European Association for Palliative Care
Non Governmental Organisation (NGO) recognised by the Council of Europe

VUmc VU University Medical Center Amsterdam

Palliative Care for Neurodegenerative Diseases in particular Dementia

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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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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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EAPC ONLUS

European Association for Palliative Care

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Remit 2010:

"to define palliative care for dementia patients as *distinct* from palliative care for other patient groups, to describe *core* issues, and to provide *future* directions for palliative care in dementia"

Palliative care in dementia (older people)

- Conceptual issues (*distinct*)
  - applicability
  - model of prioritising care goals

What is palliative care?

"Palliative care is an approach that improves the **quality of life** of patients **and their families** facing the problem associated with **not responsive to curative treatment (EAPC)** through the prevention and relief of suffering by means of **early** identification and impeccable assessment and treatment of pain and other problems**, physical, psychosocial and spiritual**"

(WHO definition of palliative care, 2002)

What is palliative care?

"Palliative care is an approach that improves the **quality of life** of patients **and their families** facing the problem associated with **progressive, advanced disease for which the prognosis is limited (EUGMS)** through the prevention and relief of suffering by means of **early** identification and impeccable assessment and treatment of pain and other problems, **physical, psychosocial and spiritual**"

(WHO definition of palliative care, 2002)

What is palliative care in dementia?

"End of life palliative care"

= "the special form of continuing care when a person with dementia is close to the end of his or her life"

"the journey of dementia care from diagnosis to palliative care."

(Dementia a public health priority, WHO 2012; World Alzheimer report, Alzheimer's disease international, 2009)

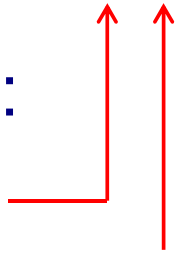
Palliative care in dementia

- Conceptual issues (*distinct*)
  - applicability
  - model of prioritising care goals
- White paper from the EAPC
  - defining of palliative care in dementia: 11 domains (*core*)
  - defining of optimal care: 57 recommendations
- Research agenda (*future*)

White paper on palliative care in dementia

- Defining palliative care in dementia:
  what are the important domains?
- Defining optimal palliative care in dementia:
  what does palliative care in dementia aspire?
- Research agenda

Prioritizing of domains



All based on:
- evidence
- consensus among experts

An international Delphi study

5-round Delphi study – aimed at reaching consensus

- Round 1: (2011) core team (12) drafts domains and recommendations
- Rounds 2-3: (2012) experts (64 from 23 countries) evaluate draft via online survey with feedback in subsequent round – revisions. Prioritizing of domains for research.
- Round 4: (2012-2013) revisions and decisions core team
- Round 5: (2012-2013) input EAPC board and members

An international Delphi study

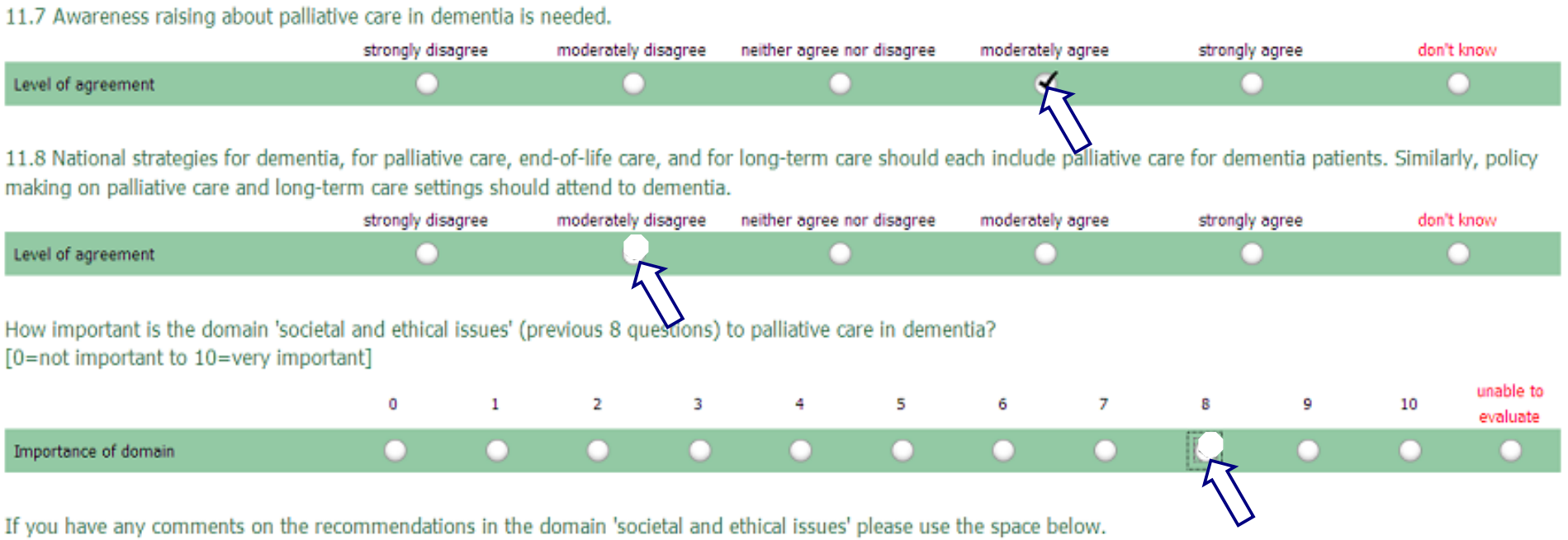
Rounds 2-3 – quantitative and qualitative

Experts on palliative care, dementia care, palliative care in dementia, care for older people; diverse professions

- Invited: 89 experts from 27 countries
- Response: 1st round 64 experts (72%) from 23 countries
  - **40 (63%) from Europe**
  - 17 (27%) from North Americas/Australia
  - 7 (11%) from South America or Far/Middle East
  - 2nd round 59 experts (66%)

An international Delphi study

Rounds 2-3 – quantitative and quantitative



EAPC Recommendations Palliative Care in Dementia – 2nd round

Prioritization for reseach agenda

Please prioritise the domains for a research agenda (meaning your rating does NOT refer to importance, but indicates where you feel that research is most needed) 1 = research is MOST needed for this domain 11 = research is LEAST needed for this domain

The easiest way to put the domains in the preferred order is to fix the domain with a left mouse click and then move the domain to the preferred place. Alternatively, you may pull down the preferred number at the left, but this results automatic renumbering and shifiting of domains simultaneously, which may be confusing.

Before you finalize, please check if the listing of domains matches your choice because this order is being submitted to the team.

- Applicability of palliative care
- Person-centred care, communication, and shared decision making
- Setting care goals and advance planning
- Continuity of care
- Prognostication and timely recognition of dying
- Avoiding overly aggressive, burdensome, or futile treatment
- Adequate treatment of symptoms and providing comfort
- Psychosocial and spiritual support
- Family care and involvement
- Education of the health care team
- Societal and ethical issues

Defining palliative care in dementia
domains

1. Applicability of palliative care
2. Person-centred care, communication, and shared decision making
3. Setting care goals and advance planning
4. Continuity of care
5. Prognostication and timely recognition of dying
6. Avoiding overly aggressive, burdensome, or futile treatment
7. Optimal treatment of symptoms and providing comfort
8. Psychosocial and spiritual support
9. Family care and involvement
10. Education of the health care team
11. Societal and ethical issues

Defining palliative care in dementia

domains

	Mean importance rating 1st round, 0-10 (SD)
1. Applicability of palliative care	8.3 (1.9)
2. Person-centred care, communication, and shared dec.m.	9.3 (1.1)
3. Setting care goals and advance planning	8.8 (1.4)
4. Continuity of care	8.9 (1.4)
5. Prognostication and timely recognition of dying	**7.3 (2.1)**
6. Avoiding overly aggressive, burdensome, or futile treatm.	9.0 (1.6)
7. Optimal treatment of symptoms and providing comfort	9.4 (1.1)
8. Psychosocial and spiritual support	8.9 (1.3)
9. Family care and involvement	9.2 (1.1)
10. Education of the health care team	9.0 (1.3)
11. Societal and ethical issues	9.2 (1.2)

Defining palliative care in dementia

domains

	Mean importance rating 1st round	2nd round
1. Applicability of palliative care	8.3 (1.9)	8.4 (1.9)
2. Person-centred care, communication, and shared dec.m.	9.3 (1.1)	
3. Setting care goals and advance planning	8.8 (1.4)	
4. Continuity of care	8.9 (1.4)	
5. Prognostication and timely recognition of dying	**7.3 (2.1)**	**8.0 (1.5)**
6. Avoiding overly aggressive, burdensome, or futile treatm.	9.0 (1.6)	
7. Optimal treatment of symptoms and providing comfort	9.4 (1.1)	
8. Psychosocial and spiritual support	8.9 (1.3)	
9. Family care and involvement	9.2 (1.1)	
10. Education of the health care team	9.0 (1.3)	
11: Societal and ethical issues	9.2 (1.2)	

Domain structure not challenged. Importance as a whole: 8.9

Limitation: no evaluation of possibly missed domains.

Defining palliative care in dementia

domains

	Mean importance rating both rounds, 0-10 (SD)
1. Applicability of palliative care	8.4 (1.9)
2 Personcentred care, communication and shared decision making:	9.3
3. Setting care goals and advance planning	8.8 (1.4)
4. Continuity of care	8.9 (1.4)
5. Prognostication and timely recognition of dying	8.0 (1.5)
6. Avoiding overly aggressive, burdensome, or futile treatm.	9.0 (1.6)
1 Optimal treatment of symptoms and providing comfort:	9.4
8. Psychosocial and spiritual support	8.9 (1.3)
9. Family care and involvement	9.2 (1.1)
10. Education of the health care team	9.0 (1.3)
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Defining palliative care in dementia

important domains link to good death more generally

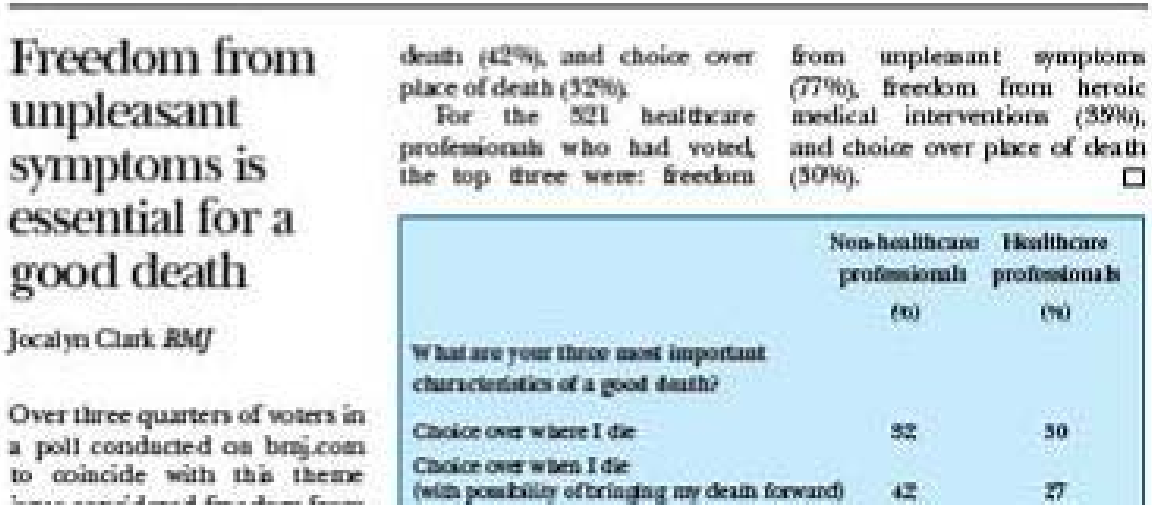
2 Personcentred care, communication and shared decision making: 9.3

Priorities according to families of patients with dementia:

- Symptoms (pain under control, breating comfortably)
- "Whole person concerns" (includes "keep dignity and self-respect")

(van der Steen et al., Int J Geriatr Psychiatr 2011)

1 Optimal treatment of symptoms and providing comfort: 9.4



Freedom from unpleasant symptoms is essential for a good death

Jocalyn Clark *BMJ*

Over three quarters of voters in a poll conducted on bmj.com to coincide with this theme

death (42%), and choice over place of death (32%).

For the 521 healthcare professionals who had voted, the top three were: freedom from unpleasant symptoms (77%), freedom from heroic medical interventions (38%), and choice over place of death (30%). □

	Non-healthcare professionals (%)	Healthcare professionals (%)
What are your three most important characteristics of a good death?		
Choice over where I die	32	30
Choice over when I die (with possibility of bringing my death forward)	42	27

Defining palliative care in dementia

domains compared to palliative care more generally

1. **Applicability of palliative care**
2. Person-centred care, communication, and shared dec.m.
3. **Setting care goals and advance planning**
4. Continuity of care
5. **Prognostication and timely recognition of dying**
6. Avoiding overly aggressive, burdensome, or futile treatm.
7. Optimal treatment of symptoms and providing comfort
8. Psychosocial and spiritual support
9. **Family care and involvement**
10. Education of the health care team
11: Societal and ethical issues

(compared with: US National Consensus Project for Quality Palliative Care, 2009)

Defining palliative care in dementia

(other) differences with palliative care in cancer

- Communicating with the patient
- Addressing of behavioral problems
- Meaning of spiritual problems not well understood
- Lower level of evidence regarding effectiveness of treatment
- Setting: more frequently long-term care
- ……..

Defining palliative care in dementia

(other) differences with palliative care in other ND??

- Similarities: may apply early, communication, ACP, family support…
- Differences: more evidence, older people, course of the dementia…

Defining palliative care in dementia

differences with (usual) dementia care

Dementia palliative care:

- Emphasises advance care planning
- Anticipates death and recognises the dying phase
- Includes systematic monitoring and addressing of symptoms
- Includes bereavement care, but not a pre-diagnosis trajectory
- Includes an explicit focus on spiritual care, less so: physical environment and practical issues

Defining palliative care in dementia

differences with (usual) dementia care

Dementia palliative care:

- Emphasises advance care planning
- Anticipates death and recognises the dying phase
- Includes systematic monitoring and addressing of symptoms
- Includes bereavement care, but not a pre-diagnosis trajectory
- Includes an explicit focus on spiritual care, less so: physical environment and practical issues

Is **anticipating death** helpful?

Caregivers believe early that dementia is a disease you can die from

⇒ patient's death more comfortable

(van der Steen, Onwuteaka-Philipsen, et al., BMC Med 2013)

What is palliative care?

"Palliative care is an approach that improves the **quality of life** of patients **and their families** facing the problem associated with **life-threatening illness**, through the **prevention** and relief of suffering by means of **early** identification and impeccable assessment and treatment of pain and other problems**, physical, psychosocial and spiritual**"

(WHO definition of palliative care, 2002)

Defining palliative care in dementia

some remaining controversies around applicability

- Expert less likely to agree with the four recommendations within Domain 1. Applicability of palliative care:
- **[removed Figures of unpublished work in progress]**

- Experts equally likely to agree (NO difference):
- **[removed Figures of unpublished work in progress]**

(van der Steen et al, paper in progress, 2014)

Defining palliative care in dementia

domains

	Mean importance rating both rounds, 0-10 (SD)
1. Applicability of palliative care	8.4 (1.9)
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Defining palliative care in dementia

domains

	Importance (rank nr)
1. Applicability of palliative care	10
2. Person-centred care, communication, and shared dec.m.	2
3. Setting care goals and advance planning	9
4. Continuity of care	8
5. Prognostication and timely recognition of dying	11
6. Avoiding overly aggressive, burdensome, or futile treatm.	5
7. Optimal treatment of symptoms and providing comfort	1
8. Psychosocial and spiritual support	7
9. Family care and involvement	3
10. Education of the health care team	6
11: Societal and ethical issues	4

Defining palliative care in dementia

domains and research priorities

	Importance	Research
1. Applicability of palliative care	10	4
2. Person-centred care, communication, and shared dec.m.	2	1
3. Setting care goals and advance planning	9	3
4. Continuity of care	8	7
5. Prognostication and timely recognition of dying	11	8
6. Avoiding overly aggressive, burdensome, or futile treatm.	5	5
7. Optimal treatment of symptoms and providing comfort	1	2
8. Psychosocial and spiritual support	7	10
9. Family care and involvement	3	6
10. Education of the health care team	6	9
11: Societal and ethical issues	4	11

Defining palliative care in dementia

domains and research priorities

	Importance	Research
1. Applicability of palliative care	10	4
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Defining palliative care in dementia

domains and research priorities

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3. Setting care goals and advance planning	9	3
4. Continuity of care	8	7
5. Prognostication and timely recognition of dying	11**	8**
6. Avoiding overly aggressive, burdensome, or futile treatm.	5*	5*
7. Optimal treatment of symptoms and providing comfort	1	2
8. Psychosocial and spiritual support	7	10
9. Family care and involvement	3	6
10. Education of the health care team	6	9
11: Societal and ethical issues	4	11

- Not important (prognostication)
- Quality of care acceptable? → 93% agree recommendations improve practice
- Sufficient evidence or knowledge → needs implementation
- Research not the best way to improve (e.g., possible level of evidence, need for "local evidence")

Defining palliative care in dementia

domains and research priorities

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Defining palliative care in dementia

domains and research priorities

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Defining palliative care in dementia

domains and research priorities

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9. Family care and involvement	3	6
10. Education of the health care team	6	9
11: Societal and ethical issues	4	11

Defining optimal palliative care in dementia
divergences → research?

- The expert panel immediately accepted 51 / 57 recommendations

- Not immediately accepted:
  - how and when palliative care applies: stages of dementia
  - discussing of prognosis ↓
  - nutrition/hydration → moderate agreement only

Defining palliative care in dementia

domains and research priorities

	Importance	Research
1. Applicability of palliative care	10	4
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4. Continuity of care	8	7
5. Prognostication and timely recognition of dying	11	8
6. Avoiding overly aggressive, burdensome, or futile treatm.	5	5
7. Optimal treatment of symptoms and providing comfort	1	2
8. Psychosocial and spiritual support	7	10
9. Family care and involvement	3	6
10. Education of the health care team	6	9
11: Societal and ethical issues	4	11

White paper on palliative care in dementia
research priorities at a national level

- Framework for setting of research agenda or priorities to improve practice
- [**removed Figure of unpublished work in progress**]

Dutch elderly care physicians

White paper on palliative care in dementia
research priorities at a national level

Most important barriers with regard to palliative care in dementia in your practice

- Dutch elderly care physicians:
- **removed Figures of unpublished work in progress**]

- GPs in N. Ireland:
- **removed Figure of unpublished work in progress**]

(*Brazil, van der Steen et al. work in progress*)

White paper on palliative care in dementia research agenda

- The Delphi expert panel prioritised for research:
  - applicability of palliative care (domain 1)
  - decision making / ACP (domains 2 and 3)
  - treating symptoms and avoiding inappropriate treatment (domains 6 and 7)
- Recommendation of further research into how to give shape to palliative care in dementia across dementia stages
- Recommendation of comparative research across Europe's rich variety of care models, with particular attention to home care and hospital settings