Defining the user role in infection control

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Summary

Background

Health policy initiatives continue to recognise the valuable role of patients and the public in improving safety; advocating information availability as well as involvement at point of care. In infection control, there is a limited understanding of how users interpret the plethora of publically available information about hospital performance, and little evidence to support strategies which include the reminding of healthcare staff to adhere to hand hygiene practices.

Aim

To understand how users define their own role in patient safety and specifically in infection control.

Methods

Through group interviews, self-completed questionnaires, and scenario evaluation, user views of 41 participants (15 carers and 26 patients with recent experience of in-patient hospital care in London, England) were collected and analysed. In addition, the projects' patient representative carried out direct observation of the research event to offer inter-rater reliability of the qualitative analysis.

Findings

Users considered evidence of systemic safety related failings when presented with hospital choices and did not discount hospitals with high ('red' flagged) MRSA rates. Further, users considered staff satisfaction within the workplace over and above user satisfaction. Those most dissatisfied with received care were unlikely to ask staff *'have you washed your hands?'*

Conclusion

This in-depth qualitative analysis of views from a relatively informed user sample shows *'what matters'* and provides new avenues for improvement initiatives. There is encouraging news here that users take a holistic view of indicators, and strategies to improve dimensions of staff satisfaction along with understanding implications of patient satisfaction are required.

Introduction

On patient involvement, the recent All-party parliamentary report in England highlights a need ‘to change the clinical paradigm from “what’s the matter” to “what matters to you”’. (p.8)¹ This necessary ‘shift in culture and power’ has been highlighted across clinical areas including patient safety.^{2,3} There is a well-established discourse surrounding the potential role and benefits of involving service users in co-designing healthcare services and delivery through consultation, followed by feedback and evaluation to improve services.^{4–6} Here, users constitute members of the public (as potential users of services), patients as current users, as well as carers and relatives of patients. Involvement of patients in decision making around their own individual treatment plans can result in enhanced self-management, and better health outcomes through increased self-efficacy.⁴ Decision making at the organisational level, in hospitals, may be viewed as a logical extension of such user involvement, if users are viewed as secondary stakeholders or as ‘temporary members’ of the hospital.⁷ Even within a hospital setting with its clearly defined organisational boundary, patients have varying degrees of membership as in-patients, out-patients or those with long-term conditions with complex, blended patient pathways.⁸

Whilst policy makers and academics advocate and evaluate user roles, some aspects of this participation remain inadequately defined.⁹ Further research is required regarding the skills and decision-making process employed by users to define their own role in patient safety and infection control specifically. When thinking of roles, issues of responsibility and blame arise and clarity of information and checking understanding is crucial. In-depth qualitative research has revealed that surgical site infections were perceived by patients to be as a result of chance or as a result of their own neglect in post-operative care; MRSA conversely was viewed as avoidable and hence the result of deficiencies in hospital management and care.¹⁰ Users are exposed to a lot of information and indicators about rates of hospital acquired infections via hospital websites as well as the media but we don’t know how users make sense of this information. Additionally, it is not completely clear how users view the espoused and potential roles promoted by healthcare organisations for them. The Chief Medical Officer’s annual report in England (2006) talked about “*strengthening the patient’s hand*” (p.20)¹¹ in response to low compliance with hand hygiene practices by hospital healthcare workers (HCWs). Some hospitals have sought involvement of patients in infection prevention and control practices at the point of care, specifically by monitoring and reminding HCWs about hand hygiene compliance.^{12–14} Some of these practices encourage patients to ask HCWs, at the point of care, ‘have you washed your hands?’, a ubiquitous strategy for patient involvement already reviewed.¹⁵

It is a fitting time to reflect upon positioning patients to monitor and question healthcare staff, when ten years after the initial Francis report, challenges persist for NHS staff to ‘speak up’.¹⁶

This paper explores users’ self-perceived roles in patient safety and specifically in infection control, describing the information needs of users and potential adverse effects,^{15,17,18} with a view to generate useful evidence *before* the resourcing of large scale, controlled, relevant studies.

Methods

In May 2014, a sample of 41 participants (15 carers, 26 patients) was recruited from across London. Recruitment was by quota sampling on ethnicity, and satisfaction level (measured on a five point Likert scale) with received care. In order to minimise respondent desirability bias, and conflict of interest, participants were recruited via an independent market research organisation, and individuals who had received care at the host organization were excluded. To minimise knowledge and confidence bias,¹⁹ HCWs were also excluded. Informed consent was obtained, and participants were reimbursed for their time.

User views were sought through a five-hour long consultation event held at Hammersmith Hospital, London. Discussions were organised in groups of 7 to 9 participants by an experienced facilitator at each table. Group interviews, self-completed questionnaires, scenario evaluation, and discrete choice activities were used to collect data. Following open questions about meaning of patient safety, open and closed questions were investigated in four main domains: responsibility for patient safety; role of patients in patient safety; specific role of reminding healthcare workers (HCW) of hand hygiene; use of publically available infection data in hospital choice (**Figure 1**).

Participants were asked to write free text or fill out short questionnaires *before* group discussion for each question to capture individual views. Non-participant observers also took notes at each table. Plenary sessions were led by a facilitator from the independent organisation to minimise bias. The plenary included an infection control information and ‘Q & A’ session, to find out if this had any immediate/short-term impact on perceptions; this session was led by an infection control research nurse (ECS) and infection control doctor (WZ). The content of the session is set out in **Table I**. The multidisciplinary research team comprising infection control practitioners, healthcare management researchers, and patient representatives took observation notes and analysed the data. In addition, the project’s patient representative (FH) provided inter-rater reliability during data analysis. All

discussions were audio recorded and transcribed. Quantitative analysis of the self-completed questionnaires comprised descriptive analysis. An integrated approach to analysis was used for the qualitative data, where an organising framework or 'start-up' list from the literature,^{6,20} is followed up by an inductive analysis.²¹

[Figure 1 about here]

Results

Participants talked freely about their hospital experiences and sources of influence including experiences of friends and family.

Patient safety – meaning and expectations

Participants brought up a number of aspects of patient safety ranging from structural issues such as levels and consistency of staffing, processes such as cleanliness of the environment and information sharing, and wider cultural aspects of a safe and friendly atmosphere. Dimensions of patient safety which were seen as important by the participants, in order of prevalence to the open question *What does patient safety include?* were as follows: emphasis on cleanliness of the environment, staff, and visitors; protecting patients from adverse incidents (e.g. misdiagnosis and wrongly prescribed drugs, infections); having well-trained and trustworthy staff; providing appropriate medical treatment; ensuring safety/security of patients and their belongings.

In this opening question, participants spoke about the preventative measures of hygiene, as well as making references to hospital acquired infections more generally:

"mixture of infection patients with no-infection patients" (User 3, Male)

"... not to go in with one illness and contract another" (Carer 2, Male)

Only one participant made specific reference to a particular hospital acquired infection (in this case MRSA). Respondents focused mainly on care whilst in hospitals with only two individuals referring to post-operative care and no mention of primary care.

A significant number of participants spoke about personal safety from other patients and feelings of vulnerability. These worries were exacerbated by perceived low levels of staffing and overstretched staff who '*do not know what is going on*'. Consistency of staffing was seen as important to minimise information loss and avert adverse events such as misdiagnosis and incorrect prescribing. In addition to these potential adverse events, concerns about

'feeling vulnerable' and 'worried will not be listened to' were highly prevalent in accounts across age groups.

Responsibility for patient safety

In response to this open question, *Who is responsible for patient safety?* notably, patients were perceived devoid of responsibility, while visitors and carers were deemed responsible (20%). Additionally, little responsibility was apportioned to macro-actors such as the government or commissioners, with an emphasis on 'all staff in hospital' and 'healthcare staff in hospital' being responsible for patient safety (**Figure 2**). On the follow up direct question, *Do patients have a role in patient safety?* all responded positively. The nature of involvement was contingent on a number of factors including severity of illness and 'type of hospital' – which was elaborated upon in the group discussions to mean '*Will we be listened to?*' Ideas for participation included anonymous (electronic) feedback.

[Figure 2 about here]

Reminding healthcare staff about hand hygiene

None of the participants had previously asked this question of HCWs for self or for others. About half of the participants reported commenting previously to staff about visible lack of environmental cleanliness. The information and Q&A session seemed to have some impact on participants' confidence about this aspect, as to the results to the prospective, intentional question '*Would you ask a HCW, have you washed your hands?*' a minority, 36%, of participants said they would ask.

[Figure 3 about here]

Figure 3 shows that the younger and older participants reported a higher intention to ask than participants aged 30-60 years. No association between gender and intention to ask was found. Equally, no differences between carers and patients were observed. The analysis did reveal interesting patterns according to level of satisfaction of received care. None of the highly dissatisfied participants answered 'yes' to this question. A minority 10% of these participants said they may ask under certain conditions, whilst 90% said that they would not ask. However, for those at the other end of the spectrum ('satisfied' or 'very satisfied with care'), the majority would ask under certain conditions (77%), the remaining 23% said they would ask. So in contrast, none of the satisfied participants ruled out the possibility of asking.

Reasons provided for unwillingness to ask ranged from feeling uncomfortable, avoiding disrespect toward HCWs, and assuming that HCWs were competent.

"I would consider the doctor / nurse to be a professional in their field. I think it would be rude and inappropriate to tell them to wash their hands." (User 25, Male)

"It's difficult to stop somebody from doing something - I'd even feel uncomfortable about asking somebody in a catering facility - I'd expect them to take offence" (User 6, Female)

Almost a third empathised with staff being busy and having to deal with challenging situations; this was another rationale for not asking. For some of those with an intention to ask, the importance of observing hand hygiene was stressed:

*"Yes - wash hands... I wouldn't want them touching me or taking my blood **without me seeing them do this.**"* (User 15, Female)

For 35% of participants (classified as 'Y/N with qualifier' in **Figure 2**), a number of conditions would determine their participation in hand hygiene monitoring behaviours. These circumstances included the staff member concerned (*"I would not ask a doctor, No I would not."* Carer 2, Female); the patient concerned (*"Definitely would for my child."* User 40, female; *"Elderly patients are too scared to ask such question."* User 29, Female); or the health status (*"If I was in severe pain or distress no as last thing on my mind - so 'No' but If in mild pain, routine exam, I would say 'have you washed your hands' though this could be insulting... maybe."* User 3, Male).

Two participants were explicit about the renewed thoughts following the information session:

"I wouldn't have had, but may do so, now it's been highlighted I think I definitely will."
(User 5, Female)

"Not sure, depends on circumstances, probably would now" (Carer 12, Male)

In contrast, when participants were presented with a different scenario about patient safety (missed medication dose of a diabetic patient) the majority were willing to 'speak up' as this was associated with immediate danger to health. Ninety percent stated that they would interrupt two HCWs to alert them of a missed dose of medication.

Hospital choice based on performance indicators

Participants took some time in trying to make sense of the numbers and the associated (red, amber, green) coding (**Figure 1**), with discussion about thresholds between amber and red. For example a higher objective rate above the 'expected' rate is not always coded red.

During discussion it became apparent that understanding that red can be attributed through quite small deviations for certain indicators was useful.

The exercise provided good insight to the level of information participants were willing to engage with when provided in the context of shared information, views and opinions. It was also apparent that information provided 'cold' would be somewhat unhelpful and unlikely to be used to 'rate' hospitals, aid decision making or indeed alleviate fears. In this context of information exchange, aggregate results for the participants show that the hospitals were ranked in order of preference as follows: First preference was shared between Trust A and B. Many respondents stated that they 'just would not go' to Trust C.

"Trust C - it would appear that staff are unhappy and avoidable infections are more than half which rings alarm bells." (User 11, Female)

"Trust A - Reason is that overall the hospital scores highly, taking into consideration that people can get an infection in all NHS hospitals." (User 39, Male)

"I would trust 'A' though it has one red, but it can be easily counter measured and fixed. The other points of 'A' are green. So they need to fix the problem for the first point. B and C has more than one problem, and it is tough and time consuming to fix. So A, B, C" (User 25, Female)

The indicator of the NHS Staff Survey 'proportion of staff who would recommend the trust as a place to work or receive treatment' was viewed as an important indicator by the majority of the participants. This indicator was perceived to be more important than the 'Friends and Family test'.

The elevated risk ('red') of HCAs in Trust A was discussed by participants in context of the other indicators and by itself did not deter users. Participants viewed HCAs as 'unavoidable' in some situations and looked for explanations to why this was the only issue. In addition, there was discussion about the period over which the data was relevant, if the elevated risk was a 'peak' value or a consistent risk over a longer period. Overall, Trust C was perceived as a 'problem' Trust with systemic patient safety failings.

Discussion

This research engaged users with experience of in-patient hospital services to afford an opportunity to explore their decision making process including appraisal of infection control fitness of hospitals. Findings are limited in generalizability by the sample size, and because data relates to participants' intentions and opinions rather than actual behaviours.

Participants did not recognise an immediate role of users in patient safety, or align themselves within the generic remit of 'infection control as everybody's responsibility'. However, on direct questioning the majority felt that patients have a role in patient safety. Their main concern referred to 'not being listened to'. Follow up after discharge was the point when patients reported feeling very vulnerable and examples of negative and positive experiences emerged. Findings indicate that a positive experience with overall care may lead to better engagement, because patients may feel that their concerns will be listened to. As in previous studies, on the specific role of patient involvement in increasing hand hygiene compliance, a minority said they would interpolate HCWs about this at the point of care.^{15,22,23} The findings in the current study are particularly important as the views were taken after a detailed presentation of the risks of hospital acquired infections and the critical role of hand hygiene in addressing this avoidable harm. Reasons for not asking spanned from fear of repercussions for future care, respect of professional knowledge and competence, to empathy for a busy, over-stretched workforce. Organisations may find it helpful to use hand hygiene as a 'tracer' to understand how patients perceive their hospital and staff, abounding on the notion that optimal organisational patient safety may reflect overall quality of care.^{3,24,25} In addition, complete absence of engagement intention in the dissatisfied users may serve as an important proxy indicator for hospitals when embarking on interventions.²⁵

There may be something particularly uncomfortable about questioning an individual's 'hygiene', as anecdotal accounts from the practitioners and patients representative corroborate, but there is also a temporal dimension. Culturally, comparing hand hygiene as a basic tenant of infection control, to smoking on hospital premises (another primary prevention measure), we are decades from having institutionalised or internalizing infection control. In this context, putting onus on patients may not be the way forward. Health system financing and delivery structures, position users at varying degrees of control, as do individual factors such as education and health literacy.²⁶ However, these do not seem to translate to levels of comfort with the suggested role of questioning or reminding.¹⁹ This research suggests that users engage in a sophisticated (or more complex than hitherto considered)^{27,28} appraisal of the information related to HCAs provided in hospital websites. An 'elevated risk' of acquiring an HCAI (visually coded red) along with no evidence of risk (green) for five other indicators did not deter users from this hospital. Hospitals with systemic problems were seen as unsafe and hospitals where improvement would be more challenging. Hospital staff need time and resources to enable meaningful conversations with patients and carers about the information that is already out in the public domain. Clinicians and organisations must take into account the health literacy of patients before proposing or

promoting the participation of these patients. Assessment by the service users in the current study aligns well with the wider suite of organisational performance and capacity indicators needed to assess optimal infection control.²⁹

Whilst users span primary, secondary and tertiary care through the life course, in this study infection control outside of hospitals care did not feature in accounts. In hospitals, users are included in governance activities through membership of governance councils in NHS Foundation hospitals membership of Patient-Led Assessments of the Care Environment (PLACE).³⁰ Generic evaluation tools are in routine use, but employment of this data to improve care is still sub-optimal.⁵

From an organisational perspective user views can help shape care which is responsive to people's individual abilities and preferences.⁹ From a health systems perspective, it is useful to bear in mind the aspirational 'fully engaged' scenario,³¹ the contribution of patient safety efforts toward this goal, but also to stop and think about the nature of this engagement.

"Levels of public engagement in relation to their health are high. Life expectancy rises considerably, health status improves dramatically and people are confident in the health system and demand high-quality care. The health service is responsive with high rates of technology uptake, particularly in relation to disease prevention. Use of resources is more efficient." (p.4)³²

Conclusion

There is encouraging news here that users take a holistic view of indicators and are interested in what is behind publically reported numbers.

The study explains why interventions which involve observing, monitoring and challenging healthcare staff are inconsistent with what users feel capable or comfortable with. New approaches which involve a more collaborative approach through sharing and interpreting information is one suggested avenue.

Strategies to improve dimensions of staff satisfaction along with understanding implications of patient satisfaction are required. Intelligent use of routinely reported feedback may therefore be useful at the organisational level. From a human factors perspective, staff satisfaction itself is an important indicator to gauge resilience or fatigue at the unit level. In addition, higher levels of staff satisfaction may result in better staff engagement with new initiatives, in a more sustainable way.

This in-depth analysis of views from a relatively informed user sample shows what matters and provides new avenues for improvement initiatives.

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Table I. Content of information session

- Definition of healthcare associated infections (HCAIs)
- Types of HCAIs
- Implications of HCAIs: morbidity, mortality, healthcare costs (national and international)
- Rates and trends of different HCAIs in English hospitals
- Take home message: hand hygiene is one of the most effective interventions to prevent the spread of HCAIs

Figure 1. Risk profiles of three trusts: based on publicly accessible process and outcome indicators, participants had to choose a trust for personal care

Indicators	Trust A	Trust B	Trust C
Avoidable infections: <i>Incidence of Meticillin-resistant Staphylococcus aureus (MRSA)</i>	Observed: 9 Expected: 2.58 Risk?: Elevated risk	Observed: 1 Expected: 2.75 Risk?: No evidence of risk	Observed: 5 Expected: 2.59 Risk?: No evidence of risk
Re-admissions: <i>Emergency readmissions following an elective admission (Cross sectional)</i>	Observed: 1880 Expected: 1763.26 Risk?: No evidence of risk	Observed: 986 Expected: 1014.07 Risk?: No evidence of risk	Observed: 1309 Expected: 1019.61 Risk?: Elevated risk
Meeting physical needs: <i>Inpatient Survey 2012 Q32 "Were you involved as much as you wanted to be in decisions about your care and treatment?" (Score out of 10)</i>	Observed: 7.01 Expected: - Risk?: No evidence of risk	Observed: 6.59 Expected: - Risk?: Risk	Observed: 7.38 Expected: - Risk?: No evidence of risk
Overall experience: <i>NHS England inpatients score from Friends and Family Test (Score out of 100)</i>	Observed: 69.96 Expected: - Risk?: No evidence of risk	Observed: 48.31 Expected: - Risk?: Risk	Observed: 69.75 Expected: - Risk?: No evidence of risk
Staff survey: <i>NHS Staff Survey - The proportion of staff who would recommend the trust as a place to work or receive treatment</i>	Observed: 68.27% Expected: 65.19% Risk?: No evidence of risk	Observed: 63.58% Expected: 65.19% Risk?: No evidence of risk	Observed: 51.56% Expected: 65.19% Risk?: Elevated risk
Staffing - Staff vs bed occupancy: <i>Ratio of all nursing staff to occupied beds</i>	Observed: 1.29 Expected: 1.82 Risk?: No evidence of risk	Observed: 2.26 Expected: 1.82 Risk?: No evidence of risk	Observed: 2.1 Expected: 1.82 Risk?: No evidence of risk
Data representing three trusts differentiated for five out of six indicators were presented and participants asked to state preferences, given that all other dimensions (travel time, cost etc.) are equal. The indicator for staffing - staff vs bed occupancy (ratio of all nursing staff to occupied beds) acted as a 'control', rated green (no evidence of risk) across the three trusts, to minimize bias, as this issue had been the focus of media attention close to the data collection period.			
Source: Care Quality Commission Intelligent Monitoring Reports			

Figure 2. Participant's perception of responsibility in patient safety

Figure 3. Response to *Would you ask a healthcare worker – have you washed your hands?*