

**Listening Makes Sense:
Understanding the Experiences of
Older People and Relatives
Using Urgent Care Services in England**

Final Study Report

by

Jackie Bridges

PhD MSN BNurs(Hons) RN RHV

March 2008

Funded by The Burdett Trust for Nursing

**Listening Makes Sense:
Understanding the Experiences of Older People and Relatives
Using Urgent Care Services in England**

Final Study Report

Project Steering Group

Dr Jackie Bridges (Chief Investigator)

Sir Jonathan Asbridge, Carillion PLC

Dr Graham Box, Chief Executive, National Association for Patient Participation

Caroline Davies, Senior Nurse for Practice Development, Brighton & Sussex
University Hospitals NHS Trust

Antonia Lynch, Nurse Consultant, Emergency Care, Barts and The London NHS
Trust

Professor Julienne Meyer, City University

Theresa Shaw, Chief Executive, Foundation of Nursing Studies

Deborah Sturdy, Nurse Adviser, Older People, Department of Health

Rob Way, Nurse Consultant, Emergency Care, Oxford Radcliffe Hospitals NHS
Trust

Dr Jackie Bridges
Senior Research Fellow
City Community and Health Sciences
City University
Philpot St
Whitechapel
London E1 2EA
United Kingdom

Tel +44 (0)20 7040 5469

Fax +44 (0)20 7040 5529

E-mail: j.m.bridges@city.ac.uk

© City University, London, United Kingdom

ISBN 978-1-900804-38-7

Table of Contents

1	Background.....	7
2	Literature Review.....	9
3	Methods.....	11
4	Findings.....	15
5	Discussion	23
6	Recommendations.....	25
	Appendix one: report of consultation phase	27

1 Background

Substantial shifts in public attitudes towards and expectations of public services, including growing expectations of greater control of and choice in service delivered, have prompted recognition of the need for more personalised services¹. While in UK health care, aspirations towards individualised or person-centred care are not new, achieving these consistently can seem elusive. Equally, a range of measures are now in place to promote lay involvement in shaping how health services are delivered, but there is general agreement that some groups are harder to involve than others. The need to improve personal experience of public services has more recently emerged as a key policy goal¹, but in order to achieve this, effective ways of exploring and responding to these experiences need to be found.

Older people have special needs when they have a health crisis, whether taking up community-based services or services at a local hospital. Greater understanding is needed of how best to deliver personalised health care to older people in ways that deal not just with the primary presenting problem, but that also address the wider range of needs that older people can have. Delivering this type of health care involves the efforts and expertise of a range of people including clinicians, support workers, managers, educationalists and service commissioners. This study uses interview data gathered from older urgent care patients and their carers from case study sites across England to draw a national picture of older people's experiences of urgent care.

Older people are key users of emergency and other urgent care services. An estimated 18% of accident and emergency patients are aged 65 years or older, with highest attendance rates in people aged over 80 years^{2,3}. Empirical work in emergency care has highlighted the special needs of older patients. For instance, they often present to the emergency department with more complicated conditions than younger people, need more time and tests, and are more likely to be admitted to hospital⁴⁻⁷. However, little is known about their experiences of emergency care.

In 2005, Sir Jonathan Asbridge, national director for patient experience in emergency care, established a national leadership programme for matrons, nurse consultants and emergency care practitioners in urgent care. The programme was delivered through a variety of modes including providing training in discovery interviews with older people and their carers⁸. The patient and carer narratives generated through the leadership programme were used by individual participants to stimulate changes in their own Trusts. Using these research questions, City University subsequently undertook a cross-analysis of 96 of these narratives:

1. What are the experiences of older people and their carers in urgent care?
2. What are the different elements of service that older people and their carers identify as significant influences on their experience?
3. How can the experience of older patients and their carers be improved?

Findings from this analysis are presented below. These findings were also shared with a wide range of stakeholders including older service users, their relatives, NHS staff and managers, Help the Aged and Age Concern England. Stakeholders were invited to devise the project recommendations set out below. More details of the consultation phase are given in appendix one.

The term ‘urgent care’ is used in here to refer to a range of services including emergency departments, out-of-hours primary care services, minor injuries units, walk-in centres, urgent care centres, and ambulance services.

The Burdett Trust for Nursing funded the thematic analysis of discovery interview transcripts, the consultation phase and the development of a range of educational resources located at www.city.ac.uk/listeningmakesense . Full ethical approval for this project is in place with Oxfordshire Research Ethics Committee.

2 Literature Review

The published research literature reflects that we understand little about the emergency care or other urgent care experiences of older people. The most extensive work has been conducted in the USA. Baraff et al.⁹ conducted five focus groups in various locations across the USA, each with 5-13 members aged 65+ years. Hedges¹⁰ surveyed 593 people (n= 418 aged 65+) from six different US locations using a structured questionnaire administered through telephone interviews. Watson et al.¹¹ conducted interviews with 12 older patients (mean age 76 years) who had been patients at 3 emergency departments in the western US. In two Scandinavian studies^{12;13}, interviews were conducted with small samples (n=7 and 11 respectively) of patients aged 65+ about their experiences of care. One New Zealand focused on people aged 80+ admitted through one emergency department combined audit findings with face-to-face and telephone interviews with 13 people¹⁴. Common findings that emerged from these six studies are shown in box one.

Box 1: Findings from published studies

- General satisfaction with services^{9-11;14}
- Trust in the quality of clinical care^{9;11-14}
- Anxieties about condition, treatment and being left alone^{9;12}
- Noticing busy staff and needs of other patients^{9;11;12}
- Importance of good staff interpersonal skills in providing dignity, comfort and relieving anxiety^{9;11-13}
- Importance of low waiting times⁹⁻¹²
- Need for information about one's condition and treatment^{9;11-13}
- Need for help with activities of daily living, including eating, drinking and relief of discomfort^{9;11-13}

Given international differences in service organisation and delivery, and in cultural expectations of ageing, health, illness and health services, generalisability of these findings to other countries cannot be assumed. Just one UK study focusing on older patients' experiences of emergency care has been located. Spilsbury et al.¹⁵ conducted qualitative observations of care and interviews with 12 emergency care patients aged 75+ from one UK department in 1997. Findings were consistent with those of other studies, but also suggested that older patients perceived negative staff attitudes based on assumptions about old age, the importance of adequate toilet facilities and the valuable role that relatives can have in communication. Again, generalisability of these findings cannot be assumed because of the single case study location, but also the degree of policy development for this patient group and for urgent care services in general since the work of Spilsbury et al.

3 Methods

A form of narrative methodology, known as discovery interview technique, was used to explore the urgent care experiences of older patients and their relatives from 31 sites across England. The research questions guiding the project are:

1. What are the experiences of older people and their relatives in urgent care?
2. What are the different elements of service that older people and their relatives identify as significant influences on their experience?
3. How can the experience of older patients and their relatives be improved?

Discovery interviews were developed in 2001 by the UK coronary heart disease collaborative (now the NHS heart improvement programme) as a way for practitioners (and other involved in service provision) to gather in patient and relative stories using one-to-one semi-structured interviews and to share them with local clinical teams to stimulate local service improvements^{16;17}. The technique has since been used as a service improvement tool with a range of other patient groups. During 2006 a Department of Health national leadership programme for urgent care matrons, nurse consultants and emergency care practitioners included training^a in discovery interviews with older people and their relatives⁸. The resulting 96 interview transcripts are the data for the main findings reported here. Biographical details for some patients (n=66, 72%) were also supplied via a written questionnaire completed by interviewers.

3.1 Sample

Inclusion criteria specified people aged 75 and over who have used the emergency care system, and their relatives. The exclusion criteria were:

- Patients/relatives who would not be able to cope physically with an interview of 30-40 minutes
- Patients/relatives who would be unable to cope mentally/psychologically with an interview lasting 30-40 minutes.
- Patients who were confused at their time of admission, when consent would be offered or at the time of interview were also to be excluded
- Patients/relatives who were distressed at any stage of the process from first being approached through to the interview itself

^a Participants were each given 1.5 days of training in conducting discovery interviews by Wendy Gray, Sheelagh Machin and Mel Wright, all of them experienced discovery interview users and trainers. Participants were subsequently invited to submit a 'practice tape' to the Department of Health for evaluation and feedback. This was seen as an important mechanism for assuring the quality of the interviews subsequently conducted. Telephone support and action learning sets were also available to interviewers through the leadership programme to enable them to reflect on progress and discuss issues of concern.

- Patients/relatives who had made a formal complaint to the Trust

Interviewers were permitted to choose a particular focus for their work, for example, to focus on those who have visited emergency care as a result of a fall. While random procedures for patient selection were advised, most interviewers in fact used a convenience sample. Twenty-two interviewers provided details of patients and relatives approached to take part in the study who refused to do so. Fifty-seven patients and relatives refused to take part, 6 patients could not be contacted again or scheduled to take part in an interview, and 5 patients died prior to the interview or were too ill to take part. Of those who refused to take part, 53 were patients and 4 were relatives. This difference is accounted for through the interviewers' practice of first approaching patients for consent to interview their relatives, thus improving the likelihood of relatives agreeing to take part. It is not known how many patients or relatives refused to take part when approached by interviewers who did not return written questionnaires. These 22 interviewers reflected a participation rate of 51% (71 out of 139).

3.2 Data Collection

Discovery interview technique involves practitioners conducting one-to-one semi-structured interviews with service users that focus on the interviewee describing their experiences in their own words. Three 'spines' to guide the interviewee's narrative through all parts of their urgent care experience were devised for this project and are shown in box two.

Fifty-six percent (43 out of 77) of interviews took place at the patient or relative's home, and 43% (33 out of 77) took place in the building in which the urgent care service was delivered (n missing = 19). Fifty-five percent (41 out of 75) took place within 7 days of the urgent care experience described, and a further 11% (8 out of 75) took place within 8 to 14 days (n missing = 21). A small number of interviews took place some time after the urgent care experience described. The longest time lapse was 12 months, a period cited for one of the interviews. One interview was conducted at 9 months and two interviews at 6 months after the experience described.

Interviews lasted between 1 and 37 minutes. The mean interview length was 12 minutes (standard deviation 6.5), the median was 11 minutes and the mode was 7 minutes. Interviewers used an audio recording device to record the interview and arranged transcription within their own organisation.

3.3 Data Analysis

QSR XSight 2.0 was used for a thematic content analysis of data¹⁸ with the aim of systematically identifying recurrent or common themes, at the same time as exploring deviant cases. This was a largely inductive process, with the exception of data on 'receiving services', for which Nolan's six senses framework¹⁹ (see box 3) was used to order data. Descriptive statistics were also used to construct a biographical profile of subjects, using questionnaire data supplied by interviewers in addition to biographical details gleaned from transcripts. Ethnic groupings used were those used by the UK Commission for Racial Equality.

3.4 Ethics

Full approval was given for this study by the relevant research ethics committee. Measures taken included interview training and quality appraisal, ensuring informed consent from interviewees, the anonymisation of interview transcripts, and a range of measures to ensure data security.

Box 2: Spines used as interview guide

Spine of themes for those admitted

- First realising something was wrong
- Getting to the A&E department
- Arriving in the A&E department
- Being in the A&E department
- Leaving the A&E department
- Arriving on the ward
- Being on the ward

Spine of themes for those who are not admitted:

- First realising something was wrong
- Getting to the department that provided care
- Arriving in the department that provided care
- Being in the department that provided care
- Leaving the department that provided care
- Arriving at home
- Settling at home

Spine of themes for those receiving care in community settings

- Thinking something was wrong
- Talking to someone about getting help and support
- Seeing someone in the NHS
- Having tests/an assessment
- Finding out what was wrong
- Getting care, treatment or support
- Being back home or on the ward

Box 3: The Six Senses Framework

In the best care environments all participants (older people, family carers and practitioners) experience a sense of:

Security – to feel safe

Belonging – to feel part of things

Continuity – to experience links and connections

Purpose – to have a goal(s) to aspire to

Achievement – to make progress towards those goals

Significance – to feel that you matter as a person

Nolan et al. 2006

4 Findings

Ninety-six people from 31 English NHS Trusts were interviewed. Sixty-nine patients and 27 relatives were interviewed. Sixty-four (72%) of patients were female and 25 (28%) were male (n missing=3). Mean patient age was 82 years (range = 75-95 years, standard deviation 5.8, n missing=23). Sixty-four of the patients were classified as White British by interviewers, 2 as White Irish and 1 as White Other (Italian). Two other participants were classified as Asian or Asian British, with no other ethnic groups apparently represented (n missing = 23). Most patients lived at home (n=64, 90%) or in sheltered accommodation (n=6, 8%, n missing=21). The main urgent care service used in the experiences described was emergency department (n=68, 75%), minor injuries unit (n=5, 5%), urgent care centre (n=5, 5%), and walk-in centre (n=5, 5%). Other narratives (n=8, 9%) covered out-of-hours GP visits, a GP admission to an in-patient unit and an ambulance journey.

The interview data resulted in six key themes, each of which is now considered in turn. Findings highlighted the reluctance that some older people have in seeking help, a diminished sense of significance while in receipt of services, the fear and anxiety that can be provoked in the alien environment of emergency care, the importance of personalized and continuous care and the key influencing role that accompanying family members can have.

4.1 Older people can delay seeking help and often need help deciding what to do

In 24 cases a decision was made by the patient and/or relative to wait before accessing services. Sometimes the delay was for a couple of hours while e.g. the relative assessed what was happening and decided what to do. In 9 cases, patients waited overnight to see if the problem resolved. In 3 cases, the wait was 2-4 days. The data reflect an approach of 'wait and see' until, for instance, pain becomes intolerable. Five of the overnight waits related to falls or other accidental injuries, and a worsening of pain or function, or a failure of the problem to resolve prompted help-seeking. Four people who waited overnight or longer were later diagnosed with cardiac problems. Two of these waited overnight with chest pain and two others waited longer than this (one for two days and one for three) with less specific symptoms.

Family members played an important part in deciding to access urgent care and were often older people's first port of call. In many cases, a relative or friend was involved in making the decision to access urgent care services, with the patient reluctant or unable to do so.

"She was alright but it was quite a bad gash...there was nothing to be done and hospital was the obvious answer...She didn't want to go, as with all elderly people she didn't want the fuss, and kept telling me it was fine. But it wasn't fine, it was quite a battle to convince her that she needed to go and then she was concerned about putting me out. I know for a fact that if we hadn't rang her

she would not have let us know she had hurt herself, it worries me sometimes, she is so fiercely independent.” (Relative 44)

Primary care medical staff, including out-of-hours services, also played an important part in prompting access to emergency care. In 28 cases, a primary care doctor was contacted, often through a local out-of-hours service. In 28 cases, the first point of contact with services was calling an ambulance, and in 23 cases individuals took themselves or were taken by a relative directly to the emergency department or walk-in centre. Just one person reported using NHS Direct.

4.2 Older people may feel they do not matter

Many older people and their relatives expressed a high satisfaction with urgent care services received and were content to play a passive role in relation to their clinical care, judging that urgent care staff knew best.

"Patient: They don't tell you, they just do it. The nurses and all that they just go about their job and they are very good at it. Its best for them to do that rather than keep mithering me about it.

Interviewer: How does that make you feel or what do you think about it?

Patient: It doesn't bother me because they know better than me what treatment I need you know. As long as they get it right that's all I want". (Patient 16)

However, older people often also reflected a diminished sense of significance¹⁹, because of the nature of the urgent care environment and a perceived power imbalance with staff. Frequent references to the needs of other patients highlighted how other people can be hard to ignore (visually and aurally) because of the particular layout of the urgent care setting. Interviewees reflected being acutely aware that staff have to juggle their needs against those of other patients.

"I mean look at it in this light I am not the only pebble on the beach, and I can't expect them to run around me and forget they have other patients" (Patient 52)

For some patients, this diminished sense of significance made them feel that they were not perceived as legitimate patients, while others were reluctant to share important information or ask for help or advice.

"The nurses do what they can, but they think I should stand up straight, but when you can't stand up straight, it's not my fault is it? You know what I mean? I suppose they think that there are others to be seen to, why are we spending all this time here. " (Patient 35)

"I wanted to [ask advice from the urgent care centre nurse] but she had been so good and she had to spend such a long time... over half an hour with me, sorting me out, gently, gently. I didn't think it was right to bother her any more, her time was precious she had probably got lots of things to do; I could hear

people outside the room so I didn't want to take up more of her time" (Patient 40)

A small number of patients mentioned that their age may have affected their perceived significance with staff:

"I wondered why are [other patients] going in front of me, it didn't worry me, then I thought, they are young, probably going to work" (Patient 13)

For some patients, a perceived power imbalance with staff constrained what they felt able to say.

"I couldn't answer her back because she was a nurse." (Patient 72)

"I don't think [the staff] found out then that I was a diabetic, so I was having ice cream and things. I don't know whether that was right or not but I don't think they found out." (Patient 35)

In summary, older people appeared at risk of feeling they did not matter, a risk exacerbated by the nature of an urgent care environment in which other patients and their needs are highly noticeable, and by a feeling that urgent care staff are in a more powerful position. This diminished sense of significance appeared to constrain some older people in expressing their needs.

4.3 The urgent care setting can provoke fear and anxiety

While some patients and their relatives were experienced users of services and knew what to expect and how to find their way round, for other patients, institutional urgent care environments, acute care environments in particular, provoked anxiety. Some people expressed a general fear of hospitals.

"Well I am a very, very nervous person. I used to be terrified of hospitals. I had my operation nine years ago and I am much less anxious now but it is still there. I don't know why really. I can just remember feeling worried" (Patient 40)

Others appeared to have expectations set by the media about hospital-acquired infections and long waiting times.

"We were waiting less than an hour before the nurse came and collected us. I thought that was good because you hear that people can wait for hours and hours" (Relative 43)

The shock and fear related to the incident or illness that prompted urgent care attendance, plus a disorientating physical environment, often led to high anxiety for patients and relatives.

"I hate ill manners at the best of times. Courtesy and manners, cost nothing, there seemed to be no consideration for how you may feel after a shock. She knows the ropes I didn't. I obviously thought I was following her instructions. They had all got the curtains open, there was someone sitting in the cubicle...but I assumed she was telling us to go and sit in with someone who was waiting, while they dealt with my mother-in-law...this raced through my mind and I thought I'll do that. I'm not very good in hospitals at the best of times...And of course I was concerned about the mother-in-law and I couldn't think straight" (Relative 44)

In summary, the nature of the urgent care setting can provoke anxieties for older patients and their relatives.

4.4 Older patients highly value a 'personal touch' from staff and help with activities like going to the toilet

Patients and relatives highly valued a kind and person-centred approach from staff. They identified the importance of staff giving information in ways that were tailored to individual needs, for example, taking into account communication difficulties or impaired cognition, while maintaining a respectful approach.

"I have seen a change in the doctors...The doctor sat on bed and explained everything they were doing and showed me the computer that showed my eye and everything. They've come a lot further than the first time. This makes me feel not as frightened, they've come a long way and they explain what can happen and would happen" (Patient 34)

"She asked me some questions, I can not remember everything, there was lots of noise ...I could not hear the lady very well" (Patient 42)

Some patients stated the value of frequent checks and regular attention from staff.

"They did come up and kept asking me – "are you alright" and I felt that was wonderful" (Patient 23)

Findings also highlighted the value of staff identifying and proactively offering help with needs such as eating, drinking, resting and getting comfortable. Being offered and getting help to use the toilet was highlighted as particularly important.

"I needed to go to the toilet. I didn't want to be a nuisance. Everyone was rushing about and I could not ask my neighbour [who was sitting with patient in emergency department]. So I tried to hold on until I came home. It was all right." (Patient 42)

In a small number of cases, relatives reported older people with multiple needs that did not appear to have been met and a perception that staff had other priorities.

"My husband went up with my dad that evening to go and see mum and they looked around and they saw mum in the bed and, because she actually has to be propped up in the bed because of her balance and everything, she had got nothing at the side of her. She had been put on her side and she'd got a dislocated shoulder anyway, and was stuck on her side and my husband said he just nearly died when he saw her, anyway she was slumped and her head was down, there were no cot sides on the bed. He managed to get someone to move her and he said the smell of urine in there was absolutely appalling, anyway they removed the sheet and she was absolutely covered from head to toe in urine. The catheter bag, because she is catheterised, had leaked so he said whilst he was there, admittedly they did attend to mum, probably 4 or 5 times, but it was the fact that he found her like that, and it is not as though they were rushing round doing anything, they were all sitting on desks having a laugh and a joke, that's what was upsetting." (Relative 60)

In summary, this set of findings highlighted the importance of good interpersonal and communication skills and of staff proactively ensuring that patients were comfortable and had their daily living needs met.

4.5 Continuity of care and good discharge planning are important

Older patients often described urgent care visits that included contact with multiple members of staff and incidents in which older people were told that something was planned (such as a physiotherapy assessment) which subsequently did not happen, or, for example, help was given getting to the toilet but not with getting back.

"I saw the doctor and he said to me what's wrong with you, so I said I told him exactly I told you, I don't know whether it was you or one of the other nurses but I told him me stomach has not been right and about going to the toilet and all that. He wrote it all down in a book but he never even looked at me and anyway, after I left there and they brought me home again and I have just carried on the same since." (Patient 10)

Frustration was also expressed at repeated assessments by medical staff.

"I was lying there waiting then two or three doctors came in. And I must admit they asked the same questions over and over again. Each doctor asks the same questions and you tell them the same details I presume that is just a precaution to ensure they get accurate information but it is quite frustrating. When you are not feeling well it is reassuring to see the doctors but not when they keep asking the same questions." (Patient 56)

In addition, a number of older people had apparently preventable trouble managing at home after their urgent care visit.

"After my neighbour left, I managed to get to the toilet. I didn't use my frame I held onto what ever I could. I had a sling around my neck you see...The doctor

said I had to keep it on for a few days. I had a slight accident...but I managed with this hand and the home help came in the morning and was able to do the laundry" (Patient 42)

This set of findings highlight the importance of a sense of continuity¹⁹. Experiences shared here highlight the need for activities to be purposeful, for plans to be followed through and to consider the impact of the illness or injury on self-care abilities when planning discharge.

4.6 Relatives accompanying patients have an important role

Findings illustrate a number of important aspects to the role of relatives who accompany older patients through their urgent care experience. The role of the relative often became more prominent when the patient had impaired cognition and/or communication abilities.

Family members (or sometimes neighbours or friends) often accompanied older patients throughout their urgent care visit. This appeared to provide patients with much-needed company and reassurance. Patients described their relatives as ‘back-up’ and ‘someone to turn to’ (Patient 27). Having a relative (or friend or neighbour) with them relieved anxiety for some patients. One patient reported that she felt better immediately when her neighbour who was visiting someone else in hospital spotted her in the emergency department and offered to sit with her. Relatives often liked to stay with patients even if the patient was not apparently aware of their presence.

Relatives also monitored the patient’s condition, the quality of the service and, if felt to be necessary, took a proactive role with staff to ensure that best care is delivered.

"She said that when you have fractured ribs, there is nothing that can be done ... you just have to wait for it to heal, there wasn't a cure, just painkillers which she had. She gave her a really good examination and I was happy with that. She was kind to [my wife] too and that was important. What I really noticed is that she spoke to [my wife]...a lot of the time people try to talk through my wife ... they ignore her as if she is invisible and just talk to me" (Relative 43)

"There was a point, I think they put the drip up on the ward by the time I got up to the ward it wasn't working properly and nobody seemed to come to check it. The wife dropped in to see me, and she sort of stirred things up about it, so they came and got it working again but after that it was OK." (Patient 59)

Relatives appeared to play a key part in information exchange between patients and staff, and also influenced patients to access services and/or stay in hospital when this was needed.

"Older people, it needs two of you to hear the same thing from both points of view. My husband is very deaf. You can't see deafness so if you don't catch what someone is saying, and it happens a lot with older people ... it's a good idea ... but there should be two of you." (Relative 03)

Relatives often had needs of their own such as refreshment, help getting home from hospital, needing to understand what is happening and dealing with work and/or other family responsibilities, but these needs took second priority to the patient's.

“Well she is 82. She had various problems for many years. I lost my father about 10 years ago and she is my mum, and the first thing that crosses your mind is ‘is this it?’. And also it’s not very nice to see any human being, let alone your mother, on the floor, so I had a kind of sick feeling in my stomach. Mad panic. Actually absolute panic really as I realized my mum was very sick, very confused, and I couldn’t show her I was panicking so it didn’t transfer to her. So it was kind of mixed feelings where I was panicking but had to remain calm and reassuring for her” (Relative 19)

This final set of findings highlights the important role that family relatives, or in some cases friends or neighbours, can have in improving urgent care experiences for older people.

5 Discussion

This study's findings confirm many of the findings from other published studies conducted in countries other than the UK and/or on a relatively small scale. These findings also add new understandings, in particular around the importance of a sense of significance for patients, and also the role that family relatives can play.

The study design and execution have strengths and limitations. Limited interviewer training in discovery interview method (1.5 days), in addition to the relatively short length of many of the interviews, may have limited interviewers' capacity to fully explore patient and relative experience. In addition, some patients and relatives may have felt constrained by the relationship of the interviewer to the service in question, and by the desire to not get staff into trouble. This may have limited their ability to be fully open. A small number of interviews were conducted a considerable period of time after the experience described and this may have affected recall of events.

This study focused on the experiences of older patients, and it is therefore not known if younger adults would have similar experiences. Other studies highlight that older people tend to evaluate care differently to younger people, often more positively²⁰⁻²². These relatively positive evaluations may be because older people's expectations of care are lower than those of younger adults^{15;23} so it seems appropriate to look in more depth at older people's experiences in particular. In addition, older people are more likely to have difficulties with, for instance, communication or mobility, making the findings presented here more likely to apply to older people than others.

Most patients included in the study were White British, aged 75-79, living in their own home and had visited the emergency department. In addition, the exclusion criteria for the study specified the exclusion of individuals who were seriously ill and/or unable to cope mentally/psychologically and/or who were confused. While a great strength of the study is its large sample (n=96) taken from a large number of English locations (n=31), findings may be limited to older patients who share the characteristics of the sample. A further strength of the study is its use of qualitative interview techniques to focus on patients and relatives telling their stories in their own words. A systematic approach to data analysis and the clear links illustrated between data and findings also add weight to the conclusions drawn here, as does the validation of the findings by participants in the consultation phase (see appendix one).

In their work on relationship-centred care, Nolan et al.¹⁹ highlighted that in the best and most enriched care environments, older patients, their relatives and staff all experience what are known as the six senses, illustrated in Box Three. This study highlights that the sense of significance, that is the sense that one matters as a person, may be of particular importance to older people in urgent care environments. Other studies have highlighted that older emergency care patients seem to have a particular tolerance for uncomfortable situations⁹ or for care not happening as desired¹¹, but we would argue that a diminished sense of significance may underpin these observations. In this study, a sense that one may not matter seemed to underlie some older patients' reluctance to ask for help or advice, and may also lead to delays in accessing services. These findings relate more

widely to the low status of older people in the UK and the primacy of technical, medical care in acute settings^{24;25}, and more research would uncover whether this sense of lower significance is perceived just by older patients and their relatives, or whether it is also be attributed to some older patients by practitioners.

This study also highlights an important role for family relatives in helping older people have a better urgent care experience, especially where there are communication difficulties or where the patient is cognitively impaired. Not only do family members offer the comfort and reassurance to patients noted by Spilsbury et al.¹⁵, but they can also play a proactive role in accessing services, and in monitoring and apparently improving the quality of care. Other studies have highlighted the importance that family carers place in having confidence and trust in the ability of professional staff to care for their relative, and the need for family carers to be involved in decision-making and to have needs of their own acknowledged and met^{26;27}, but these factors have not been identified before in relation to urgent care. Future research could focus on better articulating the needs of family members in urgent care and exploring how best to meet them.

While confirming the findings of other studies in the field, this study also adds to our understandings of older patients' experiences of urgent or emergency care. While an older person in need of urgent care may not be the 'only pebble on the beach', it is the success of services and practitioners in identifying and focusing on individual needs, that determines the quality of experience. Given their exclusion from this study, additional future research efforts should focus on the needs of care home residents, a wider range of ethnic groups and people with dementia.

6 Recommendations

Study recommendations for policy and practice were developed through consultation with a wide range of stakeholders including older service users, their relatives, NHS practitioners and managers, Help the Aged and Age Concern England. Full details are given in appendix one.

It is clear that the quality of patient experience is dependent on the ability of front-line staff to identify and focus in on individual needs. Clinicians, including medical and nursing staff, in addition to other staff such as receptionists clearly have a critical role in shaping individual's experiences of services. Staff at the front-line need exceptional communication and empathic skills among other more technical skills. They need to listen actively to patients and relatives, to orient them to the service, the environment and staff roles, to proactively offer help not just with clinical needs, but also with achieving the 'six senses', and to plan care and discharge that takes account of the full impact of the illness or injury on the individual. Older people who are unaccompanied during their urgent care visits, will need particular attention from staff, or perhaps a nominated advocate or volunteer to substitute for the role of relatives. Family relatives also need to experience the six senses and findings point towards some of the support that urgent care practitioners could offer to family members who are also experiencing shock, fear and disorientation.

The responsibility for achieving a high quality of care rests not just with front-line staff. Staff need to work in an environment that enables them to develop and use these wider skills, and in which they can access specialist help and advice where this is needed. A culture of care that values more than the delivery of technical, medical care and rewards more than the achievement of time-based targets, is hard to achieve in times of constrained resources, but the patient and relative stories gathered as part of this project show that there is currently variable success in patients feeling cared for. Commissioning that promotes these more intangible aspects of care (and that recognises that they can take more time), organisations that value their caring role using opportunities such as orientation to inculcate positive attitudes, education that turns out well-rounded practitioners that value all aspects of caring for older patients, and ongoing research and involvement mechanisms (like discovery interviews) that help us better understand how to support front-line staff in enhancing patient experiences will all help here.

In addition to the quality of care provided within urgent care, findings also point to how older people make decisions about when and how to seek help in a health crisis. Urgent care staff have a role to play in educating people on discharge about how best to respond to symptoms that persist or worsen, but primary care practitioners clearly also have an important part to play in supporting older people and family members to make an appropriate decision. During the consultation phase, many people commented on the importance of a GP who knows the patient to be available to answer queries during a health crisis. The reluctance of some older people to seek help may have important implications for patient outcomes, and so public education is key here. The low use of

services such as NHS Direct by the people in this study is interesting, and merits further investigation of how effectively such services are publicised to this population.

Much of what is recommended here has been recommended elsewhere and falls within the remit of existing initiatives, for instance, the national service framework for older people, and the Department of Health's dignity campaign. One important lesson learned throughout this project is the power that patient stories can have in making different stakeholders reflect on their part in the patient's experiences. Discovery interviews, and other similar techniques, have a part to play in service improvement, but also in education. Listening to patients using such techniques, and listening to them more closely during clinical encounters, will enable care that is more sensitive to personal needs to be delivered, and the six senses to be given close attention by service providers.

A range of resources have been produced from this study that will enable a wider audience to listen to some of these stories and reflect on their implications (see www.city.ac.uk/listeningmakessense) It is hoped that these voices of older people themselves and their relatives will galvanise even greater efforts in this important area.

Appendix one: report of consultation phase

A number of organisations, particularly the National Association for Patient Participation, facilitated, through workshops and one-to-one meetings, consultation on the study findings with a wide range of stakeholders (n=52). Individuals consulted were asked to focus on:

1. To what extent do the findings match your own experiences or perceptions?
2. What local/national changes need to be made that best respond to these findings?
Practice, policy, education, other
3. Who do these recommendations need to be shared with?
4. What are the best ways of communicating these messages?

Overall comments

There was wide agreement with the study findings. Findings resonated with people, chimed with their experience and what they knew.

People also agreed with limitations identified for the findings particularly the lack of ethnic diversity in sample, and the exclusion of people with dementia.

A wide range of recommendations were made for service provision and education in particular.

Helpful suggestions were made as to who to target with study findings and how best to do this.

Thanks are due to the following individuals for giving their time and expertise to take part in the consultation:

Jill Atkin, Alzheimer's Society North Birmingham Carers Group

Paul Beddow, Emergency Department Patient Experience Group, Derbyshire Royal Infirmary

Iris Brabrook, Emergency Department Patient Experience Group, Derbyshire Royal Infirmary

Lucy Burgess, Occupational Therapist, Barts and The London NHS Trust, London

Karen Butler, Richmond Carers Centre, London

Caroline Dennell, Emergency Department Patient Experience Group, Derbyshire Royal Infirmary

Lisa Derry, Staff Nurse, A&E, Barts and The London NHS Trust, London

Claire Dow, Consultant, Acute Medicine/Elderly Care, Barts and The London NHS Trust, London

Zoë Gulliver, Staff Nurse, A&E, Barts and The London NHS Trust, London

Gillian Guy, Chairman, Victoria Medical Centre Patient Participation Group, London

M Hackett, Emergency Department Patient Experience Group, Derbyshire Royal Infirmary

Jane Hall, Modern Matron, A&E, Derbyshire Royal Infirmary, Derby Hospitals NHS Foundation Trust

Jo Hall, Lecturer Practitioner, A&E, Barts and The London NHS Trust, London

Donald Hammond, Alzheimer's Society North Birmingham Carers Group

Marion Hanrahan, Sister, A&E, Barts and The London NHS Trust, London

Barbara Harris, Equality and Diversity Manager, Brighton & Sussex University Hospitals NHS Trust, Sussex

Paul Haworth, Physiotherapist, A&E, Barts and The London NHS Trust, London

Hazel Heath, Independent Consultant, Nursing and Older People

Audrey Hoggard, National Association for Patient Participation

Cheryl Holman, Senior Lecturer, City University, London

Philip Hurst, Policy Manager, Health & Social Care Team, Age Concern England

Pat Justice, Friends of Ivy Grove Surgery, Derbyshire

Sue Lapwood, Clinical Governance Assistant, Brighton & Sussex University Hospitals NHS Trust, Sussex

Wayne Lenton, Emergency Department Patient Experience Group, Derbyshire Royal Infirmary

Svorai Majaya, Student Nurse, Birmingham

Shaun Marten, Matron, Elderly Medicine, Brighton & Sussex University Hospitals NHS Trust, Sussex

Barbara Martin, Friends of Ivy Grove Surgery, Derbyshire

Patricia McCann, Lister House Patient Participation Group, Derbyshire

Alex Morris, Associate Nurse Specialist for the Care Home (with nursing) Support Team, Brighton and Hove

Gordon Moyes, Alzheimer's Society North Birmingham Carers Group

Julie O'Callaghan, Care Homes Facilitator, City University

Tom Owen, Deputy Director, *My Home Life*, Help the Aged

Jean Pass, Friends of Ivy Grove Surgery, Derbyshire

E Phillips, Emergency Department Patient Experience Group, Derbyshire Royal Infirmary

Sally Roberts, Lecturer, City University

Alison Robertson, Chief Nurse, Brighton & Sussex University Hospitals NHS Trust, Sussex

Fiona Robertson, Senior Staff Nurse, A&E, Barts and The London NHS Trust, London

David Sanders, Service User, Howard Street Group Practice, Derbyshire

Margaret Sanders, Service User, Howard Street Group Practice, Derbyshire

Janet Shepherd, Deputy Chief Nurse & Director of Transformation, Patient Service, NHS London

Barry Silverman, Chairman, Southwark PCT Patient and Public Involvement Forum, London

Sheila Sims, Service User, Howard Street Group Practice, Derbyshire

Simone Steele, Alzheimer's Society

Tony Stokes, Nurse Practitioner, A&E, Barts and The London NHS Trust, London

Liz Suddes, Arthur Medical, Derbyshire

Adam Tinney, Practice Development, A&E, Barts and The London NHS Trust, London

Harry Wagstaff, Handsworth Medical Practice Patient Participation Group, Essex

Angela Wagstaff, Handsworth Medical Practice Patient Participation Group, Essex

Grace Wallace, Staff Nurse, A&E, Barts and The London NHS Trust, London

Jonathan Webster, Consultant Nurse for Older People, University College London Hospitals NHS Trust

Chris West, Alzheimer's Society North Birmingham Carers Group

Patricia Wilkie, President, National Association for Patient Participation

Thanks are also due to the following individuals for their help in finalising the study recommendations:

Mark Bennett, Nurse Consultant, Emergency Medicine, MAU, Southport & Formby DGH

Sandra Collinson, Nurse Consultant, A&E, Sunderland Royal Hospital

Mary Dawood, Nurse Consultant A&E, Imperial Academic Health Science Institute, London

Carolyn Dow, Nurse Consultant, A&E, Leicester Royal Infirmary

Nancy Fontaine, Consultant Nurse Emergency & Urgent Care, Whipps Cross University Hospital NHS Trust, London

Janet English, Nurse Consultant - Medicine, CDU, Southport District General Hospital.

Andrew Frazer, Nurse Consultant, A&E, Newham University Hospital

Jane Grimshaw, Nurse Consultant, A&E, South Manchester University Hospital

Nicky Hayes, Consultant Nurse for Older People, King's College Hospital NHS Foundation Trust and Care Homes Support Team

Soline Jerram, Consultant Nurse, Older People and Intermediate Care, Berkshire East PCT

Dorthe Larsen, Nurse Consultant, Primary Care Suite, Lewisham Hospital

Angie May, Nurse Consultant, Accident and Emergency, Aintree Hospital Trust

Heather McClelland, Nurse Consultant Emergency Care, Calderdale & Huddersfield NHS Foundation Trust

Bob McMaster, Nurse Consultant, A&E, Leeds General Infirmary

Karen Robinson, Nurse Consultant, A&E, Royal Preston Hospital

Frazer Underwood, Acting Deputy Director/Consultant Nurse, Services for Older People, Leicester Royal Infirmary

References

- (1) HM Treasury. Meeting the aspirations of the British People. 2007 Pre-Budget Report and Comprehensive Spending Review. 2007. London, The Stationery Office.
- (2) Downing A, Wilson R. Older people's use of accident and emergency services. *Age & Ageing* 2004; 34(1):24-30.
- (3) Department of Health. Urgent care pathways for older people with complex needs. Best practice guidance. 2007. London, Department of Health.
- (4) Bridges J, Griffiths P, Meyer J, Dethick L. Older people in accident and emergency: implications for UK policy and practice. *Reviews in Clinical Gerontology* 2005; 14:15-24.
- (5) Grief CL. Patterns of ED use and perceptions of the elderly regarding their emergency care: a synthesis of recent research. *Journal of Emergency Nursing* 2003; 29:122-126.
- (6) Aminzadeh F, Dalziel WB. Older adults in the emergency department: a systematic review of patterns of use, adverse outcomes, and effectiveness of interventions. *Annals of Emergency Medicine* 2002; 39:238-247.
- (7) Wilber ST, Gerson LW. A research agenda for geriatric emergency medicine. *Academic Emergency Medicine* 2003; 10:251-026.
- (8) Department of Health. Developing excellence in leadership within urgent care. 2005. London, Department of Health.
- (9) Baraff L, Bernstein E, Bradley K, Franken C, Gerson L, Hannegan S et al. Perceptions of emergency care by the elderly: results of multicenter focus group interviews. *Annals of Emergency Medicine* 1992; 21:814-818.
- (10) Hedges J, Singel B, Rousseau E, al e. Geriatric Patient Emergency Visits Part II: Perceptions of visits by geriatric and younger patients. *Annals of Emergency Medicine* 1992; 21:808-813.
- (11) Watson WT, Marshall ES, Fosbinder D. Elderly patients' perceptions of care in the emergency department. *Journal of Emergency Nursing* 1999; 25(2):88-92.
- (12) Nydén K, Petersson M, Nyström M. Unsatisfied basic needs of older patients in emergency care environments - obstacles to an active role in decision making. *Journal of Clinical Nursing* 2003; 12:268-274.

- (13) Melby V, Ryan A. Caring for older people in prehospital emergency care: can nurses make a difference? *Journal of Clinical Nursing* 2005; 14:1141-1150.
- (14) Richardson S, Casey M, Hider P. Following the patient journey: older persons' experiences of emergency departments and discharge. *Accident and Emergency Nursing* 2007; 15(3):134-140.
- (15) Spilsbury K, Bridges J, Meyer J, Holman C. "The little things count". Older adults' experiences of A&E care. *Emergency Nurse* 1999; 7(6):24-32.
- (16) Matrix. CHD Collaborative. Evaluation of discovery interviews: final report. 2005. Matrix Research and Consultancy.
- (17) CHD Collaborative. Learning from patient and carer experience: a guide to using discovery interviews to improve care. 2004. Leicester, NHS Modernisation Agency.
- (18) Green J, Thorogood N. Qualitative methods for health research. London: Sage; 2004.
- (19) Nolan MR, Brown J, Davies S, Nolan J, Keady J. The Senses Framework: improving care for older people through a relationship-centred approach. 2006. Sheffield, University of Sheffield.
- (20) Cohen G. Age and health status in a patient satisfaction survey. *Social Science and Medicine* 1996; 42(7):1085-1093.
- (21) Ahmad MA, Alasad JA. Predictors of patients' experiences of nursing care in medical-surgical wards. *International Journal of Nursing Practice* 2004; 10:235-241.
- (22) Commission for Healthcare Audit and Inspection. Variations in the experiences of patients using the NHS services in England: analysis of the Healthcare Commission's 2004/2005 surveys of patients. 2006. London, Commission for Healthcare Audit and Inspection.
- (23) Owens D, Batchelor C. Patient satisfaction and the elderly. *Social Science and Medicine* 1996; 42(11):1483-1491.
- (24) Bridges J. Workforce matters: exploring a new flexible role in health care. PhD thesis. City University; London, 2004.
- (25) Flatley M, Bridges J. Promoting the art of caring for older people. *International Journal of Nursing Studies* 2008; 45(3):333-334.
- (26) Brereton L, Nolan M. Seeking partnerships between family and professional carers: stroke as a case in point. In: Nolan M, Lundh U, Grant G, Keady J, editors.

- Partnerships in family care: understanding the caregiving career. Maidenhead: Open University Press; 2003. 50-68.
- (27) Nolan M, Grant G, Keady J, Lundh U. New directions for partnerships: relationship-centred care. In: Nolan M, Lundh U, Grant G, Keady J, editors. Partnerships in family care: understanding the caregiving career. Maidenhead: Open University Press; 2003. 257-291.