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Nurses' Experiences Empowering Hospitalized Patients

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Abstract

Four focus groups were conducted to explore acute care nurses' experiences empowering patients and the facilitators and barriers they encountered during the process. Thirty-four nurses employed at four hospitals in the Midwestern United States participated in the study between February and April 2015. Facilitators of empowerment included establishing a therapeutic relationship, fostering communication, providing education, respecting patient autonomy, engaging support systems, and lifting spirit/giving hope. Barriers included conflicting information about plans of care, lack of time, fear and anxiety over unfamiliar environments and routines, ineffective or inadequate support systems, lack of/low accountability, and killing the soul. Nurses also described innovative strategies they used to overcome the barriers. The development of future inpatient empowerment interventions needs to focus on the innovative strategies nurses used to overcome barriers in addition to considering the facilitators and barriers to empowerment that nurses identified.

Empowering patients to participate in their health care has become an important component of improving the patient experience and promoting patient safety in numerous health care reform models (Patient-Centered Outcomes Research Institute, 2014; World Health Organization [WHO], 2015). The process of patient empowerment occurs within provider–patient relationships with the intention of increasing patients' capacities to take greater control of their health (WHO, 2012). Nurses can empower patients by the following: (a) helping patients actively participate in their care; (b) providing patients with access to information, support, and resources; (c) facilitating collaboration with providers, family, and friends; and (d) encouraging patient autonomy (Jerofke, 2013; Laschinger, Gilbert, Smith, & Leslie, 2010). However, this empowerment does not always occur in acute care settings.

Gaps in Empowerment Research

Although empowerment in outpatient settings has been shown to improve patient confidence, knowledge, participation in self-management behaviors, and quality of life (Chen & Li, 2009), there has been little research on empowerment in acute care settings (Prey et al., 2014). The use of empowering behaviors with medical-surgical inpatients was associated with higher levels of patient activation after discharge (Jerofke & Weiss, 2016). Unfortunately, hospitalized patients report that key components of empowerment, including discharge planning, patient education, listening, and being kept informed of care plans were missing from nursing care provided to them (Kalisch, McLaughlin, & Dabney, 2012). In addition, the majority of research on empowerment focuses on outcomes (Chen & Li, 2009), with little attention paid to processes providers use to empower patients. Understanding the nurse experience of empowering is necessary to inform the development and testing of interventions to increase the effectiveness of empowerment efforts in acute care settings.

Purpose

The purpose of this study was to explore acute care nurses' experiences empowering patients and the facilitators and barriers they encounter during the process of patient empowerment.

Method

Design

A qualitative approach was used and focus groups were conducted with nurses employed at four hospitals. Focus groups were particularly appropriate as they allow for interaction among participants that can produce knowledge about patient empowerment and it allows for gathering a large amount of data in a relatively short period of time (Krueger & Casey, 2015; Stewart & Shamdasani, 2015).

Setting

Focus groups were conducted with nurses employed at four hospitals affiliated with two large health systems in the Midwestern United States. Focus groups were held in bright and welcoming conference rooms at each of the hospitals in areas away from clinical units to help participants feel secure and comfortable with sharing their personal experiences.

Participants

Following Institutional Review Board approval from participating hospitals and the university, a total of 34 nurses (one male and 33 females) were recruited into four separate focus groups using purposive sampling. Nurse managers of each participating unit were asked by the PI to forward an email to the nursing staff advertising the study. Nurses were instructed to email the principal investigator directly to ensure confidentiality. Recruitment posters were also placed in participating units in frequented areas such as break rooms and conference rooms. Descriptive demographic data were not collected in an effort to help nurses feel comfortable discussing their experiences caring for patients on their units.

Procedure

Four focus groups were conducted between February and April 2015. Each focus group was facilitated by a doctorally prepared researcher, and notes were taken by an undergraduate nursing student. A second doctorally prepared researcher cofacilitated all but one of the focus groups. Following introduction of the study team, study aims, and emphasis of the importance of maintaining confidentiality, focus groups began with the following question: "What do you think of when you hear the words patient empowerment?" Subsequent prompts included the following: "Tell me about a situation in which you thought the patient was empowered/not empowered" and "What did the patient/nurse do or not do?" The researchers summarized main ideas and themes at the end of each focus group and asked participants whether they had anything to add. Data collection continued until saturation was reached by the end of the fourth focus group.

Data Analysis and Rigor

Audio recorded focus groups were transcribed in full by a research assistant and reviewed by the PI for accuracy. Initial analysis of the data occurred at the end of each focus group through the researchers summarizing main ideas and themes. More detailed analysis of data from each focus group occurred after the data and the note takers' observations of group member interaction were transcribed. After the two researchers independently coded the data manually, they met to review the codes, discuss the themes, and arrive at consensus agreement on coding. Differences in coding were attributed to more detailed coding by one researcher, and use of empowerment terminology found in the literature by the other researcher. An inductive approach was used to develop codes with attention given to the nurses' statements about the meaning of patient empowerment, their perceptions of the facilitators and barriers to patient empowerment, and the strategies nurses used to overcome the barriers. Detailed codes were categorized (or grouped) into broader themes. Data were examined for consistency and specificity within and across focus groups. Specific, detailed

responses based on experience were noted as enhancing the credibility of the data ([Krueger & Casey, 2015](#); [Nagle & Williams, n.d](#).).

Results

Nurses from adult medical, surgical, oncology, and critical care units from varying shifts were included in the sample. The majority (97%) was Caucasian, and each focus group consisted of six to 12 nurses. Nurses indicated that patient empowerment meant involving patients in their care and giving them control in participating in and making decisions about their care. While discussing barriers to patient empowerment, nurses spontaneously provided examples of innovative strategies they used in practice to overcome those barriers to patient empowerment.

Facilitators to the Process of Patient Empowerment

Establishing a therapeutic relationship

Nurses in all the focus groups agreed that establishing rapport and trust with patients by showing them respect was essential to the process of empowerment. Two key elements in establishing a therapeutic relationship were maintaining continuity of care and creating a safe environment. Consistent patient assignments facilitated the development of nurse–patient relationships and also contributed to patients feeling like they had a safe environment to talk openly with the nursing staff and ask questions. As explained by one nurse,

> . . . the more you know about the patient, the more that they sometimes open up, sometimes they just aren't ready to talk to you the first day you have them but the second day they're a little bit more ready, the third day they're more ready and it just gets better every day.

Fostering communication

Fostering communication with patients, families, and other disciplines was consistently identified across focus groups as an action nurses performed to empower patients. Nurses spent much of their day explaining procedures and treatment options with patients and their families using simple language so that jargon would not overwhelm patients. Nurses recognized that patients became frustrated when they received conflicting information about their plans of care. A few of the medical-surgical nurses stated that daily rounding with the multidisciplinary team was valuable to assure everyone was on the same page and to assure discharge needs were going to be met. Daily rounding could include hospitalists, social workers, specialty nurses, chaplains, dieticians, and therapists. As explained by one nurse,

> We have plenty of rounds and discussions on our unit . . . I think it is most beneficial for physicians in particular to hear the viewpoint of the nurse who is in the room with that patient for ten hours of their shift versus just going in and seeing them for thirty seconds and coming out.

Family dynamics can complicate the empowerment process. When patients are not progressing as families wish, or families are confused by the plan of care, frustrations develop. Many nurses reported requesting and coordinating family meetings with providers when difficult or ethical situations were present. One nurse explained, "Patient(s) that decide they don't want

treatment anymore . . . they're tired. And then the family comes in and talks them back into it. That's a good example of losing your empowerment for fear of disappointment to your family."

Providing education
The nurses in all focus groups reported that teaching patients and family members throughout the hospitalization was a key strategy for empowering them. Nurses routinely provided education about patient rights and accountability, their illness, self-care, and treatment options. Many nurses defined empowerment as patients being accountable for their health. Nurses felt that it was their duty to make sure patients were well informed of their treatment options so that they could make informed decisions. As one nurse stated, "Helping people learn how to take care of themselves, not only just to teach your patient but to teach them accountability that they're the ones that have to take care of themselves."

Respecting patient autonomy
Nurses acknowledged the patient's right to make informed decisions about care and indicated that health care providers needed to respect patient autonomy and self-determination. By respecting patient autonomy, nurses thought they were facilitating empowerment by collaborating with patients on setting goals rather than simply setting goals for the patient.

As one nurses stated,

> . . . asking patients and families what their goals are, even just a general goal for the day and having that conversation that what we do is really about you, not really what we want to achieve but what do you want?

Another way nurses respected patient autonomy and self-determination was by giving patients choices. The choice could be as little as what to order to eat or could be choosing when to participate in therapy or have a dressing change. As one nurse explained, "I think the more choices they get the more empowered they feel."

Engaging support systems
Patient families were often mentioned as a source of strength for patients. Families can reinforce important elements of treatment plans to patients and should be involved in their loved one's care when appropriate. For instance, one nurse explained, "Sometimes things that we say get lost in translation from our mouths to the patients' ears but sometimes hearing the same words from mom or dad, or from a sibling or child. It makes a world of difference."

Nurses also reported acting as a support system for patients, especially when family or friends were not able to visit. One nurse gave an example of the nursing staff supporting a drug abuser to stop using. Nurses also found themselves having to implement "tough love" with patients as a way to support them through difficult times. As explained by one nurse,

> You know, as much as you want to do for that patient, you know you could get them out of bed in half the amount of time, but it's the tough love . . . I'm not here to be a friend, we're here to get you moving, get you out in the hall and get you home with your family.

Lifting spirit/giving hope

Lifting spirits referred to actions nurses took to encourage patients who had experienced multiple setbacks. Nurses described varied methods to try to lift patients' spirits during times of despair. Positive reinforcement was one method used to lift the spirit. Acknowledging patient's progress tends to help the person start to see the light at the end of the tunnel. Pointing out even the small steps in a patient's progress helped them to keep going. For instance, one unit used white boards to write daily goals for the patient to see all day. Once the patient achieved the goal, the patient became more confident that progress was being made. One nurse explained, "It [positive reinforcement] helps them to continue to see that they are improving and then that they'll probably be more involved because they're not getting so burnt down on the things that they aren't able to achieve."

A unit that cared for trauma patients relied on peer mentors to help give patients hope. Peer mentors are former patients who help patients see that there is life after the hospital. As one nurse explained, "They know themselves how low you can get—patients benefit from other patients that have come through that long, dark tunnel."

Barriers to the Process of Patient Empowerment

Conflicting information about plan of care

The nurses discussed many different situations in which patients and family received conflicting information about the plan of care from different specialists or services. Nurses explained that each service tends to focus on one aspect of care without looking at the whole picture and described the phenomenon as "nobody driving the ship." As one nurse stated,

> I think they can lose their empowerment too when they're getting conflicting information about their prognosis or plan of care. One service says this isn't going to get better. Then another service says we'll fix this, you'll be good. The family and patient never really know what was up.

Another factor leading to confusion about plans of care was the changing schedule of providers that round on hospitalized patients. One nurse pointed out that patients do not always feel comfortable questioning providers and may not ask, "Who are you?" when the provider enters his or her room. When patients are unsure of who they are talking to, they may not ask the questions they have or share their thoughts or feelings regarding their treatment. Nurses tried to introduce new providers to patients when they were able and also tried to prepare patients to ask whatever questions they had when providers visited them throughout the day.

Nurses often felt responsible for filling in the missing pieces but sometimes were unsure themselves what the plan was. In those instances, nurses relied on what was written in the medical record; however, nurses stated that reading notes was not a substitute for collaborating and communicating with other disciplines. Nurses who worked on nursing units that employed multidisciplinary rounds on a daily basis reported far fewer issues with conflicting plans of care and had a greater understanding of patients' care plans.

Lack of time
Lack of time was a common barrier described by nurses in each focus group. Nurses reported that many patients' lengths of stays were becoming shorter and shorter. Insufficient time with the patient impeded the establishment of therapeutic relationships that are necessary for patient empowerment. When patients were discharged before nurses got a chance to get to know them, it was difficult to get the patient involved in their care.

Nurses also frequently discussed getting pulled in different directions or taking care of multiple high acuity patients at once. The high demand on nurses' time made it difficult to spend one-on-one time with each patient. Nurses talked about cell phones and call lights going off, making them leave one room for the next. In those instances, having someone else such as a chaplain or a specialty nurse, like a palliative care nurse, who might have fewer time constraints, sit with the patient was found to be beneficial in fostering empowerment by giving patients a chance to share their concerns and feelings.

Nurses admitted that it is not always easy to offer patients choices throughout the day regarding their care, given the great amount of tasks that need to be completed and the time it takes to involve patients in the decision-making process. One nurse explained,

> I think as nurses we are all regimented . . . and you have to do this and this so . . . I think it is very easy for us to dis-empower our patients by making all the choices for them.

As a way to give more control, that nurse would review the daily plan with patients, but then give patients the opportunity to choose when they would do things. Using that strategy allowed for the identification and completion of necessary tasks, while giving patients some control over the timing.

Fear and anxiety over unfamiliar environments and routines
While the hospital environment is familiar to nurses, hospitals are not familiar places for most patients. One nurse explained that they can become desensitized to the everyday occurrences or emotional situations that are encountered in a hospital and not realize the fear or anxiety invoked inpatients by the appearance of other patients or unfamiliar equipment. In addition, patients may become so fixated on their fear or anxiety when in the hospital that participating in their care is the last thing on their minds. As one nurse stated, "You have to take care of those core things (fear or anxiety) before you can get to education or empowerment."

Patients who have self-managed a chronic illness at home prior to hospitalization face unique challenges when hospital routines do not coincide with the way they did things at home. Sometimes when patients were admitted, substitutions in medications were made or scheduling was changed. One nurse explained,

> They're very regimented in what they do. And then they come here and it's all taken away and it's all changed and they feel lost and then they get anxious and questioning and then comes the mistrust. I think institutionalization of any kind makes a person lose their empowerment to a certain extent.

Again, the importance of allowing patients to make choices regarding flexible aspects of their care such as self-care activities, dietary preferences, or daily schedules of various therapies was stressed as a way to overcome the sense of disempowerment from institutionalization.

Ineffective or inadequate support system
Nurses reported that although in most instances, families facilitated empowerment, there were certain circumstances when families impeded empowerment. For instance, conflict occurred when families did not agree with patients' treatment wishes, especially when patients wanted to stop treatment. In those situations, families tried to change patients' minds. One nurse stated, "Sometimes the family is a great obstacle to overcome."

Nurses agreed that it is emotionally draining on them when patients and families disagreed about treatment plans. Nurses often found themselves in the middle, trying to be the peacemaker. Nurses also heard the patient's wishes when the family was not present and consequently experienced tension/frustration when the patient changed his or her mind to make the family happy. In those situations, the nurses noted that a family conference was beneficial.

Nurses noted that family members impeded empowerment when they did things for the patient, such as personal hygiene, which the patient was able to do for him or herself. Families may feel sympathetic and think they are helping patients by doing everything they can for them, when in reality, they impede progress with the patient's self-care and disempower them. In those situations, nurses need to provide education to the families to help them realize that the ultimate goal for the patient was to reach independence and get him or her home.

Last, nurses described the pain exhibited by patients who may not have family or friends visit them while hospitalized. One nurse told a story of a patient who was unmotivated and showed no interest in caring for herself while hospitalized, until a transfer was arranged to her home state where her family lived. The nurse explained, "When you're sick and you're in that situation, alone, physically alone, because your family can't come visit, you'd have nothing but time . . . emotional pain can be sometimes way more excruciating than physical pain."

Lack of or low accountability
Nurses expressed surprise by how many patients did not realize that they had the right to refuse treatment options or participate in their treatment planning. One nurse explained,

> A lot of people don't know their rights as a patient, like, oh I have to do that, or oh, well I forgot to ask the doctor that . . . a lot of times I find myself explaining that you have the right to refuse too, you have the right to monitor everything that goes into or out of your body . . . To some people that's like a revelation . . . a lot of people aren't used to advocating for themselves

Nurses from critical care units relayed stories of patients who were too sick to participate in or make decisions about their care. In those situations, nurses and physicians often needed to work with family members who were surrogate decision makers. It was particularly challenging when patients did not have advance directives expressing their preferences, because patient autonomy and self-determination might be jeopardized.

Some patients may also become very dependent on the nursing staff during hospitalization to provide self-care for them. Even when patients may be capable of walking to the bathroom, they may ask for a bedpan or ask the nurse to raise or lower the head of their bed. Nurses tried to overcome this barrier by telling patients, "We're trying to return you back to normal" to encourage patients to resume their self-care. Patient responses were usually positive to the nurses' tough love "cause they get excited when they hear the word home."

Killing the soul
Killing the soul referred to situations in which patients lost hope and were ready to give up. Patients may be on the right track to recovery and be taking baby steps forward, and then find themselves taking two or three steps back. Patients who were described as losing their spirit or hope tended to stop participating in their care. These patients would frequently decline therapy, refuse to get out of bed, and reported more physical pain. One nurse stated that an extended hospital stay full of setbacks "killed their soul." Another nurse explained it by saying, "I felt like the life in that man was just gone, things aren't moving, progressing along like they should be . . . so that's where I feel we have just taken the life out of that poor man."

Making and meeting small daily goals was one way nurses tried to get patients to see small steps that they were taking were in the right direction. Involving families in the patients' care to motivate or inspire them to keep fighting was another strategy identified. Continuity of care also helped, as nurses could pick up on changes in behavior and had the rapport with patients to inquire further about what led to changes in behavior. The importance of, "asking the right questions" or giving patients time to vent were mentioned as ways to get patients to open up and help nurses understand the impetus for the change inpatient behavior.

Discussion

Nurses in this study identified some of the same facilitators and barriers to empowerment that patients identified in prior studies. Consistent with patient reports, nurses in our study identified the importance of an effective support system and the necessity of respecting patient autonomy (Larsson, Sahlsten, Segesten, & Plos, 2011b; Sahlsten, Larsson, Sjostrom, & Plos, 2009). Nurses also confirmed patients' reports about frustrations arising from lack of agreement on the plan of care and the fear-provoking hospital environment (Eldh, Ehnfors, & Ekman, 2006; Larsson, Sahlsten, Segesten, & Plos, 2011a.). Coinciding with patient reports that nurses tended to be more task-oriented, nurses reported that time constraints and heavy workloads were barriers to taking the time to empower patients to participate in their care (Tobiano, Bucknall, Marshall, Guinane, & Chaboyer, 2015).

Through the in-depth exploration of the nurse experience of empowering hospitalized patients, it was possible to uncover innovative strategies nurses used to try to overcome barriers to empowerment, something that has been missing from prior research. Unique findings from this study included nurses' actions in reconciling conflicting provider messages, acting as intermediaries between providers, patients, and families, and addressing patients' fears and anxiety. Nurses recognized family members were key supporters and that involving them in the plan of care imparted feelings of hope in patients and gave them something to fight for. When patients' support systems were inadequate, nurses described providing that support for

patients during hospitalization. Nurses also sought out other members of the health care team that could address patient needs when time constraints prevented them from staying at the bedside. Last, nurses offered choices and flexibility in daily schedules, especially when patients were frustrated with the unknown, to encourage continued patient participation and decision making.

Effective communication was a critical facilitator of patient empowerment. As in prior studies (Pedersen, Koktved, & Nielsen, 2012), nurses reported patient frustration over conflicts about the plan of care, contributing to a lack of trust in health care providers (Joseph-Williams, Elwyn, & Edwards, 2014). Conducting daily rounds was noted as a way to not only facilitate effective communication and coordination of care but also improve nurse and patient perceptions of collaboration and build trust (Pritts & Hiller, 2014). Consistent patient assignments also contributed to effective communication by fostering therapeutic relationships and trust building.

Another key finding of our study was that patients demonstrate varying levels of accountability for their health care, with some patients presuming that they should listen to what their providers tell them and not ask questions. Whether patients choose not to participate in their care due to personal preference or have misconceptions about their role, it is important for nurses to assess how involved patients want to be in their care so that the empowerment methods nurses use can be tailored to their preferences. While the Control Preferences Scale can be used to measure the extent of control a patient wants to have when medical decisions are made (Degner, Sloan, & Venkatesh, 1997), there is not a published tool that can be used to assess other areas of patient involvement such as participation in daily rounds and discharge planning or quality improvement efforts (Agency for Healthcare Research and Quality [AHRQ], 2013). The development of such a tool could help detect patients who wish to participate more in their care and provide the opportunity to have a conversation and provide education about patient rights to be involved in health care planning and even safety initiatives.

Once patients' preferences for participating in their care are established, nurses can provide opportunities for patients to make small choices about their care such as when to shower or participate in dressing changes. Empowerment interventions designed to improve patient participation in care need to center on respecting the ethical principles of patient autonomy and self-determination. Nurses might also educate patients about their right to be involved in their care and the sorts of questions they might want to ask health care providers to obtain information for decisions about care. Future intervention research could focus on integrating tenets of the shared decision-making model (AHRQ, 2016) into empowerment efforts, as both share common attributes, including providing education, promoting patient participation, respecting patient autonomy, advocating for patients, delivering patient-centered care, and communicating and collaborating with various team members.

As in most studies, there were limitations including use of purposive sampling and underrepresentation of male and minority nurses. However, detailed description, rather than generalizability, is the strength of qualitative research. Some of the nurses in the focus groups knew each other, which could have changed group dynamics. It may have limited what stories nurses shared with the groups or it might have strengthened the detail provided about shared

patient scenarios. Last, only the views of nurses were collected during focus groups. Future studies should examine the views of hospitalized patients so that correlations between nurses' and patients' perspective can be examined.

Despite the limitations, this qualitative study adds to existing empowerment research by providing rich detail concerning innovative methods nurses used to overcome barriers to empowerment. Key innovative methods included lifting the spirits, clearing up conflicting information about plans of care, finding resource/support personnel for patients, offering patients choices whenever possible, and helping patients focus on small, reachable goals. In addition, many facilitators to patient empowerment identified by the nurses in this study are consistent with the empowering behaviors identified in Laschinger et al.'s (2010) integrated conceptual model of nurse–patient empowerment, including establishing relationships, communicating, providing education and resources, respecting autonomy, and facilitating collaboration/support with providers, family, and friends. The empowerment facilitators, barriers, and work-arounds identified by the acute care nurses in this study can be used to form the basis for a systematic patient empowerment intervention to increase patient participation in care. Future research might also focus on the development of an instrument to assess patient preferences for participating in their care.

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References
Agency for Healthcare Research and Quality. (2013). Guide to patient and family engagement in hospital quality and safety. Retrieved from http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html

Agency for Healthcare Research and Quality. (2016). Shared decision making to improve patient safety, education, and empowerment. Retrieved from https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/shareddec-1.pdf G

Chen, Y., Li, I. (2009). Effectiveness of interventions using empowerment concept for patients with chronic disease: A systematic review. JBI Library of Systematic Reviews, 7, 1177-1232.

Degner, L. F., Sloan, J. A., Venkatesh, P. (1997). The Control Preferences Scale. Canadian Journal of Nursing Research, 29(3), 21-43.

Eldh, A. C., Ehnfors, M., Ekman, I. (2006). The meaning of patient participation for patients and nurses at a nurse-led clinic for chronic heart failure. European Journal of Cardiovascular Nursing, 5, 45-53.

Jerofke, T. A. (2013). Concept analysis of empowerment from survivor and nurse perspectives within the context of cancer survivorship. Research and Theory for Nursing Practice, 27, 157-172.

Jerofke, T. A., Weiss, M. (2016). Development and psychometric analysis of the Patient Perceptions of Patient-Empowering Nurse Behaviors Scale (PPPNBS). Journal of Advanced Nursing, 72, 2923-2936.

Joseph-Williams, N., Elwyn, G., Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Education & Counseling, 94, 291-309.

Kalisch, B. J., McLaughlin, M., Dabney, B. W. (2012). Patient perceptions of missed nursing care. The Joint Commission Journal of Quality and Patient Safety, 38, 161-167.

Krueger, R. A., Casey, M. A. (2015). Focus groups: A practical guide for applied research. Los Angeles, CA: Sage.

Larsson, I. E., Sahlsten, M. J. M., Segesten, K., Plos, K. A. E. (2011a). Patients' perceptions of barriers for participation in nursing care. Scandinavian Journal of Caring Sciences, 25, 575-582.

Larsson, I. E., Sahlsten, M. J. M., Segesten, K., Plos, K. A. E. (2011b). Patients' perceptions of nurses' behaviour that influence patient participation in nursing care: A critical incident study. Nursing Research and Practice, 2011, Article 534060. doi:10.1155/2011/534060

Laschinger, H. K., Gilbert, S., Smith, L. M., Leslie, K. (2010). Towards a comprehensive theory of nurse/patient empowerment: Applying Kanter's empowerment theory to patient care. Journal of Nursing Management, 18, 4-13.

Nagle, B., Williams, N. (n.d.). Methodology brief: Introduction to focus groups. Retrieved from http://www.mmgconnect.com/projects/userfiles/file/focusgroupbrief.pdf

Patient-Centered Outcomes Research Institute. (2014). Advisory panel on patient engagement. Retrieved from http://www.pcori.org/content/advisory-panel-patient-engagement

Pedersen, B., Koktved, D. P., Nielsen, L. L. (2012). Living with side effects from cancer treatment—A challenge to target information. Scandinavian Journal of Caring Sciences, 27, 715-723.

Prey, J. E., Woollen, J., Wilcox, L., Sackeim, A. D., Hripcsak, G., Bakken, S., . . . Vawdrey, D. K. (2014). Patient engagement in the inpatient setting: A systematic review. Journal of the American Medical Informatics Association, 21, 742-750.

Pritts, K. E., Hiller, L. G. (2014). Implementation of physician and nurse patient rounding on a 42-bed medical unit. MEDSURG Nursing, 23, 408-413.

Sahlsten, M. J. M., Larsson, I. E., Sjostrom, B., Plos, K. A. E. (2009). Nurse strategies for optimizing patient participation in nursing care. Scandinavian Journal of Caring Sciences, 23, 490-497.

Stewart, D. W., Shamdasani, P. M. (2015). Focus groups: Theory and practice. Thousand Oaks, CA: Sage.

Tobiano, G., Bucknall, T., Marshall, A., Guinane, J., Chaboyer, W. (2015). Nurses' views of patient participation in nursing care. Journal of Advanced Nursing, 71, 2721-2752.

World Health Organization. (2012). Noncommunicable disease: Empowering patients. Retrieved from http://www.euro.who.int/en/health-topics/Health-systems/patient-safety/news/news/2012/5/empowering-patients

World Health Organization. (2015). Patients for patient safety. Retrieved from http://www.who.int/patientsafety/patients_for_patient/en/