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Putting the 'patient' in patient safety: a qualitative study of consumer experiences

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Abstract

Background Although patient safety has been studied extensively, little research has directly examined patient and family (consumer) perceptions. Evidence suggests that clinicians define safety differently from consumers, e.g. clinicians focus more on outcomes, whereas consumers may focus more on processes. Consumer perceptions of patient safety are important for several reasons. First, health-care policy leaders have been encouraging patients and families to take a proactive role in ensuring patient safety; therefore, an understanding of how patients define safety is needed. Second, consumer perceptions of safety could influence outcomes such as trust and satisfaction or compliance with treatment protocols. Finally, consumer perspectives could be an additional lens for viewing complex systems and processes for quality improvement efforts.

Objectives To qualitatively explore acute care consumer perceptions of patient safety.

Design and methods Thirty-nine individuals with a recent overnight hospital visit participated in one of four group interviews. Analysis followed an interpretive analytical approach.

Results Three basic themes were identified: Communication, staffing issues and medication administration. Consumers associated care process problems, such as delays or lack of information, with safety rather than as service quality problems. Participants agreed that patients need family caregivers as advocates.

Conclusions Consumers seem acutely aware of care processes they believe pose risks to safety. Perceptual measures of patient safety and quality may help to identify areas where there are higher risks of preventable adverse events.

Introduction

Concerns about patient safety have consumed health-care leaders, care providers and patients for much of the past decade. Although patient-centred care has been a focus of research and practice for two decades, we still have very little understanding of how patients interpret the level of safety in their care, and what they believe their role should be.[1] Research has focused on types and prevalence of preventable adverse events, and systems issues related to adverse events.[2–6] Media attention and initiatives to engage patients have been frequent,[7] but empirical research into how patients perceive the concept of patient safety is still lacking. Even less attention has been devoted to family caregivers' perceptions as consumers of health care. Family caregivers are increasingly recognized as key members of the patient 'unit.' [8,9] That is, family members regularly accompany patients during the hospital experience, communicate with care providers when patients cannot, and sometimes even serve as case managers of sorts.

This study contributes to the patient perception literature by qualitatively exploring acute care consumer perceptions of safety. This study defined *consumers* as patients and family members. Our study had two primary aims: (i) to identify overarching themes categorizing patient and family experiences of safety in the hospital; and (ii) to contribute to theory of how consumers' experiences of safety influence their overall perceptions of the care they receive. Directly studying consumer perceptions of safety is important for several reasons. First, health-care policy leaders have been encouraging patients and families to take a proactive role in ensuring patient safety.[10] Second, consumer perceptions of safety could influence outcomes such as trust and satisfaction, or compliance with treatment protocols.[11] Finally, consumer perspectives could be an additional lens for viewing complex systems and processes for continuous quality improvement efforts.[12] Recent research has gleaned information about how patients may define safety while studying related topics. The present study contributes to this literature by directly asking patients what made them feel safe or unsafe in the hospital.

Background

Evidence suggests that clinicians and scholars often define patient safety differently from consumers, e.g. clinicians focus more on outcomes, whereas patients and family may focus more on processes and interpersonal dynamics.[12] Patients may interpret lapses in service or interpersonal problems as safety problems when in reality such lapses may not be a threat to patient safety.[13–15] For example, Weingart *et al.*[13] used a structured interview to ask ambulatory oncology patients their experiences with specific safe care practices. The interview asked patients whether they had 'experienced a recent unsafe episode in their plan of care.' The investigators sorted responses into categories such as adverse events, close calls, errors without risk of harm and service quality incidents. Of 193 patients, 101 (52%) reported what the researchers defined as 'service quality incidents.' Service quality incidents included waits and delays, poor communication and poor coordination of care. None of these lapses in service quality had resulted in an adverse event, yet patients had defined these incidents as 'unsafe.'

Another study of ambulatory patients explored primary care patients' overall perceptions of care quality.[12] Although this study did not directly focus on patient safety, patients in focus groups indicated they were highly aware of and concerned about safety issues, particularly those related to structures and processes of care, and interpersonal skills of care providers. They noted concerns with inattention, and medication and technical errors. Moreover, patients acknowledged that problems were generally the result of faulty systems as opposed to individuals. Many patients even accepted the fact that 'mistakes happen.' Those who had trust in their care providers were more likely to see mistakes as inevitable and forgivable.

Research in the inpatient setting has found similar results. In one survey of patients discharged from Swiss hospitals, respondents indi-

cated whether they experienced any of 27 predefined 'undesirable' events while in the hospital (medical complications, process problems or interpersonal problems).[16] Interpersonal problems were strongly related to patients' overall care ratings. That is, the more interpersonal problems patients experienced the lower they rated their overall care in the hospital. Interpersonal problems included staff not respecting patient confidentiality, ignoring information given by the patient, not obtaining consent, and being handled roughly. Interestingly, medical complications (outcomes) were the least related to poor overall ratings. Some of the process problems were strongly related, such as medical records not being available, or patients not receiving enough pain medicine. It appears that patients may understand that complications are sometimes inevitable, but poor interpersonal treatment may trigger patient concerns for their safety.

One recent study interviewed discharged patients in the UK who had experienced safety problems or complained about their hospital care.[14] Patients reported technical errors such as errors in medication prescribing or in testing and treatment procedures, but they also reported interpersonal problems with clinicians, communication mistakes, and other service quality issues. Interpersonal problems were of particular concern. Patients often felt the need to speak up about something that concerned them, but then chose not to, depending on the way staff related to and behaved towards patients. This finding could have important implications for policies that encourage patients to be engaged in their safety. Many such initiatives suggest that patients 'speak up' about their care.[10]

If patients believe that certain service quality attributes indicate their safety is at risk, it is important to learn specifically what these attributes are. The present study extends recent findings by asking consumers directly what patient safety means to them and what types of circumstances occurred in the hospital that either ensured them they were safe or caused them to be concerned about their or a family member's safety. Specifically, the study explored the following research question: 'What can consumers tell us about patient safety in the hospital?'

Method

Study setting and participants

The study used a qualitative group interview approach to study patient and family perceptions of patient safety in the acute care setting. Focus groups were conducted in a facility constructed for group interviews in a large U.S. Midwestern metropolitan area. The interview room included one large conference table where participants could sit. The room included a flipchart, audio-visual equipment, and a table upon which snacks were provided.

A random-digit-dial telephone procedure was used to recruit adult consumers into the study. A professional call centre randomly sampled telephone numbers from a large metropolitan area. Recruiters asked eligibility questions from script to identify eligible participants. Adults (18+ years) who had a hospital stay of at least one night within the previous 6 months, or were the immediate family member of a patient (child or adult) with such a hospital stay, were invited into the study. Those eligible were described the study and were given information about how to attend their sessions. Because the interviews were conducted for two hours on weeknight evenings, and many participants had to travel to the facility, participants received a cash incentive ($60 USD) for participation. Thirty-nine participants attended one of four separate focus groups: (i) adult patients with an acute care visit; (ii) adult patients who had a chronic condition that required on-going hospital visits; (iii) parents of paediatric patients with an acute care visit; (iv) family caregivers of adult patients with a recent acute care or chronic health problem visit. When participants arrived for their sessions, they were checked in by a facility employee who asked their consent. Groups ranged in size from 8 to 11, with an average of 10 participants. Participants ranged in age from 20 to 69 years, with a mean age of 44 years.

Table 1 Focus group demographics

Group	Mean age	Age range	No. in group	No. of female	No. of hospitals represented
Parents of paediatric patient	39	29–57	11	7	10
Family of adult patient	44	31–54	10	8	8
Patient – chronic condition	51	33–69	10	9	9
Patient – acute condition	44	20–69	8	5	7

Participants were predominantly women, comprising 74% of the total, and had experiences in 10 hospitals which were included in seven different health systems. Demographics for each group appear in Table 1.

Procedure

A professional focus group moderator, who had extensive experience conducting focus groups related to health care, was employed to facilitate each of the groups. The moderator proceeded from a set of semi-structured questions developed in coordination with the first author. This ensured that the same questions were asked in the same manner throughout all four groups. The intended approach was to collect 'key events' from focus group participants, that is, encourage participants to explain their perceptions using descriptions of actual events.[17] The moderator first asked each group, 'When you hear the term "patient safety," what comes to mind?' After discussing each participant's current top-of-mind perception, the moderator wrote the definition of patient safety agreed upon by the research team on a flip chart: 'Health care practices that reduce the risk of harm to patients'. Given the myriad ways in which patient safety has been defined and the lack of consensus,[18] the research team developed a working definition that participants could reflect upon as they thought of their own experiences. Participants were asked to discuss their hospital experiences as a patient or family member and to discuss what happened or did not happen that impacted the safety of the patient in terms of the definition presented. Each session lasted two hours and was videotaped, and tapes were transcribed verbatim. No individual identifying information was included with the transcriptions. Interview questions appear in Table 2.

Analysis

The analysis was most closely aligned with grounded theory approaches.[19] The investigators independently conducted multiple readings of the transcripts. The first two authors each read all transcripts independently to immerse themselves in the data. The authors then read the transcripts independently a second time to begin developing a code structure and met to discuss these coding structures. From this discussion the second author developed a template that merged the code structures. The investigators then met again to discuss the data identified as representing the codes.[20] Where investigators had disagreements in what represented the codes, discussions occurred to reach consensus. Findings were then triangulated with themes identified by the focus group moderator.[19]

Table 2 Focus group questions

1. What does patient safety mean to you?
2. What are some specific hospital experiences you have had that were good or bad?
3. In thinking back on what has been discussed so far, what really stands out as critical patient safety issues, and for what reasons are these important?
4. If you were to rate a hospital regarding how well it addressed patient safety, what factors would you use to rate the hospital?

Results

Results will be discussed in terms of key themes identified: (i) communication of health information; (ii) staffing problems; (iii) medication administration and (iv) the need for family caregivers as patient advocates.

Communication of health information

All participants indicated that to feel safe they desired open, timely and accurate communication concerning the patient’s health status. There was consensus that efficient and timely information exchange between providers and patients or their families often did not occur. Often there was urgency in information requests, but obtaining it could take hours:

> I could get [test] results from the RN, but the RN wouldn’t come and see me and communicate it with me. It was really a struggle…waiting 13 h or so to get just a simple blood work test which was ordered stat and so I knew they were back (parent).

One family member noted that the typical early morning physician visits contributed to this inefficient exchange of information:

> The doctor would come so early and not always when we were there. He was gone and you were left with what the nurse was able to tell you of what happened or what my mom took from it, and sometimes she forgot to ask questions that we asked (family).

Participants wanted more effort placed on communicating to patients and family about the general care plan for patients:

> …they don’t say, “This is our plan and once he gets to this point, then maybe we’ll take him off the oxygen and then we’re going to watch him for this long.” They don’t tell you anything (parent).

Families or patients often tried to obtain information from nurses because they were more accessible than doctors. However, participants felt that not only was communication poor between providers and consumers, but communication was lacking among providers. Nurses could not provide family with information because either the nurses did not have it or they were not empowered to disclose it:

> You can’t get really upset at the nurses because they’re doing what they’re supposed to do which is, “We can’t go to the bathroom if the doctor doesn’t tell us we can.” I mean, that’s really the culture (family).

A key component of communication was the patient’s medical record, typically referred to in the United States as the ‘chart.’ All groups noted this record as central for locating information about patients; however, concern was on two key problems. First, it appeared to many that clinicians were not reviewing charts:

> My lung doctor came in and said one thing and the specialist said another thing. It got to the point where I was going home 1 day and the other doctor told me, “No, you can’t go home.” They weren’t reading the chart (patient).

Second, it was unclear whether information was actually making it into a patient’s record:

> I also had a few nurses that didn’t know why certain things were ordered for me and had to go back to the chart. And then when they couldn’t find it, they had to call the doctor and find out. That was very few, but still, it bothered me (patient).

Patients and family members indicated that they were concerned when new care providers did not seem to know what was going on with them, especially given the large numbers of clinicians’ patients typically encountered over the course of their hospital stay:

> ...knowing about the patient before you walk in the room. If I was going into an interview, or to a client, and I said, “okay, now who are you and what’s going on?” I just don’t understand that, because that should be their main focus (patient).

Staffing

All groups acknowledged that there are individuals who are incompetent or possibly indolent, but they mostly viewed staff problems as a system-level issues. One concern was understaffing and the use of agency nurses:

> They have nurses that are not hired from a hospital; they’re kind of rental nurses. And those nurses I don’t think are very good for patients. They do a sloppy job, or at least they did when I was there. Blew my vein a couple of times and then

> they ended up putting a PICC line in and I went home and a week later came back with a bone infection and had to have surgery again. I was in for 2 weeks additional (patient).

To some it appeared that more time was spent doing paperwork than providing care:

> Lots and lots of procedures, forms, and paperwork. Like that substitutes for staffing the place properly and making sure they're trained? If you push your button and nobody comes and they've got a pile of paperwork that high…and as a lawyer too, show that to somebody in a lawsuit. That pile of paperwork won't save them. You have to do the job (parent).

Participants believed the hospital was understaffed simply because they did not see many staff, or staff did not check on them as often as they thought they should. However, some perceptions of staffing were shaped by what care providers told patients directly:

> I complained to him [physician] about my terrible care and he said, ''I hate to tell you and I feel sorry for you, but you're not going to get it any better anywhere else because they're short-staffed everywhere'' (patient).

Medication administration

Many participants voiced concerns regarding the management and distribution of medications. Patients asked questions about the medications they were taking, but often staff responses left them feeling uncertain about their safety:

> I take certain medications twice a day. In the hospital, it seemed that I was getting medications all day long and I never knew what I was getting, and if I was getting the same things that I got at home. I hate to appear stupid and keep asking... I just sort of took it for granted that I was getting what I should. But I never really knew (patient).

One woman discussed reconciling her husband's medication list after he was discharged:

> When he was discharged, they sent a slip home with all the medications he was supposed to be on, which I requested, and some prescriptions for the new medications. The prescriptions were for totally different things than were on the slip. I called the doctor, and half of the prescriptions were not medications he was supposed to be on. If I hadn't been on top of that, I don't know what would have happened (family).

Some patients expressed concerns about medication distribution processes. For example,

> As far as medications, you see all these little cups. They're all the same and they're all lined up on top of a tray and it's like, how easy is it to just pick up the wrong cup or to know, ''Was that the right medication for that?'' (patient).

Need for family advocates and caregivers

Poor communication, staffing issues and potential medication errors led participants to feel that families should avoid leaving patients alone. Participants generally felt that if family members are present, they may be able to prevent problems:

> …my granddaughter was very hot, her cheeks were all flush. Well, it took me almost two hours to get her temperature checked and by that time, it was extremely high. And then they were concerned. It was around 104. I was a babysitter to them (parent).

> My daughters have been real active in sports so we've gone through multiple knee surgeries. I've always elected to spend the night with them. I know this sounds dorky, but if they've got to go to the bathroom, if you ring the bell to wait for a nurse, it might be a real long time. Is that a matter of safety? I don't really know. But you know, if they really had to go, they might try to get up and go by themselves (parent).

Discussion

Overall, this study found that patients and their family caregivers are observant and conscientious about staff behaviours and care processes; in fact, they may be on the lookout for indications that they are safe. Consumers focused mostly on processes of care, and interpersonal dynamics with care providers. Consistent with other patient studies, consumers in this study often interpreted service quality lapses as safety incidents.[12,13] Some have suggested that patients may also interpret 'emotional injuries' that result from poor service quality (e.g. frustration, not

feeling respected) as a type of harm.[13,21] This makes sense given that patients and family members may already be stressed or emotionally distraught because of the illness or injury that brought them to the acute care setting.

Several participants discussed specific errors that occurred during their hospital visit. Others discussed situations that could be classified as 'near misses.' In some cases, patients described how actions they had taken averted a potential error. However, at a higher level, care processes seemed to be the biggest concern. There was consensus that there was rarely one care provider who appeared to have a complete picture of what was happening with an individual patient. Participants were particularly concerned about this.

Communication

Participants spoke of different clinicians saying different things about their care plans and lack of coordination of information during shift changes. Participants often interpreted this to mean that clinicians were intentionally withholding 'bad news' from them, and this increased their concerns about their safety. Sometimes treatment was delayed because information was not available when it was needed. Such concerns could be valid. Administrators could simply interpret delays as a service quality problem; however, if delays result because important information is not available to staff, this could indeed mean increased risks to patient safety, not simply a problem of impatient consumers.

Staffing

All groups had concerns about staffing levels, and many expressed distrust of agency nurses. Appropriate staffing in hospitals is a complex challenge, but patients in our study viewed lack of staffing as a choice the hospital had made to cut costs. Lack of timely responses to requests or call buttons triggered more than frustration; it triggered safety fears. Participants agreed that lack of staffing was the main reason family members should accompany patients.

One surprising finding was the extent to which staff seemed to be apologizing and telling patients that they were short-staffed. Consumers believed care providers were empathizing with them, saying they would be doing more for the patient if they could. However, this type of communication to patients increased concerns about safety. Health-care leaders might attempt to explore the extent to which these messages are being sent. Telling patients that there is not enough staff to give them the care they need should be depicted as unprofessional. On the other hand, clinicians' motivation to disclose and apologize for such barriers to high-quality care could be an important indicator of staff duress over situations they cannot control. A substantial body of recent research has revealed that care providers are often distressed or even traumatized for long periods of time if they have been involved in an error in a patient's care or other stressful incidents.[22–24] Apologizing to patients, and explaining that the patient's needs would have been met had the care provider been able to be there, could be one way for overloaded clinicians to empathize with patients who are afraid or concerned. Importantly, however, if clinicians are telling patients they are short-staffed, this should be considered a systemic problem that organizational leaders need to address.

Medication administration

Participants noted several disconcerting issues with medication administration. First, the processes themselves may have been problematic, as noted by patients who were concerned about medicines sitting on trays in identical cups. One family member took on the task of reconciling her husband's current and new medication lists, a task that should have been performed by someone in the hospital, and found errors. One patient reported how he was given a pill to take, and he knew it was not his, but he had to be persistent before the nurse went to double-check. Two participants described how they had intervened to prevent what they believed were errors. Many such near misses may not be

reported in typical incident reporting systems, as patients may not even report these to clinicians.[13,25]

Additionally, several participants described how they asked questions about their medications, something that experts have been encouraging patients to do, yet some participants reported negative experiences. These accounts are troubling, because many organizations are encouraging patients to speak up and ask questions, yet, if clinicians are not receptive, this strategy could backfire.[10,11] Delbanco and Bell[26] found that patients were afraid of retribution if they questioned the care they were receiving. In addition, participants in the present study mentioned that they wanted to talk more to their nurses, but did not because they 'felt sorry' for the nurses, who appeared very busy or overworked. When care providers appear rushed, the unintended message could be not to 'bother' clinicians with questions.

Involvement of family

One important finding in this study is the extent to which family members were perceived to be essential to the patients' well-being in the hospital. All of the groups felt that relying on the family to protect the patient was not the way it should be. Participants felt compassion for the health-care workers, but blamed the hospital for 'cutting corners on patient care.' To add complexity, research is showing that family members often feel guilty over medical errors, because they feel they should prevent them.[26] Attempts to increase the role of consumers in safety could be seen as the hospital not taking full responsibility for providing the best care possible and could lead to further erosion of trust between consumers and health-care organizations.

Study contributions

This study found results consistent with recent research on patient perceptions while using a different methodological approach. That is, when consumers in the United States were asked

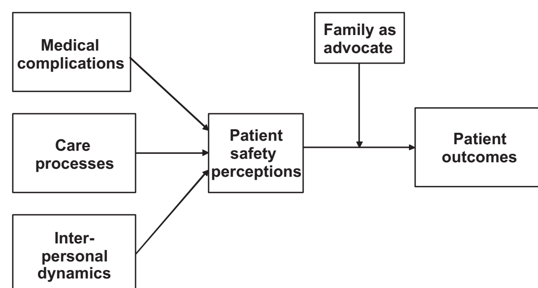

Figure 1 Proposed antecedents and outcomes of patient safety perceptions.

directly to define patient safety, their responses were consistent with patients in previous survey studies in terms of dimensions consumers care about.[12,14,16] Taken together, recent research can be organized according to the patient perception taxonomy used by Agoritsas *et al.*[16] Empirical literature suggests, and our data support, the notion that consumer experiences that affect safety concerns can be organized in terms of whether consumers experience concerns about complications, care processes or interpersonal dynamics, and how these experiences influence perceptions of safety while in the hospital. As such, we propose a conceptual framework for understanding patient experiences of safety, as depicted in Fig. 1. Given the notable role of family caregivers, our findings suggest that involving family members may moderate relationships among experiences, perceptions of safety and patient outcomes. Specifically, we propose that the presence or absence of family caregivers in the patient hospital experience will influence the extent to which patient experiences affect outcomes such as patient well-being (trust, satisfaction and physical outcomes), compliance with treatment and complaints filed against the hospital.

Future research

Future research should further explore the relationships between patient perceptions of service quality and risks of preventable adverse medical events. The findings from this and other studies demonstrate that patients clearly use service quality as a cue when forming safety

perceptions.[13,27] Whether service quality is a valid predictor for adverse medical events should be further explored. If it is, then organizations should utilize patient perceptions to proactively improve service quality problems before they result in adverse medical events.

Study limitations

Because this study used a relatively small number of participants, our findings may not represent views of all inpatients and families. Also, the nature of our sample (mean age of patients = 48) may have under-represented the views of elderly patients, who may have different experiences or concerns. However, generalization is not a concern for in-depth qualitative studies. The cash incentive to participate may have led to response bias; however, in the United States cash incentives are typical for research participants.

Conclusions

Patients and family members in this study were clearly concerned and vigilant about safety issues, and with very little prompting, were able to discuss problematic situations. Even those who felt that they generally had positive experiences could report problems with their care, or could convey a story about problems they had experienced or witnessed at other times. Although not all problems and concerns necessarily lead to adverse medical events, more attention should be paid to patient experiences and perceptions related to patient safety. Patient perceptions could be good first indicators of deeper system issues that need attention. Hospitals would be wise to recognize that 'patient safety' should not only be about how providers define it, but also how patients define and experience safety.

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Conflicts of interest

No conflicts of interest exist for any of the authors.

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