



Undertaking risk and relational work to manage vulnerability: Acute medical patients' involvement in patient safety in the NHS

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ABSTRACT

Over the last decade a wealth of studies have explored the way that patients are involved in patient safety internationally. Most begin from the premise that patients can and should take on the role of identifying and reporting safety concerns. Most give little attention, however, to the impact of the patient's health status and vulnerability on their ability to participate in their safety.

Drawing on qualitative interviews with 28 acute medical patients, this article aims to show how patients' contributions to their safety in the acute medical context are less about involvement as a deliberate intervention, and more about how patients manage their own vulnerability in their interactions with staff.

Our analysis is underpinned by theories of vulnerability and risk. This enables us to provide a deeper understanding of how vulnerability shapes patients' involvement in their safety. Acute medical patients engage in reassurance-seeking, relational and vigilance work to manage their vulnerability. Patients undertake *reassurance seeking* to obtain evidence that they can trust the organisation and the professionals who work in it and *relational* and *vigilance work* to manage the vulnerability associated with dependence on others and the unpredictability of their status as acute medical patients. Patients are made responsible for speaking up about their care but simultaneously, by virtue of the expectations of the sick role and their relational vulnerability, encouraged to remain passive, compliant or silent. We show how risk frames the extent to which patients can activate their role in creating patient safety at the point of care. Foregrounding the theory of vulnerability, the concept of the sick role and the relationship of both to risk offers new insights into the potentials and limits of patient involvement in patient safety in the acute care context.

1. Introduction

Patient safety has been a persistent issue in healthcare over the last 20 years, one that has spawned much academic and applied activity (Rowley and Waring, 2011). It has been defined as 'the avoidance, prevention, and amelioration of adverse outcomes or injuries stemming from the process of healthcare' (Vincent, 2011). Ironically not a familiar term to patients, patient safety has been mainly the province of clinicians and researchers whose aim is to reduce injuries and harms that result from 'medical management as opposed to the patient's underlying disease' (Mello et al., 2005).

This focus on clinician-led approaches to safety has led to emphasis on 'events' or 'incidents' that arise during treatment. Patients are regarded as having an important role to play in their own safety (Vincent

and Coulter, 2002; Sutton et al., 2015) but their ability to be involved depends in part on their health condition and may vary across health-care settings (Davis et al., 2007).

Acute medical patients are in a particularly precarious and unpredictable situation. Often admitted urgently, they are patients who have experienced sudden and severe symptoms that may be indicative of a life-threatening condition, and which require urgent medical treatment (Williams and Acute Medical Task Force, 2007). They may present at emergency departments before being admitted to a ward, or, if in a critical condition, intensive care (Williams and Acute Medical Task Force, 2007). Acute medical patients may deteriorate while on a ward and require further urgent treatment. They tend to be older, with multiple co-morbidities (NHS Digital, 2016a). They may also be frail, making them particularly vulnerable both to illness and to harm from

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adverse events (Vincent, 2011). Given these features, involving acute medical patients in their safety presents significant challenges.

Studies have shown that patients often see safety differently from clinicians. Patients may find it difficult to disentangle safety from other elements of the care process (Brún et al., 2017). They focus on their experiences of quality of care overall (Barrow, 2018) rather than safety as clinically defined. Other studies have emphasised that patients focus on *feeling safe* rather than *being safe*, particularly in intensive care (Wassenaar et al., 2014; Hupcey, 2000).

In this article, we argue that patient involvement in an acute care context is influenced by vulnerability, which shapes the way in which patients work to minimise risks to their safety. We begin by providing a brief overview of the literature on patient involvement in patient safety, then continue by discussing the concepts of vulnerability, risk and the sick role (Parsons, 1951), which underpin our analysis of how vulnerability influences acute medical patients' role in their safety, using the NHS in England as our setting.

2. Patient involvement in patient safety

The framing of safety as events or incidents has influenced the way that patient involvement in patient safety has been researched and understood (Sutton, 2021). We argue that patients have been involved in patient safety in various ways, including, but not limited to: (i) providing retrospective feedback on their experiences; (ii) taking an active role in their own safety by monitoring treatment, identifying risks, and speaking up when they are receiving care; and (iii) to a lesser extent, planning safety improvement (The Health Foundation, 2013). This article focuses on the second form of involvement: individual patient involvement that takes place at the point of care.

Previous research has identified that patients play a key role at the point of care, namely as 'vigilant monitors' of their care – observing their own care and treatment, and raising concerns if they are worried (Sutton et al., 2015). This role is particularly relevant in preventing medication errors, as demonstrated in literature which has identified action in the form of querying doses (Hall et al., 2010; Rainey et al., 2015; Rathert et al., 2011; Schwappach and Wernli, 2010; Weingart et al., 2004).

Elements that patients themselves identify as a safety risk reflect their awareness of safety issues and the visibility of risks to them. For example, research by O'Hara and colleagues showed that patients frequently identified communication as a principal patient safety concern, followed by availability or insufficiency of staff, environmental issues, compassion and dignity (O'Hara et al., 2018). All these elements can be considered 'front-stage' (Goffman, 1959): they are acts performed by staff and immediately visible to patients. The consequences of these acts are experienced physically and emotionally by patients undergoing care, rather than being part of the behind-the-scenes work that patients may be unaware of – i.e. less visible work that takes place to secure patient safety, such as the development and maintenance of reliable systems, policies and processes.

Although patients may identify risks to safety in situ, they may be reluctant to speak up about them, especially if this involves challenging staff, for example, in relation to infection risks due to poor handwashing (Pittet et al., 2011). Patients are more likely to raise 'factual' questions relating to safety than questions that directly challenge healthcare staff on their behaviour (Davis et al., 2008), such as asking 'Have you washed your hands?' (Davis et al., 2008; Bishop et al., 2014), for fear of damaging relationships with staff.

Although building good relationships is important for facilitating patient involvement, the nature of the typical patient role (see also sick role below), including dependence on healthcare professionals for care and vulnerability in settings such as acute care, can act as barriers to involvement. Patients are dependent on, and place trust in, healthcare professionals to provide their care: trust by its very nature can involve putting oneself in the hands of others, on the assumption that they will act in one's best interests (Mechanic, 1998). Trust may lie in tension

with any involvement in patient safety that consists of query or challenge. For example, trust can be a hindrance to the involvement of older people in some settings (Scott et al., 2012). Fear of damaging their relationship with staff has been identified as a significant barrier to patients' involvement (Entwistle et al., 2010). Speaking up about safety risks threatens the trust relationship, because any perceived criticism may provoke '*undue sensitivity on the part of the trusted*' (Entwistle and Quick, 2006) and because patients may fear the consequences (Doherty, 2012). By becoming involved in safety, therefore, patients may perceive that they risk rendering themselves *more* vulnerable.

Perceptions of risk and vulnerability, then, have key roles to play in patient involvement in safety at the point of care. This is particularly the case for patients who have been admitted to hospital acutely, suffering from serious conditions, who find themselves exposed to risk and in an especially uncertain situation.

3. Risk

Sociological theories of risk (Beck, 1992; Giddens, 1990) highlight how in late-modern societies, with their weakening of religions, traditions, and communities, lay people increasingly rely on experts to inform them of risks and how to respond to them (Lupton, 2006). Simultaneously, lay people are increasingly suspicious and doubtful about expert knowledge, leaving them in a state of continual uncertainty (Lupton, 2006). In the late-modern age, however, '*human responsibility has become attached to risk*' (Lupton, 2006). We live in a society where people are regarded both as risk causers and risk solvers. Foucault argues that risk emerges from a state of modernization where '*good citizens are encouraged to engage in self-regulation*' (Lupton, 2006). This is particularly evident in healthcare when individuals are increasingly encouraged to take care of themselves. People are effectively responsabilised to act to minimise risks to themselves, and can be held to account should they fail to manage those risks. This results in tensions for people experiencing hospitalisation for acute health conditions, who are simultaneously vulnerable and dependent on health professionals to protect them from risk, and responsabilised to speak up and manage risks to their own safety (Sutton et al., 2015; Mackintosh et al., 2017).

4. Vulnerability and the dependent patient

When patients are admitted urgently to hospital, they experience uncertainty, anxiety and fear in relation to the immediacy of the threat from ill-health or even death. Patients who are critically ill feel unsafe (Wassenaar et al., 2014; Hupcey, 2000). Underlying many patients' accounts of their hospitalisation is, at best, a profound fear of the unknown, or at worst, of dying (Craib, 2003).

Acutely ill patients are vulnerable, not only due to their illness, but also due to their dependence on healthcare professionals for care. Acutely unwell people are often in a state of 'demeaned individuality' (Kottow, 2005), experiencing a loss of integrity and dignity. Their situation and state of health results in vulnerability that goes beyond the usual interdependency of human beings. Here dependency extends into areas where usually autonomous adults would not be expected to be dependent on others in order to function (Sellman, 2005).

Being acutely unwell requires help from others for individuals' most basic needs. In nursing, dependence on care is defined as '*a nurse-patient relationship resulting from a decrease in self-care and simultaneous increase in dependence on nursing care whenever needs must be satisfied*' (Dijkstra et al., 1998). Being so dependent on others for care leaves patients '*more-than-ordinarily vulnerable*' (Sellman, 2005), and results in a loss of control over their own circumstances and bodies, so that they become reliant on the decisions and actions of healthcare professionals. This reliance, in turn, leaves the hospitalised patient exposed to even greater risks of harm, from others, as well as from their illness. (O'Neill, 1998).

Misztal (Misztal, 2011; Trust, 2011) identified three forms of vulnerability: dependence on others, the predicament of

unpredictability and the irreversible nature of past experiences and actions. We draw on the first two forms here as the most relevant. For acute medical patients, the first form of vulnerability arises from their dependence on others for the quality and safety of care. Someone taking responsibility for the person, argues Misztal, can overcome this form of vulnerability. The second form of vulnerability – arising from unpredictability – can be overcome through the act of promising or reassuring. Following Misztal (Misztal, 2011; Trust, 2011), we see the acts of taking responsibility for the dependent person, building and maintaining trust, and providing reassurance, as creating the conditions to alleviate existential and relational vulnerability. Consequently, caring for and about someone can be thought of as something that helps to mitigate the vulnerability associated with both dependency and unpredictability. By enacting vulnerability, therefore, patients may invite care and compassion from others. In doing so, however, they may also find themselves entering the ‘sick role’ (Parsons, 1951), which brings with it not only entitlements but also mutual responsibilities between carer and cared-for, as we explore next.

5. The sick role

Having fallen out of favour in recent years (Burnham, 2014), the sick role (Parsons, 1951), we argue, offers a helpful way of framing the role of vulnerability in patient involvement in safety in the acute care setting. The sick role is concerned with social order, and in particular, how a functioning society is produced and reproduced through micro-level interactions that contribute to ensuring the health of the population. Society affords doctors and patients a set of obligations and rights. Doctors are expected to be technically competent, objective, and motivated to act in the patient’s best interests and serve the community, putting aside their personal interests (Gabe and Monaghan, 2013). By meeting these obligations, doctors as a professional group earn a privileged position within society, and are permitted to undertake acts that would be seen as improper if performed by others, such as physical examination. Patients have corresponding rights and obligations. When patients become sick, they are, by virtue of being ill, excused from their normal duties in society and become ‘entitled to seek help’ (Parsons, 1951), but are expected to submit to appropriate medical care and try to get well.

The sick role thus creates normative expectations of both the healthcare professional and the patient. The healthcare professional is required to focus on the patient’s recovery, while the patient must reciprocate by displaying trust in professional expertise and comply with treatment in order to get better (Parsons, 1951).

The sick role calls for healthcare professionals to demonstrate care. Patients expect doctors to act in their best interests (Parsons, 1951). Enacting vulnerability offers a way in which acute medical patients, facing uncertainty and fear, can engage healthcare professionals in taking responsibility for patient care, providing reassurance, and resolving the threat they are facing from acute illness. By demonstrating compliance and being a ‘good patient’, a patient invites good care (Parsons, 1951).

Despite the rights afforded by the sick role, the patient undertakes a significant amount of ‘work’ when ill (Strauss et al., 1985), some of which may not be recognised as ‘work’ by healthcare professionals. Patients work to manage their vulnerability and resolve uncertainty, by asking questions in order to seek reasonable answers (Strauss et al., 1985; Scott et al., 2005). For the hospitalised acutely unwell patient, this is particularly relevant, due to the likelihood of being overwhelmed with uncertainty and in need of professional vigilance and reassurance; hence, acute medical patients engage in work to muster and ‘organise healthcare resources around their specific particular needs’ (Scott et al., 2005).

Taken together, the challenge of vulnerability and the socially sanctioned obligations of the sick role provide a basis for exploring the nature of, and possibilities for, patient involvement in safety in acute

care settings. Against the backdrop of the responsabilising pressures imposed by late modernity, however, the sick role appears to make contradictory requirements of the patient. At once, the patient should submit to medical authority and take responsibility for safety and recovery in ways that may sometimes involve challenging clinicians. Yet as Shilling among others have pointed out, the form taken by the sick role may be transient and context-specific, even if the cultural values underpinning it are a more enduring influence on social behaviour (Shilling, 2002). In this study, we address this question by foregrounding the roles of risk and vulnerability in shaping interactions between healthcare staff and acute medical patients, and examining their implications for the potentials and the limitations of patients’ roles in creating safety.

6. Methods

The research was qualitative in design. Semi-structured interviews were conducted with individuals who had been admitted to hospital as acute medical patients in the NHS in England. Purposive sampling was used. Participants were recruited as part of a wider ethnographic study of the delivery and quality of care at weekends (Aldridge et al., 2016; Tarrant et al., 2017) in medical wards in four acute hospitals (two smaller rural hospitals – sites 2 and 4 and two larger urban teaching hospitals – sites 1 and 3). Participants were recruited from short-stay assessment units and gastroenterology, respiratory and diabetic wards; all had been in hospital at some point over the weekend (see Table 1 for more information). The South West Wales Research Ethics Committee granted ethical approval (reference 13/WA/0372). Individuals were recruited after securing approval from ward managers and senior nursing staff over two waves. The first wave took place in 2016–17 and the second wave in 2017–18. Participants were provided with an information leaflet and were offered the choice to be interviewed in hospital, at home, or over the telephone.

A flexible topic guide was developed to explore patients’ understandings of safety. Questions included what the term patient safety meant to them, how safe they felt and why, and what they perceived to be their role in keeping themselves safe in hospital. The interviews were conducted by two experienced qualitative researchers and took place at a time and place convenient to participants, who each took part in one interview. All were audio-recorded with permission. All participants provided written consent immediately prior to the interview. Interviews lasted between 30 min and 1 h and were all transcribed in full. Transcripts were imported into NVivo 12 qualitative data software.

The approach to analysis was informed by the principles of thematic analysis (Braun and Clarke, 2006). The first and last author read each transcript. Transcripts were then coded to high-order nodes based on key research questions about what patient safety was, what worried or concerned patients, the extent to which they were able to raise concerns, what patients thought their role was in making care safe and their experiences of their own condition. During the coding process, the first and last author identified core themes of trust, fear and vulnerability. The coding was discussed among the remaining co-authors, in particular how the core themes interacted with patient safety, patient involvement in patient safety and the concepts of risk and the sick role.

7. Findings

The final sample included 28 individuals. For more detail about the participants and their pathways following admission, see Table 1. All names provided are pseudonyms.

8. Experiencing vulnerability and dependence

The majority of the patients interviewed were acutely unwell at the time of their hospital admission, in many cases alongside longstanding chronic conditions. As a result, they were reaching the limit of their

Table 1
Participant details and pathway.

Name	Age range (decade)	Site no and wave no.	Patient pathway	Condition
1. Donald	60s	3 wave 1	Attended A&E, moved to AMU then recruited from Gastroenterology	Severe attack of Crohn's disease
2. Jane	80s	1 wave 1	Ambulance to A&E then recruited from AMU	Suspected stroke
3. Sarah	30s	1 wave 1	Ambulance to A&E then recruited from AMU	Complications from diabetes in pregnancy
4. Joe	50s	2 wave 1	Ambulance to A&E then recruited from AMU	Collapsed with suspected stroke
5. Dorothy	70s	1 wave 1	Husband took her to A&E. Recruited from AMU	Severe stomach pain
6. Bob	70s	4 wave 1	Ambulance to A&E. Recruited from CDU	Suspected blood clot
7. Clara	80s	1 wave 1	Daughter took her to A&E. Recruited from AMU	Fall
8. Rose	80s	2 wave 1	GP referred her direct to AMU	Virus and heart condition
9. Robert	40s	2 wave 1	Taxi to A&E. Recruited from AMU	Collapse with abscess and ear infection
10. Harry	70s	3 wave 1	Ambulance to A&E. Recruited from AMU	Myasthenia gravis complications
11. Geoff	70s	3 wave 1	Ambulance to A&E, then AMU. Recruited from Gastroenterology	Heart condition and suspected GI bleed
12. Frank	60s	4 wave 1	Referral by GP. Taxi to A&E. Recruited from Respiratory	Emphysema and low oxygen levels
13. Janet	60s	4 wave 1	Daughter took to A&E Recruited from Gastroenterology.	Stomach pain and severe constipation
14. John	40s	2. Wave 2	Ambulance to A&E, moved to High dependency. Recruited from Diabetes ward.	Collapse following diabetic complications
15. Barbara	80s	1 wave 2	GP referral direct to Diabetes ward	Kidney problems
16. Walter	70s	3 wave 2	Ambulance to A&E, then AMU. Recruited from Respiratory ward	Collapse and COPD
17. David	60s	2 wave 2	Described previous admission where admitted for pneumonia via A&E. Recruited from Gastroenterology ward	Crohns disease
18. Margaret	80s	2 wave 2	GP referral straight to Gastroenterology	Long standing condition and kidney problems
19. Sally	40s	4 wave 2	Taxi to A&E. Recruited from AMU	Virus
20. Susan	60s	1 wave 2	Referred to AMU by GP. Recruited from Respiratory ward	Pneumonia
21. George	80s	3 wave 2	Ambulance to A&E then AMU. Recruited from Respiratory	Breathing difficulties
22. Julia	60s	2 wave 2	A&E then AMU. Recruited from Diabetes	Fall and kidney complications. Long standing health condition.
23. Mike	50s	4 wave 2	Ambulance to A&E. Recruited from AMU	Collapse with severe headache
24. Brian	60s	4 wave 2	A&E, then Critical Cardiac Unit. Recruited from AMU	Heart condition/breathing difficulties with COPD
25. June	80s	3 wave 2	Ambulance following collapse at GP to A&E, then AMU. Recruited from Respiratory ward	Chest infection then pneumonia
26. Dennis	80s	3 wave 2	Ambulance to A&E, then AMU. Recruited from Respiratory ward	Breathing difficulties and heart condition
27. Clive	40s	4 wave 2	Pathway unclear. Recruited from Discharge lounge	Polyps removal
28. Lorna	70s	3 wave 2	Pathway unclear. Recruited from Diabetes ward	Collapse at home, problem with swollen legs

ability to keep themselves safe at home and were anxious about what would happen to them. Hospitals were often seen, at least at the start of their admission, as places of safety. Once admitted, patients expected to be able to hand over responsibility for their safety to experts, people who were qualified to find out why they were experiencing their symptoms and make them feel better. Having someone nearby to provide comfort, reassurance and treatment was preferable to being at home, often alone, without recourse to proper medication, uncertain about their situation and afraid that they might die.

Well when I was ill I felt safer in hospital than what I did [at home] ...there was no one here to ... If anything had gone wrong that would have been me lot, you know. (26. Dennis)

Acute medical patients were reliant on others for their safety and very survival. The vulnerability arising from their illness then increased further because of this dependency. As such, they were doubly vulnerable: first, to the risk from ill health, and second, to the risk of harm from others.

When you're a patient you do feel vulnerable, I don't care who you are, as strong as you might be you feel vulnerable and you're at the mercy of the help of these people who work in these hospitals. They do a fantastic job, [...] they do their best, but they're all human the same as you or I so we all have our limitations. You can't be in two places at once, it's just not, you can't do it. (1. Donald)

A lack of control, coupled with a lack of choice over the situation they found themselves in, left many patients feeling powerless. This resulted in anxiety that required some form of reassurance that they would be kept safe from the harms that could arise from their fragile medical state and from their reliance on others for essential care. Acute medical patients had no choice but to put themselves in the hands of others if they wanted to get well. However, this did not mean they were

passive in relation to their own safety. We show that patients undertook 'risk work' (Brown and Gale, 2018; Gale et al., 2016) to manage the vulnerability arising from dependence and unpredictability. This work took three main forms: reassurance seeking; relational work; and vigilance.

9. Reassurance seeking: Am I safe here?

In order to reassure themselves that they could trust those caring for them to care for them properly, participants looked for evidence that they were safe. Evidence included both contextual and relational indicators of safety.

Contextual indicators included whether there appeared to be enough staff on duty, and the general cleanliness and orderliness of the ward environment.

There's not enough staff here, there's just not enough cover and there are nurses out there who are stressed, they should be off work themselves on a sick note, they're too stressed and I feel for them because they don't employ enough staff to cover the shifts [...] and it's putting patients in danger (1. Donald).

Hygiene levels and proper implementation of infection prevention procedures also helped to affirm or undermine patients' perceptions of the safety of the environment.

And they had one [cleaner] who was obviously training up another, and she said, you know, she started to clean in a different pattern, and she said no, you have to stick with this pattern, because then you're sure you've done everything. So I felt hugely reassured by that (20. Susan).

Observing the commitment of staff to such details fostered patients' confidence in the organisation and engendered a sense of safety. Order

and regime offered reassurance that this was a well organised, safe place for vulnerable patients.

Relational indicators of safety included evidence of caring and of trustworthiness in the performance of care. Relational indicators were found in direct interaction with staff. They included how well staff displayed competence and professionalism, how they communicated with patients, relatives and each other so that patients knew what was happening, how responsive they were to patients' needs, and how well they reassured them. In short, for patients, safety as exhibited in relational indicators meant being able to trust that they would be cared for.

It means being surrounded by people who are professionals for a start, and then in a comfortable bed and being looked after (25. June).

In order to feel safe, patients needed reassurance that staff could be relied on when they were most needed. Patients sought evidence that they could trust staff to know what they were doing.

Like every other A&E nurse I've ever come across ... they're very efficient but in a really reassuring way in a really you know you felt like you are being taken care of that they know what they're doing you can trust them (19. Sally).

Alongside clear communication, witnessing an active performance of care on the part of staff, such as seeking to control deterioration and monitoring a patient's condition closely, offered reassurance that staff were doing all they could to achieve safety.

They just [were] on the ball all the while, doing, something else, they were checking something else, that is how good they were they were just trying their best to stop everything, stop [heart] from going so fast which it was getting quite dangerous I should imagine at that stage 200 odd beats a minute. So they was on the ball from the minute, didn't stop trying to stop it and suddenly they hit a group of tablets which worked, and it started to slow down. They were monitoring, they noticed that it dropped drastically to about 150 something like that they were still monitoring it (24. Brian).

For patients who were '*more-than-ordinarily vulnerable*' (Sellman, 2005), safety was a matter of perceiving or *feeling* rather than a process of evaluating the technical aspects of care. Patients looked for evidence that trust in the organisation and staff was justified – that the organisation and staff on whom they were dependent would keep them safe.

10. Relational work: inviting safe care

One implication of this construction of safety was the importance of relational work for patients as a way of keeping themselves safe. This involved managing their dependent relationship by demonstrating they were a 'good patient', invoking the social contract and clinician obligations for care and compassion.

Participants described behaving in certain ways to demonstrate their worthiness of good care. In other words, patients wanted to demonstrate that they were 'good patients'. They engaged in relational work, avoiding being too demanding and aligning themselves with the normative expectations that came with the sick role. This included complying with their treatment, being available when required, and displaying gratitude to staff for the care that they received. Patients were sensitive and attuned to their dependent state, and for the most part were wary of undermining the trust relationship they had. They were aware that staff were very busy and were concerned to avoid being seen as 'too much trouble' by asking for things unnecessarily or by being too demanding.

I don't want to be a pain, for want of a better word, it's like I just want to – I'm there, but I don't want to be an inconvenience (23. Mike).

At the end of the day, I just thought I'm here at the weekend, I'm grateful to be here, grateful to be in, I haven't had any problems really so far, and I just thought I'm not going to fuss anybody (27. Clive).

Participants also emphasised the importance of compliance with staff instruction – as a way of maintaining relationships, as well as ensuring they were free from risks of harm. Following healthcare professionals' advice appeared to be one way of encouraging healthcare professionals to recognise patients' legitimate demand for care, and enabled them to avoid clashes with staff.

Do what you're told, you know, don't try and do what you think you should do. (26. Dennis)

And I've got to do everything in my power to let them do everything that they've got to do, and do everything that I'm supposed to do, like taking my nebuliser, taking ... Because everything is for my benefit. (16. Walter).

In some cases, this could also require a decision to put their own needs and preferences aside in the interests of a smooth relationship. For example, patients were keen to avoid disrupting staff by taking (what might be perceived as) unnecessary risks with their safety, such as trying to get to a toilet on their own, when staff expressed concern that attempting to do so would risk a fall.

I felt a nuisance always asking for a commode, and so I wanted to be able to walk to the toilet, and I really couldn't, and I found that very frustrating. So, yeah, I did sometimes think this would be a great idea, and yes I could manage it, if I could manage that gap between the bed and the next wall, you know. And the nurses were like "no! Don't do it!" So yeah, I had a role to play to ... comply. (20. Susan)

The tension between patient autonomy and dependence, particularly the risk of being regarded as a 'nuisance', was a theme that ran through many participants' narratives. Patients were conscious of the need to do as they were told, and not to interrupt staff unless it was essential, deprioritising their own needs in some cases. There was a collective sense of responsibility, with a recognition that by avoiding unnecessary demands on staff time, they would create a safer environment for all the patients on the ward.

Accordingly, participants expressed consternation at the behaviour of others who failed to exhibit these traits. As well as causing a nuisance, other patients were judged and found wanting when they failed, for example, to be compliant in taking their medication. In these instances, in the view of participants, the responsibility for their safety shifted from the professional to the patient.

They [nurses] say, "Johnny, it's time to put your ... We're going to put a nebuliser." So they put it on Right, the nurse can't stand there while that nebuliser's finished. And what do they do? They take it off. Patients take it off and put it on the side, and all that nebuliser stuff what's in it, they've never had it. But this is a case where you can't blame a nurse. A nurse can't stand there while them two ... I use my nebuliser properly. (16. Walter)

'Other' patients therefore could contribute to increased risks to their safety by adding to the workload of already busy staff when they failed to do as they were told. Avoiding creating risks to safety was part of everyone's responsibility to help to ensure that staff could perform essential tasks when urgently required on the ward.

Being a good patient also took other forms. For example, patients were concerned to show they were making every effort to become well, including displaying a positive attitude, motivating themselves to be mobile, and asking for help when it was needed.

I think if you go in there with a positive attitude I think you're going to get better a lot quicker than someone who, who doesn't have a

positive attitude. I mean I had a positive attitude [...] and I was going to get better and I was going, hopefully, to go home. (25. June)

Well I think you have got to motivate yourself, you have got to get up and walk around, you know at home you don't sit down like this for 3 or 4 hours, you get up and you walk around. (13. Janet)

These findings link to the sick role concept (Parsons, 1951), with its emphasis on the patient's obligation to become well. But rather than seeing compliance with the sick role – being a 'good' and worthy patient – as a passive or submissive position, they can instead be interpreted as relational work. This relational work is a form of patient involvement in safety, describing ways in which patients work to enhance their relationship with professionals and helps to create a safer environment in which to recover. As mentioned earlier, however, vulnerability arises from unpredictability as well as dependence (Misztal, 2011; Trust, 2011). We turn now to consider how patients managed vulnerability arising from unpredictability along with dependence.

11. Vigilance: managing unpredictability and dependence

Patients were generally vigilant while receiving care in hospital. Vigilance involved, for example, checking medication, ensuring that they were receiving the right type and dose. They also checked the extent to which hospital staff followed hygiene procedures, for example washing their hands, using gloves, avoiding cross-contaminating sterilized equipment and upholding good standards of cleanliness.

Patients were also vigilant concerning risks to other patients, looking out for them and calling for nursing help should it be needed. In this way, patients often acted as an extra pair of eyes or ears on the wards.

Just keeping a good eye out for things you know like, like old chap in bed like I had to shout nurses two or three times for him, because I knew he were trying to get out of bed on his own and he couldn't, you know, he could hardly shift, bless him. (14. John)

Patients sought out further information about their medications and their treatment. Lack of information resulted in an increased sense of unpredictability and required work to create a sense of safety for themselves.

I feel safer knowing, having checked everything before I take it, and if there is a tablet appears in my pot and I don't know what it is, I don't take it until I find out. Because sometimes they will just decide to change something or add another tablet in, and they won't have told you what it is for and so I will not take a different tablet until I have found out why it is sitting in the pot with all the others (18. Margaret).

I always ask, I found out what I have, I say why am I having this, what is this, ...why did they stop that. Can I have this at another time, so yes, [...]. About medicines, any patient who has sort of got a chronic condition or something, who has medicines they know what they are taking and there is so much patronisation from the medical nursing teams about that (22. Julia).

For some patients, medication was part of their daily lives. Often, these patients were so familiar with taking medications at home that they immediately knew when something felt wrong with what they had received. As such, they were already sensitised to risks of harm from medication errors.

When I went in they asked what tablets I take and I told them, various antibiotics, steroids [...], my normal medical what I take. On the evening when they gave me my medication I forgot all about it, it just come to mind, they went to give me my steroids again. I said I have already taken them and I was quite ill at the time when I went in, I was a bit groggy and I had got them in my hand to take them, [...], hang on, something just didn't trigger and I thought hang on I

have already had them so I called the nurse over, excuse me I have already taken these (13. Brian).

Some patients, particularly those with multiple or complex conditions, had to work hard to understand what was happening to them and to raise with healthcare staff any concerns they had. For example, John had to (a) recognise that there had been a change in his medication, (b) question whether he was being given the same or different types of tablets, and (c) explain what medication he usually took for each of his several conditions.

One day they give me two tablets, another day another one would give me five tablets, another day somebody give me six tablets, then they give me one tablet, and [...] some days I didn't even know what tablets I was taking because they were all different you know they were totally different to what I normally had ... (14. John).

Speaking up when ill, vulnerable and dependent involved a lot of effort and patients knew that it risked tainting their relationships with staff. However, in some circumstances, it became a priority to speak up about a feeling that something was 'not quite right'. One patient, who had Chronic Obstructive Pulmonary Disease (COPD) and a history of heart failure, felt that he was being treated for the former but attributed his symptoms to the latter. He became concerned that his breathing difficulties stemmed from his heart rather than his lung condition. He suggested this to the doctor treating him, who disagreed.

I went in with a chest complaint. My chest ... exasperation of COPD it was when I went in, it was quite bad actually but whilst I was in there I noticed my chest was improving but my breathing was getting worse. I pointed this out to one of the doctors, ...the doctor who was looking after me, told him I thought it was, I was in heart failure he said no, no, no it is this, it is that, it is everything but he wouldn't sort of say, he thought it wasn't heart failure. (24. Brian)

He became increasingly alarmed when the doctor dismissed his concerns.

I was really getting a bit worried because they wouldn't listen to me and I knew in my heart of hearts it was something to do with my heart because of the way I was breathing: it was a different type of breathing it was different to when it is your lungs ... It took a week, after being in there for me to get him to actually check it out with an echocardiogram.

Brian knew that there was a problem because he was not improving and excess fluid was making his feet and legs swell. He felt increasingly ill and concerned that nobody was taking him seriously. He finally felt that he could no longer tolerate what he perceived to be inaction.

In the end I finally got hold of him outside in the gangway and said, "Look I have had enough now." I wasn't happy the way he was treating me and I told him so and I said, "Really if you have got a plan you should put into practice or it is never going to do any work." Eventually he decided to send me for an echocardiogram which is on the Friday, which is bank holiday Friday, but then I never found out nothing until the following Tuesday, about the results of this echocardiogram. ... This doctor who was looking after me at the time, explained and said he was very sorry he personally hadn't thought it was anything to do with my heart, he said, "But we have had the results of the echocardiogram and you are in heart failure, down to 20%, it is very bad."

Although Brian knew enough to challenge the doctor's expertise and was familiar with how care should be given, in this instance his 'lay expertise' was insufficient to address the power imbalance between himself and the doctor. Brian's experiential knowledge was not considered adequate to inform the doctor's decision-making process earlier on in the treatment plan.

He thought I didn't know what I was talking about basically and he knew more than me, that is the impression I got. [...] I thought they could have possibly done something earlier. Because I had had heart failure before and I knew the symptoms and they didn't seem to listen, want to listen to me.

Patients who live with chronic medical conditions are generally familiar with their symptoms. In such circumstances, they may be able to judge whether they are receiving the right care rather than take it on trust that staff know what they are doing. However, patients remain dependent on others. This means that there can be a gap between what patients see as safe care and what is actually happening to them. Protecting their own safety involves 'risk work' (Brown and Gale, 2018; Gale et al., 2016) that relies on their ability to negotiate with staff about their care. But this brings attendant problems including concerns about the consequences of speaking up or the fear that staff might fail to listen to them.

These examples illustrate the sheer effort that it took for acute medical patients to monitor their care, and to raise concerns with staff given the general expectation – of which they were acutely aware – that they demonstrate deference towards clinicians. First, patients had to recognise that there was a problem and be well enough, or able enough, to articulate it. They then had to explain, sometimes repeatedly, what the problem was and why they needed something to be done about it. They then had to wait for the issue to be addressed. Sometimes this was a lengthy process; sometimes nothing happened at all. It also took effort and courage to ask those responsible for delivering their care at the bedside, when patients were at their weakest or most vulnerable, to do something differently simply because the patient had asked them to. Trust, then, had to become a two-way process. Staff had to trust that patients were raising concerns for a 'valid' reason, rather than because they were mistaken or misunderstood the treatment they were receiving, for example.

These examples demonstrate the relational difficulties of raising concerns about safety for acute medical patients. Raising concerns with a view to managing risks could also bring additional risk, born of the dependency of the relationship: in raising concerns, patients risked marking themselves as 'bad patients'.

12. Discussion

Risk and vulnerability are interrelated concepts. Risk frames understandings of vulnerabilities (Brown, 2022) which can result in people having more concern about particular vulnerabilities in some contexts than others. Here we have shown that patients perceive themselves as vulnerable to risks of harm, both from their health status, and from their dependence on the healthcare organisation and the professionals within it. Patients therefore seek ways in which to make sense of and manage risk and vulnerability, undertaking various forms of risk work.

The concept of risk work has tended to be understood in relation to how healthcare professionals understand and manage risk (Brown and Gale, 2018; Gale et al., 2016). Instead, we apply the concept to patients to show how they took steps to minimise risk and to keep themselves safe after admission to hospital. Patients conducted risk work by: seeking reassurance; being vigilant, including raising concerns, about their treatment and care; and undertaking relational work. Through relational work patients sought to manage risks by acting as 'good' patients and complying with doctors' instructions. Relational work involved drawing on and building trust, as a strategy to manage risk. Trust, is 'embedded within specific social relations' (Zinn, 2008) and is used to guide decisions drawn from everyday lived experiences. Patients drew on trust to manage their vulnerability and invite good care.

The dual roles undertaken by patients when doing vigilance and relational work exist within the wider context of the rise of responsibility in late-modern societies, where patients are increasingly urged to be 'empowered' (Trnka and Trundle, 2014), to resist medical

dominance, shop around for healthcare and to voice complaints through the appropriate channels (Lupton, 1997). However, as Lupton notes, the notion of '*the reflexive, autonomous consumer simply fails to recognise the often unconscious, unarticulated dependence that patients may have on doctors*' (Lupton, 1997). Patients may occupy both dependent and active subject positions simultaneously or variously depending on the context in which they find themselves (Williams, 2005). Our findings reframe Lupton's work (Lupton, 1997): they show that patients cannot always be reflexive, autonomous consumers of healthcare, especially in acute care. But even in acute care settings, if they have capacity, patients work to assess the most appropriate way of keeping themselves safe from harm. This risk work could take a variety of forms. Patients activated different roles according to the level of risk they perceived and where that risk primarily stemmed from. Our findings therefore contribute to understandings of the function of patient behaviour, and highlight the roles of risk and vulnerability in influencing the nature of, and possibilities for, patient involvement in patient safety.

Our findings also show how the different types of work undertaken by patients in response to risk and vulnerability can sit in tension. Hospitalisation carries with it increased risk and uncertainty both from patients' physical conditions and from their dependence on healthcare professionals for their care. Managing risks can involve placing trust in healthcare professionals, and/or the institution organisation (Chauhan and Campbell, 2021; Meyer et al., 2008), but also undertaking practices such as speaking up and questioning decisions that may introduce new risks. The difficulty for patients is that both options may increase their vulnerability, one from harm if trust is misplaced and another from potential damage to relationships from challenging healthcare professional expertise. Efforts to support patient involvement in patient safety need to attend to the risk of increased vulnerability arising from patient safety work.

Relational work was a common feature of patient accounts, and could be characterised as patients acting in line with the obligations of the sick role as traditionally constructed. The continued application of the sick role has been a focus of sociological debate, and our findings offer empirical support for some of these arguments. Burnham has contended that the sick role emphasises the conformity and compliance of the patient and downplays the patient's power and authority (Burnham, 2014) and therefore that its relevance to a society in which patients have greater access to medical knowledge, and perhaps greater expectations of a more equal relationship with clinicians, is limited. By contrast, Shilling has argued that the value of Parsons' ideas lies less in the instantiation of the sick role itself – which is historically and geographically contingent – and more as an expression of the way enduring Western cultural values, particularly in relation to the function and instrumental value of medicine, shape clinician-patient interaction (Shilling, 2002). Viewed through this lens, our findings suggest a distinctive realisation of the sick role in which patients are more active and reflexive in their choices around behaviour, but one which remains underpinned by an instrumentalist culture. We argue that a sick role is played consciously by patients who are acutely aware of the expectations placed on them by their hospitalisation, but are also mindful of wider expectations that they take responsibility for their own safety—and of the risks to them, in environments where safety is an ongoing achievement, if they fail to do so. Our data suggest that at least sometimes, this is a matter of rational calculation on the part of patients about how best to secure their own safety – or at least a matter of a heuristic sense of the relative risks of passivity versus challenge. The sick role in this late-modern setting, therefore, becomes something that is rather less readily characterised in terms of an identifiable set of compliant behaviours: rather it is instantiated dynamically in response to changing circumstances, and (explicit or subconscious) judgements about the relative importance of abiding by medical authority or conforming to wider social expectations at a particular point in time. Nevertheless, we contend that the sick role – or rather, the socio-cultural forces that underlie it – continue to shape patient involvement in patient safety,

manifested here in an implicit understanding that performing the role of cooperative and good patient remains an important element of safety and in managing risk and vulnerability.

More recent shifts towards the responsabilisation of patients to act as consumers, resist medical dominance, and voice complaints, sit uncomfortably with the realities of acute medical care and the attendant vulnerability experienced by patients. The question then becomes how best to enable a different dynamic between patients and health professionals that acknowledges the influence of late-modern expectations of the relationship between healthcare professional and patient, without exposing the patient to greater vulnerability. The expectations of ‘the good healthcare practitioner’ have already shifted from paternalistic to patient centred (McCrae, 2013) in light of the perceived limitations of the healthcare professional’s expertise. We therefore argue that there is a need for a corresponding shift in the conceptualisation of ‘the good patient’: as a partner in care – one who works cooperatively with the health professional. Cooperation encompasses both following advice and treatment, and being engaged as partners in co-producing safety by performing self-care and acting as ‘vigilant monitors’ (Sutton et al., 2015). While developments in research, policy and practice already herald the arrival of this actor as a counterpart to the responsive, patient-centred healthcare practitioner—for example through notions such as shared decision-making and coproduction—realising the role in practice is not straightforward; as our findings show, this is especially the case in relation to patient safety. It requires mutuality which creates attendant expectations. Both patients and healthcare professionals need to recognise how their interactions co-produce safety at the point of care. Seeing safety as co-produced by patients and professionals who are ‘held together by knowledge, skill, habit, and a willingness to be vulnerable’ (Batalden, 2018) might allow risk work to take place without disrupting relationships.

In England (and the rest of the UK), professional-patient interactions take place within an NHS that is under severe strain. This makes placing relationships at the centre of care practice (Bridges et al., 2019a; Oliver, 2020) difficult. A lack of relational care affects patient involvement in healthcare encounters, particularly among older patients (Bridges et al., 2019b; Hope et al., 2022). Hope and colleagues found that where staff seemed dismissive or distracted, patients avoided requesting missed care for fear of being seen as ‘bad’ patients (Hope et al., 2022). Patients who were the most dependent could experience serious omissions in care because they were less able to carry out their own care. Accordingly, patients’ involvement in their own safety depended on staff presenting as approachable and engaged. As Hope and colleagues contend:

‘Unless nursing staff can maintain face as ‘engaged’ (despite organisational constraints that can reduce their capacity to do so) patient involvement in hospital care decisions will remain at the level of rhetoric.’ (Hope et al., 2022)

In practice this means looking for ways to encourage partnerships and mutual understanding of each party’s role in healthcare interactions. Healthcare organisations and patient safety leaders might explore ways of supporting healthcare professionals to create time for staff to actively listen to patients and their concerns routinely with an ‘engaged face’.

13. Limitations

The study has some limitations. The data was collected in the NHS in England and the findings may have varying applicability to other healthcare contexts around the world. The study was conducted before the onset of the COVID-19 pandemic, which may have changed patients’ views on patient safety. Most participants were over the age of 40, with the majority aged 60 and above, and the analysis arguably focuses on the experiences of this older age group. However, this does reflect the current demographic of hospital inpatient populations in England (NHS Digital, 2016b). All participants were white British. There is evidence to

suggest that people from ethnic minority backgrounds are at higher risk from patient safety events (Chauhan et al., 2020); further research is needed to explore their views on their hospital experience, their understandings and involvement in safety and the extent to which they are able to co-create patient safety.

14. Conclusion

Within the context of late-modern society acute medical patients are increasingly urged to speak up, raise queries and take ownership of their healthcare. We highlight how this context interacts with expectations associated with the sick role to create challenges for vulnerable, hospitalised acute medical patients owing to the real or perceived risks to themselves as sick, dependent human beings. As a result, our article so demonstrates how relational vulnerability creates the conditions for silence. We have shown that patients adopt different roles to manage their vulnerability; roles that encompass both challenge and conformity. But while policies seek to empower patients and encourage joint decision-making, the vulnerability that characterises the position of the acute medical patient means that co-creating safety is particularly challenging. Supporting staff to elicit concerns from patients, and offer assurance that challenge is welcome, will be crucial in creating an environment where patients’ involvement in their own safety is optimised.

Author contributions statement

First author: Data collection, conceptualisation, analysis of data, creation and preparation of original draft. Author 2: Writing, review and editing. Author 3: Review and editing. Last author: analysis, writing, review and editing.

Declaration of competing interest

None.

Data availability

The data that has been used is confidential.

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