

## Review

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# Dying with Dementia: What We Know after More than a Decade of Research

Jenny T. van der Steen\*

*VU University Medical Center, EMGO Institute for Health and Care Research, Department of Nursing Home Medicine, and Department of Public and Occupational Health, The Netherlands*

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**Abstract.** Death with dementia is increasingly common. Although prognostication is difficult, it is an incurable life-limiting illness for which palliative care for the patient is often appropriate. Dementia patients are otherwise at risk of overtreatment with burdensome and possibly non-beneficial interventions and undertreatment of symptoms. Although recent studies indicate encouraging trends of improved palliative care, little evidence supports effectiveness of specific treatments. As of January 2010, at least 45 studies, almost all performed after 2000, have reported on treatment, comfort, symptom burden, and families' satisfaction with care. Over half (25; 56%) of these studies were in US settings, and most were small or retrospective. Few randomized trials and prospective observational studies have been performed so far, but several promising studies have been completed recently or are underway in various countries. Guidelines for care and treatment, still mostly consensus-based, support the benefits of advance care planning, continuity of care, and family and practitioner education. Assessment tools for pain, prognosis, and family evaluations of care have been developed and some have been shown to be effective in clinical practice. With increasing numbers of well-designed, large-scale studies, research in the next decade may result in better evidence-based guidelines and practice.

Keywords: Dementia, hospice care, intervention studies, palliative care, prospective studies, retrospective studies, terminal care

## INTRODUCTION

Death with dementia will probably be the fate of many of us, but until recently, it received remarkably little attention from the research community as well as from society as a whole. This article summarizes what we know about dying with dementia, identifies trends in research and guideline development, presents selected practice recommendations, and considers future directions in care for patients dying with dementia.

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\*Correspondence to: Jenny T. van der Steen, VU University Medical Center, EMGO Institute for Health and Care Research, Department of Nursing Home Medicine, Van der Boechorststraat 7, 1081BT Amsterdam, The Netherlands. Tel.: +31 20 4449694; Fax: +31 20 4448387; E-mail: j.vandersteen@vumc.nl.

## DEATH WITH DEMENTIA

Death with dementia is common and will increase over the next decades. One of nine deaths in the Netherlands involves dementia [1]. In the UK, 30% of decedents aged 65 and over have dementia [2]. Other work which was not based on assessment of cognition but relied solely on death certificates coding only underlying causes, reports much smaller percentages (i.e., 6% in the Netherlands versus 12% including direct causes) [1,3]. In the US, Alzheimer's disease is the seventh leading cause of death [4]. Most dementia patients in the US and Western Europe die in long-term care facilities [3,5].

Causes of death in community and hospital-based samples are not very different for dementia and non-dementia patients with cardiovascular disease and pneumonia being frequent causes of death [6,7]. In

nursing home-based samples, these conditions are also common causes, but about one-third of death certificates list the dementia itself (in a US study [8]), or cachexia/dehydration (in a Dutch study [9]). The difference may be due to recording practices in different settings.

Dementia follows a “frailty” pattern of decline, with patients suffering severe disability throughout the last year of life with a substantial decline in function (increased ADL dependency) in the last months of life. Concurrent illnesses may accelerate the decline but generally patients suffer a steady “prolonged dwindling” [10]. However, in patients who reach the advanced stages of dementia, their severe disability persists over the last year of life [11]. Not all patients reach the terminal phase with complete ADL-impairment, incontinence, and bedridden status. A Dutch study reported only 15% of nursing home residents with dementia ended their days in such condition [9]. Older age, male gender, comorbid disease, cognitive and functional status, and neuropsychiatric symptoms are all related to mortality [12,13]. Male gender and ADL dependency are the strongest predictors of 6-month mortality in patients with advanced dementia with no acute disease and also in dementia patients with pneumonia [13–15].

Survival of dementia patients is highly variable between individuals and also across studies with median survival from diagnosis or study entry of generally being between 5 and 9 years [16–19]. Variation across studies may be explained by different ways of defining onset of the dementia, and different age of the population under study, and by statistical adjustments. For example, one study reported median survival of 5.7 years from diagnosis, but as long as 10.5 years from onset of symptoms [20]. The patients were on average 75 years old when diagnosed with dementia and 80 upon death. Patients were older in another study (mean age was 84 at study entry), which reported shorter median survival from the onset of symptoms (6.6 years [21]). However, adjustment for the greater likelihood of missing patients who died early resulted in a reduction of median survival from 6.6 years to 3.3 years [21].

Although survival is variable both at the study and at the individual level, it is clear that dementia is a life-limiting illness [12] with survival significantly reduced compared to age-matched controls [22]. In nursing home residents, dementia is an independent risk factor for mortality [23].

The importance of recognizing dementia as a life-limiting illness lies in the applicability of palliative care, which provides supportive care to people in the

final phase of a terminal illness. In dementia patients, palliative care is also called comfort care and, in the US, hospice care. Hospice care may be more narrowly perceived as a system of US services that apply to patients with a life expectancy less than 6 months [24, 25], but was initially used as synonymous to palliative care [26].

## **SYMPTOMS AND TREATMENT AT THE END OF LIFE**

Pain, shortness of breath, and fatigue are present in over half of patients with life-threatening disease [27]. Fatigue is not often reported in dementia patients, meaning it is either less prevalent or infrequently noted (i.e., 22% in dementia patients versus 40% in non-dementia patients [28]). In contrast, pain and shortness of breath are frequently reported in dementia patients. Studies (see Box 1 for the methods of the literature search [29–32]) report pain in 12% to 76% of patients [28,33–47]. The lower percentages were reported in studies using the Minimum Data Set (MDS) [43], which is mandated in US nursing homes and is known for underreporting [48], in regards to “uncontrolled pain” [38] and in more recent work related to pain [44]. In general, 21% to 83% of dementia patients have been reported to be in pain at some point in their disease process [49,50] and pain may increase as death approaches [44,51].

Shortness of breath also increased near death [44], reported in 8% to 80% of such patients [28,33,37–41, 43–45,47,52]. Again, the lower percentages (8%) referred to MDS data [43] or to newer data (12% [28] and about 32% [44]). More typically, shortness of breath occurred in about half to three-quarters of patients.

In addition to pain and shortness of breath, US and Dutch families and Dutch nurses also reported that dementia patients experienced discomfort, restlessness, and difficulty swallowing more than other symptoms [53,54]. Agitation is a symptom which is less frequently assessed in studies on the last phase of life, but may be as common as pain and shortness of breath [28, 34,44,53,54]. One study found that psychiatric symptoms such as agitation and depression were less bothersome to family members than pain, breathing problems, and memory loss [46].

These symptoms are also prevalent in other populations with terminal illness such as advanced cancer, where 35% to 96% of patients are reported to be in pain [27,55], with a pooled prevalence of 64% in ad-

## Box 1

## Literature search on treatment and outcome in dementia at the end of life

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PubMed was searched for articles published until January 22, 2010, containing the following terms in all fields and MeSH terms:

- (1) Dementia and (end of life or end-of-life)
- (2) Dementia and palliative care
- (3) Dementia and (nursing home or nursing homes) and (decision making or satisfaction with care or prognosis)

The search was supplemented with hand searching, checking of references of eligible articles, examining possible relevant guidelines and reports, and use of information obtained via collaborating researchers in dementia at the end of life. The search refers to an update of a search performed in September 2007 which was previously published in Dutch language [29].

A total of 1339 abstracts were retrieved from PubMed (single sets resulted in 488 abstracts in set 1, 426 in set 2, and 607 in set 3).

Studies were included when published in full-text in English language, and reported quantitative data on treatment, comfort, symptom burden, and/or satisfaction with care in unselected patients with dementia or in populations with the majority of patients having dementia (frequently long-term care populations). When a later publication was in English, the non-English publication was cited as the first publication. Further, for unpublished prospective or intervention studies, the first reference to the study was equated to the first year of data collection. Included observational studies reported on status shortly before death, while (quasi) experimental studies referred to palliative care or treatment in patients with advanced dementia, or included after-death assessments. Not included were reports which focused on specific conditions, such as fever [30], pneumonia [31], or intake problems [32].

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vanced stages [55]. Shortness of breath presented in 12% to 79% of terminal cancer patients [56]. In general, about two of three patients need relief from these symptoms at the end of life [57], an approach that is appropriate for dementia patients as well.

Pneumonia is particularly associated with high levels of discomfort [31,58] with distressing symptoms occurring more frequently than in patients who die after intake problems [31]. Mitchell et al. [44] studied five symptoms prospectively and reported high and increasing levels of pain, dyspnea, agitation, aspiration, and pressure ulcers at the end of life in severely cognitively impaired nursing home residents.

Undertreatment of symptoms is a frequently-cited concern in dementia at the end of life [29,59], but few studies verify this concern with untreated pain infrequently reported [47,60,61]. An Italian study reported that over three-quarters of patients in pain were treated pharmacologically [37]. Most studies, however, do not relate pain to treatment. An Australian study cited general practitioners' reluctance to use morphine with older people and, if they ordered it, a reluctance to order a breakthrough dose [62], possibly due to concern about undesirable side effects such as sedation. Further, not all pain may always be taken away without sedation. Because pain may increase as death approaches [44, 51], a lack of recognition that the patient is dying may also result in inadequate treatment of pain.

Overtreatment with burdensome interventions is another widely reported phenomenon [29,59] although this varies across nations. Antibiotics were used in over 40% of US, UK, Swiss, and Italian patients dying with dementia [28,37,41,47,63–65]. Tube feeding was rare in the Netherlands [31], absent in a Swiss study [28], yet 21% of similar Italian patients were tube-fed [37].

Tube feeding varied between 4% and 39% in several US studies [39,45,47,63,66], and was 73% in Israel [67]. Hospitalization shortly before death was frequent in multi-site studies in US nursing homes [45,47,66].

Some encouraging trends from the Netherlands, US, and Switzerland have emerged regarding these treatment concerns. Treatment for symptom relief in dementia patients with pneumonia has increased over the last decade in the Netherlands [68]. For example, antipyretics (acetaminophen, NSAIDs) were used in 34% of patients with dementia and pneumonia in the late 1990s, and in 54% of such patients a decade later. US studies based on data from the 1990s reported inequalities between dementia patients and patients without dementia [43], but newer work shows that dementia patients benefit from hospice care as much as patients without dementia [61], and that the quality of nursing home care was at the same level [69]. A Swiss study showed that hospital care for dementia patients by a dedicated and research-minded team does not necessarily involve more aggressive care for dementia patients [28].

However, we still do not understand the extent to which symptoms can be avoided, and how care is improved most efficiently. Research may help improve the evidence base for treatment in dementia at the end of life.

## RESEARCH TRENDS IN DEMENTIA AT THE END OF LIFE

In the 1980s, Volicer introduced the concept of "hospice care" for dementia patients [26] ushering in a new era of research and a new way of thinking. Researchers

examined associations between treatment and outcome in frequently occurring treatment dilemmas, such as withholding antibiotics in patients with fever [30] or pneumonia [31], intake problems [32], and in hospitalization decisions [70,71].

Researchers also noted that affecting important outcomes at the end of life which are families' satisfaction with care and patients' quality of dying [72,73] is not an easy task [74]. Although advance care planning was increasingly performed, outcome and satisfaction with care did not improve significantly in a long-term care setting, although newer work [75] showed such effects are possible for competent patients in a hospital setting. Although satisfaction with care is not synonymous with quality of care and may be highly dependent upon expectations of care and other factors, families' satisfaction with end-of-life care is still an important outcome on its own [72] because of families' roles in care for the patient and because they will need to live on with the memories of the patient's last days. Studies in other end-of-life populations have reported improved satisfaction as a result of interventions such as consultation and coordination of care, or providing palliative or hospice care [76].

Research in dementia at the end of life has increased recently [29,59,77]. Family experiences have been described in a variety of qualitative studies (i.e., [78–85]). The results of selected studies have been integrated in a recent review, showing considerable unmet needs in families [85]. Through the beginning of 2010 (Box 1, Table 1), at least 45 studies [28,33–38,40–43,46,47,52,60,61,63,65,66,80,86–99,110] in another 26 publications [39,44,45,53,54,64,67,69,111–128] have reported (quantitative) results on treatment, outcome, or both, at the end of life in unselected populations (no concurrent disease) of dementia patients. The earliest of these studies, published in the 1990s, were from the US [40,63,106] and the UK [41,42] (Fig. 1A). Since 2003, annually, a first publication of 3 to 7 studies has appeared. The first two prospective studies and all intervention studies were limited to a single or few sites. Four of five newer prospective studies were multi-center studies involving more than 100 to several hundreds of patients. In total, over half (56% 25/45) of studies and two-thirds of publications (67%; 47 limited to US data, and one combined with Dutch data of 71 publications) originated from the US (Fig. 1B). Other studies were from various European and non-European western countries. Some outcome measures have been used in more studies [107,129–131].

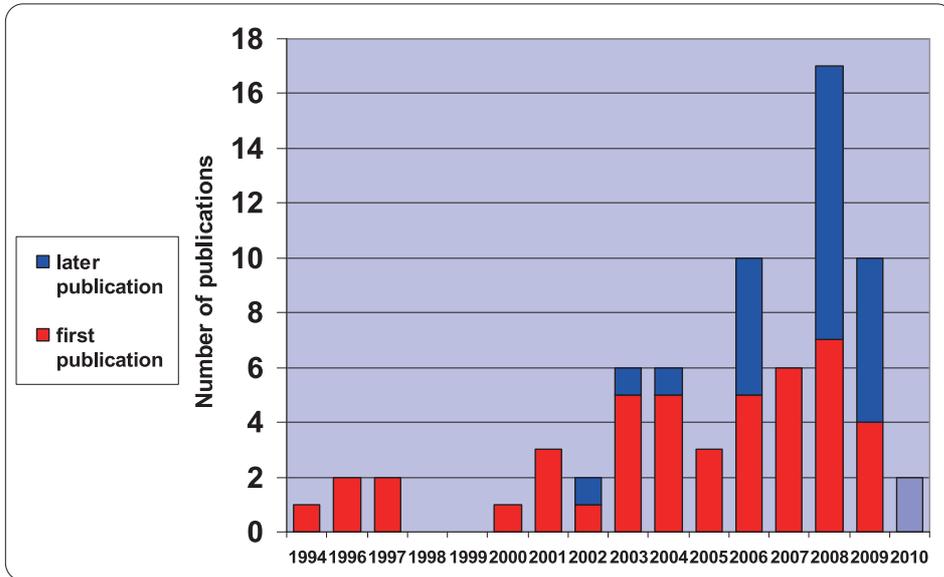
Prospective observational [60,89,91,95,102,106,108] and intervention studies [33,86,87,101,103,104,110]

provide the best evidence on how to improve care and 14 have been completed or are ongoing (Table 1). However, most studies have been small, retrospective, or both. In retrospective work, US hospice care for dementia patients has been associated with favorable evaluations by families, similar to hospice care for other conditions [61] and better compared with traditional dementia care [46], but it is unclear to what extent these findings can be attributed to enrollment in hospice and an expectation of death [45] when end-of-life care may be better perceived. This suggests that preparing families for death is a way to improve care. This approach is further validated by a study that showed that prepared families suffered from less depression and complicated grief [132], and acknowledgment as a terminal illness may also benefit patients (Table 1).

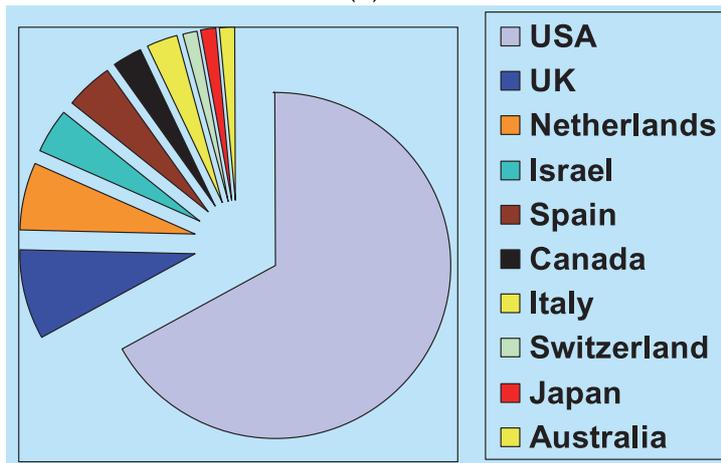
Newer and larger prospective studies include multi-center studies in the US (CASCADE; [44,64,95,115,118–120,128]), the Netherlands (DEOLD; [60]), and Italy (EOLO-PSODEC; [108] [F Toscani, personal communication]; Table 1, studies 3, 4 and 6) typically performed after initial retrospective study. Prospective studies vary as to whether they include both patient and family outcome, and some of them have restricted enrollment to advanced dementia due to feasibility and priority issues.

Several intervention studies have been performed or are ongoing in dementia at the end of life. The earliest study (performed in the 1990s and published in 2000; Table 1, intervention study 1) showed that a palliative care team failed to substantially affect treatment in a US hospital setting when it may have been too late to bring up palliative care [87]; families were often unwilling to be involved in such study in hospital settings [E.L. Sampson, personal communication about intervention study 6; [101]]. Multi-faceted programs that promote communication on end-of-life issues and continuity of care may be needed, but have not been well-tested yet (i.e., the PEACE program with no control group; study 3 [103]). A randomized double-blind, but small trial is underway (L-DOT; study 7 [107]) and potentially will provide evidence on the effectiveness of opioids to improve comfort in advanced dementia, demonstrating the ethical and practical feasibility of such studies.

There are unique concerns regarding research in dementia at the end of life. The general frailty of the patients is a frequently cited challenge in palliative care populations [73] as well as the concern that participating in research may burden the patient. Dementia patients have cognitive impairment so usually only proxies can give consent for the patient's participation.



(a)



(b)

Note: The time frame refers to first published study in 1994, until last update of search, January 22, 2010.

Fig. 1. (A) Publications (71) of studies (45) reporting treatment, symptoms, or families' satisfaction with care in patients dying with dementia: time trends. (B) Publications (71) of studies reporting treatment, symptoms, or families' satisfaction with care in patients dying with dementia: countries.

There are also the practical challenges of poor recruitment and limited follow-up [133,134]. Further, the frailty trajectory of decline results in difficult prognostication with the result that dementia may not be recognized as a terminal condition making it difficult to define an end-of-life population. Different definitions result in different study populations [135] and may result in difficulties comparing outcome across studies.

Research in dementia at the end of life also involves opportunities. Many patients reside in long-term care

institutions that provide the infrastructure to host large-scale studies. Although research in nursing home settings involves specific challenges (well described by Thompson and Chochinov [136]), it allows for the development of long-standing relationships between researchers and family caregivers and staff. Finally, international comparisons of treatment, care, and outcome benefit from differences in health care systems, and cross-national studies using the same instruments increase our understanding of the generalizability of

Table 1  
Observational and interventional studies in dementia at the end of life\*

Country and setting, years of data collection	Study name / acronym, and principal investigators	Design and data collection	Population	Main goals	Selected findings with a focus on longitudinal use of data
<i>Prospective observational studies</i>					
1. US (northeast) Veterans Affairs nursing homes; a DSCU for advanced Alzheimer's disease, and a traditional long-term care facility, both with facility-based physicians, 1991–1992 [106] [L.Volicer, personal communication]	Volicer L., et al.	Prospective cohort study. Outcome measures included the DS-DAT [129] for comfort, interventions, mortality, and costs.	114 residents of the DSCU, and 50 in the traditional long-term care facility.	To compare outcome (discomfort, interventions, mortality, and costs) between the two facility types (the DSCU employing a palliative approach).	In the DSCU, discomfort was lower and mortality was higher. There were fewer hospitalizations and costs were lower [106].
2. US nursing homes in Maryland (3) with facility-based physicians, 2000–2004 [89]	CareAD Black BS, Maust DT, Blass DM, Rabins PV, et al.	Quantitative and qualitative. Assessments by chart review, family interview (mostly face-to-face; Dr Black, personal communication) baseline, every 3 months and after death. Physician interview at baseline.	123 (up to 126 in later work) residents with dementia and life expectancy 6 months or less by physician's judgment or hospice criteria or already receiving hospice / palliative care. Recruitment was after initial and bimonthly screening.	– To describe treatment and care, and family experiences – To assess predictors of 6-month mortality. No goal of assessing patient's comfort.	– Resident white race and presence of a DNH were significant predictors of family decisions to not provide aggressive treatments [123]. – Increase in palliative medications and decrease of other, including antibiotics, near death. Other analyses were limited to baseline data (conditions and treatment associated with staff-identified pain [89]); retrospective chart review of neuropsychiatric symptoms and its treatment [121,122]; examining content of advance directives [125]; reports of semi-structured interviews with families on barriers and facilitators for completing advance directives or having care discussions [112].
3. US nursing homes in Boston area (22), most with no facility-based physicians, 2003–2007 [95]	CASCADE Mitchell SL, et al.	Quantitative. Assessments by chart review, family (telephone) and nurse (face to face) interview baseline, every 3 months and after death. Main outcome instruments include the well-tested EOLD Scales [107].	323 residents with severe cognitive impairment (CPS 5 or 6 and GDS 7) and dementia documented in chart, aged 65 and older. Recruited after initial and quarterly screening (includes residents who may have met the criteria long before enrolment).	To identify modifiable aspects of care in the course of the disease, family satisfaction with care, decision making, resident comfort, complicated grief.	– Description of clinical course for patients with pneumonia, fever, and eating problems [44]. – Frequent use of antibiotics shortly before death [64]. – Greater decision making satisfaction was associated with the resident living on a DSCU, greater resident comfort, and the proxy not being the resident's child [118]. Other analyses were cross sectional or did not include patients at the end of life (associations with satisfaction with care [115], instrument properties [128], cross sectional associations between grief and depression [120], and associations with family oversight (visiting) [119]).

Table 1, continued

Country and setting, years of data collection	Study name/ Acronym, and principal investigators	Design and data collection	Population	Main goals	Selected findings with a focus on longitudinal use of data
<p><b>4. Netherlands</b> – Nursing homes (19, with a total of 33 locations) from all over the Netherlands with facility-based physicians, <b>2007–2010</b> [60]</p>	<p><b>DEOLD</b> van der Steen JT, et al.</p>	<p>Quantitative and qualitative. Assessments with family, physician, and nurse questionnaires, every 6 months and after death; continuous monitoring of intercurrent disease by physicians; after death qualitative telephone interviews with physicians, nurses, and family. Main outcome instruments include the EOLD Scales [107], and the PAINAD [131].</p>	<p>Residents with a physician's diagnosis of dementia in variable stages recruited upon nursing home admission. 17 of 19 homes collect data prospectively and have enrolled over 350 residents.</p>	<p>– To describe treatment, care and outcome. – To assess associations of treatment and care with satisfaction with care and decision making, symptom burden and quality of dying. To subsequently determine factors most amenable for improvement. Further, to assess facilitators and barriers to early palliative care, and develop a guideline for timing of palliative care.</p>	<p>Residents' comfort when dying was predicted by how families and physicians perceived the dementia (unpublished data).</p>
<p><b>5. UK</b> – A large hospital in London, <b>June–December, 2007</b> [102]</p>	<p>Sampson EL, et al.</p>	<p>Prospective observational study; data were obtained from hospital records.</p>	<p>All patients aged over 70 with unplanned acute admission to the medical acute admissions unit. Of 617 eligible admissions, 262 had dementia.</p>	<p>– To determine prevalence of dementia among acute admissions – To assess mortality in dementia patients compared with patients without dementia. No goal of assessing patient's comfort.</p>	<p>– Of acute admissions in elderly adults, 42% had dementia. – In-hospital mortality was 18% for dementia patients, and 8% for those without dementia. Dementia and lower MMSE score were independent predictors of mortality [102].</p>
<p><b>6. Italy</b> – A stratified, representative sample of nursing homes in the Lombardia region, all with facility-based physicians, and the primary home care services for older demented people of 5 districts of the provinces of Reggio Emilia and Modena, <b>2008–2009</b> [108] [FToscami, personal communication]</p>	<p><b>EOLO-PSODEC</b> Toscani F, and Di Giulio, P</p>	<p>Prospective, quantitative design with 2-weekly assessment of comfort with the DS-DAT [129] and assessment of patient's condition and critical decisions by face-to-face interview with physicians and nurses.</p>	<p>Patients with a FAST score <math>\geq 7</math> and a prognosis of more than 2 weeks were enrolled; 315 from nursing homes, and 181 home care patients.</p>	<p>– To describe the population, end-of-life critical treatment decisions, treatment, and prescriptions – To assess discomfort – To assess possible differences between patients in nursing homes and home care.</p>	<p>Not available yet.</p>
<p><b>7. UK</b> – Up to 10 nursing homes, with no on-staff physicians are projected, <b>2008–2012</b> [91] [C. Goodman, personal communication]</p>	<p><b>EVIDEM EoL</b> Goodman C, et al.</p>	<p>Chart reviews and interviews with staff (i.e., nurse, general practitioner, social worker), family, and residents are planned. Instruments have not been included in any of the 6 other prospective studies.</p>	<p>Patients (120 to 250) in various stages of dementia; 133 have been recruited from 6 homes as of December 2009.</p>	<p>– Description of needs and provided care – From the observational data, to develop and test "specific tools and guidance."</p>	<p>Not available yet.</p>

Table 1, continued

Country and setting, years of data collection	Study name/ Acronym, and principal investigators	Design and data collection	Population	Main goals	Selected findings with a focus on longitudinal use of data
<i>Experimental work in (advanced) dementia</i>					
1. US teaching hospital in New York, during a 3-year period (dates not reported, presumably in the 1990tes) [87]	Ahronheim JC, et al.	<p><i>Intervention:</i> A palliative care team assessed patients, counseled families, and provided recommendations to the health care team.</p> <p><i>Design:</i> Randomized controlled trial. Data on treatment and care planning were obtained from chart review. Other outcomes were mortality and length of stay; no outcomes related to patient comfort.</p> <p><i>Intervention:</i> Proactive palliative care services.</p> <p><i>Design:</i> Comparison with historical controls. Chart review. Outcomes: care process, treatment goals, number of interventions and costs. No patient comfort or family outcomes.</p>	<p>Patients hospitalized with acute illness who had advanced dementia defined as FAST 6d or greater, and stable neurological deficits over the past month. Forty-eight patients were included in the intervention group, and 51 in the control group.</p> <p>Patients with advanced dementia who met FAST-based hospice enrollment criteria; 26 in the intervention group, and 26 in the retrospective control group.</p>	<p>To assess effectiveness of a palliative care team to plan palliative care and reduce burden of some interventions in a hospital setting.</p> <p>To assess effectiveness of proactive case-finding by the hospital's palliative care service compared to care as usual.</p> <p>To assess effectiveness of the intervention was effective:</p> <ul style="list-style-type: none"> <li>– Process measures differed between intervention and controls (shorter in hospital).</li> <li>– Care goals differed, with more frequently comfort only and DNR in the intervention group.</li> <li>– Number of therapeutic interventions, and therefore costs were lower in the intervention group.</li> <li>– Mortality and discharge rates did not differ [110].</li> </ul>	<p>The palliative care team intervention had little effect on burdensome interventions, and no effect on mortality, or length of stay. Palliative care plans were developed more frequently in the intervention group, but usually not earlier than upon discharge [87].</p>
2. US – ICU in an urban University-affiliated hospital, 1998–2001 [110]	Campbell ML, Guzman JA	<p>Quality improvement program.</p> <p><i>Intervention:</i> PEACE is a disease management model that incorporates advance planning, patient-centered care, family support, and a palliative care focus. An interdisciplinary team approach was implemented, with a central role for geriatricians in coordinating care.</p> <p><i>Design</i> without control group.</p> <p>Patient and family face-to-face interviews every 6 months (max. 2 years) and post-death telephone interview using the Toolkit of Instruments to Measure End-of-Life Care [130]. Interviews were to provide feedback to physicians, and for research.</p>	<p>The program is applicable from diagnosis of dementia through the terminal stages.</p>	<p>PEACE was designed as a demonstration project examining the feasibility of integrating a supportive care approach, improve referral to hospice, and to explore (other) potential benefits of the program.</p> <p>PEACE was designed as a demonstration project examining the feasibility of integrating a supportive care approach, improve referral to hospice, and to explore (other) potential benefits of the program.</p>	<p>Only non-longitudinal use of data has been described:</p> <ul style="list-style-type: none"> <li>– Description of the program [103].</li> <li>– Initial interview data (cross-sectional) through face-to-face interviews with 150 families: factors associated with caregiver burden, such as patient's behavioral problems and lack of support by the health care team [114].</li> <li>– The most bothering symptoms according to family-report (not at the end of life) were pain, memory problems, behavioral problems, changes in mood, functional dependency, and gait impairment. In most but not all cases (84%) these symptoms were documented [117].</li> </ul>
3. US – Primary care geriatrics practice in Chicago and Michigan; staff: geriatricians, nurse specialists, social worker, 1999–2000 [103,127]	PEACE program Shega JW, Sachs GA, et al.	<p>Quality improvement program.</p> <p><i>Intervention:</i> PEACE is a disease management model that incorporates advance planning, patient-centered care, family support, and a palliative care focus. An interdisciplinary team approach was implemented, with a central role for geriatricians in coordinating care.</p> <p><i>Design</i> without control group.</p> <p>Patient and family face-to-face interviews every 6 months (max. 2 years) and post-death telephone interview using the Toolkit of Instruments to Measure End-of-Life Care [130]. Interviews were to provide feedback to physicians, and for research.</p>	<p>The program is applicable from diagnosis of dementia through the terminal stages.</p>	<p>PEACE was designed as a demonstration project examining the feasibility of integrating a supportive care approach, improve referral to hospice, and to explore (other) potential benefits of the program.</p> <p>PEACE was designed as a demonstration project examining the feasibility of integrating a supportive care approach, improve referral to hospice, and to explore (other) potential benefits of the program.</p>	<p>Only non-longitudinal use of data has been described:</p> <ul style="list-style-type: none"> <li>– Description of the program [103].</li> <li>– Initial interview data (cross-sectional) through face-to-face interviews with 150 families: factors associated with caregiver burden, such as patient's behavioral problems and lack of support by the health care team [114].</li> <li>– The most bothering symptoms according to family-report (not at the end of life) were pain, memory problems, behavioral problems, changes in mood, functional dependency, and gait impairment. In most but not all cases (84%) these symptoms were documented [117].</li> </ul>

Table 1, continued

Country and settings, years of data collection	Study name/ Acronym, and principal investigators	Design and data collection	Population	Main goals	Selected findings with a focus on longitudinal use of data
<p><b>4. Australia</b> – Two long-term care facilities with no on-staff physicians, <b>2005</b> [86]</p>	<p>Abbey J, Parker D, et al.</p>	<p><i>Intervention:</i> palliative care model based on the national Guidelines for a Palliative Approach in Residential Aged Care [115]. It included education of staff (nurses, general practitioners), multidisciplinary case conferencing using the guidelines, and implementation of palliative goals.</p> <p><i>Design:</i> retrospective and prospective collection of data, including the EOLD instruments, treatments, and care planning.</p>	<p>End-stage dementia which referred to a set of criteria regarding incontinence, communication, intake of food and fluids, weight loss, pain, skin integrity, peripheral circulation, an expectation of death within 12 months.</p>	<ul style="list-style-type: none"> <li>– Description of care and outcome at the end of life</li> <li>– To develop and test a structured model of multidisciplinary palliative care.</li> </ul>	<p>– Reflections on the program. Families evaluated the program positively at baseline (i.e., 96% had confidence in the health care team) and this persisted in subsequent interviews. Twenty-nine percent of medication was classified as never appropriate and only half (46%) were always appropriate [150] in a pilot study. Overall, the authors believe the PEACE approach improved patient care through the identification and management of unmet needs. However, interventions are ill-defined, and triggers for action plans were not available, limiting reproducibility [127].</p> <p>During the 10-months trial period, 17 residents of those identified by staff as requiring a palliative approach were suitable for inclusion in the study. Of these residents, nine died. It was originally envisaged that 25 residents would qualify and comparisons would be possible with experiences of 25 residents included in a retrospective study. Pre- and post test satisfaction with care ratings were similar. There is extensive report of recommendations for further work [86].</p>
<p><b>5. Canada</b> – A large Quebec nursing home affiliated with the University, with on-staff physicians <b>2005–2006</b> [33]</p>	<p>Arcand M, et al.</p>	<p><i>Intervention:</i> Education of staff on palliative care for dementia patients; providing of a booklet on this topic to staff and families.</p> <p><i>Design:</i> pre-post test study with assessment of satisfaction with care by telephone interview with families, using the Toolkit of Instruments to Measure End-of-Life Care [130]. Additionally, chart review.</p>	<p>The pre-intervention group comprised of 27 decedents who died with advanced dementia in the facility and their families; the post-intervention group included 21 cases. Unexpected deaths, and cases in which families were not interviewed, were excluded.</p>	<p>To assess effects of the educational intervention on family satisfaction with care.</p>	<p>Although there were no significant differences between the pre-test and post-test group, almost all scores evaluating care and satisfaction were more favorable in the post-test group [33].</p>

Table 1, continued

Country and setting, years of data collection	Study name/ Acronym, and principal investigators	Design and data collection	Population	Main goals	Selected findings with a focus on longitudinal use of data
6. UK teaching hospital in London <b>2008-2009</b> [101]	Sampson EL, et al. [E.L. Sampson, personal communication and unpublished data].	Mixed-method design including qualitative work to develop the intervention. <i>Intervention:</i> a pilot palliative care intervention delivered by a nurse specialist including patient assessment and advance care planning is projected. <i>Design:</i> Semi-structured interviews with staff and family. Instruments include the EOLD-SWC. The control group is from an adjacent ward.	Patients over 70 years with advanced dementia (FAST stage 6c or worse) who have a high 6-month mortality risk and an unplanned emergency admission for treatment. Able acute medical illness. Family representatives should be available for input. Planned size of groups is 40 for each of intervention and control group.	To assess effectiveness of the palliative care intervention on procedures (i.e., adherence to care planning), family outcome (i.e., satisfaction with decision making, satisfaction with care with the EOLD-SWC [107], distress), patient's quality of life, number of interventions, and costs.	Families' reluctance to participate in a study in the hospital setting. Overall, families who participated found the intervention useful, particularly discussion of palliative care needs and prognosis. Yet, many families were reluctant to write an advanced care plan [E.L. Sampson, personal communication and unpublished data].
7. US – A Veterans Affairs Medical Center, <b>2007-2012</b> [104]	<b>L-DOT</b> Snow AL, Biladeau JA, Smit D.	Low-dose opioids trial of 8 weeks. <i>Design:</i> randomized double-blind controlled trial. Instruments used include the DS-DAT and the PAINAD [129, 131].	48 residents patients with FAST score 6 or greater and over age 55, who have a PAINAD score of at least 2 on consecutive assessments.	To assess tolerability and effect of opioid on pain and discomfort, and on agitation and symptom burden.	Not available yet.

\* Completed and ongoing studies, unselected with respect to concurrent and comorbid conditions.

Abbreviations: CareAD = Care of Nursing Home Residents with Advanced Dementia.

CASCADE = Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life.

CPS = Cognitive Performance Scale; GDS = Global Deterioration Scale.

DEOLD = Dutch End of Life in Dementia Study.

DNH = do not hospitalize.

DSCU = Dementia Special Care Unit.

DS-DAT = Discomfort Scale-Dementia of Alzheimer Type.

EOLD = End-of-Life in Dementia (Scales).

EOLO-PSODEC = End-Of-Life Observatory-Prospective Study On DEmentia Care and outcomes.

EVIDEM EoL = Evidence-based interventions in dementia towards the end of life.

FAST = Functional Assessment Staging Tool.

L-DOT = Low-Dose Opiate Therapy for Discomfort in Dementia.

MMSE = Mini-Mental State Examination.

PAINAD = Pain Assessment in Advanced Dementia.

PEACE = Palliative Excellence in Alzheimer Care Efforts.

findings [57,137]. These comparisons are especially important for European and other countries since so far most research has been US-based.

### **AVAILABILITY OF GUIDELINES FOR END OF LIFE CARE IN PATIENTS WITH DEMENTIA**

Though the availability of prospective observational and intervention studies of good quality in palliative care are limited [138,139], there is reasonable evidence for treatment of pain, dyspnea, and depression in cancer patients [140]. There is less evidence for effectiveness of treatment and care in dementia patients, meaning available guidelines specific to dementia at the end of life are mostly consensus based. Guidelines for treatment of dementia often address end-of-life issues [141] but, in general, palliative care guidelines are not specific to dementia. Some are applicable, however, as they list quality indicators for palliative care in vulnerable elders [142] or for residents of long-term care who lack decision-making capacity [143]. Volicer has also reviewed the literature on end-of-life care for dementia in long-term care settings for the US Alzheimer's Association [144], and provided a number of recommendations from his narrative review and from his clinical experience [26,143]. Recently, Alzheimer Europe also provided such recommendations [145,146]. Lloyd-Williams and Payne [147] used staff input to develop guidelines for terminal dementia specifically. This methodology may be helpful to others who wish to develop or adapt guidelines to local circumstances, enhancing acceptability to staff.

Guidelines for specific conditions have been developed, such as whether to treat pneumonia with antibiotics in patients with dementia [148], based mainly on ethical and legal considerations. Other guidelines deal with medication issues for vulnerable elders [149] and advanced dementia specifically [150].

Advance care planning (see below) is increasingly recognized as an important issue with reports on how to introduce this appearing in several countries such as Belgium [151], the US [152], and the UK [153,154]. Australia is the first country with national guidelines on palliative treatment for residents in long-term care including those with dementia [155], although only seven of 181 pages could be dedicated to advanced dementia.

### **SELECTED PRACTICE RECOMMENDATIONS FOR DEMENTIA END-OF-LIFE CARE**

This review and grading of the evidence has made clear that evidence on dementia end-of-life care is limited. Nevertheless, several approaches have been successful in practice, are included in guidelines, or are supported by study results, and have face-validity. These principles are summarized below.

#### *Palliative care*

According to the World Health Organization [156], palliative care is “an approach that improves the quality of life of patients and their families facing the problems 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.” Some have distinguished basic palliative care from specialist palliative care, the first being the standard which all health care professionals should be able to provide [157]. As indicated in this review, effectiveness of palliative care in dementia is not yet well-studied.

Because dementia is a life threatening disease, palliative care (or “comfort” or “hospice” care), with its focus on quality of life, is applicable even early in the course of illness when therapies that are intended to prolong life are still used [156,158]. An overly strict curative care-palliative care split may not be helpful [85]. Nevertheless, it may be argued that practitioners and families recognizing the need for, and applicability of, palliative care to dementia patients might in itself help improve the quality of end-of-life care for these patients. Palliative care also addresses the needs of families. Hospice care for relatives with dementia, such as the provision of respite care and volunteer services, was perceived by US families as beneficial for themselves [159].

#### *Advance care planning*

Advance care planning has been defined as “A voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline” [154]. Others [152] defined it as: “Advance care planning allows individuals to make decisions about their care if they happen to become unable to speak for themselves. Advance care planning decisions are typically based on personal values, preferences and discus-

sions with loved ones.” While these definitions focus on deliberations with patients, advance care planning also includes advanced decision making with families (proxies) of incompetent patients, and reassessment of plans when necessary. The principle is to prepare for difficult decisions before a health crisis occurs. Advance care planning fits with patient-centered care and the principles of shared decision making, which includes decision makers (proxies and patients) as partners [158]. Although in dementia there is little evidence that advance care planning affects patient or family outcomes, and its importance in decision making may vary cross-culturally [83], processes can be affected and preparation of families in general is likely helpful.

Teno [160] recommends structured planning by eliciting patient preferences, determining care goals, and then developing plans. Proxies are supposed to act according to what patients would have wanted if they were still competent, but should also act in the patient’s best interest [148,161]. It makes sense to prepare specifically for the common dementia-related problems of limited intake and infections [162]. It is recommended that advance care planning begin six months before death is anticipated [142], or, more practically, soon after admission to long-term care [143]. Plans should be documented in the chart and proxies may receive a signed copy of the form [143]. Updates are recommended on an annual basis or with a change in patient status such as transfer to another setting, significant change in the patient’s health, or availability of new treatments [143].

### *Continuity of care*

Continuity of care implies limiting transfers or limiting possible discontinuity due to transfer, but also speaks to building of relationships between families and practitioners, and between staff of institutions [163]. Hospitalization for treatable conditions such as pneumonia is probably not beneficial [70,71,164].

Adequate communication among health care providers and families includes contact with them after the death of their loved one. Families need guidance and support in transitioning from the curative mindset to a comfort care approach, and in dealing with emotions such as guilt [78,84,85]. This guidance is best provided in a relationship built on trust and familiarity. In US nursing homes, physicians have been called “missing in action” because they are frequently not there when families visit [24,165]. Having a dedicated physician who knows the patient and family well is cru-

cial for coordinating care and providing guidance [24,29,165–168]. Other members of the multi-disciplinary team of physicians, nurses, nurse practitioners, and social workers may also fulfill a coordination role, especially when specifically trained in palliative care in dementia patients.

### *Health care team skills and training*

Both families and clinicians have educational needs regarding palliative care in dementia. Several studies have indicated that families may want more information towards the end of life, even if patients sometimes wish less [169]. Education was an effective intervention for staff development in several long-term care studies [170] and a small trial has indicated possible effects on family satisfaction with care [33].

For clinicians, a one-time educational session may not be as effective without ongoing mentoring by a specialist palliative care team [171]. Staff input when developing local guidelines may also help educate the health care team [147]. Spiritual care and nursing measures may be less developed than medical care. Nursing measures, such as attention to positioning, mouth care, and cleanliness have rarely been described [146,172] and it is unclear to what extent these measures differ from usual nursing care. Culturally sensitive communication is another important skill in end-of-life care for the health care team [173].

### *Tools*

Several tools are available that estimate prognosis, assess pain, educate and communicate with families, and evaluate feedback from families.

Because of the wide variation in survival, specific predictors of prognosis may help estimate prognosis which, combined with clinical judgment, usually provides reasonable estimates [174]. Unfortunately, current risk scores [13,14,175] identify patients at low risk of dying (i.e., less than 5% or 10%), but rarely or never provide estimates for those at high (80% or 90%) risk of death. Clinical impact studies examining effects on decisions, patients or family outcomes are still rare in palliative and dementia care settings [176].

Validated pain assessment tools are widely available and can be used by nursing staff [177,178]. Use of pain tools may improve pain treatment [179,180]. The Pain Assessment in Advanced Dementia (PAINAD), developed in the US, is a brief tool (5 items) for direct observation including by observers unfamiliar with the

patient [131]. It has good psychometric properties although one of the items, Cheyne Stokes respirations, is of questionable importance in patients at the end of life. It is available and tested in English, Italian, German, and Dutch languages. Another established tool is the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). It was developed in French-speaking Canada and is currently available in French, English, and Dutch [181]. It includes 60 items and because it includes recent changes assessed in retrospect, familiarity with the patient is needed, even though it is recommended as a tool for direct observation too. For example, with the items “change in eyes,” “sleep,” or “appetite,” it is unclear how useful the tool is for direct observation of acute versus chronic pain. A shortened version includes 24 items, of which 18 are valid and reliable [182]. The third relatively well-tested and promising tool, the Doloplus, was developed in France [183] and is available in more than 5 languages, including Chinese, English, Norwegian, Dutch, and Italian. It includes 10 items for indirect observation (in retrospect) in different circumstances. Reliability was satisfactory but not for the Dutch version [184].

Booklets and decision aids to educate families and nurses [162,185,186] are also available. One is specific to decisions regarding intake problems [185]. Two more general booklets have been evaluated and received positively by families [187] and practitioners [188]. Video tools may also help support decision making and inform families on palliative care [189,190] and may be more effective than written information alone [191].

Tools for families to evaluate end-of-life care and outcome specific to dementia have been developed [107] and showed acceptable psychometric properties and feasibility in practice compared to other measures for unselected long-term care populations [192]. Effects of feedback on improvement of care have not yet been studied.

## CONCLUSION

Compared to the handful of small US and UK studies performed in the 1990's, dementia at the end of life is the subject of an increasing number of studies over the last decade, including large, multi-center observational studies in other (western) countries. Palliative care has been reported to “approach integration” in at least 35 countries, which is characterized by multiple services, awareness in health professionals, and availability of pain-relieving drugs [193]. New government-

tal support programs that include palliative care for dementia, such as the UK “End of life care strategy” [194] and the “National Dementia Strategy” [195], may help improve practice. Dementia is still not always recognized as an illness that may require palliative care for the afflicted patient, but encouraging trends in treatment show that these patients may receive the same quality of palliative care as cognitively intact patients. It is hoped that research and implementation of findings will help establish effective palliative care for dementia patients worldwide.

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