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Experiences of older people dying in nursing homes: a narrative systematic review of qualitative studies

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ABSTRACT

Objectives To identify and synthesise qualitative research from 2001 investigating older people's (65+ years) experiences of dying in nursing and care homes.

Methods and outcomes Eight electronic databases (AMED, ASSIA, CINAHL Plus, Embase, HMIC, Medline, PsychINFO and Scopus) from 2001 to July 2017 were searched. Studies were included if they were qualitative, primary research and described the experiences of dying in nursing or care homes from the perspectives of the older people themselves, their families or staff. Study quality assessment was undertaken to systematically assess methodological quality, but no studies were excluded as a result.

Results 1305 articles were identified. Nine met the inclusion criteria. North American studies dominated. Most used a mixture of observations and interviews. All the included studies highlighted the physical discomfort of dying, with many older people experiencing potentially avoidable symptoms if care were to be improved. Negative psychosocial experiences such as loneliness and depression were also often described in addition to limited support with spiritual needs.

Conclusions More qualitative research giving a holistic understanding of older people's experiences of dying in residential care homes is needed. Undertaking research on this topic is challenging and requires great sensitivity, but the dearth of qualitative research from the perspectives of those most closely involved in older people's deaths hampers service improvement.

Strengths and limitations of the study

- The qualitative focus of this review broadens our understanding of older people's experiences by highlighting important psychosocial aspects of the experience frequently omitted in quantitative studies.
- Despite being comprehensive, this review only identified nine studies, thereby highlighting an important gap in the literature.
- Study authors used varying criteria to identify the end of life or dying in older people which presented challenges to synthesising study findings.
- The most recent study was published in 2011, and all research came from Western countries.

INTRODUCTION

Worldwide, life expectancy is continuing to rise, and increasing numbers of older people require support towards the end of their lives with significant proportions of older people living in care or nursing homes. For example, across Europe and North America, more than two-thirds of care home residents are aged 80 years or older.[1] In parallel with this, the proportion of older residents dying in care homes is rising across the world.[2] In England and Wales, for example, in 2006, 19.2% of older people aged 65 years and over died in care homes,[3] compared with 24.7% a decade later.[4] Therefore, the importance of providing good end-of-life care for older people in nursing and care homes is growing.

The Gold Standards Framework was first introduced in 2000 in the UK to standardise the provision of consistent, coordinated care for people nearing the end of life. It has since been remodelled to train care home staff to deliver standardised palliative care for all patients approaching the end of life.[5] More recently, the End of Life Care Strategy[6] introduced new care pathways and initiatives to improve end-of-life care, such as Preferred Priorities of Care, a tool to enable healthcare staff to work with patients to document their wishes as they approach the end of life. In view of the variable quality of end-of-life care, national concern with the topic has continued with the development in the UK of the National End of Life Care Partnership.[7] These programmes have been recognised and adopted in many other countries. Programmes such as the Liverpool Care Pathway, for example, have been disseminated to over 20 countries in a range of settings including care homes.[8]

Evidence relating to the implementation of end-of-life care policy in care homes is sparse and limited. For example, a review

of the literature relating to the efficacy of palliative care interventions for older people living in care homes[9] found only three relevant studies. All were undertaken in the USA, and all were described as 'poor' quality. The authors suggested that care home structure and culture may be an important barrier or facilitator of the success of any approach to palliative care influencing the generalisability of the interventions. They also highlighted that the outcome measures used within the studies were predominantly process related, which may not automatically translate to positive patient experiences and that future studies should incorporate residents' views of their care.[9] A UK-based evidence synthesis[10] of the implementation of the end-of-life care policy in care homes also only identified three relevant studies. Some improvement in resident outcomes and in the ability of staff to recognise and deliver care to meet resident needs were highlighted. However, the dearth of studies and the possibility of other factors influencing care mean it is not possible to be confident that these improvements could be attributed to these interventions. Here, too, the evidence failed to highlight the experiences of those receiving the care.

Advance care planning, involving advance discussions of care needs and preferences at the end of life has been studied quite extensively in a variety of settings.[11] A systematic review of randomised controlled trials found that advance care planning for older adults facilitated increased documentation of care preferences, advance directives and improved family outcomes, but none of the studies measured patient outcomes relating to quality of life and symptom management.[11] The majority of studies in another review[12] investigated 'do not resuscitate orders' and advance care directives with only a few focusing on patient and family experiences. A case study of four care homes in the UK also revealed that advance care planning is frequently seen as a 'tick-box' exercise while it should be an individualised process, discussed at the right time and handled sensitively. However, this requires a positive culture in care homes with good leadership and staff training if it is to be effective.[13] Taken together, these publications highlight the need to bring together the evidence for how end of life is experienced by those at the centre of it—the older people themselves. Without this essential perspective, it might be argued that their care is unlikely to improve.

Future preferences concerning end-of-life care in care homes have also been investigated. For example, in one interview study, many older people in care homes said they were ready to die but were concerned about the process of dying and wanted a peaceful, pain-free death, without life-saving treatment or hospital intervention.[14] Similarly, some acceptance that end of life was approaching was also reported, but there were differences of opinion regarding the readiness to engage in end-of-life care conversations.[14] Many had not discussed this with nursing home staff. In a similar vein, missed opportunities to have conversations about end of life with residents and assumptions about end of life preferences were also reported elsewhere among nursing home residents in the USA.[15]

A recent systematic review[16] summarised the literature on what families and patients believe could be done to improve end-of-life care in nursing homes. The importance of health professionals anticipating care and support needs and providing guidance were emphasised with many participants wanting greater availability of doctors. Patients' preferences were not always recognised and participants saw room for improvement.

There is a considerable body of quantitative literature, often retrospective perceptions a long time after death, that focuses on the process of dying in care homes, with emphasis on symptom occurrence such as pain and dyspnoea or the frequency of clinical events.[17 18] Such quantitative research tends to break the experience down into measurable outcomes while not capturing the experience holistically. Although the quantitative literature is important and highlights many of the negative aspects of dying such as pain, it inevitably relies on methods such as structured questionnaires and cannot therefore be reported in the participants' own words. Consequently, quantitative methods alone may fail to capture fully less tangible psychosocial aspects of dying, such as its spiritual, psychological and emotional facets.

Review aims

As no review synthesising the qualitative research evidence relating to the experiences of older people of dying in care homes was found, this review therefore aimed to identify and synthesise the findings of qualitative studies investigating older people's (aged 65 years or over) experiences of dying in nursing or care homes. The ethical and practical challenges of undertaking research with people very close to death mean that there was likely to be limited research with older people themselves as participants. We therefore also sought to identify and synthesise research that described the experiences of these older people as perceived by their families and staff working closely with them.

Definitions

For the purposes of this review, experience encapsulates the following: psychological and emotional aspects of dying such as distress, anxiety, depression, autonomy and physical aspects such as pain or dyspnoea, sleep, cleanliness and finally, spiritual dimensions, such as faith, meaning and purpose.

Defining dying is very challenging with the term in the literature being used in a range of ways. The focus of this review was on older people at the end or very near the end of life. For this review, this was taken as 'dying'. Each identified paper was scrutinised with this in mind. We were led by how the authors described or defined dying but only included papers where the review team agreed that the majority of participants were close to death.

METHODS

The review followed the Centre for Reviews and Dissemination guidelines (CRD 2009)[19] and was reported using the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA).[20] It was registered on PROSPERO (CRD42017055954).[21]

Inclusion criteria

The following publication types were included: primary research studies investigating older people's (aged over 65 years) experiences of dying in residential care (eg, nursing or care homes, retirement homes and assisted living facilities) whether from the perspective of the older person, nursing home staff or informal carers; qualitative studies; mixed-methods studies where the qualitative findings could be separated from the quantitative findings; and published in peer-reviewed journals in the English language.

Exclusion criteria

The following were excluded: studies investigating the experiences of dying in other care contexts including hospital, hospices and older people's own homes; studies investigating the experiences of nursing home staff; studies investigating informal carers' own experiences; quantitative studies; case studies; non-peer reviewed journal articles; grey literature (eg, PhD theses and conference proceedings); and review and comment articles.

Search strategy

Eight electronic databases were searched from January 2001 to October 2015 and then updated in July 2017: Allied and Complementary Medicine Database (AMED), ASSIA, CINAHL Plus, Embase, HMIC, Medline, PsychINFO and Scopus. Searches were undertaken from 2000, because the National Service Framework for Older People, a seminal policy with wide-reaching significance, was published in 2001. This date would ensure that any relevant study was captured.

The searches combined the following terms: older people, dying, nursing or care homes and qualitative studies.

An example search strategy (MEDLINE) that was adapted for the other databases

1. exp " Aged, 80 and over" / or Aging / or exp Aged / or older people.mp.
2. exp Frail Elderly/
3. aged.tw.
4. elderly.tw.
5. geriatric*.tw.
6. older people*.tw.
7. ag?ng.tw.
8. or/1-7
9. exp Death / or exp Attitude to Death / or death.mp.
10. end of life.tw.
11. dying.tw.
12. aged care facilities.tw.
13. residential care.tw.
14. old* people* home.tw.
15. care home*.mp,tw.
16. nursing home*.mp,tw.
17. long term care.tw.
18. assisted living.tw.
19. or/ 9-11
20. or/ 13-18
21. 8 and 19 and 20
22. interview:.mp.
23. experience:.mp.
24. qualitative.tw.
25. 22 or 23 or 24
26. 21 and 25
27. limit 26 to (English language and humans and year="2001-Current")

Additional sources

To identify any relevant studies that may have not been identified through the electronic database searches, references in the only relevant review[16] and the references lists of all the included articles were scrutinised. In addition, where contact details were available, we contacted the authors of the selected articles and asked if they could suggest any other relevant studies.

Screening for relevance

After duplicate removal, the titles and abstracts of studies identified in the electronic and hand searches were independently screened by a minimum of three members of the review team. Those studies identified as potentially relevant were then retrieved for full-text review and scrutinised by a minimum of four team members. Throughout the entire process, disagreements were resolved by discussion.

Quality assessment and scoring

Assessment of study quality in qualitative research is a contentious issue because of the differing paradigms and diversity in data collection,[22] but it is also important to point out that the value of study quality ratings is limited by the fact that authors are often restricted in the details they can provide because of journal word counts. Therefore, quality assessment was undertaken to interrogate the methodological quality of the studies in a systematic fashion, rather than to exclude them. Quality assessment of the included studies was performed by a minimum of two reviewers using a qualitative quality scale.[22] This scale was adapted from other scales[23 24] and included consideration and rating of, for example, appropriateness of the study design and methods of analysis. An additional point was added to the original 11-point scale to identify whether researcher reflexivity[23] was considered. Reviewers' ratings were generally in agreement, and consensus was reached with discussion over the few differences.

Data extraction and synthesis

Synthesis of the findings was narrative, but emphasis was given to identifying where studies gave insight into older people's experiences of dying in care or nursing homes

using the following elements of experience: psychological, spiritual and cultural factors, care given and care received, physical symptoms and the physical environment. Data sources were wide and included interview and observational data. This diversity made synthesis more difficult. In order to capture what the study authors regarded as their most important findings, data incorporated in the themes and study conclusions came from their findings and discussion sections respectively. The synthesis was undertaken by three or more members of the review team and was intended to summarise and explain the study findings as presented in the text by the study authors.

Patient and public involvement

There was no patient and public involvement in this systematic review.

RESULTS

After duplicate removal, 1239 studies were identified from both the electronic and additional searches. No further studies were identified after reference list searching or contacting the included study authors. After abstract screening, 48 studies were identified for full-text review (figure 1).

Studies were excluded at this stage for a variety of reasons including inappropriate study foci, populations or settings and quantitative as opposed to qualitative methodology.

Nine studies fitted the inclusion criteria (table 1). Close scrutiny of three of these studies[25–27] suggested to the team that they incorporated the same participants. We considered reporting them together in the review but kept them separate because they focused on different aspects of older people's experiences.

Two studies[28 29] came close to inclusion but were finally excluded because, for example, their focus was more on service development or the participants were anticipating death rather than describing experiences of dying.

The earliest included study was published 16 years ago,[30] and the most recent was seven years ago.[31 32] Six studies were from North America,[25–27 30 33 34] two from

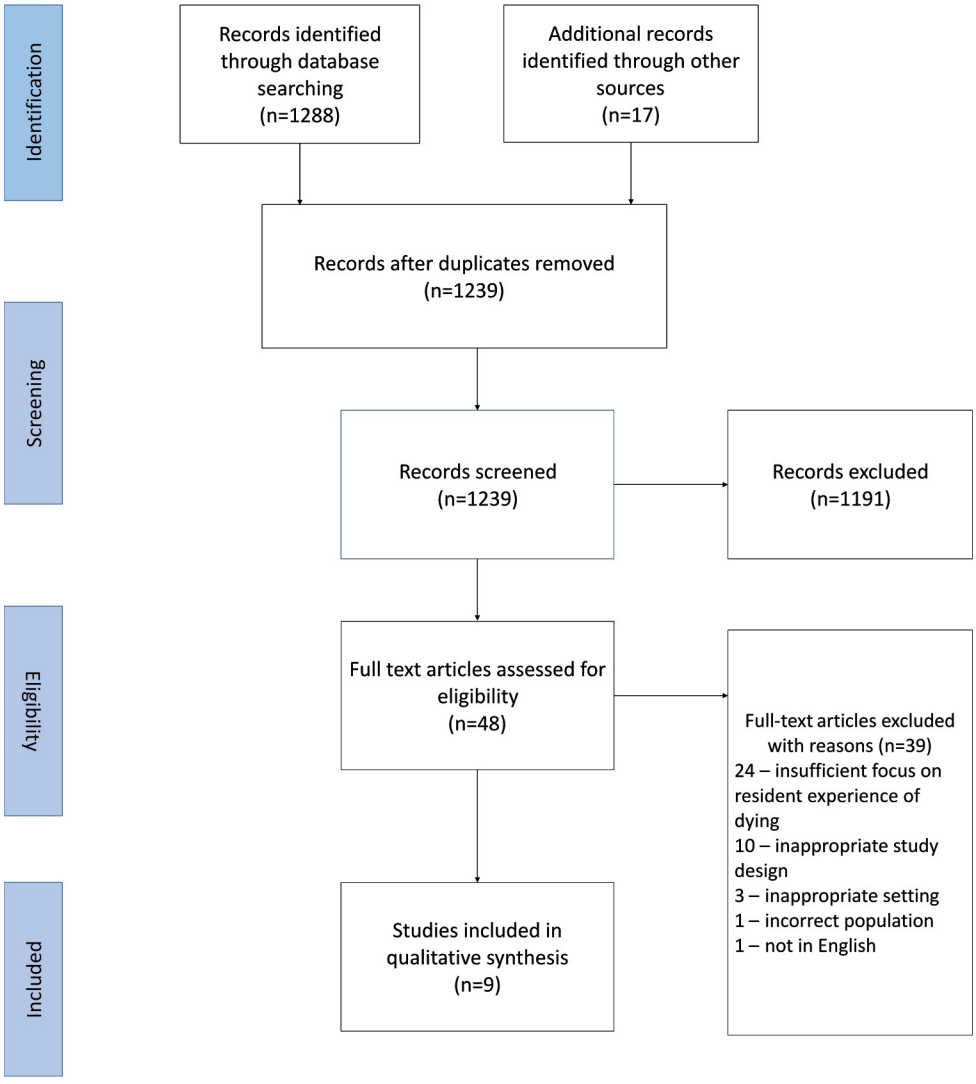

Figure 1 PRISMA flow diagram.[20] PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-analysis.

Table 1 Study aims, methods and analysis

Authors (year), country	Aims	Methods	Data analysis	Quality rating/12
Brayne *et al*[35] (2008), UK	To establish whether those dying (naturally) of old age have similar EOL experiences to those dying of a terminal illness.	Questionnaire and follow-up interview with CH staff. However, data came mainly from interviews.	Thematic analysis.	7
Chan and Kayser-Jones[27] (2005), USA	To investigate clinical, social, environmental and cultural factors influencing the care of terminally ill NH residents.	Event analysis, participant observation and in-depth interviews with NH residents, families and staff.	Event analysis of the process of dying in NHs.	7
Dwyer *et al*[31] (2011), Sweden	To reveal NH employees' views on dying and death among older people for whom they care	Seven focus groups with nursing staff (RNs and NAs) held 2–4 months after residents' deaths.	Qualitative content analysis.	10
Forbes[30] (2001), USA	To describe EOL in an NH from the perspectives of chronically ill and declining residents, their family caregivers and staff.	Participant observation, in-depth semistructured interviews, face-to-face formal/informal interviews, focus groups, health record reviews.	Data collection and analysis were simultaneous and continuous. Content analysis.	10
Goodridge *et al*[33] (2005), Canada	To examine the perspectives of family carers, nurses and healthcare aides regarding the last 72 hours of residents' lives.	Semi-structured interviews.	Thematic analysis.	11
Kayser-Jones[25] (2002), USA	To investigate the process of providing EOL care to residents dying in an NH.	Participant observation, in-depth analysis and event analysis.	NR	5
Kayser-Jones *et al*[26] (2003), USA	To investigate the physical environment and organisational factors influencing the process of providing care to terminally ill NH residents.	Participant observation, field notes. In-depth interviews. Event analysis of death and dying.	Thematic analysis.	10
Vohra *et al*[34] (2006), Canada	To explore EOL in long-term care facilities.	Mixed methods (questionnaire responses to open-ended question are reported here).	Thematic analysis.	11
Whitaker[32] (2010), Sweden	To explore and analyse how residents talk about and regard their own ageing and dying bodies in an institutional-based care context.	Seven months of participant observation and informal conversations with residents, staff and visiting family members/relatives.	Thematic analysis based on ethnographic fieldwork and grounded theory.	10

CH, care home; EOL, end of life; NA, nursing aide; NH, nursing home; NR, not recorded; RN, registered nurse.

Sweden[31 32] and one from the UK.[35] Five studies investigated the perspectives of older people themselves,[25–27 30 32] five the perceptions of informal or family carers[25 26 30 32 34] and four nursing home staff perceptions.[25 30 31 35] Reporting of participant demographic details was often limited (table 2), but more information was generally provided about older people participants than the other groups. The older people were slightly more likely to be female than male, and the mean age of the majority was late 70s. Time to death was described in a variety of ways, but the vast majority of residents were close to death; authors described them as, for example, within hours or days of death at the time of the study or described how many died during the study. With the exception of one study,[27] participants' ethnicity and religion were not reported. In terms of nursing home staff professional groups, nurses, nursing and healthcare assistants dominated, but participants also included doctors and social workers.

Except for one study that only undertook focus groups,[30] most included studies incorporated either participant observation or interviews with participants. Interviews were mostly face-to-face, although Whitaker[32] described data collection as incorporating 'informal conversations'. Written responses to an open-ended question on a questionnaire were included in one study.[34] Data analysis approaches were related to data collection methods and included content analysis, thematic analysis and event analysis (table 2).

Overall, quality rating scores were good and ranged from 5 to 11 with a mean of 9.0. The primary quality issues that reduced ratings concerned poor reporting of methods, analysis and failure to report researcher reflexivity (table 1).

None of the studies reported having a theoretical background to their research, although they were mostly ethnographic in their approach.

Table 3 and table 4 show that all the included studies highlighted the physical discomfort of dying with many older people experiencing potentially avoidable symptoms such as pain, pressure sores, dyspnoea and thirst. In all studies except Whitaker 2010,[32] physical discomfort was highlighted in association with the care given to the older person, which was often seen as inadequate both by the researchers observing and the staff themselves. Aspects of care such as inappropriate food and drink,[27] limited assessment[25] and monitoring[34] were also mentioned. Negative psychological aspects such as loneliness and depression were described in six studies.[25 30 32–35] Spiritual aspects of people's experiences such as religion and existential issues were also described.[27 30 31 33–35] However, two studies highlighted that death[30] and existential issues[31] were seldom discussed unless raised by older people themselves. In contrast to the other studies, one[34] also highlighted good spiritual and psychological care received by the older people.

Chan and Kayser-Jones study[27] stood out for focusing on the importance of cultural aspects of care emphasising the additional difficulties of Chinese people at the end of life in a USA care home in terms communication barriers and beliefs around illness and death. However, the uniqueness and individuality of older people's experiences were also clear in other studies (eg, refs 32 and 35).

The studies that included experience of dying from the perspective of the older people themselves are highlighted in table 4. Irrespective of the participant groups, many similarities are evident in the perceptions of this experience, particularly in relation to the centrality of physical symptoms and the care provided. Psychological and spiritual factors were also frequently reported themes.

DISCUSSION

Despite a comprehensive electronic database search and additional hand searching, we identified disappointingly few studies that described the subjective experiences of older people dying in nursing and care homes. One striking aspect of the searches was how few specifically investigated older residents' own experiences at the end of life. Perhaps unsurprisingly this was frequently investigated by proxy. However, those studies we did identify suggested these experiences were often poor.

Care must be taken in interpreting the findings given that few relevant studies were identified. However, seven of the nine included studies highlighted the physical discomfort of dying in a nursing or care home with older people often experiencing pain, pressure sores and thirst. Added to this, six studies described many people suffering psychologically; loneliness and depression were often highlighted. Although our aim was not originally to look at the relationship between care and experiences, most authors here made a clear direct link between inadequate care and these negative experiences, stating that they were often preventable or at least potentially alterable. This is significant as it demonstrates the impact of the physical environment and staff. Only one study[27] specifically investigated cultural aspects of these older people's experiences, a significant omission given the importance of religion and culture surrounding death.

Whitaker[32] highlighted how participants were reconciled to death and rather than fearing approaching death, accepted it, focusing more on their fear of a failing body. This was often dreaded more than dying. Although only one paper, it resonates with studies such as Mathie *et al*[14] that highlighted that despite acceptance of death, older people and staff were ambivalent about discussing end-of-life care. Such studies perhaps suggest that if care staff had open discussions about death and the potentially negative spiritual and psychological features of dying, the experiences of this vulnerable group might be better recognised, acknowledged and therefore improved. Maintaining dignity is important in all healthcare contexts but has perhaps not been sufficiently highlighted in relation to dying in residential care. Here it was only clearly highlighted in one study.[25] This is perhaps surprising given its importance in healthcare generally.

Table 2 Participant demographic characteristics and residents' length of time to death as described by the study authors

	Older people participants			Healthcare professional participants			Informal carer participants		Residents' experiences (as observed by others or identified by participants)
Authors	**n**	**Age in years: mean, range**	**% female**	**n**	**Gender**	**Role**	**n**	**Gender**	**Time to death**
Brayne *et al*[35]	N/A	N/A	N/A	10	All women.	Care assistants=5, RN=5.	N/A	N/A	Within hours or days of death.
Chan and Kayser-Jones[27]	34	Mean 78.2	59% female.	N/A	N/A	N/A	N/A	N/A	Observed from when identified as terminally ill until death.
Dwyer *et al*[31]	N/A	N/A	N/A	20	16 women, 4 men.	RN=4, NA=16.	N/A	N/A	N/A
Forbes[30]	13	NR	77% female.	30	NR	Included social workers, nurses, NAs, administrators and therapists.	3	NR	6/13 residents died during data collection.
Goodridge *et al*[33]	NA	N/A	N/A	22	NR	Nurses=14, healthcare aides=8.	4	NR	72 hours before death.
Kayser-Jones[25]	117 (observed), 35 (interviewed)	Mean 79, range 39–101.	54% female.	102	NR	RN, LVN and CNAs=66, physician=36.	52	NR	Observed from when identified as terminally ill until death.
Kayser-Jones *et al*[26]	117 (observed), 35 (interviewed)	Mean 79, range 39–101.	54% female.	102	NR	Nursing staff=66, physicians=36.	52		Observed 1 day–15 months before death. Mean 45 days.
Vohra *et al*[34]	N/A	N/A	N/A	N/A	N/A	N/A	104	NR	Last 4 weeks of life.
Whitaker[32]	'About 30' on ward	71–101	Approx. 83% female.	NR	NR	NR but included nursing staff.	NR	NR	Terminally ill or in final stages of life.

CNA, certified nursing assistants; LVN, liscensed vocational nurse; NA, nursing aide; N/A, not applicable; NR, not recorded; RN, registered nurse.

Table 3 Study themes and conclusions

Authors	Authors' identified themes	Authors' conclusions
Brayne *et al*[35]	From interviews (I); from questionnaire (Q). Hallucinations or ELES (I): seeing children: four reported patients seeing apparitions of children shortly before death this appeared to provide comfort (I); dreams: eight spoke about the power and impact dreams can have in preparing for death. Patients dreamt about other patients or family members (I); lucid moments: seven reported residents with dementia and confusion becoming lucid in the last few days (I); physical changes: some reported how physically incapacitated residents could pull themselves up or do something that they normally be unable to do (I). Need for reconciliation (I). Unconscious/confused residents becoming lucid just before death (Q); dreams or visions that help prepare for death or have significant meaning to help with unfinished business (Q); seeing dead relatives or children just before death (Q); synchronistic events at the time of death (Q); the dying speaking about transiting to a new reality (Q); desire to heal family rifts (Q); appearance of birds or animals close to death (Q).	ELEs are powerful subjective experiences with profound personal meaning, not a mechanical process. Dying is an intensely individual experience requiring extreme sensitivity and acceptance from care providers. Some unconscious residents can hold off death until loved ones arrive. These ELEs were neither rare nor surprising. Hallucinations evoked confusion and anxiety, whereas other ELEs focused on inner peace and acceptance of death.
Chan and Kayser-Jones[27]	Main themes: language barriers: most were unable to speak English resulting in difficulties expressing needs, socialising and suboptimal symptom management (eg, pain and dyspnoea). Nutrition: Chinese residents disliked Western food and drink and consumed little of it. Iced water was often served, but they preferred hot water or tea. Therefore, families often provided Chinese food. Beliefs and customs: Chinese residents shared similar beliefs and customs (eg, family involvement in care, traditional Chinese medicine, Buddhist spiritual beliefs and end-of-life care) that influenced how they defined health and envisioned healthcare provision.	Cultural diversity in NH populations is increasing, making cultural sensitivity increasingly important. Communication barriers, dislike of Western food and differing cultural beliefs and customs were factors that significantly influenced EOL care for Chinese residents. Knowledge of Chinese cultural beliefs can help HCPs develop interdisciplinary and culturally sensitive plans for them.
Dwyer *et al*[31]	Five themes: a mixture of resident and staff experiences (1) Alleviating suffering and pain. (2) Finding meaning in everyday life. (3) Revealing thoughts and attitudes about death. (4) Caring for the dead person's body. (5) Coping with perceived gap of personal ideals and reality of what staff could provide. Older people often suffered pain before death. Existential issues were infrequently discussed unless raised by the older person.	Greater understanding is needed of palliative care philosophy to develop the care of people dying in NHs. Until NHs are viewed as places of dying and death, care will not be developed and tailored to meet the needs of dying residents.
Forbes[30]	Five interactive and dynamic themes emerged relating to contextual factors affecting EOL care: communication, quality of life, staff education, teamwork and work environment. Although residents expressed acceptance of death, the process of dying was described by both staff and residents as cold, lonely and painful. Staff, carers and residents valued hospice care. Residents expressed a readiness for death but noted that staff did not initiate discussions about it.	The dying process is not addressed and acknowledged for many NH residents. This leaves little opportunity to prepare for death. Development of polices and staff educational programmes to provide good EOL care is warranted. Discussion surrounding EOL goals or treatment preferences was noticeably absent.

Continued

Table 3 Continued

Authors	Authors' identified themes	Authors' conclusions
Goodridge *et al*[33]	Two main themes were identified: staff caring behaviour (included physical, cognitive and emotional domains) and residents' unique experience of dying (including restlessness). Dyspnoea was more common than pain at EOL. Both were distressing for residents. Staff caring behaviour was central to residents' experiences.	Nurse and HCA caring behaviour was central to the residents' experiences. Emotional support for the resident and their family and appropriate and timely management of symptoms were key to the quality of EOL.
Kayser-Jones[25]	The main factors influencing the experience of dying were: poor attention to cultural needs, cognitive status (cognitively impaired or comatose residents were often neglected), insufficient staffing and poor communication between care providers, residents and families. There was inadequate assessment, monitoring and management of pain, depression, loneliness, fear, constipation, isolation, anxiety, oedema, anorexia, insomnia and fatigue. Dignity was often lost in the last days.	Progress has been made developing principles and guidelines for the care of people at EOL, but barriers and facilitators in implementing these principles need to be investigated to ensure everyone can die comfortably and with dignity. Families should be allowed more time to talk about their fears and concerns.
Kayser-Jones *et al*[26]	The physical environment was not conducive to end-of-life care. Rooms were crowded, unclean with insufficient linen and supplies, lacked privacy, noisy and lacking facilities for relatives to stay overnight with dying residents. Inadequate staffing and lack of supervision were among the most significant organisational factors influencing care. Staff felt stressed and overwhelmed. This meant they were unable to meet residents' needs.	The environment is an inappropriate for EOL care. To ensure people dying in NHs receive adequate care, changes must be made: separate units with space and a quiet atmosphere for terminally ill residents; MDTs must meet with residents and families to establish a care plan to ensure a safe and comfortable death and effective family support; continuing palliative education and in-service programmes for NH staff and adequate staffing and supervision are needed.
Vohra *et al*[34]	Comments fell into two themes.(1) Appreciation of care: subthemes: psychosocial support (including personal, loving and sensitive), family care and spiritual care (provided by clergy and staff). (2) Concerns with care: subthemes: physical care (including pain control, toileting, monitoring and breathing), staffing levels (often insufficient), staff knowledge (often insufficient), physician availability, communication (poor with families), physical environment (including lack of privacy and temperature and noise).	There is a need for improvement in EOL education and care skills for staff.
Whitaker[32]	Five themes in how residents talked about their bodies: (1) the incapable body, move to NH is a disruptive event, frustration over loss of control, grief and distress over loss of function. (2) Bodily needs–bodily dependence: a sense their bodies belonged to staff; some saw dependence as sad; for others, it generated feelings of safety, security and comfort. (3) Bodily change and alienation: women more concerned about appearance, men about loss of hearing, sight and so on. Teeth and nail care are important to all, to look good and smell nice. Dying process masks their sense of self. (4) Inevitable death of the body—body slowly dying, getting steadily weaker, losing taste, extreme fatigue, skin and bone. Death as life consumed for some a yearning for others. A lack of power to a restricted life. (5) Body stories and 'body wanderings': the body as a tool for communication, a need for body contact, not just tasks of care but for confirmation.	The body is central to the spatial and temporal order of the NH and constitutes the existential midpoint for the lives of older people. It is not death but the bodily decline and disintegration (before death) that older people fear most. Powerlessness before the irreversible ageing and dying process and how we care for the oldest old is focused on the tasks of caring, not the existential questions. The slow and irreversible process of prolonged dying can be seen as an unworthy, undignified life phase.

ELES, end-of-life experiences; EOL, end of life; HCPs, healthcare professionals; I, from interviews; MDT, multidisciplinary team; NA, not applicable; NH, nursing home; NR, not recorded; Q, from questionniares; RN, registered nurse.

Table 4 Reported themes mapped onto the key aspects of older people's experiences as defined for the review.

Authors	Physical symptoms	Physical environment	Psychological factors	Cultural factors	Spiritual factors	Care given/ received
Brayne *et al*[35]	X		X		X	
Chan and Kayser-Jones[27]	**X**	**X**		**X**	**X**	**X**
Dwyer *et al*[31]	X				X	X
Forbes[30]	**X**	**X**	**X**		**X**	**X**
Goodridge *et al*[33]	X		X			X
Kayser-Jones[25]	**X**		**X**			**X**
Kayser-Jones *et al*[26]	**X**	**X**				**X**
Vohra *et al*[34]	X	X	X		X	X
Whitaker[32]	**X**		**X**			

X in bold text reflect studies incorporating the views of older people themselves.

Although only nine studies were identified, these studies have implications for our understanding of the what it is like to die in a care home or nursing home. The aspects of their experiences that were described suggest that more could be done to improve their experiences whether in terms of pain or other symptom relief or the overall physical environment. Insufficient staffing[26 34] and poor communication[25 27 30] were highlighted, although there was recognition of the challenges for staff. The role of families was not always highlighted but improved communication[25 34] and flexibility in their involvement was suggested.[26]

The dearth of research in the area and the fact that the most recent included paper was published in 2011 was striking. There are many possible explanations for the overall lack of research; for example, investigating the topic is potentially very challenging and distressing and requires great sensitivity. It is also associated with many potential ethical concerns with such a vulnerable group. However, the fact that no relevant studies were found after 2011 is harder to explain. In the UK, policy changes relating to end-of-life care in 2008[6] increased attention on palliative care, but despite this, we identified very few studies relevant to our research question either in the UK or elsewhere or after this date. Our literature searches suggest that the recent focus may be more on the impact of advance care planning, staff knowledge about care of dying patients and quantitative studies measuring outcomes of symptom management (eg, refs 11 and 12). As we have shown, very little published research focuses on subjective experiences, an essential facet to our review.

Some of the challenges in undertaking research in this area were perhaps also reflected in the difficulties we encountered during the review. The first of these related to the problems defining 'dying'. Authors often used very different definitions ranging from the 'within hours or days of death'[35] to terminally ill or in the final stages of life[32] and described this in varying ways (table 2). We decided to make pragmatic decisions together as a review team and to restrict the included studies to where scrutiny of the articles suggested to us that all or the majority of older people being observed or interviewed were very near to death, but this was clearly a limitation. Our decision to include only studies focusing on this period was to ensure we came as close as possible to capturing this final point in residents' lives, but we were reliant on our interpretation of the authors' descriptions.

Another difficulty during the review was defining what was meant by 'experiences' in this context. The quantitative literature gives some insight into the characteristics of dying in nursing homes, but the aim of the review was to try and capture the experience more holistically (rather than, for example, process outcomes). Therefore, quantitative studies were excluded.

Another challenge related to our aim to capture older people's experience in their own words. There are obvious potential ethical and practical issues in recruiting older people who are close to death, and many residents in nursing homes have cognitive and communication problems adding to the difficulties of gathering their experiences directly from them. Our initial searches identified several studies describing participants' future preferences surrounding their death (eg, ref 14) but few describing their experiences of dying. We also found many studies that investigated the often difficult experiences of those supporting the dying person such as healthcare staff[36] and family carers.[37] The decision to include the perceptions of others, such as families and staff and not just the older people themselves, was taken to allow us to gain as much information as possible from those close to the older person but with the caveat that these had to be about their perceptions of the older persons' experiences. Unfortunately, we identified too few studies to allow us to compare the perspectives of these diverse groups and future research that simultaneously captures the experiences of the older person and those supporting them is needed to address this limitation.

Strengths and limitations of the review

Many of the review's limitations such as the paucity of recent relevant publications, and the diversity of authors' definitions of dying, have been highlighted

earlier. In addition, the studies, although all qualitative, used different methods and had varying aims making synthesis challenging. It might be argued that the study that included analysis of open-ended questions in a questionnaire[35] should not have been included, but the framing of the analysis was qualitative and it was included for comprehensiveness. However, overall the review was comprehensive including seven data bases, additional hand searching and input from authors of the selected papers. An additional strength of the review was the multidisciplinary nature of the review team that included researchers from nursing, social care and social sciences. This ensured a diversity of perspectives.

Another potential limitation was the exclusion of quantitative studies from the review. However, these studies were excluded because of their focus on clinical interventions, care processes and measurable outcomes such as pressure sores and dyspnoea, rather than the entire experience from participants' perspectives and in their own words. Participants' responses in quantitative research are constrained by the limited response options available and give only partial insight into specific aspects of experiences rather than capturing their experiences as a whole.

However, this decision to exclude quantitative studies potentially means that some aspects of people's experiences when dying, such as the extent of the pain and discomfort, may not be receiving sufficient emphasis here. Our study also highlighted the sometimes poor attention given to spiritual and psychological experiences, and authors often made an explicit link between inadequate care and negative experiences. However, the fact that many measurable clinical outcomes such as pain were described in the included qualitative studies suggests that findings from qualitative studies are complementary to those from quantitative ones. Case studies were also excluded because of their acknowledged general weaknesses in data analysis, reporting and overall lack of generalisability.[38]

We also did not include reports of older people who died in hospital after being moved from their nursing homes shortly before their death. This is a very important aspect of many people's experiences and is often regarded as undesirable.[39] These transitions deserve recognition and exploration but have a different focus and were not included here.

Finally, we are also unable to say whether our findings are unique to nursing and care home contexts or whether these are a better or worse place to die than, for example, in hospital or at home.

Strengths and limitations of the included studies

An aim of our review was to provide a more holistic picture of the experiences of older people dying in care homes. By bringing these study findings together, we have arguably taken a small step in this direction, but future research needs to have this as a priority. Without an in-depth understanding of these experiences, it is hard to see how interventions can be expected to improve older people's experiences. Similarly, although potentially challenging, research needs to start including more people with cognitive difficulties to learn about their experiences. This will require greater user involvement in setting research questions and in subsequent research design but as their involvement is gaining momentum in other research, studies here could also benefit from this.

The included studies were of variable quality, and despite a rigorous search strategy, the latest study was published in 2010, making it difficult to be confident that the experiences highlighted here reflect the current situation. Certainly, in the UK, poor care in general is often highlighted, and campaigns such as the 'Fix dementia care'[40] suggest that care needs to be improved.

The studies were also only undertaken in a limited number of Western countries (North America, Sweden and the UK), making it impossible to be confident of their relevance to other countries because of the diversity of healthcare contexts.

There was also a perhaps surprising lack of detail given about the older people and about the study participants. For example, participant ethnicity and religion and relationships with family carers were seldom if ever reported. The inclusion of such information would further our understanding here.

It was also striking that, apart from two studies,[31 35] all studies included some participant observation. Again, this means that the majority were researchers' observations of their experiences. The lack of reported considerations of reflexivity are therefore particularly surprising.

Another noticeable feature of the included studies was how few individual researchers have published on the topic with one researcher involved in three publications.[25–27] It is difficult to explain the involvement of so few researchers, but this may also reflect the challenges of undertaking research in the area and possibly also limits the breadth of the research undertaken.

Future research

Notwithstanding the ethical and practical challenges in investigating this important topic, clearly more high-quality, sensitive research into older people's experiences would help us understand and potentially improve how people die in nursing homes. Much more needs to be known about how the psychological and spiritual experiences of dying residents could be managed and how we can meet the cultural values and needs of older people in residential care facing death. Furthermore, unlike much of the research identified here, future qualitative research should be grounded in explicit, appropriate epistemological positions to enhance the transferability of the findings.

CONCLUSIONS

The findings of this review highlight numerous significant continuing issues faced by older people dying in nursing and care homes. The challenges, both practical and ethical, to investigating death may well be contributing factors to the

limited research available on this important topic. Despite the dearth of relevant studies, this review highlighted the critical value of professional sensitivity to broader psychosocial aspects of older people's dying experience in care homes. Too often investigations have focused on aspects of care that can be more easily measured and delineated by policies and protocols. This research identifies the ongoing need for enhanced professional consciousness of psychological, social and cultural elements inherent within dying. The expereince of dying is a complex, multifaceted one, and timing of interventions, including advance care planning, can be critical to the value for dying people. In reviewing the available research, the team were struck by the many aspects of care and experiences identified that seemed potentially avoidable. The combined findings within this review suggest that much more can and should be done in understanding and supporting older people dying in nursing homes. Perhaps in the future, a more comprehensive picture might be gained by adopting an appreciative enquiry approach[41] focusing on positive experiences and what works well, rather than on negative aspects of older people's experiences.

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