



BMJ Open Urgent care for patients with dementia: a scoping review of associated factors and stakeholder experiences

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ABSTRACT

Objectives People with dementia are more vulnerable to complications in urgent health situations due to older age, increased comorbidity, higher dependency on others and cognitive impairment. This review explored the factors associated with urgent care use in dementia and the experiences of people with dementia, informal carers and professionals.

Design Scoping review. The search strategy and data synthesis were informed by people with dementia and carers.

Data sources Searches of CINAHL, Embase, Medline, PsycINFO, PubMed were conducted alongside handsearches of relevant journals and the grey literature through 15 January 2019.

Eligibility criteria Empirical studies including all research designs, and other published literature exploring factors associated with urgent care use in prehospital and emergency room settings for people with dementia were included. Two authors independently screened studies for inclusion.

Data extraction and synthesis Data were extracted using charting techniques and findings were synthesised according to content and themes.

Results Of 2967 records identified, 54 studies were included in the review. Specific factors that influenced use of urgent care included: (1) common age-related conditions occurring alongside dementia, (2) dementia as a diagnosis increasing or decreasing urgent care use, (3) informal and professional carers, (4) patient characteristics such as older age or behavioural symptoms and (5) the presence or absence of community support services. Included studies reported three crucial components of urgent care situations: (1) knowledge of the patient and dementia as a condition, (2) inadequate non-emergency health and social care support and (3) informal carer education and stress.

Conclusions The scoping review highlighted a wider variety of sometimes competing factors that were associated with urgent care situations. Improved and increased community support for non-urgent situations, such as integrated care, caregiver education and dementia specialists, will both mitigate avoidable urgent care use and improve the experience of those in crisis.

BACKGROUND

Over 90% of people with dementia have another health condition,¹ with the average number of comorbid conditions of people with dementia aged over 65 double that

Strengths and limitations of this study

- The involvement of people with dementia and informal carers in the protocol design and throughout the review process ensured the research addressed the concerns of all key stakeholders.
- The scoping review methodology allowed a broad research question and inclusion criteria while maintaining a systematic search and data extraction process.
- The primary limitation was the exclusion of research reported in languages other than English.
- Scoping review methodology does not include a formal quality appraisal process, which means the scientific quality of the studies has not been taken into account.

of those without dementia.² This necessitates higher use of healthcare services than people without dementia.³ People with dementia are an at-risk patient group when accessing healthcare services in urgent situations due to their cognitive frailty.⁴ They may also be vulnerable to important changes being made when unplanned, urgent care is required, such as introducing or increasing social care support, institutionalisation, prescribing, deprescribing and hospital admission.¹ However, the impact of dementia on a patient's communication can lead to less involvement in treatment.⁵ Evidence in non-urgent care shows that even when decision making appears shared, people with dementia are not always fully informed of the options and the interests of other stakeholders may take precedent.^{6 7} 'Diagnostic overshadowing' can also occur, where people may be receiving substandard care because dementia takes precedent above other conditions.⁸

Research demonstrates a complex picture when considering how people with dementia access urgent care. A quarter of UK hospital beds are made up with people with dementia over 65 and people with dementia stay in

hospital for longer than people without.⁹ However, people with dementia are less likely to be taken to hospital after calling the emergency services.¹⁰ This may indicate that people with dementia are presenting straight to emergency rooms rather than going through ambulatory services.¹⁰ It also suggests that people with dementia may present through the ambulance service with lower-acuity issues that do not convert to needing hospital attendance.

A further complexity lies in the fact that there are often professional or informal carers involved in urgent care situations in dementia. Informal or professional carers often contact services on behalf of the person with dementia and thus must describe symptoms that are not their own, resulting in complex and inexact triage.^{11 12} Caregivers for those with dementia report a lack of flexibility in community and hospital services to treat dementia symptoms.¹³ There is evidence of informal carer frustration surrounding the lack of alternatives to hospitals and the lack of time in urgent care services to cater for those with complex needs.¹⁴

While avoidance of hospitalisation is considered increasingly important in dementia care, there is little research that specifically aims to explore what factors affect urgent care situations when patients have dementia or how different stakeholders experience urgent care.⁸ The care provided in urgent situations is broad, encompassing in-hours and out-of-hours primary care, telecare telephone advice services, as well as emergency and prehospital services.¹⁵ An overview of the literature is, therefore, integral to planning future research in this area. The aim of this scoping review of the literature is to examine: (1) the factors associated with urgent care use in dementia and (2) the experiences of people with dementia, informal carers and professionals in urgent care situations.

METHODS

A scoping review methodology was chosen due to the broad, multifaceted nature of how people with dementia access urgent care. Scoping reviews enable description of the foci of available research, thus identifying any gaps in the literature.¹⁶ The Joanna Briggs Institute Methodology for Scoping Reviews was followed¹⁷; a protocol has been published on the lead author's University website.

Patient and public involvement

People with dementia and informal carers of those with dementia informed protocol development, ensuring the relevance of the research question to all stakeholders.¹⁸ This was an iterative process through discussions with the study steering group (one person with dementia and five carers) and through written feedback from five Alzheimer's Society Service User Review Panels. The initial focus of the review was urgent primary care but the group members felt that they would often bypass primary care in urgent situations, instead presenting to emergency services. In response to this stakeholder input,

the research questions were revised to include all types of urgent care. The terms 'doctor', 'receptionist', 'choice' and 'choose' were also added to the search strategy. The study steering group of people with experience of dementia and two Alzheimer's Society Living Well with Dementia groups (10 people with dementia) informed the data synthesis by highlighting what features of the coded data were most salient to their experiences. This feedback influenced the synthesis of the findings into the resulting themes.

Research questions

1. What factors are associated with urgent care use in dementia?
2. What are the experiences of people with dementia, informal carers and professionals in urgent care situations?

Inclusion and exclusion criteria

Types of studies: Published and unpublished studies were included, with no date restrictions. Only studies published in the English language were included, due to a lack of resources for translation. All study designs, including evidence from qualitative, quantitative and mixed-methods research, were included, as well as theoretical papers and other documents, such as reports, websites, guidelines, leaflets and commentaries. Systematic reviews that met the inclusion criteria were searched and papers relevant to this review were extracted for screening.

Participants: Included studies clearly stated that they include people with dementia, informal carers of people with dementia and/or professional caregivers working with people with dementia. All types and stages of dementia were included, as well as all types of informal or professional carer. Studies exploring older populations or people in care homes where dementia was not specified were not included.

Concepts: Included studies explored urgent care when patients have dementia. Studies that solely reported numbers of people with dementia accessing urgent care as compared with larger cohorts, with no additional contextual findings regarding dementia, were excluded. Similarly, studies that focus on specifically on end-of-life care planning with only incidental discussion of 'do-not-hospitalise' orders were not included.

Context: Services accessed in urgent situations were defined as 'non-routine' care, primarily in prehospital settings: urgent primary care, telephone advice services and ambulance services. While studies examining accident and emergency department settings were included as an exploration of the interface between community and hospital care, studies that focused solely of the provision of emergency treatment of acutely life-threatening conditions within hospitals were excluded. Studies that reported hospitalisation as a result of urgent care decision making were included, but trials and reports of interventions where the primary outcome was avoiding hospitalisation were excluded. There is an ongoing systematic

Table 1 Information sources

Databases	Handsearch	Grey literature
CINAHL	Aging and Mental Health	Canada Theses
Embase	Alzheimer's Disease and Associated Disorders	DART European Theses
Medline	American Journal of Alzheimer's Disease and other dementias	EThOS UK Theses
PsycINFO	BMC Geriatrics	Informa Healthcare website
PubMed	British Journal of General Practice	ProQuest: (wire feeds, trade journals, dissertations, theses, news/magazines, conference papers, books, reports)
	Clinical Gerontologist	WorldCat global library
	Dementia	
	International Journal of Geriatric Psychiatry	Online guidance: RCGP clinician training resources, Alzheimer's Society website, Dementia Roadmap website, Dementia Knowledge Centre
	International Psychogeriatrics	
	Journal of Aging Studies	
	Journal of the American Geriatrics Society	
	Academic Emergency Medicine	
	Age & Ageing	
	Archives of Internal Medicine	

review of intervention studies aiming to avoid hospitalisation in dementia.¹⁹

Search strategy

The information sources and search terms are outlined in [table 1](#) and [box 1](#). Sources were searched from inception to 15th January 2019. Search terms were chosen through discussion with clinicians, people with dementia and informal carers, and an information specialist.

The search results were downloaded into Endnote X9 and were initially screened for inclusion based on title and abstract, followed by full-text screening. Over a process of three meetings, papers were jointly screened by authors JD and PX, to ensure clarity in the inclusion criteria and to identify any disagreements. JD then independently screened the remaining studies, with PX double screening a further 20%. Where JD was uncertain

Box 1 Search terms

Search Termsterms

1. One exp Dementia/
2. (dementia* or alzheimer*).ti,ab,kf,hw.
3. 1 or 2
4. Four exp Ambulatory Care/
5. ((urgent or primary) adj (healthcare or care)).ti,ab,kf,hw.
6. Emergencies/
7. Seven exp Emergency Medical Services/
8. (emergency or emergencies or hotline* or hot line* or telephone or telecare or "111" or "999" or weekend or hospital* or evening* or out of hours or urgent or night* or A&E or ambulance or ambulatory).ti,ab,kf,hw.
9. 4 or 5 or 6 or 7 or 8
10. Ten exp Health Personnel/
11. (nurse* or nursing staff or doctor* or physician* or paramedic* or receptionist* or care home staff or care home staff or GP* or general practitioner*).ti,ab,kf,hw.
12. 10 or 11
13. Decision Making/
14. Health Communication/
15. (decision* or choice* or choos* or response* or understand* or options or triag*).ti,ab,kf,hw.
16. (communicat* adj3 (patient* or carer*)).ti,ab,kf,hw.
17. 13 or 14 or 15 or 16
18. 3 and 9 and 12 and 17
19. 3 and 9 and 12

over inclusion, studies were discussed as a study team to ensure no relevant materials were excluded.

Reference lists of included papers that were not empirical research (eg, reviews, editorials, guidelines) were searched for any relevant primary research to be included in the final review. Forward and backward citation searches of included papers were then undertaken. Keywords of included papers were then screened against the original search terms to ensure that they had all been included.

Data extraction

Following scoping review methodology, data were extracted by charting study findings, resulting in a descriptive summary of included studies. JD led on data extraction, with PX independently extracting data from 33% of the studies to check for accuracy.

Data synthesis

Study results relevant to the research questions were coded line by line for content, setting and type of participants using NVivo V.12. The codes were grouped according to setting and type of participants to allow description of the studies. They were then regrouped according to content of the codes, using methods from thematic analysis, first creating categories of codes with similar content and then forming groups of categories according to similarities and differences. These were discussed with the patient and public involvement groups to ensure clarity and relevance. This allowed a thematic description of (1) factors

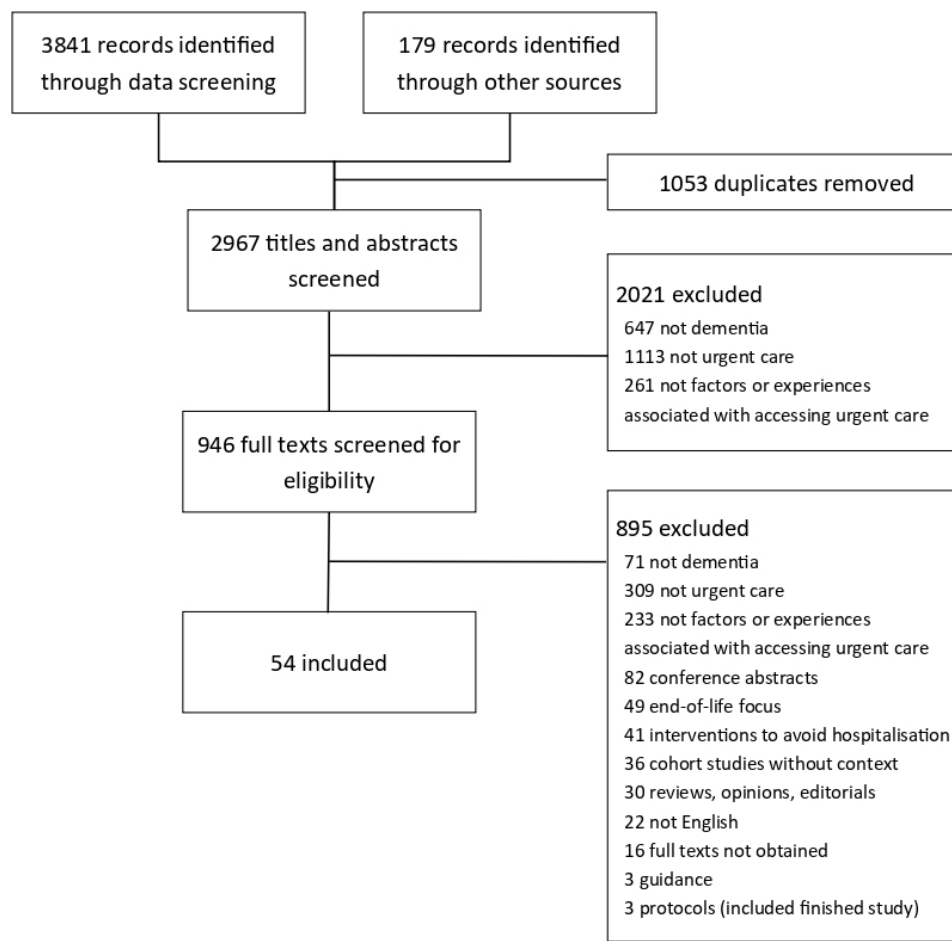


Figure 1 PRISMA flow chart. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

associated with urgent care use in dementia and (2) stakeholder experiences of urgent care use in dementia.

RESULTS

Included studies

Figure 1 contains a flow chart of the screening process. Database searches identified 3841 records, with a further 179 identified from other sources. After duplicates were removed, 2967 titles and abstracts were screened, 946 records were retained for full-text screening. Fifty-four studies were included in the scoping review.

Study characteristics

Table 2 provides a summary of the included studies. Twenty-six (48%) of the studies were conducted in the USA, 10 (18.5%) in the UK, 5 (9.5%) in Canada, 3 in the Netherlands, 2 (1.6% each) in France and China, and the remaining 5 in Taiwan, Ireland, Republic of Korea, Australia and Italy. The studies were published between 1991 and 2019, with 57% (n=31) published in the last 5 years. Twenty-two (41%) of the studies followed a prospective study design. Twelve (22%) were qualitative studies, nine (17%) were retrospective, five (9%) were surveys, five (9%) were mixed methods and one followed a Delphi process. The majority of studies included people

with all types of dementia or did not specify type of dementia. Four studies included only people with Alzheimer's disease and one study specified inclusion of participants with Alzheimer's disease, Vascular dementia and Parkinson's dementia.

Factors associated with urgent care use in dementia

Forty-five studies reported factors that were associated with urgent care use in dementia. These are listed in table 3, illustrating a number of contradictory findings.

Common comorbidities alongside dementia

Table 4 provides a summary of conditions discussed in the included studies occurring alongside dementia. Comorbidities were mostly described as 'age related',²⁰ rather than dementia related, but studies considered whether people with dementia were more likely to access urgent care for these conditions. Two studies reported people with dementia being more susceptible to hospitalisation for 'ambulatory care sensitive' conditions, conditions that could be treated outside of hospital, meaning hospital could have been avoided.^{21 22} Nine studies reported a statistically significant increase in urgent service use when people with dementia have other medical conditions.^{10 20 23-29} However, there was not a consensus; two

Table 2 Summary of studies

Authors and date	Country	Research Question/Aim	Study population (no and type)	Methods	Factors affecting access to urgent care for people with dementia
Abrahamson <i>et al.</i> ²⁵ (2016)	USA	To better understand the experiences of surrogate decision makers in the NH to hospital transfer decision making process	20 family members of residents from 9 nursing facilities who had experienced a hospital transfer within the past 3 months.	Semi-structured interviews. Data collected within Optimising Patient Transfers. Impacting Medical quality and Improving Symptoms: Transforming Institutional Care project.	Family member as advocate (formal with Power of Attorney or informal) for people with dementia. No relationship between family and care facility doctor. All information through nursing staff. 19/20 saw recent decision to hospitalise as appropriate. 3 themes: (1) Capacity to provide care: better medical care in hospital, more personalisation in home; (2) Resident vs Family choices: Advance directives not always taken into account by family, more challenging due to uncertainty of hospitalisation to help patient; (3) Issues at 'hand off': Poor communication between home and hospital leads to patient preferences not being taken into account.
Agyemang <i>et al.</i> ²⁶ (2017)	The Netherlands	To assess differences between ethnic minority groups and the Dutch ethnic population in (1) short-term (1 year) and long-term (3 years) mortality risks after a first hospitalisation or referral to a day clinic for dementia and (2) readmission risk.	59201 patients with dementia, identified through: hospital discharge register, population register, and national cause of death register.	Patients were followed up from their earliest date of a first hospitalisation or visit at the day clinic, until the end of the study period (31/12/2010) or until death of the patient.	All ethnic minority groups (except Indonesians) had a higher risk of readmission, particularly with Turkish (HR 1.85; 95% CI 1.27 to 2.69) and Surinamese (HR 1.25; 95% CI 1.01 to 1.53) dementia patients. Adjustment for age and sex abolished the difference with Surinamese (HR 1.17; 95% CI 0.95 to 1.45). The difference between Turkish was no longer statistically significant after further adjustment for comorbidities (HR 1.41; 95% CI 0.96 to 2.05). The readmission risk after day clinic visit with dementia did not differ between the ethnic groups.
Albert <i>et al.</i> ²⁷ (1999)	USA	To achieve a clearer understanding of whether AD is associated with greater hospital utilisation.	2334 participants in the Washington Heights Inwood Columbia Ageing Project (WHICAP).	Hospital admissions were monitored from 01/01/1996 to 30/09/1997. Research physicians recorded reasons for hospitalisation, patient self-reports and comorbidities reported.	Risk of hospitalisation did not differ with age or ethnicity. Higher levels of education lead to fewer hospitalisations ($p < 0.03$). More comorbidities lead to increased hospitalisation ($p < 0.0001$). Hospitalisation risk was 15.9% for subjects with mild to moderate dementia (OR (OR) 1.4, 95% CI (CI): 1.0 to 1.9) and 26.4% with advanced dementia (OR 2.7, 95% CI 1.5-4.6). Of subjects with AD who were hospitalised, 40.8% had pneumonia or other infection, compared with 27.2% among non-AD subjects ($p < 0.05$). 7/22 (31.8%) of AD subjects who died were hospitalised, compared with 5/34 (14.7%) of non-AD subjects who died ($p < 0.01$).
Amador <i>et al.</i> ²⁸ (2014)	England	What characteristics of care home residents with dementia are associated with emergency ambulance service use?	133 residents with dementia across 6 care homes.	Examined data on use of ambulances in a wider longitudinal study of people with dementia. Logistic regression analyses adjusted for factors potentially associated with emergency ambulance service use. Clustered standard errors were used to account for the potential effect of the care home on use of an emergency ambulance.	Reasons for contact: Trauma from fall (42%), respiratory (9%), cardiovascular (7%), gastrointestinal (6%), genitourinary (6%). Emergency ambulance contacts resulted in: admission to hospital (43% of trauma), returning home following assessment in A&E (32.6%, 38% of all trauma), non-conveyance (24.3%, 22% of trauma). Impact of characteristics: (1) Each year of age increases odds of ambulance contact by 6.1% and GP practice contact by 15%; (2) The effects of gender, length of residency, number of comorbidities, admission route into the home and number of contacts with a district nurse were not significant; (3) When contacts with a GP is increased by one unit, residents had 1.235 times greater odds (17% increase) of ambulance contact; (4) The odds of using ambulance services for residents admitted from a relative's home were 90% lower than those admitted from their own home.
Andrieu <i>et al.</i> ²⁴ (2002)	France	To evaluate the frequency of and determine predictive factors for acute hospitalisation in a prospective study of patients with AD.	134 patients with AD (having received the diagnosis <5 years ago) recruited from a memory clinic.	A cohort of the first 134 patients recruited into the ELISA Study, a longitudinal prospective study. Information was obtained by telephone interview with the caregiver at 3 and 9 months. Predictive factors were evaluated. Variables that were statistically significant in univariate analysis were entered into a multiple stepwise logistic regression model.	22/134 had one acute hospitalisation, 7 two, 2 three, 1 four. Variables predicting acute hospitalisation in univariate analysis: Level of education, activities of daily living (ADL)-bathing, ADL-toileting, ADL-feeding, total ADL score, IADL A scale, history of fall, and behaviour disorders. (not age, sex, cognitive function). Predictors from multivariate model: dependency for ADL-bathing (OR 4.98; 95% CI: 1.90 to 13.42, $p = 0.0012$), frequency of behavioural troubles as assessed by the caregiver (OR 1.055; 95% CI: 1.01 to 1.1, $p = 0.017$). Predictors when caregiver factors excluded: dependency for ADL-bathing (OR 5.65; 95% CI 2.3 to 14.4, $p < 0.0012$), low educational level.
Benner <i>et al.</i> ²⁶ (2018)	USA	To (1) determine rates of and reasons for hospitalisations and ED visits by persons with dementia as reported by their family caregivers and (2) examine whether the family caregivers took any actions to prevent these healthcare events.	63 family caregivers of people with dementia	Descriptive design. Family caregivers of persons with dementia were given a one-time survey about the use of healthcare services for their care recipient and any actions they took to prevent hospitalisations and ED visits. Data from the open-ended survey questions were reviewed and categorised.	19.1% care recipients had visited ED and 11.1% had been in hospital in month prior to survey. Reasons for hospitalisation: fall-related injury ($n = 3$), abdominal pain/obstructed common duct, fluid in the lungs, gall bladder surgery, a mental status change, and urination problems ($n = 1$ for all). Reasons for ED visit (all $n = 2$): behavioural issues, a fall-related injury, a heart-related illness, a medication adjustment, and urinary tract infection. Preventative measures taken by caregivers: giving medications, seeking healthcare services, obtaining HC services, and asking friends or family for advice.

Continued

Table 2 Continued

Boltz <i>et al</i> ⁴⁶ (2018)	USA	To examine the influence of family caregiver strain and anxiety on prehospitalisation functional decline in medical patients with dementia, controlling for patient characteristics.	136 dyads of older adults with dementia and their informal primary caregivers (FCGs).	Secondary analysis from two comparative, repeated measures datasets. Patient measures were completed on admission, via observation, input from staff, chart abstracting or interview.	82% patients showed decrements in ADL function prior to admission to the hospital (losing 8.7 points on Barthel Scale). Depression, baseline physical function, dementia severity, and caregiver strain were associated with preadmission change in function and explained 40% of the variance. Age and caregiver anxiety were not associated with change in function.
Carter and Porell ⁴¹ (2005)	USA	To examine the extent to which residents of nursing facilities with AD and dementia may be differentially affected by certain facility-level structural and organisational risk factors of ambulatory care-sensitive hospitalisations and quality-of-care practices.	19 802 NH residents with dementia and 19 958 NH residents without dementia.	Data from the Management Minutes Questionnaire served as the core data file to which other three data sources were linked: hospital claims data from the Medicare Provider Analysis and Review (1990–1993), Medicare Provider of Service files and cost reports from the Massachusetts Rate Setting Commission (1991–1993) and the Massachusetts death registry file (1991–1993).	9% of dementia cases contained at least one hospitalisation; nearly 41% were classified as ambulatory-care sensitive. 15% pneumonia, 11% gastroenteritis, 7% kidney infection or UTI. NHs with higher hospitalisation rates had a greater proportion of ambulatory-care sensitive hospitalisations. Individual factors: (1) Weight loss/gain increase odds of hospitalisation, particularly with gastroenteritis (odds 35% greater); (2) Accident in past 90 days associated with 53% increased odds for hospitalisation with kidney infection or UTI. Organisation factors: (1) Non-profit status significantly lowers the odds of hospitalisation for infectious conditions (OR, 0.90; p=0.028); (2) Odds ratios indicate a 62% reduction in the odds of experiencing a hospitalisation in facilities with on-site nurse practitioner; (3) Addition of one full time RN per 100 residents is associated with 3% lesser odds of hospitalisation, 5% lesser for a kidney or UTI infection; (4) Each percentage point increase in staffing hours from pooled services, the odds of ambulatory care sensitive hospitalisations are increased 1%.
Chang <i>et al</i> ⁴⁷ (2015)	Taiwan	To explore the roles of dementia subtypes, cerebrovascular risk factors, systemic diseases, and the aetiology for admission in predicting recurrent or prolong hospitalisation.	203 patients with AD, Vascular dementia (VaD) or Parkinson's related dementia.	Observational cohort study with observation periods from 2007 to 2014. Logistic regression analyses were used to identify predictors of recurrent or prolong hospitalisation within 4 years follow-up period.	Aetiology for admission in descending order: acute delirium, newly onset stroke, pneumonia, fall-related hip fracture, UTI. AD patients had a higher frequency of delirium than VaD (OR 1.829, 95% CI 1.313 to 2.547, p=0.001). Patients with VaD had higher frequency of fall-related fracture compared with AD (OR 8.024, 95% CI 1.023 to 62.972, p=0.021). No effect of type of dementia on infection rate or recurrent hospitalisation. No effect of age on recurrent hospitalisation. Coronary artery disease, pneumonia, urinary tract infection, or fall-related fracture were associated with frequent admission.
Clay ⁴⁸ (2008)	UK	To identify factors that led residents to be admitted to hospital as emergencies.	17 residents admitted to hospital from one NH over the course of 1 year. Interview with manager of one NH.	Thesis study—mixed methods. Data analysis of case studies of NH residents admitted to hospital over the period of 1 year and interviews. Hospital Episode Statistics (HES) study data analysed but not extracted for this review (results not stratified for dementia).	Family carers do not recognise dementia as a terminal illness, and put pressure on professional to prolong life at all costs. Manager of NH saw all hospitalisations as unavoidable, except the cases where patients had advanced pneumonia and infections. Nurses do not communicate to clinicians that patients have advanced dementia, leading to inappropriate admissions.
Cloutier and Penning ⁴² (2017)	Canada	(1) How well do our quantitative data map onto our mothers' experiences? (2) What lessons do our mothers' experiences offer for the care of older women with dementia?	761 women over 65 who made the transition from HC to residential care between 2008 and 2012.	Triangulated quantitative data from funded research programme, with author personal narratives about their mothers who lived with dementia.	Women with dementia who transition from HC to residential care experience more hospitalisations than those who just have HC or just residential care after their diagnosis. Hospitalisations become less frequent after transitioning to residential care. Hospitalisations were an important of journey to care facility.
Cogen <i>et al</i> ⁴⁰ (1992)	USA	To determine surrogate decision makers' attitudes towards providing or withholding care in five hypothetical clinical situations with people with dementia in NHs.	102 surrogate decision makers (family or closest contact who are identified by the NH as the contact for decision making).	Postal survey about different hypothetical scenarios, and whether they would accept or reject the following hypothetical clinical situations: (1) tube feeding, (2) hospitalisation for pneumonia, (3) transfer from a hospital floor to the ICU in the face of worsening sepsis, (4) mechanical ventilation for respiratory failure, (5) CPR.	Treatment in all situations was elected by 14.7%, while 11.8% said no to all. Tube feeding and cardiopulmonary resuscitation (CPR) were the least accepted interventions (36.4% and 31.6%). No difference in treat responses by surrogate age or years of education. Small correlation (p<0.05) between male gender and positive treat response. No correlation between experience of treatment and choice. 3.1% surrogates made decisions solely on statements the patient had made in the past. In 69.7% responses decisions were made independently of any previous statements from the patient.

Continued

Table 2 Continued

D'Agata <i>et al</i> ⁶⁰ (2013)	USA	To describe the presentation of suspected urinary tract infections (UTIs) in NH residents with advanced dementia and how they align to minimum criteria for diagnosis (presence of symptoms (eg, fever, dysuria, frequency), as well as positive findings on urinalyses and urine cultures).	266 people with dementia residing in NHs.	Data were obtained from the ongoing Study of Pathogen Resistance and Exposure to Antimicrobials in Dementia (SPREAD). For each suspected UTI episode, documentation of the following was ascertained: (1) whether the resident had a Foley catheter, (2) temperature data, (3) the presence of the following symptoms: new dysuria, frequency, urgency, hematuria, costovertebral tenderness, suprapubic pain, change in mental status (ie, 'mental status change', 'lethargy' or 'alteration from cognitive status from baseline'), or rigours. Whether or not urine analyses were obtained was recorded.	72 (27.1%) NH residents had a UTI in the 12 months follow-up period. Mental status changes were the only symptom or sign in 35.9% of reported UTIs, 16% of UTI cases met the minimum criteria to initiate antimicrobials. A mental status change was more commonly documented (48.3% vs 13.3%) and fever was less commonly documented (19.0% vs 33.3%) for episodes in non-catheterised vs catheterised residents. The proportion of episodes for which the minimum criteria to initiate antimicrobial were met based on signs and symptoms was also lower among non-catheterised residents (12.9% vs 40.0%). Urinalyses and cultures were performed in 101 out of 131 UTI episodes. 79.2% were positive on both tests. This percentage was not different in residents who met the minimum criteria for diagnosis or not. 15% of suspected UTI episodes had both the minimum signs of symptoms and positive laboratory findings. 77.9% of suspected UTIs were treated with antimicrobials. 74.5% of those who did not meet the minimum criteria were treated with microbials.
Donnelly <i>et al</i> ⁶² (2017)	Ireland	To examine how inadequacies in the healthcare system impact on long-term care admissions of people with dementia	16 family carers of people with dementia and 22 healthcare professionals.	Semistructured individual interviews. Themes developed through the 'One Sheet of Paper' method.	Economic crisis has limited effective homecare which causes hospital admissions. Lack of community care services means that families have to go to acute hospitals in times of crisis. Acute hospital admission takes decision about transferring patient to long term care out of the family carer's hands—removing guilt. While conversations about ACP are instigated by community care staff, often only in hospital setting they are taken seriously
Gessert <i>et al</i> ⁴⁹ (2006)	USA	To enhance understanding of rural–urban differences in end-of-life care for people with severe dementia.	3710 residents with 'irreversible cognitive impairment': 1886 from 1016 rural NHs and 1824 from urban NHs.	Analysed Minimum Data Set records, linked with: Medicare Hospice files; Medicare Denominator files; Centers for Medicare and Medicaid Services (CMS) Provider of Services and CMS Provider Analysis and Review files.	Urban residents more likely to have had a stroke. Rural residents with dementia are more likely to be hospitalised, while urban residents are more likely to have longer admission or be admitted to ICU. Non-white people with dementia are more likely to be hospitalised in both rural and urban communities. Medicaid and advance directives are associated with lower levels of hospitalisation.
Givens <i>et al</i> ⁶⁰ (2012)	USA	To examine the primary diagnoses associated with hospital transfer (hospitalisation or ED) visit, and the frequency and predictors of hospital transfer in the setting of acute illness.	323 NH residents with advanced dementia	Participants were from the Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-life (CASCADE) study, a prospective cohort study of NH residents with advanced dementia and their healthcare proxies (HCPs). Resident assessments were conducted at baseline and quarterly using medical record reviews, nurse interviews and clinical examinations.	There were 74 hospitalisations and 60 ED visits in the 18 month period. Reasons for hospitalisation: suspected infection (59%, mostly respiratory 41%), gastrointestinal bleeds (8%), respiratory distress (7%), fracture (5%), congestive heart failure (3%), and other single occurrence diagnoses (18%). Reasons for ED - feeding tube-related complications (47%), fall (13%), urogenital infections (8%), skin infections (7%), gastrointestinal infections (7%), respiratory infections (5%), fractures (3%), and other single occurrence diagnoses (10%). 11% of medical events resulted in hospital transfer. Resident characteristics associated with being transferred to the hospital: younger age, male gender, non-white race, not being on a special care unit, presence of a feeding tube, lack of do-not-hospitalise (DNH) order, and having chronic obstructive pulmonary disease. Younger HCP age and event type were associated with hospital transfer in the unadjusted analysis. Pneumonia and other acute medical events were more likely than febrile episodes to result in hospital transfer. In adjusted analysis, younger resident age, the event type, presence of chronic obstructive pulmonary disease and the lack of a DNH order were associated with a greater likelihood of hospital transfer.
Givens <i>et al</i> ⁶³ (2015)	USA	To use data from a prospective cohort study of NH residents with advanced dementia and their proxies to compare proxy awareness of suspected infections with documentation of discussions. To identify resident, proxy and infectious episode characteristics associated with proxy awareness and discussion documentation.	362 residents with dementia	SPREAD, a 5-year prospective cohort study of NH residents with advanced dementia and their healthcare proxies. Resident data were collected for up to 12 months from full chart review assessments and monthly infection screens. Proxy telephone interviews.	240 residents had at least one infection over 12 months. 7.9% of infections resulted in hospitalisation (or ED), 71.7% were treated with antimicrobials. In 36.6% of infection episodes, residents had do not hospitalise orders. Proxies were only aware of 39.5% of recorded infections, and of these they participated in 57.1% of the decisions (22.5% overall decisions). Proxy awareness was associated with treatment with antimicrobials (adjusted OR (AOR)=3.43, 95% CI 1.94 to 6.05), hospital transfer (AOR=3.00, 95% CI=1.19 to 7.53), occurrence within 30 days of death (AOR=3.32, 95% CI 1.54 to 7.18), and fewer days between documented date of infectious episode and study interview (AOR=2.71, 95% CI 1.63 to 4.51).

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Goodman <i>et al</i> ⁴⁵ (2017)	UK	<p>(1) What is the range of health service delivery models designed to maintain care home residents outside hospital? (2) What features of these delivery models are associated with positive outcomes? (3) How are these features / mechanisms associated with key outcomes? (4) How are these features / mechanisms associated with costs? (5) What configuration of these features would be recommended to promote continuity of care?</p>	<p>In total, 242 residents were recruited across the three sites (four care homes per site, between 4% and 80% of residents with cognitive impairment). 181 interviews were completed with residents, relatives, HCPs and care home staff.</p>	<p>Phase 1: Interviewed NHS and local authority commissioners, providers of services to care homes, representatives from the regulator, care home managers and residents and their families. (+literature review) Phase 2: Purposively recruited 12 care homes and tracked the care residents home for 12 months. Interviewed care home staff, residents, family and visiting healthcare professionals (HCPs). Conducted an online survey with care home staff to assess their satisfaction with the healthcare services received.</p>	<p>Three sites had different dementia provision: Site 1—access to specialist dementia outreach team (with different clinical specialists); Site 2—access to dementia advice and support service; Site 3—one dementia specialist nurse over several sites. Residents with cognitive impairment had fewer primary care contacts. Lack of dementia training leads to poor care from NHS services, specifically in appropriate coordination of care. Dementia training uneven across care homes, even with same provider, but very useful in improving care (for example encouraging to eat or drink). Evidence of language that depersonalises people with dementia used by HCPs who visit patients in care homes. One dementia specialist nurse over several homes means there is not enough time per patient. Dementia specialist nurse cannot access GP notes and does not share paperwork with care home, can only share with other services with consent. Specialist nurse provision can be 'stop-start' with lack of continuity. GPs not always aware of dementia specialist services for care homes. Care home staff not understanding behavioural symptoms of dementia adds burden to GPs. Care home site three had lower antibiotic prescribing than the other two—could be due to involvement of dementia specialist nurse. Antipsychotic reviewing by dementia nurse specialist reduced prescribing in site 3. Out of hours services important to reduce hospitalisations, including out of hours dementia specialist in site 3. Out of hours services to care homes not suitable for people with dementia, for example have to be admitted to hospital to see a psychiatrist. Hospitals have poor understanding of how care homes work. Care home staff feel that some clinicians who come in don't have enough knowledge about dementia. Relative concerned that diagnosis of dementia means her mother gets less access to care (would not be the same with cancer). Dementia-related challenging behaviours in care homes can affect staff (and external clinician) ability to make appropriate decisions. Lack of dementia specialists in care homes has led to police being involved in cases with challenging behaviour. Context is important when evaluating people with dementia's challenging behaviour in care homes. External clinicians aren't always present so they can't understand. Clinicians don't always engage with people with dementia when called to care home for challenging behaviour, will rely on notes. Formal complaint will make clinicians take it seriously. Care home staff believe that further dementia training will not solve problem of challenging behaviour, need to work closely with specialist services. GPs see dealing with challenging and aggressive behaviour as the most difficult aspect of their work in care homes. NHS staff do not change their health provision appropriately for people in care homes, lacking expertise in dementia. Specialist NHS services that work closely with care homes may improve patient care (eg, dementia specialists). Key challenge in care homes is when people with dementia whose behaviours and distress cannot be managed by care home staff—leading to uncoordinated responses, escalation of service involvement and demand on emergency services. Linking with dementia specialists allows an appropriate response to crises.</p>
Grober <i>et al</i> ²⁵ (2012)	USA	<p>To determine whether dementia status and medical burden were independent predictors of ED visits and hospitalisations in older patients from an urban geriatric practice participating in a primary care based cognitive screening programme.</p>	<p>300 total participants (46 with dementia, 254 without).</p>	<p>Patients recruited from the dementia screening project conducted in the Geriatric Ambulatory Practice (GAP). Cognitive status established at baseline and follow-up. Clinical Looking Glass, Montefiore's clinical information system, was used to retrieve number of ED visits and hospitalisations. Comorbidities were recorded and evaluated for severity. Associations were explored.</p>	<p>Persons with dementia made 261 ED visits over 269 person-years of follow-up, for an unadjusted rate of 0.97 ED visits per year. Persons with dementia had a 49% higher rate of ED visits than persons without dementia (incidence rate ratio (IRR)=1.49; 95% CI 1.06 to 2.09; p=0.023). For each point increase of medical burden, there was an 11% higher risk of an ED visit (IRR=1.11; 95% CI 1.06 to 1.16; p=0.000). Functional capacity did not predict ED visits (p=0.95). Age was not a significant predictor of ED visits (p>0.30). Persons with dementia accounted for 173 inpatient hospital admissions over 269 person-years of follow-up, for an unadjusted rate of 0.64 admissions per year. Persons with dementia had a 37% higher rate than persons without dementia, but the model adjusted for age only, dementia status did not predict hospitalisations (p=0.08). Additional adjustment for medical burden strengthened the effect of dementia status (IRR 1.37; 95% CI 0.99 to 1.89; p=0.055). For each point increase of medical burden, there was a 13% higher risk of a hospital admission (IRR 1.13; 95% CI 1.09 to 1.17; p=0.000). Age and functional capacity did not predict hospitalisations (p>0.45).</p>
Hunter <i>et al</i> ⁶² (2017)	Canada	<p>The purpose of this study was to understand safety and harm in rural ED transitional care for community-dwelling older adults with dementia from the perspective of HCPs.</p>	<p>12 healthcare professionals (HCPs) from two rural EDs.</p>	<p>Interview study with HCPs who work in the ED or consult on cases involving people with dementia. Ongoing and iterative qualitative analysis. Participants were from nursing, social work, occupational therapy, physical therapy and medicine.</p>	<p>Noise, overcrowding and lack of privacy created a sense of chaos and tension as part of the milieu. Traffic, commotion and noise made it difficult for patients with dementia to communicate their needs. Pressure to perform in ED means that HCPs feel unable to provide optimum care, which inadvertently leads to person with dementia being a lower priority. HCPs see themselves as 'too busy' to prioritise dementia patients. Pressure of ED means that decisions are made in crisis. People with dementia end up in the ED due to family burnout. Having family carer present can reduce potential harm to person with dementia. Specialist knowledge (through experience and training) can help caring for people with dementia in the ED. Need to see context, the person with dementia as a whole person, in making decisions for people with dementia in the ED. Rural communities can make decision making easier in the ED, because people know each other. Lack of resources affects decision making in ED, may be able to discharge people home with appropriate care, but not always available.</p>

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Husaini <i>et al.</i> ³³ (2003)	USA	Are there racial differences in the effect of dementia on the use and costs of healthcare services?	1366 people with dementia.	Examined a 5% random sample (n=33688) of white (n=30 089) and African-American (n=3599) Medicare beneficiaries in Tennessee who filed claims from 1991 to 1993 and investigated racial and gender differences in the number of inpatient hospital days, outpatient visits, and physician visits and in whether the person visited an ED during the 3 years period.	There was no difference in emergency service use by people with dementia according to ethnicity. African Americans with dementia spent significantly more days in the hospital than their white counterparts (about 4.5 days more). African Americans with a diagnosis of dementia had more than three times as many hospitalisation days as those without dementia. All people with dementia were more likely to use emergency and outpatient services than people without dementia. Healthcare costs for African American people with dementia are significantly higher than for African Americans without dementia and white Americans with dementia - partly attributable to higher use of emergency services.
Jacobsohn <i>et al.</i> ³⁵ (2019)	USA	To explore stakeholders' perspectives on the decisions and drivers influencing ED use in dementia and suggestions for effectively addressing unmet needs.	27 stakeholders: Informal carers (n=4), emergency medicine physicians (n=4), primary care physicians (PCPs, n=5), geriatric healthcare providers (physician, nurse, n=5), ageing service providers (n=6), and community paramedics (CPs, n=3).	Semistructured interviews with informal carers emergency services staff. Thematic analysis identified meaningful patterns in the data.	Three themes: (1) System Fragmentation Influences Emergency Care Use: Lack of communication between healthcare providers and integration in community services; GP practices and paramedics are not aware of dementia-care resources, so do not refer or coordinate. Ageing service providers do not have means to update medical professionals on changes in individual care; Emergency care staff do not always know why people with dementia have ended up in their care, impedes ability to provide quality care; Dementia diagnosis is not always in patients medical record, so emergency staff cannot give appropriate care. (2) Informational, Decision-Making, and Social Support Needs Influence Emergency Care: Caregivers don't know what to do in urgent situations which leads to emergency care use. Caregivers find it hard to talk to GPs about crisis situations - think they don't have the correct knowledge, and don't want to burden them; GPs don't feel they have the training, knowledge or time to help caregivers with dementia; Caregiver need for respite can lead to people with dementia in emergency care. (3) EDs Are Not Designed to Optimally Address PwD and Caregiver Needs: People end up in EDs as the only way to access care; Emergency clinicians focus on physical problems, which may lead to hospitalisation without taking into account social or environmental reasons; Emergency care is challenging because just focus on crisis rather than root cause (because of time and staffing constraints). Options to Prevent and Address Emergency Care Needs: (1) Can avoid emergency care by preventing crises in the first place using non-emergency services or new approaches to care; (2) Better advanced care planning and better information provision to carers could reduce emergency service use (although will always be needed); (3) Increased access to primary or urgent care services may work, but this may not be feasible or a better alternative; (4) Integrated dementia specialists in primary care and increased HC could decrease emergency services use.
Kim <i>et al.</i> ⁴¹ (2019)	Republic of Korea	This study tested two hypotheses: (1) the type of LTC services are associated with the incidence of hip fracture, and (2) the association between the type of LTC service and the incidence of hip fracture would differ by sex, region, whether the patient had a predetermined risk of hip fracture during the mandatory assessment of benefit eligibility, and ambulatory status.	7112 people with a diagnosis of dementia and a long term care insurance benefit coverage level of 1 or 2; 2802 (39.4%) in HC and 4310 (60.6%) in institutional care.	Analysis of the Korean Elderly Cohort data set from 2008 to 2013.	115 people (1.6%) experienced hip fractures in the time period. 3.2% of people in institutional care had hip fractures, 0.6% of those in HC. As compared with those receiving HC, those receiving institutional care had a higher adjusted hazards ratio (HR) for hip fracture (HR=4.23, 95% CI 2.83 to 6.58). Among those receiving IC, the following groups had a higher adjusted HR for hip fracture: females (HR=4.73, 95% CI, 2.96 to 7.53 vs male: HR=3.54, 95% CI, 1.24 to 10.09); rural (HR=4.69, 95% CI, 2.60 to 8.44 vs urban areas: HR=4.26, 95% CI, 2.27 to 7.90); those who were not deemed 'at risk' (HR=5.27, 95% CI 2.15 to 12.92 vs those who had a predetermined risk: HR=4.09, 95% CI, 2.53 to 6.62); partially ambulatory (HR=4.96, 95% CI 2.24 to 11.00); not ambulatory (HR=4.62, 95% CI, 2.69 to 7.97 vs those who were ambulatory: HR=2.21, 95% CI, 0.61 to 8.02). As compared with those received HC, participants who received IC without a clinic room had a higher adjusted HR for hip fracture (HR=4.55, 95% CI 2.69 to 7.70).
Kupeli <i>et al.</i> ⁶³ (2018)	UK	We aimed to identify the barriers to providing integrated care as understood by healthcare professionals (HCPs) working with people with advanced dementia residing in care homes (all with some nursing beds).	14 HCPs: 3 healthcare assistants, 1 nurse, 1 clinical nurse manager, 1 memory clinic manager, 2 care home managers, 1 specialist dementia nurse, 1 mental health nurse, 1 specialist occupational therapist, 2 commissioners.	Realist approach and in-depth interactive interviews. Transcripts were analysed using thematic analysis.	Care home staff argued that they were not provided with the training or support from external service providers to recognise and respond to symptoms presented by people with advanced dementia as they approached the end of life, such as pain. Fragmented relationships between care home staff and external HCPs. Care home staff feel undervalued by HCPs, don't feel listened to; takes trust away from the relationship at a detriment to the resident. Lengthy processes involved in HCP services external to care home (eg, advance care planning, referrals) causes disjointed care within care homes. Poor communication between care homes and hospitals. Care home staff see residents as having right to refuse food or drink, external HCPs don't understand this and blame the home. Care home staff and HCPs work in silos, integration is needed. Diffused responsibility in care homes, no one clinician takes overall responsibility.

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37 (2005)	USA	To identify staff perceptions of key administrative attitudes toward tube feeding, antibiotic use, and hospital transfers of NH residents with end-stage dementia.	138 NH social service staff members, from non-profit or public facilities (n=93) and for-profit facilities (n=45).	Questionnaire study.	45% of social service staff identified their respective facility's medical director as the most influential medical decision-maker, 25% directors of nursing, 10% administrators, 10% family caregivers. Medical directors of care homes were more likely than other staff to discourage tube feeding, antibiotics and hospitalisation of residents with end stage dementia. 10% overall actively discouraged antibiotic use. 13% medical directors, 9% nurses, 7% (n=1) administrators. 49% overall actively encourage antibiotic use, along with 41% medical directors, 59% directors of nursing, and 57 administrators. 37% overall discourage hospitalisation except for comfort care: social service staff perceived that 48% medical directors took this position, compared with 21% directors of nursing, and 27% administrators. 39% of all key administrative staff were perceived to actively encourage hospitalisation: 38% medical directors, 47% directors of nursing, 50% administrators.
LaMantia <i>et al</i> ⁶⁴ (2017)	USA	To understand medical professionals' experience with, barriers to, and strategies for identifying and treating older adults with delirium in the prehospital and ED environments.	31 professionals who care for people with delirium in emergency settings: 11 nurses, 11 EMS providers, and nine physicians.	six semistructured focus group interviews, analysed with thematic analysis.	Greatest challenge in treating delirium is in the ED environment: limited time and resources. Challenge in identifying delirium in ED because do not have knowledge of the patient's baseline cognitive status. Clinicians don't do assessments for delirium in ED, rely on clinical experience, presence of predisposing factors (such as UTI) and disinhibited behaviour. Physicians are more comfortable than nurses in treating delirium in ED (although admit some cases might be missed). Factors to help treat delirium in ED - education, guidance and communication between EMS and ED, tools to help diagnose.
Le Guen <i>et al</i> ⁶¹ (2016)	France	To (1) measure how often very elderly patients were asked for their opinions during triage in EDs, and (2) to study the individual and organisational characteristics that influence the likelihood that patients will be asked to express a preference.	2115 patients, 325 with dementia (15%) from 15 hospitals, admitted to the ED for conditions which might require transfer to the intensive care unit (ICU).	Post hoc analysis of data gathered in ICE-CUB, a prospective, multicentre cohort study that included patients over 80 presenting at an ED in a condition potentially requiring intensive care.	A history of dementia reduced the probability of patients being asked their opinion on transfer to ICU from EDs. This was confirmed in multivariate analyses (OR 0.47, 95% CI: 0.25 to 0.83).
Ledgerd <i>et al</i> ²⁸ (2016)	UK	To identify the main causes of crisis and interventions to treat or prevent crisis in persons with dementia, based on different stakeholder perspectives.	719 questionnaires respondents: 20 academics (2.8%), 562 health sector staff (78.2%), 54 family carers (7.5%), 23 social care sector staff (3.2%), 16 emergency services staff (2.2%), 12 voluntary sector staff (1.7%), 4 people with dementia (0.5%), and 28 others (3.9%). Grouped into four groups: physical health staff, mental health staff, academics and consumers.	An online survey to explore primary causes of crisis and distinguish interventions useful for managing or preventing a crisis for people with dementia, part of a modified Delphi Process.	Causes of crisis: (1) Behavioural and psychological issues: memory, paranoid / suspicious behaviour; (2) Physical health: Falls, infection, delirium, immobility and incontinence key risk factors; (3) Vulnerability: inability to identify potential risks, poor nutrition, abuse, poor hygiene, lack of support services and safety outdoors; (4) Family carer: carers' physical and mental health, burden and the sudden absence or death; (5) Environment: hazards around the home, daily tasks, consumers the person with dementia living alone, changes in the home environment, being unable to access essential amenities, inadequate community services, lack of suitably trained care staff, lack of coordination between services. Interventions to manage a crisis: (1) Professional healthcare support: 24 hours availability, access to safeguarding team, telephone helpline, single point of contact; (2) Social HC: Emergency, flexible care services; (3) Family carer: Respite; (4) Home living environment: communication equipment, having family carer and supportive friends and neighbours, special assistive technology, assistance with medication. Interventions to prevent a crisis: (1) Professional healthcare support: early referrals to support services, a coordinated care plan, specialist training for health staff, multidisciplinary assessments and provision of purposeful activities, involving people with dementia in decisions and medication reviews; (2) Social HC: Presence and training of HC staff, day care services, flexible services and a centrally held database of needs and preferences of people with dementia; (3) Family carer: Family carer education, counselling and advice, and involvement in planning of care; (4) Home living environment: daily routine, including support for medication, family carer and the support of friends and neighbours also important, home adaptations and equipment highly regarded, along with prompts and cues around the home, specialist assistive technology and purposeful activities consistently valued across groups. 'Behavioural/psychological factors' was ranked as the most likely category to cause a crisis, while the 'environment' was ranked lowest by all participant groups.
Lin <i>et al</i> ⁶² (2017)	USA	To examine the frequency and costs of potentially avoidable hospitalisations (PAHs) and unplanned 30-day readmissions in the entire Medicare fee-for-service population with dementia.	2749172 Medicare fee-for-service beneficiaries age over 65 with a claims-based Alzheimer's disease and related dementias (ADRD) diagnosis.	Analysis of Medicare Provider Analysis and Review files, measuring avoidable hospitalisations (defined as acute (ie, bacterial pneumonia, urinary tract infection, and dehydration) and chronic (ie, diabetes, hypertension, heart failure (HF), angina without a cardiac procedure, and asthma/chronic obstructive pulmonary disease (COPD)) conditions) and readmissions.	10% (280,547) had at least one ambulatory care sensitive hospitalisation. There were a total of 369 165 ambulatory care sensitive hospitalisations in total, suggesting 14% of hospitalisations for people with dementia could be avoidable. Infections are the most common cause for ambulatory care sensitive hospitalisations. 18% of patients were readmitted within 30 days of discharge from hospital, 73% of these once, 18% twice and 9% three or more times. Readmission varied by diagnosis of the index hospitalisation: 22% for HF, 21% for COPD, 19% for acute myocardial infarction, 18% for coronary artery bypass graft, 15% for pneumonia, 12% for stroke, and 9% for total hip or knee arthroplasty. 33% of those initially hospitalised for HF were readmitted for HF again within 30 days of discharge.

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Palan Lopez <i>et al.</i> ⁶⁴ (2017)	USA	To increase an understanding of how decisions are made to transfer NH residents with advanced dementia to hospital, from the perspective of NH nurses and physicians.	20 providers from 9 NHs.	Interviews and analysis involving three levels of coding using NVivo.	three reasons why NHs don't want to send pwd to hospital (1) hospitals are not safe (2) fiscal pressures to avoid transfers (3) negative prior experiences Two phases in decision making about hospitalisation: (1) Laying the groundwork: finding out surrogates' preferences for hypothetical acute events and obtain do-not-hospitalise order. Necessitates (a) establishing trust (b) foreshadowing likelihood of acute event (c) illuminating hazards of hospitalisation; (2) Responding to the acute event: Three factors affect decisions: (a) ability to provide care in NH, (b) NH providers' comfort with end of life conversations, (c) surrogates' preferences have precedent over DNH or staff.
Mitchell <i>et al.</i> ⁶⁵ (2009)	USA	To gain a better understanding of the clinical trajectory of end-stage dementia.	323 residents with advanced dementia from 22 NHs.	18 month, multicentre, prospective study. Data were collected from resident chart reviews, interviews with nurses, and brief physical examinations at baseline and once per quarter. Data were collected from proxies once per quarter.	54.8% (177 residents) died over the 18month course of the study. The probability of at least one episode of pneumonia was 41.1%; a febrile episode, 52.6%; and an eating problem, 85.8%. 42 sentinel events occurred in 31 residents (9.6%): Seizures (33.3%), gastrointestinal bleeding (26.2%), hip fractures (7.1.0%), other bone fractures (9.5%), stroke (7.1%), pulmonary embolus (2.3%), myocardial infarction (2.3%), other (11.9%). Sentinel events rarely precipitated death – only seven occurred during the last 3months of life among residents who died. 16.7% were hospitalised, 9.6% were taken to the ER. The most common reason for hospitalisations was pneumonia (68.2%), infections (13.6%), heart failure (9.1%), hip fracture (4.5%), dehydration (4.5%), 81.4% of the proxies felt they understood which clinical complications to expect in advanced dementia, only 32.5% stated that a physician had counselled them about these complications. Residents whose healthcare proxies believed that the resident had less than 6months to live and understood the clinical complications expected in advanced dementia were less likely to undergo a burdensome intervention during the final 3months of life (adjusted OR, 0.12; 95% CI, 0.04 to 0.37). There was no association with whether proxies had been counselled about complications.
Mitchell <i>et al.</i> ⁶⁶ (2014)	USA	To (1) describe the occurrence and management of suspected infectious episodes, specifically whether antimicrobial treatment initiation was appropriate based on consensus guidelines, (2) identify factors associated with appropriate antimicrobial treatment, (3) describe the prevalence and acquisition of MDRO colonisation, (4) examine the association between antimicrobial exposure and acquisition.	362 residents with advanced dementia from 35 NHs.	Data obtained from the SPREAD study, a prospective cohort study. Resident data were collected for 12 months from 2 assessment types; full assessments (at baseline, quarterly thereafter, and within 14 days of death) and infection screens (monthly). Proxy telephone interviews were conducted at baseline, quarterly thereafter, and 2 months after a resident's death (referred to month before death).	At baseline, 94.8% of proxies stated that the primary goal of care was comfort. 32.9% were counselled by clinicians that infections were common in advanced dementia; 37.8% were counselled about antimicrobial use; 45.3% were asked their preferences regarding antimicrobial use. 66.3% of residents experienced at least one suspected infection (range, 0–9). Total of 496 episodes: respiratory tract n=148 (29.8%), urinary tract n=196 (39.5%), skin, n=69 (13.9%), fever with unclear source n=83 (16.7%). Other episode characteristics included hospital transfer 11.1%, physician examination within 72 hours 56.7%, documented discussion between the proxy and clinician, 53.9%. 51.9% of residents had at least one antimicrobial course. 72.4% of total infections were treated with antimicrobials (n=359) - respiratory tract 70.3% (n=104), urinary tract 75.5% (n=148), skin 95.8% (n=66), febrile only 49.4% (n=41). 44.0% of treated episodes met the minimum criteria for antimicrobial prescription (n=158 of 359), respiratory tract 33.7% (n=35), urinary tract 18.9% (n=28), skin 95.4% (n=63), and febrile only 78.0% (n=32). Variables significantly associated with minimum criteria being present were proxy counselled about antimicrobials (adjusted OR (AOR), 1.42; 95% CI, 1.08 to 1.86) and source not the urinary tract (respiratory tract AOR, 2.33(95% CI, 1.12–4.84); febrile episode AOR, 14.92 (95% CI 5.16 to 43.14); and skin AOR, 102.92(95% CI 28.49 to 371.85).
Molloy <i>et al.</i> ⁶⁴ (1991)	Canada	To determine what treatment decisions physicians will make when faced with a hypothetical incompetent elderly patient with life-threatening gastrointestinal bleeding and to examine the relative importance of physician characteristics and factors in making those decisions.	1160 physicians (internists, residents, family physicians and specialists attending family practice, medical and geriatric rounds in large teaching hospitals in Australia, Brazil, Canada, Scotland, Sweden, the United States and Wales.)	Survey with case vignette of man with dementia with life-threatening gastrointestinal bleeding. Physicians were asked to choose between four treatment options: supportive care (SUPP), limited therapeutic care (LIM), maximum therapeutic care without admission to the intensive care unit (ICU) (IMAX) and maximum care with admission to the ICU (MICU).	SUPP was chosen by 93 (8.1%) of the respondents, LIM by 475 (41.5%), MAX by 368 (32.2%) and MICU by 208 (18.2%). Factors considered 'extremely important': patient wishes 57.3%, ethical concerns 43.8%, family wishes 19.1%, level of dementia 17.2%, legal concerns 15.9%, physician's religion by 5.4%, patient's age 2.0%, hospital costs by 1.5%. Variables independently predictive of physicians' treatment choices: <ul style="list-style-type: none"> ▲ level of dementia (the higher the level of importance, the less aggressive the care) ▲ country of residence (from most to least aggressive care: Brazil, the USA, Canada, Sweden, Wales, Scotland and Australia) ▲ duration of practice (the more years, the less aggressive the treatment) ▲ legal concerns (the higher the level of importance, the more aggressive treatment) ▲ patient's age (the higher the level of importance, the less aggressive treatment) ▲ ethical concerns (the higher level of importance, the more aggressive treatment).

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Table 2 Continued

Ng et al. ²⁶ (2014)	USA	To identify risk factors for utilisation of the ER by people with dementia.	296 veterans with dementia and their caregivers.	Subpopulation of those recruited for trial testing 'Partners in Dementia Care' intervention. Categorical ER use (over the 12 months following the interview) and number of ER visits was recorded. The veteran's affairs (VA) ER use data came from administrative records, obtained from the VA National Patient Care Database SE data files. Data for non-VA ER use came from self-reports. Patient caregivers were asked to complete a structured telephone interview at study baseline.	56% had one or more ER visits. None of the predisposing factors, such as patient or caregiver race, age, education, gender, were significant for predicting either use of the ER or number of admissions. Enrolment priority was significant for predicting categorical use of and number of admissions to the ER ($p<0.02$), with the highest priority group being the most likely to use ER services. Income and proximity to ER were not significant predictors. Patient personal care composite score was significant for predicting both categorical use of the ER ($p<0.008$) and repeat ER admissions ($p<0.04$). Patient behaviour problems and number of chronic conditions were not significant for predicting categorical use of the ER. Patient behaviour problems showed a trend associated with increased number of ER admissions ($p<0.06$) Patient's number of chronic conditions was predictive of the number of ER admissions ($p<0.01$). Relationship strain was the only significant caregiver variable for predicting the number of ER admissions ($p=0.04$). Multivariate model, priority grouping ($p<0.03$) and the patient's personal care composite were significant ($p<0.02$) for categorical ER use, number of patient's chronic conditions trending toward significance for repeat ER visits ($p=0.06$). Veterans at the two northern region sites were most likely to use ER services: categorical VA use ($p<0.007$) and repeat ER use ($p<0.05$).
Orrell and Bebbington ⁵¹ (1995)	UK.	To examine the life events experienced by senile dementia sufferers both before a dated acute deterioration and before admission as day-patients or in-patients.	70 patients with senile dementia admitted as day-patients or in-patients to a psychogeriatric assessment unit, with two control groups: 50 people with dementia living in the community, and 50 age and sex matched cognitively intact adults.	Participants identified through hospital records, with control groups identified through GP surgeries. Mental state, changes in environment and routine, dates of deterioration of mental state and life events were recorded from subject and informant interviews.	Dementia patients had shorter duration of diagnosis than the controls (40.7 months vs 60.5 months). No difference in severity of dementia between those who had been admitted as psychogeriatric patients and those who hadn't. People with dementia who were admitted to hospital did not have more life events than the control groups in the period before admission. Patients with dementia had significantly more life events leading to routine change than the other two groups: for the 0–3 months period ($\chi^2=6.69$; $p=0.035$), the 4–6 month period ($\chi^2=6.18$; $p=0.046$) and the 0–6 month period before admission ($\chi^2=11.21$; $p=0.0037$). The relative odds of admission, given an independent or possibly independent event with routine change in the preceding 3 months, was 4.3 (95% CI 1.1 to 19.9). The difference between the dementia patients and dementia controls on amount of events leading to change of routine before the date of deterioration was also significant ($p=0.022$). Dementia patients experienced more events with environment change in the 0–3 month period before admission (Fisher's $p=0.045$), but not in the period 4–6 months before admission, meaning the significance in the overall 0–6 month period was reduced (c.f. fit elderly: Fisher's $p=0.030$; c.f. dementia controls: Fisher's $p=0.093$).
Parke et al. ⁶⁵ (2013)	Canada	To identify factors that facilitate or impede safe transitional care in the ED for community dwelling older adults with dementia and to identify solutions that would support Registered Nurses' (RN) roles to provide gerontologically sensitive care that could be tested in future studies.	Ten older adult-family caregiver dyads, ten ED RNs, and four Nurse Practitioners (NPs) from hospital geriatric consultative teams	Interpretive, descriptive exploratory design with three iterative, interrelated phases: conducted interviews, created a photographic narrative journal (PNJ), and held photo elicitation focus groups.	There are a cycle of inter-related negative reinforcing consequences that begin at triage on arrival to the ED. Dementia not a priority in ED, priority goes to acute physiological problem: quote from RN "the focus of the ED is to find today's problem, fix it and send them home." Older adults with dementia are potentially 'under-triaged' (not seen as having acute problems when they actually do) because they may not be able to explain their symptoms. 'Under-triaging' can also occur because nurses assume older adults come to the ED without acute problems. Dementia can be treated as 'just another comorbidity' when triaging in the ED. Under triaging can lead to people with dementia staying in ED longer, exacerbating the risk of picking up another problem: dehydration, incontinence etc. Long waits mean that caregivers were left to deal with the older adult's anxiety, restless behaviour, and efforts to leave the ED. Chaotic and unfamiliar place can make people with dementia feel 'panicky'. Little contact from staff can make this worse. ED staff try to find people with dementia a bed in view of the nursing station. Time restrictions mean that basic care needs such as nutrition, hydration, toileting and mobility are neglected, which had potentially serious repercussions. Catheters can be kept in or inserted as the least time consuming solution to toileting problems. Similarly, restraints are used to deal with mobility risks. Little staff communication leaves caregivers in limbo, although some have more positive experiences.
Peel and Harding ⁶⁷ (2014)	UK	To explore the issue of accessing dementia health and social care support services from carers' own perspectives.	190 carers of people with dementia.	These data are drawn from two connected research projects ('Duties to Care' and 'Dementia Talking'), which included a multi-method online and paper questionnaire, followed up with four focus groups and eleven semistructured in-depth interviews.	Carers find accessing support a 'maze' and a 'batttle'. Support was easier to organise in a crisis situation, or at a point when carers were unable to cope rather than being put in place and planned appropriately. Carers reported that a crisis was 'engineered' through needs assessments in order to access respite: 'in that emergency time situation, things can get put together very well. My care coordinator was trying to request respite for nine months ahead of when I would be going to take it. And she was fighting a losing battle, so in the end, she put in for emergency respite, and it worked'

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Table 2 Continued

Robinson <i>et al</i> ⁶⁶ (2012)	Canada	To identify key elements influencing the success of transitions in care for residents moving between NHs and EDs from multiple perspectives within the three settings of care (NH, Emergency Medical Services (EMS), and ED).	7 NH residents (all had cognitive performance scores between 0–2), 20 family members and 44 professional healthcare providers (registered nurses, licensed practical nurses, paramedics, physicians, and administrators).	Interviews about transitions between services in the past 12 months, analysed using constant comparison.	<p>five elements identified for successful transition (not all dementia specific):</p> <ul style="list-style-type: none"> ▲ 'Knowing the resident': Their beliefs, preferences, values, and what is normal for them day-to-day. Especially with dementia, where because residents were often unable to convey this critical information themselves. ▲ 'Clinical geriatric knowledge and skilled assessment' ▲ 'Positive relationships: the relational context of care': both between family and staff, and between different staff members. ▲ 'Communication of information'—notification, explanation (detailed and comprehensive descriptions of both the resident and the situation—particularly important in dementia) and conversation. ▲ 'Timeliness': particularly in the ED, where for people with dementia a delay can lead to a decline.
Rosenwax <i>et al</i> ⁶⁷ (2015)	Australia	To describe patterns in the use of the ED by people who had dementia in their last year of life and determine whether this was modified by the use of community-based palliative care services.	5261 people with dementia and a comparative cohort comprised 2865 decedents.	A retrospective cohort study of the last year of life of persons with dementia. A pool of decedents was identified from death registration records. Decedents were identified from the Western Australia Data Linkage System of each decedent's linked death registration, hospital discharge records, ED visits, mental health outpatient visits and community-based care services data in the last year of life was provided by the Data Linkage Branch of the Health Department Western Australia.	<p>More than 70% of decedents in both the dementia and comparative cohorts attended an ED at least once in the last year of life. The comparative cohort had a greater number of days visiting EDs compared with the dementia cohort, particularly in the days closer to death. Visits to the ED by the dementia cohort tended towards being triaged as less urgent although 3.6% of the dementia cohort were categorised as requiring resuscitation compared with 2.9% of the comparative cohort. The dementia cohort had a higher proportion of neurological and mental disorder presenting symptoms and fall- and injury-related symptoms at presentation to ED; the comparative cohort had more cardiac and abdominal pain presentations. The pattern of cumulative number of days visiting ED for decedents with dementia in other diseases was similar to the comparative cohort: 2.7 (95% CI) 2.4 to 3.0) days compared with 2.7 (95% CI 2.6 to 2.8) days. The rate of visiting ED was much lower with decedents with Alzheimer's dementia compared with other dementias: 1.7 (95% CI: 1.6 to 1.7) visits to ED in last year of life. Decedents with dementia who received regular care in a care facility visited the ED 1.4 times more often than those receiving community-based palliative care (95% CI: 1.1 to 1.9). Those receiving regular care in private residences visited EDs 6.7 (95% CI - 4.7–9.6) times more frequently and those receiving regular care in a care facility visited EDs and 3.1 (95% CI - 2.2–4.2) times more frequently than those of dementia cohort who were receiving palliative care. Other factors that increased risk of ED visit: being male, being younger and living with dementia with other diseases rather than Alzheimer's or vascular dementia, living in outer regional and remote areas, having certain types of comorbid conditions, being partnered at the time of death, prior history of ED visits.</p>
Rudolph <i>et al</i> ²⁸ (2010)	USA	To clinically identify patients with AD at high risk for hospitalisation based on baseline risk factors.	827 patients with AD.	Participants followed from the Massachusetts AD Research Centre (MADRC) to ascertain the principal admitting diagnoses associated with hospitalisation, and to evaluate baseline risk factors for hospitalisation, including demographic, AD-related, and illness-related factors. Participants were followed up for a median of 3 years.	<p>542 patients (66%) were hospitalised at least once during their follow-up period, 389 (47%) were rehospitalised after their initial hospitalisation for a median of two hospitalisations per person. Patients were most commonly admitted for syncope, fall, or trauma (26%), ischaemic heart disease (17%), gastrointestinal disease (9%), pneumonia (6%), and delirium or mental status change (5%). Five significant risk factors for hospitalisation were identified in unadjusted and adjusted analyses (the C-statistic was 0.66 (95% CI 0.63 to 0.68)):</p> <ul style="list-style-type: none"> ▲ high comorbidity, associated with an 87% greater adjusted risk of hospitalisation. ▲ acute hospitalisation in the past year (65% greater adjusted risk) ▲ older age (51% greater adjusted risk) ▲ male (27% greater adjusted risk) ▲ shorter duration of symptoms (26% greater adjusted risk). Blessed Information-Memory-Concentration (BIMC) score and MADRC Dementia Severity Rating (dementia severity scores), family history of dementia, speed of initial onset, course of disease, race, education level, and marital status were not significant predictors of hospitalisation. A larger number of risk factors significantly increases the risk of hospitalisation: participants with one risk factor were 1.8 times as likely to be hospitalised as those with no risk factors, those with two or three risk factors were 3.0 times as likely, and those with four to five risk factors were 6.1 times as likely. Thus, the number of risk factors at baseline directly affects the risk of subsequent hospitalisation.

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Sadak <i>et al.</i> ⁵⁶ (2017)	USA	To describe the experiences of dementia family caregivers during their care recipient's health crises with the aim of identifying opportunities for new caregiver-focused interventions.	20 family caregivers of people living with dementia who had a hospitalisation for ambulatory care sensitive conditions (ACSC; that could be managed in outpatient care) and/or a fall-related injury in the prior 12 months.	Family caregivers of people with dementia who had consented to be recontacted were selected from participants in our previous (2014–2016) qualitative studies of caregivers' self-assessed knowledge and skills to manage patients' health. Semi-structured interviews were conducted and analysed using interpretive phenomenological analysis and thematic analysis.	Reasons for hospitalisation: Dehydration (n=2), GI ulcers (n=2), urinary tract infection (n=3), congestive heart failure (n=3), hypertension (n=2), hypotension (n=1), urinary retention (n=1), COPD (n=1), hyperglycaemic (n=2), fracture (n=3). 4 Themes: (1) Caregiver is uncertain how to interpret and act on the change; Caregiver cannot identify symptomatic precursors to impending patient health crisis and does not know what to do; caregiver has to guess because the patient cannot report symptoms; pressure to make urgent decisions; outpatient clinicians did not offer enough help. (2) Caregiver is unable to provide necessary care; caregiver is unable to meet patient's need due to personal illness, physical limitations or distance; caregiver has no or poor informal support; caregiver cannot manage care recipient behaviours; caregiver is unable to prevent injury or exacerbation of ACSC. (3) The health crisis negatively affected the caregiver's well-being and self-care; poor or disrupted caregiver self-care and routine; caregiver's negative emotional states; caregiver sleep disturbance. (4) Mitigating factors may prevent caregiver crisis during care recipient's acute health changes; caregiver is able to identify that something is wrong early on; caregiver maintains self-care; outpatient clinicians were helpful, listened, acted fast.
Saib and Sharp ⁸³ (1999)	UK	To explore whether there is any association between weather parameters such as relative humidity, sunshine hours, diurnal variations in temperature and rainfall and the dementia admissions compared with other psychiatric admissions.	189 people with dementia who had been admitted to psychiatric hospital.	Data were obtained from the Information Department of Winwick Hospital on all dementia during 1993. The Meteorological Office collects daily information on maximum and minimum temperatures, total rainfall, sunshine hours and maximum relative humidity.	189 (9%) of total 2070 psychiatric admissions were of people with dementia. There were significantly fewer dementia admissions over the weekends (14% of total dementia admissions) compared with all other admissions (35% of all other admissions) during the same period. Small significant negative correlation between humidity in 2 weeks prior to admission and females with dementia being admitted ($r = -0.262$, $p < 0.05$). No significant correlation was found between number of dementia admissions and any of the weather parameters.
Sharpp and Young ⁵⁵ (2016)	USA	To provide a description of the rate and reasons of healthcare incidents of residents with dementia and transfers to the ED.	71 residents with dementia, 9 family carers, 14 employees of AL communities (caregivers and medication technicians).	Prospective mixed-methods study. Data were collected over 6 months in two dementia-only assisted living (AL) communities. AL administrators provided blinded demographic data (age, race, ethnicity, and gender) and data fields from incident reports monthly. Family members participated in interviews. Two focus groups were held with employees. Findings from quantitative and qualitative analyses were triangulated.	207 incidents occurred over 6 months: falls (133, 64%), changes in condition (20), agitation (20), infections (17), other illnesses (9), medication errors (2), syncope (6). 77 incidents (37%) included transfer to the ED by ambulance. 45/77 (58%) were because of a fall, 14 infections, 6 other illnesses, 6 changes in condition, 6 syncope/TIA. Eight residents were responsible for 47% of ED visits; each of the eight residents were transferred less than three times. 37/45 falls (82%) resulted in ED transfers where no treatment was provided and no changes to the residents' care were made. AL Community B had significantly ($p = 0.037$) more falls than community A. Five residents accounted for 36% of the falls, and 60% of falls were from people falling over at least three times. 25/77 (31%) ED visits resulted in admission to hospital. Staff feel frustration and helplessness: not realistic to increase staff or restrict patients to stop falls. Case study: family caregiver whose mother fell 14 times in 3 months. With AL physician completed a Physicians Order for Life Sustaining Treatment form, and indicated that the resident should not be transferred from the community. This reduced ED visits to 1 in next 3 months, despite nine further falls. Another strategy to minimise ED transfers: communication with family when incident occurs so they can try to handle it without need for ED.

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Table 2 Continued

Sloane <i>et al</i> ⁸¹ (2017)	USA	To (1) determine the most common symptoms of people with dementia as reported by caregivers, (2) identify the relative incidence of behavioural, organ-specific, and nonspecific medical symptoms in these individuals, (3) record the frequency of ED visits, hospitalisations and death during 6 months of follow-up; and to determine which symptoms were associated with an increased risk of hospitalisation and ED use.	136 person with dementia/caregiver dyads.	6 months longitudinal prospective study; participating caregiver was interviewed at baseline, 3 and 6 months.	At least one new or worsening symptom was reported by 99% of caregivers: organ-specific (90%), behavioural (89%), and non-specific (88%) were equally common. The average caregiver reported seven new or worsening symptoms during the study period, and 76% of caregivers reported all three categories of symptoms. The 10 most common symptoms reported were worsening confusion (74%), decreased activity (65%), agitation (57%), hallucinations/delusions (46%), voice and speaking problems (46%), not eating or drinking (44%), anxiety (42%), aggression (37%), not taking care of self (36%), and falls (36%). There was no association between type of dementia and worsening symptom. Only constipation and pressure ulcers were associated with dementia stage, both more common in later stages of dementia. In study period there were 6 deaths, 31 hospitalisations, 41 ED visits without hospitalisation, and 10 relocations to AL, communities or NH. Most common reasons for hospitalisation included infection (35%), symptoms related to AD/BD progression such as dehydration or behavioural outburst (16%), and cardiovascular events (13%). Most common reasons for ED visits without hospitalisation: 20% were for gastrointestinal symptoms and 34% for either falls, passing out, or seizures. Organ-specific symptoms were most strongly associated with acute medical service use (OR 3.17, p=0.02); behavioural symptoms were not associated with acute medical service use (OR 1.44, p=0.38); and nonspecific symptoms had an intermediate association trend (OR 2.08, p=0.10). The strongest associations with acute medical service use were in relation to eight individual symptoms (all p<0.01): voice and speaking problems (OR 2.33, p=0.010), skin injuries (OR 3.49, p=0.001), concern about urinary tract infection (OR 3.47, p=0.006), blood pressure concerns (7.07, p<0.001), pressure ulcers (OR 4.48, p=0.007), hallucinations/delusions (OR 3.72, p<0.001), falls (OR 3.20, p<0.001), and night-time sleep problems (OR 2.40, p=0.014). In addition, 8 uncommon organ-specific complaints (chest pain, diabetes, head injury, passing out, vomiting, blood in the urine, nosebleeds, and hip fracture) together were moderately associated (OR 2.01, p=0.001) with medical service use.
Smith <i>et al</i> ⁸¹ (2008)	USA	To explore the perceptions, experiences, and beliefs of ED providers about palliative care in the ED (not dementia specific).	26 ED staff: 14 physicians, 10 residents, 4 attending physicians, 6 nurses, 2 social workers, 4 technicians.	Qualitative study using three focus groups of ED providers. Qualitative analyses were conducted with an iterative process and following standard grounded theory techniques.	Palliative care in ED defined as an effort to reduce symptoms in patients who were actively dying, labelled 'comfort care.' Conflict between advance care planning and proxy wishes for example, in dementia where there is a do-not-hospitalise order in place and family says otherwise. This is made particularly difficult where person with dementia can't speak for themselves.
Tian <i>et al</i> (2013) ⁸⁴	China	To examine healthcare utilisation, and associated costs in patients with AD, with and without dysphagia.	8997 patients with a ICD-10 diagnosis of AD, split into two groups with (485) and without (8492) dysphagia.	A retrospective claims analysis, using data from two sources: the MarketScans Commercial Claims and Encumbrance and Medicare Supplemental and Coordination of Benefits databases from 1 October 2006 to 30 September 2010. Quantitative analysis allows comparison between two groups.	Patients with dysphagia had a 2.3 times higher likelihood of all-cause hospitalisations (OR=2.26, 95% CI=1.70-2.99, p=0.001) and 1.5 times higher likelihood of all-cause ER visits (OR=1.45, 95% CI=1.12 to 1.87, p=0.007) compared with patients without dysphagia. Patients with dysphagia had a higher likelihood for AD-related hospitalisations (OR=2.31, 95% CI=1.49 to 3.58, p=0.001) and AD-related ER visits (OR=1.91, 95% CI=1.33 to 2.75, p=0.001) during the 12 months follow-up period.
Toot <i>et al</i> ⁸³ (2013)	UK	To identify factors which could precipitate crises and identify interventions to help manage crises for people with dementia living at home and their carers.	18 people with dementia, 15 family carers and 19 staff from older people's home treatment teams and community mental health teams.	Focus groups with different stakeholders, focusing on all types of causes of crisis involving people with dementia and their carers including psychiatric, physical health and care-related factors as well as helpful crisis interventions and support.	Themes for causes of crisis: hazards in the home: causing falls; carer related: depression, burden; environmental/social changes: for example, carer illness, families moving; behavioural/psychological: wandering, aggression; physical health: incontinence, falls, infections, poor eating and drinking; access to community services: understaffed, undertrained, hard to access. Themes for preventing crises: home adaptations and technology; community care services; family carer education and training: for example, first aid; professional healthcare services: easier access and better service delivery in A&E, out of hours doctors, regular physical health checks, care coordinator and care plan.

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Table 2 Continued

Toscani <i>et al</i> ⁴⁹ (2015)	Italy	To describe and compare the critical decisions (CDs) made for patients with advanced dementia in NH and in home care (HC) services.	496 patients with advanced dementia (315 in the NHs and 181 in HC), 362 patients had follow-up data at 6 months.	A multicentre prospective observational cohort study (the End-of-Life Observatory: Prospective Study on Dementia patients Care study) was conducted from June 2007 to May 2009. CDs were defined as: (1) starting a treatment, (2) withholding a treatment, (3) withdrawing a treatment. Researchers abstracted information from the clinical records at baseline. Discomfort and change in clinical treatment was recorded every 2 weeks until 6-month follow-up period is over or death. Physicians identified CDs from records.	CDs were made for 267 patients (95 had two or more): 190 patients in NHs (60.3%) and 77 in HC (42.5%), with a range of 1–11 CDs (median 3) among the NH patients and 1–5 (median 2) among the HC patients. No CDs were made for 46% of patients (239/496). The proportion of patients without CDs was higher in HC (HC: 104; 57.5%; NHs: 125; 39.7%; p<0.001). All interventions were withheld in 5.6% of the CDs (36/644). Problems that led to a CD: infections (46.5%, 300/644 CDs), nutritional problems (20.6%, 133 CDs), worsening of a pre-existing disease (9.3%, 60 CDs). The most frequent CD was to administer antibiotics (26.6% in NHs, 25.7% in HC). Differences between settings: antibiotics plus hydration were provided more frequently in the NHs than in HC (18.0% vs 4.5%), the decision to hospitalise a patient was more frequently reported in HC (25.5% than in the NHs (3.1 %). Reasons for hospitalisation: in HC, 6/39 were for acute events (falls, seizures, and other reasons), 33/39 for worsening of general conditions. In the NHs, the majority of the 15 hospitalisations were associated with acute/severe events (falls, 5 cases; anaemia, 4 cases). No NH patients with a prognosis of >15 days were admitted to the hospital; 8/42 admissions with a prognosis of >15 days, were admitted to the hospital. In HC, the withholding of all possible interventions was more frequent (11.5% vs 3.7% in NHs). Physicians autonomously took 57.7% (345/598) CDs, in 14.7% decisions were made together with the family. In only three cases (0.5%), the final decisions were made by the family or by the patient's legal representative; all of these decisions concerned withholding interventions. In the NHs, half of CDs (50.0%); 11 cases were missing information) were discussed before they were implemented; 76.0% were communicated to the family post hoc. In HC, all decisions to withhold all interventions were made with the family and, with the exception of two cases, corresponded with physician preference. Purpose of CDs: reducing symptoms or suffering (NH 81.1%, HC 57.0%) and prolonging survival (NH 27.5%, HC 23.1%), ease death (31 - but never only reason.)
van de Vorst <i>et al</i> ⁴⁸ (2017)	The Netherlands	To evaluate the impact of cardiovascular disease (CVD) on mortality and hospital readmission risk in hospitalised dementia patients.	59 194 patients with dementia, split into subgroups according to history of CVD (36.9% or not.	Information from three databases was linked, the Dutch Hospital Discharge Register, the Dutch Population Register, and the National Cause of Death Register. Patients were followed up for 1 year.	In day clinic patients with a history of CVD, 49.7% was readmitted to hospital within 1 year, compared with 40.6% of those without a history of CVD (p<0.05). Of the hospitalised patients with a history of CVD, 37.3% was (re) admitted within 1 year, compared with 28.1% those without a history of CVD.
van der Steen ⁵⁷ (2009)	The Netherlands	To compare recent treatment of patients with dementia and pneumonia in Dutch NH to those from our studies in the late 1990s, examining whether there has been an increased tendency to provide symptom relief.	778 people with dementia and physicians and from 53 NH.	Initial prospective cohort studies (in 1996 and 1999) compared with survey of clinicians in 53 of the same NH in 2006.	Antibiotic use, hospitalisation rate, and supportive treatment were similar in the newer and the older cohort: antibiotics were withheld in 21% and 23% of cases, respectively; hospitalisation at 1% in both cohorts. Intent to relieve symptoms increased significantly in the newer cohort: goal of relieving fever (73% increase); relieving shortness of breath (more than doubled); and relieving coughing (fivefold increase). This led to increased use of antipyretics, opiates, oxygen, bronchodilators, and corticosteroids. Physicians' self-reported changes in their treatment approach over the last 10 years. Approximately half (49%) report they now treat to relieve symptoms more frequently while reporting little change in their tendency to prescribe antibiotics. The decisions to treat with antibiotics, provide symptom relief, or prescribe opioids were not associated with physicians' experience, age, gender, or training status (p>0.10) in either of the two cohorts.

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Table 2 Continued

Voss <i>et al</i> ¹⁰ (2018)	UK	To determine how often ambulances are called to older people with comorbidities including dementia, and if these patients are more likely to be conveyed to hospital.	3037 ambulance patient care records of patients over 65; 421 people with dementia and 2567 comparators.	A retrospective cross-sectional study of ambulance patient care records. Data were extracted by two researchers using a predefined template and coding structure. Analysis was exploratory; descriptive statistics employed.	Ambulance calls to people with dementia were more likely to be to a residential or NH (41.9%; 95% CI 35.6% to 48.3%) than in the comparator group (5.4%; 95% CI 4.3% to 6.7%). Calls to individuals living in their own home were more likely in the comparator group (81.0%; 95% CI 78.8% to 83.0%) than the dementia group (52.8%; 95% CI 46.4% to 59.2%). Reason for call: less likely a cardiac or respiratory problem in the dementia group (4.8%; 95% CI 3.0% to 7.3% and 5.8%; 95% CI 3.7% to 8.4%) than the comparator group (10.8%; 95% CI 9.6% to 12.1% and 11.2%; 95% CI 10.0% to 12.5%); more likely to be for a fall in the dementia group (15.6%; 95% CI 12.2% to 19.4%) than in the comparator group (9.1%; 95% CI 8.0% to 10.3%). Provisional diagnosis as recorded by the attending clinician; patients with dementia were less often diagnosed with cardiac or respiratory problems (4.6%; 95% CI 2.8% to 7.1% and 5.4%; CI 3.4% to 8.0%) than patients in the comparator group (11.7%; 95% CI 10.4% to 13.0% and 11.1%; 95% CI 9.9% to 12.4%); traumatic injuries and falls were more prevalent in the dementia group (20.0%; 95% CI 16.2% to 24.1% and 11.4%; 95% CI 8.5% to 14.9%) than in the comparator group (13.5%; 95% CI 12.2% to 14.9% and 7.3%; 95% CI 6.3% to 8.4%). Social circumstances: patients with dementia were more likely to be living in a care home and to have a care package in place; only 6.7% (95% CI 4.2% to 10.0%) of patients with dementia were recorded as living in their own home without a care package compared with 31.7% (95% CI 29.5% to 33.9%) of the comparator group; 12.4% (95% CI 9.0% to 16.6%) of patients with dementia were living with extended family without a care package compared with 32.1% (95% CI 30.0% to 34.3%) of the comparator group; 25.8% (95% CI 21.0% to 31.0%) and 22.6% (95% CI 18.1% to 27.6%) of patients with dementia were living in a nursing or residential home compared with 3.5% (95% CI 2.7% to 4.5%) and 3.6% (95% CI 2.8% to 4.6%) of the comparator group. Frailty: 70.2% (95% CI 63.1% to 76.6%) of patients in the dementia group were assessed as moderately to severely frail compared with 30.5% (95% CI 27.6% to 33.6%) in the comparator group; 7.4% (95% CI 4.1% to 12.2%) of patients in the dementia group were assessed as managing well or being very fit compared with 43.7% (95% CI 40.5% to 47.0%) in the comparator group. Ambulance call cycle time and conveyance to hospital: mean duration of the call (time of arrival on scene to time of closing the call) was shorter for people with dementia (85.2min 95% CI 81.5 to 88.8) than for the comparator group (89.8min 95% CI 88.2 to 91.5); patients in the dementia group were less likely to be taken to hospital (50.4%; 95% CI 45.5% to 55.2%) compared with those in the comparator group (62.7%; 95% CI 60.8% to 64.6%); fewer patients in the dementia group were recorded as experiencing pain (25.6%; 95% CI 21.5% to 30.1%) than in the comparator group (39.5%; 95% CI 37.6% to 41.4%). Comorbidities: 352 of the 421 cases with dementia (83.6%; 95% CI 79.7% to 87.0%) had at least one comorbidity recorded, and for the comparator group it was 2076 of 2567 cases (80.9%; 95% CI 79.3% to 82.4%). Respiratory and cardiac comorbidities were less likely to be recorded for patients with dementia, whereas neurological disorders, stroke and musculoskeletal conditions were more prevalent; the presence of one or more comorbidities increased call cycle time and conveyance rate, irrespective of dementia.
Yu <i>et al</i> ⁶⁰ (2015)	China	To (1) to describe the typical clinical management pathways for AD patients diagnosed by physicians specialised in dementia care, focussing on urban areas of China where pharmacological treatments are available; (2) evaluate the impact of disease severity and symptoms on healthcare resource utilisation and amount of caregiving required; (3) determine the unit costs of the healthcare resources associated with the management of AD.	Nine physicians specialising in AD and two general hospital administrators.	Delphi interviews and consensus panel. Physicians were interviewed on the diagnosis and referral process, course of illness and patient management in AD. Hospital administrators provided information on the financial cost of AD.	Qualitative results from Delphi interviews: main drivers of healthcare resource utilisation by AD patients are the presence of neuropsychological symptoms, such as agitation or aggression, and loss of independence leading to hospitalisation and aggravating the burden on caregivers. 70%-80% of AD patients develop age-related comorbidities, such as bone fractures, diabetes, chronic obstructive pulmonary disease, heart failure, pneumonia and urinary tract infection - also a frequent cause of hospitalisation and mortality. Delphi panel consensus: The majority of hospital visits after AD diagnosis are due to age-related comorbidities. AD patients with comorbidities are more likely to be hospitalised, and for longer periods of time, than non-AD patients with the same conditions. Patients in the moderate and severe stages of disease who suffer from agitation or aggression and/or have lost functional independence are particularly vulnerable for hospitalisation. Dependent and aggressive AD patients are more likely to be hospitalised (70%-90% probability) than accepted in a NH (0%-20% probability), while the opposite is true for dependent and non-aggressive patients (5%-35% probability of hospitalisation vs 80% probability of being accepted in a NH). The average length of hospitalisation was 2 months.

Continued

Table 2 Continued

Zhao <i>et al.</i> ²² (2008)	USA	To identify differences in direct healthcare costs and utilisation, and common reasons for ER visits and inpatient admissions between Medicare beneficiaries with an AD diagnosis and controls, after comprehensively adjusting for the presence of other comorbidities.	627 775 individuals aged 65 or older, subsample of 25 109 with AD and three times as many of control group, matched for age, sex, regional distribution and mean length of eligibility.	Data were obtained from the MEDSTAT MarketScan Medicare Supplemental and Coordination of Benefits (COB) Database for 2003 and 2004 for individuals aged 65 and above with comprehensive medical and pharmacy claims. Illness burden was measured by a comprehensive disease classification and scoring system and used to produce estimates of the marginal effect of AD on inpatient, ER, pharmacy and other utilisation and costs. Reasons for ER visits and inpatient admissions were also examined for both AD and control cohorts, and logistic regression was used to assess the contribution of AD to the most common reasons for ER visits and hospitalisations controlling for differences in overall illness burden.	Rates of ER visits (41% vs 27%), inpatient hospital stays (30% vs 20%), and home healthcare (7% vs 4%) were about 50% higher for AD patients than for controls. Controlling for overall illness burden, the excess utilisation attributed to AD for inpatient services, ER visits, and home healthcare were all significant ($p<0.05$). AD cohort used fewer physician office and outpatient hospital visits (both $p<0.05$). Spending in the AD cohort was higher for all but two categories of services (outpatient services and office visits) compared with controls, but AD spending was less variable (coefficient of variation (CV) was lower). Excess pharmacy costs associated with AD were US\$1,711, more than twice that of any other expense category ($p<0.05$). 10 most common reasons for ER visits: contusion/superficial injury, chest pain, syncope and collapse, open wound (except eye and lower arm), cystitis (or other UTIs), other general symptoms, pneumonia, abdominal/pelvis symptoms, stupor/altered consciousness/trans global amnesia/febrile convulsions, disorders of fluid/electrolyte/acid-base balance, for example, dehydration. The AD and control cohorts shared 6 of their 10 most common reasons, and their top two reasons were the same. The AD cohort had higher raw ER use rates than controls for all 14 reasons listed, and significantly higher risk-adjusted use rates for 11 of them with ORs ranging as high as 5.85 for stupors and other states of altered consciousness. Heart failure was the only reason for visit that had risk-adjusted ER use rate lower for AD patients than for controls (OR=0.87, $p<0.05$). The odds of an individual in the AD cohort having an ER visit for any reason was 74% greater than for controls, 10 most common reasons for in-patient admissions: pneumonia, femoral fracture, cystitis or UTI, heart failure, cerebral degeneration/AD, disorders of fluid/electrolyte/ac-dbase balance (dehydration), septicemia/shock, syncope and collapse, aspiration pneumonia, pre-cerebral or cerebral arterial occlusion with infarction, 3 of the top reasons for admission (hip fracture, other and unspecified pneumonia, and urinary tract infections) were shared with control cohort. Even after controlling for illness burden, patients in the AD cohort were more likely to be hospitalised for most of the reasons listed, including pneumonia, infections, syncope and hip fracture. AD patients were less likely to be admitted to the hospital due to heart failure or coronary atherosclerosis and other coronary ischaemic heart disease (all $p<0.05$) compared with those in the control cohort. AD patients were less likely to be admitted for osteoarthritis of lower leg. The odds for an inpatient admission were 55% greater for AD patients than for controls.
Zhu <i>et al.</i> ²⁴ (2015)	USA	To examine the relative contribution of functional impairment and cognitive deficits on risk of hospitalisation and costs.	1805 patients never diagnosed with dementia during study period, 221 diagnosed with dementia at enrolment.	Participants were recruited from the WHICAP. At study entry, each subject underwent an in-person interview of general health and functional ability followed by a standardised assessment. Subjects were followed at approximately 18month intervals until death or drop out. A longitudinal data set of hospitalisation during each assessment interval was constructed. Logistic regressions were used to examine risks for all-cause and ambulatory care sensitive admissions.	Number of chronic conditions was similar between prevalent and non-dementia groups (2.8±2.0 vs 2.6±2.0). The most common conditions included hypertension (64%), arthritis (53%), and diabetes (21%). Subjects with dementia were more likely to have had a stroke (17.6% vs 9.2%), chronic heart failure (9.5% vs 4.6%), and angina (3.2% vs 0.8%), but less likely to have cancer (6.3% vs 14.5%), 19.6% of people without dementia and 30.3% of subjects with dementia had at least one hospitalisation. Subjects with dementia had higher number of hospitalisations (1.9±1.3 vs. 1.6±1.1) and days of hospitalisations. Most subjects with dementia had at least one ambulatory care sensitive admission (83.5%) as did non-dementia subjects (79.3%). All ACS admission rates were higher for subjects with dementia. Compared with matched subjects without dementia, subjects with dementia had higher risk of hospitalisation (OR=1.462, 95% CI (1.244 to 1.942), longer hospital length of stay (LOS) (IRR=1.059, 95% CI=0.998 to 1.129), and 18% higher Medicare expenditures (95% CI=0.022 to 0.410). Subjects' functional deficits were significantly associated with higher risks of hospitalisation, longer LOS, and higher Medicare expenditures. Subjects' cognitive deficits also were significantly associated with higher risks of hospitalisation and longer LOS, but were not associated with Medicare expenditures. Ambulatory sensitive hospitalisations: subjects with dementia had higher risk of hospitalisations for urinary tract infections (UTIs) (OR 2.111, 95% CI 1.224 to 3.641) and dehydration (OR 2.390, 95% CI 1.404 to 4.070). Subjects' functional deficits were associated with increased risk of hospitalisations for diabetes, UTI, and dehydration, but decreased risk of hospitalisations for hypertension. Better cognitive score was associated with decreased risk of hospitalisations for diabetes, pneumonia and asthma, and marginally for hypertension.

AD, Alzheimer's disease; ED, emergency department; ER, emergency room; GP, general practitioner; NH, nursing home; NHS, National Health Service.

Table 3 Factors associated with urgent care use

Factor	Increased urgent care use(*)	Decreased urgent care use(†)	No association with urgent care use‡
More/specific comorbidities	n=9 Albert <i>et al</i> ²³ (1999), Andreiu <i>et al</i> ²⁴ (2002), Grober <i>et al</i> ²⁵ (2012), Ng <i>et al</i> ²⁶ (2014), Rosenwax <i>et al</i> (2015), Rudolph <i>et al</i> ²⁸ (2010), Toscani <i>et al</i> ²⁹ (2015), Voss <i>et al</i> ^{10 14} (2018), Yu <i>et al</i> ²⁰ (2015)		n=2 Amador <i>et al</i> ³⁰ (2014), Sloane <i>et al</i> ³¹ (2017)
Having dementia (compared with people without dementia)	n=4 Husaini <i>et al</i> ³³ (2003), Yu <i>et al</i> ²⁰ (2015), Zhao <i>et al</i> ³² (2008), Zhu <i>et al</i> ³⁴ (2015)	n=4 Albert <i>et al</i> ²³ (1999), Rosenwax <i>et al</i> ²⁷ (2015), Voss <i>et al</i> ^{10 14} (2018), Zhao ³² <i>et al</i> (2008)	n=2 Grober <i>et al</i> ²⁵ (2012), Rosenwax <i>et al</i> ²⁷ (2015)
Presence of family carer	n=4 Cogen <i>et al</i> ⁴⁰ (1992), Ledgerd <i>et al</i> ³⁸ (2016), Ng <i>et al</i> ²⁶ (2014), Rosenwax <i>et al</i> ²⁷ (2015)	n=6 Abrahamson <i>et al</i> ³⁵ (2015), Amador <i>et al</i> ³⁰ (2014), Benner <i>et al</i> ³⁶ (2018), Hunter <i>et al</i> ⁶² (2017), Ledgerd <i>et al</i> ³⁸ (2016), Toot <i>et al</i> ³⁹ (2013)	n=1 Cogen <i>et al</i> ⁴⁰ (1992)
Older age	n=5 Amador <i>et al</i> ³⁰ (2014), Givens <i>et al</i> ⁴³ 2012, Molloy <i>et al</i> ⁴⁴ (1991), Rosenwax <i>et al</i> ²⁷ (2015), Rudolph <i>et al</i> ²⁸ (2010)		n=4 (Albert <i>et al</i> ²³ (1999), Boltz <i>et al</i> ⁴⁶ (2018), Chang <i>et al</i> ⁴⁷ (2015), Grober <i>et al</i> ²⁵ (2012))
Behavioural Symptoms	n=5 Andrieu <i>et al</i> ²⁴ (2002), Goodman <i>et al</i> ⁴⁵ (2017), Ledgerd <i>et al</i> ³⁸ (2016), Toot <i>et al</i> ³⁹ (2013), Yu <i>et al</i> ²⁰ (2015)		n=2 Ng <i>et al</i> ²⁶ (2014), Sloane <i>et al</i> ³¹ (2017)
Advance care planning		n=7 Donnelly <i>et al</i> ⁵² (2017), Gessert <i>et al</i> ⁴⁹ (2006), Givens <i>et al</i> ⁵⁰ (2012), Jacobsohn <i>et al</i> ⁵³ (2019), Palan Lopez <i>et al</i> ⁵⁴ (2017), Rosenwax <i>et al</i> ²⁷ (2015), Sharpp <i>et al</i> ⁵⁵ (2016).	
Ethnicity	n=3 Agyemang <i>et al</i> ⁴⁸ (2016), Gessert <i>et al</i> ⁴⁹ (2006), Givens <i>et al</i> ⁵⁰ (2012)		n=3 Albert <i>et al</i> ²³ (1999), Husaini <i>et al</i> ³³ (2003), Rudolph <i>et al</i> ²⁸ (2010)
High dependency on others	n=5 Andrieu <i>et al</i> ²⁴ (2002), Cloutier <i>et al</i> ⁴² (2017), Ledgerd <i>et al</i> ³⁸ (2016), Ng <i>et al</i> ²⁶ (2014), Yu <i>et al</i> ²⁰ (2015)		n=1 Grober <i>et al</i> ²⁵ (2012)
Geographical location of residence	n=6 Gessert <i>et al</i> ⁴⁹ (2006), Kim <i>et al</i> ⁴¹ (2019), Molloy <i>et al</i> ⁴⁴ (1991), Ng <i>et al</i> ²⁶ (2014), Rosenwax <i>et al</i> ²⁷ (2015), van der Steen <i>et al</i> ⁵⁷ (2009)		
Living in care facility	n=3 Kim <i>et al</i> ⁴¹ (2019), Rosenwax <i>et al</i> ²⁷ (2015), Toscani <i>et al</i> ²⁹ (2015)	n=2 (Cloutier <i>et al</i> ⁴² (2017), Toscani <i>et al</i> ²⁹ (2015))	
Adequate outpatient services		n=4 Jacobsohn <i>et al</i> ⁵³ (2019), Ledgerd <i>et al</i> ³⁸ (2016), Sadak <i>et al</i> ⁵⁶ (2017), Toot <i>et al</i> ³⁹ (2013)	
Type of dementia	n=2 Chang <i>et al</i> ⁴⁷ (2015), Rosenwax <i>et al</i> ²⁷ (2015)		n=1 Chang <i>et al</i> ⁴⁷ (2015)
Gender	n=4 Givens <i>et al</i> ⁵⁰ (2012), Kim <i>et al</i> ⁴¹ (2019), Rosenwax <i>et al</i> ²⁷ (2015), Rudolph <i>et al</i> ²⁸ (2010)		
Higher levels of cognitive impairment	n=3 Albert <i>et al</i> ²³ (1999), Molloy <i>et al</i> ⁴⁴ (1991), Zhu <i>et al</i> ³⁴ (2015)		n=1 Rudolph <i>et al</i> ²⁸ (2010)
Technological support at home		n=3 Carter and Porrell <i>et al</i> ²¹ (2005), Ledgerd <i>et al</i> ³⁸ (2016), Toot <i>et al</i> ³⁹ (2013)	

Continued

**Table 3** Continued

Factor	Increased urgent care use(*)	Decreased urgent care use(†)	No association with urgent care use‡
Lower level of education	n=2 Albert <i>et al</i> ²³ (1999), Andrieu <i>et al</i> ²⁴ (2002)		n=1 Rudolph <i>et al</i> ²⁸ (2010)
Shorter duration of diagnosis	n=2 Orrell and Bebbington ⁵¹ (1995), Rudolph <i>et al</i> ²⁸ (2010)		
Increase in nursing home staffing		n=2 Carter and Porrell <i>et al</i> ²¹ (2005), Goodman <i>et al</i> ⁴⁵ (2017)	

*Factors shown to increase urgent care use in one study only: low weight, life changes, more contacts with GP, humidity, ethical concerns about patient, legal concerns.

†Factors shown to prevent urgent care use in one study only: younger clinician age, Medicaid, the weekend, non profit status of care home.

‡Additional factors shown by one study to have no association with urgent care use: gender, income, marital status, proximity to emergency department. GP, general practitioner.

studies that found no association between comorbidities and accessing urgent care.^{30 31}

Diagnosis of dementia

Twelve studies compared hospitalisation or emergency department use in dementia with those without dementia. Studies were evenly split between whether having dementia increased^{20 32–34} or decreased^{10 23 27 32} urgent care use. Zhao *et al* found that people with dementia were more likely to be hospitalised overall than people without dementia, but they

were less likely to be hospitalised for osteoarthritis or heart conditions.³² Two studies found no increase or decrease in hospital use for dementia compared with people without dementia.^{25 27}

Role of informal and professional carers

Informal carers, in making decisions and providing support for people with dementia, were reported to prevent situations arising such that urgent care was needed.^{30 35–39} However, a relationship strain or abuse or neglect from informal carers could cause increased

Table 4 Reasons for accessing urgent care

Condition	References
Infections	n=18 Amador <i>et al</i> ³⁰ (2014), Benner <i>et al</i> ³⁶ (2018), Carter and Porell ²¹ (2005), Chang <i>et al</i> (2015) ⁴⁷ , Clay ⁶⁹ (2008), D'Agata <i>et al</i> ⁶⁰ (2013), Givens <i>et al</i> ⁵⁰ (2012), Givens <i>et al</i> ⁴³ (2015), Ledgerd <i>et al</i> ³⁸ (2016), Lin <i>et al</i> ²² (2017), Mitchell <i>et al</i> (2009), ⁶⁸ Mitchell <i>et al</i> ⁵⁸ (2014), Rudolph <i>et al</i> ²⁸ (2010), Sharpp <i>et al</i> ⁵⁵ (2016), Sloane <i>et al</i> ³¹ (2017), Toot <i>et al</i> ³⁹ (2013), Toscani <i>et al</i> ³⁹ (2015), Zhao <i>et al</i> ³² (2008).
Behavioural symptoms and/or delirium	n=14 Andrieu <i>et al</i> ²⁴ (2002), Benner <i>et al</i> ³⁶ (2018), Boltz <i>et al</i> ⁴⁶ (2018), Chang <i>et al</i> ⁴⁷ (2015), Givens <i>et al</i> ⁵⁰ (2012), Ledgerd <i>et al</i> ³⁸ (2016), Mitchell <i>et al</i> ⁶⁸ (2009), Rudolph <i>et al</i> ²⁸ (2010), Sadak <i>et al</i> ⁵⁶ (2017), Sharpp <i>et al</i> ⁵⁵ (2016), Sloane <i>et al</i> ³¹ (2017), Toot <i>et al</i> ³⁹ (2013), Toscani <i>et al</i> ²⁹ (2015), Zhao <i>et al</i> ³² (2008)
Falls/Injuries	n=14 Amador <i>et al</i> ³⁰ (2014), Andrieu <i>et al</i> ²⁴ (2002), Benner <i>et al</i> ³⁶ (2018), Chang <i>et al</i> ⁴⁷ (2015), Givens <i>et al</i> ⁵⁰ (2012), Kim <i>et al</i> ⁴¹ (2019), Ledgerd <i>et al</i> ³⁸ (2016), Lin <i>et al</i> ²² (2017), Mitchell <i>et al</i> ⁵⁸ (2009), Rudolph <i>et al</i> ²⁸ (2010), Sadak <i>et al</i> ⁵⁶ (2017), Sharpp <i>et al</i> ⁵⁵ (2017), Sloane <i>et al</i> ³¹ (2017), Zhao <i>et al</i> ³² (2008)
Heart and/or respiratory disease	n=11 Amador <i>et al</i> ³⁰ (2014), Chang <i>et al</i> ⁴⁷ (2015), Givens <i>et al</i> ⁵⁰ (2012), Lin <i>et al</i> ²² (2017), Mitchell <i>et al</i> ⁶⁸ (2009), Rudolph <i>et al</i> ²⁸ (2010), Sadak <i>et al</i> ⁵⁶ (2017), Sharpp <i>et al</i> ⁵⁵ (2016), Sloane <i>et al</i> ³¹ (2017), van de Vorst <i>et al</i> ⁴⁸ (2017), Zhao <i>et al</i> ³² (2008)
Gastrointestinal	n=8 Amador <i>et al</i> ³⁰ (2014), Benner <i>et al</i> ³⁶ (2018), Givens <i>et al</i> ⁵⁰ (2012), Mitchell <i>et al</i> ⁶⁸ (2009), Rudolph <i>et al</i> ²⁸ (2010), Sadak <i>et al</i> ⁵⁶ (2017), Sloane <i>et al</i> ³¹ (2017), Zhao <i>et al</i> ³² (2008)
Syncopal and/or seizures	n=5 Mitchell <i>et al</i> ⁶⁸ (2009), Rudolph <i>et al</i> ²⁸ (2010), Sharpp <i>et al</i> ⁵⁵ (2016), Sloane <i>et al</i> ³¹ (2017), Zhao <i>et al</i> ³² (2008)
Disability and/or immobility	n=3 Kim <i>et al</i> ⁴¹ (2019), Ledgerd <i>et al</i> ³⁸ (2016), Sloane <i>et al</i> ³¹ (2017)
Stroke	Chang <i>et al</i> ⁴⁷ (2015)
Aphasia and/or dysphagia	Tian <i>et al</i> (2013) ⁸⁴
Incontinence	Ledgerd <i>et al</i> ³⁸ (2016)

urgent care use, and informal carers were also reported to increase use when the person with dementia is closer to death.^{26 27 38 40} Cogen *et al* found that male carers increased urgent care use but there was no association with carer age or education level and urgent care use.⁴⁰ The person with dementia living in a care facility was shown to increase access to urgent care,^{27 29 41} although Toscani *et al* found that while there were more urgent situations with people with dementia living in care homes, they were less likely to go to hospital.²⁹ Cloutier *et al* also found a decrease in hospitalisation after people with dementia were admitted to residential care.⁴²

Symptoms and characteristics of the person with dementia

Older age^{27 28 30 43 44} and the presence of behavioural symptoms^{20 24 38 39 45} were reported to increase urgent care use. While there were no studies that reported these factors as being associated with a decrease in urgent care use, there were four^{23 25 46 47} and two^{26 31} studies, respectively, that found no association. This was also the case with ethnicity; studies reported increased urgent care use for non-white compared with white people with dementia,^{48–50} while others reported no association.^{23 28 33} Similarly, higher dependency,^{20 24 26 38 42} higher level of cognitive impairment^{23 34 44} and lower levels of education^{23 24} were shown by some studies to be associated with increased urgent care use, while others showed no association.^{25 28} There was some association with gender and increased urgent care use, with males reported as more likely to be hospitalised or visit emergency departments^{27 28 50} and one study reporting females more likely to have hip fractures.⁴¹

There were some differences in reasons for urgent care use according to type of dementia, with Chang *et al* showing that people with vascular dementia had higher frequencies of falls and delirium, and Rosenwax *et al* reporting fewer visits to emergency departments for people with Alzheimer's disease.^{27 47} Chang *et al* found no difference in recurrent hospitalisations between dementia type.⁴⁷ Two studies found that a shorter duration of dementia diagnosis was specifically associated with emergency psychiatric care.^{28 51}

Variation in service organisation and location

Advance care planning was cited as preventative for urgent care use, but identified as difficult to put in place.^{27 49 50 52–55} Adequate outpatient services, specifically care coordinators and support in the home, were also identified to prevent urgent care use.^{38 39 53 56} Accidents in the home were highlighted as key causes of crises and resulting access to urgent care, and technological support within the home was seen as a way to avoid this.^{21 38 39}

Six studies reported associations between geographical locations and increased urgent care use, including different levels of urgent care use in different countries,^{44 57} more urgent care use in rural over urban areas^{27 41 49} and more urgent care use in northern over southern regions.²⁶

Stakeholder experiences of urgent care use in dementia

Thirty-one studies considered stakeholder experiences in more detail. Stakeholders experienced various situations in urgent care: from hospitalisation decisions,^{35 37 54} to withholding treatment at the end of life,^{29 37 58 59} to prescribing antibiotics.^{57 58 60}

Three factors were considered to play particularly important roles in how people with dementia access urgent care and how care is experienced.

Knowledge of dementia as a condition and individual patient back stories

Specialist and in-depth knowledge of both dementia as a condition, and each individual person with dementia, was a priority in 20 studies. People with dementia were commonly not involved in decision making.^{44 61} They were reported to be in less pain and more likely to be marked as less urgent than those without dementia.^{10 27} There was concern among carers that a dementia diagnosis led to exclusion from specialist care services that a diagnosis of cancer might not.^{42 45} General practitioners (GPs) were reported to find behavioural symptoms in care homes as the most challenging part of their job,⁴⁵ with patients with dementia seen as a burden on time.^{53 62}

A lack of understanding of dementia was identified as a trigger for crises for people with dementia across settings. Increased training in dementia was reported as important to prevent crises in care homes,^{38 45 63} but specific staff employed as dementia specialists were reported as having a particularly beneficial effect. These could be placed within care homes^{39 45 50} or based in outpatient, primary care settings with constant contact with care homes.^{38 45 53}

Emergency department staff had specific challenges related to the time-pressured environment, where the focus was on the acute presenting problem rather than dementia.^{53 62 64 65} This could be compounded by the presence of delirium.⁶⁴ Dementia could also make it harder for staff to identify the reason for visiting the emergency department, which lead to undertriaging and longer waiting times for patients.⁶⁵ That some people with dementia were unable to describe their symptoms was a particular problem.^{59 62 65} For those in care homes, information exchange between informal carers, professionals and emergency services was seen as a pivotal factor to improve access to urgent care, and one which was often lacking.^{41 45 54 55 58 66}

Inadequate health and social care support leads to accessing urgent care

Fourteen studies reported that outpatient care and home support were not sufficient for people with dementia. There were two sides to this issue. First, a lack of outpatient or community support would cause crises, with situations worsening for people with dementia and their caregivers until hospital admission is necessary.^{45 56 63} Second, informal carers find themselves in a challenging situation and have nowhere to go for support other than an emergency department, despite acknowledging

that the situation may not be urgent.^{38 52 67} Once a crisis point had been reached, support services became available where they were not available before.⁶⁷ This could be due to service organisation factors, for example, not being able to access a psychiatrist unless the person with dementia is admitted,⁴⁵ or economic factors, with insufficient funds and staffing in outpatient services.⁵²

Professional carers reported feeling frustrated by limitations on their ability to avoid emergency situations in dementia.⁵⁵ There were not always the staff available to control extreme behavioural symptoms.⁴⁵ Additionally, professional carers report resistance from informal carers to engage in end-of-life discussions, resulting in people with dementia being hospitalised or aggressively treated even in late stages of their condition.⁵⁴

Influence of informal carers in accessing urgent care

The role of the informal carer was explored in detail in 12 studies. Caregiver burden, characterised by negative emotional state, strain and sleep disturbance, was seen as a crucial factor in why people with dementia end up accessing urgent care, particularly emergency departments and hospitals.^{39 53 56 62} Caregiver strain was found to be associated with a change in functioning of people with dementia prior to hospital admission.⁴⁶ Sudden caregiver physical illness or limitations on providing care also lead to urgent situations arising for people with dementia.^{38 39 56}

This results in a vicious circle, with stress and guilt causing further damage to caregiver well-being.⁵⁶ Correspondingly, support for carers was critical for preventing urgent situations in dementia, with strategies to maintain self-care and access to respite, including emergency respite in the home, identified as paramount.^{38 39 56}

Another challenge of informal caring was the need to identify symptoms or avoid situations that may lead to urgent care situations.⁵⁶ Carers' lack of knowledge about how to recognise and manage healthcare situations, and what the treatment options were, lead to increased urgent care use.⁵³ Additionally, as the situation escalates, caregivers may be under pressure to make decisions quickly, leading to inappropriate care.⁵⁶ Caregiver education and counselling was therefore reported to be key in reducing urgent care use and providing support for caregivers to manage changes in symptoms appropriately.^{38 39} This was seen as particularly important regarding end of life decision making in urgent situations, for example Mitchell *et al* found that carers who had been counselled about expected complications and prognosis in advanced dementia were less likely to choose burdensome interventions such as hospitalisation in the last 3 months of life.⁶⁸

Barriers between informal carers and health and social care services was a particular challenge that lead to urgent care use. Lack of support meant that hospitalisation resulting in the person with dementia discharged to residential care was experienced as a relief for stressed carers, who had felt guilty about making this decision on their own.⁵² Carers reported finding it hard to speak to GPs and community services about potential crisis

situations.⁵³ There were also barriers identified by professionals, with reports from care facility and emergency department staff of carers directly contradicting instructions in advance care plans, ordering more burdensome interventions.^{35 59 69} Medical professionals were seen to take the lead in decision making in urgent care.^{29 37} Involvement of informal carers was reported to lead to more aggressive treatment, for example, carer awareness of infection episodes for people with dementia in care homes lead to increased hospital transfers.⁴³ Informal carers were not always informed by care home staff or clinicians if their relative with dementia had an infection, with under half being told if the patient with dementia had been prescribed antibiotics.⁵⁸

DISCUSSION

The existing research exploring urgent care in dementia reports complex care scenarios affected by comorbidities, characteristics associated with dementia as a condition such as memory loss and behavioural symptoms, informal and professional carers, and the quality of outpatient healthcare services. A lack of understanding of dementia and knowledge about the patient as an individual, inadequate community support, and competing demands of informal and professional carers can cause additional challenges to the person with dementia receiving appropriate care.

The strengths of this scoping review are the systematic nature of the search and data extraction process. The broad research question and inclusion criteria allowed a wide variety of studies to be included. The involvement of people with dementia and informal carers in the design of the study and throughout the review process strengthened the review in ensuring the research addressed the concerns of key stakeholders. The primary limitation was the inclusion of only English language research. Additionally, the included studies explored dementia as an overarching condition, and therefore, the different effects of different types of dementia were not examined. Scoping review methodology does not include a formal quality appraisal process, which means the scientific quality of the studies has not been taken into account.

Considering the nature of a scoping review and the broad research questions, it was unsurprising that the 54 included studies explored a broad spectrum of factors associated with urgent situations for people with dementia, and that there were some competing findings. Sociodemographic factors such as older age, gender, ethnicity, lower education and geographical location were shown by some studies to increase urgent care use, while other studies showed no association. However, the studies did not discuss whether these factors are dementia specific, and there is research showing similar patterns in other patient groups.^{70–72} Similarly, comorbidity increases acute care use in other chronic illnesses.⁷³ The heterogeneity of dementia, both in terms of manifest symptoms and disease severity, adds to the challenge of unpicking

the relationship between a dementia diagnosis and urgent care use. That very few of the studies differentiated between dementia type meant that this could not be unpicked in this review.

There are two key implications for policy-makers and clinicians arising from this review. However, both rely on an increase of support for people with dementia and their carers in the community. First, a large proportion of the included studies identified insufficient care and support, in a variety of areas, as a key cause for crises occurring, as well as the reason people with dementia are admitted to hospital unnecessarily. Economic causes, such as low staffing levels in care homes or lack of services, were partly to blame, which is also reflected in other literature.^{74 75} However, a lack of communication between existing services was also detrimental to appropriate care, which has also been identified in other studies of dementia services.⁴ There is much recent research highlighting the benefits of integrated care for people with dementia, especially regarding patient-specific information being easily shared across different services, both between health and social care services and between community and hospital based services.⁷⁴ The use of dementia specialists has also been highlighted as key to higher quality care, which was also identified in the review.⁷⁶ The results of this review add to this, with a specific focus on how integrated services can both prevent inappropriate urgent care use and improve experiences.

The second key implication is reflected in the different priorities of stakeholders, which were particularly prevalent when it came to end-of-life decisions that arise in urgent situations. Advance care planning was identified as crucial in preventing unnecessary hospitalisation in urgent situations, but can be a challenge to implement, as has been discussed in the wider end-of-life care literature.⁷⁷ Timely planning on what to do in urgent situations is advised to avoid problems of decision-making capacity,⁷⁸ but memory clinics and GPs have highlighted challenges of initiating these conversations when people are adjusting to living with their new diagnosis and capacity is not yet an issue.^{79 80} Education of caregivers about how dementia progresses and the situations that may arise at end of life was highlighted as key in this review, as it has been in others.⁷⁸ However, this will again rely on more resources and support for people with dementia and their families prior to urgent care situations arising.

Future research in this area will benefit from inclusion of the perspectives of people with dementia, which were included in only 6 of the 54 studies.^{38 39 45 46 65 66} This may be due to the complex nature of urgent care situations, where time constraints make more dementia-appropriate recruitment methods⁸¹ challenging, and those in advanced dementia not being able to participate in interviews. Future research could adapt from more traditional methodologies to explore the experiences of people with dementia. For example, studies have successfully used ethnographic or observational techniques to capture how decisions are made in non-urgent care settings,

and using similar methods in urgent care would be beneficial in providing guidance and training to professionals.^{6 82} The included studies are dominated by large cohort studies, providing descriptive data on how many people with dementia in different contexts and settings access different types of urgent care, and what characteristics are associated with this. A future review could provide a meta-analysis of the available cohort studies in this area, in order to provide a definitive list of factors that increase or prevent urgent care use.

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