

## End-of-life care in dementia: a literature review on the global context

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### Abstract

**Introduction:** Management of dementia has become a major public health problem. For patients with advanced, progressive and incurable illnesses, End-of-life care (EOLC) helps living well as much as possible until death. In dementia, EOLC has important implications for the patient, family and society.

**Objective:** It was realized a literature review attempted to explore the EOLC in dementia in the global context.

**Methods:** The literature review was carried out in mid-2022. Google Scholar was searched for relevant articles. 'End-of-life care' and 'dementia' were used as the keywords. Forty-six articles identified as relevant, were reviewed. Findings were compiled under identified broad headings. **Results:** Importance of EOLC in dementia, planning EOLC, scales used in evaluating EOLC, perceptions of patients and family including preferences, priorities, quality and satisfaction on EOLC, enablers for good EOLC, barriers & challenges in EOLC and improving EOLC for dementia patients were the broad headings identified. Often family members had limited knowledge about the disease and were unprepared for decision-making. Preferences of the patients and their family carers or healthcare providers sometimes differed. Communicative, relational and organizational challenges were present during care. Communication on advance care planning improved satisfaction with care. Psycho-social aspects of care is an important aspect. Knowledge on dementia has to be improved among all parties involved. Early decisions on palliative and EOLC options should be taken. **Conclusion:** Care providers and family should consider patient preferences when deciding and planning EOLC.

Patient views need to be obtained early in the course of the disease.

**Keywords:** Dementia. End-of-life care. Global context.

### Introduction

It has been identified that life expectancy increased globally by more than six years between the time period of 2000 and 2019 [1]. In 2000, the life expectancy was 66.8 years, while it increased to 73.4 years by 2019 [1]. Dementia mainly affects older people, and it can be collectively defined as several diseases affecting memory, thinking, and the ability to perform daily activities, which gets worse over time [2]. Due to increased longevity, more and more individuals are at risk of developing progressive degenerative dementias [3]. Dementia is identified as a major cause of disability and dependency among older adults worldwide [3]. However, it has to be noted that dementia is not part of normal ageing [4]. In 2012, the number of people living with dementia in the world was estimated as 35.6 million, which was predicted to double by 2030 and more than triple by 2050 [5]. By 2019, an estimated 55.2 million people were living with dementia [6,7]. It is projected that, by 2050, the number would rise to 139 million [7].

In this current context of increased longevity, management of progressive degenerative dementia has become a major public health problem. Dementia is seriously disabling for those affected with the disease, and at the same time, it can often be a devastating experience for their caregivers and families [5]. For patients with advanced, progressive and incurable



illnesses, End-of-life care (EOLC) helps in living well as much as possible until their death.

In dementia, End-of-Life Care offered to patients will have important implications not only for the patient, but also for the family as well as the community in general. Advance care planning plays a major role in dementia management, since a person who is newly diagnosed with dementia may be unable to predict the later stages of the disease. Therefore, it is important to make plans for the end of life before the affected become incapable of taking decisions on end-of-life care [8].

Understanding this grave situation where dementia is considered a public health priority, and the place for end-of-life care and advance care planning in dementia, this literature review was conducted to explore the global context related to end-of-life care in dementia.

## Methods

This literature review was conducted in mid-2022. Google Scholar was the search engine which was used in the search for relevant articles available in English Language. The key words entered for the search were 'end-of-life care' and 'dementia'. The articles appearing in the search were reviewed for their relevance and used in the literature review. Forty-six articles published from 2001-2022 were identified as relevant and thus, reviewed for literature. The obtained articles were read through, and the relevant literature was extracted and compiled under identified headings. The headings were decided based on the aspects which are commonly considered in end-of-life care.

## Results and Discussion

Through the review of the forty-six articles identified as relevant to the topic concerned, the following broad headings were identified to be used in compiling the literature: importance of EOLC in dementia, Planning EOLC, scales used in evaluating EOLC, perceptions of patients and family including preferences, priorities, quality and satisfaction on EOLC, enablers for good EOLC, barriers & challenges in EOLC and improving EOLC for dementia patients.

### Importance of End-of-Life Care

End-of-life care enables patients with advanced, progressive and incurable illnesses to live as well as possible until death [9]. Downs and others have described four different models which can be used to understand dementia, which are, as a neurological condition, as a neuro-psychiatric condition, as a normal part of ageing and seeing dementia from a person-centred perspective [10]. When dementia is seen from

a person-centred context, it facilitates an engagement with palliative care, which supports to enrich the end-of-life experience of people affected with dementia, as well as their families and healthcare staff working with them [10]. Effective palliative care for those affected with advanced dementia is useful for reducing distressing symptoms, increasing quality of life, reducing the burden on caregivers, and also ensuring that decisions on treatment go in line with the wishes of the patient and planned goals of care [11].

A shift is observed where an increasing number are seen to be dying in a nursing home or assisted living rather than at hospital, and more are dying at home, too [12]. However, experience from Hong Kong has identified that end-of-life services provided to patients with advanced dementia is limited, with special emphasis on those living in residential care homes, where they are sent to acute hospitals when they are sick, irrespective of their wish, premorbid status, diagnosis and prognosis [13]. It is noteworthy that this might not be the patient's perception of a good death.

The presence of advance directives decreased hospital stay and increased the likelihood of dying in a nursing home [14]. A retrospective cohort study by Luth and others revealed that beneficiaries from racial and ethnic groups minoritized with dementia experienced more intensive service use [15]. Volicer and others identified that among dementia patients, those dying at home had fewer symptoms and less discomfort than those dying in other settings, implying that quality end-of-life care can be provided at home, facilitated by hospice programs, effective pain control and psychiatric care [14]. However, in a review by Raymond and others, it is stated that, though admission to the hospital could be undesirable at the end of life, at instances of great diagnostic and prognostic uncertainty, it may still occur [16].

In a scoping review by Elliot and colleagues, they have identified three key areas for improvement [17]. Knowledge on dementia in general, among healthcare providers as well as those affected with dementia and their families and caregivers, needs to be increased, with special emphasis on advanced and end-of-life stages of the disease. Decisions should be made through informed and early conversations about palliative and end-of-life care options available. Thirdly, a person-centered approach needs to be adopted in with palliative and end-of-life care, to be provided at preferred care settings [17]. Volicer identified that quality palliative care is an effective alternative to aggressive treatment [12].

The supportive and palliative care needs of both patient and family need to be identified and met by end-of-life care [9]. For dementia patients, in the terminal



phase, it is important to have good communication skills with the patient and family members, enabling them to understand the condition and to better cope with their suffering [18]. Goodman and others have identified three types of uncertainties in care, conceptualized as treatment uncertainty, relational uncertainty and service uncertainty [19].

### Planning End-of-Life Care

A qualitative exploratory study using focus group discussions by Gessert and colleagues revealed that family members were not well-prepared for their decision-making roles with regard to the care of their relative suffering from dementia [20]. Limited understanding of the natural progression of the disease was identified. They had felt uncomfortable in setting goals for their relatives' end-of-life care, and they have had limited experience with death. It was also revealed that the family members didn't have adequate communication regarding the EOLC planning with health professionals [20]. The study emphasized the important role of clinicians in redefining and improving the experiences of families in end-of-life situations.

Another qualitative study involving close family relatives of patients as a series of single cases has identified that family caregivers required sufficient encouragement in asking the right questions during advance care planning [21]. For some of the participants involved in this study, there were uncertainties on what advance care planning was, and the discussions have been an uncomfortable experience. The study stated that advance care planning is a complex activity influenced by many factors, importantly including the readiness of the family caregiver in participating in EOLC discussions.

### Scales Used in Evaluating End-of-Life Care

This literature review also tried to briefly explore the scales which are available for assessing end-of-life care in dementia. Volicer and others (2001) [22] have identified a lack of instruments to specifically address the issues which are unique for persons dying with dementia. Kiely and colleagues have also mentioned that the lack of availability of valid and reliable instruments for measuring the experiences of older persons with advanced dementia had implications for the limited palliative care research for dementia [23]. They have assessed the validity and reliability of three End-of-Life in Dementia (EOLD) Scales and have come to the conclusion that the Satisfaction with the terminal care (SWC-EOLD), Symptom management (SM-EOLD) and Comfort during the last 7 days of life (CADEOLD) scales used in dementia demonstrated internal

consistency reliability and convergent validity [23]. The SM-EOLD scale was found to be sensitive in detecting changes in level of comfort according to changes in key outcomes, while the SWC-EOLD scale was sensitive to detect differences in levels of satisfaction according to changes in key outcomes [24].

Another study evaluated the validity and reliability of ten after-death instruments which are commonly used to assess the perceptions of family and professional caregivers on Quality of Care (QOC) or Quality of Dying (QOD) with dementia at the end-of-life. Out of the instruments assessed for QOC, the SWC-EOLD and Family perceptions of care scale (FPCS) showed better validity and internal consistency than the others assessed. With regard to the instruments on QOD, the CAD-EOLD and the Mini-suffering state examination (MSSE) were found to be most valid and internally consistent, compared to the other assessed instruments [25].

### Perceptions of Patients and Family Including Preferences, Priorities, Quality and Satisfaction on End-of-Life Care

People with dementia had difficulty considering their future selves, while carers wanted much control at the end of life [26]. An interview-based study by Goodman and colleagues provides implications that paying attention to and documenting the everyday accounts and observations on important aspects identified by older people with dementia in long term care would enrich the methods of assessment, care planning and documentation that focus on dying [27]. Another qualitative study using interviews and a focus group revealed seven areas as important to end-of-life care for people with dementia and their family carers: Being cared for 'in place', being comfortable at the end of life, a skilled care team, importance and value of making future plans, faith in family members, trust in professionals and fitting care together - coordination and the role of families [28].

It has been observed that at times, there were mismatches between what the patients and the healthcare providers perceived as important [29]. While the resident dementia patients found comfort, presence of family, familiar staff and surroundings as important, the nurses believed that they needed good communication, pain management, advance care planning, being cared for by knowledgeable staff and the inclusion of their families [29]. An interview based qualitative study conducted among caregivers by Davies and colleagues revealed that the caregivers believed that care at the end-of-life need not be complex [30]. The findings suggested that the caregivers are not



expecting intensive medical treatments and processes for judging the quality of care but are expecting a holistic person centred approach to care incorporating interpersonal and social aspects of care.

Qualitative, semi-structured interviews among nursing-home nurses were conducted in a study by Lundin & Godskesen to identify the communication, relational and organizational challenges the nurses caring for patients with advanced dementia and pain at the end-of-life are coming across. The study identified that having good relationships with the other healthcare professionals, having vast and relevant professional experience, and having adequate time to care for the patients with advanced dementia and their relatives facilitated good palliative care and pain management [31]. In a study by Toles and colleagues, family decision-makers reported poor quality end-of-life communication in both nursing home staff and clinicians [32].

The implications generated in a study by Lee and others (2017) [33], were the need to recognize, value and support the expertise of nursing and care home staff in this area, both within the 'organization' and from better collaborative working with other relevant healthcare services. The study also identified that ensuring continuity of care, as well as engaging in early discussions with both the patients and their families to identify their personal wishes, lead to better quality care. Davies and others (2014) [34] identified that the perceptions of the carers regarding accepting or denying the death of their relative were diverse, and that it must be respected by healthcare professionals involved in the EOLC during planning and implementing the care plan for the patient, where the plan requires personalization to the particular patient and family.

Better communication, greater patient comfort without tube feeding, and care in a specialized dementia unit were the modifiable factors identified as improving satisfaction with care in advanced dementia [35]. A study by McCarron and colleagues has recommended more practice relationship based and collaborative approaches in provision of care, as well as a stronger evidence-based research programme focusing on the timing and efficacy of palliative care, for persons affected with dementia [36].

### Enablers for Good End-of-Life Care

Integration of emotional and technical expertise is necessary in successfully engaging with people with dementia and family members and helping them to recognize the progression of the disease [33]. Identifying and responding to the physical care needs of the dementia patient must be included in any approach of care, including ensuring adequate food and fluid

intake, efficiently attending to personal care and hygiene and pain control [37]. Care professionals who were interviewed in the study mentioned the importance of having a holistic approach incorporating the patient's physical, psychological, social, emotional and cultural needs. Staff education, supervision and specialist inputs can enable the provision of EOLC [37]. Leadership and management of care, integrating clinical expertise, continuity of care, and use of guidelines are all helpful for good EOLC [38], and so are timely planning of the discussions and co-ordination of care [39].

In a study by Stewart-Archer and others (2015) [40], the factors which were identified as optimizing EOLC were skilled nursing staff, acceptance of finality of death, family response where the family acted according to the wishes of the patient, honest communication about the status and peace and tranquility, where peaceful, quiet environments suggested patients well taken care for and needs well-met. The study revealed that the patients believed that honest communication would facilitate making decisions concerning life and death, planning for the future and would allow greater control and self-determination.

### Barriers & Challenges in End-of-Life Care

End-of-life care for dementia patients brings up questions about the appropriate role of patient autonomy, the meaning of self and the challenges of determining futility [41]. A study done by Lamahewa and colleagues to explore difficulties in decision making for practitioners and family carers at the end-of-life for people with dementia revealed that challenges of delivering coherent care in dynamic systems, uncertainty amongst decision makers, internal and external conflicts amongst decision makers and lack of preparedness for the end of life contributed to difficulties in making decisions at the end of life [42].

Sachs and colleagues state that some of the barriers identified in providing excellent EOLC are, dementia not seen as a terminal illness which is appropriate for adopting a palliative care approach, psychological and emotional challenges of withholding treatment, for example tube feeding, difficulty in assessing and managing pain in cognitively impaired patients, difficulties in management of behavioral problems and psychiatric symptoms, challenges associated with stress in caregivers, as well as other economic and systemic issues in providing EOLC [43]. Behavioural and psychological symptoms associated with dementia always pose a challenging issue, even in the advanced stage [44].

Five areas were identified by Denning and team as barriers for good EOLC. These included poor coordination





in the care pathways where the medical and social needs were complex for dementia patients, negative impact of hospital admissions, variable awareness of advance care planning, physical and emotional demands of caring over long periods of time and the perceptions of carers about unpredictable and fragmented services and healthcare providers having little or no training in dementia, in particular regarding communication and managing behavioural problems [45].

A study by Armstrong and colleagues [46] have identified health system factors, facility factors, hospice factors and physician level factors, as barriers for good end-of-life care in dementia. Physician related barriers identified included not having a discussion that dementia can be terminal, no education provided regarding what to expect at end of life, not recommending palliative care or hospice and lack of support for the caregiver.

In a study by Thune-Boyle et al. (2010) [47], it was identified that the understanding of dementia and the progression of the disease among the participants was poor, and so was the provision of information regarding the future<sup>47</sup>. Difficulties in communicating with advanced dementia patients result in uncertain pain assessment, where there are difficulties in the differentiation of pain from anxiety [48].

In 2002, Blasi et al.[49] and others revealed the barriers for EOLC as measurement issues regarding quality of care and quality of life, unavailability or not considering advance directives, cost factors, healthcare system factors, and caregiver factors leading to inappropriate interventions and poor management of symptoms in patients.

### Improving End-of-life Care for Dementia Patients

Kupeli and colleagues state that it is of much importance to maintain relationships between healthcare professionals, care home staff and family carers in EOL care in dementia, which requires a collaborative approach [50]. Advance care planning is a cornerstone of the EOLC strategy, and it is considered a possible way of improving choice and autonomy for patients with dementia [51]. End-of-life discussions should be an ongoing process, providing appropriate time and space, preferably conducted by a skilled coordinator [52]. In order to ensure that the wishes of people with dementia are respected, their views should be obtained early in the disease before their ability to consider the future is compromised [26].

Key areas include increasing knowledge about dementia in patients, family members and care providers, having informed, early conversations and decision-making about palliative and end-of-life care options and providing a person-centered approach by allowing end-of-life care to occur in preferred care

settings [53]. Kaasalainen and colleagues have suggested that long-term care homes should implement a palliative approach to dementia care, while engaging people with dementia in advance care planning early. Their end-of-life symptoms and psychosocial and spiritual needs require effective management. Family members should be prepared and supported for decision making at end-of-life, followed by provision of after death care. Grief and bereavement support should be provided to family members as well as long-term care home staff and surviving residents [54].

In 2010, Gove and team have proposed a set of recommendations on end-of-life care for people with dementia, which incorporated recommendations for improvement focusing on people with dementia, carers, healthcare professionals and policymakers [55]. A comprehensive dementia care programme with dedicated nurse practitioner care managers was found to be able to provide high-quality end-of-life care, with good engagement in advance care planning, high hospice use rates and low use of acute care during last six months of life, for the enrollees [56].

This literature review attempted to identify the important aspects related to end-of-life care for dementia patients in the global context. Since the review used a single selected search engine, it could have limited the retrieval of some of the literature available. However, forty-six articles across the world had been used for extracting information, which were compiled under identified headings. Identifying the importance of end-of-life care and advance care planning will support streamlining the initiatives taken in the management of dementia patients. Future reviews could focus on identifying the global context of advance care planning and its benefits for the patients, carers and family.

### Conclusion

End-of-life care is beneficial for the patient as well as the family members. Advance care planning is an important aspect of dementia care. However, it should be carried out during the early stages of dementia when the patient is able to make decisions and express preferences. Carers and relatives should be educated and encouraged to actively participate in discussions related to advance care planning, and end-of-life discussions should be an ongoing process. Psycho-social aspects of care is an important area to consider.

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No additional data are available.

## Conflict of interest

The authors declare no conflict of interest.

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## References

1. World Health Organization. Global Health Estimates: Life expectancy and healthy life expectancy. Retrieved on 25th July 2023 from <https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghelifeexpectancy-and-healthy-life-expectancy>.
2. World Health Organization. Dementia. Retrieved on 26 July 2023 from <https://www.who.int/news-room/fact-sheets/detail/dementia>.
3. World Health Organization. (2017). Global action plan on the public health response to dementia 2017 – 2025. Geneva: World Health Organization.
4. National Institute on Ageing. What Is Dementia? Symptoms, Types, and Diagnosis. Retrieved on 26 July 2023 from <https://www.nia.nih.gov/health/what-is-dementia>.
5. World Health Organization and Alzheimer's Disease International. (2012). Dementia: A Public Health Priority. Geneva: World Health Organization.
6. World health Organization. (2022). A blueprint for dementia research. Geneva: World Health Organization.
7. World Health Organization. (2021). Global status report on the public health response to dementia. Geneva: World Health Organization.
8. National Institute on Ageing. End-of-Life Care for People with Dementia. Retrieved on 27 July 2023 from <https://www.nia.nih.gov/health/end-of-life-care-people-dementia>.
9. Treloar A, Crugel M, Adamis D. Palliative and end of life care of dementia at home is feasible and rewarding - Results from the 'Hope for Home' study. *Dementia*, 2009, 8(3), 335–347.
10. Downs M, Small N, Froggatt K. Explanatory models of dementia: links to end-of-life care. *International Journal of Palliative Nursing*, 2006, 12 (5), 209-213.
11. Bartley MM, Suarez L, Shafi RMA, Baruth JM, Benarroch AJM, Lapid MI. Dementia Care at End of Life: Current Approaches. *Current Psychiatry Reports*, 2018, 20 (50).
12. Volicer L. End-of-life Care for People with Dementia in Residential Care Settings. *Alzheimer's Association*. 2005.
13. Luk JkH, Chan FHW. End-of-life care for advanced dementia patients in residential care home—a Hong Kong perspective. *Annals of Palliative Medicine*, 2018, 7(3), 359-364.
14. Volicer L, Hurley AC, Blasi ZV. Characteristics of dementia end-of-life care across care settings. *American Journal of Hospice & Palliative Care*, 2003, 20 (3), 191-200.
15. Luth EA, Manful A, Prigerson HG, Xiang L, Reich A, Semco R, et al. Associations between dementia diagnosis and end-of-life care utilization. *Journal of the American Geriatrics Society*, 2022, 1-13.
16. Raymond M, Warner A, Davies N, Nicholas N, Manthorpe J, Iliffe S. Palliative and end of life care for people with dementia: lessons for clinical commissioners. *Primary Health Care Research & Development*, 2014, 15, 406–417. doi:10.1017/S146342361300039X
17. Elliot V, Morgan D, Kosteniuk J, Bayly M, Chow AF, Cammer A., et al. Palliative and end-of-life care for people living with dementia in rural areas: A scoping review. *PLoS ONE*, 2021, 16(1), e0244976.
18. Michel J, Pautex S, Zekry D, Zulian G, Gold G. End-of-Life Care of Persons With Dementia. *Journal of Gerontology:Medical Sciences*, 2002, 57A (10), M640–M644.
19. Goodman C, Froggatt K, Amador S, Mathie E, Mayrhofer A. End of life care interventions for people with dementia in care homes: addressing uncertainty within a framework for service delivery and evaluation. *BMC Palliative Care*. 2015 Sep 17;14(1).
20. Gessert CE, Forbes S, Bern-Klug M. Planning End-of-life Care for Patients with Dementia: Roles of



- Families and Health Professionals. *Omega*, 2001, 42(4), 273–291.
21. Ashton SE, Roe B, Jack B, McClelland B. End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia – A qualitative study. *Dementia*, 2014, 0 (0), 1-18.
22. Volicer L, Hurley AC, Blasi ZV. Scales for Evaluation of End-of-Life Care in Dementia. *Alzheimer Disease and Associated Disorders*, 2001, 15(4), 194–200.
23. Kiely DK, Volicer L, Teno J, Jones RN, Prigerson HG, Mitchell SL. The Validity and Reliability of Scales for the Evaluation of End-of-Life Care in Advanced Dementia. *Alzheimer Dis Assoc Disord*, 2006, 20(3), 176–181.
24. Kiely DK, Shaffer ML, Mitchell SL. Scales for the Evaluation of End-of-Life Care in Advanced Dementia: Sensitivity to Change. *Alzheimer Dis Assoc Disord.*, 2012, 26(4), 358–363. doi:10.1097/WAD.0b013e318247c41b.
25. Soest-Poortvliet MCV, Steen JYV, Zimmerman S, Cohen LW, Klapwijk MS, Bezemer M, et al. Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Qual Life Res.* 2012, 21, 671–684.
26. Denning KH, Jones L, Sampson EL. Preferences for end-of-life care: A nominal group study of people with dementia and their family carers. *Palliative Medicine*, 2012, 27(5), 409–417.
27. Goodman C, Amador S, Elmore N, Machen I, Mathie E. Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. *Int J Nurs Stud.*, 2013, 50(12), 1639-47. doi: 10.1016/j.ijnurstu.2013.06.008.
28. Poole M, Bamford C, McLellan C, Lee RP, Exley C, Hughes JC., et al. End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliative Medicine*, 2018, 32(3), 631–642.
29. Mulqueen K, Coffey A. Preferences of residents with dementia for end of life care. *Nursing Older People*, 2017, 29(2), 26-30.
30. Davies N, Rait G, Maio L, Iliffe S. Family caregivers' conceptualisation of quality end-of-life care for people with dementia: A qualitative study. *Palliative Medicine*. 2017, 31(8), 726-733. doi:10.1177/0269216316673552
31. Lundin E, Godskesen T. End-of-life care for people with advanced dementia and pain: a qualitative study in Swedish nursing homes. *BMC Nursing*, 2021, 20(48).
32. Toles M, Song M, Lin F, Hanson LC. Perceptions of family decision-makers of nursing home residents with advanced dementia regarding the quality of communication around end-of-life care. *J Am Med Dir Assoc*, 2018, 19(10), 879–883.
33. Lee RP, Bamford C, Poole M, McLellan E, Exley C, Robinson L. End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice. *PLoS ONE*, 2017, 12(6), e0179355.
34. Davies N, Maio L, Rait G, Iliffe S. Quality end-of-life care for dementia: What have family carers told us so far? A narrative synthesis. *Palliative Medicine*, 2014, 28(7), 919–930.
35. Engel SE, Kiely DK, Mitchell SL. Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. *J Am Geriatr Soc*, 2006, 54(10), 1567–1572.
36. McCarron M, McCallion P, Fahey-McCarthy E, Connaire, K. Staff Perceptions of Essential Prerequisites Underpinning End-of-Life Care for Persons With Intellectual Disability and Advanced Dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 2010, 7(2), 143– 152.
37. Lawrence V, Samsi, Murray J, Harari D, Banerjee S. Dying well with dementia: qualitative examination of end-of-life care. *The British Journal of Psychiatry*, 2011, 199, 417–422.
38. Lee RP, Bamford C, Exley C, Robinson L. Expert views on the factors enabling good end of life care for people with dementia: a qualitative study. *BMC Palliative Care*, 2015, 14(32).
39. Bamford C, Lee R, McLellan E, Poole M, Harrison-Dening K, Hughes J, et al. What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders. *BMC Geriatrics*, 2018, 18(302).
40. Stewart-Archer LA, Afghani A, Toye CM, Gomez FA. Dialogue on Ideal End-of-Life Care for Those With Dementia. *American Journal of Hospice & Palliative Medicine*, 2015, 32(6), 620630.
41. Gusmano M. End-of-life care for patients with dementia in the United States: institutional realities. *Health Economics, Policy and Law*, 2012, 7, 485–498. doi:10.1017/S1744133112000266.
42. Lamahewa K, Mathew R, Iliffe S, Wilcock J, Manthorpe J, Sampson EL, et al. A qualitative study exploring the difficulties influencing decision making at the end of life for people with dementia. *Health Expectations*, 2018, 21, 118–



- 127.
43. Sachs GA, Shega JW, Cox-Hayley D. Barriers to Excellent End-of-life Care for Patients with Dementia. *J Gen Intern Med*, 2004, 19, 1057–1063.
44. Kumar S, Kuriakose JR. End-of-life care issues in advanced dementia. *Mental Health in Family Medicine*, 2013, 10, 129–32.
45. Dening KH, Greenish W, Jones L, Mandal U, Sampson EL. Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study. *BMJ Supportive & Palliative Care*. 2012. doi:10.1136/bmjspcare-2011-000178.
46. Armstrong MJ, Alliance S, Corsentino P, Maixner SM, Paulson HL, Taylor A. Caregiver Reported Barriers to Quality End-of-Life Care in Dementia with Lewy Bodies: A Qualitative Analysis. *Am J Hosp Palliat Care*, 2020, 37(9), 728–737. doi:10.1177/1049909119897241.
47. Thuné-Boyle ICV, Sampson EL, Jones L, King M, Lee DR, Blanchard MR. Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia*, 2020, 9(2), 259–284. doi:10.1177/1471301209354026.
48. Lundin E, Godskesen TE. End-of-life care for people with advanced dementia and pain: a qualitative study in Swedish nursing homes. *BMC Nursing*, 2021, 20 (48). <https://doi.org/10.1186/s12912-021-00566-7>
49. Blasi ZV, Hurley AC, Volicer L. End-of-Life Care in Dementia: A Review of Problems, Prospects, and Solutions in Practice. *Journal of the American Medical Directors Association*. 2002, DOI: 10.1016/S1525-8610(04)70414-4
50. Kupeli N, Sampson EL, Leavey G, Harrington J, Davis S, Candy B, et al. Context, mechanisms and outcomes in end-of-life care for people with advanced dementia: family carers perspective. *BMC Palliative Care*, 2019, 18 (87). <https://doi.org/10.1186/s12904-019-0467-9>
51. Sampson EL, Burns A, Richards M. Improving end-of-life care for people with dementia. *The British Journal of Psychiatry*, 2011, 199, 357–359.
52. Saini G, Sampson EL, Davis S, Kupeli N, Harrington J, Leavey G, et al. An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes. *BMC Palliative Care*, 2016, 15 (55). DOI 10.1186/s12904-016-0127-2
53. Elliot V, Morgan D, Kosteniuk J, Bayly M, Chow AF, Cammer A, et al. Palliative and end-of-life care for people living with dementia in rural areas: A scoping review. *PLoS ONE*, 2021, 16(1), e0244976. <https://doi.org/10.1371/journal.pone.0244976>
54. Kaasalainen S, McKeary L, Vellani S, Pereira J. Improving End-of-Life Care for People with Dementia in LTC Homes During the COVID-19 Pandemic and Beyond. *Canadian Geriatrics Journal*, 2021, 24 (3), 164–169.
55. Gove D, Sparr S, Dos Santos Bernardo AMC, Cosgrave MP, Jansen S, Martensson B., et al. Recommendations on end-of-life care for people with dementia. *J Nutr Health Aging*, 2010, 14, 136–139. <https://doi.org/10.1007/s12603-009-0229-0>
56. Jennings LA, Turner M, Keebler C, Burton CH, Romero T, Wenger NS, et al. The Effect of a Comprehensive Dementia Care Management Program on End-of-Life Care. *Journal of the American Geriatrics Society*, 2019, 67(3), 443–448.