

Patients' Perspectives of Engagement as a Safety Strategy

Chasity Burrows Walters, PhD, RN, and Elizabeth A. Duthie, RN, PhD, CPPS

Walters is the director of patient and caregiver engagement at Memorial Sloan Kettering Cancer Center, and Duthie is the director of patient safety at the Montefiore Medical Center, both in New York, NY.

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Walters can be reached at burrowsc@mskcc.org, with copy to editor at ONFEditor@ons.org.

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Purpose/Objectives: To describe patient engagement as a safety strategy from the perspective of hospitalized surgical patients with cancer.

Research Approach: Qualitative, descriptive approach using grounded theory.

Setting: Memorial Sloan Kettering Cancer Center in New York, New York.

Participants: 13 hospitalized surgical patients with cancer.

Methodologic Approach: Grounded theory with maximum variation sampling.

Findings: Participants' perceptions regarding their engagement as a patient safety strategy were expressed through three overarching themes: the word "patient" obscures the message, safety is a shared responsibility, and involvement in safety is a right. Themes were further defined by eight subthemes.

Conclusions: Using direct messaging, such as "your safety" as opposed to "patient safety," and teaching patients specific behaviors to maintain their safety appeared to facilitate patient engagement and increase awareness of safety issues. Patients may be willing to accept some responsibility for ensuring their safety by engaging in behaviors that are intuitive or that they are clearly instructed to do; however, they described their involvement in their safety as a right, not an obligation.

Interpretation: Clear, inviting, multimodal communication appears to have the greatest potential to enhance patients' engagement in their safety. Nurses' ongoing assessment of patients' ability to engage is critical insofar as it provides the opportunity to encourage engagement without placing undue burden on them. By employing communication techniques that consider patients' perspectives, nurses can support patient engagement.

More than 15 years after the seminal Institute of Medicine (2000) report *To Err Is Human: Building a Safer Health System* identified iatrogenic events as a leading cause of death among Americans, patient safety continues to pose a challenge to the U.S. healthcare system (National Patient Safety Foundation [NPSF], 2015). One of the most prominent initiatives that spawned from the patient safety movement has been the drive for patient engagement as a patient safety strategy (Doherty & Stravropoulou, 2012; NPSF Lucian Leape Institute, 2014; Schwappach, 2010; Severinsson & Holm, 2015; Wright et al., 2016). This trend, described as the "What can patients do to prevent medical mistakes?" movement (Wachter, 2010), continues to be fueled by the support of thought leaders and regulatory bodies alike (Joint Commission, 2016; NPSF Lucian Leape Institute, 2014).

Evidence suggests that most patients are willing to engage and capable of engaging in actions recommended by various patient safety organizations, such as asking questions, providing information, and reporting when their safety has been compromised (Berger, Flickinger, Pfoh, Martinez, & Dy, 2014; Davis, Sevdalis, &

Vincent, 2011; Doherty & Stravropoulou, 2012; King et al., 2010; Maurer, Dardess, Carman, Frazier, & Smeeding, 2012; Schwappach, 2010; Ward et al., 2011); however, little is known about the way healthcare providers (HCPs) may support patient engagement as a safety strategy (Doherty & Stravropoulou, 2012; Lawton et al., 2017; Martin, Navne, & Lipczak, 2013; Maurer et al., 2012; Ward & Armitage, 2012). In addition, despite the growing body of research (Lawton et al., 2017), the patient's perspective has been underreported (Maurer et al., 2012; Schwappach, 2010; Ward et al., 2011; Wright et al., 2016). Accordingly, the purpose of this study was to explore patients' perceptions regarding their engagement in their care as a patient safety strategy.

Methods

Because the objective of this research warranted exploration of a phenomenon as understood by the patients themselves, it was best suited to a qualitative approach (Denzin & Lincoln, 1998; Strauss & Corbin, 1990). Specifically, this study employed Corbin and Strauss's (2008) grounded theory, an inductive methodology used to build strong empirical foundations for theory. A purposive sampling frame was used to recruit participants, and maximum variation sampling was employed to maximize the diversity relevant to the participants' health literacy levels, because health literacy is considered to be an integral factor in patient engagement in other contexts (McCormack, Thomas, Lewis, & Rudd, 2017). As described by Onwuegbuzie and Leech (2007), at least three cases per subgroup were included in this study, representing adequate, marginal, and inadequate health literacy. Participants were recruited to the point of data saturation, which is when no new information is gathered that contributes to one's understanding of the phenomenon (Morse & Field, 1995). This study was approved by Memorial Sloan Kettering Cancer Center's institutional review board, and all participants provided written informed consent.

Participants

Participants were recruited from a 43-bed inpatient unit specializing in the care of patients who have undergone colorectal surgery for cancer. The average length of stay of 5.36 days on this unit allowed for ample time for patients to experience opportunities for engagement.

To be considered eligible to participate in this study, patients met the following criteria: able to participate in an open-ended interview and complete a written questionnaire and measurement tool in English, aged 18 years or older, admitted to the Colorectal Surgery Service on the inpatient colorectal surgery

unit, and had surgery during the present admission for a colorectal malignancy.

Following chart review to identify eligible participants, 40 patients were invited to participate in this study. Twenty-one potential participants asked the principal investigator to return another time; however, most were receiving care, were engaged with visitors, or were discharged on follow-up. Of those present at follow-up, six patients refused because of fatigue ($n = 3$), anxiety related to awaiting test results ($n = 1$), and focus on going home later that day ($n = 2$). Informed consent was obtained from the remaining 13 patients (see Table 1).

Data Collection

Data collection included semistructured interviews, demographic questionnaires, and the Short Test of Functional Health Literacy in Adults (STOFHLA). The good internal reliability of the STOFHLA (Cronbach

TABLE 1. Sample Characteristics (N = 13)

Characteristic	\bar{X}	SD	Range
Age (years)	67.15	11.2	48–90
Previous hospitalizations	3.23	2.42	1–8
Days from admission to interview	5.69	2.66	2–13
Characteristic	n		
Gender			
Female	9		
Male	4		
Level of education			
High school graduate or GED	3		
Partial college (at least a year) or vocational training	3		
Standard college or university graduate	5		
Graduate degree or professional training	2		
Income (\$)			
10,000–29,999	2		
30,000–49,999	5		
50,000–69,999	2		
70,000–89,999	–		
90,000 or more	4		
Occupation status			
Retired	6		
On leave	5		
Disabled	1		
Employed	1		
Race			
White	9		
Black or African American	2		
Mixed race/other	1		
Native Hawaiian or other Pacific Islander	1		
Hispanic or Latino			
No	12		
Yes	1		
Health literacy level			
Adequate	7		
Marginal	3		
Inadequate	3		

alpha = 0.97) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999) and relatively short time to complete (seven minutes) has made the STOFHLA a widely used instrument in adult healthcare settings. Possible scores on the STOFHLA are 0–16 (inadequate health literacy), 17–22 (marginal health literacy), and 23–36 (adequate functional health literacy).

Although an interview guide was used, flexibility allowed the participants to add their own insights and permitted for unanticipated points to be raised (Hopf, 2004). The interviews continued as long as necessary, driven by the participant, ranging from 23–64 minutes each. Each interview was audio recorded and transcribed and was supplemented by analytic memos to detail the reflections of the researcher (Bogdan & Biklen, 2003; Corbin & Strauss, 2008) until data saturation was achieved.

Data Analysis

The constant comparative method described by Corbin and Strauss (2008) guided the coding of the data. As is customary with grounded theory, data analysis began immediately following the first interview, and transcripts were reread and compared, with additional themes being coded as they emerged. Existing codes were clarified, expanded, and relabeled, leading to the refinement of concepts in terms of their properties, dimensions, and levels of abstraction. This process of constant comparison gradually led to a more refined qualitative coding system that was applied to all interview transcripts.

Memos and notes related to the stance of the researcher and raw data, including transcripts, recordings, and field notes, were tracked in a dedicated NVivo project folder to provide an audit trail. To further contribute to reliability, a second coder coded 20% of the transcript data (Miles & Huberman, 1994). NVivo coding comparison inquiries demonstrated agreement across all codes (92%–99%), and kappa coefficients were excellent (0.76–0.87).

Results

The process of data analysis revealed three overarching themes: the word “patient” obscures the message, safety is a shared responsibility, and involvement in safety is a right. Within those are eight subthemes.

The Word “Patient” Obscures the Message

To assess their familiarity with the concept, participants were asked what they knew about patient safety. Only three participants reported that they had heard of patient safety. However, the participants in this study unanimously described the word safety as

a familiar concept. When examined in isolation, safety was described simply as the prevention of harm or, as described by several participants, not getting hurt. However, when participants reunified the word patient to safety, their responses shifted to a less declarative tone. Several participants began their interpretations with “I guess it means” and went on to refer to patients as people other than themselves, such as “a patient not getting hurt.” This theme captures the disconnect that emerged between the phrase used by the healthcare system (patient safety) and that which emerged as meaningful to the participants (safety).

Awareness of safety issues: As the meaning of patient safety unfolded for the participants, the first subtheme surfaced. Although all participants promptly articulated an awareness of particular safety issues, primarily falls and infections, they universally relayed a broadened array of examples as they came to realize that patient safety meant their own safety. In some cases, the participants described their awareness as intuitive, such as navigating the environment to avoid trips and falls. In other instances, participants described how direct communication about safety concerns prompted or enhanced their awareness, such as the nurse educating a participant about hand hygiene.

Medical errors are different: The second subtheme captures the notion that participants’ attitudes toward their role in the prevention of medical errors were quite different than those of safety more broadly. When Helen, a 71-year-old woman with adequate health literacy, recalled a news story in which a patient had surgery on the incorrect side, she stated, “I don’t understand how these things happen. . . . It’s like practitioners fall asleep at the wheel.” As she went on to discuss the complexities of health care, Helen concluded, “I don’t see anything patients can do about that.” Helen’s remarks were not unique; medical errors were considered a failure of a human being or system, and acknowledging them during a hospitalization was considered counter to the implicit trust the participants felt was necessary between patients and their HCPs. Overall, participants stated that the prevention of medical errors is an issue to be addressed by HCPs and hospital administrators, not patients.

Safety Is a Shared Responsibility

Participants conveyed their belief that the responsibility for their safety while hospitalized is shared among patients, hospital administrators, and HCPs. Participants expressed their responsibility to engage in familiar behaviors that protect their safety, and, oftentimes, their informal caregivers (e.g., friends, family) work in this regard as an extension of themselves. Hospital administrators, generally referred to by participants as “the hospital,” were described as

having the responsibility to provide environmental cues that facilitate patient engagement in their safety. HCPs were identified as the primary means of keeping patients free from harm.

Although the participants communicated the notion of shared responsibility, they did not imply that sharing was equal. As Amy, a 58-year-old woman with adequate health literacy stated, “I think everybody should always take some responsibility for their own welfare to the extent they are able.” The essential caveat of ability was noted throughout the interviews, as was willingness, albeit to a lesser extent. Notably, the participants unequivocally expressed their belief that the healthcare system should not rely on patients to protect their own safety. Thomas, a 63-year-old man with adequate health literacy, illustrated this notion:

I don't think patients should have to do anything to be safe [while in the hospital]. In an ideal world, they should have the best standard of care no matter what. In an ideal world, the end results should be the same.

Using common sense: Participants indicated that patients should practice the same behaviors while hospitalized as they would elsewhere. Although the nature of the hazards patients may encounter in the hospital setting are often unfamiliar (e.g., tangled drainage tubes and IV lines), participants described how the fundamental strategies remain the same (e.g., using caution when ambulating). That said, participants noted that, although using common sense is an inherent way for patients to keep themselves safe while hospitalized, one's ability to do so may change over time and because of circumstances. For example, physical and cognitive impairments may render patients transiently unable to safeguard themselves, even where the most intuitive behaviors are concerned.

Informal caregivers have a role: Captured under this subtheme, many participants described their informal caregivers (e.g., visitors) as extensions of themselves and their HCPs when it came to their safety. Most participants described instances in which their informal caregivers physically assisted them during their hospitalization. In each of these instances, the participants conveyed examples of when they relied on their informal caregivers to perform tasks for which they would have called for assistance had that informal caregiver not been there. Most commonly, this included assisting the participants in getting to the bathroom, in some cases watching for pulling on lines and tubes and in others providing support for the physically weakened participant. Participants were not only comfortable with their

informal caregivers in this role; they expected it. As Amy stated, “I mean, if you have a family member and they can be helpful, or a visitor, as I say, they should.”

Environmental cues facilitate involvement: This subtheme emerged as an integral way in which hospitals can facilitate patient involvement in their safety. Participants suggested that signage and assistive devices in patients' rooms may reinforce messages delivered verbally by HCPs, such as signs reminding them to call for help and brightly marked railings.

Implicit trust in healthcare providers: The participants in this study shared the tacit understanding that HCPs have a duty to protect patients from harm, the accounts of which are described in this subtheme. Participants described their HCPs as having the responsibility of discerning whether information they have about a patient, regardless of its source, has any safety implications. If an HCP feels the information merits action, that provider is expected to act accordingly. Conversely, participants perceive that HCP inaction is indicative of a lack of safety implications. As Dorothy, a 90-year-old female with marginal health literacy, articulated, “I just want to say what I've got to say. He [the doctor] can decide whether it matters.”

Involvement in Safety Is a Right

Participants unanimously declared their beliefs that engaging in actions to ensure their safety is a right. They described two conditions necessary to support that right: HCPs' openness to communication about safety (inviting communication) and HCPs' flexibility regarding patients' changing levels of engagement (involvement is dynamic).

Inviting communication: Participants in the current study emphasized the importance of HCPs inviting communication by being open to questions and information provided by patients and, by extension, their informal caregivers. Jose, a 54-year-old male with inadequate health literacy, described his reluctance to engage HCPs, stating: “You don't want to take up too much time because you could be distracting them from something else they need to do.” Half of the participants, representing a range of health literacy levels, described how their concern about being a burden could overpower their willingness to be involved in their care. To the extent that HCPs invite patient engagement in safety through verbal and nonverbal cues, participants stated they were more likely to engage.

Involvement is dynamic: Participants expressed their need for flexibility on the part of their HCPs, because patients' ability and willingness to be engaged in their safety can change during their hospitalization. Participants described how a lack of desire for information at one point does not necessarily mean that it

should not be offered again in a subsequent interaction. Likewise, as Thomas expressed, when patients do not ask questions, “It may be true that they don’t have any, but it might also be that we just don’t have the energy to bother.”

Discussion

The current study adds to the extant literature addressing patient engagement as a safety strategy by bringing forth the views of the patients themselves. Collectively, the themes that emerged shed light on the role patients wish to play in ensuring their own safety while hospitalized and how nurses may facilitate that engagement.

The failure of the term “patient safety” to resonate with the participants in the current study was striking. Despite the prolific nature of patient safety campaigns, including those in the hospital in which the current study took place, few participants reported having heard of the term. This challenges the myopic perspective that has informed campaigns encouraging patient involvement in patient safety and suggests that those designing campaigns consider simplifying the message directed toward patients to “your safety,” or simply “safety.”

Whether describing outcomes or intended behaviors, the use of precise lay terms with patients appears to be a necessary strategy to elicit and provide information. Even within wider patient safety campaigns, the use of specific terms is common (Davis et al., 2011; Schwappach, Frank, Buschmann, & Babst, 2013). Indeed, those studies intending to capture a wider range of reports employ specific examples of safety-related outcomes and behaviors to elicit patients’ perspectives, such as hand hygiene enforcement, surgical site marking, and knowledge about medications. Well into the course of their interviews, participants in this study identified a multitude of safety issues, suggesting the potential impact of communication regarding these concerns. This is supported by Schwappach’s (2010) systematic review of patient involvement in patient safety, which suggested addressing specific interventions in the context of care.

The distinction made by participants in this study between safety issues and medical errors is also an important contribution to the literature. Although a small number of studies address medical errors specifically (Davis et al., 2011; Schwappach & Wernli, 2011; Zhang et al., 2012), the literature addressing patient engagement in their safety overwhelmingly fails to differentiate medical error from the wider domain of patient safety. Still, the notion that patients are in a prime position to intercept errors, particularly

at what Reason (1990) conceptualizes as the “sharp end” of care, is widely acknowledged as sensible. The extent to which previous research is representative of patients’ differentiation of the two terms is unclear, clouding the science surrounding what is known about patient engagement in patient safety versus medical error prevention.

Whereas participants in the current study described their involvement in the prevention of medical errors as unfavorable, they did express willingness and, in some instances, a responsibility to be involved in their safety. The participants spoke of a shared responsibility; however, it was not an equal sharing. Rather, they described their role as bearing the responsibility for everyday behaviors to the extent that they are able with an important caveat: their safety should not depend on their engagement. Drawing from the science of human factors, Lyons (2007) posited that any reliance on patients is fundamentally flawed, particularly given their vulnerability secondary to stress and illness.

The dynamic property of patients’ willingness to be involved in their safety was a salient finding of the current study. This study elicited the perspectives at one particular point in time; however, the insight gained adds new knowledge to the field regarding how patients’ views may change over time. Although the temporal qualities associated with engagement in patient safety are not explicated in the existing literature, the notion that involvement is dynamic is commensurate with Thompson’s (2007) concept analysis that addressed involvement in the broader healthcare context. Likewise, the changes in the engagement of patients with cancer were discussed by Sinding et al. (2010), who described how as the amount of medical information being presented increased, some participants relinquished the power they had been exercising as involved, informed decision makers to HCPs.

Limitations

Although the current study consisted of a relatively small number of participants, it was appropriate, because the study intended to add depth to the literature, not generalizability of findings. However, several limitations are noted. First, it took place in a comprehensive cancer center. Although the design included participants representing a range of health literacy levels, it may still be reasonable to assume that those seeking care at a comprehensive care center, outside of their medical home, may be more likely to take an active role in their health care and may not be representative of the broader population of adults with cancer. The current study included only English-speaking participants, whose experiences and perceptions may differ from those with little or no English

proficiency. In addition, a self-selection bias may exist; the perceptions of those who volunteered to participate may differ from those who declined. Finally, this research study was not designed to evaluate other psychosocial factors that may influence perceptions regarding engagement as a safety strategy, such as anxiety, depression, or social support.

Implications for Nursing

To the extent that patients accept following instructions provided by their HCPs as part of their responsibility for their safety, nurses must communicate effectively. For example, concordance between body language and verbal messages appears to influence patients' willingness to engage in safety-related behaviors. However, even with inviting verbal language, patients may perceive an encounter as uninviting when a nurse is distracted or standing by the door. In addition, patient engagement necessitates that instructions are provided clearly and reinforced over time verbally, as well as through cues in the environment.

The language used is also important. Using the term "patient" to qualify safety messages when communicating to patients may serve only to increase the time it takes for them to process the message. Instead, nurses should provide clear direction with some rationale. The word "safety" resonates with patients; when patients appear unable to process the reason(s) for desired behaviors, phrases like "for your safety" may lend some credence.

Nurses must identify creative ways to infuse information related to patient safety into the delivery of care. Although studies have demonstrated the efficacy of reading materials and watching videos (Davis et al., 2011, 2012; Schwappach et al., 2013), the most efficacious format and timing of such interventions remains unknown. In addition, the extent to which written materials are useful in the reality of the hospital environment remains unknown; however, evident from the current study is that print materials may be ineffective, and increasing the burden of information is undesirable.

Patients' engagement in safety is dynamic; as care complexity increases, coping may decrease, and a shift from patients' level of engagement initially to a less involved state may occur. Adjusting accordingly is the HCP's responsibility. In addition, efforts to invite patient engagement should extend to their informal caregivers, because they are integral in the patients' experience.

Many patients will not have the requisite knowledge to decide which facts or behaviors may be important for their safety. In practice, this translates into the need for astute listening skills, filtering information with a professional lens to determine whether action

Knowledge Translation

- Nurses must identify creative ways to infuse information related to patients' safety into the delivery of care.
- Instructions should be provided clearly, accompanied by a simply stated rationale, and reinforced over time.
- Cues in the environment, such as thoughtfully placed signage, may also encourage patient engagement.

is required. In addition, as experts, nurses are obliged to be cognizant of the physical environment, looking for hazards based on their knowledge regarding patient safety.

Implications for Future Research

Additional research is necessary to understand the extent to which these findings translate across a range of illnesses, with varying courses of treatment and anticipated outcomes. Because patient engagement often includes some form of communication, the role of cultural and linguistic influences should be examined. Patients' perspectives can be placed within the context of a hospital's or healthcare system's patient safety culture by studying the linkages between patient safety culture survey results and patients' engagement in their safety.

Although the current study addressed the overarching topic of patient safety, additional research may explore particular aspects of safety that present concerns patients feel comfortable engaging in, such as preventing falls and communicating with their HCPs. Finally, the current study focused exclusively on patients. The role informal caregivers play in the care of hospitalized patients was evident, but whether those strategies differ when geared toward patients versus informal caregivers remains unknown.

Conclusion

Patient engagement as a patient safety strategy is recommended by numerous organizations and advocacy groups and, consequently, has been embedded in policy. However, the available literature primarily consists of quantitative methods drawn from the HCP perspective, leaving an imperative to understand patients' perspectives. The findings of the current study suggest that patients are likely to internalize messages around patient safety when they are framed in a direct manner (e.g., "your safety") and when specific, actionable terms are provided and reinforced. In addition, patients acknowledge their role in sharing responsibility for their safety when they are able and

willing to do so. Finally, the current study suggests that, although patients see their engagement as a right, they perceive that the responsibility for their safety ultimately lies with HCPs.

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