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QUALITATIVE PAPER

Care home residents who die in hospital: exploring factors, processes and experiences

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Abstract

Background: Care home residents are increasingly frail with complex health and social care needs. Their transfer to hospital at the end-of-life can be associated with unwanted interventions and distress. However, hospitals do enable provision of care that some residents wish to receive. We aimed to explore the factors that influence hospital admission of care home residents who then died in hospital.
Methods: This study combined in-depth case note review of care home residents dying in two Scottish teaching hospitals during a 6-month period and semi-structured interviews with a purposive sample of 26 care home staff and two relatives.
Results: During the 6-month period, 109 care home residents died in hospital. Most admissions occurred out-of-hours (69%) and most were due to a sudden event or acute change in clinical condition (72%). Length of stay in hospital before death was short, with 42% of deaths occurring within 3 days. Anticipatory Care Planning (ACP) regarding hospital admission was documented in 44%. Care home staff wanted to care for residents who were dying; however, uncertain trajectories of decline, acute events, challenges of ACP, relationship with family and lack of external support impeded this.
Conclusions: Managing acute changes on the background of uncertain trajectories is challenging in care homes. Enhanced support is required to improve and embed ACP in care homes and to provide rapid, 24 hours-a-day support to manage difficult symptoms and acute changes.

Keywords: *care homes, anticipatory care planning, hospital admission, death, NHS24, illness trajectories, early palliative care, older people, qualitative*

Key points

- Care home staff are generally eager to provide end-of-life care within the care home.
- The majority of admissions to hospital were triggered by sudden or acute change in symptoms.
- Managing these acute deteriorations on the background of uncertain decline trajectories is challenging.
- Having an anticipatory plan in place, whilst very important, may not in itself ensure residents die in their preferred place.
- Care homes require support structures which provide both proactive and timely responsive unscheduled care.

Introduction

In the UK around 400,000 people live in care homes [1]. In Scotland, there are approximately 870 care homes for some 33,000 residents [2]. The term "care home" (CH) is used to refer to care homes with and without on-site nurses—both provide 24-hour care but the latter rely on district nurses to provide nursing care. Residents are registered with and cared for by local general practitioners.

People living in CHs are increasingly frail with complex health and social care needs [3–6], [7]. Thus, the length of time spent living in the CH before death is shorter

[4, 5]. Additionally, around 80% of CH residents are living with dementia [8]. In this context of a high proportion of CH residents with cognitive impairment, high levels of frailty, and a high risk of deterioration and death, transfers to hospital can be associated with increased confusion, distress and adverse outcomes [9]. Most CH residents express a wish to stay in the CH and avoid hospitalisation towards the end-of-life [10–12]. Despite this, CH residents are not a homogenous group and, for some, the complexity of their healthcare needs mean that acute hospitals, whilst necessitating an undesirable transfer, can provide healthcare they wish to receive [12]. Therefore, there are instances when death in hospital may be part of good, person-centred end-of-life care [13] and the best option within available services [14]. However, for others, transfer to hospital may result in unwanted interventions and additional distress [15], [16].

Anticipatory Care Planning (ACP) may facilitate the delivery of care most in keeping with resident wishes and increase resident and family satisfaction [17]. It can also decrease emergency hospital admissions [17]. Despite these benefits, the process of carrying out ACP in a CH setting is challenging and the quality of written documentation can vary [18], [19]. In Scotland, Key Information Summaries (KIS) are patient electronic summaries in which ACP is documented. They are created by the GP and can be accessed by all NHS staff in primary and secondary care with the aim of improving communication and continuity of care [20].

Existing UK research suggests that whilst the majority of CH residents die in the CH, and most CH residents admitted to hospital do not die in hospital, a small but significant group die in hospital [4, 10], [21–22], [23]. There is limited information about this group, what they are admitted with, what happens to them in hospital, what they die of and whether ACP preferences and wishes had been documented. By focussing on in-depth data on CH residents admitted to hospital and who then died in hospital, we sought detailed insights into the challenges of providing end-of-life care in CHs.

This paper explores the factors that influenced hospital admission of CH residents who then died in hospital. We describe the characteristics of this group and the extent of documented ACP and explore the experiences of CH staff and relatives.

Methods

Design

This mixed methods study was undertaken in Scotland within the catchment of two teaching hospitals serving 89 CHs. It combined in-depth hospital case note review and semi-structured qualitative interviews with the aim of bringing together strengths from both quantitative and qualitative methods to enable to a deeper appreciation of the issues [24].

Sample and recruitment

CH residents who were admitted to hospital and then died in hospital (between September 2017–February 2018) were identified using a report writing tool which cross-references a list of CH addresses used in routine clinical work, against deaths in hospital. A monthly report was created and then manually verified to ensure the addresses were CHs. Residents aged under 65 years and people admitted from sheltered housing were excluded. Based on exploratory data, we predicted that there would be around 100 deaths in the 6-month period giving us a sufficient sample to analyse, allow for seasonal variation and fit with the time period of the study.

A purposive sample of cases from the monthly in-hospital death report was identified to be explored in more depth in by interviewing CH managers/staff and if possible relatives. The purposive sample included: type of presenting symptom, details of completed ACP on KIS and, CHs with/without on-site nursing. This was based on the quantitative data, existing literature and initial interviews. We aimed to carry out around 20 interviews as this was felt to be achievable in the period of the study and, based on the experience of the research team, would be sufficient to identify key themes.

CH managers were contacted via email 1–4 months following the resident's death including an information sheet and an invitation to participate. This was followed up by a phone call after 2 weeks if there was no response. The CH manager was asked to identify other staff members who were on shift when the resident was admitted to hospital or who were directly involved in the resident's care. These members of staff were then invited to participate. CH managers were also asked to invite the resident's next of kin to participate in the study by sending them a pre-prepared invitation letter and information sheet 3 months after the death.

Data collection

Data were collected between September 2017 and May 2018. The hospital case notes were reviewed, data were extracted and entered into an anonymised database by a single researcher GA, a Geriatric Medicine registrar with 8 years of experience in hospital medicine and training in qualitative research (see Appendix 1).

CH staff and relatives who agreed to participate completed a consent form, and semi-structured interviews were carried out by GA. The interviews were structured around the individual deceased resident but also sought to explore the wider issues around care in the CH and decision-making regarding hospital admission (see Appendix 2). Interviews were digitally recorded and transcribed verbatim by GA. Interview transcripts were then entered into the software Nvivo (QSR International Pty Ltd, 2017) to aid organisation.

Analysis

Descriptive statistics were used to analyse the quantitative data. The interview transcripts and field notes were analysed

together with data from the hospital case notes using a six-stage method of thematic analysis [25]. During analysis, the data were synthesised to explore the individual case admissions, the admissions collectively and also more general concepts that arose in interviews. Analysis was undertaken inductively from the data but was also informed by the existing CH and palliative care literature. The initial step was familiarisation and immersion in the data with multiple readings of the interview transcripts, field notes and hospital case notes. Following this, initial codes were applied. To add rigour, initial transcripts were coded independently by GA, and JH and SAM (both experienced qualitative researchers) and then discussed together. In the third step, provisional themes were created. Fourthly, these were examined against the coded data to ensure they were representative and also against the data set as a whole. During this step, coded data were moved between themes and the hierarchy of themes manipulated and a thematic "map" of the analysis created. The analysis was finalised by defining overarching themes.

Ethics

Ethics approval was granted by the South East Scotland Regional Ethics Committee (Ref 17/SS/0089). Approval to review patient hospital case notes was granted by the Caldicott Guardian (Ref CG/DF/16141). The hospitals also granted management approval.

Results

Hospital case note review

A total of 109 CH residents were identified as having died in hospital during the 6-month period. They were admitted from 61 different CHs (70% of local CHs).

Sixty percent were residents from CHs with on-site nursing. Table 1 outlines their characteristics.

In 59 (54%) cases, the admitting hospital clinician documented an impression that the resident was likely to be dying or had experienced a "terminal event". A short trial of treatment (for example intravenous antibiotics) was commenced in most cases. These trials of curative intent were often concurrent with medication to control symptoms during the last days of life. In most of these cases, treatment was discontinued after 1–2 days and a purely comfort focus adopted.

In six residents, no hospital-specific intervention was instituted with recognition in the case notes that the resident was dying on arrival to hospital.

Although most residents had a KIS, only 48 (44%) had documented wishes regarding hospitalisation (See Table 1). Extracts from anticipatory care plans documented on KIS in these 48 residents are given in Table 2.

Qualitative interviews

In total, 26 CH staff from 14 CHs agreed to be interviewed. Often more than one CH resident had died from the same CH in the 6-month period. In total, 26 deceased residents were discussed (see Table 3). The interviews were based around the specific resident case; however, staff often cited examples of other residents they had cared for or discussed the issues in more general terms.

Twenty five interviews were carried out: nine CH managers (CHMs), seven deputy managers (CHDMs), six CH registered nurses (CHNs) and four care assistants (CHCs). Ten of the CHs had onsite registered nurses (Nursing Care Homes—NCHs) and four had social care staff and no registered nurses (Residential Care Homes—RCHs). All interviews were carried out as individual interviews except one in which the CHN was interviewed along with the manager. Interviews were carried out within the CH and lasted between 14 and 37 minutes.

The two relatives interviewed were both daughters (D) of CH residents; both interviews were carried out in their own homes, lasting 41 and 42 minutes.

Table 1. Characteristics of CH residents who died in hospital ($n = 109$)

Mean age	84.7 years (range 68–103, SD 7.39)
Male residents	46 (43%)
Five or more medical diagnoses	78 (72%)
Lived in CH less than 2 months	22 (20%)
Admitted out-of-hours (6 PM–8 AM weekdays and weekends)	75 (69%)
Median length of stay in hospital before death	5 days (IQR 1–12) (range 5 minutes to 93 days)
Death within 3 days of hospital admission	46 (42%)
Death within 7 days of hospital admission	67 (61%)
Death within 14 days of hospital admission	85 (78%)
Presenting symptoms:	
Breathing difficulty	38 (35%)
Less responsive/drowsy	17 (16%)
Vomiting	14 (13%)
Trauma	9 (8%)
General decline	9 (8%)
Neurological symptoms	7 (6%)
Other	15 (14%)
Investigation in hospital:	
Blood tests	108 (99%)
Chest X-Ray	107 (98%)
Arterial blood gas	23 (21%)
Other imaging	36 (33%)
Interventions in hospital:	
Intravenous fluids	88 (81%)
Intravenous antibiotics	82 (75%)
Oral antibiotics	7 (6%)
Prescribed end-of-life medications	74 (68%)
Syringe driver	33 (30%)
Anticipatory care planning documentation:	
Key information summary present	84 (77%)
Wishes re hospital admission documented	48 (44%)
- Stay in CH	22 (20%)
- Consider admission but ideally	16 (15%)
- Avoid	
- Admit for investigation and management	10 (9%)

Table 2. Documented wishes regarding hospital admission

Category of documented wishes regarding hospital admission (total number in category)	Examples from resident key information summaries (Resident unique identifier number)
Avoid admission to hospital and remain in CH ($n = 22$)	"Has advanced dementia, DNACPR in place. Family asks to avoid invasive interventions including intravenous antibiotics. Largely immobile, doubly incontinent. Avoid hospital if possible." (R49) "Declining hospital, wants to die, only wants comfort care." (R97) "Does not want to be admitted to hospital. Will not accept any hospital-based interventions. Increasingly frail and focus should be on minimising symptoms." (R88)
Consider admission but ideally remain in CH ($n = 16$)	"Not keen on hospitals and not for resuscitation. To keep in nursing home or CH if possible though would be admitted if clinically indicated and she could be persuaded to go." (R53) "Husband wishes to discuss with doctors at time of emergency to decide whether to admit or not." (R60) "Advanced dementia but patient is independent. When previously unwell daughter decided to keep comfortable and observe closely. Felt at that time hospital admission would be traumatic. Discuss if condition deteriorates." (R35)
Admit to hospital for intervention ($n = 10$)	"In the event of a clinical deterioration she would like to be admitted to hospital for treatment." (R33) "DNACPR but good quality of life, should be for transfer to hospital if unwell. Active ward level care but not for ITU/HDU." (R51)

Analysis of the data led to the development of five main themes which are described below. Table 3 highlights the aspects of these themes in relation to the specific deceased residents discussed. Quotations are followed by the participant's role, type of CH, CH identifier and, where relevant, the resident unique identifier. All names in the text are pseudonyms.

Theme 1—Staff eager to provide end-of-life care in the CH

Nearly all CH staff mentioned their desire to provide care for residents when they were dying. This was rooted both in a perception that hospitals were likely to be unfamiliar, undignified places to die, and also that in the CH it would be possible to provide a more comfortable death with enhanced support for relatives.

"I don't know anybody that wants to die in hospital. Especially people with dementia that are familiar, the staff are familiar, they've got their room, everything, d'you know, and I think to put them in an acute, sort of medical ward and to have to die there is very undignified and I think it must be hard for the families as well." (CHDM/NCH19)

CH staff described feeling disappointed when residents died in hospital and spoke about the lack of an opportunity to *"close the chapter"* (CHM/RCH29) or say goodbye properly. Becoming attached to the residents and seeing them almost as part of their own family was a common experience for CH staff at all levels. This underpinned their desire to care for residents in the CH and made it challenging when residents became acutely unwell.

"of course we do form attachment with the residents and it's so difficult seeing them, you know, having difficulty of breathing and you don't have anything to give them, you've given all the meds you've got, you've given the inhalers, but it's oxygen you need, you need them to go to hospital." (CHDM/NCH3)

Theme 2—Inherent unpredictability in residents' decline

During many of the interviews, there was a clear sense that staff had viewed admission to hospital as aiming to provide acute care and there was an expectation that the resident would return. One 91-year-old woman, with dementia and multimorbidity who had been gradually declining over months, developed vomiting for a few days followed by severe abdominal pain prompting admission to hospital. She died after 18 hours in hospital of intra-abdominal sepsis from caecal volvulus.

'it was a complete surprise because that was not expected at all, you know, we were really upset when Sarah passed away . . . she wasn't end-of-life by any, we were completely, completely dumbfounded. (CHDM/NCH11/R13)

Variability and inherent unpredictability in CH residents' decline was a significant challenge for CH staff in responding to acute changes. Managing the uncertainty of multiple patterns of declining was compounded by the experience of the resident themselves or other residents having appeared to be dying then "bouncing back" and recovering for a period.

'sometimes they become ill and later on they bounce back, more and more of our residents is like that. We thought that they will be, you know, gone, but later on 'oh! she's back again', you know." (CHN/NCH3)

In addition to this, staff perceived the complexity and frailty of residents to be increasing whilst their length of stay in the CH, and opportunity for staff to get to know them, was shorter. This made recognising changes and decision-making when an acute event occurred harder.

Theme 3—Family decision-making is key and may change

Family was seen as key in decision-making regarding hospital admission. CH staff described being unable to "override" family decision for hospital even when they felt

Table 3. Details of cases discussed in interviews ($n = 26$) with data from interviews exploring reason for admission to hospital

Resident unique ID	Type of CH	Past medical history	Reason for admission to hospital	Length of stay in hospital before death	Anticipatory care plan (ACP) detailed in key information summary (KIS)	Quotes from interview Followed by participant code CHM—manager, CHDM—deputy manager, CHN—registered nurse, CHC—care assistant, D—daughter Link to theme number
1	NCH	CCF, epilepsy, cerebral palsy, registered blind	Collapse, less responsive. No preceding symptoms	7 hours	Stay at CH keep comfortable and relieve any distressing symptoms in familiar environment.	*"there wasn't any sort of sign that he was becoming more unwell or anything. He had had a fall that evening and had become quite acutely unwell and unresponsive after his fall. At that point he was transferred to hospital." CHN* Theme 2
4	NCH	Stroke, pulmonary embolus	Gradually deteriorating over months then very loose stool and SOB In CH 8 months. Last hospital admission >1 year previously.	4 days	For resuscitation as per hospital discharge	"*the health is slightly deteriorating, refusing to eat, and then it started that his bowels became loose, loose, loose, loose and became unwell with that, yeah I think the loose stool really that's why he was sent to the hospital and his oxygen level is very low*." CHN Theme 2 "*we discussed as well to the GP anyway, it's what is best and the family agree as well, much better to send to the hospital. Maybe, you know, we don't know, sometimes they become ill and later on they bounce back*." CHN Theme 2 and 3
5	RCH	Vascular dementia, AF, alcohol excess	Declining over 2 weeks then severe hip pain	5 days	Decided with daughter for comfort care in the CH. Anticipatory medications in place	"*he had deteriorated again and the concern for us was that he was dehydrating and that we weren't sure if he was getting a chest infection as well. But the interventions that he needed we couldn't do here . . . at that point there may have been anticipatory meds in place but we weren't expecting them to be end-of-life at that point and I think that's why we were surprised when he did pass away because it was so sudden*." CHM Themes 2 and 5 *"it was NHS 24 we called just to get somebody out just to give us some advice and it was the paramedics that ended up coming out. But we discussed with them that we thought he'd be better staying here and they agreed with us but his daughter wanted him to go to hospital . . . . she felt that she wanted him to go in to see if giving him more fluids and IV antibiotics was going to make him any better. But obviously it didn't so . . . ."* CHC Theme 3 and 5
12	NCH	Dementia, CCF, AF, myelodysplasia	Unwell for a few days then collapse with low blood pressure and low oxygen saturations	10 hours	No KIS	*"his blood pressure had dropped and his saturations dropped so it was a medical emergency I would say, erm so had to take him to find out what was going on. I think that was the right decision to send to hospital, like I said his functional level was reasonably well you know and erm, family were coming in, he was up and about walking."* CHM Theme 2
13	NCH	Vascular dementia, stroke, CCF, AF, diabetes, aortic stenosis	Vomiting for a few days, sudden onset of severe abdominal pain and worsening vomiting	18 hours	No ACP on KIS	*"we didn't expect it. We thought, you know with vomiting they could have found the root and give antiemetics, rehydrate her and she'd been back." CHDM* Theme 2 *"we needed, and I think she needed a bit more support so we, she wasn't end-of-life by any means" CHDM* Theme 5

(Continued)

Table 3. Continued

Resident unique ID	Type of CH	Past medical history	Reason for admission to hospital	Length of stay in hospital before death	Anticipatory care plan (ACP) detailed in key information summary (KIS)	Quotes from interviews Followed by participant code CHM—manager, CHDM—deputy manager, CHN—registered nurse, CHC—care assistant, D—daughter Link to theme number
14	NCH	Dementia, subdural haematoma, fractured hip, registered blind	Declining over 6 months, losing weight, less well, treated for a chest infection then less responsive and worse	19 hours	Stay at NH and relieve any distressing symptoms in a familiar environment.	*"She was just becoming more frail and gradually declining but the family found it quite difficult to accept. She had become unwell, she'd been treated for infection, she had taken a kind of dip so the staff had called NHS 24 for advice knowing that the family would want her to go to hospital." CHDM* Theme 3 *'she wasn't at end-of-life but she was approaching so it maybe that she might not have survived all that much longer anyway because you could see that she was starting to withdraw, so that maybe wasn't the right thing to do [going into hospital] but it was for the family.* CHDM Theme 3
15	NCH	Frontal dementia, stroke, sciatica	Unwell for a few days vomiting and generally unwell, admitted as worse	16 hours	No ACP on KIS	*"He went downhill quite rapidly, went off eating, fluid intake wasn't great, urine output wasn't very good. The GP was contacted and said try and push fluids but again he started to vomit, bile with a cough and then he became quite short of breath so we phoned the NHS 24 an ambulance came and they advised that he was taken in."* CHDM Theme 2
17	NCH	Dementia, COPD, diabetes, catheter, HTN	Unwell and few days then acutely worse with vomiting In CH 1 month	2 days	No ACP	*"he was always really chirpy and always really cheerful so you kind of got connected to him very quickly" CHM* Theme 1 *"I think he was coming to the end of his life but I'm not sure that the family was ready to acknowledge that." CHM* Theme 3
28	NCH	Dementia, AF, depression, HTN, hypothyroid	Found unresponsive and covered in vomit	21 days	No KIS	*"her family didn't [engage with CH]. So I think, you know, how families respond to us and how family react to us, affects our relationship with the family."* CHM Theme 3
37	NCH	Asthma, IHD, CKD, HTN, previous delirium	Unwell 1–2 weeks then marked increase in breathlessness	2 days	Advanced dementia, AWI and DNACPR – discuss change in condition with daughter.	*"the nurse had said 'well what would you like to do?' and she herself had said 'I'm really not well I do want to go into hospital'. So that choice was given to her and she decided that she wanted to go. And I think, well, at that time we were fully expecting her to come back . . . . . .It was awful that she died in hospital from our point of view because she was so at home here and this was her home."* CHM Theme 1 and 2
38	NCH	Dementia, fractured hip, psoriasis	Less well for a few days then more drowsy and arm swollen In CH <2 months	2 days	Advanced dementia, AWI and DNACPR – discuss change in condition with daughter.	"*she was on a DNACPR and that sort of thing but doctor had seen her and thought, like she thought it was a really quite severe chest infection and that she would probably benefit from some IV antibiotics and obviously there was concern about this right arm swelling as to whether it was cellulitis or not, they were very keen for her to be seen for that."* CHM Theme 2 "*with her only having been in such a short time it's quite difficult to make that sort of assessment as to whether, that was her out of sorts."* CHDM Theme 2

(Continued)

Table 3. Continued

Resident unique ID	Type of CH	Past medical history	Reason for admission to hospital	Length of stay in hospital before death	Anticipatory care plan (ACP) detailed in key information summary (KIS)	Quotes from interviews Followed by participant code CHM—manager, CHDM—deputy manager, CHN—registered nurse, CHC—care assistant, D—daughter Link to theme number
39	RCH	Dementia, IHD, AF, rectal cancer, MVR, osteoporosis	Sudden onset left sided weakness In CH 1 year	4 days	In event of stroke, infection and not responding to oral antibiotics or if unable to eat or drink his POA would like him admitted to hospital for full medical treatment.	"*He was really like ill 1 day, he vomited, you know, all over himself. I don't know how keen the family were for him to, like they wanted him to go to hospital whereas we were kind of like, 'you know, best to have him here'*." CHC Theme 1 and 3 "*I think they [family] just wanted that sort of peace of mind, but poor* ∗***resident 39***, *he had various things wrong with him but it was still a shock, you know, when he went into hospital and then that was kind of it. I thought he's really unwell but I didn't expect him to go, it was a shock.*" CHC Theme 2 and 3.
40	RCH	Dementia, stroke, IHD, COPD, AF, rheumatoid arthritis	Unwell few weeks with cough and SOB then admitted as worsening breathing and fatigue	9 days	Patient has strong conviction she should be for resuscitation. For transfer to hospital as clinically appropriate	*"I remember the day she was admitted into hospital she said 'you're making me go', I said 'you really need to go'. I think she had to get IV antibiotics and we couldn't, the orals just weren't touching her here. So that was really quite sad . . . . because you always expect they're going to come back." CHM* Themes 2 and 5
42	NCH	COPD, IHD, IBD, fractured hip, aortic stenosis	Worsening SOB for 9 days, acutely worse, very low saturations.	9	No ACP on KIS	"*his oxygen levels were just going lower and lower and lower to the point where we thought we can't leave him. We know that he doesn't want to go into hospital, that was his wishes, not to, but we needed to do something, so we called an ambulance. The crew came out and gave him some oxygen and they thought it would be in his best interests to go into hospital.*" CHDM Themes 2 and 5
					Only in CH 10 days.	*'I didn't really know them very well. I now know the nurse very well that had phoned that day, if I'd known her . . . She phoned to say he's really struggling, we need to get the ambulance and I could hear my dad saying "no", so I said "no he doesn't want that, can we not get the respiratory team?" and I think she tried and she must have phoned me about 2 or 3 times that day and in the end they'd actually just called the ambulance because his oxygen levels were so low that she said there wasn't a, an alternative so. Erm, and she said by that stage he was resigned to going back into hospital so we just let him go at that stage.'* D Theme 3 and 5
52	NCH	Dementia, hip fracture	Unwell for a few days, several out-of-hours GP reviews then much worse -vomiting and less responsive. In CH 6 months	1 day	Please avoid further admission for this lady as she has probable undiagnosed malignancy. Treat palliatively if she declines.	*'she was in quite a lot of pain, she was looking quite cold and clammy and sweaty, she'd taken to her bed, erm, which wasn't like her at all, she was normally up and walking about so that was very unlike her. Her son was actually in and was getting so worried that eventually I was on the phone and I said "I'll just phone a 999'. I think it was just the shock because even though she'd broken her hip she'd sort of bounced back from it if you like and here she was deteriorating right in front of his eyes, it would have just been horrible . . . "* CHN Theme 2 and 3 "*nobody was really aware of what was wrong with her, apparently the hospital consultants knew that she had a mass and they knew that it was not for treatment*." CHM Theme 4 and 5
62	NCH	Dementia, diabetes, oesophageal stricture, osteoporosis	Deteriorating over several months then further deterioration, high blood pressure, agitated	8 days	Avoid admission where possible, for medical assessment and discussion with family where possible	*'her family were the ones who wanted her in that hospital. I think she would have been better here. Like she was so poorly, she was so frail, she was only like 30 odd kilograms, she was just fading away. She was familiar here with the surroundings, with the staff,* ***(pause 2 secs)*** *but sometimes we're overpowered so . . . ..* 'CHC Themes 1 and 3 *"I think the staff felt very sad about that, erm, having looked after her for some time I think they would have appreciated the opportunity to complete her journey, erm, but we didn't get that.."* CHM Theme 1

(Continued)

Table 3. Continued

Resident unique ID	Type of CH	Past medical history	Reason for admission to hospital	Length of stay in hospital before death	Anticipatory care plan (ACP) detailed in key information summary (KIS)	Quotes from interviews Followed by participant code CHM—manager, CHDM—deputy manager, CHN—registered nurse, CHC—care assistant, D—daughter Link to theme number
69	RCH	Dementia, HTN, osteoporosis	Unwell for 1 week then fall from bed. GP assessed and found low oxygen sats and temperature	18 days	Medical management as clinically appropriate	"*we have an end-of-life care plan here, she had a DNACPR in place and the doctor keeps the anticipatory care plans on electronic record and we don't have a copy of that . . . We knew that she was a church of Scotland, that she wanted a burial, that she wanted the GP and district nurse involved and erm, she wanted to see the minister when she became terminally ill. So we do that side of things, usually on admission. But in terms of what the anticipatory care is – we don't know*." CHM Theme 4 and 5
75	NCH	Dementia, COPD, HTN, rectovaginal fistula	Unwell 2 weeks with breathlessness and cough, started antibiotics then acutely worse SOB	12 hours	Swallowing difficulty. Daughter very keen she should have full medical treatment no DNAR status.	*"The family didn't accept their mum's condition very well with her deterioration, like they didn't have a DNACPR in place, ... the family just couldn't see the severity of what we were" CHM* Theme 3 "*the plan was she wasn't going to go to hospital, it would just be a peaceful, you know, keep her here where she knew everybody but she took such a massive deterioration very quickly overnight and the family decided no they wanted her to be treated, and that's where we got into difficulty because everybody then started to go 'oh, we don't think she's going to even make the journey' . . . it was very traumatic"* CHDM Theme 1 and 3
76	NCH	Dementia, IHD, depression, HTN, osteoporosis, anaemia	Sudden onset of SOB and choking	1 day	Main priority is to be in the CH with husband but he would accept admission if thought clinically necessary.	*"they couldn't stop her coughing and gasping, you know, and by the time they rang me she must have already been suffering for a few hours quite honestly, and it was at night time and they said 'we can't help her, we've called the services' . . . ..we had decided that should it come to a heart attack or something like that, no, you know, no, at their age, you know. But that was a different thing, that wasn't a sort of resuscitation scenario. Something had to be done to alleviate it in some way, even if it couldn't be addressed permanently, she was suffering, you know. They couldn't do anything about it in the home, but it was, as I say, hours, it was too awful for words waiting."* D Theme 5
77	RCH	Epilepsy, subdural haematoma, CCF, dementia, TIA,	Sudden onset of seizures	1 day	No ACP on KIS	*"it just happened, just out of nowhere, you know, before breakfast, the carer walked past the room, saw that she was going into a fit in her bed."* CHM Theme 2 *"I think it was our duty of care, that we couldn't have watched that without medical help, you know, because we're all for people, you know, if, if there had been deteriorating health that would have been different but because she was having a seizure, I mean we couldn't have.. we would have seen her like dying in front of our eyes, we needed something to give her a chance to come back . . . .there's no way we could have stood and watched that without medical intervention."* CHM Theme 5

(Continued)

Table 3. Continued

Resident unique ID	Type of CH	Past medical history	Reason for admission to hospital	Length of stay in hospital before death	Anticipatory care plan (ACP) detailed in key information summary (KIS)	Quotes from interviews Followed by participant code CHM—manager, CHDM—deputy manager, CHN—registered nurse, CHC—care assistant, D—daughter Link to theme number
78	RCH	Dementia	Unwell a few days then much more SOB, agitated and jaw dislocated	1 day	No KIS	*"it was really up to her daughter, who had power of attorney and stuff and acted on behalf of her mum's best wishes kind of thing. So we had actually discussed that, we'd discussed it at her 6 month review to see if medically we could manage within the care home, she would remain here and been looked after but unfortunately with the dislocated jaw and things like that it was kind of out with our range kind of thing that we could manage."* CHDM Theme 3 and 5 *"it was so unexpected, we didn't think she was going to die, if you know what I mean, she was going to be treated for that and return home and then if she was to then decline we would have managed that in the home but I think because it was something quite unusual and unexpected we didn't really have much a choice, kind of thing, the hospital was the best place really in that circumstance."* CHDM Theme 2
79	NCH	Dementia, dysphagia, depression	Declining for 2 months with new renal failure, poor appetite then became increasingly drowsy	2 days	Please avoid admission unless for acute remediable conditions. Consider H@H	"*So we were trying to treat her with antibiotics and things and she became really unwell but the last few days she was really, really unwell, not eating, and it was actually the GP decided that it was probably the end-of-life for her at that time. And it was the GP's decision to leave her here and for us to look after her, but unfortunately her son wanted her to go to the hospital. They were very grateful family, you know, but still we can't override..*" CHM Theme 3
82	NCH	Dementia, severe CCF, IHD, depression, diabetes, HTN	Unwell 2 days then generally worse with SOB	4 days	No ACP on KIS	*"GP came out and said, 'no this man has got pneumonia'. So, erm, we phoned the family and the family decided that because we were talking about an acute episode, they wanted him to have the opportunity to, to recover and unfortunately he didn't.*" CHM Theme 2 and 3
94	RCH	Dementia, COPD, IHD, AF, sciatica, stroke, HTN	Recent admission with pneumonia, worsening breathing, further course of antibiotics but deteriorating	6 hours	Would like to be managed in familiar setting and relieve distressing symptoms	"*it was quite a shock, it was very, very quick because we thought maybe if she'd got another er, kind of antibiotic it might improve, or maybe if she have some oxygen in the hospital for a couple of days that might improve, because apart from her breathing there wasn't any problems*." CHDM Theme 2
98	NCH	Dementia, severe CCF, left ventricular aneurysm	Unwell for a few days then suddenly breathless and low sats In CH 2 years	1 day	Bedbound and cognitive impairment. In event of acute illness would like to be kept comfortable in CH.	*"her saturation was really low so, we didn't know really how to manage that, because it was er, late at night and in the morning she was fine but then she really quickly changed. So the GP was already away at home, so I had to phone the NHS and get their opinion but before that I decide to phone the family. Her daughter asked me—'do you think she will get better in the hospital?' I said 'we never know er, but in my opinion she needs a medical assessment and it would be now,' and then I decide to phone the ambulance because the family was agreeing." CHN* Theme 2, 3and 5 *"to be honest, I haven't thought to read all the care plan before to phone the NHS, because I was thinking more emergency than care plan, but the thing I'm looking for first is the DNACPR but if, for example, there was just one form used for the DNACPR and 'no admission for hospital' yeah I wouldn't have rung"* CHN Theme 4
100	NCH	Asthma, Dementia, IHD, osteoporosis	Unwell for a few days then acutely worse with chest pain and SOB In CH 3 weeks	3 days	No ACP info on KIS	"*so it was an emergency, before that she was not drinking very well, she was very vocal and distressed, she was not really eating well. The family was already aware of all that so when this happened I phoned the family first because we didn't have a care plan made for her. And they say 'oh yeah if you think she needs to go to the hospital, send her to the hospital'*." CHN Theme 2 and 3 "*the care plan was not made, she had a DNACPR but as it was new. She was new resident here, I decide to phone the family first, if I have to phone the GP, he would not be able to come in a few minutes so it was ambulance*." CHN Theme 2 and 5

NCH = Nursing Care Home, RCH = Residential Care Home, SOB = short of breath, AF = atrial fibrillation, CCF = congestive cardiac failure, IHD = ischaemic heart disease, COPD = chronic obstructive pulmonary disease, CKD = chronic kidney disease, HTN = hypertension, AWI = adults without incapacity, IBD = inflammatory bowel disease, MVR = mitral valve replacement, sats = oxygen saturations, POA—power of attorney

it was not in the residents' best interest. CH staff gave multiple examples of having undertaken ACP discussions with families but then, when an acute event occurred or the resident deteriorated, the family changed their mind. One resident had deteriorated rapidly over several days; a plan had been put in place with the GP and the daughter for end-of-life care in the CH with anticipatory medications prescribed and his KIS updated. However, he deteriorated further and at that point the daughter changed her mind and he was admitted to hospital.

"she, I don't know, I think it was just a spur of the moment and she just thought -no I want him in the hospital." (CHC/RCH4/R5)

A number of reasons behind family changing their mind were suggested by CH staff including panic, fear and the desire to ensure everything has been done.

"I think it's just the fear. I think it's the fear and I think it's guilt that they maybe didn't try hard enough to save them." (CHDM/NCH19)

Both daughters interviewed described feeling that when their parent deteriorated acutely and was symptomatic this could not be managed in the CH and hospital was the only option.

The family relationship with the CH and the degree of trust they have in the CH was seen by both staff and family to impact the ability of the CH staff to support the family in decision-making. One daughter described a lack of confidence in the ability of the CH to deal with her father's complex health needs contributing to the decision to go to hospital (which he expressed a wish to avoid).

"so I think in my personal view they were a bit slow. For me, I wasn't sure what experience they had in people like Dad." (D/NCH11/R42)

Having confidence in CH staff was especially challenging when residents deteriorated soon after moving to the CH before family and staff had developed a relationship.

Theme 4—Anticipatory care planning and electronic summaries are useful but need to be shared

Nearly all CH staff referenced ACP documentation, when in place, as a positive intervention enabling quality care for residents and appropriate decisions about hospitalisation. Part of the benefit was having broached in advance with family the discussion about hospitalisation, thereby reducing the need for rushed decisions in a crisis. ACP documentation was also seen as improving communication within the CH team.

"it helps when there's, if you've not got regular staff and if it's documented then it's, you know, it's in writing, it's there for everybody to see." (CHN/NCH11)

Undertaking ACP conversations was seen as challenging requiring sensitivity and a relationship with the resident/-family prior to undertaking.

"it's quite difficult, so that's something else that we look at kind of when's the best time to ask?...Is it something that should be given just as part of the admission documentation generally, or should we wait until the 4 week review once they've moved in? But even then it's just really difficult, because you don't want to say, 'oh yeah welcome to CH61, what are we going to do when you die?!" (CHDM/NCH61)

All but one CH staff interviewed had heard of KIS, however their experience of using them varied. For the majority, the KIS was seen as more the domain of the GP and, because of lack of access, CHs relied on the GP to provide a printed copy for their notes. The end-of-life care plans used as part of the CH documentation were valued more highly. A particular concern with the KIS was the potential for it not to be updated in the context of rapidly changing health status of residents and the lack of access to it for CH staff.

CH staff felt they often had inadequate information regarding their residents in particular on admission to the CH and after hospital admission. In one CH both the deputy manager and staff nurse described not being told about a presumed malignancy in a resident who then became acutely unwell. The KIS documented a probable malignancy and a plan to provide comfort care in the CH in the event of a deterioration. However, the CH team was not aware of the KIS and she was admitted to hospital.

"I think if we'd known a wee bit more because apparently she had some kind of abdominal mass, I knew nothing about it, there was nothing about it in her notes either after she moved in here or from any preadmission assessments or anything . . . . So if I'd known that maybe it's something we'd have been able to bear in mind." (CHN/NCH38/R52)

Theme 5—CH staff need better support day and night

We have seen above the importance of CH staff having adequate information about residents. CH staff also valued access to advice to out-of-hours. NHS 24 was a valued source of advice; however, the logistics of calling and waiting was frequently described as frustrating. In particular, when residents deteriorated acutely or unexpectedly rapid advice and support was required.

"It's a very cumbersome process . . . . . there's no priority given to care homes, erm, our phone calls go into the same waiting list as anybody else's . . . . . so if you add the initial phone call to when the GP actually turns up here it could be 10 hours, which for a family waiting with their relative is a long time, it's a long time for us to field." (CHM/NCH13)

When managing acute deterioration in residents who did not wish to be transferred to hospital, CH staff described needing support quickly.

"When someone is sat there and they're cyanosed and they just look absolutely dreadful you do need to sometimes step in and even if that is just having the paramedic come to give oxygen to relieve the symptoms." (CHDM/NCH11)

Several staff members also described feeling that they were unable to provide the care the resident needed in the CH and that hospital was the only available option (see cases 5, 12,13, 40, 42, 76–78, 98, 100 Table 3).

The local "Hospital-at-Home", a team providing active treatment in a patient's home or CH that would otherwise require acute hospital inpatient care, was appraised highly

by staff from both NCHs and RCHs. It was seen as a positive way to manage acute illness in residents in the CH environment.

"I think that is such a fantastic service that it [Hospital-at-home] provides, and they come in just like if somebody was in hospital, so bring all the equipment, they can stay here for 4 hours with one patient and give us all that time and give us all the support that we need." (CHM/RCH51)

CH teams needed support for prescription of anticipatory medications, obtaining them and, in the case of CHs without onsite nurses, administering them. Most CHs described a pre-emptive approach to asking the GP for anticipatory medication prescription, especially if a weekend was approaching, due to previous challenging experiences. Examples included the "out-of-hours" GP being reticent to prescribe, and also several CH staff described driving around multiple pharmacies in the city to find one with the medications in stock.

"we can't stock it [end-of-life medications] which is really, really difficult . . . there have been multiple times when somebody's deteriorated over the weekend and we've not got anything." (CHM/NCH19)

CH staff at all levels spoke about the need for training to enable them to provide high quality end-of-life care. Training was needed to give staff confidence to deliver appropriate care.

Discussion

CH staff want to provide care so residents can live and then die well in the CH. However, uncertain dwindling trajectories, multimorbidity including cognitive impairment and acute deteriorations in residents can make symptom control and recognising dying challenging. Moreover, some residents decline shortly after being admitted to CHs, when staff have not had the opportunity to get to know them or their family.

In some cases, where there was a clear trajectory of decline, CH staff had recognised the resident was dying and wanted to provide care in the CH but family members felt hospital admission was needed. The reasons behind this were numerous including family relationship with the CH, which was seen as a key influence on their decision-making. ACP, whilst important, is challenging, and in isolation does not necessarily result in care in keeping with resident or family wishes.

In order to provide person-centred end-of-life care, CH staff need adequate support systems which are multifaceted and provide rapid, 24-hour support. Support is needed for advice, and to facilitate rapid assessment of CH residents who have declined acutely. This finding is in keeping with recent British Geriatrics Society Guidance [26] and other UK work advocating closer working relationships between CHs and the NHS [27]. The proportion of residents admitted from RCHs and NCHs reflected the proportion of each CH type in the local area suggesting that all types of CH, including those with on-site nurses, require additional support.

Whilst CH staff frequently raised access to anticipatory medications as a key issue in managing end-of-life in the CH they did not identify lack of such medications as the reason for admission in the specific cases discussed. It is interesting to note that 68% of the 109 residents had anticipatory medications prescribed in hospital. However, this was sometimes after several days and investigations when it became apparent the resident was dying. Previous work has reported the need for uncomplicated access to anticipatory medications, including out-of-hours [28], [29]. However, a recent systematic review suggests that there is insufficient evidence to draw conclusions about the impact of such prescribing on the prevention of crisis hospital admissions [30]. The need for support in training, particularly in end-of-life care has also been reported previously [28, 31].

There is little in the published literature on the need for CH staff to have adequate background clinical information on residents in order to provide care; however, this was strongly expressed in our study. When caring for older people with complex health needs, it is vital that CHs have access to all background information, especially after hospital admission [6].

Whilst CH staff perceived ACP as important in decision-making regarding hospitalisation, only 44% of residents had wishes regarding hospitalisation documented on their KIS. The interview data revealed potential reasons for this including the variable opinions of KIS held by CH staff, a preference for CH end-of-life care plans, and the difficulties in undertaking ACP discussions. The disconnect between documented wishes on the KIS and the CH staff's interpretation of resident wishes in cases 5, 14, 52 and 94 (see Table 3) highlights the challenge of communicating, sharing and documenting this kind of complex information. Those deceased CH residents (22/109) who had a KIS documenting a wish to avoid hospital and remain in the CH but died in hospital are particularly interesting. These cases may represent person-centred decision-making in which the clinical situation was evaluated and an informed decision made to veer from previous wishes in light of new circumstances. They may however represent how, when an acute change occurs, lack of preparation and inadequate support can lead to sudden decisions which are not in line with an individual's overall aims. Previous authors have proposed increased focus on preparing those caring for CH residents (and residents themselves) for "in-the-moment" decision-making when acute events occur in addition to documenting ACP [32, 33]. Giving families, and also CH staff, an awareness of the likelihood of acute changes occurring as CH residents decline, and an appreciation of the potential benefits and disadvantages of different treatment options, could help residents achieve their preferences when such changes occur.

Although this study focussed only on those who died in hospital, triggers for admission of CH residents appeared similar to previous studies which looked at all admissions [34], [35]. This underlines the challenge for CH staff and

external professionals in distinguishing when CH residents are actually dying versus when they might benefit from hospital care and "bounce back" [36]. Uncertainty engendered by unpredictable decline trajectories with episodes of "bouncing back" is recognised as underpinning the difficulty determining the most appropriate course of action when residents become unwell [31, 36, 37]. Strategies that acknowledge this innate uncertainty but draw attention to residents' overall likely trajectory and help CH staff and family interpret acute changes in that context may aid decision-making when acute changes occur [38], [39]. This includes specific tools for CHs to provide structure to recognition of overall trajectory such as the Prospective Prognostic Planning Tool [28, 40]. Such strategies and approaches to communication may also improve family relationship with, and their degree of trust in CH staff, which our study suggests is likely to influence family decision-making regarding hospital admission.

The CH staff described sending many of the residents to hospital with the aim of establishing a diagnosis and instituting curative treatment. The data documenting relatively high rates of investigation and intervention (see Table 1) suggest that the hospital teams had similar aims. It is interesting to note, however, that over half of admitting hospital clinicians documented an impression that the resident was likely to be dying and the majority of residents died after a short stay in hospital. This perhaps suggests that some of the hopes for curative treatment were unfounded, or perhaps further highlights the pervasive uncertainty associated with caring for this complex, multi-morbid group. Clearly, there are instances in which transfer to hospital for CH residents is both necessary and desirable. It is paramount that people living in CHs have equal access to all NHS services. However, the capacity to give a trial of treatment within the CH, in cases where there is uncertainty as to the potential for recovery, could avoid unwanted transfers. Hospital-at-Home services could be a method of achieving this, enabling a trial of treatment, such as IV antibiotics, without the potential distress caused by transferring to an unfamiliar environment [41]. The challenge for Hospital-at-Home and similar services is responding to acute deteriorations that happen out-of-hours. Other studies have also found that over 50% of transfers to hospital occur out-of-hours [22], [42] and suggested that support during this period is especially important [28, 42]. Further research is needed to explore the optimal service design to prevent and respond to acute changes in CH residents 24 hours a day.

Strengths and limitations

This study is innovative as it takes a mixed methods approach and links data between the hospital and CH setting in relation to end-of-life care. The use of cases identified in hospital as an "entrance point" to CHs, a platform around which to build interviews, and to enable interpretation of the differing sources of data on one individual adds richness and depth to the analysis.

We used an NHS report writing tool to identify CH residents. Similar tools using CH address, rather than postcode alone or "source of admission" coding, have been found to have high sensitivity and specificity [43]. The use of address to identify CH residents is however, not without issue, in particular keeping any address list up-to-date in the dynamic context of CHs changing name and new CHs starting [43, 44]. It is therefore possible that some admissions from CHs were missed. The study design involved CH managers identifying other staff to participate; this could have led to gatekeeping of some potential participants. Additionally, despite the aim to recruit both a manager and other staff member for each case, a higher proportion of CHMs and CHDMs were recruited. More senior staff may not have been directly involved in the decision to admit to hospital and their experiences may differ from those of more junior staff creating a potential bias to the data. Recruitment of bereaved relatives has been acknowledged as complex in previous research; unfortunately, in our study only two relatives participated limiting the interpretation of this valuable perspective [45]. This in-depth study was carried out using data on CH resident deaths in two hospitals in Scotland and therefore is not immediately generalisable to a wider context in view of the specific background of GP cover of CHs, NHS 24 support and the use of KIS. However, similar findings in the literature suggest it may have national and international relevance in similar contexts.

A clear message from this study is the challenge of managing acute deteriorations in the CH setting and need for improved support to CHs. We recommend that support is needed in terms of sharing of information with CHs, embedding ACP and rapid assessment and management when there is an acute deterioration. More research is needed to establish the ideal model for delivery.

Supplementary data

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

Declaration of Conflicts of Interest

None.

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