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A qualitative comparison of care home staff and palliative care specialists' experiences of providing end of life care to people living and dying with dementia in care homes in two countries: A focus group study

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Abstract

Background: Palliative care for people with dementia dying in care homes is an important aspect of long-term care. Whilst there is consensus about the principles of palliative care, less is known about how care home staff negotiate and influence decisions around end of life and how organisational context shapes that process.

Aim: To explore the views and experiences of care home staff and palliative care specialists on end of life care in care homes and understand how care home settings affected palliative care provision in England and Australia.

Design/participants: Eight focus groups in Australia and England with care home staff and palliative care specialists ($n = 49$). Reflexive thematic analysis was undertaken.

Findings: Australian participants reported collaboration between care home staff, visiting professions and family members though case conferences. English participants discussed resident-focussed involvement from specialists that was less formally organised. Negotiating roles and responsibilities in end of life care; the importance of relationships to overcome deficiencies in formal processes; and the legitimacy and authority of advance care planning at times of crisis were recurring themes. The organisation and embedding of end of life care in processes and practices of care homes differed; this closely linked to care home procedures in Australia but was less apparent in England.

Conclusion: In both countries, partnership working was recognised and valued as key to effective palliative care. Work that enables care home staff to identify challenges with visiting professionals, such as agreeing priorities for care and negotiating their shared responsibilities, may lead to context-sensitive, sustainable solutions.

Keywords

Care homes, dementia, palliative care, focus groups, qualitative research

What is already known about the topic?

- Care home staff provide substantial support for residents with dementia approaching end of life.
- Optimal palliative and end of life care for people living with dementia has been defined by the European Association for Palliative Care.
- Interventions to support good end of life care in care homes exist but few have been co-created with care home staff.

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What this paper adds?

- This study highlights how care home routines and care home policies impact end of life care for people with dementia by determining who has responsibility for different aspects of care and how decisions for care are discussed between professionals and family members.
- Care home staff identified three factors that facilitated continuity of care; (1) knowing the resident over time, (2) sharing information and (3) their enduring working relationships with palliative care specialists.
- At times of crisis, decisions for care are more likely to be influenced by care home and visiting staffs' concerns around risk and responsibility than being informed by documented preferences and written plans.

Implications for practice, theory or policy

- Efforts to improve end of life care for people with dementia living in care homes need to consider how the structures and organisation of care within and linked to the facility can be used to enhance provision.
- Palliative care specialists and dementia care specialists should be supported to define and negotiate their responsibilities to care home residents and encouraged to adopt a collaborative approach.
- Designing interventions with care home staff that value their knowledge and recognise their contribution to end of life care are likely to lead to relevant and useful resources.

Introduction

An estimated 47 million people are living with dementia worldwide and this figure continues to grow.[1,2] As the condition progresses it is common in high income countries (as defined by the Organisation for Economic Cooperation and Development) for people with dementia to move into care homes (long term care facilities which may or may not include on-site nursing provision).[3] In the UK, approximately a third of people with dementia live in care homes[4] and account for at least 60% of the care home population.[5,6] In Australia, over 50% of care home residents are living with dementia.[7] Two thirds of people with dementia will die in a care home.[8]

In England and Australia, the provision of end of life care to older people resident in care homes relies on a combination of in-house expertise (including on-site nursing in some care homes) and visiting services from primary care staff with generalist palliative care expertise (General Practitioners and community nurses) and specialist palliative care services. Access to palliative care services however is variable and is affected by factors such as staff training, local provision and availability of funds for palliative care provision.[9,10]

The European Association for Palliative Care (EAPC) defined optimal palliative care for people with dementia across 11 core domains based on empirical evidence and expert consensus.[11] These domains collectively provide a framework that informs palliative care practice, policy and research. In a recent review we mapped palliative care interventions for people with dementia living in care homes onto the domains of the EAPC framework.[12] There were a range of interventions but few, if any, were developed with care home staff involvement. The organisational context is known to influence the implementation and effectiveness of interventions,[13] however few studies included in the review discussed how the organisational context of the care home and the health and care services they accessed influenced the approaches taken.

This paper extends the review work and reports on a cross national focus group study of care home and palliative care staff to explore palliative care provision for people with dementia living and dying in care homes. The study aimed to understand the influence of context for end of life care in care homes by comparing the views and experiences of care home staff and palliative care specialists in England and Australia.

Method

Study design

The central research question was, 'What are the contextual influences on the uptake and implementation of end of life care interventions for people with dementia dying in care homes in England and Australia?' Qualitative research recognises that context influences how people make sense of their experiences and that meaning is interpreted and created through data analysis.[14] Given the exploratory nature of the study, focus groups[15] were used to understand care home staff and palliative care specialists' shared and divergent views and experiences of end of life care with people with dementia between the two countries.

Population

All levels of care home staff (from care assistants to care home managers) and community palliative care specialists were eligible for the study. Inclusion criteria required that; (i) care home staff had experience of supporting residents with dementia at end of life, (ii) palliative care specialists had worked with care homes to assess, advise and support end of life care for residents with dementia.

Setting

Care homes and community palliative care services in England and Australia.

Sampling approach

A purposive sample of participants representing care home staff (nurses, assistants, diversional therapists, team leads and managers) and palliative care specialists in two countries (England, Australia) were approached via their organisations.

Recruitment

Emails were sent to care homes and community palliative care teams detailing the purpose of the study. Organisations helped identify potential participants who were sent information sheets in advance of arranging dates for focus groups. Before conducting focus groups, informed written consent was obtained from all participants.

Data collection

We conducted eight focus groups; four in each country. Each focus group involved between four and eight participants. Focus groups with care home assistants and care home team leads were held at their place of work to facilitate participation during working hours. Focus groups with care home managers and palliative care specialists were held at neutral, community facilities as an extension to routine team meetings. Focus groups in both countries were organised using a schedule to discuss:

(1) What are the priorities for end of life care for people dying with dementia in care homes?
(2) What facilitates and inhibits applying end of life care interventions for people dying with dementia in care homes?

The focus groups were conducted by two researchers in England (SD, MH) and DP in Australia between September and December 2018. Focus groups were recorded and transcribed verbatim, field notes supplemented transcriptions. The average duration of the focus groups was 45 min.

Interactions between participants during group discussions provided insights for commonalities in experiences and where there were alterative perspectives related to end of life care with people with dementia.

Data analysis

Audio recordings of focus groups were transcribed verbatim. Transcripts were uploaded into NVIVO 11 to support analysis. Reflexive thematic analysis[14] was led by one researcher (MH) in discussion with co-authors about categorisation and interpretation. The first stage was familiarisation and clarification about how the data reflected the different countries' systems of care. The structure and coding of descriptive data was guided by the EAPC domains of what needs to be in place for end of life care for people with dementia (Table 1). The developing codes were reviewed, merged and created into themes. Summarised and example data were tabulated by theme and focus group characteristics (care home staff England, care home staff Australia, palliative care specialists England, palliative care specialists Australia) for review within the research team. Convergent and divergent contextual themes that cut across the initial coding were discussed. For example, we considered the different ways participants described sharing information about the resident and their end of life care needs. For staff, one method was through the use stories that communicated what good care looked like, whereas for palliative care specialists it was how they used documentation to reflect what should happen. Both care home staff and palliative care specialists emphasised the importance of key activities, such as early conversations to know the person's priorities, but these were reinforced in different ways. Analysis was revisited with a focus on drawing out the crosscutting themes.

Ethical considerations

We obtained written consent from all participants prior to the start of the focus groups. Ethical considerations were set out at the start of focus groups: that everyone's views were to be respected, that conversations were likely to include sensitive and confidential information and should therefore not be discussed outside of the group, that participants and their discussions would be anonymous. Ethical approval was obtained from the University of Hertfordshire (reference aHSK/SF/UH/03334) and University Technology Sydney (reference ETH18-3154).

Findings

A total of 49 staff participated in participated in eight focus groups. These include 28 care home staff (nurses, assistants, diversional therapists, team leads, managers) and 21 Palliative Care Specialists (Table 2).

Table 1. European Association of Palliative Care priorities for palliative care in dementia.

Domain	Recommendations
Domain 1. Applicability of palliative care	Recognising dementias as terminal conditions to: • anticipate challenges • adequate provision of palliative care and access to specialist palliative care for people with complex needs • Improving quality of life, maintaining function and maximising comfort • recognise goals changing over time • adequate treatment and care for all needs including behavioural and psychological symptoms of dementia, comorbid diseases and health problems.
Domain 2. Person-centred care, communication and shared decision making	• View care from the person's perspective • Shared decision making with the person and family caregiver as partners • The health care team provide information on trajectory, palliative care and involvement in care • Respond to specific and varying needs • Preferences for place of care should be honoured as a principle, but balanced with best interest, safety and family caregiver burden • Regular discussions with multidisciplinary team
Domain 3. Setting care goals and advance planning	• Prioritising of explicit global care goals • Proactive advance care planning with the person and their family • Support people to plan for the future. • As dementia advances best interest may be to maximisation of comfort • Advance care planning should be revisited with the person and their family regularly and following significant changes in health • Care plans should be documented and accessible to relevant professionals
Domain 4. Continuity of care	• Care should be continuous, even when transferred and by all disciplines • Early appointment with a central coordinator from their care team. • Care plans communicated between healthcare professionals and the person and families when care is transferred
Domain 5. Prognostication and timely recognition of dying	• Timely discussion of the terminal nature of dementia to support preparedness for the future. • Discussions of prognosis supported by clinical judgement and assessment tools
Domain 6. Avoiding overly aggressive, burdensome or futile treatment	• Transfer to the hospital considered in relation to the care goals, risks and benefits • Medication for chronic conditions and comorbid diseases reviewed regularly • Restraints avoided whenever possible • Hydration, preferably subcutaneous, may be provided if appropriate • Permanent enteral tube nutrition may not be beneficial and should as a rule be avoided • Antibiotics may be appropriate to alleviating the symptoms of infection.
Domain 7. Optimal treatment of symptoms and providing comfort	• A holistic approach to treatment of symptoms • Use of tools to assess pain, discomfort and behaviour and evaluate effectiveness of interventions. • Non-pharmacological and pharmacological treatment of physical symptoms, challenging behaviour or discomfort should be pursued as needed • Nursing care is very important to ensure comfort in patients near death. • Specialist palliative care teams may support staff in long-term care settings. Managing behavioural symptoms may need additional dementia care specialist expertise.
Domain 8. Psychosocial and spiritual support	• People with dementia and families may need emotional support • Spiritual caregiving includes assessment of religious affiliation and involvement. Referral to experienced spiritual counsellors may be appropriate • Religious activities, such as rituals, songs and services may help • For dying people, a comfortable environment is desirable.
Domain 9. Family care and involvement	• Families may suffer from caregiver burden and may need support. • Key times for support are upon diagnosis, when dealing with challenging behaviour, with health problems, with institutionalisation, with a major decline in health and when death is near • Families need education regarding the progressive course of the dementia and (palliative care) treatment options • Families may wish to be involved in care even when the patient is admitted to an institution providing long-term care. • Families need support in their new role as (future) proxy decision maker. • Professional caregivers should have an understanding of families' needs • Bereavement support should be offered • Following death, family members should be allowed adequate time to adjust

(Continued)

Table 1. (Continued)

Domain	Recommendations
Domain 10. Education of the health care team	• The health care team needs to have adequate skills in applying a palliative care approach to dementia • Core competencies comprise domains 1 to 9
Domain 11. Societal and ethical issues	• Equal access to palliative care on the same footing as people with other diseases • Family caregivers should have access to adequate support • Collaboration between dementia and palliative care should be promoted • Training of physicians and nurses should include palliative care for illness other than cancer • Professional caregivers should be motivated to work in dementia and palliative care • Economic and systemic incentives should encourage excellent end-of-life care for people with dementia • Awareness raising about palliative care in dementia is needed • National strategies for dementia, for palliative care, end-of-life care and for long-term care should each include palliative care for dementia patients.

Table 2. Focus group participants.

Focus group	Number of participants	Participant role	Country
FG1	7	Care home managers	England
FG2	4	Care home staff	England
FG3	5	Care home staff	England
FG4	4	Care home staff	Australia
FG5	8	Care home staff	Australia
FG6	8	Palliative care specialists	England
FG7	6	Palliative care specialists	Australia
FG8	7	Palliative care specialists	Australia

The groups discussed what they considered to be the priorities of end of life care, their professional experiences of providing and supporting care at end of life and their experiences of training in end of life care. We identified six themes common to the focus group discussions: (1) the organisation of care and routine ways of working; (2) how continuity of care is achieved; (3) palliative care specialists working with care home staff to provide person-centred end of life care; (4) the role and purpose of documentation; (5) how aspects of end of life care were organised and prioritised; (6) expectations for care home staff in the provision of end of life care and how they are supported to deal with bereavement.

The organisation of care and routine ways of working

Structural elements of care, such as care routines and palliative care protocols had implications for end of life and usual care provision in both countries. They guided who was involved in palliative care and who had responsibilities for increased monitoring of residents nearing end of life. Multiple stakeholders were involved in discussions and decisions related to residents' end of life care, although the factors that care home staff considered supportive of these discussions differed between countries. Data suggested a health-led approach was favoured in Australia. Care home staff reported using case conferences for care planning discussions and reviews that were attended by senior care home staff, visiting health care professionals and family members. In England, discussions and planning activities, while being documented, appeared to be more informally organised.

> 'They [family] know wishes from before, so it's having that advance care plan, it's having those discussions with the family, it's knowing all of those things. . . so it's being able to work together to make sure that the resident gets the best end of life care they can have'. (England, Care Home Staff, FG1)

In both countries, when residents were recognised as actively dying, senior care home staff created care plans that set out the actions for staff and were used to record the completion of observations and care tasks. Care home staff in both countries reported prioritising staff spending more time with dying residents. The care plans legitimised additional time with residents as part of care home staffs' work to maximise a resident's comfort. For Australian care home staff, discussions focussed on the essential care tasks that were specified in the resident's care plan and were supported by the organisation's standard end of life care resources. While English care home staff referred briefly to these tasks, they stressed providing comfort and not being left alone.

> 'We usually have the comfort care kit in every home. . . Every two hours we have to go for the oral care kit, eye care kit. . . We do have the slide sheet, when we reposition them, we don't want to do manually, we just use the slide sheet. . . Always there will be a kit in the room'. (Australia, Care Home Staff, FG5)

The policies that set out usual care and treatment practices had implications for end of life care, such as who was responsible for the administration of PRN medication. English palliative care specialists explained that care home policies and protocols could define whether residents received treatment from on-site qualified staff or relied on treatment from visiting practitioners from the primary care team.

> ‘Even in nursing homes which have residential and nursing floors. . . if the patient is deemed to be staying on the residential floor because that’s where they’re happier and comfortable . . . if that person requires just-in-case medication, injection, the nurse can’t come down and give it, they have to still rely, for that person, on district nurses. So, then it’s actually the policies and the procedures and structures of these nursing homes and why those things can’t happen’. (England, Palliative Care Specialist, FG6)

These examples may not reflect the how all care homes in England organise their qualified staff but instead demonstrates how palliative care specialists needed to adapt how they worked with care homes based on the organisation’s systems of care. This did not emerge as an issue in the Australian focus groups.

How continuity of care is achieved in end of life care

In both countries, care home staff framed continuity for end of life care as caring for residents from admission through to their death. Care home staff in both countries emphasised how their accumulated knowledge of residents with dementia who had difficulty communicating their needs as important to decision making.

> ‘let’s say you’re a new RN, it’s your first day, you won’t be able [to recognise changes in residents] - they’re deteriorating, definitely. But if you work there for a month, you’ll see their deterioration gradually’. (Australia, Care Home Staff, FG4)

Care assistants had the most contact with residents, they were often responsible for reporting changes to more senior staff. These interactions and knowledge exchanges were less formal and important for triggering how care was planned and documented. Senior staff had responsibility for reviewing the resident and liaising with external healthcare professionals and family. In England, while systems were in place to consult and inform on changes in residents’ health status, initial recognition of change and the subsequent processes to follow appeared to be reactive and rely on the individual actions of senior staff members. In Australia, a more structured approach to sharing and reviewing information and continuity was suggested through repeated reference to case conferences and peer to peer discussions to inform staff and families.

> ‘let’s say a certain resident started to deteriorate and a couple of nurses observe it that she’s deteriorating for a week and you’ll see that massive difference from her previous condition now. That might be a call for a case conference’. (Australia, Care Home Staff, FG4)

In both countries, care homes requested input from palliative care specialists to assess residents, provide guidance for care and organise treatment. Referrals were made either via GPs or directly by senior care home staff.

Palliative care specialists’ involvement was a negotiated process. How well care home staff knew them and if there were key staff to liaise with influenced the quality of their working relationships. Evidence of engagement that extended beyond discrete resident referrals and opportunities to develop staffs’ end of life expertise were indicative of effective collaborations.

> ‘a 25-year-old who is a senior carer in one of our care homes, she rings me often and I go in often. . . she says ‘I need to tell you this, I need to tell you this’. . . I’m amazed by the change in her, because she has got that confidence and yes, she is on a managerial path. And I encourage it’, (England, Palliative Care Specialists, FG6)

Palliative care specialists working with care home staff to provide person-centred end of life care

Palliative care specialists in both countries reported their key contribution as working with care home staff when there were uncertainties about a person’s needs and how to support them. They considered their input supported flexible approaches and gave permission for staff to prioritise residents’ preferences and needs over care home routines and usual practice.

> ‘There was a carer worried about one of her residents because she’s was only eating breakfast. . . I went through all the sort of things with her, nausea, is it a psychological thing, loads of things, and I said to her “Have you offered her breakfast at lunch or dinner?”. . . Came back and she said, “She’s had three meals a deal for the last week because she has had breakfast.” Psychologically, some people can’t eat a roast dinner in bed’. (England, Palliative Care Specialists, FG6)

In both countries many requests to visit were described by the specialists as unnecessary or inappropriate.

> ‘what happens in some of our areas where we have good pall [palliative] care support, they just refer everybody, even a simple decline. . .’ (Australia, Palliative Care Specialists, FG8)

Defining the specialist contribution did not however, always reflect residents’ experiences. Palliative care specialists in Australia questioned whether referrals for behaviours that challenged staff at end of life blurred the boundaries between their role and that of dementia care and mental health specialists. This was less of a concern in the English palliative care specialist focus group, and one hospice service had employed a dementia care specialist who worked with care homes.

> 'Very often we get referrals from people with very awkward behaviour when actually they probably should have been referred to a psych geriatrician. . . But we've become a bit of a one stop shop I think in a lot of ways'. (Australia, Palliative Care Specialists, FG7)

Palliative care specialists in both countries considered their involvement with complex behaviours occurred from lack of knowledge and access to alternative services. They did not see that addressing behaviours that staff found challenging could be integral to providing specialist end of life care for care home residents. This could also be related to palliative care specialists' assumptions about how they worked as specialists, which did not appear to include contact with other services as care coordinators for advice and additional support. While focus groups discussed examples of collaborative working between palliative care specialists and care home staff to explore and meet individual resident's needs, there seemed to be fewer expectations that there would be liaison between healthcare specialities caring for the resident. This was most apparent, in situations where a resident's dementia affected how they interpreted palliative care needs.

The role and purpose of documentation

In both countries, documentation, including advance care plans, was an important part of end of life care. End of life conversations with families were recognised by care home staff as both emotionally sensitive and having implications for professional and legal responsibilities. Organisational imperatives to complete end of life paperwork during an admission to a care home meant that care home staff had a structure and a timeframe for initiating these conversations with residents and families. The incentive was to demonstrate that a conversation had happened:

> 'We like to kind of talk about end of life care when someone first comes in, however sometimes it's quite difficult because they're going from living at home to a care home. . . So, we tend to kind of do it more at the six-week review or a little bit later, depending on how the relationship has been with the family'. (England, Care Home Staff, FG2)

> '. . . using tools to say, well - unplanned hospital admissions and so you have to start to engage with those conversations with family. There's a lot of fear around what if we've missed something and you haven't fixed it'. (Australia, Care Home Staff, FG5)

Advance care planning was often complicated by uncertainty in the disease trajectory and unexpected events. Documented preferences and priorities were not always helpful. Palliative care specialists in both countries questioned whether the written plans retained their legitimacy at times of crisis both for staff within the care home and for external healthcare professionals. Australian palliative care staff reported that, despite documentation, care home staff would contact families to confirm care and treatment decisions. In England, palliative care specialists reported that once care home staff contacted emergency services, known and written plans could be disregarded by attending services. In both countries, a risk averse approach to decision making was linked to the potential repercussions for professionals or their organisation, such as concerns around safeguarding, and was thought to explain why documented preferences could be overlooked.

> 'If you don't have an advance care plan that specifically says that, they could still be sending them to hospital for a fall. . . it's protecting yourself as well. . .Because if you don't do that, they'll say, well why did you not send them to hospital'. (Australia, Care Home Staff, FG5)

A recurring theme in both countries was the role palliative care specialists as legitimating and supporting the decisions of care home staff were. Their presence in the care home at the time of a crisis enabled plans for care and treatment to be upheld. Their input could prevent a transfer to hospital and this willingness to take responsibility for the decision was recognised as important.

How aspects of end of life care were organised and prioritised

Residents' life stories were used to inform care planning and communicate a shared understanding to care home staff in both countries of what should be prioritised. There were differences in how life stories were linked to care home processes. In Australia, residents' life stories were built into the structure of handovers to reinforce how care home staff understood the residents they cared for. English care home staff drew on the same principles, but these were less embedded in routine care home processes. Examples of how they had individualised care for particular residents in the past appeared to be used to build the narrative of how the care home supported people at the end of life and reinforce personalised approaches.

> 'we created a more homely environment for people to die instead of a sterile room. . . I have a gentleman who was a birdwatcher, he won many awards, so we have birds hanging from his roof, the ceiling. And over by the window, so when he turns over, because he was on two-hourly turns, we have a birdfeeder and actual birds come there and feed'. (England, Care Home Staff, FG1)

In both countries, care home staffs' examples of managing residents' comfort were influenced by nursing qualifications or having worked closely with nursing care home staff to provide end of life care. Australian care home staff with nursing qualifications referenced the use of assessment tools, such as for recording observations of pain or screening for delirium.

> 'Every time we see someone with a challenging behaviour or a change in their behaviour, we always use delirium screening; do this, do that. We have a process to follow'. (Australia, Care Home Staff, FG5)

Care home assistants in the English residential care home discussed comfort in terms of social and emotional needs, their focus was more on the changes they were able to influence.

Expectations for care home staff in the provision of end of life care and how they are supported to deal with bereavement

Palliative care specialists acknowledged that their own skills in end of life care had been achieved through extensive clinical training. In both countries, they considered there was a gap between what care home staff were expected to know and act upon and what was reasonable considering the training they received.

> '. . . [within the care home there] maybe no nurses, so nobody has a clue about anatomy and physiology and we're expecting them to learn from us, which we're trying to teach them, but actually it took us a long time to learn the "A and P" [anatomy and physiology]'. (England, Palliative Care Specialists, FG6)

Understanding care home staffs' experience was an important consideration for palliative care specialists when planning training and reflecting on their involvement with care homes. They acknowledged the connection that care home staff had with their residents and their enthusiasm for end of life care training was underpinned by a desire to provide good care for their residents.

> 'And a lot of them do end of life care really well, because a lot of these girls that are on the floor, their residents are their families and I think often they need support both emotionally as well as practically'. (England, Palliative care specialists, FG5)

Care home staff discussed the tension of managing their own emotions while supporting grieving family members and other residents. Protocols for privacy and procedures for sharing for informing could add to dilemmas for informing and supporting fellow residents.

> '. . . when we've got other residents in the house, that you don't want to sort of be sad because then that makes them sad. I think we've encountered a few times where the residents haven't been notified for a day or two that a resident's passed away and it's like, where's the one. . . I think everyone's scared of upsetting, but I think it's just a part of life'. (Australia, Care Home Staff, FG5)

Formal bereavement support for care home staff depended on their organisation recognising this as an important element of staff care and their access to resources, such as affiliations with religious bodies and knowledge of support services. Care home staff provided peer support and staffing rotas were adapted to accommodate staff struggling when a resident was at end of life or following their death.

Discussion

This exploratory study compared the views and experiences of care home staff and palliative care specialists working with people with dementia living and dying in care homes in England and Australia. Themes common to both countries were the importance of knowing the resident, being present and the negotiated nature of the relationship with palliative care specialists. Differences were how the care of people at the end of life was organised and embedded into the systems of care. Contextual factors, such as care home routines, protocols, staff turnover, relationships with visiting specialists and accepted ways of working, influenced how end of life care was organised and discussed by care home staff.

Our systematic review of palliative care interventions used in care homes[12] identified few studies that addressed continuity of care for people with dementia at the end of life. The review concluded that defining continuity of care in care home settings was important but under researched. Care home staff in both countries in this study discussed continuity of care in relation to their ability to detect subtle changes in a residents' health. The difference was that the Australian participants appeared to formalise this process using regular case conferences for sharing information about residents with colleagues, relatives and external healthcare professionals. Previous research has demonstrated how systems and processes that organise and standardise contact between care homes, families and visiting professionals can benefit relational work.[16–19] In England, it was less explicit, the centrality of the resident's story and preferences were documented. They were however expressed as shared principles illustrated and reinforced by examples of exemplary care (staying with the resident, reorganising their room and changing staffing routines). One supported a systematic approach that involved all staff, the other was more reactive, less procedural or health dominated but arguably more susceptible to key people and information being missed.

The role of the palliative care specialist in long-term care is under explored. The findings demonstrated how the role was negotiated in three ways. Firstly, as providers of support for the unusual or difficult case, secondly as the clinician affirming and reinforcing the skills of the care home staff and thirdly, and more controversially, as the person to whom all things palliative were referred. Most residents were living and dying with dementia, however the specialists' involvement and knowledge of dementia care were unclear. Concerns that they often received referrals which would be more appropriately directed to dementia care specialists raises questions about how specialist working in and with care homes work together.[20] Previous research of healthcare service use in English care homes has highlighted the importance of access to dementia specialist for both residents with dementia and the care home staff working with them and the need to coordinate within the care home how different services work together.[16]

Unresolved was how to define what it is reasonable to expect from a workforce with limited access to training and variable clinician engagement. Staff were simultaneously characterised as unskilled or lacking the ability to be involved in care discussions yet able to provide insightful and personalised end of life care with minimal need for specialist support. This tension underlay recurring themes around how documentation and palliative care specialists legitimised care home staffs' time to work with dying residents and permitted them to focus on end of life priorities rather than routine tasks. This resonates with findings from a realist review of Namaste care in that care home staff are considered capable of providing skilled, person-centred care, but required the structure of a Namaste care programme or equivalent end of life care focussed programme to have the permission and opportunity to work outside of their day-to-day role.[21]

The emotional labour of conducting end of life conversations with families while feeling underprepared for this role has been recognised as a barrier to care home staff discussing resident preferences.[22] Our findings suggest that, in addition to training and professional experiences in end of life care, organisational processes and paperwork may support staff to initiate end of life conversations by providing a structure that forms part of the fundamental information gathering for care planning. However, it is important that documentation is meaningful to care planning and that completion of documentation does not become the motivation for end of life discussions,[23] otherwise there could be a negative impact to the relationship between care home staff and families that underpins the quality of these discussions.

Working with dying residents and coping with their death of a resident is an inevitable part of working in a care home.[24] Care home staff are likely to have to manage a number of resident deaths in the course of a year. Flu seasons and the COVID-19 pandemic can cluster deaths in a short space of time.[25] Finding ways to support bereaved care home staff is important. Our research suggested that in both countries, care homes had developed rituals for commemorating residents and made short-term adjustments to working patterns. While emotional support was provided informally between colleagues in the care home, there was limited evidence of additional external support.

Overall, the findings found more similarities than differences in how care home staff in the two countries provide end of life care and work with palliative care specialists. Achieving continuity of care was achieved in a range of ways, with less formal approaches favoured in the English accounts. Further work could test how these affected resident outcomes and if it benefitted some more than others.

Strengths and limitations

This was an exploratory study of palliative care in care homes for people with dementia in two countries. The care homes that participated had previous involvement in training and end of life care interventions. This contextual information is important when considering the findings. However, they do indicate that even when staff are better supported there are fundamental difficulties in providing optimal palliative care for people with dementia living in care homes; a finding which is likely to be more acutely apparent in care homes where this involvement has not been available.

The focus groups included a small selection of care home and palliative care staff from one area geographical area in each country. It is possible that findings reflect local differences rather than national level understanding and approaches to end of life care for people with dementia living and dying in care homes. However, themes were comparable across countries and demonstrated how the care home context framed staff responses.

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Authorship

The CG and DP designed the study. MH led data analysis and drafting of the manuscript, FB, CG and DP provided critical feedback on data analysis and amendments to article drafts. All authors consented to submission of the manuscript.

Declaration of conflicting interests

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Data sharing statement

Anonymised data that support the findings of this study are available on request from the corresponding author (MH).

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