

Palliative Care for People with Dementia and their Families

Jenny T. van der Steen, PhD

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Leiden University Medical Center
Department of Public Health and Primary Care
And Radboudumc university medical center Nijmegen
Department of Primary and Community Care



The Netherlands

Palliative care

What is palliative care in dementia?

- Fits & benefits
- Understanding & controversies
- Families & patients

Research

- Past
- Present
- Hot or not

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)

To which diseases does palliative apply?

- WHO: applies to “patients and their families facing the problems associated with **lifethreatening** illness”
- US National consensus project: “**debilitating chronic or life-threatening** illness”
- European Association for Palliative Care (EAPC): “care of patients whose disease is **not responsive to curative treatment**”
- European Union Geriatric Medicine Society (EUGMS): applies to “**progressive, advanced disease for which the prognosis is limited**”

Does palliative care apply to dementia?

- Cannot be cured, life limiting

Palliative care: expert (end-of-life) care for people for whom there is no cure

Does palliative care apply to dementia?

- Cannot be cured, life limiting
- Patients and families
- Complex, specific needs
- Anticipation of problems
- Person-centered, holistic, multi-disciplinary care
- Focus on quality of life
- Good death: dignity and low symptom burden

Does palliative care apply to dementia?

Nevertheless..

What should we know about dementia in the 21st century?

Delphi study with 19 UK dementia experts

(Annear et al., BMC Ger 2015)

Very high consensus ($\geq 80\%$ very important)

- "Dementia is a terminal condition that will result in death"
- "A person-centred approach to care is appropriate...."
- "Pain" "depression" [etc] "should be identified and treated"
- "It is important to plan the future care ...once a diagnosis...."

Very low consensus (40% very important)

- "A palliative approach to care is appropriate for a person with dementia"

What is palliative care in dementia?



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

White paper from the European Association for Palliative Care:

theoretical [framework](#)

- defined palliative care in dementia: 11 domains
- defined optimal care: 57 recommendations

Delphi study with transparent procedures, all based on:

- evidence
- consensus among experts (64 from 23 countries)

(van der Steen, Radbruch, et al.; EAPC, Palliat Med 2014)

Defining (optimal) palliative care in dementia

Domain 7. Optimal treatment of symptoms and providing comfort

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.

Self assessment pain rating scales can often be used in mild and moderate dementia, but in severe dementia, should be supplemented by observation of body language and facial expression which may provide valid clues to patients being in pain.¹⁶⁴⁻¹⁶⁶ A variety of tools to assess pain in dementia have been developed and some tools have been tested in multiple studies with positive results, and have also provided cut off points suggesting the need for interventions.¹⁶⁷⁻¹⁷⁰ These include the Pain Assessment in Advanced Dementia (PAINAD) scale¹⁷¹ (cutoff for pain 2 of 10 points¹⁷²), the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)¹⁷³ (cutoff for pain 4 of 24 of reduced-item PACSLAC¹⁷⁴), and Doloplus¹⁷⁵ (cutoff for pain 5 of 30¹⁷²). Some tools are rather

Defining palliative care in dementia

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

Mean importance rating
of experts (0 to 10)

2 Personcentred care, communication and shared decision making: 9.3

3. Setting care goals and advance planning

4. Continuity of care

Also most important for research

5. Prognostication and timely recognition of dying

6. Avoiding overly aggressive, burdensome, or futile treatment

1 Optimal treatment of symptoms and providing comfort: 9.4

8. Psychosocial and spiritual support

9. Family care and involvement

10. Education of the health care team

11. Societal and ethical issues

Most important barriers according to
UK and Dutch physicians:
Acceptance general public (part of domain 1)
Education of the health care team (domain 10)
(Galway, Brazil, van der Steen, under review)

Defining palliative care in dementia

Differences with cancer

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

Differences with cancer

1. **Applicability of palliative care**
2. Person-centred care, communication, and shared decision making
3. **Setting care goals and advance planning**
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6. Avoiding overly aggressive, burdensome, or futile treatment
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- 11: Societal and ethical issues

Defining palliative care in dementia

Dementia strategies

- Overlapping domains
- No explicit reference to palliative care in 10 of 16 strategies:
Wales, Scotland (1st), France, the Netherlands, Denmark, Norway, US, Japan, South Korea (2)
- Explicit reference to palliative care in 6 strategies:
 - some sentences: Scotland (2nd), Australia and Finland
 - dedicated section: England, Northern Ireland and Sweden

Narrowly defined: as end-of-life care

Palliative care versus end-of-life care: just semantics?

Or, palliative care as an approach that promotes early awareness and anticipation of the end of life?

(Nakanishi et al., Int Psychogeriatr 2015)

Defining palliative care in dementia

Differences with “usual” dementia care

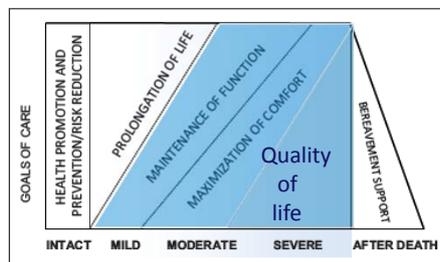
Dementia palliative care:

- Anticipates death and recognises the dying phase
- Emphasises advance care planning
- 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

Palliative care in dementia controversies



- Prognostication: accurate, important?
- What to do in case of food and fluid intake problems?
- When to start palliative care – early phase?



Living well with dementia

Quality of life

—————> Dementia severity

(van der Steen et al., *Int Psychogeriatr* 2016)

Family roles

- Care giver
- Care recipient (emotionally involved, pre-grief)
- Provide information about care preferences
- Proxy decision maker (substitute, or involved)
- Help interpret behaviour (pain, discomfort, unmet needs)
- Provide feedback to help improve the care

Family outcomes

Survey in community; n = 1287 family caregivers in the Netherlands

Burden of care (14-item Self-Perceived Pressure from Informal Care Scale; unadjusted analyses)

	Dementia	No dementia
End of life		
Not end of life		

(van de Boogaard JA et al., MS UNDER REVIEW; RESULTS REMOVED)

Family outcomes

Survey in community; n = 1287 family caregivers in the Netherlands

Positive caregiving experience (6-item Positive Experiences Scale ; unadjusted analyses)

	Dementia	No dementia
End of life		
Not end of life		

(van de Boogaard JA et al., MS UNDER REVIEW; RESULTS REMOVED)

Research questions.....

Develop effective palliative care interventions for each stage

- How to increase positive family caregiving experiences?
- When, how and for whom exactly is anticipating the end of life important?
- At what point do we stop attempts to improve prognostication, and focus on managing uncertainty?
- What is the evidence for managing food and fluid intake problems in terms of patient comfort and family satisfaction?
- How do we balance and integrate medical approach (symptoms) and a social approach (dignity)?
- How do we best link palliative care and dementia care expertise? (organisations, caregivers)
- What are the best educational approaches, for whom?

Research: past

1967 St. Christopher's hospice London



1970-ies

- cancer palliative care for the dying + research
- non-treatment of infections in US nursing homes (Brown)

1246

THE NEW ENGLAND JOURNAL OF MEDICINE

May 31, 1979

NONTREATMENT OF FEVER IN EXTENDED-CARE FACILITIES

NORMAN K. BROWN, M.D., AND DONOVAN J. THOMPSON, PH.D.

Abstract In a study of decisions not to treat febrile patients, we reviewed the medical records of 1256 people admitted to nine extended-care facilities in Seattle during 1973. Fever, defined as two temperatures of 38.33°C to 38.83°C (101 to 101.9°F) within 24 hours or one temperature >38.88°C (102°F), developed in 190 patients before two years of stay. Active treatment, defined as antibiotics or hospitalization (or both), was ordered for fever in 109 patients, of whom 10 (9 per cent) died. Active treatment was not ordered for 81 patients, of whom 48 (59 per cent) died.

The pre-decision factors that showed a significant relation ($P < 0.05$) to such nontreatment were: diagnosis, mental status, mobility, pain, narcotics prescribed, size of the facility, relation of the physician to the patient and medical-record statements documenting the patient's deterioration or plans for nontreatment in general. This pattern of nontreatment suggests that physicians and nurses did not intend to treat these patients actively and that high mortality was expected. (N Engl J Med 300:1246-1250, 1979)

PHYSICIANS have been accused of prolonging life at any cost. However, surveys of health pro-

chronic disease. Examples of such changes were confusion, reduced responsiveness, weakness, poor eating or more specific manifestations of febrile illness ($P < 0.05$).

43%, and unrelated to dementia

Research: past

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1970-ies

- cancer palliative care for the dying + research
- non-treatment of infections in US nursing homes (Brown)

1980-ies

- Hospice care for people with dementia

Hospice Approach to the Treatment of Patients With Advanced Dementia of the Alzheimer Type

Ladislav Volicer, MD, PhD; Yvette Rheume, BSN, RN; June Brown, LCW; Kathy Fabiszewski, RN, MS; Roger Brady, MDiv



Research: past

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1970-ies

- cancer palliative care for the dying + research
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1980-ies

- Hospice care for people with dementia

1990-ies

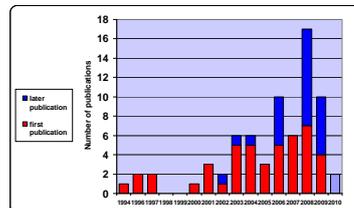
- A few studies in US and UK

2000 →

Longitudinal observational studies

2003-2007 CASCADE, US Mitchell et al. "advanced dementia = terminal"

2007-2011 DEOLD Netherlands "and so is moderate dementia"



(van der Steen, JAD 2010)

Research: present

Hot topics - Development and testing of interventions

- Of tools that support **advance** care planning



Research: present

Hot topics - Development and testing of interventions

- Of tools that support **advance** care planning
- Of tools to help identify **symptoms**

Behavior	0	1	2	Score
Breathing Independent of vocalization	• Normal	• Occasional labored breathing • Short period of hyperventilation	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations	
Negative vocalization	• None	• Occasional moan or groan • Low-level speech with a negative or disapproving quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	
Facial expression	• Smiling or inexpressive	• Sad • Frightened • Frown	• Facial grimacing	
Body language	• Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling or pushing away • Striking out	
Consolability	• No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract, or reassure	
TOTAL SCORE				

(Warden et al., 2003)

Research: present

Hot topics - Development and testing of interventions

- Of tools that support **advance** care planning
- Of tools to help identify **symptoms**
- Of complex palliative care interventions that involve **families**



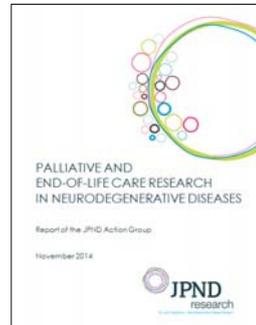
Research: future

What research we do NOT want

What research we no longer need in neurodegenerative disease at the end of life: The case of research in dementia

A complete silence. That was what we got back from the European experts who had been energetically discussing research priorities in palliative care in neurodegenerative disease (ND) until a short while ago.¹ The chair, an entertaining professor with good manners, must have felt the unease and quickly refocused the group to their task. But, wasn't this the best question of all day? What research we no longer need? As scientists able to consider different

(van der Steen and Goodman, Palliat Med 2015)



In sum

We need rigorous research and implementation of effective interventions

We need a better understanding of how and when to apply palliative care

Because palliative care has a lot to offer for people with dementia and their families

Promising strategies link dementia care expertise to expertise in palliative care

itvandersteen@lumc.nl