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Teresa Arline Jerofke

Jennifer Jean Dahlman

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Patients' Perspectives on Engaging in Their Healthcare while Hospitalized

Teresa Jerofke-Owen

Marquette University, Milwaukee, Wisconsin

Jennifer Dahlman

Marquette University, Milwaukee, Wisconsin

Abstract

Aims and objectives

To examine patients' experiences and preferences for engaging in their healthcare while hospitalised.

Background

Promoting patient engagement or involvement in healthcare has become an important component of contemporary, consumer-oriented approaches to quality care. Previous research on patient engagement highlights that preferences for engagement are not assessed while hospitalised, leading to patient role confusion and frustration.

Methods

Semistructured interviews were conducted with patients from January–March 2017 to examine their experiences and preferences for engaging in their care while hospitalised on medical-surgical units in the United

States. Inductive thematic analysis was used to uncover the themes from the interview transcriptions. The reporting of research findings followed the COREQ checklist.

Results

Seventeen patients, eight male and nine female, aged between 19–83 years old were interviewed. Patients had a difficult time articulating how they participated in their care while hospitalised, with the majority stating there were few decisions to be made. Many patients felt that decisions were made prior to or during hospitalisation for them. Patients described their engagement through the following themes: sharing the subjective, involvement of family, information-gathering, constraints, “I let them take care of me,” and variability.

Conclusions

Engagement is a dual responsibility of both nurses and patients. Patients’ experiences highlight that engagement preferences and experiences are not universal between patients, speaking to the importance of assessing patient preferences for engagement in health care upon hospital admission.

Relevance to clinical practice

The articulation of what patients actually experience in the hospital setting contributes to improve nursing practice by offering insight into what is important to the patient and how best to engage with them in their care. The constraints that patients reported facing related to their healthcare engagement should be used to inform the delivery of future engagement interventions in the acute care setting.

What does this paper contribute to the wider global clinical community?

- While patient engagement has become an important component of contemporary, consumer-oriented health care, patients experience constraints to their engagement while hospitalised.
- Nurses should be educated about the importance of establishing partnerships with patients and strategies they can use to engage patients in processes of decision-making, goal-setting, treatment planning and self-care through a model of shared accountability.
- Patient preferences for engagement should be assessed upon hospital admission and throughout the patient's stay, so that engagement strategies can be tailored to individual patient needs.

1 INTRODUCTION

Promoting patient engagement has become an important component of contemporary, consumer-oriented approaches to quality care delivery (Agency for Healthcare Research and Quality [AHRQ], [2013](#); Nursing Alliance for Quality Care, [2012](#); Patient-Centered Outcomes Research Institute [PCORI], [2014](#)). Although the term “patient engagement” has been used in numerous publications and contemporary strategies for improving health outcomes, there is lack of consensus of a clear definition. A recent concept analysis conducted by Higgins, Larson, and Schnall ([2017](#)) provided the following definition: “the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximising outcomes or experiences of care” (p. 33). The Patient Health Engagement model (Graffigna, Barelo, Bonanomi, & Riva, [2017](#)) characterises patient engagement as the motivation and self-determination a patient has to become an active player in his or her health care and is influenced by how the patient thinks, feels and acts. For the purpose of this study, patient engagement is understood to be the active participation a patient demonstrates in his or her health care. While nurses continue to be urged to implement care initiatives meant to engage patients in their care, little research has been carried out examining patient preferences for engagement in health care, especially in the hospital setting (Oxelmark, Ulin, Chaboyer, Bucknall, & Ringdal, [2017](#); Prey et al., [2014](#)). In other words, what components of

their care are patients interested in engaging in, how are they currently engaging in their care, and are there components of their care they are being engaged in that they are not interested in?

2 BACKGROUND

Various methods have been used by providers to engage patients in their care including information-sharing, encouraging decision-making and goal-setting, inviting patients and families to participate in daily rounds, encouraging the use of electronic health records (EHRs), and involving patients in quality improvement efforts (AHRQ, [2013](#); Swartwout, Drenkard, McGuinn, Grant, & El-Zein, [2016](#); Vaismoradi, Jordan, & Kangasniemi, [2014](#)). Weingart et al. ([2011](#)) demonstrated a 50% reduction in adverse events in hospitalised patients when they were engaged in their care. Patient engagement occurs throughout the continuum of care and serves as a mechanism to initiate or sustain health practices (Carman et al., [2013](#)). Patient engagement efforts are especially necessary in the acute care setting, where patients may face new diagnoses or be discharged home with new treatment plans, as engagement is associated with improved patient satisfaction (Dudas et al., [2013](#); Dwamena et al., [2012](#)), perceived quality of care, greater confidence in choices of treatment, and participation in self-management behaviours such as activities of daily living and medication management (Burton, Blundell, Jones, Fraser, & Elwyn, [2010](#); Ekman et al., [2012](#); Kuntz et al., [2014](#); Tzeng & Yin, [2014](#)).

Personalisation was one of the attributes Higgins et al. ([2017](#)) used to describe the concept of patient engagement; referring to the need to tailor engagement efforts to the unique needs and circumstances of each patient. Factors such as gender, age, culture, severity of illness and education levels have been associated with patient engagement preferences (Aasen, [2015](#); Florin, Ehrenberg, & Ehnfors, [2008](#); Hawley & Morris, [2017](#); Sainio & Lauri, [2003](#)), suggesting that a one-size fits all approach to patient engagement should not be used in practice. In previous studies, only 20% of acute care nurses reported asking about patient expectations (Rozenblum et al., [2011](#)) and only 52% of nurses ensured that patients knew the goals of their care (Eloranta et al., [2014](#)). In a study on patient participation during nurse handover in Israel, nurse receptiveness to patient participation and questioning was limited, with nurses often ignoring patients and talking amongst themselves (Drach-Zahavy & Shilman, [2015](#)). Thirty-seven per cent of patients in a study by Florin, Ehrenberg, and Ehnfors ([2006](#)) reported wanting a more active role in their treatment decision-making than they had while hospitalised, highlighting the need to assess for patient preferences for engagement.

The patient engagement experience can also be influenced by organisational factors that occur in a hospital setting. Hospitals can be an unfamiliar place for many patients, creating anxiety and fear that may interfere with patient engagement in care (Jerofke-Owen & Bull, [2018](#)). Patients may encounter providers they do not know or teams of unfamiliar faces, making them uncomfortable to ask questions (Tobiano, Marshall, Bucknall, & Chaboyer, [2015](#)). At last, patients' engagement in care is less likely when nurses seem task-oriented and busy (Tobiano, Marshall, et al., [2015](#)). It is important to examine the patient experience of healthcare engagement, so that efforts can be tailored to patient needs. The purpose of this study was to examine patients' experiences and preferences for engaging in their care while hospitalised on medical-surgical units in the United States to provide a mechanism to strengthen the delivery of future engagement interventions in the acute care setting.

3 METHODS

This qualitative descriptive study was conducted from January–March 2017 after institutional review board approval (ethics review) was granted from the participating hospital and university. A purposive sample of patients from seven medical-surgical inpatient units was recruited from a large Magnet-designated academic medical centre in the Midwestern United States. Purposive sampling was an appropriate method (Munhall, [2012](#)) to enrol patients of various ethnicities, ages and medical backgrounds, as preferences for engagement in health care have shown to differ based on those patient characteristics. Patients were

approached in person and told about the study if nursing staff verified they could speak and understand English, and did not have a history of diagnosed cognitive or developmental impairments. There were no patient refusals for participation in the study. Following informed consent, patients were asked to complete a demographic form for the purpose of sample description.

Semistructured interviews were conducted during hospitalisation, in patient rooms with the door closed to minimise distractions, by the first author, a female, doctorally-prepared academic researcher, with prior experience in qualitative research and acute care (Jerofke-Owen & Bull, [2018](#)). On a few occasions, spouses of the patients were present during the interview and patients welcomed their input throughout the interviews. Interviews were audio-recorded with permission from the patients. The researcher and participants did not have relationships prior to the commencement of the study. Following introductions and an explanation of the purpose of the research study, all interviews started with the opening statement, "Tell me a little about how you participate in taking care of your health." Interviews continued with other open-ended questions and prompting statements, which can be found in [Table 1](#). Interviews ranged from 10 min–1 hr depending on the breadth of information patients had to share. At the end of the interviews, patients were asked whether they thought there was anything pertinent that was not covered in the interview. Rapport was established with patients using prompts and body language to convey an interest in what they were saying (Green & Thorogood, [2009](#)). Interpretation of the data was summarised at the end of interviews so that patients could confirm the findings with the first author. Patients were given a \$25 grocery store gift card for their time. Interviews proceeded until data saturation was reached.

Table 1. Semistructured interview guide

1 Tell me a little about how you participate in taking care of your health
2 What parts of your health care would you like to be involved in that you aren't at this time
3 Tell me how the nurses involved you in your health care
4 Has your involvement in health care changed over time.... if so, how?
5 Can you think of any decisions or choices you've had to make about your health while you've been in the hospital
6 What kind of decisions do you want to be involved in

A graduate nursing student transcribed interviews verbatim. An additional graduate nursing student verified transcriptions against the recordings for accuracy. Inductive content analysis (Elo & Kyngas, [2008](#)) was conducted by the first and second authors. The unit of analysis was the whole interview, so that the voice of participants could be used as the context for meaning unit during the analysis process. Each transcription was read multiple times to obtain a sense of the patient experience during which time open coding was performed. The two authors coded the data independently to assure confirmability of the data. The process of open coding was used while taking notes in the margins of the transcripts. The notes and headings created during open coding were listed on a code sheet and were formulated into categories. During abstraction, categories were grouped together to become larger more inclusive themes that were named using words and text from the transcriptions. Themes were further verified by returning to the original transcriptions to ensure that the theme names and quotations selected supported the original context.

Numerous strategies were used to promote the trustworthiness of the study's findings (Lincoln & Guba, [1985](#)). An inquiry audit was conducted by having a researcher, not involved in study design or data collection, examine the process and findings of the study to determine whether the interpretations were supported by the data. In addition, the PI kept an audit trail of notes taken during interviews and throughout the data analysis process. At

last, purposive sampling was used to provide depth to patient experiences from patients of varying ages, genders, ethnicities and diagnoses.

4 RESULTS

Seventeen patients, eight male and nine female, aged between 19–83 years old were interviewed. The patients had multiple co-morbidities including hypertension, coronary artery disease, cancer and diabetes and the majority had been hospitalised multiple times in the last year. The majority of patients were Caucasian and all had at least a high school diploma (Table 2). When patients were asked to self-rank their health, only three patients selected “very good” and none “excellent” (Table 2).

Table 2. Participant characteristics

Characteristics	Participants (<i>N</i> = 17)	Mean	Range
Age		55	19–83
Gender			
Male	8		
Female	9		
Marital status			
Married	7		
Single	3		
Divorced/separated	2		
Widowed	3		
Other	1		
Race/Ethnicity			
African American	3		
Hispanic	1		
White	13		
Education level			
High school graduate	5		
Some college/specialised training	6		
College graduate	2		
Graduate degree	3		
Current chronic conditions			
HTN	5		
CAD	6		
Hyperlipidemia	2		
Asthma	1		
DM	2		
Arthritis	3		
Cancer	6		
Other	4		
Prior hospitalisation within last year			
Yes	12		
No	4		
Self-rated health			
Poor	2		
Fair	4		
Good	7		
Very good	3		

Excellent	0		
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During the interviews, patients often had a hard time articulating how they participated in their health care outside of self-care activities such as ambulating in the hallways, making good food choices and taking their medications as directed. Patients frankly stated they had never truly thought about their preferences for engagement in their health care prior to the interview. While patients weren't always able to identify specific ways they were involved in their care, their engagement, including the nurse role, became evident within the stories that they told about their experiences while hospitalised. Nurses helped to engage patients in their care by teaching patients about their medications and self-care, telling them their vital signs, sharing with them why they were doing things or what they were looking for, updating them on the plan, providing encouragement and involving families in patients' care.

Patients described their engagement through the following six themes: sharing the subjective, involvement of family, information-gathering, constraints, "I let them take care of me," and variability.

4.1 Sharing the subjective

Patients discussed the importance of collaboration with their providers as a method to engage in their care and share subjective information that the provider might not otherwise know. One patient stated, "See I can't do it without them, and they can't do it without me, so as long as we're working together. I would be feeling useless and hopeless if I was just laying back in the bed and letting them do everything (female, age 50)." An older male patient stated, "And I have found at almost 70 that the health care for the patient improves if the person can be interactive with the provider so the provider understands the why, not only the what."

Patients found it helpful to be viewed as experts in the subjective experience of their own care when providers asked questions. As one patient stated, "Usually they are pretty good about asking me what has worked in the past. I'll speak up when needed (female, age 23)" Another patient explained:

When they don't know what I know it's like ok you just have to do this, like if I'm used to pillows I can't have my head too low. I have to let them know my breathing is compromised if I lay too low or you know whatever, so I have to let them know what makes me feel better. (female, age 50)

Another patient talked about sharing information from one shift to another to avoid errors from being made. He felt he needed to be interactive to, "ensure that I've given the care provider enough information to make a good decision on how to keep me alive and whole and help him teach me how I can participate (male, age 69)."

4.2 Involvement of family

Many of the patients also discussed involving their family in their care. Three of the married men in the study talked about their spouses playing a very active role in their health care. Spouses often acted to research a diagnosis or treatments, reinforce the plan of care, or explain things to the patient if he or she forgot what was discussed. One patient explained, "I'm having him be my eyes and ears too (female, age 53)." In the case of one patient, family acted as a filter and decision-maker. The patient's wife and son made the majority of his health choices because he didn't understand medical things and would get too overwhelmed by too much information. He explained:

Personally I don't understand it. I leave that up to her and my son, which I am lucky to have one here at all times. Most people don't have that, and the burden doesn't come back on to me because I truthfully just get it confused and wrong. (male, age 64)

Patients also reported that family members helped them engage in their care by collaborating with them to create questions for the health care team and reminding them to ask their questions. A 19-year-old female patient discussed the support she sought from her parents, “if the doctor tells me to do something at home and I really don't want to do it, that's when my parents will step in and make me realise where my doctor is coming from.”

Sometimes family members had experience with the same health issue that the patient had and provided the patient with advice about what worked for them in the past:

I have a lot of immediate family members that have Crohn's disease as well, so I think the most helpful thing is seeing them do the same thing and having them kinda help me with, like with reminding me to take my medications and sort of guiding me what I should and shouldn't do. (female, age 23)

4.3 Information-gathering

Patients discussed gathering information about their health condition from a variety of sources including their providers, the Internet, and their EHRs. Patients described engagement in their health care as actively listening to what the healthcare team had to say and asking questions. Many of the patients wished that they knew more about what went on behind the scenes. One patient explained, “I'd like to be in the meetings with the doctors and hear what they're saying....you know they try to put things on my terms but I think they discuss more things outside the room (female, age 53).” While many patients were interested in hearing what their medical teams had to say, some patients were not interested in being a part of bedside rounds. One patient stated that he did not wish to participate in rounds but would rather hear the summary after rounds had been completed:

There might be some stuff I don't want to hear..you know I'm sure that when they come around here they all have different opinions and its like a skull session that they talk amongst themselves and they come up with what they're gonna say, and uh, I don't have to know everybody's certain opinions. (male, age 67)

Each of the participating nursing units used dry-eraser boards in patient rooms to provide a place to write down provider names, goals for the day, important information or patient questions. When asked about the boards, patients often reported that the plan of care goals or questions written on the boards “came from the nurse (male, age 69).” Another patient stated, “that's basically just, I think it's more for their [nurses] benefit than it is mine (male, age 65).” Patients did however, find the boards helpful:

You know to keep me updated, I might be forgetful that day, they're very helpful with keeping me up to date with what the current date is and the information on that, what my expectancies would be, the plan and the goals and any questions I might still want to ask or who to call and know what to do. (female, age 50)

A few patients relied on the Internet heavily for medical information and knew enough to go to reputable sites. One patient explained that he spent a lot of time sorting out good from bad information. One patient who had a rare disorder talked about being “proactive” and spent much time doing outside research about the latest treatments, joining support groups and seeking out clinical trials that may help her disorder. A cancer patient in her 20s discussed how she found blogging websites helpful for coping with her diagnosis if she ignored the negative comments on the websites.

Patients reported that providers in general did not seem happy when they did their own outside research on the Internet. Patients were often told that the information they found on the Internet did not apply to them or that

“you can't read anything like that on the internet.” None of the patients were directed to access reputable Internet resources by their providers. One patient discussed how he compared different websites for information and he would believe the information that seemed consistent between them all or another patient looked for a recognisable name, such as a large healthcare organisation, when looking for health information online.

Six of the seventeen patients reported that they avoided the Internet because of misinformation or scary information that could be found on the sites. As one patient explained, “I just think I get misled by a lot of that stuff. There's a lot of gloom and doom and I'd rather not read the odds of survival when they were low for my type of cancer (male, age 61).” One patient stated that her brother “got me going on that [internet] and I just finally stopped. I thought I was ready for death (female, age 64).”

The healthcare system in which the patients were hospitalised offers access to the patients' EHRs. Many patients found being able to access their records helpful and utilized aspects of the system often. Services used included checking laboratories and test results, looking at appointment times, making appointments, looking up medication lists, refilling medications and asking nonurgent medical questions. Of the 17 patients interviewed, four patients were not interested in accessing their EHR, one did not know about the service and one was interested but not yet using it. Reasons that patients did not access their EHRs included not having a computer and/or Internet, worries over security issues, liking hard copies and liking to go over things with the provider so results are not misinterpreted. Concerning security issues, one patient stated, “Everything is like, well if you do this with the internet, this could go here or this could go there. It's just like, I don't even bank on the internet if I don't have to for anything, just for security cases, yes (male, age 64).” None of the eleven patients who used their EHR knew all of the services that came with the use of their EHR.

4.4 Constraints

While describing their experiences engaging in their care, many patients discussed obstacles they faced while in the hospital. Lack of comfort asking questions was a common issue patients experienced while hospitalised. Much of the lack of questioning came from the fact that patients viewed providers as being busier in an acute care setting. One patient was very concerned about having to start a new therapy for cancer, but had not voiced her concerns or asked questions about the new therapy. She stated:

It's hard for them because if I was in their office they'll talk to me for an hour and a half but when they're doing their rounds and they're more busy.....I guess I wish I could have a doctor's appointment tomorrow cause I know he would explain it a lot further. (female, age 60)

Another patient did not ask her questions because they dealt with embarrassing topics to her such as incontinence and diarrhoea, “I just don't want to ask the questions....sometimes they're embarrassing you know and it's hard (female, age 83).”

Some of the patients explained that during rounds, providers talked at a high level that was hard to understand. Another patient described rounds in his room, “Sometimes it's a little intimidating having that many people in the room (male, age 61).” Another patient explained that she often doesn't ask questions during rounds “I just kinda go with it because I know they're busy and I know they want to get outta there and I'm ok with that (female, age 23).”

Hospital processes also were mentioned as barriers to participating in their health care. One patient explained his concern that nurses didn't talk about his care in front of him, taking away from a feeling of partnership and stated, “that's one of the best practices, never let the patient hear what you're saying, so I have to try really hard to listen (male, age 69).” The patient felt that he had to verify at change in shift what was said to the new

nurse about him to ensure that the information “matches what they've told me” to ensure errors were not made and the plan of care didn't change without his knowledge. Another patient explained frustrations over pain management processes, as the starting dose was never enough to manage her pain and she felt her concerns were not heard, “But there's only so much they can do when it's very like you know there's a lot of hoops that need to be jumped through to start medications, that sort of thing (female, age 23).”

A delay in finding out test and procedural results or not knowing when testing was scheduled was another source of frustration for patients. One patient stated, “I mean I have business cards. I could call somebody I suppose but it's like perhaps they should be forthcoming with the results of that, as soon as they get them so that you're not sitting there wondering what were the results (female, age 53).” Concerning the scheduling of tests and procedures, patients reported that even the nurses often didn't know when things were going to happen until the last minute, so they felt bad when they kept asking what was going on. As one patient elaborated, “It's hard sometimes to know what's going on when you're in the hospital. No one knew anything for what seemed like forever, but that's just a problem where it's one person of 30 that might know the answer, but you don't get to talk to them (male, age 61).”

At last, independence and self-care were limited in some patients because of being hooked up to machines or being labelled a fall risk. As stated by a patient, “You know, they don't want me to walk by myself, but I'm doing quite well, but fine, you know, to call for walks and do stuff like that (male, age 64).” He felt having to call for assistance to walk limited the number of times he could walk per day. Another patient reported she was not taking care of herself in the hospital because, “[I] just haven't been able to get out of bed or I'm hooked up to machines and I really can't move around and such (female, age 53).” This was frustrating to her because she was very active in her self-care at home before her physical limitations.

4.5 “I let them take care of me”

Many patients had the attitude that during hospitalisation, their health care was in the hands of the hospital staff and it was their responsibility to follow their orders. As stated by one patient, “Pretty much I'm like a robot (female, age 60).” The majority of patients also needed much prompting to identify any decisions or choices they made while hospitalised:

I don't really do anything for my health in the hospital. I let them take care of me....I would be making the decisions but there's very few decisions to be made, usually, it's usually made before I'm in the hospital. (male, age 61)

A few patients also liked to defer decisions about medications and treatments to their providers because they felt the providers were the experts. One patient explained, even if his providers educated him about his options, he did not think he would be qualified to make a decision about his treatment plan, “I don't think that I would have the knowledge, even trying to get it from them, in order to make a good decision (male, age 64).” Another stated, “Unless it's something that I've heard something bad about I usually don't have an opinion on it because I trust doctors to know what's in my best interest (male, age 65).”

When patients who liked to defer decision-making to providers were asked whether they would still do something if they didn't agree with it or know why they were being asked to do it, they stated, “I would assume that they are the knowledgeable people and I would do it (male, age 74).” and “Well who am I to say? I don't specialise in that so I feel that is why you should be going along with it, so I'm not going to dispute it in any way (male, age 54).” Another explained:

I suppose a person can refuse any test they don't want, but it's not gonna do me any good by refusing it. I mean, if a doctor says they want to do a test, it's because they want to get a better picture of what's

going on with you and only a test can reveal that...If a doctor tells me I'd like to do a test, I figure, 'yeah, let's do it.' I'm not going to sit there and second-guess my physician. (male, age 65)

With the exception of one patient who felt it was his responsibility to make sure communication was consistent between shifts to avoid "the luck of the medical system (male, age 69)," none of the patients talked about participating in their care in terms of promoting their safety. When asked whether they would like to participate in safety initiatives, patients had the attitude that measures were already in place with their providers and they did not see their place in the initiatives. Patients were asked if they would feel comfortable reminding providers to wash their hands. The majority of patients held the assumption that hands were washed before they came in their room or felt that providers always washed hands in their rooms. One patient did not feel she would be able to ask a provider to wash his/her hands if it was not done in front of her. As one patient said, "Probably not because as far as I can tell they just do it automatically (female, age 60)."

4.6 Variability

Many of the patients discussed how their engagement in health care changed over time. Some felt they took more responsibility as they got older, not only because they were diagnosed with more conditions, but also because they had more time to focus and take care of their health. One patient explained, "I would do more for my health now than I did before, just because of the severity of what I had done (male, age 67)." Another patient defined his involvement in his health care before his cancer diagnosis as a "non-entity and non-problem (male, age 61)." A patient who had many years of misdiagnosis stated:

I've become more concerned. I've participated a lot more, because I don't trust a lot of doctors anymore, sadly you should be able to trust them but you don't always, so I research, I learn more about the doctors themselves too. (female, age 35)

One patient used to have a "wait for it to get better" attitude, but after her health declined and she was given a serious diagnosis she now had the attitude that, "I'll be a lot more conscious about what's going on with my body than I was before. If I think there's something wrong and there's a gut instinct saying there's something wrong, I'm not going to put it off (female, age 60)."

All of the patients reported that their engagement preferences would not change in times of emergency. Patients reported that they still wanted to know what was going on with their care and make decisions as long as they possibly could in relation to their capacity. In the case that they would not be able to make a decision during an emergency, they would at least hope that their families would express their preferences and be heard by the healthcare team. Many patients also discussed having to trust that their providers would make the best decisions for them if they were unable to communicate their preferences.

5 DISCUSSION

This study supports engagement efforts, which are included in numerous contemporary strategies for improving health outcomes and provides a mechanism to inform future engagement interventions aimed at improving the patient experience, quality of care and patient safety. Consistent with Sloan and Knowles (2017), many patients in this study shared feelings that everything was decided for them before or during hospitalisation, and they could not identify a decision that they made while hospitalised. Efforts need to be made by nurses to involve patients in decision-making, even if it is something as simple as when to ambulate in the halls or when they would like to wash up. Giving patients more control over simple things during their hospitalisation can combat feelings of powerlessness and disengagement that may occur during hospitalisation (Jerofke-Owen & Bull, 2018).

Contrary to prior research, which has shown that older patients tend to defer decision-making to their physicians (Ekdahl, Andersson, & Friedrichsen, [2010](#)), patients of varying ages in this study found medical information overwhelming and made the intentional decision to have their physicians or family members make their treatment decisions. While those patients deferred treatment decision-making to others, they still wanted to engage in other areas of their care such as participating in therapy, sharing their subjective experience, and learning about their diagnosis in a language they could understand. Consistent with prior studies, the majority of patients who used language consistent with “following doctors’ orders” in this study were male (Arnetz & Arnetz, [2009](#); Florin et al., [2008](#)). These findings highlight the importance of not making assumptions that a patient is disengaged in his or her care if decision-making is deferred to others, as there are many other components of care that patients may be interested in engaging in. It is also important for nurses and other healthcare providers to ensure that male patients are educated about the importance of participating in their treatment planning and are given opportunities to share their subjective concerns and needs.

Much like results from Ringdal, Chaboyer, Ulin, Bucknall, and Oxelmark's ([2017](#)) study, there were also patients who felt that nurses and physicians in the hospital setting were much busier than in the outpatient setting, and held back from asking them questions or sharing their concerns. As in prior studies, the female patients in this study were more likely to share their subjective concerns with their providers than the male patients, regardless of age (Florin et al., [2008](#); Street, Gordon, Ward, Krupat, & Kravitz, [2005](#)). Something as simple as asking patients if they have any questions or concerns rather than assuming patients will speak up on their own could address issues that otherwise would not have been brought to light. Nurses should emphasise to patients the importance of writing their questions down, so they do not forget to ask when appropriate. Tobiano, Bucknall, Marshall, Guinane, and Chaboyer ([2015](#)) found that while nurses acknowledged their role as a facilitator to patient engagement, they often felt they did not have the time it took to engage patients in their care or were worried patient safety would be at risk if engagement strategies did not align with patient abilities. Nurses need to be educated about simple ways they can engage patients in their care based on patient preferences and abilities.

Patients also reported that their engagement was limited by not always knowing what was going to happen that day or their laboratory or test results from prior days. The addition of bedside rounds could help keep everyone updated on the patients’ plans of care and many patients were interested in being active participants in rounds if brought to the organisation. Bedside shift-to-shift nursing handoffs have been associated with patients who felt more informed and involved in their care, provide an opportunity for patients to correct errors during handoffs, and instil greater feelings of respect and trust in providers (Mardis et al., [2015](#)).

Another surprising finding from the study was the varying levels of comfort using electronic health resources. Some patients talked about avoiding the Internet so that they would not read scary information. Patients also shared that providers did not seem to support the information they found on the Internet, stating that the information “didn't pertain” to them or telling them to stop looking online. While some patients were confident they accessed reliable sources on the Internet, it cannot be assumed that all patients have that level of health literacy. It is becoming more commonplace for patients to search for health-related information online (Amante, Hogan, Pagoto, English, & Lapane, [2015](#)). Providers should take the time to provide patients with reputable sources to access online if they so choose or organisations should start putting more education materials on their websites that patients can access.

Patients in this study also valued having access to their EHRs. Aspects of their EHRs that they used included the ability to make appointments, request refills, check medication lists, access laboratory and test results, and ask nonurgent medical questions. Not all of the patients who used their EHRs were aware of the full potential of what they could do with their records and were surprised to hear they could make appointments online or send

questions to their providers. Patients may benefit from a short tutorial about the use of their EHRs while hospitalised, so they can use it to the fullness of its potential.

Patients did not speak of their engagement in terms of promoting their safety while hospitalised. This conflicts with the Joint Commission on Accreditation of Healthcare Organization in the United States' mandate that health care organisations promote patient participation in a culture of safety (AHRQ, [2017](#)). While a few patients reported that they would feel comfortable speaking up if something did not seem right in their care, none of them discussed efforts made by the healthcare organisation to educate them about ways they could prevent errors while hospitalised. The sense of security that patients felt for trusting the medical team to "do what's best" and the disinterest in participating in safety initiatives is concerning. Patients in this study assumed that providers had washed hands before entering the room and some discussed not feeling comfortable questioning providers about it. Other patients were happy simply knowing the names of the medications they were given while hospitalised. Given that adverse events occur in an estimated 10% of hospitalisations (Rafter et al., [2015](#)), it is important for nurses to encourage patients to watch out for their own safety to help ensure that adverse events do not occur. Activities that patients can participate in include requesting that bedrails be put up, ensuring that their identification is checked before medication dispensing, participating in shift report, medication reconciliation, and ensuring visible handwashing (AHRQ, [2017](#); Herrin et al., [2016](#)). Patients can be engaged in fall prevention programmes (Growdon, Shorr, & Inouye, [2017](#)) as a method to promote patient safety, while giving patients a sense of responsibility in their care and independence while hospitalised. Nurses should consider other ways to reduce the impact of restricted mobility imposed by equipment and precautions.

While each of the participating nursing units used dry-eraser boards in patient rooms as a method to engage patients in their care, it was quite shocking to hear patients make comments that the boards were there for the nurses and that they did not contribute to the construction of the goals or the information written on the boards. This is consistent with prior studies, which have demonstrated nurse preferences for controlling the creation of patient care plans (Eldh, Ehnfors, & Ekman, [2006](#); Tobiano, Marshall, Bucknall, & Chaboyer, [2016](#)). Massaro ([2013](#)) found that use of dry-eraser boards on an obstetric unit to identify providers, organise information, and mutually create goals, led to high patient satisfaction scores and ease of keeping track of and reaching goals for patients. The use of dry-eraser boards in patient rooms to improve communication was also one of the recommendations of Institute for Healthcare Improvement ([2018](#)) and Robert Wood Johnson's *Transforming Care at the Bedside*. Further education needs to be done for nursing staff and patients so that the boards can be used to the fullness of their potential, emphasising the importance of creating patient goals with and not for the patient. Adopting a model of shared accountability, in which providers and patients create partnerships to actively engage patients in setting goals, making treatment decisions and care planning, can help patients feel like a valued, active member of the healthcare team, leading to favourable outcomes through sustained health behaviours (Peterson et al., [2014](#)).

It is vital for providers to identify patient preferences regarding engagement early on and educate the patients on the benefits of being active in health care decisions. Patients reported that their engagement in health care changed over time based on their situations, highlighting the need for repeated assessments of patient preferences for engagement throughout the continuum of care. Future engagement interventions should focus on the patient experiences shared during this study and the constraints and frustrations patients voiced. The availability of a psychometrically sound tool for clinicians to use within the EHR to precisely determine patients' individual preferences for engagement in their care, leading to more personalised strategies to actively engage patients in their care should be the next step in patient engagement research. The integration of a tested tool into the EHR would make it possible to examine the relationships between patient preferences for engagement and patient outcomes.

6 STRENGTHS AND LIMITATIONS

One interviewer conducted all of the interviews to maintain credibility and dependability. Enrolling a wide variety of patients of differing ages, gender, ethnicity and diagnoses further enhanced the credibility of the data. Data were also collected until saturation occurred. Patients in this study were well educated, which may have influenced their health literacy and perceptions of engagement in care. Interviews were conducted in the patients' hospital rooms and not a neutral location. On a few occasions, interviews were interrupted by visitors or patient care, which could have influenced what information patients chose to share with the researcher. This study was conducted at one hospital, which had instituted numerous engagement strategies such as the dry-erase boards and an EHR system. In addition, this study specifically examined patients' experiences with and preferences for engagement while hospitalised. Patient preferences for engagement during acute hospitalisation may be different than their preferences at other points in the continuum of care when they are not experiencing acute illness or the disruption associated with hospitalisation. Future studies should be conducted to examine the patient experience and patient preferences for engagement at other healthcare organisations, which may have different engagement cultures or during various points in the continuum of care, as patients' needs may change based on the setting they are in.

7 CONCLUSION

Engagement is a dual responsibility of both providers and patients. Many patients had never thought about how they engaged in their care before having the conversation about it during the interviews. Patients in this study and in prior studies indicated that engagement preferences are not universal, highlighting the need to assess patients' individual preferences for engagement. Various methods patients used to engage in their care became evident through stories patients told during interviews and included sharing subjective information with their providers, involving their family members in their care and decision-making, gathering information by asking questions and accessing their EHRs, and seeking outside resources including those found electronically. Future studies should focus on creating and testing a tool that nurses could use on admission to assess patient preferences for engagement in health care, so that nursing care could be tailored to each individual patients' unique situation.

8 RELEVANCE TO CLINICAL PRACTICE

Nurses play a key role in facilitating engagement efforts with hospitalised patients. The articulation of what patients actually experience in the hospital setting contributes to improved nursing practice by offering insight into what is important to the patient and how best to engage with them in their care. Patients described unique constraints they encountered while hospitalised that hindered their ability to engage in their care including not having opportunities to make decisions, feeling like providers were too busy to answer questions, not knowing what the plan of care was, and feeling overwhelmed by medical information. The acknowledgement of those constraints is important to inform the delivery of future engagement interventions in the acute care setting and the design of EHR-driven systems for establishing preferences early in the course of hospitalisation. Future interventions should focus on strengthening nurses' abilities to provide opportunities for patients to engage in their care and advocate for patients' to discuss their healthcare concerns with other professionals.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Study design: TAJO; data collection: TAJO; article drafting: TAJO, JD; data interpretation and revision and final approval of the article: TAJO, JD.

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