Perceptions and experiences of residents and relatives of emergencies in care homes: a systematic review and metasynthesis of qualitative research

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Abstract

Background: the perceptions and experiences of care home residents and their families are important for understanding and improving the quality of emergency care.

Methods: we conducted a systematic review and metasynthesis to understand the perceptions and experiences of care home residents and their family members who experienced medical emergencies in a care home setting. The review protocol was registered in PROSPERO (CRD42020167018). We searched five electronic databases, MEDLINE, CINAHL, PubMed, Cochrane Library and PsycINFO, supplemented with internet searches and forward and backward citation tracking from included studies and review articles. Data were synthesised thematically following the Thomas and Harden approach. The Critical Appraisal Skills Programme qualitative checklist was used to assess the quality of studies included in this review.

Results: of the 6,140 references retrieved, 10 studies from four countries (Australia, Canada, UK and USA) were included in the review and metasynthesis. All the included studies were assessed as being of good quality. Through an iterative approach, we developed six analytical themes: (i) infrastructure and process requirements in care homes to prevent and address emergencies; (ii) the decision to transfer to hospital; (iii) experiences of transfer and hospitalisation for older patients; (iv) good communication is vital for desirable outcomes; (v) legal, regulatory and ethical concerns and (vi) trusting relationships enabled residents to feel safe.

Conclusions: the emergency care experience for care home residents can be enhanced by ensuring resources, staff capacity and processes for high quality care and trusting relationships between staff, patients and relatives, underpinned by good communication and attention to ethical practice.

Keywords: care homes, emergencies, emergency medical services, qualitative, metasynthesis, older people, systematic review

Key Points

• Understanding perceptions and experiences of care home residents and their families are key to improving emergency care quality.
Introduction

Medical emergencies in residential or nursing care homes are common and costly, often resulting in calls to out-of-hours general practitioners (GPs) or emergency medical services, with ambulance attendance frequently resulting in hospital transfer and concomitant costs and risks of hospitalisation. Although rates of transfer vary between countries, one systematic review reported at least 30 transfers per 100 residents annually from residential care to emergency departments (EDs). Estimates from a nationally representative US sample suggest that older (≥65 years) nursing home (NH) residents alone accounted for 14 million ED visits. Care home residents representing 2.8% of the older population in England account for 6.5% of ED attendances.

Residents transferred to hospital are often admitted (almost half in one study), and those hospitalised are more likely to die compared with those in community dwellings. Hospital transfer is considered preventable if ‘an existing condition would have been managed optimally in the NH at an earlier stage or when adequate prevention would have avoided its initial presentation’ [5]. Although definitions of appropriateness and potential preventability of transfers are contested [5], over half of emergency transfers are deemed potentially preventable using international criteria [6].

Concerns over risks and costs of preventable admission mean that previous research has focused largely, but not exclusively, on rates and reasons for transfer to hospital. Provider factors affecting transfer include unclear expectations, staffing capacity and capability, limited access to multidisciplinary support or communication problems with decision-makers [7]. Frontline staff faced with a resident’s worsening condition, family insistence or physician recommendation, deem transfers to be unavoidable [8]. NH characteristics, such as staff-resident ratio and skills [9] or advance care planning and support from local health services, may also affect emergency care and reduce hospital transfers [10]. Relatives are important advocates for residents [11] with previous studies finding that family concerns about NH care, lack of advance care planning or preparedness for end-of-life care and goals of care may be factors in transfer decisions [12].

Most previous systematic reviews on emergencies in care homes have focussed on transfer to ED decisions [2, 13, 14], with less concern for wider considerations of quality. To ensure high quality emergency care that is effective and efficient, safe and provides good service user experiences [15], we need to understand the wider experiences of emergency care provided within care homes from the perspectives of residents and their relatives. One systematic review conducted by Puls et al. [16], exploring family members’ experiences and involvement in transfer decisions from NH to hospital, described the important role of family members in facilitating communication between residents and medical staff, and between NHs and hospitals.

Quality of health care in care homes has been conceptualised in terms of systems, based on structure (contextual, organisation and staffing), process (care processes) and outcomes (care quality, resident characteristics and longer term outcomes) [17]. Goodman et al.’s [18] realist review describes the importance of relational working between care home staff and other professionals, supported by contextual factors including finance, protocols, clinical expertise and structured assessment and care planning. High quality emergency care for older people requires access to community services, pathways, comprehensive assessment, good communication between services and commissioning for care coordination, underpinned by sound knowledge of frailty syndromes [19]. The framework for enhanced health in care homes [20] includes: enhanced primary care support; multidisciplinary team support and coordination of care; reablement and rehabilitation; high quality end-of-life and dementia care; joined-up commissioning; workforce development and information technology and data.

Less is known about care home residents’ and their relatives’ perspectives on medical emergencies and how quality of emergency care can be improved. The aim of this systematic review was to provide a comprehensive synthesis of the perceptions and experiences of care home residents and their relatives, who have experienced medical emergencies in a care home setting.

Methods

This systematic review and metasynthesis adhered to ENTREQ (enhancing transparency in reporting the synthesis of qualitative research) guidelines [21]. The review protocol was registered on the international prospective register of systematic reviews registration database (PROSPERO-CRD42020167018). The research question was ‘What are the perceptions and experiences of residents and their relatives of medical emergencies in care homes?’. We used the term ‘care homes’ to include all residential care and nursing facilities. We included qualitative studies, and mixed methods studies that contained qualitative data, from interviews or focus groups with care home residents and/or their relatives/caregivers. Only English language papers were eligible for inclusion, due to resource availability.
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Figure 1. Flowchart of the selection process of articles.

Search strategy
Databases (MEDLINE, CINAHL, PubMed, Cochrane Library and PsycINFO) were searched from inception to April 2020. This was supplemented with internet searching (google scholar) and screening of reference lists from the selected articles and review articles. Search strategies were developed with support from our research librarian (MO) including a combination of the following keywords and related terms: care homes, residents, family and qualitative research (see Appendix 1, Supplementary data are available in Age and Ageing online). Three reviewers conducted database searches (FC, IJ and KS). Search results were exported to Excel, where duplicates were removed.

Study selection
Screening was conducted independently by four reviewers (DL, IJ, FC and KS). The first phase was title and abstract screening. Full texts, including articles that could not be excluded based on title and abstract, were retrieved and assessed for relevance, and reasons for exclusion recorded (see Figure 1). Eligibility discrepancies were resolved through discussion and/or inclusion of an additional reviewer (AS).

Data extraction and quality assessment
A standardised, pre-piloted form was used to extract data from included studies for assessment of quality and data
synthesis. Information extracted included: study details (title, authors, date and country), methods (aims, objectives, research questions, study design, setting, data collection methods and data analysis), participant characteristics (demographics, inclusion/exclusion criteria, method of recruitment, sample selection and sample size) and study findings (main and secondary outcomes and author conclusions). Data were extracted by two reviewers (IJ and DW) and checked for accuracy by a third (DL).

Low quality was not an exclusion criterion. Quality was assessed using the Critical Appraisal Skills Programme (CASP) qualitative checklist (Critical Appraisal Skills Programme, 2019; https://casp-uk.net/casp-tools-checklists/), including domains of research aims, methodology, research design and strategy, methods of data collection and communication between researchers and participants, ethical considerations, rigour of data analysis and the clarity and value of study findings.

Two reviewers (IJ and DW) independently assessed study quality. Discrepancies were resolved by a third reviewer (FC). Further discrepancies were resolved by discussion and in consultation with a fourth reviewer when needed (DL).

Data synthesis

Thematic synthesis, following the Thomas and Harden approach, was used to synthesise qualitative data supported by NVivo 12 [22]. This was done by two reviewers (DL and IJ), in three stages: (i) free line-by-line coding employing an inductive analysis of findings from primary studies; (ii) organisation of these ‘free codes’ into related areas to construct ‘descriptive’ themes and (iii) development of ‘analytical’ themes. As a means of validating the findings, reviewers undertook repeated reading of the included study results and discussions with the wider review team.

Results

After removing duplicate citations, 6,140 distinct citations were identified, of which 6,027 were excluded based on title and abstract (Figure 1). For the remaining 113 citations, full text papers were obtained and screened, resulting in 10 studies meeting eligibility for inclusion.

Characteristics of included studies

The 10 included studies (Table 1), were published between 1989 and 2020, from four countries, Australia [13, 23], Canada [24, 25], UK [26] and USA [11, 27–30], and comprised 179 residents and 193 family members. All the studies recruited participants through care facilities, bar one [23], which placed adverts in two major newspapers (in Melbourne, Australia). Most studies recruited participants from NH facilities [11, 24, 25, 27, 28, 30], one included National Health Service (NHS) community care teams, care homes and NHs [26], with the remainder describing experiences of residents and/or families of those in residential aged care facilities (RACF) [13], a care facility [23] and an assisted living facility [29]. Two included studies [11, 23] explored family members’ experiences of care home emergency transfers, whereas the other eight explored experiences of a wide range of stakeholders (residents, care home staff and ED staff) involved in care home to ED transfer decisions.

Quality appraisal

Overall, the included studies provided clear research aims, and were appraised as good across most key criteria related to their design and conduct as described in the CASP tool. However, none of the included studies described the relationship between researchers and participants. Where criteria are described as unclear it was potentially due to lack of reporting by study authors rather than methodological quality. For example, Abrahamson et al. [11] did not discuss their research design in the context of their study aims. Some studies [25, 26, 28, 30] did not report sufficient detail of study information presented to participants before recruitment. Finally, one study [28] did not provide enough detail about the rigour of data analysis methods employed (Table 2).

Themes

Six ‘analytical’ themes were developed through discussion and revisiting the aim of the review.

Theme 1: infrastructure and processes in care homes to prevent and address emergencies

Residents lacked faith in medical care provided in the care home, highlighting concerns about access to clinical assessment and care. They felt insecure about being unwell, reported difficulties convincing nurses that they were sick and experienced delays in their condition being taken seriously.

I think they’re mainly to do with aged care and not so much with sick care. I mean, they haven’t even got a bloody thermometer here. How the hell are they supposed to look after someone like me? [resident 9] [13]

Family members also expressed that care homes were able to provide basic care, but less well equipped to deal with medical problems.

Good long-term care and knowledge of the resident was linked to earlier detection and, by implication, treatment. There was a perception that lack of routine care could increase the likelihood of emergency situations arising.

The nurses and respiratory therapists that are with him every second of the day, they know what he needs and they have just grown to catch the illness earlier. They just know how to take care of him. (Respondent B, daughter) [11]
In contrast, there were also positive experiences of emergency care. Structural constraints, such as lack of experienced or knowledgeable nursing staff, poor access to medical advice and staff shortages, were reported. Lack of knowledge of patients and illnesses were problematic for assessment and management of acute conditions.

Unqualified staff were felt to be inadequately equipped for emergencies and lack of trained staff was felt to increase the pressure to transfer unwell residents to hospital. This was perceived by family members to lead to misdiagnosis or diagnostic delay and unnecessary transfer to hospital. These problems were exacerbated by staff shortages. The lack of contact, availability or response of physicians affected both routine and emergency care.

**Theme 2: the decision to transfer to hospital**

The decision to transfer overlapped and interconnected with other themes. Relatives understood the importance of listening to residents and considering their preferences about...
transfer. ‘Resident wishes and desires emerged as important to family members who had participated in a hospitalisation decision’ [11]. However, there was ambivalence among residents and relatives about transfer to ED. Some wished to be transferred and felt safer in the ED, whereas others did not wish to be moved from the care home.

In the ideal situation, discussion and involvement of the resident, family members and staff led to a collective decision. However, residents felt they were not always consulted. Differences in perspectives of residents, family members and staff sometimes led to conflict in transfer decisions.

There were also perceived delays in transfer due to lack of knowledge among staff or access to medical assessment or diagnostics. In some settings there were financial barriers to transfer, such as the additional costs of hospital and the NH bed while the resident was an inpatient, and costs of transport back to the care home. Despite this, ED was often felt to be the only safe option, particularly when other alternatives, such as attendance of a doctor, were not available.

**Theme 3: experiences of transfer and hospitalisation**

Residents felt safer transferred to an ED for urgent care rather than remaining in the care home.

Residents overwhelmingly described a sense of security associated with ED transfer. [resident 6] [13].

Despite this perception of security, residents also often viewed the ED as ‘busy, chaotic and demanding’ and as a result ‘felt ignored or forgotten’ [13]. Residents were positive about ED staff, but often negative about their experience of EDs.

Family members also perceived EDs to be safer and more able to provide urgent medical care but ‘were concerned that resources in ED were inadequate to provide care to older patients’ [23] based on their personal experiences in the past and experiences with the residents. They also thought EDs were overcrowded and noisy, with long waits, all worsening older patients’ confusion. Relatives were also concerned about ED nurses’ skills and considered specialist staff might be better treating older patients.

Simple things such as remembering to speak more loudly to older people who have a loss of hearing, or taking the time to explain procedures in a way the older person could understand, were important to relatives, and would improve their experience [23].

Relatives felt they had an important role in the ED as advocates and medical historians. Although the decision to transfer was often perceived positively, inpatient care was often considered poor for various reasons. Problems with return to the care home after hospitalisation, including lack of medicines or ambulance transport, were also reported.

**Theme 4: good communication is vital for acceptable outcomes**

Information sharing and communication were important at every stage of emergency care for residents and family members. Residents described how they were involved with decisions.

I just sort of say ‘well if I’m not very happy with that what do you think we can do’. and we just have a little private conversation between the staff and me. And we arrive at what we both agree on. [P04] [26]

Occasionally residents were asked to provide information during transfers but were not able to provide sufficiently detailed information. Sometimes residents felt ignored, or even described facilitating communication between professionals. Most family members felt confident in nursing staff...
to communicate with them and welcomed the information provided.

Relatives also felt confident to ask for clarification when they needed to. However, sometimes information conveyed to relatives was perceived to be inadequate or unclear.

Residents and family members were less positive about interprofessional or interorganisational communication, where lack of communication was a factor in transfers to hospital and was perceived to have adversely affected patient safety.

In some cases, frustrated physicians hospitalised patients after having difficulty obtaining reliable information about the patient’s condition from the nursing staff [28].

Theme 5: legal, regulatory and ethical concerns

Whether family members had legal authority through a Power of Attorney or not, they recognised they had an important role as advocates for their loved ones during emergency situations. Care home staff enabled relatives to make choices in decisions about active treatment or palliative care for care home residents.

They said they could just keep him comfortable in the nursing home, and make him a hospice patient. We opted to send him to the hospital to have antibiotics. Because he was up walking around . . . he was able to have a little quality of life so I figured he may have a few more years left, maybe he had some quality of life left. (Respondent E, niece) [11].

Relatives felt healthcare staff sometimes ignored relatives’ legal authority or their professional obligations took precedence.

Ethical concerns included end-of-life decisions, where ‘family members described the end-of-life choices as a particularly challenging aspect of their role’ [11]. Family members were aware of advanced directions, but these were sometimes considered less relevant. Family members reported being upset about having to make life and death decisions during the emergency episode.

One person reported being faced with an end-of-life discussion as soon as she arrived to the ED: ‘I got so upset when that nurse confronted me . . . I got really stressed out . . . they wanted me to make a life and death decision ... ‘Do you want us to revive her?’ That was put squarely on my shoulders’ (Interview 8) [23].

Care homes varied in their use of ‘do not hospitalise’ (DNH) orders but both staff and relatives tried to consider the best interests of the resident.

Theme 6: trusting relationships enabled residents to feel safe

Positive ongoing relationships between residents, relatives and staff were felt to engender trust and lead to better care and positive outcomes. Trust in the trained professional looking after them was also important for relatives in helping residents to feel safe.

Relatives described having trust in care home staff with regards to decision-making and emergency transfers.

In some circumstances relatives reported that they had complete trust in the decision-making process of staff, and had essentially given staff an imprimatur to make whatever decisions that staff felt were best for the resident: I think, I accept that’s that – they do the right thing (relative 12) [15].

Discussion

This systematic review included 10 studies from four countries (Australia, Canada, UK and USA) published between 1989 and 2020. Six main themes were identified: (i) infrastructure and process requirements in care homes to prevent and address emergencies; (ii) the decision to transfer to hospital; (iii) experiences of transfer and hospitalisation for older patients; (iv) good communication is vital for desirable outcomes; (v) legal, regulatory and ethical concerns and (vi) trusting relationships enabled residents to feel safe. This review supports and adds to guidance on urgent and emergency care for older people [18] and supports the importance of enhancing relational as well as structural elements for quality improvement in this setting [17, 31].

Residents and relatives perceived that care home infrastructure and processes were inadequate to prevent or deal with emergencies due to lack of staff, training, access to medical and nursing professionals and diagnostic facilities. Transfer decisions were complex, contested or delayed, which residents and relatives perceived to be linked to these deficiencies, but also to conflicting wishes and communication problems among stakeholders. Good information sharing and communication between residents, relatives and healthcare staff were perceived to be vital for good health outcomes and experiences. The legal status of family members, regulatory responsibilities of staff and ethical concerns around advance care planning and end-of-life decisions were an important area for improvement. Finally, trusting relationships among residents, relatives and staff were considered essential for provision of safe urgent care.

Although this review focused on wider experience of emergencies in care homes, transfers and hospital admissions were an important experience outcome [1]. Arends et al. [14] systematic review of residents’, family members’ and carers’ views on transfer decisions, found, not surprisingly, that transfers occurred when there was expectation of better clinical or quality of life outcomes for the resident. Other reasons reported, similar to this review, were lack of resources or low confidence in care provided, problems with care planning or communication, threat of litigation or conflicting views about transfer [14].

Some residents and relatives described a sense of security when residents attended EDs and were placed under medical
care. Others described EDs being ‘busy and chaotic’ and not best suited for older residents with special needs or complex health conditions [2]. Some residents said they would have preferred to have been treated in the care home [32].

Relatives in this review described feeling that they had important roles as advocates for their loved ones during emergency situations, and they felt good communication and listening to the wishes of residents, where possible, was key. Puls et al. [33] found that transfer decisions were influenced by the quality of NH and hospital care, perceived illness severity and the extent to which they were aware of, accepted and were prepared to uphold resident wishes. NHs often lacked staff capacity, the scope of practice needed and access to specialist support in their decisions to transfer [7]. Relatives also described, how, in the ideal situation, discussion and involvement of the resident, family members and staff should lead to a collective decision.

This study and others discussed here highlight the importance of enhancing care home infrastructure for the prevention and treatment of emergencies, through ensuring sufficient staff capacity, increasing training [37] and providing access to clinical expertise from GPs or other health professionals [38]. Better monitoring, enabling earlier detection and intervention, may also help improve care and experiences [39], particularly for residents with long-term conditions associated with higher ED use, including chronic heart, lung and renal disease [40, 41].

Legal, regulatory and ethical concerns in our study extended beyond initial concerns about litigation, and ensuring bests interests of the resident to the conditions for maximising benefits and reducing risk of harm before and during the emergency journey, creating autonomy for residents and for relatives acting on their behalf, while ensuring equitable care for this group of vulnerable older people, particularly during end-of-life [34]. The concerns among relatives that care homes were under-resourced or staff were overworked affected their decisions about care for their loved ones, their need to maintain dignity and avoid being a burden, particularly during end-of-life care [35].

Finally, an important consideration for improving experiences of residents and relatives was ensuring trusting relationships and good communication between patients, relatives, care home staff and other organisations. Previous qualitative studies of patient and carer experiences of emergency situations also found that good communication and professionalism of staff engendered confidence, which together with continuity of care and a timely response produced reassurance for users of emergency care [36].

Strengths and limitations
This study, presenting the first metasynthesis of resident and relatives’ perspectives of emergencies in care homes, followed ENTREQ guidelines and a rigorous prespecified protocol, ensuring a comprehensive search and a transparent, replicable review process. All included studies were independently assessed using the CASP quality appraisal checklist, which assesses different domains of qualitative research. Included studies were overall deemed to be of good quality, which provides increased confidence in the results. Family members have an important role [42], and this review drew upon the combined experiences and perceptions of both the care home residents and their relatives.

The data from 10 studies and four countries may have included very different experiences of emergencies in care homes. Most studies included in this review were based in NHs, even though this is not where most older people living in long-term care reside [43]. However, many experiences described by residents and their relatives were similar across studies.

Implications for practice and research
More research is needed on managing emergencies in UK care homes, eliciting experiences of residents and relatives, as increasing efforts are directed at interventions that reduce the need for hospital transfer. Where transfers are needed, experiences could be improved by ensuring decisions are fully discussed, where possible, with the resident and legally authorised representatives that EDs are optimised for this patient group, and arrangements planned for return to the care home.

Other important factors include sound knowledge and skills to assess the patient, good relationships and communication between residents, families, care home staff and other professionals and timely action [25].

Conclusion
This review highlights ways to improve the emergency care experiences in care homes, from prevention, to early assessment and transfer, by ensuring resources, capacity and processes for high quality care. Trusting relationships between residents and stakeholders, underpinned by good communication and attention to ethical practice, were also considered important.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in Age and Ageing online.

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