

White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care

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European Association for Palliative Care (EAPC)

Abstract

Background: Dementia is a life-limiting disease without curative treatments. Patients and families may need palliative care specific to dementia.

Aim: To define optimal palliative care in dementia.

Methods: Five-round Delphi study. Based on literature, a core group of 12 experts from 6 countries drafted a set of core domains with salient recommendations for each domain. We invited 89 experts from 27 countries to evaluate these in a two-round online survey with feedback. Consensus was determined according to predefined criteria. The fourth round involved decisions by the core team, and the fifth involved input from the European Association for Palliative Care.

Results: A total of 64 (72%) experts from 23 countries evaluated a set of 11 domains and 57 recommendations. There was immediate and full consensus on the following eight domains, including the recommendations: person-centred care, communication and shared decision-making; optimal treatment of symptoms and providing comfort (these two identified as central to care and research); setting care goals and advance planning; continuity of care; psychosocial and spiritual support; family care and involvement; education of the health care team; and societal and ethical issues. After revision, full consensus was additionally reached for prognostication and timely recognition of dying. Recommendations on nutrition and dehydration (avoiding overly aggressive, burdensome or futile treatment) and on dementia stages in relation to care goals (applicability of palliative care) achieved moderate consensus.

Conclusion: We have provided the first definition of palliative care in dementia based on evidence and consensus, a framework to provide guidance for clinical practice, policy and research.

Keywords

Comfort care, consensus, dementia, end of life, guidelines, palliative care

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Introduction

Dementia is a major health problem worldwide. In 2010, about 35.6 million people were living with dementia, and this number will almost double by 2030.^{1,2} Because no cure is foreseen in the near future, many people will die with or from dementia. Death with or from dementia markedly increases with age: a UK study showed that 6% of people aged 65–69 years had dementia at death, increasing to over 58% of those aged 95 and over.³

Dementia is also a life-limiting disease,^{4–8} although not always an independent risk factor in selected hospitalized samples,^{9–11} nor when adjusted for possible mediators such as decreased intake of foods and fluids.^{11,12} Palliative care may help address patients' and families' concerns and needs.¹³ Traditionally, clinicians and researchers within the palliative care community have focused on care for advanced-stage cancer patients. For these patients, early access to palliative care improves quality of life and may even prolong life.¹⁴ Such high-quality evidence is not yet available for palliative care in dementia, although dementia care at the end of life is increasingly being studied.¹⁵

Disease trajectories differ for dementia and cancer patients. Cancer patients may experience a substantial decline in function in the last months or weeks of life, and diseased trajectories are relatively well-defined.^{16–18} Even though impairments are progressive, with dementia, there may be prolonged 'dwindling'¹⁶ and severe disability may persist for years.¹⁸ Survival is variable, and studies have reported means or medians of between about 3 and 10 years.^{15,19} At an individual level, patients may survive to the last phase of dementia with severe physical and cognitive impairment but may also die earlier from dementia-related health problems such as pneumonia and intake problems or comorbid disease.^{20–22} Therefore, prognostication in dementia is difficult.^{4,23} Furthermore, in addition to physical and cognitive problems, behavioural problems or neuropsychiatric symptoms, such as apathy or depression, frequently develop as part of the dementia trajectory.²⁴

The different courses of patient deterioration warrant dementia-specific palliative care strategies. For example, treatment decisions more frequently need to consider comorbid disease. Furthermore, health-care professionals need specific expertise in managing behavioural problems and in anticipating, assessing and managing physical and cognitive problems. Communicating with patients and families of people with dementia requires special skills because the cognitive problems associated with dementia complicate decision making around a host of issues. Support for families is needed to help them in their role as proxy decision-makers in more advanced dementia and to deal with a high burden of care and chronic grief caused by the continuing deterioration of the patient.

Despite the availability of generic definitions of palliative care,^{13,25} and local eligibility criteria, it is unclear exactly what palliative care in dementia entails. So far, there has not been any accepted definition or standard of palliative care specific to dementia. Based on evidence and consensus, we aimed to define palliative care for dementia patients as distinct from palliative care for other patient groups. We focused on older people with dementia because prevalence increases strongly with age.³ Furthermore, young-onset dementia (before 65 years) presents a different set of challenges.²⁶ We also focused on progressive dementias, excluding dementia caused, for example, by brain trauma.

In this official position paper of the European Association for Palliative Care (EAPC Onlus), we define palliative care in dementia by describing its core domains and by defining optimal care. We present a set of recommendations for all those who provide palliative care to people with dementia. We additionally consider a research agenda to provide guidance for clinical practice, policy and for future research specific to palliative care in dementia.

Methods

An expert consensus process was conducted on behalf of the EAPC. We performed a Delphi study to build systematic consensus. The process was characterized by anonymity in the sense of protecting the Delphi results from the influences of group conformity, iteration (allowing for change of opinions), controlled feedback (i.e. results of the previous rounds were communicated), a statistical group response and the ability to combine the responses with empirical evidence or literature.^{27,28} The protocol was approved by the local scientific committee in Amsterdam (WC2011-065), and confidentiality of individual responses was ensured by the processing of coded data.

Delphi round 1: drafting of domains and recommendations by a core group

In the first qualitative and unstructured round,^{29,30} a core group of 12 experts (the authors) from six countries drafted a set of core domains. For each domain, recommendations were also drafted that were perceived to be most important in terms of giving shape to palliative care in dementia. The recommendations were supported by explanatory text citing relevant empirical studies and (preferably) reviews (Box1).^{31–36} We also referred to position papers, legal documents and clinical experience where evidence was sparse.

Box 1. Resources for the development of the recommendations on palliative care and treatment of older people with Alzheimer's disease and other progressive dementias.

Literature – on palliative care in dementia

Input for Delphi study round 1, and subsequent rounds if experts pointed out an omission

- Evidence from empirical studies or reviews when available (e.g. on pain tools^{31–33});
- Guidelines or other syntheses combining evidence with consensus or positions (e.g. the chapter on advanced dementia in the 'Guidelines for a Palliative Approach in Residential Aged Care' from the Australian government³⁴);
- Position papers and policy reports (e.g. UK national strategies on palliative care³⁵);
- Legal documents referring to rights, legal status and requirements (e.g. on the legal status of advance directives in Europe³⁶).

Expert input – variable professions and expertise related to palliative care, dementia care or palliative care in dementia

Evaluations were qualitative only in Delphi rounds 1 and 5 and were both qualitative and quantitative in rounds 2–4. Rounds 2–5 each resulted in revisions, and feedback was provided in rounds 3 and 4

- Core group of 12 experts from 6 countries (input in all rounds, and in particular rounds 1 and 4);
- Panel of 64 experts from 23 countries (online survey rounds 2 and 3);
- EAPC Board and national membership organizations (round 5, open comments).

The core group comprised expertise in medicine, nursing, social work and counselling, ethics, patient involvement, epidemiology and research methodology. All members were knowledgeable about palliative care or dementia care (mostly both) on the basis of research, education or clinical experience. The draft set was developed in 2011, and references to literature were added if important gaps were identified in subsequent rounds, or new evidence emerged (Box 1).

Delphi rounds 2 and 3: evaluation by an expert panel with online survey

In spring 2012, the core group, on behalf of the EAPC, invited a panel of 89 experts from 27 countries to evaluate the domains and recommendations in a two-round online survey developed with Survey Monkey (online survey software and questionnaire tool: <http://www.surveymonkey.com>). The explanatory text with each of the recommendations was not itself part of the evaluation but was available upon request.

Health professionals or researchers who specialized in either palliative care or dementia care (or both) were purposefully invited to participate, having been identified through the networks of the core group. We also sought input from outside Europe. All the relevant domains of palliative care, including psychosocial and spiritual care, were covered. In the third round, we included only items on which full consensus was not reached in round 2. Feedback included summarized comments and overall and personal scores. Revisions were discussed within the core group.

The panellists evaluated the importance of the overall set and the domains to palliative care in dementia on a 10-point scale where 0 = not important and 10 = very important. We accepted a domain where the mean score was ≥ 8 , which suggested an acceptable level of consensus about its importance; where the means were between 6 and 8, we fed back revised domains and we eliminated those scoring ≤ 6 .³⁷

The recommendations were evaluated on a 5-point scale (although numbers were not provided to the panellists) as follows: 'strongly disagree' (1), 'moderately disagree' (2), 'neither agree, nor disagree' (3), 'moderately agree' (4) and 'strongly agree' (5). We accepted the recommendations, all of which were positively formulated, as full consensus if there was high, or very high agreement based on measures of central tendencies and dispersion. Very high agreement was defined as a median of 5, an interquartile range (IQR) of 0 and $\geq 80\%$ scoring a 4 or 5.³⁸ Furthermore, high agreement was median 5, IQR ≤ 1 and $\geq 80\%$ scoring a 4 or 5. We fed back recommendations with moderate and low agreement only. Moderate agreement or consensus was defined as a median of 4–5, IQR ≤ 2 and $\geq 60\%$ scoring a 4 or 5. Low agreement (no consensus) was a median of 4–5, and (IQR ≤ 2 or IQR $\geq 60\%$ scoring a 4 or 5). We rejected those with medians between 2 and 4 as showing no agreement. In parallel, we defined, for example, very high disagreement with median 1 and IQR = 0 and $\geq 80\%$ scoring 1 or 2 (full consensus on very high disagreement). We additionally phrased statements, some in directions opposite to what we expected, on the usefulness of the set and on the applicability of palliative care across stages of dementia. In round 3, we also asked panellists to prioritize domains for research from 1 (research most needed) to 11 (research least needed for this domain), which we recoded 10–0, respectively, to match the importance scale.

Round 2 was open for feedback for 40 days (19 April–28 May), and we sent out three general and two personal reminders to nonrespondents. Round 3 was open for 69 days over summer months (June 15–August 22) with two general and four personal reminders.

Delphi round 4: decisions by the core group on the recommendations without full consensus

Recommendations with moderate agreement after round 3 were revised by five core group members based on the feedback in rounds 2–3. The other seven members independently indicated their preference for either the last circulated or the revised version. A revised recommendation was accepted as full consensus finally, if preferred by at least five of the other members (i.e. a total of 10/12 preferred the revised version).

Delphi round 5: adapting of the explanatory text as suggested by the EAPC

In Autumn 2012, the full set, including the explanatory text, was sent to the EAPC Board of Directors and to the 51 EAPC collective member associations inviting comments.

Results

Round 1

The draft set comprised 11 domains and 57 recommendations (Box 2 presents the final versions) along with explanatory text (final versions available online supplementary Annex). When recommendations overlapped, we referred to the other recommendation as shown in Box 3.

Box 2. The 11 domains and 57 recommendations on palliative care and treatment: final version.

Domain 1. Applicability of palliative care

- 1.1 Dementia can realistically be regarded as a terminal condition. It can also be characterized as a chronic disease or, in connection with particular aspects, as a geriatric problem. However, recognizing its eventual terminal nature is the basis for anticipating future problems and an impetus to the provision of adequate palliative care.
- 1.2 Improving quality of life, maintaining function and maximizing comfort, which are also goals of palliative care, can be considered appropriate in dementia throughout the disease trajectory, with the emphasis on particular goals changing over time.

- 1.3 Palliative care for dementia should be conceived as having two aspects. The baseline is a palliative care approach. For patients with complex problems, specialist palliative care should be available.
- 1.4 A palliative care approach refers to all treatment and care in dementia, including adequate treatment of behavioural and psychological symptoms of dementia, comorbid diseases, and (inter- or concurrent) health problems.

Domain 2. Person-centred care, communication and shared decision making

- 2.1 Perceived problems in caring for a patient with dementia should be viewed from the patient's perspective, applying the concept of person-centred care.
- 2.2 Shared decision making includes the patient and family caregiver as partners and is an appealing model that should be aimed for.
- 2.3 The health care team should ask for and address families' and patients' information needs on the course of the dementia trajectory, palliative care and involvement in care.
- 2.4 Responding to the patient's and family's specific and varying needs throughout the disease trajectory is paramount.
- 2.5 Current or previously expressed preferences with regard to place of care should be honoured as a principle, but best interest, safety and family caregiver burden issues should also be given weight in decisions on place of care.
- 2.6 Within the multidisciplinary team, patient and family issues should be discussed on a regular basis.

Domain 3. Setting care goals and advance planning

- 3.1 Prioritizing of explicit global care goals helps guide care and evaluate its appropriateness.
- 3.2 Anticipating progression of the disease, advance care planning is proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited.
- 3.3 Formats of advance care plans may vary in terms of preferences, the amount of detail required, and what is available in the specific setting for the individual.
- 3.4 In mild dementia, people need support in planning for the future.
- 3.5 In more severe dementia and when death approaches, the patient's best interest may be increasingly served with a primary goal of maximization of comfort.
- 3.6 Advance care planning is a process, and plans should be revisited with patient and family on a regular basis and following any significant change in health condition.
- 3.7 Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.

Domain 4. Continuity of care

- 4.1 Care should be continuous; there should be no interruption even with transfer.
- 4.2 Continuous care refers to care provided by all disciplines.
- 4.3 All patients should benefit from the early appointment of a central coordinator from within their care team.
- 4.4 Transfers between settings require communication on care plans between former and new professional caregivers and patient and families.

Domain 5. Prognostication and timely recognition of dying

- 5.1 Timely discussion of the terminal nature of the disease may enhance families' and patients' feelings of preparedness for the future.
- 5.2 Prognostication in dementia is challenging and mortality cannot be predicted accurately. However, combining clinical judgement and tools for mortality predictions can provide an indication which may facilitate discussion of prognosis.

Domain 6. Avoiding overly aggressive, burdensome or futile treatment

- 6.1 Transfer to the hospital and the associated risks and benefits should be considered prudently in relation to the care goals and taking into account also the stage of the dementia.
- 6.2 Medication for chronic conditions and comorbid diseases should be reviewed regularly in light of care goals, estimated life expectancy, and the effects and side effects of treatment.
- 6.3 Restraints should be avoided whenever possible.
- 6.4 Hydration, preferably subcutaneous, may be provided if appropriate, such as in case of infection; it is inappropriate in the dying phase (*only moderate consensus*).
- 6.5 Permanent enteral tube nutrition may not be beneficial and should as a rule be avoided in dementia; skillful hand feeding is preferred (*only moderate consensus*).
- 6.6 Antibiotics may be appropriate in treating infections with the goal of increasing comfort by alleviating the symptoms of infection. Life-prolonging effects need to be considered, especially in case of treatment decisions around pneumonia.

Domain 7. Optimal treatment of symptoms and providing comfort

- 7.1 A holistic approach to treatment of symptoms is paramount because symptoms occur frequently and may be interrelated, or expressed differently (e.g., when pain is expressed as agitation).
- 7.2 Distinguishing between sources of discomfort (e.g., pain or being cold) in severe dementia is facilitated by integrating views of more caregivers.
- 7.3 Tools to assess pain, discomfort and behaviour should be used for screening and monitoring of patients with moderate and severe dementia, evaluating effectiveness of interventions.

- 7.4 Both non-pharmacological and pharmacological treatment of physical symptoms, challenging behaviour or discomfort should be pursued as needed.
- 7.5 Nursing care is very important to ensure comfort in patients near death.
- 7.6 Specialist palliative care teams may support staff in long-term care settings in dealing with specific symptoms, while maintaining continuity of care. In managing behavioural symptoms, however, palliative care teams may need additional dementia care specialist expertise.

Domain 8. Psychosocial and spiritual support

- 8.1 In mild dementia, as also in the later stages, patients may be aware of their condition, and patients and families may need emotional support.
- 8.2 Spiritual caregiving in dementia should include at least assessment of religious affiliation and involvement, sources of support and spiritual well being; in addition, referral to experienced spiritual counsellors such as those working in nursing homes may be appropriate.
- 8.3 Religious activities, such as rituals, songs, and services may help the patient because these may be recognized even in severe dementia.
- 8.4 For dying people, a comfortable environment is desirable.

Domain 9. Family care and involvement

- 9.1 Families may suffer from caregiver burden, may struggle to combine caring with their other duties and may need social support.
- 9.2 Families may need support throughout the trajectory, but especially upon diagnosis, when dealing with challenging behaviour, with health problems, with institutionalization, with a major decline in health and when death is near.
- 9.3 Families need education regarding the progressive course of the dementia and (palliative care) treatment options; this should be a continuous process addressing specific needs in different stages, examining family receptiveness.
- 9.4 Family involvement may be encouraged; many families may wish to be involved in care even when the patient is admitted to an institution providing long-term care.
- 9.5 Families need support in their new role as (future) proxy decision maker.
- 9.6 Professional caregivers should have an understanding of families' needs related to suffering from chronic or prolonged grief through the various stages, and with evident decline.
- 9.7 Bereavement support should be offered.
- 9.8 Following the death of the patient, family members should be allowed adequate time to adjust after often a long period of caring for the patient.

Domain 10. Education of the health care team

- 10.1 The health care team in its entirety, including allied health professionals and volunteers, needs to have adequate skills in applying a palliative care approach to dementia.

(Box Continued)

10.2 Core competencies comprise all of the above listed domains (1 to 9). All competencies should be available within a health care team, and preferably all individual members of the team should be able to provide at least a baseline palliative care approach.

Domain 11. Societal and ethical issues

11.1 Wherever patients reside, patients with dementia should have access to palliative care on the same footing as patients with other diseases which are unresponsive to curative treatment.

11.2 Family caregivers should have access to adequate support to combine caring for the patient with dementia with other duties.

11.3 Collaboration between dementia and palliative care should be promoted.

11.4 Curricula for training of physicians and nurses at both undergraduate and postgraduate level, as part of continuing professional education, should include palliative care for patients with illness other than cancer.

11.5 Professional caregivers should be motivated to work in dementia and palliative care and adequate funding for sufficient staffing is needed.

11.6 Economic and systemic incentives should encourage excellent end-of-life care for patients with dementia.

11.7 Awareness raising about palliative care in dementia is needed.

11.8 National strategies for dementia, for palliative care, end-of-life care, and for long-term care should each include palliative care for dementia patients. Similarly, policy making on palliative care and long-term care settings should attend to dementia.

^aExplanatory text with each recommendations is available as an online-only supplementary Annex.

Box 3. Two recommendations including explanatory text of final version.

1. Applicability of palliative care

1.1 Dementia can realistically be regarded as a terminal condition. It can also be characterized as a chronic disease or, in connection with particular aspects, as a geriatric problem. However, recognizing its eventual terminal nature is the basis for anticipating future problems and an impetus to the provision of adequate palliative care.

Most dementias, such as Alzheimer's disease, are inevitably progressive, life shortening and ultimately lead to death even if patients may live for many years.¹⁻³ The perception of dementia as a terminal disease has been associated with greater comfort in patients dying with dementia.⁴

Some have suggested that labelling dementia care as palliative care might in itself result in improved patient care.⁵ The principles and practice of geriatric or gerontological medicine should also apply, because dementia, as a chronic condition, is often related to cerebrovascular and

cardiovascular disease,⁶ albeit dementia also affects younger people. Whatever other models apply, a core element should be anticipating inevitable decline and death, and related to this, anticipating specific needs.

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1.4 A palliative care approach refers to all treatment and care in dementia, including adequate treatment of behavioural and psychological symptoms of dementia, comorbid diseases, and (inter- or concurrent) health problems

Behavioural and psychological symptoms of dementia (BPSD) including behaviour that challenges caregivers such as agitation, or that may be a problem for the patient, such as apathy, are an important aspect of dementia. It may be related to other problems, such as cognitive impairment, depression, or pain.¹⁸⁻²¹ Often, such symptoms are also burdensome for families.²² The multidisciplinary palliative approach may be helpful in anticipating, assessing and managing problems. With challenging behaviour, integration of the specific expertise from the fields of geriatrics and dementia care specialists is recommended, with a significant role for (clinical) psychology. Of note, a palliative approach does not aim to hasten death nor to prolong life, and therefore does not preclude treatment of health problems such as infections with antibiotics, because this may be the best way to resolve burdensome symptoms.

Note also 6.2, medication, and 11.3, collaboration

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Round 2

Of the 89 invited experts, 64 (72%) from 23 countries completed the online survey (Table 1). Six experts requested the explanatory text.

The overall rating of importance for the set to palliative care in dementia was 8.9 (Table 2), and it ranged from 6 to 10. Mean domain ratings were all 8 and higher, except for 'prognostication and timely recognition of dying', which received a mean rating of 7.3 in round 2. Very high or high agreement was achieved for 51 of 57 recommendations, whereas the experts agreed moderately on the other six, which included the two of the prognostication domain, two of four recommendations under 'applicability of palliative care' and two of six from 'avoiding overly aggressive, burdensome or futile treatment'. The main comments referred to tools for prognostication being of little help, concerns about relabelling all dementia care as palliative care (1.2 and 1.4 in Box 2) and dogmatism regarding artificial nutrition and rehydration, where an individual approach, taking into account cultural issues, was recommended (6.4 and 6.5 in Box 2).

Furthermore, there was very high agreement that palliative care in dementia was important (Table 3). There was high agreement that complying with the set of recommendations would result in improved care (median = 5, IQR = 1 and 93% agreement; not in Table 3). However, there was no consensus on the importance of dementia severity (Table 3). Agreement was moderate on Figure 1 representing appropriate care goals across stages of dementia (median = 4, IQR = 2 and 70% agreement; the explanation was added later in response to feedback).

Round 3

We fed back to the expert panel the six recommendations with moderate agreement (all revised but for one, on hydration— 6.4 in Box 2) and a revised Figure 1, and added statements on applicability across dementia sever-

Table 1. Characteristics of Delphi panellists (n = 64, round 2, evaluation of full set of domains and recommendations).

Female gender, %	58
Age, mean number of years, SD and range	M = 52.9, SD = 8.0 and range = 34–72
Residence, %	
Europe	63
North America	19
South America	2
Australia/New Zealand	8
Far/Middle East	9
Profession, %	
Physician	61
Nurse	16
Other	23
Researcher, %	36
Professional experience, mean number of years, SD and range	M = 25.9, SD = 8.4 and range = 3–41
Respondent felt having expertise, %	
In palliative care	94
In dementia care	95
In palliative care in dementia specifically	70

SD = standard deviation.

ity (Table 3). A total of 59 of the 64 panellists (92%) from 22 countries responded. Two recommendations (1.4 and 5.1 in Box 2) reached high agreement and were accepted. The panellists also re-evaluated the importance of the domain on prognostication with the two revised recommendations. It was accepted this time (mean = 8.0).

Round 4

The revised versions of two of the four remaining recommendations (1.2 and 5.2 in Box 2) were accepted by the core group and therefore finally qualified as having achieved full consensus. The team was divided about the revised recommendations on artificial nutrition and hydration (6.4 and 6.5 in Box 2), and therefore, we kept the versions as evaluated in round 3, noting that there was moderate consensus only (Box 2). This also applied to the revised text in Figure 1, concerning which, however, we incorporated feedback from the core group and revised again.

Round 5

Four member associations from four countries commented on usefulness in their country specifically, such as issuing pocket-format recommendations and integrating with local work. Comments of four board members resulted in a few revisions of the explanatory text, after which the Board of Directors approved.

Table 2. Experts' ratings of domains as important to palliative care in dementia and rating of priorities for research.

Domain	Importance rating, ^a mean (SD)	Rank number importance	Priority for research rank, ^b mean (SD)	Rank number priority for research	Correlation rank numbers: Spearman coefficient ^d (p-value)
	Round 2 (n = 64) and, if applicable, round 3 (n = 59)		Round 3, n = 55 ^c		
Overall rating for the importance of the set of recommendations	8.9 (1.2)	N/A	N/A	N/A	-
1. Applicability of palliative care	8.3 (1.9), round 2 8.4 (1.9), round 3	10	5.3 (3.8)	4	+0.03 (0.83)
2. Person-centred care, communication and shared decision-making	9.3 (1.1)	2	7.6 (2.6)	1	-0.15 (0.26)
3. Setting care goals and advance planning	8.8 (1.4)	9	6.3 (2.9)	3	-0.006 (0.97)
4. Continuity of care	8.9 (1.4)	8	5.0 (2.8)	7	-0.11 (0.42)
5. Prognostication and timely recognition of dying	7.3 (2.2), round 2 8.0 (1.5), ^e round 3	11	3.9 (3.2)	8	+0.44 (0.001)
6. Avoiding overly aggressive, burdensome or futile treatment	9.1 (1.6)	5	5.2 (3.0)	5	+0.29 (0.03)
7. Optimal treatment of symptoms and providing comfort	9.4 (1.1)	1	6.7 (2.4)	2	+0.21 (0.13)
8. Psychosocial and spiritual support	8.9 (1.3)	7	3.8 (2.2)	10	+0.17 (0.21)
9. Family care and involvement	9.2 (1.1)	3	5.1 (2.3)	6	+0.15 (0.27)
10. Education of the health-care team	9.0 (1.3)	6	3.9 (2.6)	9	-0.005 (0.97)
11. Societal and ethical issues	9.2 (1.2)	4	2.2 (3.1)	11	-0.10 (0.48)

SD: standard deviation; '-': not tested.

^a0 = not important to 10 = very important.

^b0 = research is least needed for this domain to 10 = research is most needed for this domain. Note that respondents could select each rank number for research priority only once.

^cn = 55 responses (completing of this last item of the Delphi round 3 was optional so not required to save responses and complete the survey, and four experts preferred not to indicate priorities).

^dCorrelation last round (round 3 rating), if available.

^eMean rating of 8.04, which was above the cut-off of 8 for acceptance.

Research priorities

The two domains that received the highest importance ratings were also identified as research priorities (Table 2): 'person-centred care, communication and shared decision making' and 'optimal treatment of symptoms and providing comfort'. Of note, there were no significant correlations between individual ratings of importance for palliative care versus for research, except for 'prognostication and timely recognition of dying' and 'avoiding overly aggressive, burdensome or futile treatment', where the same experts who tended to give higher importance ratings also tended to indicate these domains as a research priority. The lowest research priority ratings were for 'societal and ethical issues' and 'psychosocial and spiritual support'.

Discussion

Recognizing the need for palliative care in dementia, the EAPC has commissioned this research-based position paper. A thorough Delphi study was employed to achieve a consensus on defining optimal palliative care for older people with dementia on a theoretical and more practical level, pro-

viding recommendations on the provision of palliative care in Europe and elsewhere. The initial structure of the domains that emerged from the literature on palliative care in dementia when drafting recommendations sufficed as it was not challenged by any of the 64 experts in our international panel. The first domain, 'applicability of palliative care', is mostly conceptual, whereas the eight following domains are more clinically oriented. The last two domains address education and ethical/societal issues, which may be particularly relevant for policymaking at different levels, including the training level. We specifically wished to evaluate both conceptual and clinically oriented domains with the Delphi panel because we were interested in their relevance, not only for clinical practice but also for policy and research.

Six of the initial 57 recommendations did not immediately achieve full consensus and five were revised, after which all domains were accepted as important to palliative care in dementia (rating 8 or higher on the 0–10 scale). Moreover, the minimum rating for importance overall was as high as 6. We thus found a strong consensus despite a modest evidence base. The first phase of the Delphi study was prepared within a multidisciplinary and international core group, which may have been representative of expert opinion generally and, therefore,

Table 3. Importance of palliative care in dementia and dementia severity.

Statement (n, round)	Agreement	%	Median (IQR) and total % (dis)agreed	Conclusion
With regard to care and treatment, I feel that palliative care is ...	Response options			
Important in older people with Alzheimer's disease and other progressive dementias (n = 64, item included in round 2).	Strongly disagree	0	Strongly agree (0)	Very high agreement (full consensus)
	Moderately disagree	0	0 disagreed and 95% agreed	
	Neither agree nor disagree	5		
	Moderately agree	11		
	Strongly agree	84		
ONLY important in older people with SEVERE dementia (n = 64, item included in round 2).	Strongly disagree	48	Moderately disagree (2.5)	Low disagreement (no consensus)
	Moderately disagree	27	75% disagreed and 25% agreed	
	Neither agree nor disagree	0		
	Moderately agree	16		
	Strongly agree	9		
EQUALLY important in older people with severe dementia as it is to less severe dementia ^a (n = 59, item included in round 3)	Strongly disagree	14	Moderately agree (3)	No agreement (rejected)
	Moderately disagree	29	42% disagreed and 51% agreed	
	Neither agree nor disagree	7		
	Moderately agree	15		
	Strongly agree	36		
MORE important in older people with severe dementia as it is to less severe dementia ^a (n = 59, item included in round 3)	Strongly disagree	8	Moderately agree (3)	Low agreement (no consensus)
	Moderately disagree	19	27% disagreed and 64% agreed	
	Neither agree nor disagree	8		
	Moderately agree	20		
	Strongly agree	44		

IQR: interquartile range.

^aTwo persons agreed strongly on both statements (equally, and more important, same round); nobody disagreed strongly on both statements.

more likely to achieve consensus with participants in later phases of the study. In addition, it may be that the guidance had sufficient generalizability to be non-controversial. There was high agreement that adherence to the guidance would result in improved care locally, meaning the recommendations reflect aspirations rather than describing common practice.

Most recommendations were based on full consensus; guidance was refined in the cases of recommendations without full

consensus. However, we had to take a position on the two recommendations on which there was only moderate consensus even after four Delphi rounds. These concerned nutrition and hydration, which have also been identified as particularly culturally sensitive in cross-national comparative work on family guidance in palliative care in dementia.³⁹ While the guidance in the recommendations was retained, we used the panelists' comments to differentiate and improve the explanatory text.

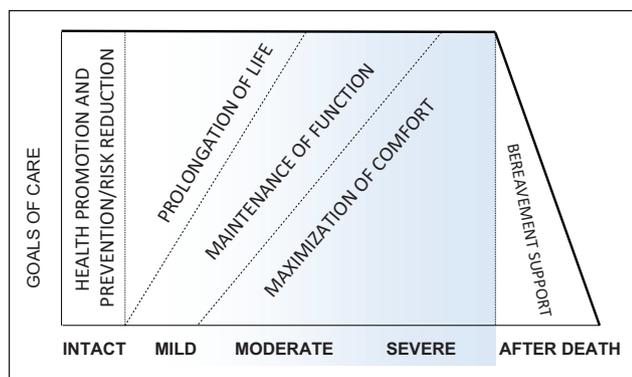


Figure 1. Dementia progression and suggested prioritizing of care goals.

Explanation: The figure represents a model of changing care goals and priorities throughout the course of the dementia. It suggests prioritizing of care goals that may apply at the same time but have variable relevance to different stages of dementia. More than one care goal may apply at the same time. For example, for a patient with moderate dementia, the three goals may apply simultaneously but maximization of comfort and maintenance of function may be prioritized over prolongation of life.

As with any model, the visualization of care goals represents an abstraction of reality, and in practice will need tailoring to needs and preferences of patients and families. The figure does not directly relate to a palliative curative dichotomy. Nevertheless, the goals of maintenance of function which may include delaying of disease progression and maximization of comfort best represent a focus on quality of life and are therefore most compatible with palliative care.

Note also 9.6, while bereavement support is provided after death, families may need early support for chronic or prolonged grief.

Of note, there was moderate agreement among experts on this recommendation (as opposed to high agreement for most other recommendations). The explanation was extended based on the feedback of the experts which indicated that it needed further clarification.

The current 11-domain framework differs from, but the core elements resemble, 'domains' and 'key elements' identified for palliative care more generally in an earlier consensus project (2009).⁴⁰ Six of the eight domains in that project, however, are formulated more neutrally as 'aspects', such as 'physical aspects of care'. Some of their 'key elements' are domains in our work, such as the key element 'continuity of care across settings'. As in our work, domains are linked to specific guidance (guidelines). Furthermore, domains inevitably overlap to some extent as in our work, such as 'structure and processes of care' and 'care of the imminently dying patient'. Indeed, some attributes of good death, such as dignity and being free from pain, may be important for all,⁴¹⁻⁴⁵ which is consistent with our findings in connection with 'person-centred care, communication and shared decision making' and 'optimal treatment of symptoms and providing comfort', which are both identified as central to care.

The topics addressed overlap to a large extent, but the guidance provided in the 2009 generic project is rarely specific, or even applicable, to dementia. Alzheimer associations provide more specific guidance, but explicit links to specific evidence or a transparent consensus-driven approach are sometimes lacking. Alzheimer Europe grouped 55

recommendations by people with dementia, family carers, health professionals and policymakers/state.⁴⁶ The US Alzheimer's Association provides nine recommended care practices for long-term care.⁴⁷ Dementia-specific work emphasizes the various roles of families, and (advance) decision making. Interviewing 49 experts across the globe, the US Alzheimer's Association found that 'communication and decision making about care' was the most important area underlying all other key characteristics of quality end-of-life care.⁴⁸ Specific to our current work is an emphasis on applicability of palliative care, the importance of prognostication and avoiding aggressive treatments, based on the assumption that it is important to realize that dementia is a potentially terminal disease for which palliative care may be beneficial.

A goal-oriented approach simplifies decision making for patients with multiple conditions.⁴⁹ Future work should address the applicability of palliative care and appropriate care goals across all stages of dementia. Our visualization of a changing mix of three possible care goals adopts Gillick's suggested goals for chronically ill elderly patients in need of long-term care.⁵⁰ Distinguishing the three goals, namely, prolongation of life, maintenance of function and comfort, may be more helpful in dementia than the 'disease-modifying (curative)' versus 'symptom management (palliative)' dichotomy proposed by Lynn and Adamson¹⁷ a decade ago. We visualize how the three goals may co-exist and suggest how priorities may change over time, where the last two of the three goals are most consistent with the concept of palliative care. We found, however, that there is clearly no consensus among experts as to which stages palliative care applies best, although there was a tendency for agreement on its applicability to all stages, but more so in more severe dementia.

Obviously, how to give shape to palliative care in dementia across dementia stages needs further study, especially given the increasing possibility of early diagnosis.⁵¹ For example, recommendations may be refined so as to differentiate between its relevance for severe or less severe dementia, or between needs that are more likely soon after diagnosis versus those occurring in the dying phase. An exclusive focus only on advanced dementia⁵² is not helpful. The notion of 'supportive care', to present a broader view of the ways in which care in dementia can be conceptualized, has also been recommended.⁵³

The highest research priority expert ratings were for the *when* and *how* of decision making and providing physical comfort (i.e. the three domains 'person-centred care, communication and shared decision making', 'setting care goals and advance planning' and 'optimal treatment of symptoms and providing comfort'). These were the domains generally found important. The exception was advance planning, where the research priority is, however, consistent with recent reports on lack of evidence.^{54,55} Furthermore, research into prognostication and avoiding aggressive treatment was favoured, in particular by experts who acknowledge its importance to palliative care in dementia. Noteworthy is that

the lowest research priority ratings overall were for ‘societal and ethical issues’ and ‘psychosocial and spiritual support’. Perhaps this is related to an under-representation of panellist with specific expertise in ethics, policy, psychological and spiritual support; a general focus on medical aspects of palliative care or a perception of research being less efficient in its ability to address these aspects specifically.

Available evidence is generally stronger for institutional long-term care than community settings, probably because many patients die in these settings.^{56,57} In addition, there are practical reasons to encourage this sort of work in long-term care settings, which have also been the focus of diverse research and policy initiatives. However, when palliative care is initiated early, professional caregivers with only limited experience of people with dementia may require guidance. Therefore, palliative care research for dementia patients at home and in hospitals deserves more attention, perhaps using comparative research methods, which could take advantage of the rich variety of care models in use across European countries. Compared to evidence on effective strategies of palliative care in cancer, evidence for dementia and other progressive chronic diseases is modest.⁵⁸ More specifically, recently published data from the United Kingdom suggests that a 15-fold increase is required to reach parity with research into heart disease, and a 30-fold increase is required to achieve parity with cancer research.² The situation might be as bad for palliative care. Our work may need an update in a few years to include new evidence and other developments, such as the more stringent policies regarding the use of restraint in several European countries.

The Delphi methodology allowed for efficient work with geographically dispersed experts.³⁸ There are no firm rules regarding consensus levels for Delphi studies,^{30,59} but our cut-off for full consensus (80% or higher scoring 4 or 5 indicating agreement, along with a median of 5 and IQR at most of 1) seems conservative compared to reported cut-offs between 51% and 100%.^{30,59,60} It was not feasible to perform systematic literature reviews on all topics where these were lacking, and the explanatory text needs updating when more evidence becomes available. Both evidence and expert views were mostly from Western countries. Whereas the mean proportionate increase in dementia in Europe by 2050 is estimated to be 87%, to almost 19 million; for Africa, the projected increase is 370%, to almost 9 million; and for Asia, the projected increase is 282%, to 61 million.^{1,2}

Implementation in other regions may, therefore, need adjustment according to local culture and practice, for example, regarding sensitivities around treating intake problems and families’ needs for information regarding euthanasia.^{39,61} In general, dissemination to practitioners should involve those specializing in palliative care who may require specific information about, say, the course of dementia, and those specializing in dementia interested in learning how to apply palliative care principles to their patients. We did not indicate relevance to specific disciplines because many recommendations are

relevant to all. Palliative care is multidisciplinary by nature. Tasks may overlap and differ by country. For implementation, however, such discipline orientation may be helpful. The domain structure and recommendations may be used as a framework to help to identify gaps in curricula or in information provided to families, in the development and implementation of policies, to develop quality indicators or to make comparisons with (future) definitions or conceptualisations of palliative care in other progressive chronic diseases such as organ failure. We encourage translation, dissemination and implementation for use in practice and policymaking.

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