Living with Frailty - What Healthcare Issues Matter to an Older Person? A Focus Group Study

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Abstract

Background The study set out to interview older people with frailty and find out what healthcare issues matter to them. Older people with frailty are an important population subgroup. In the United Kingdom, over 65s already outnumber under 16s, and this is expected to increase. Research into health issues has been undertaken by the International Consortium for Health Outcomes Measurement (ICHOM) and this study builds on that. Recent research has been undertaken in America into health issues. However, these studies were not specifically focused on older people.

Methods A scoping review of the literature was undertaken to highlight any gaps in this area of research. Thereafter a focus group interview was carried out with six older people with frailty. Qualitative research often uses smaller samples than quantitative research. Braun and Clarke recommend that for a small project, such as this one, 6-10 interviews should be held. Braun and Clarke state that smaller groups (three to eight participants) work best in terms of generating a rich discussion and have the added benefit of being easier to manage. The six participants were aged 65 years and over and had mild to moderate frailty using the Rockwood Clinical Frailty Scale. The interview was recorded and transcribed, analysed and themes identified.

Results The eight themes identified were trust in medical professionals, vulnerability of being an older person in hospital, polypharmacy and wastage of medication, discharge planning and co-ordination of care at home, taking responsibility for your own health, nomenclature, autonomy and falls.

Conclusion This study has identified themes to raise awareness among health care professionals about what health issues matter to older people with frailty. The study findings will provide an opportunity for meaningful discussions around what is needed to meet these preferred health issues.

Background Of Study

This study provided an opportunity for older people with frailty to discuss and share their views on what health issues matter to them. The qualitative nature of the research allows for in depth, rich and descriptive data to be collected. Themes about health issues that matter to older people with frailty were identified. A scoping review of the literature on health issues in older people including older people with frailty was undertaken, a focus group interview with older people with frailty to
ascertain their views on health issues done, and findings have been shared at a national conference. Overall feedback from the conference was extremely positive and numerous delegates confirmed the need for research such as this. Several delegated asked how providers of health care services would address the issues raised from the focus group and how these could be implemented into the everyday running of, for example, GP appointments, clinics, A&E etc.

**What is frailty?**

Frailty is defined as a loss of physiological reserves across multiple organ systems and increasing vulnerability to decompensation after a stressor event. Older people usually may have other problems such as social and cognitive conditions. They may suffer with deafness, eyesight and memory problems. They may walk slowly, fatigue easily and some can become housebound, or only able to leave their home with help. Frailty in Older People is an area that is being increasingly studied due to the socioeconomic impact it has. England is an ageing nation, therefore the impact of frailty is likely to only increase further.

As part of the new General Practitioner General Medical Services (GP GMS) contract introduced in 2017-18, GPs must now identify older people with frailty. It is being reported that some older people do not agree with being identified as frail and concerns were raised that the frailty label might be misapplied or use pejoratively.

In healthcare practice clinicians will look chronological and/or biological age, comorbidity and dependency to determine how frail a person is. When older adults and the wider public were asked for their perception of frailty, they perceived it as a label applied to end-of-life patients, cancer syndromes and patients who needed high dependency care. A recent study concluded that there is widespread dislike to the term frailty. It concluded that a wider dialogue is needed with older people, health/social workers and policy makers to find out more inclusive ways to define this population. Most importantly the study found that we need to find out from older people what they can do and what they want from services, and design services based on these.
In England 5% of people aged 60-69 have frailty. This rises to 65% in people aged over 90. In England there are 1.8 million people aged over 60 and 0.8 million people aged over 80 living with frailty¹.

ICHOM⁴ has provided a list of recommended outcomes that should be measured when identifying the areas most important to older persons:

**Symptoms, Functioning and Quality of Life** - Autonomy and control, mood and emotional health, pain, activities of daily living, loneliness and isolation.

**Care** - Carer burden.

**Healthcare responsiveness** - Participation and decision-making.

**Clinical status** - Frailty, overall and cause-specific survival and time spent in hospital.

**Quality of death** - Place of death.

**Disutility of care** - Polypharmacy and falls.

**Methods**

**Paradigm & Theory**

The paradigm for undertaking this project is an interpretivist one.⁵ This project included a literature review and interviewing older people with frailty to explore what health issues matter to them. It is important to gain an insight into the lives of the participants and an understanding of what they want from healthcare services.

The qualitative approach includes (Silverman 2000) the analysis of words which are not reducible to numbers and is a more natural form of data collection that more closely resembles real life⁶.

Qualitative research has a focus on meanings, and what a person has to say. A qualitative approach is the preferred method, as opposed to quantitative, for this type of study as it allows us to retain a focus on the older persons’ own framing around issues and their own terms of reference, rather than having this directed by the researcher.⁷ The focus group discussion can be flexible and questioning can evolve to suit the participants. This will enable a far richer and deeper understanding of the participant’s views than quantitative data.
We need to see the healthcare services for older people through the eyes of older people with frailty. Research should be respondent-led, valid and interested in gaining an insight into the older person’s individual meanings and motives. The National Health Service (NHS) encourages and supports patient-centred care therefore it is important that any healthcare service is tailored to the needs of the patient and achieving the best possible outcomes for their health and wellbeing. It is important to gain an insight of the opinions and feelings of older people with frailty in this research.\(^5\)

It has been suggested that by understanding what outcomes matter to older people with frailty it would allow clinicians and policymakers to align health care services to the needs of this group.\(^4\)

**Participants**

This study involved interviewing older people with frailty.

Questionnaires were open-ended with some topic prompts, rather than specific points, to encourage and facilitate a good discussion. This is a more appropriate form of research as individuals have different experiences and often view their reality in very different ways, therefore participants were encouraged to speak freely and feel involved in the research.\(^5\)

The interview lasted approximately two hours. Participants were aged 65 years and over, and had mild to moderate frailty i.e. 4 to 5 on the Clinical Frailty Scale \(^8\). Participants had to be able to make their own way to and from the interview. They were not incentivised and were responsible for their own travel costs. The author KT had held a talk regarding this research at the Sefton Older Persons Forum a few weeks earlier and had asked for participants to take part. Details of the criteria above were given and six people volunteered. In accordance with Braun and Clarke’s recommendations on numbers for focus groups, we had achieved enough participants to generate a rich discussion.\(^7\) Due to some of the sensitive topics that were to be discussed, it has been shown that smaller group sizes react better to discussing these issues.\(^36\)

Participants were given a ‘Participant Information Sheet’ to read before the focus group took place. The information sheet gave details about what the study was about, why the person had been invited
to take part, information on what happens to the recordings and any typed or handwritten notes, risks/benefits of the study and what to do if they wanted to withdraw their participation. Once the participant read the form and was happy to proceed, they were asked to sign a Participant Consent Form confirming their understanding of the information sheet and providing their consent to taking part in the study and being recorded. The tape machine was placed in full view of all participants and they could ask for it to be switched off at any time, for example if they needed a break or to ask a question.

A semi-structured questionnaire prompt-guide was designed using health outcomes identified by ICHOM, a literature review and discussion amongst the authors KT and AA as prompts to encourage as much feedback from participants as possible. A list of themes had been chosen from the ICHOM work with older people and used as bullet points/triggers for the focus group interview. Participants could “tell their story” and these questions were simply used to start the conversations.

The principal investigator (KT), after ethics approval, had flyers and participant information sheet distributed in several older people’s forums and only those who contacted her were then approached to see if they would be eligible for the study. Once consent was obtained after explaining and answering any questions a date and venue was agreed for the focus group interview. The interview, venue and arrangements to get the participants in one place was facilitated by the older people’s forum. Their responses formed the basis of the data collected and were used to identify health issues that are important to them.

To ensure that the research findings were valid and reliable the principal investigator KT implemented the following recommended strategies. KT, in addition to recording, made notes, and had regular discussions with the research supervisor AA, for support and guidance. Noble & Smith suggested seeking out similarities and/or differences across accounts to ensure different perspectives are represented and following-up with participants to confirm whether the final themes identified adequately reflect their views and what was discussed during interviews.

**The Interview**
The interview was recorded using a digital recorder and handwritten notes or comments made as appropriate. The audio recording was transcribed. The six participants needed very little prompting throughout the focus group interview. They were very willing to put across their views and talked openly. Often something a participant would say would prompt a question from KT asking them to explain further or asking for other members of the group to give their opinion. The two hours passed very quickly, and the conversation flowed freely and without any pauses.

We were seeking patterns with the themes but qualitative data allows for the exploration of differences and divergence within the data. The report included a balance between analytic commentary and data extracts. Themes were presented coherently and in an organised manner. According to Braun & Clarke (2013) the ‘themes should work together to tell a story about the data’.

**Data Analysis**

The aim was to generate rich data i.e. ‘thick descriptions’ from each participant by allowing them to talk openly and give as much information as possible.

Qualitative data uses words - written and spoken language. It values personal involvement and the method is less fixed. We can change topics or direction depending on the themes that arise. It has been shown that data generated by qualitative studies of this type have been associated with a high level of validity because the data collected from participants tends to be trustworthy and honest. Data was analysed as per the steps of Braun and Clarke. See Figure 1.

**Figure 1 - Braun and Clarke (reproduced with kind permission of the authors)**

**Ethics**

Ethical approval was granted by the University of Liverpool’s Health and Life Sciences Research Ethics Committee (application number 4163).
It was imperative that the following principles were agreed and met:

All information received from participants to be anonymised and kept confidential. Only generic information such as age and gender will be recorded on the questionnaires. No identifying features such as date of birth, name or address will be recorded. No photographs were to be taken without prior consent.

Participation was voluntary and informed consent gained from those taking part in the focus group. Participants were free to withdraw from the focus group at any time and withdraw any information that they have submitted.

No health and safety issues were identified regarding the interviewing participants and the interview took place in a local library, where local health and safety rules applied.

The interviewer KT conducted herself in a manner acceptable to the University of Liverpool Medical School’s rules and regulations and those set by the General Medical Council in relation to medical students.

Data was stored in line with the University of Liverpool’s Research Data Management policy.

Results

The focus group met on the morning of 6th February 2019 at Crosby Library in Liverpool. Six older people with frailty attended together with KT, principal investigator, and Justine Shenton, older persons’ advocate and forum co-ordinator. AA was in a nearby room for support and to answer any questions.

The focus group lasted for just under two hours and about 12,000 words were transcribed from the interview.

The data was transcribed over a period of eight hours. Themes have been identified and named to enable the researcher to present the themes in an organised and logical manner. Although many topics and issues were discussed, topics that were particularly important to the focus group were extracted and pulled together into themes.

The following themes were raised.

Trust in Medical Professionals

The group all raised the concern about ‘Do Not Attempt Resuscitation’ notices being placed on their medical records without consent. A ‘DNAR’ is a document that decides whether cardiopulmonary resuscitation (CPR) should be carried out on a patient who has stopped breathing. It is an invasive procedure that can result in broken ribs and is not always successful. One participant described doctors with a “nod and a wink”, insinuating that patients are kept in the dark. It is true to say that doctors have the final say with to a DNAR being placed on the patient’s file. The GMC says doctors are under no obligation to prolong life if they think the treatment is not in the patient’s best interests. Age Concern also expressed concerns that older people were being written off. Newspapers reported the case of Jill Baker, 67, who was suffering from stomach cancer and septicaemia, and discovered a ‘do not resuscitate form’ on her file without having obtained her or her husband’s consent or knowledge.

The group talked about the Liverpool Care Pathway and, although designed for terminally ill people, it was being used a tool for older frail people to “simply ease them into the next world”. Possibly to free up beds for younger patients. The Daily Mail a story called ‘Bed-blocking by Elderly Patients Rises’ which has done little to stem the belief that older people with frailty.
a burden to the NHS.\textsuperscript{23} This is one of many similar themed stories printed by the Daily Mail. Participants in the group reported stories of relatives being placed on the Liverpool Care Pathway without their permission or knowledge, or friends had similar experiences with regards to the pathway or DNAR forms. The group also talked about infections and one participant stated “[you] are frightened of coming out with more than you \textit{\begin{small}with\end{small}}”. The group reported a lack of trust around cleanliness of hospitals and one reported having to complain about the hospital staff repeatedly having no antibacterial gel in them. One reported wanting to get out of hospital as quickly as possible to avoid the fear of infection. The participants concerns are not unfounded. Hospital acquired pneumonia is the second most common hospital infection and has the highest crude mortality.\textsuperscript{24}

One of the participants sadly lost a baby daughter many years ago and unbeknownst to them and their partner, their daughter’s organs were stripped from her body in what later become the infamous Alder Hey organ scandal.\textsuperscript{25} The illegal retention of organs took place from 1988 to 1996 and all of the participants were familiar with the story and its background. One of the participants stated that they were due to have an operation but were refusing to go in as they “do not trust them [doctors]”.

Although the group did discuss participants disclosed that they “had never had time” after going into hospital. It is possible that the hearsay and negative stories they have reported around DNAR forms and the organ scandal have marred their overall opinion.

**Vulnerability of Being an Older Person in Hospital**

Two participants reported being placed on trolleys in A&E whilst waiting for a bed and having to deal with drunk and aggressive patients. One of the participants stated “If you’re on a trolley, which I was because my balance had gone. This girl, she was young, she was up and down the corridor. I was on a trolley there. And she was up and down all the time ‘I want a doctor, doctor’. She went on and on and on. And then suddenly she was patting me again and she went ‘Ahhh, are you alright lov saying ‘No I’m not alright!’ “. The participant stated she felt vulnerable. The other participant, with a similar story, said she felt vulnerable because there were so many people around. However, it is a concern that a patient who cannot defend themselves or flee from a situation is vulnerable in hospitals. Violence in hospitals places patients at risk and care for our most vulnerable, is not a myth. Research shows that 45% of NHS staff had sustained a physical injury from a patient or visitor at some point during their career.\textsuperscript{26} A year on from the introduction of the zero tolerance policy, the NHS continues to lose over £69m a year because of violent episodes.\textsuperscript{26} Violence between patients is difficult to quantify as research findings displays numerous results regarding assault against NHS staff, rather than patients. In any event, it is safe to assume that violence goes on in hospital, particularly in setting, and for an older frail person witnessing this, not least being involved, is distressing. One suggestion raised in the focus group was a separate area for older people with frailty in A&E, although the group unanimously agreed that they would not separate hospital, simply a separate area.

**Polypharmacy and the Wastage of Medication**

Polypharmacy means issues related to multiple drug consumption and excessive drug use.\textsuperscript{27} It is a healthcare outcome that was previously identified by ICHOM.\textsuperscript{4} Participants of the focus group identified the issue of the ‘wasting’ of medication due to polypharmacy. One participant reported taking numerous drugs including statins, antihypertensive medication, PPIs and C clamps. However, they only required the Quinoline on an ad hoc basis but were forced to order it monthly on their repeat prescription. This was because if they asked to “suspend” any drug then it would be removed from their list of regular medications and they would report difficulty in having it reinstated. One participant stated she was going on holiday last year had asked for a double repeat prescription as she would be away for a while. Since then, despite numerous attempts, she was unable to cancel the double prescription and has been receiving twice the required amount of medication each month. Medicine Waste UK\textsuperscript{28} have confirmed that this is indeed a problem and patients are ordering and receiving medication that they do not need. A report from the Department of Health estimated that unused medication costs the NHS approximately £50m per year\textsuperscript{29} and that patients are ordering and receiving medication that they do not need. A lot more difficult in practice, especially for older people with frailty who are ordering numerous drugs monthly.

**Discharge Planning & Co-Ordination of Care at Home**

The group talked about going home after a hospital admission and wanting to leave hospital as quickly as possible. Patients are often discharged but due to there being no-one to care for them at home, discharges are delayed. Majeed et al (2012) carried out a study into delayed discharge and found that older people with frailty who are admitted acutely and require medically optimised for discharge but due to there being no-one to care for them at home, discharges are delayed.\textsuperscript{54} The group also talked about going home after a hospital admission and wanting to leave hospital as quickly as possible. Patients can be delayed discharge planning and co-ordination of care at home. Participants of this focus group identified the issue of the ‘wasting’ of medication due to polypharmacy.

One participant stated that they were due to have an operation but were refusing to go in as they “do not trust them [doctors]”. The main concern seemed to be the delay of waiting for this to be put in place and having to stay longer in hospital than necessary.

**Taking Responsibility for Your Own Health**

One participant talked about society not taking responsibility for their own health which resonated with the group. One participant stated “Yes, I think we expect far too much sometimes [from the NHS]. Far too much! And people have got to take respons for their own health. End of”. The group discussed that there needs to be more awareness of what different services are available for healthcare problems than people turning up to A&E with minor problems due to shortage of GP appointments. The group also raised issues about being full of drunk people on Friday and Saturday nights, and this linked in with the theme of ‘Vulnerability of Being an Old in Hospital’. In a 2010 survey by the UK NHS, it was revealed that £4.2 billion yearly is spent on obesity treatments, £2.7 billion is being full of drunk people on Friday and Saturday nights, and this linked in with the theme of ‘Vulnerability of Being an Older Person in Hospital’. In a 2010 survey by the UK NHS, it was revealed that £4.2 billion yearly is spent on obesity treatments, £2.7 billion is spent on alcohol abuse and £1 billion on STDs. Missed medical appointments also costs the NHS £160 m per annum.\textsuperscript{30} The group is fair to blame older people with frailty for issues such as ‘bed-blocking’ as purported by the Daily Mail. The group discusses attending A&E for minor issues and having a better screening system in place. Although this issue applies not only to older people with frailty, but all people accessing the NHS, it was included as a theme as there is scope for older people, who may not have access to the internet, to understand how to improve and care for their own health “responsibility” and what services are available.

**Nomenclature**
The naming of things, people, places changes with generations, politics, culture etc. Older people with frailty have been called a wide variety of descriptors from geriatric to old, frail, elderly and more. When asked about what they would prefer to be addressed as, they were unanimous in the opinion of word ‘geriatric’ or ‘geriatrician’ not being used. A participant suggested ‘senior citizens’ sounds better which the group agreed with. With respect to the term frail, the group also agreed that they like this terminology being used. One participant stated, ‘If you put words down like that [frail] it makes them feel horrible said, ‘I don’t feel frail’ and ‘It seems to be landed just on your age. Frail, elderly, vulnerable... it seems to be landed on you’. It’s what people look at first and they should be looking at the person. What you can do, not what you can’t do.’ It was decided that elderly was no longer an acceptable word to describe older people with frailty, is it now time to stop using the terms and frail? The participants of the focus group agreed so.

**Autonomy**

Autonomy was another healthcare outcome identified by ICHOM and was again deemed important by the focus group. When asked if it was important to have control over decisions being made about you the group all responded yes. Patient-centred care is an important part of NHS care and a topic that is regularly discussed and taught at medical school. Evidence shows that patients who are actively involved in their own care and treatment have better outcomes and experiences. This study reinforces the findings of ICHOM that older people with frailty want to be involved in decisions being made about them, and that patient-centred care continues to be an integral part of delivering healthcare services.

**Falls**

The group all reported worries regarding falls. At least two participants described suffering fractures as a result of falls. According to Public Health England, the total cost of fragility fractures annually to the UK has been estimated at £4.4 billion which includes £1.1 billion for social care; hip fractures account for around £2 billion of this sum. Some of the participants had taken part in ‘fall training’ run by the forum they attend and the Forum Co-ordinator described sessions that had been run including talks on exercises, physiotherapy and the use of a personal alarm to call for help. Falls continues to be a strain on the NHS budget worry for older people. Addressing this concern with older people with frailty with their healthcare provider is important, a regarding falls prevention will reassure patients and hopefully avoid accidents. The National Falls Prevention Coordination ‘Falls and fracture consensus statement’ could be a useful tool for healthcare providers to discuss with patients at the outset of their treatment, regardless of what their admission or appointment is for.

**Discussion**

The focus group interview revealed a diverse range of issues that older people with frailty wish to be addressed.

Solutions were raised by the older people with frailty during the interview and the principal investigator, KT, has also attempted to further suggest solutions.
More awareness and openness around ‘Do Not Attempt Resuscitation’ forms. Older people with frailty are worried they will placed on their file to “free up beds”. This is creating a mistrust between older people and health professionals. Older people do not wish to be judged simply on their age, but their actual capabilities. Although medical professionals do have the say it is imperative that they do not make assumptions around resuscitation and involve the patient in decisions.

The worry of hospital acquired infections was a reason that older people with frailty put off seeking treatment. Infection control have a role in speaking to patients pre-admission with education on handwashing and disposing of waste i.e. tissues. This was a way to reassure older people and reduce cross infection. Currently there are signs displayed on wards asking visitor to wash their hands but no formal education in place. This could be a five-minute chat with an older person around the reasons for handwashing and good hygiene.

Interviewees were concerned about feeling vulnerable, particularly in an A&E setting. The idea of a separate area in A&E for people with frailty was discussed. The issue of older people being left out on trolleys in a busy A&E department must be addressed. There are financial pressures and hospitals are struggling to meet their four-hour waiting targets, but it is clearly an important issue considering that violence does occur in hospital.

Interviewees reported accounts of telling hospital staff they, or their friends, had family waiting at home for them when this was true. The media does not help with their portrayal of older people with frailty as ‘bed-blockers’. This is a misleading term discouraging older people with frailty to seek treatment. We must appreciate the financial constraints on the NHS and soc however, there does need to be robust systems in place for older people with frailty needing care at home. Delays are costing the NHS money and causing unnecessary distress to older people who wish to go home. This needs to be addressed as a matter of importance.

The interviewees reported frustration at not being able to suspend or easily change monthly medication requirements. This was given medication each month and most participants reported difficulties with medicine wastage. This is no doubt a nationwide problem.

The issue of ‘taking responsibility for your own health’ was raised and it was felt it is important to give older people with frailty tools to take care of themselves. There should be ongoing education on polypharmacy, falls and accessing the different types of healthcare services. Providing education and advice at every available opportunity may serve to reduce issues.

The interviewees confirmed that they do not like to be referred to as geriatric or frail, they wish to be judged on what they are an individual, rather than making assumptions based on their age.

The theme of autonomy was raised. We no longer practice paternalistic medicine and instead take a patient-centred approach. This has been shown to improve patient outcomes and regardless of a frail, older person’s age, we must continue to involve them in decisions around their care. This theme was identified by ICHOM and the group emphatically agreed with this.

Falls was a big worry for the interviewees. It has already been shown to be a huge financial burden for the NHS. The old ‘prevention is better than a cure’ stands true, particularly in this case and there is easily accessible information on prevent such as the NHS’s ‘Falls and fracture consensus statement’. This outcome was also identified by ICHOM and is an important that needs to be addressed. Not only can we educate older people with frailty on falls prevention, which links into taking responsibility for your own health and autonomy, but we can offer some reassurance.

Conclusions

There is a definite opportunity to provide better care, reduce falls and medication wastage, reduce discharge delays and be more efficient and effective in the NHS.

This research has shown that there is scope for improvement and there is a lot more that can be done on addressing health issues for older people with frailty. Feedback from the international conference was overwhelmingly positive. The authors hope that the issues raised in this research will allow clinicians to offer more personalised care for older people with frailty.

Abbreviations

AA - Asangaeedem Akpan (Dr)
A&E – Accident and Emergency
CPR - Cardiopulmonary resuscitation
DNAR – Do Not Attempt Resuscitation
GMC – General Medical Council
GP GMS - General Practitioner General Medical Services
ICHOM - International Consortium for Health Outcomes Measurement
KT – Kathryn Tipping  
NHS – National Health Service  
PPI – Proton Pump Inhibitor  
STD – Sexually transmitted disease

Declarations
Ethics approval and consent to participate – Ethical approval was granted by the University of Liverpool’s Health and Life Sciences Research Ethics Committee (application number 4163). Participants provided written consent to take part. 
Consent for publication – not applicable. 
Availability of data and materials – the transcript from the focus group is available from the author. 
Competing interests – none. 
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Authors' contributions – KT undertook the study and wrote this research paper. AA acted as research supervisor and undertook numerous revisions of the paper at various stages. 
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Figures
Figure 1

Braun and Clarke (reproduced with kind permission of the authors)