'I don't want to cause any trouble': the attitudes of hospital patients towards patient empowerment strategies to reduce healthcare-acquired infections

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Abstract

Background: Patients have, traditionally, been assumed to be the passive party in the healthcare-associated infections equation, with relatively little research focused on the patients' perspective. This study aimed to explore the attitudes of hospital patients towards patient empowerment as one of the key components of patient engagement.

Methods: Semi-structured interviews were undertaken with surgical patients from a major public hospital in Sydney, Australia.

Findings: While participants acknowledged that patients could play a role in preventing infections while in hospital, that role was largely associated with maintaining their own personal hygiene. No reference was made to patients interacting with staff members. Some participants said that they would feel comfortable and happy to engage with staff, while others voiced concerns. Some about not wanting to 'cause trouble or start fires' and therefore would not tell staff members to perform hand hygiene. Some participants articulated a fear that their care may be negatively affected if they directly engaged or confronted clinicians about their behaviours.

Conclusion: We found that patient engagement remains an underused method of preventing healthcare-associated infections, and the deep-seated public fears about individual vulnerabilities still need to be addressed.

Keywords

Empowerment, hospital, patient, healthcare workers, healthcare-acquired infections, infection control.

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Background

Until recently, patient safety has largely been viewed as the remit of healthcare workers (HCWs) and the patient has often been assumed to be the passive party in the patient safety space. A more informed dialogue between providers and patients has emerged recently, supported by the World Health Organization (WHO) at an international level, arguing for a more active role for patients within the quality improvement movement. Within this context, patients and their families are acknowledged as providing a unique perspective on the system and in doing so help to identify risks and solutions for reducing harm caused by clinical errors (World Health Organization, 2004). Increasing the engagement of patients in their care has been used as a strategy to promote medication adherence,

improve patient safety after surgery and foster open communication with HCWs (World Health Organization, 2009).

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Patients' active involvement in their own healthcare within the hospital context is a function of both what patients do in relation to their health and their interactions with health professionals (Entwistle, 2007). Strategies to involve patients in clinical safety fall into five general categories including: (1) working with patients so that they are better able to manage their treatment regime safely; (2) getting patients to intervene directly; (3) supporting patients to share information with and ask questions of clinicians; (4) inviting patients to provide feedback on the care received; and (5) directly involving patients in system wide improvement strategies to improve safety (e.g. personally reporting errors and sitting on governance committees) (King et al., 2010; Peat et al., 2010).

Consumer engagement strategies do not generally rely on patients to check on the delivery of their healthcare to ensure their safety; rather they actively involve patients in their own care, while other efforts are made to improve their safety. By asking questions, patients are thought to be more informed about their conditions and thus better equipped to participate in a range of safety-related behaviours if required (e.g. alerting a surgeon if they think that they have developed a surgical wound infection).

The risk of acquiring a healthcare-acquired infection (HCAI) is universal and pervades every healthcare facility and system worldwide. The prevalence of HCAIs is an important indicator of the safety and quality of medical care. These infections are associated with additional costs, prolonged hospital stays, and excess morbidity and mortality (Bates et al., 2009). To date, patients have often been assumed to be the passive party in the HCAIs equation, and very little research has been done on a patient focus as contributing to the solution to the problem of HCAIs. Previous studies have suggested that patient participation does yield positive results, and that patients can not only participate in strategies to improve their own hand hygiene (HH) but also to engage with hospital staff and encourage them to comply with HH. In this study, we explored in depth the perceptions of surgical patients in Sydney, Australia towards the concept of patient empowerment and to examine their willingness to engage with health professionals to promote infection control in hospital.

Methods

Study design

Fifteen semi-structured interviews were undertaken based on a convenience sample of hospital patients from a major public hospital in Sydney, Australia between September and October 2013. The Human Research Ethics Committee (HREC) of the South Eastern Sydney Local Health District-Northern Sector (SESLHD-NS) approved the study.

Participants

The researchers liaised with the Nurse Unit Manager (NUM) from the surgical wards to identify admitted patients

who fitted the eligibility criteria (aged 18 years, able to communicate in English, able to provide written consent). Researchers attended the wards on different days and times to recruit participants. Patients were only approached if they were awake, not waiting for surgery or discharge, and not visibly distressed. During this 2-month study period researchers approached patients who met these criteria, spoke to them about the study and invited them to participate. Patients were recruited into the study when full written consent had been received. A grocery voucher was given to all participants to compensate them for their time. Recruitment continued until data saturation was reached.

Data collection

An interview guide was developed by HS/JT/LP and reviewed by the other researchers to identify key areas of interest for the study. This included a series of questions related to the following topics: knowledge of HCAIs and strategies to prevent them; information needs; willingness to question healthcare staff about their treatment; willingness to ask factual vs. challenging questions related to the quality and safety of their healthcare; attitudes towards a proposed 'empowerment' intervention (i.e. encouraging engagement with staff around HH, wound care, cleanliness, infection awareness etc.); and perceived barriers and facilitators towards using an empowerment strategy. The list served only as a general direction for the researcher during each interview. Paraphrasing and additional questions were added to seek clarification in order that the study captured the range of opinions and was sufficiently flexible to accommodate different scenarios. Questions were asked in an open-ended manner to allow room for expansion. For example, interviews often began with a broad question like 'What words come to your mind when I say the word "infection"? to allow participants to freely discuss their opinions. Prompts were only given when the interviewer deemed that it was necessary to encourage the conversation back to topic or to address a certain issue. During the interviews, informal member checking was conducted during the later interviews by summarizing the information previously obtained and then asking participants to reflect on their views, feelings and experiences towards the summary. The purpose of member checking is to decrease the incorrect interpretation of data, with the overall goal of providing findings that are authentic (Creswell, 2007).

Participants were also asked to complete a short (2-minute) survey that collected general demographic information. The questions were pre-tested among a small sample to ensure they were acceptable, understandable and unambiguous, and that open-ended questions elicited the expected type of response.

Data analysis

The interviews were transcribed verbatim and analysed thematically. Transcripts for each taped interview were checked

for internal consistency and corroborated with other interviews. NVivo 10 was used to facilitate the analysis. Following repeated and close reading of the individual interview transcripts, two researchers (HS and AAC) independently constructed a code list of major themes emerging from the data. Those code lists were compared and cross-checked and a final list was compiled. An agreed thematic framework was then applied to another subsample of transcripts and further modified. Using this final framework, all of the 15 transcripts were analysed and coded.

Results

A total of 15 interviews were undertaken between September and October 2013. Of the patients interviewed, seven were women, the average age was 47 years (range: 23–74 years), most were born in Australia (13/15) and seven had completed a diploma or degree. Seven of the 12 patients aged <65 years (age of retirement in New South Wales) were currently working. Eight patients had been previously admitted to hospital (range of visits: 1–10), while 3/8 had previously been diagnosed with a HCAI. Only three patients had previously received information about HCAs and two of these patients had prior admissions, however 8/15 reported having sufficient knowledge.

The interview results are presented below according to the themes that were identified.

Varying degrees of knowledge and concerns

Among the patients interviewed there were varying degrees of knowledge about the nature of infections and how they are acquired. Very few associated the word ‘infection’ with its potential source (i.e. either a bacterial or viral pathogen). Instead they spoke about the outcomes of acquiring an infection (i.e. feeling unwell, dying, having a fever). When participants did refer to HCAI, they mostly spoke about ‘golden staph’. Patients who reported previously having a HCAI or another infection type appeared to be slightly more knowledgeable about how HCAI are transmitted and about the associated risks for patients. Participants associated disease transmission in the hospital with unclean environments (‘dirty toilets’) and spoke about the number of times, for example, that they had seen the floors being cleaned. Participants were more likely to talk about patients being responsible for transmitting infections than other actors, including clinicians, in the facility. Infection transmission was associated with poor hygiene (especially among patients). Participants were relatively positive about the hygiene behaviours of the staff. However, one participant did note that he had observed that staff members were not as compliant with infection control when they were in a hurry.

‘I do notice some in a hurry, will dash in and do this and do that and do that, have no gloves on or nothing, and that makes you concerned, you know.’ (Participant 5, aged >65 years, male)

There were mixed responses in regards to our enquiries about whether patients felt concerned about HCAs. While some stated that they were not worried or concerned, one asserted that:

‘I’ve always got concerns the minute, the minute I enter a hospital sort of that, you know, Are people washing their hands?’ (Participant 13, aged 50–65 years, female)

Low levels of information provision

Most participants reported not previously receiving any information on HCAs and/or infection control. None of the patients had previously seen information pamphlets about HCAs but a couple of participants indicated that they had seen posters about HH. One participant acknowledged that it was not always easy to receive basic information from doctors as they are ‘they’re always in a hurry’ and it was sometimes up to the patient to fill in the gaps.

‘I think it’s very difficult when people are very short of time to gain, to gain maximum information... Because they [the doctors] come in for snippets, give you a minute here and a minute there and then, as a patient, you have to collate all the information. So it’s difficult.’ (Participant 13, aged 50–65 years, female)

Need to be more aware of personal hygiene

A number of participants stated that they felt that patients and their family members should be playing an active role in the prevention of HCAs. When asked to elaborate on what this role could be, participants indicated the belief that both patients and their families should be vigilant about their own personal hygiene and their hand-washing. Some expressed the view that the responsibility was on the staff members to prevent infections in the hospital, while others said patients could assist by ‘doing what they are told’. There was no mention of interacting with staff members about these issues, about talking to staff members about HCAs, or about asking or prompting them to perform any infection control tasks such as HH.

Engaging with staff members

There was a mixed response when participants were specifically asked about whether they would be comfortable to ask or prompt a staff member to engage with infection control strategies. At one end of the spectrum, participants suggested that patient have a right to ask staff members about infection control and/or asking them to wash their hands, and that they would feel comfortable and happy to do so. One participant suggested that infection control should be an open issue and that patients should feel comfortable to ask ‘Have you washed your hands?’ or ‘You’re coughing, you should cover your mouth and nose’. While they did not

feel that there were any negatives associated with introducing patient empowerment strategies into the hospital, they did acknowledge that some patients would find it challenging asking these questions to staff members of the opposite gender and/or senior staff members.

There were others, however, who felt that they were unlikely ever to be able to question or comment on a staff members behaviour. Feeling intimidated, embarrassed or shy was some of the reasons suggested by participants about why they would not engage with staff. The potential outcomes of engaging patients was questioned by one participant who said 'It may do a little bit of good, but I honestly can't see it doing a lot of good... my opinion is they should just left to ... they should be left to go and do ... they're all well-trained, and I think 99% of them would be doing the right thing'.

Among those who supported the concept of engaging with staff members and among those who did not, there were participants with and without previous hospital admissions (single and multiple visits).

Don't want to upset the staff members

Some participants felt that if they questioned the staff member's habits that it might upset or embarrass or annoy the staff members.

'Doctors might take it the wrong way, and think they've been to medicine school for so long and maybe get offended by it, or something. But I guess it's up to the individual person.' (Participant 7, aged 40–50 years, female)

'You don't know how they're going to take it and maybe... you interfere too much with their work... Nobody likes it when somebody else is interfering with your job.' (Participant 8, aged 50–65 years, female)

'I just don't want to cause fires, don't want to cause trouble.' (Participant 12, aged 30–40 years, female)

This idea of 'interfering' in the staff members' work went beyond the patients' concern about professional courtesy, to concerns about the potential ramifications of this type of engagement. Active engagement by the patient was seen as an implied criticism of the work of the staff members, one with potential for real harm:

'I just think you might get him offside. I mean, he's someone who's ... you know, you're putting your healthcare in their hands but if you, sort of, are telling them what to do, they might get a bit off-put by that.' (Participant 6, aged 20–30 years, male)

'I suppose the nurses could get a little bit upset that they're getting told how to do their job... I don't know if they might see it as coming across quite rude and I don't know if that will negatively affect how they treat you in the hospital.' (Participant 10, aged 20–30 years, male)

'If they're going to look after you, you don't want to start as if you're being clever to them and ... because you

might get backlashes for some reason.' (Participant 2, aged >65 years, male)

Being shy or feeling intimidated or embarrassed were reasons suggested by participants who stated that they would not ask their staff members. Participants placed these feelings on a gradient: patients were in general more reluctant to speak to senior doctors and to cleaning staff, than to nurses. This was linked to the feeling that nurses (especially the younger ones) are around all the time and 'happy to do things for the patients'.

'I would probably feel a bit intimidated by saying something to a doctor about, "Hey, wash your hands".' (Participant 6, aged 20–30 years, male)

'Probably not so much the cleaners... Maybe the nurses, yes, because they are coming up quite close and touching me and, you know, changing my things.' (Participant 10, aged 20–30 years, male)

There were, however, certain circumstances when it was deemed to be more acceptable to intervene. For example, if a patient saw the staff member (doctor, nurse or ancillary staff member) going to the bathroom and not washing their hands afterwards or constantly not washing their hands, participants acknowledge that they would probably intervene.

Discussion

Using qualitative methods, this study explored the opinions of hospital patients towards the use of patient empowerment. We found that there were low levels of health literacy about HCAs and very little provision of information. While participants did acknowledge that patients could play a role in preventing infections in hospitals, their position was around maintaining personal hygiene. There was no reference made to patients interacting with staff members. Concerns about having their healthcare negatively impacted on were one of the barriers suggested by participants when asked whether they would prompt a staff member to HH. Patients were motivated primarily to maintain a good relationship with their clinician and hospital staff in the interests of receiving good quality care.

To date, there have been mixed results among the studies that have documented patient beliefs and intentions regarding whether they would prompt a staff member to perform HH. While some survey-based studies have reported close to 80% of their population having a positive attitude, other studies have reported rates, which are considerably lower (Duncanson and Pearson, 2005; Wu et al., 2013). In a large survey undertaken by the UK National Patient Safety Agency, 530 members of the public and 215 hospital patients (from surgical and medical wards in five UK hospitals) were questioned about whether they would ask their HCWs to clean their hands. Around 50% of members of the

public were either 'not very likely' or 'not at all likely' to ask a nurse to clean his/her hands when changing a leg wound dressing if they had not witnessed them doing it. When the same question was asked of hospital patients, almost all (94%) respondents indicated that they had not asked their nurse or doctor to clean their hands. Both groups assumed that the HCW would have already cleaned their hands if they had not seen them doing it. The concern of not wanting to 'annoy' the HCW was also identified in this survey-based study. In support of our findings, the survey also noted that people would feel too embarrassed or shy to ask and were also less likely to ask a doctor than a nurse. Again in support of our findings, the surveyed hospital patients reported that they would like to receive information about HH and the use of hand rub (Pittet et al., 2011).

Multiple interlinked factors have been found to influence patients' intention to get actively involved in preventing such medical errors as failure to sanitise hands. These factors can be broadly divided into: endogenous (i.e. the feeling of being able to prevent an error or to provide input and believing in the perceived effectiveness of taking preventative action); and exogenous (e.g. socioeconomic factors such as age, gender, ethnicity, education, employment) and other external factors (e.g. availability of information, personal experiences and social norms) (Hibbard et al., 2005; Schwappach, 2010).

Promoting a culture of safety and HCAs reduction must involve everyone, top to bottom, in the process. By necessity, this must include the patient. However, patients often perceive their status as passive (subordinate to HCWs), and this is considered to be the most significant barrier in helping to reduce clinical errors (Doherty and Stavropoulou, 2012). The occupational hierarchy and relationships between patients and staff are especially important in determining patient safety attitudes and behaviours (Doherty and Stavropoulou, 2012). These relationships are constantly shifting further away from a rigid paternalistic structure to facilitate more patient autonomy in decision-making and influencing their own care (Deber et al., 2007). Nevertheless, HCW authority is still very strong, and some patients feel uncomfortable challenging the judgement or actions of their caregivers for the fear of being labelled as 'difficult', of offending staff and/or because of concerns of compromising their healthcare and safety (Burnett et al., 2010). For some patients, the concept of 'confronting' HCWs goes against societal expectations and accepted norms (Davis et al., 2008; Hibbard et al., 2005; Marella et al., 2007), potentially deterring patients from participation in medical error prevention in general, and enquiring about HH specifically (Hibbard et al., 2005).

Our participants expressed anxiety about interacting with staff members around infection control. Many felt that by asking staff members to undertake HH that it would annoy the health professional, which could lead to potential consequences on the quality of healthcare delivered. While

we did not explore this, it could be hypothesised that an ongoing dialogue between HCWs and patients may relieve these fears. Recent studies have shown that by notifying patients that HCWs appreciate the HH reminders there is an increase in the level of willingness to actively participate in programs. For example, Longtin et al. (2009) found that the willingness of their patients to remind HCWs to perform HH doubled following the introduction of an explicit invitation (nurses: 34% to 83%; doctors: 30% to 78%). In 2013, a large Taiwanese study of hospitalised patients and their families found that respondents willingness increased significantly (48.9% to 74% for doctors and 50.8% to 76.3% for nurses); when the participant believed that the HCWs would appreciate such a reminder (Wu et al., 2013). Lastly, a large multinational survey also found that invitations from HCWs to patients had a positive impact on the patient's willingness to provide reminders (increase from 52% to 86%) (World Health Organization, 2009).

While it is now established that patients need the encouragement of their health providers to feel comfortable enough to engage with strategies to reduce infections in the hospital, there is still debate about how to deliver those messages. There is not a single approach to help patients and families become active partners in their care and encourage their vocal and continual involvement. The use of posters, pamphlets, scripts and visual aids ('fuzzy weebles', rubber grips, badges) has all been previously suggested as mechanisms to promote HCW/patient interaction around HH (Lent et al., 2009; McGuckin et al., 1999). However, there has not been a comprehensive evaluation of these mechanisms and one cannot currently conclude which approach (or combination of approaches) works most effectively. Regardless of what strategy is implemented, the most important factor is HCWs engaging with patients, speaking to them about HCAs, about how they can engage in supporting infection control and how they can wash their hands properly.

A recent initiative that was undertaken by the Children's Healthcare of Atlanta to engage patients (children and adolescents) and their families' members was a programme titled 'Good Health is in YOUR hands'. The 2007 programme involved putting up posters and educating patients and staff. It was later expanded to include the 'Foam Up' initiative, which was an interdisciplinary and multifaceted programme which aimed to improve HH among staff and patients. While the program did incorporate the use of posters and computer-based reminders for staff, it also included a number of innovations to improve the impact. For example, the program incorporated a ticket system, which could be utilised by people who felt unable to verbally tell someone to perform HH but were able to hand the person a 'ticket'. In addition, they develop scripted responses for staff members who were reminded to 'foam up' and for patients and their family members to assist them in encouraging the staff to 'foam up'. Lastly, the programme also

incorporated the use of stickers that could be passed onto employees who had performed excellent HH. It created a level of competitiveness between the staff members in collecting the most stickers. Evaluation data have documented high levels of adherence with the 'foam up' program (97%), high HH compliance rates (91.5%) and associated reductions in bloodstream infections by 64% (Children's Healthcare of Atlanta, 2014).

One of the main strengths of our study is that we used in-depth interviews to elicit a greater depth in the information. We do acknowledge that interviews were only undertaken with a select group of participants, and in particular acknowledge the limitations of only having English-speaking participants, and so the possibility of other important themes emerging cannot be ruled out. This was a small, qualitative study, and the findings should be explored further in larger studies.

The WHO supports the idea of patients being actively involved in observing and asking staff about their hand-washing practices. However, there is the potential to involve the patient in a range of different infection control initiatives. In this study, we focused on surgical patients because of the high level of preventable infections that are still being reported each year in this group. The surgical pathway for most non-emergency patients includes opportunities for empowerment: (1) prior to the patient being admitted (i.e. encouraging patients to stop smoking and/or to lose weight or to encourage them to speak to their GP about vaccination); (2) during pre-admission clinic (to teach them about HH or to educate them about infection control); (3) or during the hospital stay (i.e. encouraging patients to ask questions or speak up about concerns/changes, asking patients to educate their visitors, and encouraging patients to ask HCWs to perform HH); or (4) after the patient is discharged (i.e. educating patients about the signs and symptoms of surgical site infections, encouraging them to talk to their GP, etc.). The essential attribute of patient empowerment is respect for the patient's unique and valuable perspectives. The axiom 'the patient is the only person present at all stages of their care' is very relevant in this context. By shifting away from the traditional setting, in which only HCWs have a place in the prevention of HAIs, to a place where patients also have a role, this project has the potential to reduce the burden that HAIs place on the patient and the healthcare system.

Conclusion

The capacity of patients and their family members to make a contribution to their safety is strongly shaped by their relationship with staff members. Patients will continue to be unwilling or unable to engage with staff or adopt behaviours to promote infection control, unless they are empowered and encouraged by their health providers. Hospitals need to consider the introduction of mechanisms that bridge

this gap and minimise the barriers to patient participation in order to maximise the benefits in infection prevention, which can be gained from empowerment programmes. In order to monitor the progress, ensure that planned actions are implemented and that there are high levels of compliance with patient empowerment programmes, dedicated indicators of patient involvement need to be developed and implemented.

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Declaration of conflicting interest

The authors declare that there is no conflict of interest.

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