

What are the goals of care for older people living with frailty when they access urgent care? Are those goals attained? A qualitative view of patient and carer perspectives

Abstract (255)

Study Objective

Little is known of the goals of care of older people living with frailty when they access urgent care. Equally whether these goals are attained from a patient and carer perspective is often unclear. This qualitative study examined the views of older people living with frailty and their families in relation to specific episodes of urgent care, what they wanted to achieve and whether those goals were attained.

Methods

Semi-structured interviews with older people living with frailty and their families between Jan and July 2019. Patient and carer participants were recruited in three hospitals in England and interviewed following the urgent care episode. Interviews were audio-recorded, transcribed verbatim and analysed following the principles of the Framework approach. Results were validated by an older people's involvement group.

Results

Forty participants were interviewed either alone or jointly (24 patients and 16 carers), describing episodes of urgent care which started in ED for 28 patients. The goals of care for participants accessing emergency care were that their medical problem be diagnosed and resolved; information about tests and treatment be given to them and their relatives; they receive an appropriate well-planned discharge to their own home with support where needed and without readmission or re-attendance at ED; and that they retain mobility, function and normal activities. Participants perceived that many of these goals of care were not attained.

Conclusions

Older people living with frailty have heterogeneous urgent care goals which require individual ascertainment. Identifying these goals of care early could result in improved attainment through person-centred care.

Key messages

What is already known on this subject?	What this study adds?	How this study might affect research, practice or policy?
Older people seek holistic, sensitive, and informed urgent care, but there is very little evidence for what is desired by those living with frailty. Frailty is a key discriminator in outcomes from urgent care.	A person-centred evaluation of what older people living with frailty want from episodes of urgent care Evidence of the discrepancy between what patients and	EDs may wish to explore incorporating an assessment of preferences or outcomes for older people living with frailty who have urgent care needs. These preferences/outcomes

<p>Outcomes are currently reported using service metrics, which do not necessarily capture people's attainment of what they desired.</p>	<p>carers want from emergency care and what they actually get</p> <p>The perspectives of older people living with frailty and their carers on whether their urgent care goals are met</p>	<p>might influence immediate clinical care and be used for evaluation, in turn improving the delivery of patient centred care.</p>
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Introduction

Frailty is a state of vulnerability to poor resolution of homeostasis after a stressor event and is a consequence of cumulative decline in many physiological systems during a lifetime(1). In the emergency setting, frailty can be measured at triage using validated measures such as the Clinical Frailty Scale(2, 3). Around one-third of people aged 65 years or older attending for emergency care (in England) have at least mild frailty(4). It is well documented that older people living with frailty have poor clinical outcomes from episodes of emergency care(4). What is not known is how they perceive the episode of care, what their goals of care are in accessing emergency care, and whether these are attained.

The process of care (interactions between patient and clinicians, or patients and the care environment) can influence the outcomes from care (what the individual was hoping to achieve – what matters to them). The International Consortium for Health Outcome Measurement (ICHOM) identified a standard set of health outcomes that matter to older people(5), but this does not explicitly focus on emergency care, nor does it distinguish between those living with frailty, and those who are not. Thus, it is currently unclear what outcomes matter most to older people living with frailty who are receiving emergency care.

The aim of this paper is to explore the emergency care goals of older people living with frailty, and how well these goals were met for the participants in our study. It provides a person-centred view of what older people with frailty go through as they access emergency care and progress through the system, from a non-clinical perspective.

Methods

Recruitment and Sampling

Participants were recruited by research nurses and clinical staff in Emergency Departments (EDs) in three sites in England between January and June 2019. Recruitment was undertaken by experienced research nurses (sites 1 and 2) and clinical staff (site 3) using a purposive recruitment strategy which tried to reflect the population of interest according to: frailty (Clinical Frailty Scale – CFS(6)), age, sex, ethnicity, cognitive impairment, place of residence, mode of arrival (ambulance or independent), whether seen in 'majors' or 'minors', different days of the week and different times of the day. The CFS is a 9-point scale representing different levels of frailty(6). Starting at 1 (very fit), the scale progresses through increasing levels of frailty to 8 (very severely frail), and 9 (terminally ill). Participants were included if they had mild or greater frailty (≥ 5 on the Clinical Frailty Scale). Informed consent was taken by staff who recruited participants within 72 hours of participants' entry to ED, with the majority being recruited on the day of attendance.

Where there were barriers to providing informed consent, such as cognitive or sensory impairment that could not be overcome, key informants such as relatives or loved ones were asked to provide consultee consent on behalf, in keeping with English ethical research guidelines. In the majority of cases, interviews took place within 30 days of the patient's ED attendance. Most took place in the patient/carer's usual place of residence – typically their own home, but sometimes the family home, sheltered accommodation or care home. Four interviews, all with carers, took place via telephone at their request. Interviews were audio recorded and lasted approximately 60 minutes each.

Data was collected via semi-structured in-depth interviews using a topic guide informed by the relevant literature(7) and designed in collaboration with lay co-researchers. The interviews were undertaken by two experienced non-clinical qualitative researchers who were not part of the care team. The interviewers regularly debriefed and compared field notes, as well as working conjointly on developing the coding framework to ensure consistency. Interviews explored patient views on their recent emergency care experience, their goals of care in accessing those services and whether they were attained. Carers/relatives were also interviewed, alongside or separate from participants according to individual preferences.

Data Analysis

All interviews were transcribed verbatim by a professional contractor and analysed in NVivo. The Framework approach(8) was used for analysis including *a priori* themes contained in the topic guide and themes emerging from the data. Framework is an approach to qualitative analysis designed for applied, often policy-related research, intended to enable systematic, transparent analysis of empirical datasets, often by teams, towards identified practical objectives. The data was read by two researchers initially to identify themes from the data inductively. Data was organised under *a priori* and emerging themes using code identifiers, new themes were added as they emerged. *A priori* themes included circumstances leading to ED attendance, what happened there and what happened afterwards. Generated themes were regularly discussed for reliability and validation with wider members of the research team (SC and/or JvO) and our lay co-researchers. Emerging themes included patient and carer views on their experiences and whether their care goals were met. Data collection and analysis were concurrent, with early findings directing further enquiries in interviews.

Patient and public involvement

The study was supported by the involvement of two lay collaborators (PR and JL) who advised on recruitment, co-designed topic guides, and supported the conduct and analysis of interviews. In addition, study updates were shared with the wider Leicester, Leicestershire and Rutland Older Persons Patient and Public Involvement (PPI) Research Forum on a quarterly basis where feedback was provided.

Ethics statement

The study was submitted to the London South East Research Ethics Committee for review which classified it as service evaluation. Accordingly ethical approval was granted by the University of Leicester’s Sub Committee for Medicine and Biological Science. Ethics Reference: 17525-spc3-1s:healthsciences.

Results

Participants

In total, 40 participants were interviewed: 24 patients and 16 carers who, between them, described ED attendances for 28 patients across the three sites (*Table 1*).

Table 1 Patient demographics and ED attendance details

	Site 1	Site 2	Site 3	Total
Male	1	3	5	9

Female	7	9	3	19
Aged 75-84	2	6	4	12
Aged 85+	6	6	4	16
CFS Frailty Score 5-6	7	9	8	24
CFS Frailty Score 7	1	3	0	4
White	8	11	8	27
Asian	0	1	0	1
Black	0	0	0	0
ED Majors	8	11	7	26
ED Minors	0	1	1	2
Lives alone or with spouse	6	9	7	18
Lives with other family members e.g. son/daughter	2	1	1	4
Lives in sheltered accommodation	2	1	0	3
Lives in a care home	0	2	0	2
Lives in own home with live in carers	0	1	0	1
Travelled to hospital by ambulance	8	11	7	26
Travelled to hospital independently / with family	0	1	1	2
Has cognitive impairment	1	1	3	5
Does not have cognitive impairment	7	11	5	23
Attended ED on a weekday	4	12	4	20
Attended ED on a weekend	4	0	4	8
Attended ED in hours (9-5 Mon-Fri)	2	10	3	15
Attended ED out of hours	6	2	5	13

Findings

Findings are presented as goals of care and attainment of those goals (expressed verbatim or illustrated through experiences).

Physical and medical goals of care

Some participants attended ED to be 'checked out' or simply to have their medical problem diagnosed and treated. Those with chronic conditions wanted the current exacerbation of their condition to be controlled and a plan made for ongoing symptom control. Though this may seem like an obvious goal, what was striking was that it was rarely attained. Some (though not all) participants felt that they had not been diagnosed and their condition had not been treated. Some felt they were sent home as their symptoms dissipated, with no explanation of the cause. Some respondents felt that they had not had diagnostics and treatment due to their age.

Participants attended ED hoping, but not necessarily expecting, that they would leave feeling better. Many did not feel better when they were sent home, and about a third felt that they deteriorated whilst in hospital (admitted participants). Reasons for deterioration in hospital included: falls, changes in medication, hospital acquired conditions, deconditioning and loss of function caused by reduced mobility.

Several participants who were spouses of hospitalised participants felt that they themselves deteriorated whilst their partner was in hospital due to hours spent travelling and visiting or lack of help at home.

Box 1: Quotes illustrating physical and medical goals and attainment (I – interviewer, P – participant, C – carer)

Physical and medical goals of care identified by participants	
I	<i>So what's important to you is that the clinical side –</i>
P	<i>Is that they get the diagnosis and the treatment right and send me off home. [S1 07PC]</i>
P	<i>Well I just wanted to make sure everything was checked out. You know, I didn't know whether I'd have to have a scan or an x-ray, and it was just the x-ray. [S2 03P]</i>
P	<i>The pain in my legs I want medication pretty quickly. Because it can get really painful. And then I don't know what to do with myself. [S2 15P]</i>
P	<i>I was hoping they'd find a reason for my distended stomach [S2 05P]</i>
Participant views on attainment of care goals	
C	<i>... they said 'well we'll put him on antibiotics', I said 'yes and he'll be in for a couple of days and you'll send him home, nobody seems to ask the question why'. [S3 06PC]</i>
I	<i>... did you ever get a diagnosis or did they say what they thought it was?</i>
P	<i>No, I didn't know what it was... because they didn't know what it was, I felt I'd take up everybody's time. [S1 02P]</i>
C	<i>Three weeks later we were still chasing this scan because she'd been moved and they didn't know on the new ward that she was after a scan [S1 07PC]</i>
P	<i>I feel it was a waste of time ... [S1 10PC]</i>

P Even when you go up the doctor's they say, you know, 'he's 85 years old, you know, what do you want me to do?'... That's their attitude, you know.

I Did you feel that that was the attitude in hospital as well?

P Well yeah I do, yeah.

C He was just left like a piece of meat. [S3 02PC]

C He was actually worse when he come out than when he went in. [S3 02PC]

Goals of care concerning information and involvement in decision making

When admitted, participants and their carers wanted information about their tests, diagnosis, treatment and care. They wanted to be informed about what was wrong with them, what was happening to them and why, and for that information to be accurate and consistent. Six respondents stated that they felt that they had been well informed about their condition and their treatment. However, participants, relatives and carers often felt uninformed about their tests, diagnoses, treatment, care, prognosis, and discharge. Participants left with unanswered questions, with some feeling unable or not knowing what to ask. There were examples of participants being moved, being told they couldn't eat, or undergoing tests without being told when or why.

Admitted participants stated that it was important for them to be involved in decisions about their treatment and care, though not everyone felt this way. Some wanted the clinicians to make decisions for them. Being involved in decision making required being given enough information to make an informed choice, and is therefore linked to information about diagnosis, treatment and care. Some participants did feel involved in decisions about their care and that their wishes were listened to. Others, however, felt that decisions were made about their treatment and care without consultation.

When admitted, participants felt it important to share information with relatives and carers to assist with understanding and recall of information provided, advocacy, and arranging family support. On many occasions poor communication or missing information caused frustration, especially when participants had hearing difficulties or cognitive impairment. Part of the issue for relatives was that there was rarely anyone around to explain things during visiting hours. Relatives and carers perceived staff as too busy to take time out to talk or even as unwilling to give information.

Medication changes were not explicitly mentioned as desired by our participants, i.e. they did not go to hospital with this in mind yet changes in medication whilst in hospital were common. What participants did want, was information about why medications were indicated or changed. Those who had medication changes did not always know why and could experience problems such as new side effects and deterioration in conditions. Some participants were unclear about what their medication should be at discharge and whether changes implemented in hospital were to be continued. GPs were not always informed of medication changes, and in some cases, GPs revoked these changes and reverted back to pre-hospital medication regimen.

Participants and carers were unsure about what they should do after discharge in terms of self-care; they felt this information should be given prior to discharge.

Box 2: Quotes illustrating expectations around Information and decision making and whether these were achieved

Goals of care around Information and Involvement in decision making	
P	<i>I'd also like the thorough checks to be done as quickly as possible and to be kept informed as to what the checks are for [S110PC]</i>
I	<i>And do you think is it important to you that they involve you in any decisions?</i>
P	<i>Oh lord, yeah. It is for me. Because I like to know what's happening to my body, I mean, OK if it's bad news, you've got to deal with it but, yeah, I think it's much better to, from my point of view, to know what's facing you as opposed to sort of pushing it under the carpet sort of thing. And then eventually, I mean, I think you know when there's something really wrong with your body but, as I say, that's me, not everybody wants that [S2 12P]</i>
C	<i>What we call, it's reverse triage. The doctors will come and do their spiel and then the patients will turn round and say "Excuse me what did he say? What did he mean?" so we're then doing another triage but after the doctor's done it, just explaining as to what ... [S1 07PC]</i>
P	<i>I always want to know what it is and if they introduce me to a new tablet I want to know why. [S2 15P]</i>
Participant views on attainment of care goals	
P	<i>... he didn't tell me anything and I thought well why doesn't somebody tell me, maybe I should have asked, but you're in their territory, not your own, you know. [S1 08P]</i>
P	<i>No. You're just an idiot. They treat you, if you're over 80 they treat the older generation as an idiot. And I don't like that. You might as well know what I think of them. [S2 06P]</i>
C	<i>... my general kind of issue is that nobody talks to me and trying to find out information is so hard and trying to find somebody to talk to. So you will see the healthcare assistants, so they come round and then it's all very much 'well I need to go and find a nurse to speak to you', but you can't find them, they're so busy, there's never anybody around... there's nobody around to talk to you, to update you on what's going on. And it's so frustrating. [S2 02C]</i>
C	<i>when dad got discharged they said 'we've stopped the propranol tablet'.... So we took dad a week later and spoke to the GP, [name], and he said 'ah, you're here because they've stopped your losartan tablet', 'no, they've stopped the propranol tablet', 'no, not on this record'... [S3 02PC]</i>
C	<i>... She was sent home with a morphine patch, there was no others supplied. They finally came when there were new dosset boxes that had come from the chemist, but nobody had told me that it was supposed to be me that was changing them and giving me any advice on what I was supposed to do. [S2 02C]</i>

Discharge and discharge planning

A key goal identified by participants was to get home as quickly as possible; most did not want to be admitted. But participants wanted to feel 'fit enough', and 'able to manage' before being sent home. For some this related to previous experiences of readmissions after going home 'too soon'. This is not to say that participants expected to feel completely well, and indeed some felt they would recover better at home. Some participants were sent home before they felt well enough, suggesting

to them that the hospital needed the bed. Some felt guilty about ‘taking up a bed’, and one was told they were fit to go home despite their carer also being in hospital. Relatives, who themselves often had frailty, were often anxious about coping post-discharge.

Participants wanted to be involved in their discharge planning and often needed their relatives’ and carers’ support. Decisions about discharge could feel very last minute and information confused and conflicting. Some participants felt that they were discharged suddenly without warning. One participant, whose family had not been told she was being discharged, was woken early in the morning and taken to the discharge lounge in night clothes and told to put on someone else’s clothes.

Participants and relatives wanted clear information about when a discharge would happen, and what home or community support was being arranged. Going home during daytime, having a carer or relative present, and being helped into the house were seen as important. Discharges were not always well planned. Participants and family were not always asked about whether help was needed at home on discharge. Very long, uncomfortable waits were common and distressing, and usually caused by waiting for medication, discharge letters, porters and transport. One patient was discharged without medication. Participants were discharged alone at night, sometimes with minimal assistance; one patient was left on her doorstep at 2am.

Participants did not want repeat admission and wanted their health issues to be addressed to prevent this from happening. Of the 14 participants who had experienced a previous admission, ten perceived that the subsequent admission was for the same problem. They felt that if their issues had been investigated and resolved the first time, then a re-attendance would not have been necessary. One respondent felt that if an adequate discharge package of care had been provided then a subsequent admission may not have happened.

Box 3: Quotes illustrating hopes and expectations for discharge and whether these were achieved

Goals of care for discharge and discharge planning	
<i>P</i>	<i>That was number one. To go into hospital to be treated, and to get out as fast as you can. ... You know, as soon as you get in, you want to get out. [S1 09PC]</i>
<i>P</i>	<i>on the Tuesday night [day of discharge from hospital] I thought how am I going to get upstairs? So I went up on my bottom. My husband was at the back of me. And when I got to the top – oh no, I can’t push myself up to stand.... Came all the way downstairs on my bottom again and I slept in this chair. [S2 03P]</i>
<i>P</i>	<i>I did say. I said “I want to get home” but I said “I’m not going home without I’m right this time” because obviously something wasn’t right last time ... After the last few times I thought I’m going to be cautious this time ... [S1 07PC]</i>
<i>P</i>	<i>I’ve said to the doctors, the consultants ... As long as I’m, I’m fine you know, and I can get back home and I feel well. But I don’t want to come back again. [S1 07PC]</i>
Participant views on attainment of care goals	
<i>P</i>	<i>...they were going to send me home then, I wasn’t really fit enough, I didn’t feel fit enough, but they were going to send me home [S1 05P]</i>

C (hospital) rang me and ... she said 'you need carers', I thought well nothing's been discussed about him coming home yet, let alone think about carers, you know [S3 08C]

P ... the arrangement was that they'd let my wife know and my granddaughter would come down and pick me up. Now unbeknownst to me they rang my wife and told her that they were releasing me but they were providing transport for me. Now about two or three hours after they told her, I was wondering why she hadn't rung me or anything. They told me the same thing and I was – I was devastated. I was so mad about it. [S1 10PC]

I 'Cause I mean did they ask you anything about that in hospital, whether you needed any equipment or anything like that?

P No they didn't. [S2 03P]

P Then the second time was ten days after I'd been discharged the first time. [S1 06P]

Ongoing treatment and care

Participants and their relatives hoped that they would be referred on for in-patient or out-patient specialist care, if required. Five participants in our study were transferred to a different hospital for specialist care. Others were referred for out-patient appointments, although they did not always know what for.

Participants expected that their GP would be given information about their emergency care episode, informed of diagnoses, changes in medication and ongoing care. There was an expectation that if ongoing support from community health services was required then this would be communicated and coordinated for them. Respondents hoped to be visited at home by community nursing or therapy services following their emergency. In some cases this appeared to have happened smoothly - often due to proactive communication by the patient or their relatives. However, communication with primary health care and community services on discharge was generally felt to be poor, and referrals or appointments were not always completed.

Participants wanted to receive social care support on discharge if needed. Some stated that they were not asked if they needed support. Eight participants received temporary or permanent additional support at home after discharge. There were problems coordinating discharges with (re)starting new and existing care packages. One patient with serious mental health issues had her medication changed by the hospital, but no information on this had been passed to her family or care staff who prompted medication.

Box 4: Quotes illustrating hopes and expectations for ongoing treatment/care and whether these were achieved

Goals of care for ongoing treatment and support

C So in theory, in that case, you could have – I know it's very difficult but you could have something like a checklist within the hospital, if a person's come in with heart failure, you know refer heart nurse, you know age query, continence query, the things, and use it as a tick list before a patient's discharged. [S1 07PC]

C Well for example, I was talking to a nurse earlier on this morning from [hospital] who's following up from his discharge and apparently on his discharge papers which we've got a copy of somewhere, it says that the GP is to monitor whatever by blood test. [S3 06PC]

C I think as a result as well, this time, rather than the first time mum went in, they're getting the heart nurse to do a home visit, sensory team, continence team. Now this in theory could have all gone on on her first discharge. I mean it's people obviously like [name], carers that come, that say "Oh are so and so involved?" We don't know about things like that and we weren't pointed in that direction. So with help from everybody else we're more aware of what mum – and I'm not talking about Benefits, I'm talking about health, medical you know. [S1 07PC]

Participant views on attainment of care goals

C She's seen the letter, she opened the letter, and she was sitting here in the dark when I come over and I said 'what's the matter with you?', she said 'thank God you've come, I'm panicking'.

I It doesn't say what it's for. How bizarre. It doesn't say what it's for, does it?

C Well no. She read the letter and she was on one because she was panicking because she thought she had to go back in. [S3 03PC]

P Now here, I'm afraid here we come to a hitch, because on 4th March they informed my doctor's surgery when I came out of hospital what my new regime was and I'm afraid it must have got lost in the post or something because it didn't get put properly onto my notes until 23rd April [S1 06P]

C Fortunately this week I've been with social services and I think maybe the district nurse has been out to do it. The care home didn't get the new care plan so she was assessed by occupational therapy I think maybe on the Monday, sent home on the Wednesday. She was assessed because before she went in she only had carers twice a day. It was assessed that she needed carers at a minimum three times a day but her medication had been set up as four times a day ... [S2 02C]

Function and mobility

Participants want to retain or regain their mobility by being supported and encouraged to be mobile in hospital and at home after discharge. They wanted physiotherapy, adaptations such as handrails at home, and equipment such as walking frames. Many participants in our study felt that they lost mobility as a result of their urgent care episode. Some felt prevented from being mobile in hospital, being told they couldn't go anywhere alone but then staff not being available to go with them. Participants also felt unsupported to regain mobility at home, with only four receiving physiotherapy after discharge and six receiving equipment. Many purchased their own equipment.

Participants want to return to their normal activities such as personal care, cooking, housework, enjoying their gardens and going out. Participants wanted to maintain or regain their independence, living in their own homes with minimal support. Most of our respondents maintained their independence after their emergency care, either because their health and function did not deteriorate to the extent that they lost their functionality, or because they received help at home.

Care needs often increased during hospitalisation, with two participants being discharged to care homes, two having increased care packages, and a further six receiving temporary support.

Box 5: Quotes illustrating hopes and expectations for function and mobility and whether these were achieved

Goals of care for function and mobility	
P	<i>I just wanted to be normal. I couldn't understand why I couldn't get them other three bloody yards to the toilet because of that wire, it was connected up and they wouldn't disconnect it and I asked for it to be disconnected, which they disconnected it for a couple of minutes, a few minutes, that's all that it took. [S3 06PC]</i>
P	<i>I want to be right... [I would like to] be able to get outside and sit outside 'cause I like my garden. [S1 07PC]</i>
P	<i>Yes, I want to get back I want to get back at walking about.</i>
I	<i>Ok.</i>
P	<i>If I can walk round here potter into the kitchen and back which I was doing until the fall came. [S2 15P]</i>
P	<i>... So yeah, my ideal is to be, if I can be semi-independent, let's put it – semi-independent. That's the best thing I can describe it. There's things that I won't be able to do like change my bedding for a start now, and certain things. And I have a cleaner anyway. But that's it really. [S1 07PC]</i>
Participant views on attainment of care goals	
C	<i>Well when you go into hospital, you always come, your mobility is always worse when you come out. Dad couldn't walk from the car up to here.</i>
P	<i>I can hardly walk now.</i>
C	<i>We had to put him on the strollator, the four wheel drive chair, and drag dad up because he couldn't walk.</i>
I	<i>Whereas when he went in he could.</i>
C	<i>Yeah. [S3 02PC]</i>
P	<i>Yeah, for some reason. I tried to walk a bit in there but of course there's not many places, you know, I kept going to the toilet, I mean, I'd wash myself and just walk up the top and come back again but perhaps it wasn't enough, I don't know. [S3 05PC]</i>
P	<i>You can't get out, you're stuck in here, I'm dependent on my son to take me out in the car, I can't go anywhere, I belong to three walking groups, which I've had to give up. [S1 06P]</i>

Discussion

Summary

This paper explores the goals of care of older people living with frailty and their families/carers during an urgent care episode. The key finding was the discrepancy between what people sought and what was attained.

Table 1: Summary of Urgent care goals for older people living with frailty and whether these were attained

Physical and medical goals of care	Were these attained?
<ul style="list-style-type: none"> • Getting the medical problem sorted – diagnosis and treatment • Getting checked out – diagnostic tests, x rays etc • Pain and symptom relief • Feeling better 	<ul style="list-style-type: none"> • Many felt they were not diagnosed and treated • Most people had diagnostic tests • Most had symptom relief • Most stated that they did not feel better when discharged • Admitted participants often deteriorated • Spouses of admitted participants struggled to maintain their own health
Care goals concerning Information and Involvement in decision making	Were these attained?
<ul style="list-style-type: none"> • Information about diagnosis and treatment • Involvement in decision making about care and treatment • Information sharing with relatives and carers • Information about medication changes • Information about aftercare 	<ul style="list-style-type: none"> • Lack of information about diagnosis and treatment • Lack of involvement in decision making about care and treatment • Lack of information sharing with relatives • Lack of information about changes in medication • Lack of information about aftercare
Care goals concerning ongoing treatment and care	Were these attained?
<ul style="list-style-type: none"> • Referral for specialist health services • Communication and coordination with primary care and community health services • Communication and Coordination with Social Care Services 	<ul style="list-style-type: none"> • Some referrals, but much confusion • Lack of communication and coordination with primary care • Lack of communication and coordination with social care services
Function and Mobility goals of care	Were these attained?
<ul style="list-style-type: none"> • Retaining / Regaining Mobility • Returning to normal activities • Maintaining Independence 	<ul style="list-style-type: none"> • Many experienced deterioration in mobility due to hospital stay • Many felt they had not returned to usual activities at time of interview • Most had retained their independence

How does this fit with the existing evidence?

This research adds to existing evidence by expanding the issues identified by older people, in particular those living with frailty, who are poorly represented in previous work(9, 10). Whilst previous work has elicited emergency nurses' perceptions and expectations of older people(11, 12),

there is a paucity of research addressing patients experience and less still on patients' outcomes or expectations. We do know that older people living with frailty have specific needs that differ from older people more generally in emergency settings, notably centred on autonomy and security(10, 13, 14). Existing outcomes measures for older people(5) do not address all of the goals of urgent care identified by our participants from their perspective, for example: addressing the medical problem and feeling better; receiving information about diagnosis and treatment, medication changes and involving relatives and carers; involvement in discharge planning and appropriate discharge; referral, communication and coordination with primary and social care; returning to usual activities; not being readmitted or needing to re-attend ED. It is somewhat surprising and perhaps disappointing that some of these goals of care were really very modest yet were often not attained.

Our participants did not particularly discuss mental health as desired goals of care other than perceiving these as medical needs requiring attention. They did not expect urgent health care episodes to tackle their experiences of loneliness and isolation. Carer burden was evident from our interviews.

Strengths and limitations

To our knowledge, it is the first paper discussing goals of care and their (non-)attainment for older people with frailty and emergency care needs. Participants were interviewed by expert, non-clinical researchers with subsequent clinical validation, facilitating free and open discourse about healthcare. In this cohort of older people living with frailty, we were able to identify multiple domains of meaningful goals of care not apparently addressed in previous reviews(10), adding to the understanding of how these might be better elicited and addressed. This study took place in three English hospitals with quite different emergency care processes, yet the goals of care identified were consistent across all three. There was a lack of ethnic diversity in our sample, despite the efforts of the recruitment staff. We also failed to recruit participants with high frailty scores, who may have a different focus in terms of goals of care.

Implications for policy and practice

Older people living with frailty are known to have poorer service-centred outcomes from urgent care(15). These interviews describe limited attainment of person-centred goals of care, with many participants reporting un-attained goals or deteriorating while in hospital; this qualitative description adds depth to previous studies reporting on poor outcomes from emergency(4, 16) and acute care(17-19) in older people living with frailty.

Emergency care research and quality improvement usually focuses upon service metrics such as length of stay and readmission rates, which do not necessarily align with patient perspectives(20, 21). Such service metrics are relatively easy to generate but may not be meaningful to older people with frailty(10, 22). In particular, holistic, person-centred care which can best-serve people living with frailty is poorly captured using such metrics(10).

There is a need for improved communication across the whole pathway of care, with patients being able to feel involved at every stage. Readmissions are a concern within increasingly pressurised systems – the data presented here fits with other reports that have identified that many reasons for readmission might reasonably be identified during the index acute admission(23, 24). It might be that a focus on delivering patient-centred care, driven by eliciting and addressing patient care goals, might lead not only to higher quality care, but also more efficient care. For example, if patients

report that their goal is to improve function, and this is the focus of the acute admission, then readmissions might be avoided. There is a growing body of evidence to support holistic care that focuses upon function improving outcomes such as reduced readmission and institutionalisation in the urgent care context(25).

Implications for future research

Future research could explore if capturing goals of care at the beginning and throughout an urgent care episode might influence clinical care and pathways, and thence the achievement of said goals. Engagement in research of people of minority-ethnic backgrounds is needed, as is engagement of people with high levels of frailty.

Conclusion

The majority of participants in our study did not attain their goals of care and many deteriorated or experienced adverse effects in hospital and difficulties after discharge. Attainment of care goals though early goal setting from first contact to post discharge for older people living with frailty and urgent care needs should be improved. Further work is needed to develop goal-oriented care for older people living with frailty which is personalised to their specific needs.

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