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## Patient Engagement as a Patient Safety Strategy: Patients' Perspectives

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### Abstract

**Purpose/Objectives**—To describe patient engagement as a patient safety strategy from the perspective of hospitalized surgical oncology patients.

**Research Approach**—Qualitative, descriptive approach using grounded theory.

**Setting**—A National Cancer Institute-designated cancer center in the northeastern United States.

**Participants**—Thirteen hospitalized surgical oncology patients.

**Methodological Approach**—Grounded theory with maximum variation sampling.

**Findings**—Participants' perceptions regarding their engagement as a patient safety strategy were expressed through three overarching themes: 1) the word patient obscures the message; 2) safety is a shared responsibility; and 3) involvement in safety is a right. Themes were further defined by eight subthemes.

**Interpretation**—Using direct messaging, such as “your safety” as opposed to “patient safety” and teaching patients specific behaviors to maintain their safety appear 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 describe their involvement in their safety as a right, not an obligation.

**Implications for Nursing**—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 in so far 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.

**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. Nurses should assess patients' desire and ability to be engaged regularly, and extend communications encouraging engagement to patients' visitors.

## Keywords

Patient Safety; Patient Participation; Grounded Theory; Health Literacy

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## Background

Fifteen years after the sentinel Institute of Medicine report *To Err is Human* identified iatrogenic events as a leading cause of death among Americans (Kohn, Corrigan, & Donaldson, 2000), patient safety continues to pose a challenge to the US healthcare system (National Patient Safety Foundation (NPSF), 2015). One of the most prominent initiatives spawned from the patient safety movement has been the drive for patient engagement as a patient safety strategy (Doherty & Stravropoulou, 2012; Schwappach, 2010; NPSF's Lucian Leape Institute, 2014; 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 (NPSF Lucian Leape Institute, 2014; Joint Commission, 2016).

The evidence suggests that patients are both willing 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 et al., 2014; Davis, Sevdalis, & Vincent, 2011; Doherty & Stravropoulou, 2012; King et al., 2010; Maurer et al., 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 et al., 2013; Maurer et al., 2012; Ward et al., 2012). Moreover, despite the growing body of research (Lawton et al., 2017), the patients' 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 (Lincoln & Denzin, 1998; Strauss & Corbin, 1990). Specifically, this study employed Corbin and Strauss' grounded theory method (2008), 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 (HL) levels, as HL is considered an integral factor in patient engagement in other contexts (McCormack et al., 2017). As described by Onwuegbuzie and Leech (2007), at least three cases per subgroup were included in this study, representing adequate, marginal, and inadequate HL. 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 the 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: 1) able to participate in an open-ended interview and complete a written questionnaire and measurement tool in English; 2) age 18 or older; 3) admitted to the Colorectal Surgery Service on the inpatient colorectal surgery unit; and 4) had surgery during the present admission for a colorectal malignancy. Following chart review to identify eligible participants, forty patients were invited to participate in this study. Twenty-one potential participants asked the principal investigator to return another time, however most were either receiving care, engaged with visitors, or were discharged upon follow-up. Of those present at follow-up, six patients refused due to 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 thirteen patients (see Table 1).

## Data Collection

Data collection included semi-structured interviews, demographic questionnaires, and the Short Test of Functional Health Literacy in Adults (STOFHLA). The very good internal reliability of the STOFHLA ( $\alpha = 0.97$ ) [Baker et al., 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 as follows: 0–16 (inadequate HL), 17–22 (marginal HL), and 23–36 (adequate functional HL).

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 to 64 minutes each. Each interview was audio-recorded and transcribed, and supplemented by analytic memos to detail the reflections of the researcher (Bogden & Bilken, 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 of the 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 (92.03–98.69%) and Kappa coefficients were excellent (0.76–0.87).

## Results

The process of data analysis revealed three overarching themes: 1) the word “patient” obscures the message; 2) safety is a shared responsibility; and 3) involvement in safety is a right. Within those are eight subthemes (see Table 2).

### 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 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.” When participants reunified the word “patient” to “safety,” however, 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 persons other than themselves, such as “a patient not getting hurt.” The theme *the word “patient” obscures the message* 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).

As the meaning of patient safety unfolded for the participants, the first subtheme, *awareness of safety issues*, surfaced. While all of the 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 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 either prompted or enhanced their awareness, such as the nurse educating a participant about hand hygiene.

The second subtheme, *medical errors are different*, 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 HL, recalled a news story wherein 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 healthcare, Helen concluded with “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 the course of a hospitalization was considered counter to the implicit trust the participants felt was necessary between patient and their HCP. 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 amongst patients, hospital administrators, and HCPs. Participants’ expressed their

responsibility to engage in familiar behaviors that protect their safety, and often times their informal caregivers (e.g., friends and 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 HL states, “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 HL, illustrates this notion most adamantly:

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.

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

Captured under the subtheme *informal caregivers have a role*, many participants described their informal caregivers (e.g., visitors) as extensions of themselves and their HCPs when it comes to their safety. Most participants described instances wherein 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 they would have called for assistance for 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.”

The subtheme *environmental cues facilitate involvement* 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, as well as independently providing messages that participants considered helpful to their engagement in safety, such as railings that were brightly marked.

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 the subtheme *implicit trust in healthcare providers*. Participants described their HCP as having the responsibility of discerning whether information they have about a patient, regardless of its source, has any safety implications. If the HCP feels the information merits action, that provider is expected to act accordingly. Conversely, participants perceive HCP inaction is indicative of a lack of safety implications. As Dorothy, a 90 year-old woman with marginal HL articulates, “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 to patients’ changing levels of engagement (*involvement is dynamic*).

Participants in this 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 man with inadequate HL, 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.” Indeed half of the participants, representing a range of HL 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 both verbal and nonverbal cues, participants stated they were more likely to engage.

Explicated in the subtheme *involvement is dynamic*, participants expressed their need for flexibility on the part of their HCPs, as 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**

This 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 from this study shed light on the role patients wish to play in ensuring their own safety while hospitalized and how nurses might facilitate that engagement.

The failure of the term “patient safety” to resonate with the participants in this study was striking. Despite the prolific nature of patient safety campaigns, including those in the hospital in which this study took place, few participants in this study reported having heard of the term. This challenges the myopic perspective that has informed campaigns encouraging patient involvement in patient safety and suggests 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 both elicit and provide information. Even within wider patient safety campaigns, the use of specific terms is common (Davis et al., 2011; Schwappach et al., 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 enforcing hand hygiene, 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 suggests 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, 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. Yet 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, hence clouding the science surrounding what is known about patient engagement in patient safety versus medical error prevention.

Whereas participants in this 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. Indeed drawing from the science of human factors, Lyons (2007) posits 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 this study. This study elicited the perspectives at one particular point in time; however, the insight gained from this study 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 which addresses involvement in the broader healthcare context. Likewise, the changes in oncology patients’ engagement are discussed by Sinding and colleagues (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.

## Conclusion

Patient engagement as a patient safety strategy is recommended by numerous organizations and advocacy groups, and consequently has been embedded in policy. The available literature, however, primarily consists of quantitative methods drawn from the HCP perspective, leaving an imperative to understand patients' perspectives. The findings of this study suggest 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. Additionally, patients acknowledge their role in sharing responsibility for their safety when they are able and willing to do so. Finally, this study suggests that while patients see their engagement as a right, they perceive the responsibility for their safety ultimately lies with HCPs.

## Limitations

Although this study consisted of a relatively small number of participants, it was appropriate as the study intended to add depth to the literature, not generalizability of findings. However, several limitations are noted. First, this study took place in a comprehensive cancer center. While the design of this study included participants representing a range of HL 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 healthcare and may not be representative of the broader population of adults with cancer. This study included only English-speaking participants, whose experiences and perceptions may differ from those with little or no English proficiency. Additionally, there may be a self-selection bias; it is possible that the perceptions of those who volunteered to participate 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, it is imperative that nurses communicate effectively. For example, concordance between body language and verbal messages appears to influence patients' willingness to engage in safety-related behaviors. Even with inviting verbal language, however, patients may perceive an encounter as uninviting when a nurse is distracted or standing by the door. Furthermore, 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, it appears likely that phrases "for your safety" may lend some credence.



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

Furthermore, 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. It is the responsibility of the HCP to adjust accordingly. Additionally, efforts to invite patient engagement should extend to their informal caregivers as 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 is required. Additionally, as experts, nurses are obliged to be cognizant of the physical environment, looking for hazards based on their knowledge regarding patient safety.

## Directions for Future Research

Further 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. Additionally, because patient engagement oft includes some form of communication, the role of cultural and linguistic influences should be examined. Furthermore, patients' perspectives can be placed within the context of a hospital or healthcare system's patient safety culture by studying the linkages between patient safety culture survey results and patients' engagement in their safety.

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

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**Table 1**

## Participant Characteristics

Variables	<i>n</i> (%)
Gender	
Male	4 (31%)
Female	9 (69%)
Education	
Less than seventh grade	0
Junior high school (seventh through ninth grade)	0
Partial high school (tenth through eleventh grade)	0
High school graduate/GED	3 (23%)
Partial college (at least one year) or vocational training	3 (23%)
Standard college or university graduate	5 (38%)
Graduate degree or professional training	2 (15%)
Income	
Less than \$10,000	0
\$10,000 – \$29,999	2 (15%)
\$30,000 – \$49,999	5 (38%)
\$50,000 – \$69,999	2 (15%)
\$70,000 – \$89,999	0
\$90,000 or more	4 (31%)
Occupation Status	
Employed	1 (8%)
Student	0
On leave	5 (38%)
Homemaker	0
Disabled	1 (8%)
Retired	6 (46%)
Race	
American Indian or Alaska Native	0
Asian/Pacific Islander	0
Black or African-American	2 (15%)
Mixed Race/Other	1 (8%)
Native Hawaiian or Other Pacific Islander	1 (8%)
White	9 (69%)
Hispanic or Latino	
No	12 (92%)
Yes	1 (8%)
Health Literacy Level	
Adequate	7 (54%)
Marginal	3 (23%)
Inadequate	3 (23%)

Variables	<i>n</i> (%)
Age	
48 – 90 (mean 67.15, SD 11.20)	
Number of previous hospitalizations	
1 – 8 (mean 3.23, SD 2.42)	
Days between admission date and interview	
2 – 13 (mean 5.69, SD 2.66)	

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**Table 2**

Themes and Subthemes

<b>The word “patient” obscures the message</b>
Awareness of safety issues
Medical errors are different
<b>Safety is a shared responsibility</b>
Using common sense
Informal caregivers have a role
Environmental cues facilitate involvement
Implicit trust in healthcare providers
<b>Involvement in safety is a right</b>
Inviting communication
Involvement is dynamic

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