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Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life

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Abstract

Background: Increasing number of people are dying with advanced dementia. Comfort and quality of life are key goals of care.

Aims: To describe (1) physical and psychological symptoms, (2) health and social care service utilisation and (3) care at end of life in people with advanced dementia.

Design: 9-month prospective cohort study.

Setting and participants: Greater London, England, people with advanced dementia (Functional Assessment Staging Scale 6e and above) from 14 nursing homes or their own homes.

Main outcome measures: At study entry and monthly: prescriptions, Charlson Comorbidity Index, pressure sore risk/severity (Waterlow Scale/Stirling Scale, respectively), acute medical events, pain (Pain Assessment in Advanced Dementia), neuropsychiatric symptoms (Neuropsychiatric Inventory), quality of life (Quality of Life in Late-Stage Dementia Scale), resource use (Resource Utilization in Dementia Questionnaire and Client Services Receipt Inventory), presence/type of advance care plans, interventions, mortality, place of death and comfort (Symptom Management at End of Life in Dementia Scale).

Results: Of 159 potential participants, 85 were recruited (62% alive at end of follow-up). Pain (11% at rest, 61% on movement) and significant agitation (54%) were common and persistent. Aspiration, dyspnoea, septicaemia and pneumonia were more frequent in those who died. In total, 76% had 'do not resuscitate' statements, less than 40% advance care plans. Most received primary care visits, there was little input from geriatrics or mental health but contact with emergency paramedics was common.

Conclusion: People with advanced dementia lived with distressing symptoms. Service provision was not tailored to their needs. Longitudinal multidisciplinary input could optimise symptom control and quality of life.

Keywords

Dementia, palliative care, behavioural symptoms, psychomotor agitation, pain, residential facilities, quality of healthcare, primary healthcare, resource allocation

What is already known about this topic?

1. The World Health Organization has named dementia as the seventh leading cause of death worldwide, and deaths due to dementias more than doubled between 2000 and 2015.
2. Detailed longitudinal data on symptom burden and healthcare utilisation in advanced dementia are sparse.
3. Intervention development for people with advanced dementia has lacked a strong clinical evidence base.

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What this paper adds?

1. People with advanced dementia live with chronic and persistent symptoms, including pain and agitation.
2. There are few acute clinical events that predict impending death and thus prognosis is uncertain.
3. Despite complex physical and psychiatric needs, most care is provided by general practitioners or emergency services with little input from specialists such as geriatricians or palliative care.

Implications for practice, theory or policy

1. Nursing home residents with advanced dementia require multidisciplinary, multi-speciality care, and nursing home staff need more support from external healthcare services.
2. The potentially long, slow decline in advanced dementia as death approaches and uncertainty about the duration need to be taken into account in planning and delivery of services.
3. People with advanced dementia would benefit from care focussing on management of physical and psychological symptoms. Further study is required to establish the best models for providing this care.

Introduction

Approximately 850,000 people in the United Kingdom have dementia.[1] One-third of people aged over 65 years in the United Kingdom will die with some form of dementia,[2] the majority will die in care homes[3,4] and advanced dementia is becoming a leading cause of death in the United Kingdom and across the world.[5–7]

It has been suggested that the key goals of end-of-life care for people with dementia should be to maximise comfort and quality of life,[8,9] but concerns have been raised about the quality of care provided.[10,11] Barriers to providing good end-of-life care include structures of service provision, difficulties in estimating prognosis and uncertainty around when the person is entering the terminal phase.[12] Studies from the United States, The Netherlands, Belgium and Italy[13–16] have demonstrated a high symptom burden in people with advanced dementia, but there has not been a detailed, prospective longitudinal study of physical and psychological symptoms and service use in this population in the United Kingdom. Data on the UK context would inform service provision and may facilitate international comparisons in treatment and outcomes, enhancing our understanding of how context influences the provision of end-of-life care.

The 3-year Compassion Programme (National Institute for Health Research (NIHR) reference number CRN-PCRN 12621; 12623) used realist methods[17] and combined data from multiple sources (including this cohort study)[18,19] to develop and implement a complex intervention to improve end-of-life care in advanced dementia.[20,21] In this article, we report on a 9-month longitudinal cohort study of people with advanced dementia. Our aims were to

1. Describe the course of physical and psychological symptoms;
2. Examine health and social care service utilisation;
3. Describe the care received at the end of life.

Methods

Setting

We recruited people with advanced dementia from May 2012–December 2014, from six Clinical Commissioning Groups (CCG; National Health Service (NHS) organisations overseeing healthcare delivery in England) across Greater London. To reflect the estimated place of residence of people with advanced dementia in the United Kingdom, we aimed to recruit 100 people with advanced dementia, 70 from nursing homes and 30 residing in their own homes.[1] We purposively selected 14 nursing homes ensuring a representative range of

- Care Quality Commission (CQC; public body of the Department of Health which regulates and inspects health and social care services in England) ratings;
- Gold Standards Framework (GSF; national training programme enabling staff to provide generalist care at the end of life) implementation;[22]
- Number of beds;
- Ownership (private company or state services);
- Areas of socio-economic and ethnic diversity.

The majority (90%) of UK nursing homes are privately owned, but residents should have equitable access to all core NHS services, such as primary and secondary care (including mental health), and palliative care. However, access to chiropody, opticians and physiotherapy is less consistently provided by statutory services and nursing homes, and residents or their families may purchase this care privately.

To recruit people with advanced dementia residing in their own homes, we used general practices in five CCG areas of greater London; practice staff screened patient

Table 1. Study measures.

Measure	Purpose	Source[a]	Time of assessment
Bedford Alzheimer Nursing Scale (BANS)[26]	8-item scale stages severe memory impairment. Range of 7–28, scores over 17 indicate severe dementia[27]	2, 3, 4	Study entry
Waterlow Scale[28]	Pressure sore risk: 10+ 'At Risk', 15+ 'High Risk', 20+ 'Very High Risk'	2, 3, 4	Study entry/monthly
Stirling Wound Assessment Scale[29]	Assesses extent of wound damage	2, 3, 4	Study entry/monthly
Pain Assessment IN Advanced Dementia (PAINAD)[30]	Rated during care tasks and at rest, scores ⩾2 indicate pain is present[31]	1	Study entry/monthly
Cohen Mansfield Agitation Inventory (CMAI)[32]	Rates agitated behaviours, range of 29–203, scores of 39 and above indicate clinically significant agitation	2, 3, 4	Study entry/monthly
The Neuropsychiatric Inventory (NPI)[33]	Assesses behavioural and psychological symptoms in dementia	2, 3, 4	Study entry/monthly
Symptom Management at the End of Life in Dementia Scale[34] (SM-EOLD)	Assesses comfort and pain in the prior 30 days, range of 0–45, higher scores indicate better symptom control	3, 4[b]	Study entry/monthly
Quality of Life in Late-Stage Dementia Scale (QUALID)[35]	Quality of life in the prior week, range of 11–55, lower scores indicate better quality of life	3, 4	Study entry/monthly
The Resource Utilization in Dementia Questionnaire (RUD-LITE)[36]	Formal and informal health and social care resource use	2, 3, 4	Study entry/monthly/ post death
Client Services Receipt Inventory (CSRI)[37]	As above but more financially based	2, 3, 4	Study entry/monthly/ post death

[a] 1 – observation of person with dementia; 2 – primary care records; 3 – nursing home staff and 4 – carer.
[b] Rated by staff if resident in care home and by family member if still resident in their own home.

lists to identify potential participants. To ensure access to primary care records, we recruited participants (both those residing at home and those in nursing homes) who were registered with practices linked to the Primary Care Research Network which works with general practitioners (GPs) to support research.

Inclusion and exclusion criteria

Nursing home and primary care staff identified potential participants meeting the following criteria: clinical diagnosis of dementia aged over 65 years and at Functional Assessment Staging (FAST) grade 6e and above[23] (one of: doubly incontinent and speaks only a few words, unable to walk, loss of intelligible speech, unable to smile, unable to hold their head up). For recruitment and consent procedures, see Jones et al.[17]

Data collection

At study entry, we documented demographics, Charlson Comorbidity Index (CCI)[24] (19 diseases weighted on their association with mortality); prescribed medications;[25] advance directives, advance statements and lasting power of attorney. Research staff assessed participants using validated scales, through direct observation or in consultation with carers and nursing home staff. Study measures (see Table 1) included physical symptoms: pain (Pain Assessment IN Advanced Dementia (PAINAD) Scale,[30] scores of 2 or greater indicate clinically significant pain),[31] pressure sore risk (Waterlow Scale)[28] and pressure sore severity (Stirling Scale);[29] neuropsychiatric symptoms: Neuropsychiatric Inventory (NPI)[33] and Cohen Mansfield Agitation Inventory (CMAI; scores of over 39 indicate clinically significant agitation),[32] comfort (Symptom Management at the End of Life in Dementia (SM-EOLD)),[34] quality of life (Quality of Life in Late-Stage Dementia (QUALID))[35] and service use with the Client Services Receipt Inventory (CSRI) and the Resource Utilization in Dementia-Lite (RUD-LITE) Scales.[36,37]

Participants were assessed every 4 weeks for a maximum of 9 months. In addition, we documented events from the prior month:

- Painful or burdensome interventions, for example, enteral feeding tubes, venous or arterial blood tests and mechanical ventilation.[38]
- Symptoms documented as being common or problematic in advanced dementia: dehydration, constipation, difficulty swallowing, insufficient oral intake, weight loss, aspirating/choking on swallowing and difficulties breathing.[13]
- Acute clinical events: seizures, fever, urinary tract infection, pneumonia and septicaemia.[39]
- After death, we collected information from staff and/or family carers on whether the death had been 'expected', whether there was a 'do not attempt resuscitation' (DNAR) order at the time of death, place and primary cause of death.

Data were collected prospectively on paper case-report forms. A new form was used at each visit so raters would not be influenced by previous scores.

Analysis

Participant characteristics were described using mean values or medians for continuous variables (with standard deviation (SD) or inter-quartile range (IQR)) and frequencies (percentages) for categorical variables at four time points: (1) study entry, (2) for those who died at the final visit prior to death, (3) for those who were still alive at the end of the study at the final visit and (4) for the whole cohort at the final visit. If more than 20% of questionnaire items were missing, the total was set as missing for the individual as this may have implied non-completion of the whole questionnaire. If less than 20% of items were missing per individual, mean scores were imputed.[40] Analyses were performed using Stata 13.

Ethics

Our approach was based on the UK Mental Capacity Act 2005, and a personal or a nominated 'professional' consultee gave their informed written agreement for the person with advanced dementia to participate[17] (National Research Ethics Committee East of England approval 12/EE/0003).

Results

Of 159 potential participants with advanced dementia, 85 were recruited, 79 resided in nursing homes and 6 in their own homes (Online Figure 1). At study entry, all questionnaires were completed. In total, 21 (0.6%) individual questionnaires over follow-up had one or two missing items which were imputed. At the last visit, data collection varied from missing in two participants (2%) on the entire Confusion Assessment Method (CAM), QUALID and PAINAD at rest scales to missing in six participants (7%) on the PAINAD activity scale and symptoms proforma.

Cohort characteristics

The majority were women (median age of 85 years, IQR of 81–90). Median length of nursing home residence was 3 years (IQR of 1–5). For the 53 (62%) participants alive, at end of follow-up, a median number of 9 (IQR of 8–9) assessments were completed. Mortality at 9 months was 37%, 32 participants died, with a median of four assessments (IQR of 2.5–6.5). At study entry, 76% of the cohort had a DNAR order, 30% had an advance care plan, 40% a documented preferred place of death and 40% a lasting power of attorney.

Diagnoses and comorbidities

Alzheimer's disease followed by vascular dementia were most common. The mean Bedford Alzheimer Nursing Scale (BANS) score was 21 (SD = 3.4), indicating participants were severely impaired. Participants had an average Charlson comorbidity score of 6 (SD = 1.5), and 38% were taking 6–9 different classes of drugs (Table 2).

Clinical symptoms

At study entry, 53% were at very high risk of pressure sores (Waterlow Scale). On the Stirling pressure sore severity scale, 22% had early signs of pressure sores and 16 participants (19%) had partial-to-full skin thickness loss. Pressure sore risk and prevalence of pressure sores remained constant throughout follow-up and there were no differences in pressure sore risk between those who died and those who were still alive at the final assessment (Table 3 and Figure 1).

The proportion of participants observed to be in pain at study entry, both at rest (11%) and during movement (61%), changed little during follow-up (Figure 1). Over half of participants had clinically significant agitation on the CMAI at study entry (54%) with a slight reduction at the final assessment for those who died (45%) compared to those still alive (56%). Other common psychiatric symptoms at study entry were depression (36%), anxiety (35%), apathy (53%), motor disturbances (33%) and night-time behaviours (waking during the night or sleeping excessively during the day (44%)). The prevalence of these remained unchanged throughout follow-up for all participants, apart from depression which increased to 42% of those alive at the end of the study and 48% who died and motor disturbances which increased to 48% of those who remained alive and 50% of those who died (Table 3).

The commonest physical symptoms at study entry were difficulty swallowing (42%) and weight loss in the prior month (34%). At the final study visit, a higher proportion of those who died experienced aspiration on swallowing (20% compared to 4% those who remained alive) and breathing difficulties (47% compared to 21% of those who remained alive).

Acute clinical events

Urinary tract infection was the commonest acute medical event at study entry (14% of participants in the prior month). Septicaemia and pneumonia occurred in 17% of participants who died compared to those who were alive at the final study assessment (septicaemia 2% and pneumonia 4%).

Quality of life and comfort

Quality of life (QUALID Scale) remained constant from study entry (24.4, SD = 6.8) until final study assessment (24.3, SD = 5.3) deteriorating slightly towards death (25.8, SD = 7.0) (higher scores indicate lower quality of life) as did scores for comfort on the SM-EOLD (Table 3 and Figure 1).

Table 2. Characteristics of people with advanced dementia (*n* = 85).

	N (%) (*n* = 85)
Age, median (IQR)	85 (81–90)
Gender: female	67 (79)
Ethnicity	
White British	59 (69)
White Irish	8 (10)
Other White	7 (8)
Chinese	1 (1)
Black Caribbean	8 (10)
Other Asian	2 (2)
Religious background (*n* = 82)	
Christian	57 (70)
Jewish	2 (2)
No specific	10 (12)
Other	13 (16)
FAST score	
6e–7b: doubly incontinent loss of ability to speak > 6 words	35 (41)
7c–e: ambulatory ability lost–cannot hold up head independently	50 (59)
Previous dementia diagnosis (*n* = 71)	
Dementia	22 (31)
Alzheimer's disease	31 (44)
Vascular dementia	14 (20)
Lewy body dementia	2 (3)
No previous diagnosis	2 (3)
Other psychiatric history (*n* = 78)	
Depression	25(32)
Schizophrenia	9 (12)
Other (alcohol abuse, psychosis and paranoia)	3 (4)
None	41 (53)
Time in nursing home, years (*n* = 76), median (IQR)	3 (1–5)
Admitted to nursing home from (*n* = 67)	
Private home	20 (30)
Residential home	13 (19)
Other nursing home	10 (15)
Acute care hospital	19 (28)
Other (psychiatric hospital, rehab hospital and sheltered housing)	5 (7)
Charlson comorbidities, mean (SD)	6.5 (1.5)
Bedford Alzheimer Nursing Scale, mean (SD)	21 (3.4)
Number of medications, median (IQR)	6 (5–10)
Number of drug classes	
0–2	10 (12)
3–5	43 (51)
6–9	32 (38)
Do not attempt resuscitation order complete (*n* = 84)	
No	20 (24)
Yes	64 (76)
Advanced decision to refuse treatment (*n* = 83)	
No	79 (95)
Yes	4 (5)
Advanced statement (*n* = 82)	
No	57 (70)
Yes	25 (30)
Preferred place of death (*n* = 78)	
No	47 (60)
Yes	31 (40)

(Continued)

Table 2. (Continued)

	N (%) (*n* = 85)
Remain in current location (nursing home/own home)	30 (97)
Go to hospital	1 (3)
Lasting Power of Attorney in place (*n* = 73)	
No	44 (60)
Yes	29 (40)

IQR: inter-quartile range; FAST: Functional Assessment Staging Scale; SD: standard deviation.

Service use

General (acute) hospital admission was infrequent in the month prior to study entry (0.18 admissions per participant) and remained low during follow-up (Table 4). Use of outpatient services was more frequent. In the month prior to study entry, there were 0.31 contacts per participant with paramedics or emergency ambulance services and 10.3% saw a paramedic. In the month prior to death, there were 0.75 paramedic contacts per participant and 19% were seen by a paramedic at the nursing home.

Participants had no contacts with community nursing services, although contact with 'specialist' nurses increased to 12.5% of those who died (from 7.7% at baseline) likely due to palliative care nurses being called in. Contact with other professionals such as chiropodist, optician and dentist was more frequent. The majority of participants were seen by a GP during the study and 96% of those who died saw a GP in their last month. There was little contact with geriatricians, neurologists, psychiatrists or community psychiatric nurses.

Care received at the end of life

The most frequent interventions in the month prior to death were blood tests (14%) and urinary catheters (14%). Death was 'expected' in 90% of cases; 81% died in the nursing home and one person died in their own home. Of those who died, 34% were referred to and 28% were seen by the palliative care team. A DNAR was in place for 93% of those who died, and the commonest cause of death was aspiration pneumonia (Table 5).

Discussion

Course of physical and psychological symptoms

Mortality at 9 months (37%) was comparable to 6-month mortality rates in people with advanced dementia from the United States (18%), Italy (20%) and The Netherlands (37%).[41–43] The commonest physical symptoms at study entry were difficulty swallowing and weight loss. Pain on movement, agitation and apathy were also frequent and persisted at clinically significant levels throughout the study. Aspiration and breathing difficulties increased in the month prior to death, and the commonest acute events prior to death were septicaemia and pneumonia.

Our participants were similar in disease severity and demographics to cohorts from The Netherlands,[44] Belgium[45] (for whom data were collected retrospectively after death) and the United States,[39] which also found pain, agitation and dyspnoea to be the commonest symptoms.[39,46] As the end of life approaches, difficulties in swallowing, problems with eating and risk of pneumonia also increase.[13] We report a comparable symptom profile in the United Kingdom and, in addition, demonstrate how these symptoms were chronic and unchanging. This is important as our participants were unable to express their needs and were, therefore, vulnerable to long-term suffering. However, despite concerns regarding suboptimal care in the United Kingdom,[10] mean symptom management scores (SM-EOLD) were similar to those found in The Netherlands[44] and Belgium,[15] but lower than found in the United States.[47]

Service use

General Practitioners were the main providers of medical care with most participants having contact during the study. Despite the prevalence of chronic pain and psychiatric symptoms, little specialist healthcare was provided. Of 85 participants, only 5 saw a geriatrician and a psychiatrist with negligible contact with community psychiatric nurses. Paramedics were major providers of assessment and healthcare towards the end of life (although few contacts led to acute hospital admissions) suggesting a reactive response to needs. In the United Kingdom, studies have found that nursing home residents are often poorly served by existing healthcare arrangements[48] and receive less planned and more emergency care than those living in the community.[49] Use of social care services also increased in the month prior to death; 25% of participants who died having contact compared to an average of 4.6% of participants during follow-up. There was more contact with chiropodists, dentists and opticians, reflecting how these services are often purchased-in by care homes or by relatives.

Care received at the end of life

Apart from septicaemia and pneumonia, indicators of impending death were not clearly identifiable. Palliative care outreach teams saw 28% of those who died (34%

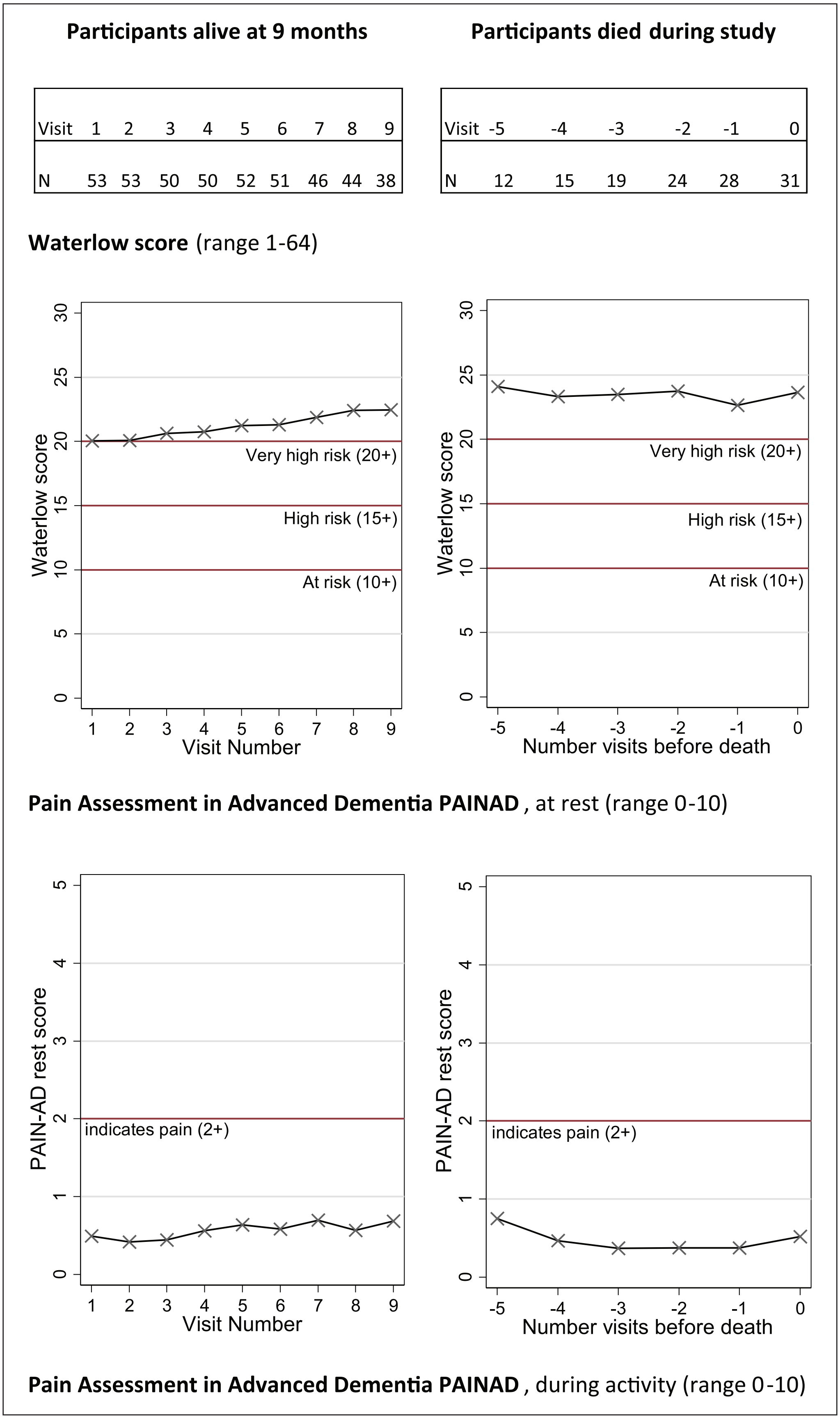
Table 3. Physical and psychological symptoms, quality of life and comfort in people with advanced dementia (*n* = 85).

Variable	Study entry (*n* = 85)	Final visit (if alive) (*n* = 52)[a]	Final visit (if died) (*n* = 31)	Final visit (all participants) (*n* = 83)
Waterlow Scale, *n* (%)				
High risk: 15+	32 (38)	14 (27)	8 (26)	22 (27)
Very high risk: 20+	45(53)	36 (69)	21 (68)	57 (69)
Stirling (Stage 1 or above)	19 (22)	17 (33)	8 (27)	25 (31)
PAINAD, *n* (%)				
Rest (score 2+)	9 (11)	10 (19)	4 (13)	14 (17)
Movement (score 2+)	52 (61)	29 (60)	17 (55)	46 (58)
CMAI				
Behavioural disturbances (39+)	46 (54)	29 (56)	14 (45)	43 (52)
Mean (SD)	45.5 (16.6)	45.5 (17.8)	40.8 (13.0)	43.7 (16.1)
NPI				
Number of symptoms, median (IQR)	3 (2–5)	4 (1.5–6)	4 (2–5)	4 (2–6)
Symptoms, *n* (%)				
Delusions	3 (4)	4 (8)	0 (0)	4 (5)
Hallucinations	18 (21)	14 (27)	7 (43)	21 (25)
Agitation or aggression	47 (55)	28 (54)	17 (51)	45 (54)
Depression	31 (36)	22 (42)	10 (48)	32 (39)
Anxiety	30 (35)	22 (42)	5 (37)	27 (33)
Elation or euphoria	10 (12)	6 (12)	1 (18)	7 (8)
Apathy	45 (53)	27 (52)	20 (49)	47 (57)
Disinhibitions	10 (12)	9 (17)	0 (0)	9 (11)
Irritability	20 (24)	11 (21)	7 (43)	18 (22)
Motor disturbances	28 (33)	25 (48)	12 (50)	37 (45)
Night-time behaviours	37 (44)	16 (31)	13 (50)	29 (35)
Appetite and eating	20 (24)	20 (38)	19 (61)	39 (47)
Clinical symptoms, *n* (%)				
Dehydration	4 (5)	1 (2)	3 (10)	4 (5)
Constipation	11 (13)	7 (14)	3 (10)	10 (12)
Difficulty swallowing	36 (42)	31 (61)	17 (57)	48 (59)
Documented as aspirating on swallowing	6 (7)	2 (4)	6 (20)	8 (10)
Insufficient oral intake	12 (14)	7 (13)	5 (17)	12 (15)
Weight loss in past month	28 (34)	24 (46)	16 (53)	40 (49)
Breathing difficulties	16 (19)	11 (21)	15 (47)	26 (31)
Acute clinical events, *n* (%)				
Urinary tract infection	12 (14)	5 (10)	4 (13)	9 (11)
Pneumonia	4 (5)	2 (4)	5 (17)	7 (9)
Fever	1 (1)	2 (4)	1 (3)	3 (4)
Septicaemia	1 (1)	1 (2)	5 (17)	6 (7)
Seizures	7 (8)	4 (8)	1 (3)	5 (6)
QUALID, mean (SD)	24.5 (6.7)	24.3 (5.3)	25.8 (7.0)	24.9 (6.0)
SM-EOLD, mean (SD)	28.1 (8.1)	26.3 (8.1)	27.0 (6.0)	26.5 (7.4)

PAINAD: Pain Assessment in Advanced Dementia; CMAI: Cohen Mansfield Agitation Inventory; SD: standard deviation; NPI: Neuropsychiatric Inventory; IQR: inter-quartile range; QUALID: Quality of Life in Late-Stage Dementia Scale; SM-EOLD: Symptom Management at the End of Life in Dementia Scale.

[a] Two participants were alive at the end of follow-up but data were not available, one participant was admitted to hospital and another moved away.

were referred), predominantly in the month prior to death.[40] This proportion is higher than in the United States (25%)[50] and The Netherlands (2.5%);[51] however, there are differences in healthcare provision between these countries. In The Netherlands, nursing homes have a dedicated physician who provides the majority of medical and palliative care 'in-house'. Nursing homes in our study were poorly serviced by community medical services and did not have dedicated physicians, thus palliative care teams were called in at the end of life to assist with symptom management. Although 76% of our participants had DNAR orders, only 5% had an advance decision to refuse treatment, the same proportion as that found in The Netherlands,[52] 40% had a recorded



Visit	1	2	3	4	5	6	7	8	9
N	53	53	50	50	52	51	46	44	38

Visit	-5	-4	-3	-2	-1	0
N	12	15	19	24	28	31

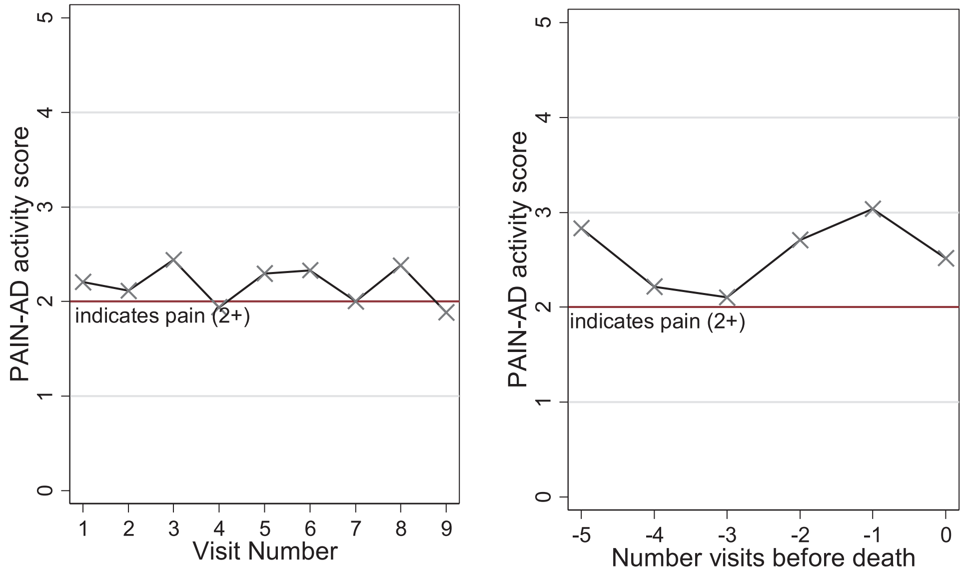
(Figure 1.Continued)

Participants alive at 9 months

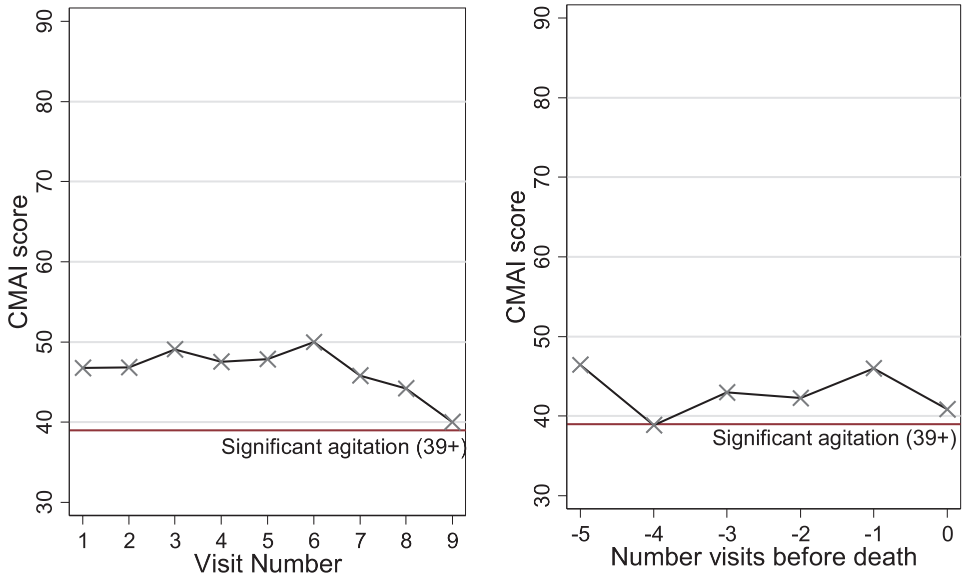
Visit	1	2	3	4	5	6	7	8	9
N	53	53	50	50	52	51	46	44	38

Participants died during study

Visit	-5	-4	-3	-2	-1	0
N	12	15	19	24	28	31

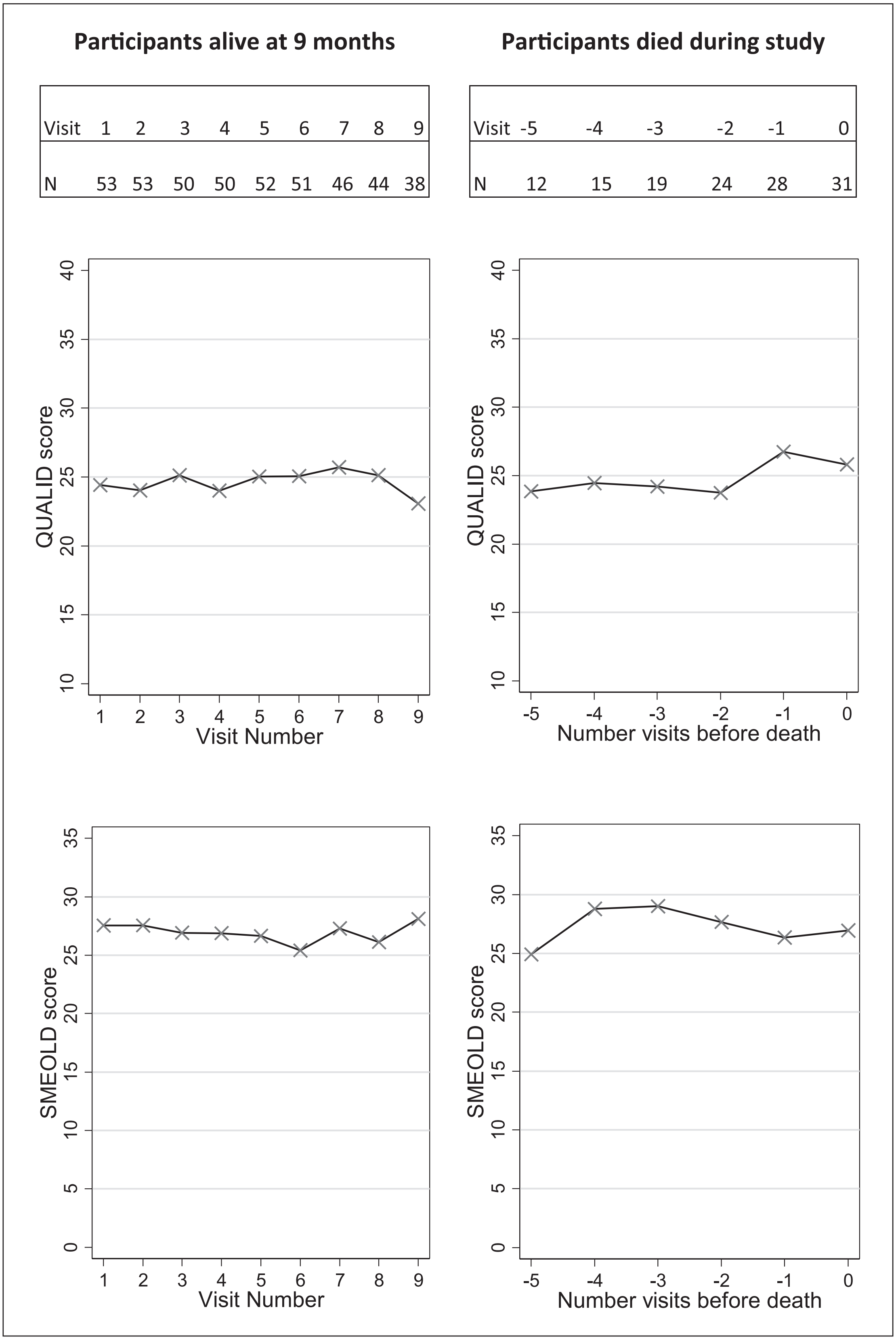


Cohen-Mansfield Agitation Inventory, CMAI (range 29-203)



Quality of Life in Late Stage Dementia Scale, QUALID (range 11-55)

(Figure 1.Continued)



Participants alive at 9 months

Visit	1	2	3	4	5	6	7	8	9
N	53	53	50	50	52	51	46	44	38

Participants died during study

Visit	-5	-4	-3	-2	-1	0
N	12	15	19	24	28	31

Figure 1. Changes in symptoms over time in people with advanced dementia ($n = 85$).

Table 4. Service use data from Client Services Receipt Inventory and Resource Utilization in Dementia Questionnaire in people with advanced dementia (*n* = 85).

	Study entry (*n* = 85)	Throughout follow-up[a]	Final visit if alive (*n* = 26/52)	Final visit died (*n* = 16/31)
Service use in previous month[b], mean (SD)				
General hospital inpatient	0.18 (0.39)	0.17 (0.38)	0.17 (0.39)	0.18 (0.41)
Most common reason	Asp pneum; decr BP	Asp pneum, unrespons	Asp pneum	Pneum, UTI
Outpatient services	0.25 (0.45)	0.2 (0.4)	0.33 (0.5)	0.33 (0.52)
Most common reason	Lesions; fits	Eyes; lesions	Eyes, High BP	Assessm, leg surgery
Paramedic called instances, called (% residents)	10.3%	9.5%	8.0%	19.0%
Number of contacts	0.31 (0.48)	0.64 (0.7)	0.5 (0.58)	0.75 (0.5)
Community matron	0	0	0	0
Practice nurse	0	0	0	0
Night nurse	0	0	0	0
Specialist nurse, called (% residents)	7.7%	7.1%	4.0%	12.5%
Service use in previous month[c], mean (% of residents)				
GP	45 (66)	37.63 (81)	31 (78)	23 (96)
Geriatrician	0	0.38 (1)	0	2 (5)
Neurologist	0	0.33 (1)	0	0
Psychiatrist	2 (3)	0.33 (1)	0	0
Physiotherapist	1 (1)	0.63 (2)	1 (3)	0
Occupational Therapist	3 (5)	3.62 (8)	3 (8)	0
Psychologist	0	0.38 (1)	1 (3)	0
Other[d]	27 (41)	21.88 (43)	21 (58)	9 (44)
Number of contacts	0.43 (1.09)	0.74 (1.18)	0.25 (0.5)	1.67 (2.08)
Other community doctor, called (% residents)	5.7	1.7	4	6.3
Number of contacts	0.08 (0.29)	0.16 (0.37)	0.33 (0.58)	0.5 (0.7)
Social worker, (% residents)	10.3	4.6	4	25
Number of contacts	0.25 (0.45)	0.31 (0.47)	0.25 (0.5)	0.8 (0.45)
Mental health psychiatric nurse (% residents)	0	0.1	0	0
Number of contacts		0.09 (0.29)		
Other community health services (% residents)	73.7	30.3	16.7	66.7
Which most common services	Chiropody, optician	Chiropody, dentist, optician	Optician	Dentist, IMCA
Number of contacts	0.57 (0.5)	0.2 (0.4)	0.08 (0.28)	0.4 (0.55)

SD: standard deviation; Asp pneum: aspiration pneumonia; decr BP: decreased blood pressure; unrespons: unresponsive; UTI: urinary tract infection; BP: blood pressure; Assessm: assessment; IMCA: independent mental capacity advocate; CSRI: Client Services Receipt Inventory; RUD: Resource Utilization in Dementia Questionnaire.

[a] Averaged (excluding at study entry).

[b] Based on CSRI.

[c] Based on RUD.

[d] Other services include pharmacist, tissue viability nurse, lymphoedema nurse, stoma nurse, phlebotomist, continence assessment, funding assessor, nursing fee care review, CQC regulatory visit, equipment assessment and pacemaker check.

preferred place of death and 16% died in hospitals. Care planning focussed on resuscitation decisions and place of death, rather than the type of care that the person would like to receive. Numerous initiatives have tried to address a lack of advance care planning in nursing homes,[28] but there are systemic challenges to effective implementation.[44]

Strengths and weaknesses

We did not reach our recruitment target despite extending our recruitment period and receiving support from the Primary Care Research Network; many GPs did not hold records of patients with advanced dementia, and it was difficult to locate people living in their own homes. We recruited

Table 5. Symptoms and interventions at dying, place of death in people with advanced dementia ($n=85$).

Factor	N (%) ($N=32$)
Interventions (Painful Interventions Scale; $n=29$)	
Phlebotomy (venous blood test)	4 (14)
Arterial blood gas testing	3 (10)
Central line placed	0 (0)
I-V drip/catheter	3 (10)
NG or PEG inserted	1 (3)
Urinary catheter inserted	4 (14)
Pressure sores	8 (28)
Mechanical ventilation/CPAP or BIPAP	0 (0)
Circumstances ($n=29$)	
Expected event[a], yes	26 (90)
DNAR form present, yes	27 (93)
Palliative care referral, yes	10 (34)
Palliative care saw patient, yes	8 (28)
Primary cause of death ($n=21$)	
Aspiration pneumonia/chest infection	11 (52)
Congestive cardiac failure	1 (5)
Dementia	7 (33)
Cancer	2 (10)
Place of death ($n=32$)	
Nursing home	26 (81)
Own home	1 (3)
Acute hospital	5 (16)

I-V: intravenous; NG: nasogastric; PEG: percutaneous entero-gastrostomy; CPAP: continuous positive airway pressure; BIPAP: bi-level positive airway pressure; DNAR: do not attempt resuscitation order.
[a]Determined by consensus discussion with family carers (where available), care home staff and primary care team.

from a range of nursing homes, ensuring these were representative by purposively sampling by size, CQC rating, ownership and local socio-economic factors to reflect the current UK nursing home market. In the United Kingdom, 25% of nursing homes are rated 'inadequate' or 'requires improvement'; in London, 20% receive a similar rating and 28% of nursing homes in our study were in this category. Thus, by these measures, our study nursing homes are more representative of the United Kingdom in general, rather than of London. We cannot be sure that our participants are representative of people in the United Kingdom with advanced dementia as no comparative data are available. However, the demographic composition of our cohort is similar to that of UK[48] and international studies of advanced dementia.[13,46] Nursing home documentation was not standardised, particularly for comorbidity, service use and interventions. Previous studies have been mainly retrospective, relying on symptom recall. We used detailed prospective methods[44,45] and reliable validated tools to allow international comparisons.

Implications for clinical practice

Many current policies and tools focus on making an advance care plan, particularly regarding the preferred place of death. These can be beneficial but rely on identifying those who are approaching the end of life and, as our data suggest, this is challenging. Complex symptoms require active specialist intervention, multidisciplinary working and effective care coordination, but GPs feel they do not have the time or knowledge to do this.[53] Increased collaboration between geriatric medicine, palliative care and psychiatry may be helpful but should be coordinated and supported by adequate resourcing and service commissioning.[54] Although the evidence base for interventions in dementia end-of-life care remains limited,[55] considering data used in our development of a complex intervention to improve care in advanced dementia,[20] we suggest a coordinated needs-based longitudinal approach should be developed and tested.[12] A recent survey found 'hospice enabled care' is an emerging model for palliative care for people with dementia in the United Kingdom.[56] This involves palliative care specialists, predominantly nurses, providing care coordination and symptom management expertise to nursing home residents,[12] and this may warrant further formal evaluation.

Policy and end-of-life care interventions promote the importance of end-of-life care in dementia[8] and have focused on the place of death; but to improve comfort and quality of life, better management of chronic symptoms is required.[53] This would enable people to live and die well with dementia.

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Data sharing

Anonymised open-access copy of the research data is available in UCL Discovery at http://discovery.ucl.ac.uk/1566784/.

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References

1. Knapp M and Privette A. *Dementia UK*. London: Alzheimer's Society, 2007.
2. Brayne C, Gao L, Dewey M, et al. Dementia before death in ageing societies – the promise of prevention and the reality. *PLoS Med* 2006; 3: e397.

3. Banerjee S and Owen J. *Living well with dementia: a national dementia strategy*. London: Department of Health, 2009.
4. Sleeman KE, Ho YK, Verne J, et al. Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001–2010. *BMC Neurol* 2014; 14: 59.
5. Weuve J, Hebert LE, Scherr PA, et al. Deaths in the United States among persons with Alzheimer's disease. *Alzheimers Dement* 2014; 10: e40–e46.
6. Etkind SN, Bone AE, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 2017; 15: 102.
7. World Health Organization. *Global Health Observatory (GHO) data: mortality and global health estimates*. Geneva: World Health Organization, 2017.
8. Van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014; 28: 197–209.
9. Barclay S, Froggatt K, Crang C, et al. Living in uncertain times: trajectories to death in residential care homes. *Br J Gen Pract* 2014; 64: e576–e583.
10. Sampson EL, Burns A and Richards M. Improving end-of-life care for people with dementia. *Br J Psychiatry* 2011; 199: 357–359.
11. Van der Steen JT. Dying with dementia: what we know after more than a decade of research. *J Alzheimers Dis* 2010; 22: 37–55.
12. Goodman C, Froggatt K, Amador S, et al. End of life care interventions for people with dementia in care homes: addressing uncertainty within a framework for service delivery and evaluation. *BMC Palliat Care* 2015; 14: 42.
13. Mitchell SL, Kiely DK and Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med* 2004; 164: 321–326.
14. Hendriks SA, Smalbrugge M, Hertogh CM, et al. Dying with dementia: symptoms, treatment, and quality of life in the last week of life. *J Pain Symptom Manage* 2014; 47: 710–720.
15. Van Uden N, Van den Block L, Van der Steen JT, et al. Quality of dying of nursing home residents with dementia as judged by relatives. *Int Psychogeriatr* 2013; 25: 1697–1707.
16. Di Giulio P, Toscani F, Villani D, et al. Dying with advanced dementia in long-term care geriatric institutions: a retrospective study. *J Palliat Med* 2008; 11: 1023–1028.
17. Jones L, Harrington J, Scott S, et al. CoMPASs: IOn programme (care of memory problems in advanced stages of dementia: improving our knowledge): protocol for a mixed methods study. *BMJ Open* 2012; 2: e002265.
18. Ferlie EB and Shortell SM. Improving the quality of health care in the United Kingdom and the United States: a framework for change. *Milbank Q* 2001; 79: 281–315.
19. Grol RP, Bosch MC, Hulscher ME, et al. Planning and studying improvement in patient care: the use of theoretical perspectives. *Milbank Q* 2007; 85: 93–138.
20. Jones L, Candy B, Davis S, et al. Development of a model for integrated care at the end of life in advanced dementia: a whole systems UK-wide approach. *Palliat Med* 2016; 30: 279–295.
21. Elliott M, Harrington J, Moore K, et al. A protocol for an exploratory phase I mixed-methods study of enhanced integrated care for care home residents with advanced dementia: the Compassion Intervention. *BMJ Open* 2014; 4: e005661.
22. Gold Standards Framework. The Gold Standards Framework. NHS End of Life Care Programme, http://www.goldstandardsframework.org.uk/ (2008, accessed 11 October 2008).
23. Reisberg B. Functional assessment staging (FAST). *Psychopharmacol Bull* 1988; 24: 653–659.
24. Charlson ME. Studies of prognosis: progress and pitfalls. *J Gen Intern Med* 1987; 2: 359–361.
25. Schneeweiss S, Seeger JD, Maclure M, et al. Performance of comorbidity scores to control for confounding in epidemiologic studies using claims data. *Am J Epidemiol* 2001; 154: 854–864.
26. Volicer L, Hurley AC, Lathi DC, et al. Measurement of severity in advanced Alzheimer's disease. *J Gerontol* 1994; 49: M223–M226.
27. Van der Steen JT, Volicer L, Gerritsen DL, et al. Defining severe dementia with the Minimum Data Set. *Int J Geriatr Psychiatry* 2006; 21: 1099–1106.
28. Waterlow J. Pressure sores: a risk assessment card. *Nurs Times* 1985; 81: 49–55.
29. Reid J and Morrison M. Classification of pressure sore severity. *Nurs Times* 1994; 90: 46–50.
30. Warden V, Hurley AC and Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc*. 2003; 4: 9–15.
31. Zwakhalen SM, Van der Steen JT and Najim MD. Which score most likely represents pain on the observational PAINAD pain scale for patients with dementia? *J Am Med Dir Assoc* 2012; 13: 384–389.
32. Cohen-Mansfield J, Marx MS and Rosenthal AS. A description of agitation in a nursing home. *J Gerontol* 1989; 44: M77–M84.
33. Cummings JL, Mega M, Gray K, et al. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology* 1994; 44: 2308–2314.
34. Kiely DK, Volicer L, Teno J, et al. The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis Assoc Disord* 2006; 20: 176–181.
35. Weiner MF, Martin-Cook K, Svetlik DA, et al. The quality of life in late-stage dementia (QUALID) scale. *J Am Med Dir Assoc* 2000; 1: 114–116.
36. Wimo A and Winblad B. Resource utilization in dementia: RUD Lite. *Brain Aging* 2003; 3: 48–59.
37. Beecham J and Knapp M. Costing psychiatric interventions. In: Thornicroft G (ed.) *Measuring mental health needs*. London: Gaskell, 2001, pp. 200–224.
38. Morrison RS, Ahronheim JC, Morrison GR, et al. Pain and discomfort associated with common hospital procedures and experiences. *J Pain Symptom Manage* 1998; 15: 91–101.
39. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009; 361: 1529–1538.
40. Shrive FM, Stuart H, Quan H, et al. Dealing with missing data in a multi-question depression scale: a comparison of imputation methods. *BMC Med Res Methodol* 2006; 6: 57.

41. Van der Steen JT, Mitchell SL, Frijters DH, et al. Prediction of 6-month mortality in nursing home residents with advanced dementia: validity of a risk score. *J Am Med Dir Assoc* 2007; 8: 464–468.
42. Mitchell SL, Miller SC, Teno JM, et al. Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. *JAMA* 2010; 304: 1929–1935.
43. Toscani F, Van der Steen JT, Finetti S, et al. Critical decisions for older people with advanced dementia: a prospective study in long-term institutions and district home care. *J Am Med Dir Assoc* 2015; 16: 535.e13–e20.
44. Van der Steen JT, Gijsberts MJ, Muller MT, et al. Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. *Int Psychogeriatr* 2009; 21: 321–329.
45. Vandervoort A, Van den Block L, Van der Steen JT, et al. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. *J Am Med Dir Assoc* 2013; 14: 485–492.
46. Hendriks SA, Smalbrugge M, Galindo-Garre F, et al. From admission to death: prevalence and course of pain, agitation, and shortness of breath, and treatment of these symptoms in nursing home residents with dementia. *J Am Med Dir Assoc* 2015; 16: 475–481.
47. Cohen LW, Van der Steen JT, Reed D, et al. Family perceptions of end-of-life care for long-term care residents with dementia: differences between the United States and The Netherlands. *J Am Geriatr Soc* 2012; 60: 316–322.
48. Gordon AL, Franklin M, Bradshaw L, et al. Health status of UK care home residents: a cohort study. *Age Ageing* 2014; 43: 97–103.
49. Smith P, Sherlaw-Johnson C, Ariti C, et al. *Focus on: hospital admissions from care homes*. London: The Health Foundation, 2015.
50. Miller SC, Lima JC, Looze J, et al. Dying in U.S. nursing homes with advanced dementia: how does health care use differ for residents with, versus without, end-of-life medicare skilled nursing facility care? *J Palliat Med* 2012; 15: 43–50.
51. Van der Steen JT, Deliens L, Koopmans RT, et al. Physicians' perceptions of suffering in people with dementia at the end of life. *Palliat Support Care*. Epub ahead of print 23 January 2017. DOI: 10.1017/S1478951516000985.
52. Hendriks SA, Smalbrugge M, Deliens L, et al. End-of-life treatment decisions in nursing home residents dying with dementia in The Netherlands. *Int J Geriatr Psychiatry*. Epub ahead of print 29 December 2016. DOI: 10.1002/gps.4650.
53. Kupeli N, Leavey G, Harrington J, et al. What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective. *Dementia*. Epub ahead of print 1 March 2016. DOI: 10.1177/1471301216636302.
54. Albers G, Froggatt K, Van den Block L, et al. A qualitative exploration of the collaborative working between palliative care and geriatric medicine: barriers and facilitators from a European perspective. *BMC Palliat Care* 2016; 15: 47.
55. Murphy E, Froggatt K, Connolly S, et al. Palliative care interventions in advanced dementia. *Cochrane Database Syst Rev* 2016; 12: CD011513.
56. Amador S, Goodman C, Robinson L, et al. UK end-of-life care services in dementia, initiatives and sustainability: results of a national online survey. *BMJ Support Palliat Care*. Epub ahead of print 14 October 2016. DOI: 10.1136/bmjspcare-2016-001138.