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Interviewing older people about their experiences of emergency hospital admission: methodology in health services research

Abstract: This essay makes the case for increased use of patient-centred methodologies, which involve patients and the public, in the area of emergency admissions research in the United Kingdom. Emergency admission research has rarely made use of the patient voice when attempting to find a rate of ‘inappropriate’ admission for older people, instead focusing on professional viewpoints and more abstract tools. We argue for the important insights that patients and their families bring to emergency admissions research and for the need to listen to and use these voices to find more holistic responses to the issue of unplanned admissions to hospital for those aged over 65. This area of health services research is highly complex, but without involving the patient viewpoint we risk not understanding the full story of events leading up to admission and what preventative measures might have helped, and therefore we also risk developing less effective, simplistic solutions. In the face of increasing challenges to the NHS’s ability to provide safe, effective and affordable care for older people, researchers need to listen to those with direct and longitudinal experience of their ill health and admission.

Keywords: Emergency Hospital Admission; Inappropriate Admissions; Older People; Patient and Public Involvement; Qualitative Methods

This essay reflects on the methodology used in a qualitative, mixed methods empirical study into older people’s experiences of emergency admission to hospital in the English National Health Service (NHS), and the insights learned from this for emergency admissions research. The essay will outline our approach to the research and the methods used before going on to

explore the reasons why this methodology appears to be so unusual. We argue for the need to work *with* those directly affected by certain health experiences and those who use health services when doing research, and discuss the benefits and challenges of this approach.

The issue of emergency admission of older people to hospital is not new [1, 2] and, alongside the academic and clinical research, has received considerable media attention and generated significant policy discussion and debate. [3, 4] It is a highly complex issue with no clear-cut solutions, but there are compelling reasons for further investigation. As we have outlined elsewhere, those aged over 65 account for two million unplanned admissions each year, which is around 68% of hospital emergency bed days. [5, 6, 7] With the current political and financial focus on NHS performance, it is important to explore solutions to the issue of unplanned admissions, as well as to test some of the underlying assumptions behind the public discussion and media coverage. These assumptions are often based on the idea that there are a large number of ‘inappropriate’ emergency admissions and that older people are taking up beds unnecessarily. [8, 9] The article will explore the project’s research aims and research findings, before going on to explore the lack of patient voice in emergency admissions research, and the benefits and challenges of following this approach.

Research aims

‘Who Knows Best?: Older People’s Contribution to Understanding and Preventing Avoidable Hospital Admissions’ was conducted at the University of Birmingham by the authors, in partnership with Professor David Oliver, Royal Berkshire NHS Trust; Dr Sally Jones, Heart of England NHS Foundation Trust; and Dr Iain Wilkinson, Surrey and Sussex Healthcare NHS Trust. We also worked in conjunction with the NHS Confederation, the Association of Directors of Adult Social Services, Age UK, the Social Care Institute for Excellence, and Agewell. The project was funded by the NIHR Research for Patient Benefit Fund (PB-PG-

0712-28045), running from 2014-2016. During this time we interviewed 104 older people from across the three Trust sites, interviewed 40 frontline staff, surveyed 45 GPs and hospital doctors connected with the older people's care, and ran a focus group with staff at each Trust site. Our study intended to discover a rate of inappropriate admissions, in addition to talking to older people themselves and frontline staff, and then meaningfully using that data in outputs: previous research has collected qualitative data from older people but then not gone on to make use of it in outputs and publications. From our literature search, we appear to be the only study that has followed this approach in the United Kingdom and internationallyⁱ.

[10] The practice of speaking to patients themselves about their experience is rare in emergency admissions research, with a consequent lack of patient voice. We were surprised at this finding and it forced us to reflect on the issue of whose voices are most common in emergency admissions research and why this might be. Our interviews with older people themselves are a distinctive feature of our study. These interviews were semi-structured, lasting between thirty minutes and two hours, and focused on participants' understanding of why they had been admitted at the time and what had happened leading up to the admission, as well as eliciting reflections on their time in hospital. [5]

Research Findings

As our literature search into emergency admissions research showed there is no clear evidence of inappropriate rates of admission. [10] Our own research also found that front line staff had widely different opinions as to how many of the patients they saw 'really needed' to be in hospital (ranging from 1-10% to 41-50%; see Box 1 for a summary of key findings). Staff estimates are an inexact measure, but they reveal the wide range of viewpoints even among the clinical team. If one person feels that everyone they see needs to be in hospital,

but a colleague at the same site says that only half the people they see need to be there, then there is clearly a lack of consensus about the indicators for admission and the extent and nature of the ‘problem’. [5]

Box 1: Key Project Findings [5]

- 104 patients or carers interviewed.
- Spoke to 40 frontline staff (A&E consultant; admission avoidance team leaders; community nurse practitioner (based in hospital); consultant acute medical unit; consultant geriatricians; consultant surgeon; dementia nurse consultant; deputy medical director; emergency department therapies team leader; falls sister; GPs; head of a voluntary organisation; matrons (hospital and community); occupational therapists; physiotherapists; senior mental health practitioner; senior nurses; service navigation team leaders; strategic manager); conducted three focus groups at three sites; and sent a survey to each consenting patient’s hospital doctor and GP.
- There is a difference between ‘inappropriate’ and ‘preventable’ admissions, with the former being unnecessary at that time, but the latter suggesting that the admission was appropriate, but intervention upstream may have prevented the crisis.
- Staff ‘guesstimated’ between 1-10% and 41-50% of admissions were inappropriate.
- Only 9 of the 104 patients felt they were ‘inappropriately’ admitted at the time of admission (and even these people seemed very unwell at the time of their admission). This is a key finding, and very different to previous research (which hasn’t engaged directly with older people in the same way) and to the assumptions in ongoing media and policy debates (which imply that a potentially significant proportion of older people in hospital may not need to be there).
- None of the hospital doctors or GPs felt the admission was inappropriate.
- There was a focus on ‘upstream prevention’ and the need for more preventative action: more GP accessibility, work with ambulance services, and geriatrician presence in accident and emergency centres.
- The solutions needed for upstream prevention are system-wide and that there isn’t a single ‘easy answer’ to the issue of older people’s emergency admissions (for example, a single service or new intervention which would ‘solve’ this problem and significantly reduce admissions).
- Hospital is still a default destination.

Lack of Patient Voice in Emergency Admissions Research

The lack of interaction with older people themselves in emergency admissions research is a key finding from our research, suggesting that in this area of health services research, our

methods are quite innovative. Emergency admissions research has focused on clinical decision-making and the use of admissions rating tools, such as the Appropriateness Evaluation Protocol (AEP) and the Intensity-Severity-Discharge Review System with Adult Criteria (ISD-A). [11, 2] In trying to make sense of emergency admissions – a political and highly charged concern within the NHS – these data can appear to be ‘objective’ and credible. Use of such data avoids making judgements upon those involved in the admission, and instead deals with the ‘facts’ of the event and post-admission outcomes. This may seem commendable, and is certainly understandable in a system focused on auditing and reporting of numerical data to both internal and external bodies. However, by reducing the complexity of the admission to certain check list criteria, we lose the ability to assess the admission from a more human perspective. In addition, by only involving clinicians, we lose the voice of the patient with the understanding of what led them to crisis point. Emergency admissions to hospital are highly complex events, and to remove the human stories and decision-making is to produce an unrealistic picture of events and therefore to be unable to tackle any concerns appropriately. This can lead to simplistic responses, which will ultimately be ineffective in solving the problem (such as a single service or intervention); more holistic responses are required.

The lack of patient viewpoints and in-depth qualitative research designs in emergency admissions research may be contributing to poorly-informed decision-making at all levels. Ethnographic studies into other areas of health, which include patient experience, have provided valuable insights. For example, an ethnographic study by Keyser-Jones into the experience of dying provides detailed insight into the ways patients and families experience care around the time of death, and how, in many cases, needs were not being fully met. [12] This was in part due to limited staffing, which had a significant impact on care. However, talking to patients also revealed the more mundane and everyday issues that made their

experience of death more difficult, including inattention to eating habits and cultural differences in eating, lack of communication about death and grief, and lack of understanding around the need to continue to take part in activities, such as being taken for a walk in the sunshine and enjoying fresh air. The study's focus on patient experience, and ethnographic observation, provided this information, which patients were often unable to express to staff. Ethnographic insight into emergency admissions was completely lacking in our review [10]. We can only speculate as to the reasons for this, but it fits with the wider picture in which patient experience is absent. Though our study did not include observation of admissions, it provided insights into patient experiences similar to Keyser-Jones' study, giving a more comprehensive picture of the lead-up to the admission and the admission itself. [12; 5] The older person, their close loved ones and carers provide a longitudinal perspective that cannot be gained in any other way. This perspective can provide insights that professionals do not have, due to their necessarily episodic contact with patients. The need for this holistic overview is something research in this area should be mindful of.

As Nolan et al. argue, health research tends to fall on a continuum of patient and public involvement (PPI), with the user role being anything from 'subject' to 'investigator' and the researcher role being anything from 'investigator' to 'mentor'. [13] Our project falls somewhere in between these two approaches, but much emergency admissions research has fallen squarely at the end where users are subjects and researchers are investigators – when it has involved patients and the public at all. With the importance of patient and public involvement in research increasingly recognised, the lack of patient voice here is an obvious concern.

As one of our team has previously argued, we do need to be critical of the use of PPI and not use it as a tick-box exercise without assessing the potential benefits to those taking part (as

well as the research outcomes). [14] However, in the area of emergency admissions, patients, families and carers have been side-lined in favour of professional and clinical viewpoints, and the use of abstract tools, to an extent that is unhelpful. The issue of ‘inappropriate’ emergency admissions for those over 65 has not been solved yet and using more patient-centred methodologies may well be a way forward.

Furthermore, some might argue that there could be vested political and media interests in this issue, making it is easier to claim that we could manage better within existing resources if those who do not need to be in hospital are not admitted (in other words, if resources were better organised and/or managed). However, our project results suggest that both patients and professionals felt the majority of participants were appropriately admitted, and challenge the previous literature and assumptions (which, as we have argued, seem to have been shaped without engaging directly with older people themselves). [see also 5]

Interviewing Older People: Benefits and Challenges for Emergency Admissions

Research

Benefits

In speaking to older people and their families, we were able to learn many important things about the admission that other methodologies do not allow. We discovered detailed stories of individuals’ medical and social needs; the important role of family in making a decision to go to hospital; the history of visits to other health professionals before the admission, both routine and irregular; and we heard about some mistakes and missed opportunities. A key finding was that the majority of our sample felt they were *not* inappropriately admitted to hospital, but that they needed to be there at that time. These narratives from the person experiencing the admission add important details to our understanding of how an older person comes to be admitted to hospital.

The story of one of our participants provides an example of the insights gained by eliciting patient perspectives. This patient had chronic renal problems, and tried unsuccessfully to access help and advice in the community from her GP. Unfortunately, due to long waiting times, she was unable to see her GP in time and decided to go to the local walk-in health centre. She was seen by a professional unfamiliar with her background and prescribed incorrect medicine. Her condition therefore deteriorated, resulting in an emergency admission. This admission was clearly necessary and appropriate at the time, but her story suggests that timely access to her GP may have prevented the problem from progressing, or allowed for a planned procedure. This insight would not have been revealed by more traditional measurements of in/appropriate admissions.

Another of our participants described how she waited three days to call an ambulance after falling down the stairs, and only did so when family came to visit and persuaded her it was necessary. Similarly, a participant with breathing problems was only persuaded to go to hospital by his daughters, one of whom was a medical professional, despite the seriousness of his condition. There is no doubt these participants needed to be in hospital, but their concerns about wasting the time and resources of the NHS would not have been revealed without the time spent in discussion with them.

As a final example, a carer we spoke with described her mother's vascular dementia and the caring responsibilities she had increasingly taken on in recent years. She and her husband act as her mother's sole carers and, when they both became very unwell themselves, her mother was left without support. She had an accident and needed admission, and a long hospital stay followed as social care was not accessible. The lack of social care support that could be accessed quickly in times of emergency resulted in an emergency admission, and an extended stay in hospital beyond her medical need. These stories illuminate the close connection

between medical and social care for some of our sample, and the significance of the limited availability of social care to those in need.

Talking to carers about the lead-up to and the admission itself revealed a level of frustration with the system. Carers and family members often felt left out of decision-making, despite being the person who would have to continue the care of their relative following discharge from hospital. The study showed the importance of involving carers in planning discussions, as they can provide a perspective on the older person, their everyday health, and what is 'normal' for them that even the older person may not be able to provide. Carers are crucial, particularly when social care services are so stretched.

Challenges

There are challenges in conducting this kind of research and most come down to moral and ethical concerns (which tend to be of concern in any qualitative project). The carer perspective, though providing many valuable insights, as outlined above, also raises some difficult ethical questions for researchers. Carers' everyday involvement means they come to have tangible and in-depth knowledge of the person and their health, and it is understandable they wish to be heard as an important partner in their care. However, the carer's voice should not outweigh that of the older person themselves in research settings. This can be difficult to manage if carers want to be interviewed alongside the person they care for; researchers have to be prepared to negotiate this dynamic and create opportunities in the conversation for the older person to tell their own story. This requires considerable interviewing skill and how these issues might be managed strategies should be discussed in research team meetings.

In our project, these interview dynamics did not tend to arise, as when we met with carers it was usually because the clinicians we worked with had decided that the older person themselves was unable to consent to take part. Carers in our study participated as consultees

under the Mental Capacity Act. This was an attempt to ensure that the experiences of those with dementia – as captured by their carers – were not excluded, even when patients were seriously ill. We recognise the shortcomings of this approach in excluding the patient’s own voice, but we had also to be cognisant of the ethical requirements of the Mental Capacity Act and the NHS, which are intended to keep people safe. NHS ethics committees may, understandably, have concerns around the inclusion of participants with dementia and whether and how researchers engage with them, as well as more general concerns about discussing sensitive issues with patients who are unwell. Such ethical requirements in any research project may introduce certain restrictions on what can be done and these are always worth revisiting and debating [15], to ensure the best possible response.

A final challenge is the ‘moral economy’ that exists in relation to emergency admissions and use of NHS resources. It is of course a morally charged question to ask someone whether they think their admission was appropriate, and likely that people will want to say ‘yes’. There is an argument, which holds across a number of disciplines, that more anonymous methods can minimise the effect of this desire to be seen as using services appropriately and not being a burden [16] In this project we sought to triangulate the perspective of the older person or their carer/family member with a professional opinion, to see whether there were disagreements or tensions.

Conclusion

Speaking to older people allows for a greater understanding of the complexity of emergency admissions and reveals the need for medical *and* social responses; for better communication between health services, social services and the patient; and the need to utilise the expertise of the third sector. Our findings also highlight the importance of key people to the health of the older person, in particular their GP and family members. These insights are needed in

order to comprehensively understand the dynamics around emergency admissions. Again, our research suggests the majority of admissions are appropriate and that the solutions needed for upstream prevention are system-wide and that there is no single ‘easy answer’ to the issue of older people’s emergency admissions (for example, a single service we could set up or a new intervention which would ‘solve’ this problem and significantly reduce admissions). [5]

Such information allows researchers, clinicians, policymakers, politicians, and the public to respond to the issue in more informed ways; the methods we use and the approach to research that we take creates certain kinds of knowledge and understanding, which can open up or close down potential practice and policy responses. In looking at the emergency admissions of older people from the patient perspective, we gain a more holistic understanding of the issue.

Emergency admissions research has relied on the opinions of professionals and rating tools at the expense of patient involvement. There is certainly an important place for the views of professionals, and even, in certain circumstances, for tools, but without patient viewpoints we learn only part of the story, and not always a fully useful one for finding solutions rather than simply naming an admission as appropriate or otherwise. It would appear that, in this area of health services research, there has been an unwillingness to listen to and take seriously patient perspectives.

As Nolan et al argue, those we include in our research reflect our opinion of whose voices deserve to be heard. [13] By sharing the platform with patients and the public we acknowledge that they have insights equally worthy of discussion and consideration as those of professionals. This creates a commitment to hearing a wider range of viewpoints and allows a more holistic, but also potentially more complex understanding of the issues at stake, as well as the possible solutions. Emergency admissions research to date has involved

patients and the public in highly limited ways. [10] We would argue that this area of health services research, in order to meet the needs of an increasing older population, while also effectively using NHS resources, should embrace more patient-centred methodologies.

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ⁱ This search was conducted by the Health Services Management Centre specialist library, University of Birmingham. The following databases were searched: the Health Management Information Consortium database; MEDLINE; the Social Science Citation Index; the Applied Social Sciences Index and Abstracts; AGEINFO; CareData Abstracts; and Social Care Online. Searches were on English language articles only. For a full description of this search, including more information on these databases, search terms, and inclusion and exclusion criteria see 10.