3 months after death.
48	Moore	2020	to explore whether preparation for the end of life is associated with pre-death grief in caregivers of persons with dementia	Quantitative	Cross-sectional	UK	Home or care home	Caregivers of persons with dementia living at home or in a care home (n=150)
49	Moore	2020	To explore current practice and the role of UK care homes and Admiral Nurses in helping persons with dementia and their family carers prepare for end-of-life.	Quantitative	Cross-sectional	UK	Not setting specific	UK Admiral Nurses (n=95) and care homes (n=27)
50	Mulqueen & Coffey	2016	To explore the preferences of residents with dementia for their end-of-life care, and nurses' perceptions	Qualitative	Nominal qualitative study	Ireland	Long term care facility (n=1)	Nurses (n=6)

			of these preferences					
51	Noh	2016	To explore perceptions of support in decision making among proxies of persons with dementia	Qualitative	Semi-structured interviews (n=20)	USA	Not setting specific	Proxies of people with dementia (n=23)
52	Perri	2020	To evaluate whether integration of early palliative care specialist consultation into an LTC home would be feasible through the implementation of videoconferencing during routine interdisciplinary care conferences	Mixed-methods	Pilot study: mixed-methods evaluation	Canada	Pilot communities (n=2)	Nursing home residents (n=61): two-thirds of the residents had dementia as their primary diagnosis; 10 residents had advanced dementia
53	Pettigrew	2019	To examine factors that influence decision-making, preferences, and plans related to ACP and end-of-life care among persons with dementia and their caregivers, and examine how these may differ by race	Quantitative	Cross-sectional survey study	USA	Geographically dispersed Alzheimer's Disease Centers n=13)	Racially diverse caregivers of persons with dementia (n=431)
54	Poole	2018	To compare the views of persons with dementia and family carers of	Qualitative	Interviews (n=32) and focus groups (n=1)	England	Services providing end-of-life care (n=6)	People with early-stage dementia, living at home (n=11) and current

			persons with dementia on optimal end-of-life care					and bereaved carers (n=25)
55	Poppe	2013	To explore the acceptability of discussing ACP with people with memory problems and mild dementia shortly after diagnosis	Qualitative	In-depth interviews	UK	One memory clinic and one community mental health team	Dementia patients (n=12) and carers (n=8)
56	Quinn	2021	characterize decedents who received palliative care in last yr of life re: pt, disease, provider-level factors	Quantitative	population based cohort study; linked administrative data	Canada	administrative health data=145,709	decedents who received pal care in last year of life, dying between 2010-2017
57	Robinson	2013	To explore professionals' experiences on the implementation of ACP in two areas of clinical care, dementia and palliative care	Qualitative	14 focus groups and 18 interviews	England	Primary care trust (n=1), acute hospitals (n=2), ambulance trust (n=1) and local authority (n=1) and voluntary organizations and the legal sector	Professionals (n=95)
58	Ryan	2012	To explore the experiences of health care practitioners working in palliative care and sought to establish the issues relating to end-of-life care for persons with dementia	Qualitative	8 focus groups and 4 individual interviews	UK	Acute hospitals, general practice, hospices and specialist palliative care units (n not known)	Palliative care practitioners including medical, nursing and allied health professionals (n=58)

59	Ryan & McKeown	2018	To understand ways in which persons with dementia and their long-term co-residing partners consider and plan, or do not plan, for future medical and social care in the light of a recent diagnosis	Qualitative	Interviews	UK	Not setting specific	people who have recently been diagnosed with dementia and their co-residing partner (n=16)
60	Sævareid	2019	To investigate how implementing ACP with a whole-ward approach impact patient participation in nursing homes.	Quantitative	Rct	Norway	Nursing homes (n=8)	At T0 (after the 12-month intervention period) (n=151) – at T1 (n=88, 58.3 %)
61	Sampson	2015	To examine a range of European national palliative care guidelines to determine if, and how well, pain detection and management for people dying with impaired cognition are covered	Quantitative	Survey study and document analysis	11 countries (BE, FI, IS, IL, IT, NL, NO, RO, ES, CH, UK)	Country level	Palliative care guidelines (n=11)
62	Sharda	2020	To examine the association of inpatient palliative care consultation with care	Quantitative	Cross-sectional	USA	Tertiary academic medical center and affiliated community hospital	Patients with dementia (n=927)

			outcomes in hospitalized persons with dementia.					
63	Song	2019	To adapt an efficacious ACP intervention, SPIRIT (sharing patient's illness representations to increase trust), and to assess whether SPIRIT could help persons with dementia engage in ACP	Mixed methods	Survey & interview	USA	Outpatient brain health center (n=1)	Dyads of persons with dementia in early stages (recent Montreal Cognitive Assessment, score 13) and their surrogates (n=23)
64	Sussman	2021	Explore perceptions of and experiences with ACP, and concerns about planning for eol, including practices that support engagement with ACP	Qualitative	5 focus groups (n=18 participants); semantic thematic analysis	Canada	Alzheimer Society chapters in Ontario and Quebec n=10 persons with dementia and n=8 family caregivers	n=18; 10 persons with dementia with preserved communication abilities, 8 family members acting as caregivers
65	Tapsfield	2019	To describe the current reach of anticipatory and palliative care, and to explore GPs' views on using Key Information Summaries (KIS)	Qualitative	Interviews	Schotland	Not setting specific	GPs (n=10)
66	Ten Koppel	2019	Characterize and compare long term care facilities' palliative care: acp,	quantitative	cross-sectional retrospective analysis	Belgium, England, Netherlands, Poland, Finland, Italy	n=1298, 300 long term care facilities	enrollees (patients and facilities) in PACE study, Jan-Dec 2015

			timing of pal care					
67	Tilburgs	2020	To study the effects of an educational intervention for GPs aimed at initiating and optimizing ACP	Quantitative	Rct	The Netherlands	GP practices	Dutch GPs (all from different practices) (n=38)
68	Torke	2010	To determine the extent to which hospice and nonhospice palliative care programs provide services to patients with dementia and to describe barriers and facilitators to providing nonhospice palliative care	Quantitative	Telephone and web-based survey	USA	Hospice programs (n=240), palliative care programs providing hospice and non-hospice (n=173), and programs providing nonhospice palliative care (n=13)	Directors (non provided)
69	van der Steen	2016	To assess whether practicing physicians in who provide most of the end-of-life care, differ in finding that ACP in dementia should start at diagnosis	Quantitative	Cross-sectional study	UK and the Netherlands	Primary care (n not known)	Elderly care physicians who are on the staff of nursing homes (n=188) and GPs (n=133)
70	van der Steen	2016	(1) To examine the opinions of the international panel of experts around the applicability of palliative care in dementia; (2)	Mixed-methods	Five-round Delphi study (secondary analysis)	23 countries	Not setting specific	Experts (n=64)

			To examine which experts found it less important or less applicable					
71	van der Steen	2014	To define optimal palliative care in dementia	Qualitative	Five-round Delphi study	23 countries	Not setting specific	Experts (n=64)
72	Van Rickstal	2020	To explore the engagement in and the conceptualization of ACP and to identify potential similarities and differences in this area between USA and BE persons with young-onset dementia and their family caregivers.	Qualitative	Qualitative	Belgium & USA	Not setting specific	Adult family caregivers of persons with young-onset dementia (n=13 US; n=15 BE)
73	van Riet Raap	2015	To explore when professionals consider a person with dementia in need of palliative care	Qualitative	Case-vignette and constant comparitive method	6 countries (FR, DE, IT, NO, PO, NL)	Long-term care facilities (n=13)	Professionals (n=84)
74	van Soest-Poortvliet	2014	To describe care goals in nursing home patients with dementia and factors associated with establishing a comfort care goal	Quantitative	Prospective data collection	the Netherlands	Nursing home organizations (n=17) covering 28 LTC facilities	Newly admitted patients with dementia (n=372)

75	Vandervoort	2014	(1) To examine the extent to which the family physicians, nurses, and the relative most involved in the resident's care are informed about, ACP, written advance directives, and physician treatment orders for residents dying with dementia: (2) To examine the congruence among GP, nurse, and relative regarding the content of ACP	Quantitative	Retrospective post-mortem survey	Belgium	Nursing homes (n=69)	Deceased residents with dementia (n=205)
76	Vandervoort	2012	To describe the prevalence of documented ACP among nursing home residents with dementia, and associated clinical characteristics and outcomes	Quantitative	Retrospective post-mortem survey	Belgium	Nursing homes (n=594)	Deceased residents with dementia (n=764, participants were the family physicians, nurses, and the relative most involved in the resident's care)
77	Wang	2019	To develop a deep learning algorithm using longitudinal electronic	Quantitative	Retrospective cohort study	USA	Partners healthcare System (an integrated health care delivery system)	Adult patients with dementia who visited the health care system (n=26,921)

			health records to predict mortality risk as a proxy indicator for identifying patients with dementia who may benefit from palliative care					