The role of patients and their relatives in 'speaking up' about their own safety – a qualitative study of acute illness

Helen Rainey MSc BSc(Hons) RN,* Kathryn Ehrich PhD, MSc, BA(Hons),† Nicola Mackintosh PhD MSc BSc(Hons) Mgt Dip RN‡ and Jane Sandall PhD MSc BSc(Hons) RM RN HV§

*Clinical Nurse Specialist, King's Health Partners, Kidney Clinic, Tower Wing, Guy's Hospital, Great Maze Pond, †Visiting Research Fellow, Division of Women's Health, King's College London, Women's Health Academic Centre, King's Health Partners, North Wing, St. Thomas' Hospital, ‡Research Associate and NIHR Patient Safety & Service Quality Research Fellow, Division of Women's Health, King's College London, Women's Health Academic Centre, King's Health Partners, North Wing, St. Thomas' Hospital, Westminster Bridge Road, and §Professor of Women's Health, Division of Women's Health, King's College London, Women's Health Academic Centre, King's Health Partners, North Wing, St. Thomas' Hospital, Westminster Bridge Road, London

Abstract

Background Poor recognition of and response to acute illness in hospitalized patients continues to cause significant harm despite the implementation of safety strategies such as early warning scores. Patients and their relatives may be able to contribute to their own safety by speaking up about changes in condition, but little is known about the factors that influence this. This study examined the experiences and views of patients and their relatives to determine the potential for involvement in promoting their own safety.

Methods This data set is drawn from a wider ethnographic study of the management of the acutely ill patient in hospital. Thirteen patients and seven relatives from two medical settings in two UK NHS Trusts were interviewed. Thematic analysis identified factors likely to influence patients' and their relatives' ability to contribute to the management of deterioration.

Results All patients interviewed had experienced their acute illness within the context of a long-term health problem. Speaking up was influenced by the ability to recognize changes in clinical condition, self-monitoring, confidence and trust, and culture and system of health care. When patients or relatives did raise concerns, health-care staff had a mediating effect on their comfort with and the effectiveness of speaking up.

Implications Safety strategies based on patient involvement must take account of the complexities of acute illness. Those that promote partnership may be more acceptable to patients, their families and staff than those that promote challenging behaviour and may ultimately prove to be most safe and effective.

Background

Current international policy emphasizes the increased involvement of patients and relatives in health care to improve services, and it has been suggested that increased patient and public involvement in safety strategies both at a policy level[1] and an individual level[2] could help prevent medical errors and adverse events. For patients receiving health care, these strategies include interventions that aim to promote involvement in safety-related behaviour[3–5] but there is debate about the appropriateness and effectiveness of such strategies with concern that they may unreasonably transfer responsibility for safety onto already disadvantaged patients[6] or their relatives.[7] Patients do not view involvement in different safety-related behaviours uniformly, and strategies that require patients to speak up or to challenge health-care professionals appear to be particularly problematic.[8,9] A review of educational safety campaigns found that despite a positive attitude about engagement in safety, patients' willingness to act is not always reflected in their actual behaviour when confronted with a potential safety incident and that initiatives aimed at involving patients in safety must promote both complex behavioural change amongst patients and a cultural change in health-care institutions.[10]

The management of acutely ill hospitalized patients is an important quality and safety priority internationally[11–13] with the potential to significantly reduce patient harm.[14] Early detection of physiological deterioration with rapid access to critical care services when appropriate is recognized as essential to improve outcomes for these patients, and a number of safety solutions have been developed to promote this including early warning scores (EWS) and critical care outreach teams (CCOT).[15] Despite the introduction of such tools in many NHS acute hospitals,[16] patients continue to suffer harm including avoidable deaths.[17–19] Strategies that facilitate patients' and relatives' involvement in the early detection of acute illness[20] have been proposed as a way in which patients and relatives may be able to contribute to their own

safety, and the US Joint Commission standard for the management of deterioration recommends that all patients and their families should be informed about how to seek assistance if they have concerns about their condition.[21] However, there is no such recommendation in the UK, and the role of patients and relatives in managing deterioration has had little consideration in health-care planning here.[22]

Research to date has focused on the role of health-care staff in recognizing and responding to the acutely ill patient[23] but it has been reported that patients or their relatives may recognize signs of their deteriorating condition before staff.[24] A safety strategy that facilitates patients speaking up has the potential to lead to earlier initiation of treatment, but there are also reports that health-care staff do not always respond appropriately to patients' and relatives' concerns with devastating consequences.[25,26] One case of poor staff response in South Carolina, United States, led to the Lewis Blackman Patient Safety Act which requires hospitals to provide a mechanism whereby patients can access prompt assistance for resolution of medical care concerns.[27] This example of patient and public involvement leading to policy change is based on the assumption that a mechanism that would have been effective in an individual case will also be effective more widely but evidence to support this is lacking. Systems that incorporate family concern into the calling criteria for critical care rapid response teams have been associated with a reduction in respiratory arrests in children,[28–30] but the improvements in outcomes were related to the introduction of the whole system and not directly to intervention by families. Alternative strategies enable patients or families to call critical care services directly but the acceptability of these to patients and relatives is unclear with few calls made.[31,32] High visibility of the CCOT on the general wards increased patients' and relatives' comfort level when calling the team but requires significant investment of resources.[33] Evaluation of strategies has focused on the appropriateness of calls that were made by patients or relatives but not on why calls were *not* made. Little is known

about the experiences of patients who become acutely unwell and their relatives. Exploration of this may suggest ways in which resources can be directed most effectively.

This article reports our findings from a study investigating the experiences and views of patients whose condition had deteriorated whilst in hospital and of their relatives. We aimed to identify the barriers to, and facilitators of, patients and relatives speaking up about their worsening condition to determine the potential for increased involvement of patients and relatives in safety strategies. This was part of a wider study looking at the use of safety tools by health-care staff in acute medicine and maternity care in two urban acute NHS hospitals.[34]

Methods

Data collection

The data reported here were collected as part of a larger ethnographic study of the implementation of safety tools used in the management of acute illness in hospital.[34] Patients and relatives were recruited to explore their experiences of becoming acutely unwell or developing complications in hospital, and participants took part in semi-structured interviews to examine this. Interviews were conducted over a period of 12 months from February 2010 to February 2011 with a focus on patients discharged home from one acute medical ward in each of two urban acute NHS hospitals. One hospital had implemented an EWS to help identify patients showing early signs of acute illness, and the other had both an EWS and a CCOT composed of critical care nurses to enable prompt access to critical care expertise. Patients' or relatives' concerns were not included in either EWS and they could not self-refer to the CCOT. One ward specialized in patients with diabetes and one those with respiratory conditions.

Purposive sampling[35] aimed to recruit a spread of patients who had experienced a step-up in their care, ranging from those who had had a life-threatening event requiring transfer to intensive or high dependency care to those who experienced a relatively minor complication or

worsening of clinical condition that was successfully managed on the ward. This sampling aimed to identify patients who had had diverse experiences of acute illness as there was a possibility that the degree of patient involvement in care was associated with the severity of deterioration. We aimed to recruit eight patients from each study site to explore this. Eligible patients were identified from discharge summaries at both hospitals and from referrals to the CCOT in one. Patients and relatives who were unwilling, cognitively or physically unable to participate in an interview or too distressed were excluded from the study. Patients with a new diagnosis of a terminal illness and relatives of patients who had died were also excluded. Participants were able to withdraw from the study at any time.

Patients were contacted by telephone and those agreeing to participate in the study were sent an information leaflet and contacted at least 1 week later to arrange an interview. Patients were invited to identify a relative who they thought might wish to contribute to the study. Relatives were also welcomed to be present in interviews as support to patients as all were recovering from acute illness. Some patients identified friends or informal carers to participate, but we have used the term 'relative' throughout to encompass these significant relationships.

The interviewers took a narrative approach to elicit stories of acute illness and to encourage patients and relatives to reflect on their experiences and share their thoughts and feelings.[36] It has been suggested that this approach can enhance researchers' awareness of participants' perspectives and is appropriate when participants are potentially vulnerable due to their ill health.[37] Interviews started with a general question about the patient's experience in hospital with follow-up questions if needed to facilitate the story-telling process. The revised interview schedule is presented in Appendix 1. All interviews were conducted at the patients' home apart from with one relative who wished to be interviewed at work. Interviews were conducted by HR, an experienced nurse, and NM, an experienced social science researcher with a health-care background.

Written consent was obtained prior to interviews, and the interviews were audio-taped and transcribed verbatim. NHS Research Ethics Committee approval was obtained (ref 08/H0808/178).

Analysis

Directed content analysis[38] of interview data was used to identify common themes with transcripts initially read in full by all members of the team to gain an understanding of the patients' stories. Text relating to how the patient's deteriorating clinical condition was recognized, patients' and relatives' understandings of episodes of acute illness and speaking up was then highlighted and coded by HR. Initial coding was influenced by reviews that have highlighted both patient-related factors and health-care worker-related factors as important determinants of participation in safety strategies.[39,40] However, these factors were interlinked throughout many accounts, and new codes were identified that encompass this. Coding was reviewed with KE, an experienced social scientist, and themes were identified that may explain why and when patients or relatives speak up about acute illness. Emerging themes were discussed and agreed at regular team meetings, and the project team reviewed all cases to ensure that each theme was fully explored. Early analysis was formally reviewed with the project team once half the interviews were complete, and early findings were presented to the Trusts for comment. The emerging themes were used to modify the interview schedule and inform subsequent interviews and analysis. The potential for any association between patient attributes and themes was considered during the analysis. Data were stored and managed using QSR NVivo 8.0 (www.qsrinternational.com).

Findings

Recruitment and interviews

Fourteen patients were recruited with 13 patients and seven relatives interviewed.

Table 1 summarizes details of patient demographics, inclusion criteria and interviews. Thirty-four patients were approached and six were recruited from site A and eight from site B. Six patients chose to be interviewed with a relative present; one requested that we interview his relative alone as he had no recollection of the changes in his condition.

Fewer eligible patients were identified than anticipated. Recruitment was therefore extended over 12 months. Recruitment from site A was suspended after 10 months because of a service reconfiguration leading to a change in patient characteristics. Of the 20 patients who declined to participate, 13 stated this was because they were undergoing further investigations or had continuing health problems.

Most of the acutely ill patients recruited were older people with a median age of 72 years (range, 50–85), and all participants spoke English. All had an underlying chronic illness and reported contact with community and hospital health-care providers over many years. The relatives that participated in interviews described close involvement in providing care to the patients at home and gave detailed accounts of the patients' health issues. Where patients found speaking difficult, relatives took a more prominent role in the interview process with patients' speaking when they wished to clarify or correct an account. The themes emerged from the data despite the differences in age, gender, ethnicity and place of escalation of care of the participants. Themes were not associated with study site, the severity of acute illness or the presence of relatives.

Factors that influence patients and relatives speaking up about becoming acutely ill

Patients and relatives described their experiences of acute illness within the context of living with chronic health conditions and many related their experiences at home to events in hospital. This provided insights into how patients experience and are able to respond to changes in clinical condition. Four themes emerged that influenced patients and relatives

Table 1 Summary of patient demographics, inclusion criteria and interviews

Patient no.	Age	Gender	Ethnicity	Escalation of care	Interview participants		Length of interview (min)	Time between discharge and interview (days)
1	77	F	White-British	HDU	P	R	55	68*
2	85	M	White-British	HDU	P	R	46	83*
3	82	M	White-British	Ward management	P	R	17	16
4	79	M	White-British	Ward management	P		20	42
5	71	F	White-British	Specialist unit	P		45	25
6	81	F	Black-Caribbean	ICU	P	R	18	61
7	57	M	White-British	ICU		R	22	28
8	50	M	Black-Caribbean	Ward management	P		13	46
9	51	F	Black-Caribbean	Ward management	P		65	52
10	65	F	White-British	Ward management	P		80	60
11	73	F	Black-Caribbean	Ward management	P	R	18	22
12	61	F	White-British	ICU	P		11	36
13	74	F	White-British	Ward management	P	R	73	98*
14	69	F	White-British	ICU	P		37	28

P, Patient; R, Relative.
*Patient had readmission prior to interview.

speaking up about acute illness – the ability to recognize changes in clinical condition, self-monitoring, confidence and trust, and culture and system of health care.

Ability to recognize changes in clinical condition
Many patients were unable to participate actively in the management of their acute illness due to limited ability to recognize the change in their clinical condition. Data to illustrate this theme are presented in Table 2.

Some patients were unaware of their deterioration because of sensory impairment, either related to their underlying condition such as diabetic neuropathy preventing pain being felt from infected ulcers or because of pre-existing poor cognitive function. Others were unable to participate due to a reduced level of consciousness caused by their acute illness. These vulnerable patients were entirely dependent on others, either relatives or health-care staff, to detect and respond appropriately to changes in

their clinical condition. Relatives of such patients described a responsibility to speak up on their behalf, and this is discussed in the section on self-monitoring below.

The presence or absence of symptoms was an important indicator of change in clinical condition for patients and relatives. They were unable to detect changes when no new symptoms ensued such as when a low platelet count was detected through a blood test before it could lead to further complications. However, even when symptoms were present, some patients and relatives were unsure of their significance and relied on health-care staff to identify that this was an indication of deterioration. This was partly because patients routinely experienced myriad symptoms related to their underlying chronic illness and contrasted with a patient who spoke up in an obvious emergency after witnessing another fall.

Some patients and relatives described how previous experiences of acute illness helped them to identify symptoms that indicated that

Table 2 Data to illustrate 'ability to recognize changes in clinical condition'

'He took one look at it, and because it was all covered up, the whole of the foot, I had no way of knowing or seeing that these toes were all red and swollen, because being diabetic there's no feeling at all. Um … so he said, "Oh, I don't like the look of that,"' Patient 10

'I wouldn't have noticed it, because I would have just thought I was coughing for the … for the sake of it, sort of thing, you know. It was just one of them days when my cough decided to play up. That's what I would have thought.' Patient 5

'My son, because I've still got a son at home, he found me unconscious in the bathroom, thinking that I'd just fallen asleep or I'd fallen out of my wheelchair in the bathroom, so he put me up and put me to bed, that was on the Saturday night. And up until Sunday afternoon nobody could wake me.' Patient 12

'Anyway, this night she fell out of bed. So I was ringing the buzzer for the nurse and shouting out, 'Nurse,' at the top of my voice, all the hospital must have heard me, but they didn't seem to. Anyway, they come running, 'What's the matter?' I said, "Look, she's fallen out of bed."' Patient 5

'Well I thought, oh, I'd best call the ambulance because they told me before I had to. And my doctor said, "If you're not too good and I'm not, you know, or it's late at night, call the ambulance." She said, "But if it's during the day call me and then I'll … call the, do the ambulance for you and tell them, explain everything." But she said, "If it's at night call, you know, try and call it yourself," which I did. Like I did before. And they said, "It's a good job you called us, if you'd left it a bit longer …" you know. So I said, "Well," I said, "I couldn't," I said, "I thought I was going to … get bet-, you know, work it off me." So one of them said, "Well we all think like that,"' Patient 14

their condition was deteriorating. Advice from health-care staff was a valuable adjunct to personal experience, but some patients did not recall receiving this and were concerned that early signs of future illness would be missed.

The inability to recognize *changes* in clinical condition was a key factor that prevented patients and relatives speaking up about acute illness. Many of those interviewed had also not been aware of the *severity* of their illness so did not speak up.

Self-monitoring

Patients with chronic conditions and their relatives already undertake varying degrees of self-monitoring to manage their condition at home and many described the symptoms that had led them to seek further help. It might be expected that active monitoring for changes in clinical condition by patients or relatives would increase detection of acute illness, but in hospital most reported a more passive role. Data to illustrate this theme are presented in Table 3.

By patients

Health-care staff routinely performed all monitoring tasks, for example, staff measured blood sugar levels for diabetic patients even though such patients usually measured this themselves

at home. This may be appropriate when patients are acutely unwell but reduced the opportunities for patients to be involved in their care. Only one patient described attempts to be fully involved in her own care but she reported that staff prioritized objective markers of illness above her own experience and felt that this contributed to her suffering further complications. This patient reported a number of instances when the response from staff to her concerns was poor leading to worsening symptoms and delays in treatment. She described how most nursing staff 'humoured' her involvement in her care rather than treating her as an equal partner and reported conflict with one nurse suggesting that not all welcomed this contribution.

Although most patients reported little involvement in monitoring their clinical condition, a further four reported speaking up to prevent medication errors suggesting that they were actively monitoring this more familiar aspect of their care. These patients were confident that they knew their own medications and were 'right' to speak up although again some reported a poor response from staff to their concerns.

By relatives

Relatives reported vigilance and advocacy on behalf of patients as a key part of their role

Table 3 Data to illustrate 'self-monitoring'

By patients

'But whilst I was there, they took my blood sugars and they found that they was up in the air.' Patient 4

'And so at night if my blood, if my blood test was … below ten I never took the last lot of insulin. You know, because I found, as I say, a couple of times I did that I had hypo because it's like one, I remember one of the nights I asked the nurse what was … for the life of me I couldn't understand why I couldn't remember what my … the blood test was when they took it, and I remember I asked her what it was and she told me it was 16, and, and I knew … and I knew it couldn't have been 16 after because at three o'clock my … she panicked because my blood sugar had gone down to four. And obviously the panic attack, I mean the sweating, because once you have a hypo it's just like a panic attack.' Patient 9

'They all thought I was hilarious! [Laughs] They all thought I was quite amusing and hilarious because … every bit of medication I was having I had to question it. [Laughs]' Patient 9

'I didn't recognise the tablet when the night staff came on, and I practically had a stand-up argument except I was sitting down at the time, and er … and she said, "Well that's what you've been written up as." So my complaint was, if someone had, a doctor had put it onto the computer they should have come and told me, being that I'm the patient and I'm the one that's taking it, plus I know my medication, they should have informed me that they've changed it.' Patient 10

By relatives

Relative: 'If I say to a nurse, when she was very poorly I'd say "That doesn't look right…" you know, they'll check.'
Interviewer: 'And have there been times when you've said that and actually it's been OK?'
Relative: 'Yes. Oh yes, they go, "Oh that's nothing to worry about." Or they'll explain what, why that's happening.' Relative of Patient 1.

'Then the discharge, she wasn't well enough, I could hear it on the phone and I said, "She's not well enough, plus I've got a chest infection." "Oh well you're safe after three days so she can come home." I said, "She's not well enough." Next thing they went, "OK, we'll keep her another forty-eight hours." Then my husband got a phone call, a message to say she's being discharged today.' Relative of Patient 1

'If we had any cause for concerns we would point it out, if not to the nurse, staff nurse, we'll try to point it out to the doctor, and if we didn't feel things were going the way we would like it to do, you know, we would make appointments to see somebody when they're available to be seen. So it's not all the time you would get the appointment to see them, but when we do, you know, know when they are actually on duty we'll make an effort to be there.' Relative of Patient 6

'And they told me … And nothing was too much. They'd get the staff nurse to come to the phone and she'd tell me all what was happening before I went in, you know, to make sure that everything was fine' Relative of Patient 3

and expressed concern for patients who do not have access to this support, but none recalled that their speaking up had led to earlier detection of acute illness. Some relatives had spoken up about symptoms and been reassured when staff took action to check their significance. One patient's relative found this helpful because although assessment did not result in an intervention, it did lead to explanations about symptoms. However, she also recalled an occasion when her assessment that her mother was not well enough to be discharged home was disregarded. Again this suggests that objective measures of acute illness (determined by staff) had more weight than relatives' subjective experience.

When patients were unable to speak up due to cognitive impairment or the severity of the acute illness, their relatives described taking a greater role in monitoring care. Relatives were comfortable raising concerns, but some described delays – for example describing the need to make appointments to discuss concerns rather than being able to resolve issues immediately.

Restricted visiting times, and work and family commitments meant that relatives were not always present at the bedside and this limited the opportunities for detection of changes in condition by relatives. Relatives commonly described staff giving them information about the patient's clinical condition rather than monitoring progress themselves and became anxious when they were unable to obtain this information from health-care staff over the phone.

Self-monitoring for changes in condition was rarely described by hospitalized patients and may not be welcomed by all staff. Relatives were often away from the bedside, which further limited the opportunities for detection of changes in condition by patients and relatives.

Confidence and trust

Confidence and trust was an important theme that emerged in relation to self-monitoring. Data to illustrate this are presented in Table 4.

Many patients reported that they trusted the health-care staff who cared for them and this emerged particularly from the narratives of patients who rated their care highly. Patients were confident when they felt that their care was appropriate for their medical needs as evidenced by provision of correct medication, diet, fluids and help with personal care but were less able to assess the quality of medical treatment. Patients and relatives considered that health-care staff possessed superior knowledge at the time of acute illness, and most were confident that appropriate care was being given even though (or perhaps because) they may not have understood all that was going on.

Many patients described the significance of their long relationship with a trusted hospital or clinician and particularly valued being recognized and treated as an individual. Relatives also valued relationships with staff and were only comfortable leaving patients when they were confident in the standard of care provided.

Many patients and relatives described variability between and within different hospitals but few reported speaking up about care when they were concerned. Rather patients and relatives reported that they hoped they could avoid certain hospitals or wards in the future with some reporting that they had spoken up during subsequent admissions to request this. Whilst this could reflect discomfort when challenging staff, it may also reflect a lack of confidence that speaking up would lead to resolution of concerns. One relative lost trust following an unsatisfactory response from staff to concerns about her brother's treatment, and she subsequently removed him from hospital and presented him for readmission elsewhere.

Patients and relatives who trusted that staff were monitoring for changes in condition rarely described being vigilant for signs of acute illness. However, when concerns were unresolved, patients and relatives lost confidence and avoided future contact with some hospitals or wards.

Culture and system of health care

The underlying culture and system of health care was an important influencing factor on patients and relatives speaking up, and data to illustrate this are presented in Table 5.

Table 4 Data to illustrate 'confidence and trust'

'I didn't realise he was as sick as what he was, and um … when they took him in the isolation, um … I was thinking and wondering what was going on, because they were sort of like, there was someone there looking after him, they were bringing X-ray machines in, um … and I thought, I didn't … I thought, oh perhaps, you know, they're just keeping a good eye on him, basically, which I wasn't worried about. But then I got a phone call to say that he'd been taken into intensive care, um … and that did worry me a bit, you know, because obviously someone's got to be extremely unwell'. Relative of Patient 7

'I felt really safe and… it was nice to know that people understood what was actually wrong with me, and if I needed different treatment I was there and it would have happened.' Patient 12

'They've become quite familiar with her, so they will say, "Oh yes, I remember," and then that becomes really nice because at least the nurse that really knew my mum will still go out of her way to make sure she's comfortable.' Relative of Patient 6

'I said, "Have you asked x to fax over some notes previous?" because he hadn't been there for about, oh, five years. And they hadn't done it. They hadn't contacted his GP. Um, and so I said, "Well it's not good enough, I'm sorry, I'm taking him out." … I said,: "No I'm sorry, he's going to x." I said, "I know he'll get a better standard of care there."' Relative of Patient 7

Table 5 Data to illustrate 'culture and system of health care'

'[The nurses] are zoom zoom zoom, they're too busy to have little conversation, chat, you know, make you feel more … better.' Relative of Patient 11

'Every time they walked in and out or they went to another patient they used to call out to whoever they, you know 'Are you all right? You all right? You sure? You want anything?' You know, no matter who it was they were so … kind and caring.' Patient 14

'The only thing she gets upset about when she's in hospital is other patients demanding too much from the nurses! [Laughs] When they can do things their self…She won't, um, just call the nurse willy-nilly, and she gets quite upset when she's laying there or whatever, trying to do something, and you've got someone who's quite capable going, 'Nurse! Nurse! Nurse!'' Relative of Patient 13

'If one person in there who's supposed to be attending you, right, takes a dislike to you, and I'm not surmising this, it's truthful, and they don't like you, and it's put all round the ward who attends you, and they all stick on that one, that person, whoever it may be. So you're condemned straightaway.' Patient 2

'You get a card and there's a help number on it or you ring the ward. Basically: "Well we can't help you, there's no doctors on the ward." So I ring the GP: "Well I can't help you." I said, "Well can you just come out and verify that she's got a chest infection?" "Well you know. Take her to hospital."' Relative of Patient 1

A number of patients and relatives reported that staff appeared too busy to talk. This reduced opportunities when patients could raise concerns or report new symptoms and contrasts with two patients who were reassured when they felt that staff were available should they need them.

The impression that staff were overburdened may reduce the likelihood that patients and relatives will speak up about changes in symptoms unless they are certain that this is a sign of significant deterioration. This may be because of a desire to reduce the burden on staff but also could be because of concerns about the response from staff. One patient felt that his care was adversely affected following calls for assistance whilst others thought that care was compromised because of a lack of resources, despite the best efforts of staff.

Patients and relatives reported that the lack of resources meant services needed to focus on acutely ill patients and accepted that once they were recovering they became less of a priority. This caused difficulties for some as less time was spent planning for discharge or discussing strategies that could help with the on-going management of chronic illness.

Early detection of future episodes of acute illness and the need for rapid access to health services was a concern for many patients and relatives. Most described how they had spoken up about their deteriorating condition at home when they had first become concerned that they were unwell. The response from health-care staff was used to validate concerns and also to provide reassurance that they were using services appropriately. However, some patients described difficulties in accessing health care when the seriousness of their condition was not recognized by health-care staff or when systems designed to expedite access were ineffective.

Patients and relatives described a health-care system that has limited resources and where their own needs must be balanced with those of others. This underlying culture was reflected in their desire to use services as advised, but meant that at times they accepted that their own health needs were not fully met.

Discussion

Delay in the identification of acute illness in hospital is a safety problem that may be amenable to intervention by patients and relatives. This exploration of patients' and relatives' experiences has identified a number of factors that influenced their ability to speak up about deterioration. Many patients and relatives were unaware of the severity of their acute illness, and patients were often unable to take a more active role due to their clinical condition whilst relatives were not always present at the bedside. This reflects Rier's account of his own acute illness, where the severity of his illness led to his taking an unexpectedly (to him)

passive role in his care.[41] Most patients and relatives trusted health-care staff when they were acutely unwell and had confidence in staffs' expertise. It has been reported that most acute care patients believe they should be able to trust they are receiving competent care, rather than taking a leadership role in their safety[42] and our study supports this finding.

One patient described monitoring aspects of her clinical condition in hospital, and others were vigilant for objective threats to their safety such as medication errors. This suggests that some patients are comfortable with this role and there may be potential to develop this further. However, it has been reported that practitioners may subtly inhibit the active participation of patients in treatment decisions[43] and that the reluctance of nurses to share information makes it more difficult for patients to be fully involved in their care.[44] This practice was also reported in our study and may be a significant barrier to increased involvement. Our ethnographic study found that staff prioritize the objective markers of acute illness included in EWS over tacit signs,[34] and patients and relatives similarly reported that their subjective experience of their own health was sometimes disregarded.

Some patients and relatives perceived health-care staff to be overburdened and may be reluctant to speak up to health-care staff, both because they did not want to interrupt busy staff, but also because of concerns that their care would be adversely affected. This supports findings from other studies of acute patients[44,45] and suggests that strategies aimed at encouraging patients and relatives to speak up will need to overcome any reluctance and address issues regarding provider response.

Some patients and relatives recognized the importance of developing new knowledge and skills to enable them to manage their condition at home, but this was perceived to be a low priority for hospital staff who focused on acute care. Also mechanisms designed to improve access were sometimes unreliable. Our findings suggest that a lack of information about symptoms and problems accessing services may con-tribute to the severity of future exacerbations of illness. Relatives valued good communication from staff to keep them informed but also because many had a key role in ensuring the safety of patients after discharge. This aspect of their role was sometimes marginalized, with little consideration of the difficulties that they may face at home at times.

Practical implications

Peat *et al.*[46] have developed a framework for evaluating safety strategies and highlighted the importance of examining how an intervention is intended to work. The findings from our study suggest that in this health-care setting, many patients and relatives would be unlikely to speak up about acute illness in hospital and that safety strategies reliant on intervention by patients and relatives need to take account of the barriers identified.

Many patients were unaware of the severity of their clinical condition or were unsure of the significance of symptoms. It is unlikely that such patients and relatives would be comfortable to bypass known, trusted staff by self-referring to critical care teams, and an alternative approach that encourages staff to genuinely engage with patients and relatives may be more successful at detecting acute illness. It has been reported that patients are more likely to ask questions if encouraged to do so by staff,[9] and our findings suggest that patients and relatives will be more likely to volunteer their concerns if staff actively seek their views. Inclusion of 'patients and relatives concerns' as a parameter in EWS could promote this dialogue and would allow measurement of the frequency of the occurrence of such concerns.

When patients and relatives did raise concerns, they did not always receive a satisfactory response from staff. Further study is warranted to examine the behaviour of health-care staff in response to patients' and relatives' raising concerns and the impact of organizational culture on this.

This research indicates how pathways of acute illness influence the ability of patients to

speak up about changes in clinical condition. The focus of current strategies is to view deterioration as a discrete acute event but these accounts from patients and relatives suggest that for some patients acute illness occurs as an exacerbation of underlying disease. For such patients, strategies that promote earlier intervention at home as well as in hospital could help to reduce harm from deterioration. The period of recovery following an acute illness may also provide an opportunity to educate patients with chronic conditions about signs of potential complications and strategies that promote successful self-management at home.

Limitations

We acknowledge a number of limitations to this small-scale, exploratory, qualitative study. More women than men took part despite similar numbers being approached, and the sample did not fully reflect the ethnic diversity of the local population. Recruitment was limited to two medical wards and all patients had a chronic illness – patients from other specialities or with different medical and surgical conditions may report different experiences. All participants had survived their acute illness, and findings from relatives of patients who died may be different.

All participants in the study spoke English, and consideration should be given to the experiences of patients and relatives from different cultural and language backgrounds. This is particularly important when developing safety strategies that aim to promote patients' and relatives' speaking up. Findings may also not be applicable to health-care settings outside of the UK NHS, and similar studies could be carried out with both similar and different patient groups elsewhere.

Lastly this study is based on the memories of patients who had suffered an acute illness and their relatives. We aimed to interview participants 1–2 months after discharge but some interviews were delayed due to readmissions and there was also a delay between the onset of acute illness and discharge. Recall of events may have been affected by this delay and by

on-going health problems. Furthermore we were not able to check the final analysis with participants and thus missed the opportunity to search for further negative evidence. This study reflects the authors' interpretations of the meanings that patients and relatives retrospectively gave to their experiences rather than utilizing contemporaneous accounts.

Conclusion

This study indicates that strategies aimed at encouraging patients and relatives to speak up about their safety need to consider the complexity of acute illness and the specific challenges faced by those with chronic health conditions. Examination of patients' and relatives' experiences suggests that intervention by health-care staff is needed to help overcome barriers to involvement and that staff should actively encourage patients and relatives to speak up about their concerns. Safety strategies that emphasize that patients' and relatives' involvement will be welcomed may ultimately prove most safe and effective.

Acknowledgements

Disclaimer

Funding

(NIHR) and is funded by the Department of Health.

References

1 World Health Organisation. Patients for patient safety, 2009. Available at: http://www.who.int/patientsafety/patients_for_patient/en/, accessed April 2011.

2 Vincent CA, Coulter A. Patient safety: what about the patient? *Quality & Safety in Health Care*, 2002; **11**: 76–80.

3 The Joint Commission. Speak up, 2002. Available at: http://www.jointcommission.org/facts_about_speak_up_initiatives/, accessed October 2011.

4 McGuckin M, Waterman R, Storr J *et al.* Evaluation of a patient-empowering hand hygiene programme in the UK. *Journal of Hospital Infection*, 2001; **48**: 222–227.

5 DiGiovanni CW, Kang L, Manuel J. Patient compliance in avoiding wrong-site surgery. *Journal of Bone & Joint Surgery: American volume*, 2003; **85-A**: 815–819.

6 Entwistle VA, Mello MM, Brennan TA. Advising patients about patient safety: current initiatives risk shifting responsibility. *Joint Commission Journal on Quality & Patient Safety*, 2005; **31**: 483–494.

7 Entwistle V. Nursing shortages and patient safety problems in hospital care: is clinical monitoring by families part of the solution? *Health Expectations*, 2004; **7**: 1–5.

8 Entwistle VA, McCaughan D, Watt IS *et al.* Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality & Safety in Health Care*, 2010; **19**: 1–7.

9 Davis RE, Sevdalis N, Vincent CA. Patient involvement in patient safety: how willing are patients to participate? *BMJ Quality & Safety*, 2011; **20**: 108–114.

10 Schwappach DLB. Engaging patients as vigilant partners in safety. A systematic review. *Medical Care Research and Review*, 2010; **67**: 119–148.

11 Patient Safety First. To reduce in-hospital cardiac arrest and mortality rate through earlier recognition of the deteriorating patient, 2008. Available at: http://www.patientsafetyfirst.nhs.uk/Content.aspx?path=/interventions/Deterioration/, accessed June 2011.

12 Australian Commission on Safety & Quality in Healthcare. Recognising and responding to clinical deterioration, 2008. Available at: http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/prog-patientsrisk-lp, accessed June 2011.

13 Institute for Healthcare Improvement. *5 Million Lives Campaign. Getting Started Kit: Rapid Response Teams.* Cambridge, MA: Institute for Healthcare Improvement, 2008.

14 McQuillan P, Pilkington S, Allan A *et al.* Confidential inquiry into quality of care before admission to intensive care. *British Medical Journal*, 1998; **316**: 1853–1858.

15 National Institute for Health & Clinical Excellence (NICE). *Acutely Ill Patients in Hospital, Recognition of and Response to Acute Illness in Adults in Hospital.* CG50. London: NICE, 2007.

16 Rowan K. Evaluation of outreach services in critical care. SDO Project 08/1404/074. National Institute for Health Research, 2007.

17 National Patient Safety Agency (NPSA). *Safer Care for the Acutely Ill Patient: Learning from Serious Incidents.* London: NPSA, 2007.

18 National Confidential Enquiry into Patient Outcome & Death (NCEPOD). *Acute Kidney Injury: Adding Insult to Injury?* London: NCEPOD, 2009.

19 National Confidential Enquiry into Patient Outcome & Death (NCEPOD). *Death in Acute Hospitals: Caring to the End?* London: NCEPOD, 2009.

20 DeVita MA, Smith GB, Adam SK *et al.* "Identifying the hospitalised patient in crisis" – a consensus conference on the afferent limb of rapid response systems. *Resuscitation*, 2010; **81**: 375–382.

21 The Joint Commission. Sentinel Event Alert (44): Preventing maternal death, 2010. Available at: http://www.jointcommission.org/assets/1/18/SEA_44.PDF, accessed June 2011.

22 Odell M, Victor C, Oliver D. Nurses' role in detecting deterioration in ward patients: systematic literature review. *Journal of Advanced Nursing*, 2009; **65**: 1992–2006.

23 McGaughey J, Alderdice F, Fowler R, Kapila A, Mayhew A, Moutray M. Outreach and Early Warning Systems (EWS) for the prevention of intensive care admission and death of critically ill adult patients on general hospital wards. *Cochrane Database Systematic Review*, 2007: CD005529.

24 Cioffi J. Recognition of patients who require emergency assistance: a descriptive study. *Heart & Lung: The Journal of Acute and Critical Care*, 2000; **29**: 262–268.

25 Mullan K. Patients… not numbers, People… not statistics: Patients Association, 2009. Available at: http://www.patients-association.com, accessed June 2011.

26 Parliamentary & Health Service Ombudsman. *Care and Compassion?* London: Parliamentary and Health Service Ombudsman, 2011.

27 South Carolina Department of Health and Environmental Control. Lewis Blackman Hospital

Patient Safety Act, 2005. Available at: http://www.scdhec.gov/health/licen/LewisBlackmanAct.pdf, accessed June 2011.

28 Brilli RJ, Gibson R, Luria JW *et al.* Implementation of a medical emergency team in a large pediatric teaching hospital prevents respiratory and cardiopulmonary arrests outside the intensive care unit. *Pediatric Critical Care Medicine*, 2007; **8**: 236–246.

29 Hunt EA, Zimmer KP, Rinke ML *et al.* Transition from a traditional code team to a medical emergency team and categorization of cardiopulmonary arrests in a children's center. *Archives of Pediatrics & Adolescent Medicine*, 2008; **162**: 117–122.

30 Tibballs J, Kinney S. Reduction of hospital mortality and of preventable cardiac arrest and death on introduction of a pediatric medical emergency team. *Pediatric Critical Care Medicine*, 2009; **10**: 306–312.

31 Ray EM, Smith R, Massie S *et al.* Family alert: implementing direct family activation of a pediatric rapid response team. *Joint Commission Journal on Quality & Patient Safety*, 2009; **35**: 575–580.

32 Odell M, Gerber K, Gager M. Call 4 Concern: patient and relative activated critical care outreach. *British Journal of Nursing*, 2010; **19**: 1390–1395.

33 Gerdik C, Vallish RO, Miles K, Godwin SA, Wludyka PS, Panni MK. Successful implementation of a family and patient activated rapid response team in an adult level 1 trauma center. *Resuscitation*, 2010; **81**: 1676–1681.

34 Mackintosh N, Rainey H, Sandall J. Understanding how rapid response systems may improve safety for the acutely ill patient: learning from the frontline. *BMJ Quality & Safety*, 2012; **21**: 135–144.

35 Pope C, Mays N. Reaching the parts other methods cannot reach - an introduction to qualitative methods in health and health-services research. *British Medical Journal*, 1995; **311**: 42–45.

36 Freshwater D, Holloway I. Narrative research. In: Gerrish K, Lacey A (eds) *The Research Process in Nursing*, 6th edn. Oxford: Wiley Blackwell, 2010:188–197.

37 Holloway I, Freshwater D. Vulnerable story telling: narrative research in nursing. *Journal of Research in Nursing*, 2007; **12**: 703–711.

38 Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*, 2005; **15**: 1277–1288.

39 Davis RE, Jacklin R, Sevdalis N, Vincent CA. Patient involvement in patient safety: what factors influence patient participation and engagement? *Health Expectations*, 2007; **10**: 259–267.

40 Longtin Y, Sax H, Leape LL, Sheridan SE, Donaldson L, Pittet D. Patient participation: current knowledge and applicability to patient safety. *Mayo Clinic Proceedings*, 2010; **85**: 53–62.

41 Rier DA. The missing voice of the critically ill: a medical sociologist's first person account. *Sociology of Health and Illness*, 2000; **22**: 68–93.

42 Rathert C, Huddleston N, Pak Y. Acute care patients discuss the patient role in patient safety. *Health Care Management Review*, 2011; **36**: 134–144.

43 Paterson B. Myth of empowerment in chronic illness. *Journal of Advanced Nursing*, 2001; **34**: 574–581.

44 Henderson S. Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *Journal of Clinical Nursing*, 2003; **12**: 501–508.

45 Sorlie V, Torjuul K, Ross A, Kihlgren M. Satisfied patients are also vulnerable patients - narratives from an acute care ward. *Journal of Clinical Nursing*, 2006; **15**: 1240–1246.

46 Peat M, Entwistle V, Hall J, Birks Y, Golder S. Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. *Journal of Health Services Research & Policy*, 2010; **15**: 17–25.

Appendix 1 Interview schedule

Managing complications in acute medicine topic guide for interviews with patients and relatives

Introduction: Outline purpose of study and this particular strand of data collection. Explain that we are interested in finding out their personal stories; there are no 'right' or 'wrong' answers to any of the questions. Reiterate voluntary nature and safeguarding of confidentiality. Offer opportunity to raise further questions/concerns. Take consent.

1. It would be really helpful for me if you could start off by telling me about your recent experience of being in hospital.

2. During your stay in hospital were you aware of any changes in your condition?

   Yes
   a If yes, what changes were you aware of?
   b How did you feel when you were really ill?
   c What, if anything, were you most worried about when you were really ill?
   d When you felt unwell what did you do?

e Do you think these concerns (your worries) were shared by your relatives, nursing or medical staff?

f Did you tell the nurses/doctors that you were feeling unwell? Why did you/didn't you tell them?

g Did you draw on any previous experience of being unwell or anything else in your life to help you to understand what was happening?

No

a If no, explain briefly why they have been selected to take part?

b How did you feel at this point in your stay in hospital?

c What, if anything, worried you at this time?

d Do you think that your relatives, nursing or medical staff were ever worried?

e Have you ever had times before when you have felt very unwell?

f If you felt very unwell what did you do?

g Did you tell the nurses/doctors that you were feeling unwell? Why did you/didn't you tell them?

h Did you draw on any previous experience of being unwell or anything else in your life to help you to understand what was happening?

3 Do you feel that the nurses and doctors picked up that your condition was changing? How do you feel they responded?

a What, if any, aspects of this acute stage of your illness do you feel were managed well?

b What, if any, aspects of this acute stage of your illness do you feel were not managed well?

c Was there anything about this acute stage of your illness that could have been improved? If yes, did this have any consequences for you and your recovery?

4 How did it feel being on this particular ward when you were unwell?

a What did the staff do that made you feel cared for and well managed?

b What, if anything, do you feel is different about this ward compared to other wards or hospitals?

5 Has your experience of being unwell changed your view of the hospital?

6 Based on your experience do you have any take home message for the staff?