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# Perceptions of pediatric nurses and parents of hospitalized children engaged in shared decision making.

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PERCEPTIONS OF PEDIATRIC NURSES AND PARENTS OF HOSPITALIZED  
CHILDREN ENGAGED IN SHARED DECISION MAKING

By

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B.S.N., Eastern Kentucky University, 1980  
M.S.N., University of Cincinnati, 1987

A Dissertation  
Submitted to the Faculty of the  
School of Nursing of the University of Louisville  
In Partial Fulfillment of the Requirements  
For the Degree of

Doctor of Philosophy

School of Nursing  
University of Louisville  
Louisville, Kentucky

May 2018

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A Dissertation Approved

April 30, 2018

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## DEDICATION

As a daughter, I am dedicating this dissertation to my parents, Bonnie and Jack English. Throughout my life, they have supported my dream of earning a PhD in Nursing. Without their love, support, and belief that all things are possible through faith in God I would not have completed this journey. There are not enough words to say “thank you” for your encouragement and unending love. As a mother, I am dedicating this study to my three sons: Logan, Lucas and Landen. Their patience, love, and understanding, has been the rock that allowed me to complete this degree. Each one of my boys provided me with support in their own special way and I am forever grateful. Thank you for your support, patience, and the ability to see my vision. You are wonderful! To my husband, Larry, this dedication focuses on your quiet approach to life and ability to see the need to take such a large undertaking one-step at a time – thank you.

Dr. Tracy Brewer, this dedication is long overdue for the years you have encouraged me to “keep moving forward.” Dr. Brewer has been a wonderful and very dear friend providing immense support, critical comments, and inspiration while always lending a listening ear. Her intellect, inquisitive mind yet realistic approach aided me in critically thinking through this research process as it related to situations focused on engagement in shared decision-making.

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Members of the English and Robinson families who have loved and guided me over the years to become the person I am today.

## ABSTRACT

### PERCEPTIONS OF PEDIATRIC NURSES AND PARENTS OF HOSPITALIZED CHILDREN ENGAGED IN SHARED DECISION MAKING

Lisa English Long

April 30, 2018

Achievement of optimal quality in today's healthcare environment practices means that clinical practices must be based on evidence. Evidence-based practice (EBP) is the integration of research findings, clinician expertise, and patient-centeredness that includes a focus on preferences and values (Melnyk & Fineout-Overholt, 2015). EBP is a contemporary standard for effective, high quality clinical practice. An area within EBP needing increased attention is the aspect of patient preferences and values. The process of Shared Decision Making (SDM) incorporates assessment of preferences and values within a process in which where patients, families and healthcare professionals collaborate to make decisions regarding patient care.

The purpose of this dissertation was to describe perceptions of parents and nurses in a pediatric inpatient setting about SDM and to adapt an existing SDM tool for use in the pediatric clinical setting. Three manuscripts are included in this dissertation: (1)



critical review of SDM literature focusing on care of acutely ill children; (2) adaptation of existing reliable and valid SDM physician and adult patient -focused tools to a pediatric nurse and parent-focused SDM tools, and (3) a mixed methods approach assessing parent and nurse perceptions of SDM in an acute care facility and interview sessions with nurses to share thoughts and suggestions on use of shared decision making in the pediatric clinical setting.

The first manuscript consists of a critical review of the literature focused on shared decision making. Results identified a need for research to be conducted on implementing and measuring shared decision making in the pediatric setting. The second manuscript reports the findings from a study using cognitive interviewing to adapt adult and physician SDM tools for use in pediatric settings with nurses and parents. The third manuscript reports the findings of the mixed methods study on the use of the adapted SDM tools in a pediatric hospital setting with nurses and parents of hospitalized children.

A summary of the findings based on the completed research includes several overall insights. First, the existing adult tools were successfully adapted for use in the pediatric setting based on parent and nurse feedback. Second, the quantitative findings from the mixed methods study identified consistency in positive perceptions of nurses and parents with regard to SDM in caring for an acutely ill hospitalized child. The qualitative data from this study identified the need for enhanced parent-nurse communication and strategies for a team approach to hospital-based care.

This dissertation makes an original contribution to scientific knowledge for pediatric nursing care by providing a feasible tool for use in clinical settings, as well as providing new knowledge for nurse clinicians about the importance of and approaches to shared decision-making with parents of hospitalized children.

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## CHAPTER I: INTRODUCTION

The purpose of this dissertation was to identify perceptions of shared decision making (SDM) with parents of hospitalized children and pediatric nurses providing care to children in the hospital. An introduction, three manuscripts, and a conclusion chapter synthesizing the findings, comprise the dissertation.

Chapter 2 reviewed the literature examining SDM, historical perspectives of SDM, patient preferences and values, clinical practice guidelines, and SDM within pediatric healthcare. In healthcare settings, evidence-based practice (EBP) is a key component of the provision of care. Within EBP, patient preferences and values are key components within the decision making process. If healthcare providers are truly engaged in EBP, the patient will be a member of the team and healthcare professionals will focus on integration of those preferences. When sharing of ideas, asking patients and families for their preference related to care options occurs when providers and parents are engaging in SDM. If this does not happen SDM is not occurring and the possibility of negative health consequences may occur to the patient. The review of the literature focused on the overall issue of SDM, which included patient preferences and values, decision aides and clinical practice guidelines, followed by a discussion of SDM in the

pediatric healthcare setting. An initial study was conducted using a cognitive interviewing method. This study (Chapter 3) adapted existed SDM tools commonly used by physicians and adult patients into SDM tools appropriate for use by nurses and parents of pediatric patients in an acute care setting (Phase 1). The second study (Chapter 4) was a mixed-methods study conducted in two phases. Initially (Phase 2), parents of hospitalized children and pediatric nurses caring for pediatric patients completed the adapted SDM tools. The quantitative data collected in Phase 2 were analyzed and shared with nurses in qualitative, interview sessions (Phase 3). Finally, a synthesis and discussion of the findings (Chapter 5) from the three manuscripts is provided.

The conceptual framework for this study is based on the “Person-Centered Nursing (PCN) Framework” (McCormick & McCance, 2006). This framework focuses on the person as the center of care and decisions needing to be made regarding healthcare issues. Engagement of the patient to achieve desired outcomes is a central focus with care based on this framework. An adaptation of the framework, “The Person and Family Centered Framework” addresses the integration of the family into making decisions regarding a child’s treatment within a healthcare setting.

### **Theoretical Underpinnings**

The concept of SDM arises from the “patient preferences and values” component of the evidence-based practice (EBP) process (Appendix A, Figure 1). The ultimate goal of the process is quality patient outcomes, regardless of the setting. EBP is a problem solving approach to clinical practice that integrates the most relevant best evidence to



address a clinical question, patient preferences and values, and the clinician's expertise (Melnik & Fineout-Overholt, 2015). It is further explained as the conscientious and judicious use of current best evidence along with clinical expertise and patient and family preferences to make healthcare decisions (Coffey, McCarthy, McCormack, Wright, & Slater, 2007; Cook, 1998; Porter-O'Grady & Malloch, 2006; Sacket, Straus, Richardson, Rosenberg, & Haynes, 2000; Sigma Theta Tau, 2010).

Engagement in EBP has become the expectation for nursing and allied health professionals within the healthcare arena. This engagement has expanded to include the use of evidence in decision-making at the point of care (Barr et al., 2013; Becker et al., 2008; Dickinson et al., 2009; Ford, Rolfe, & Kirkpatrick, 2011; Heater, Becker, & Olsen, 1988; Hager, Loprinzi, & Stone, 2013; Medves et al., 2010; Montgomery et al., 2013).

Shared decision making has been referred to as a process, a conceptual framework, a theoretical construct (Arcuri, Montagnini, Clavi, & Goss, 2013), and an action analysis (Wolf, 2001). Multiple theoretical perspectives are noted in the literature that address and support SDM. Examples of theories include: Elwyn's Model of competencies, Theory of Planned Behavior, Social Psychology, and Decision Analysis. The Process Model of Shared Decision Making serves as the framework for this study. Each of these perspectives will be brief.

Elwyn, Edwards, Kinnersley, and Grol (2000) proposed a Model of Competencies that provides the practitioner with direction in engaging patients in decision making

processes. The steps of the model are derived from the key principles of SDM and have been conceptualized as a process for advancing SDM at the point of care. Ajzen's (1988), Theory of Planned Behavior, states that one's intention is what leads to the behavior change. Predictors of intention have been identified to include attitude, subjective norms, and perceived behavioral control. Social Psychology is the understanding of individual behavior in a social context. Human behavior involves the way in which feelings, thoughts, beliefs, intentions, and goals are developed and how those factors influence human interaction with each other (McLeod, 2007).

Decision analysis is a prescriptive model of decision making, specifically addressing improving how individuals make decisions (Chapman & Sonnenberg, 2000). This approach tries to maximize individuals' expected utility by helping move toward the decision that is the best choice for their situation, focusing on situations requiring complex decisions (Thompson & Dowding, 2002).

The Process Model of Shared Decision Making (Appendix B, Figure 2) was further developed by Kriston et al. (2010) after identifying the absence of a theory-driven, psychometrically sound self-assessment tool that measured patient's perspective on SDM. The conceptual basis for the development of this process model was Elwyn's model of competencies for SDM. The competencies were developed through the conduct of a qualitative study using focus groups of experienced general practitioners who identified a sequence of skills that needed to occur during the exchange between practitioner and patient (Elwyn, Edwards, Kinnersley, & Grol, 2000). The work of

Kriston et al. (2010) provides both the conceptual basis and practical application of SDM that is used in this study. The four theoretical key components of the Process Model of SDM are inter-related and essential for application of the nine practical steps when nurses and patients engage in SDM.

### **Conceptual Framework**

The Person-Centered Nursing (PCN) Framework (McCormack & McCance, 2006) supports the implementation of this study. This conceptual framework (Appendix C) consists of multiple levels and constructs in addressing a practice in which SDM is a focus of the care environment. The four constructs include: 1) prerequisites which focus on the attributes of the nurse, 2) the care environment which focuses on the context within which care is delivered, 3) person-centered processes which focus on delivering care through a range of activities, and 4) expected outcomes which are the results of effective PCN.

Prerequisites that focus on the nurse include: knowing self, professional competence, interpersonal skills, job commitment, and ability to demonstrate clarity of beliefs and values. The focus on the care environment should include: appropriate skill mix, systems that facilitate shared decision making, sharing of power, effective staff relationships, supportive organizational systems, and a culture of support for innovation and risk-taking. Person-centered processes focus on the delivery of care and should include: acknowledgement and use of patient's values and beliefs, being actively engaged, having sympathetic presence, implementation of SDM and assuring the

provision of holistic care. Outcomes, the expected result of implementation of PCN, includes: satisfaction with care, involvement in the care processes, feelings of well-being and creation of a therapeutic environment (McCormack & McCance, 2006).

The core of the framework is a focus on outcomes. To obtain the outcomes, the process begins at the outer most area of the model in which prerequisites are present and must be considered to move through the process. The next two levels of the model continue to support person centered care: the care environment that is necessary to support effective care during care processes. Achievement of these levels then leads to the attainment of quality outcomes.

The adapted version of the Person-Centered Nursing Framework, the Person and Family Centered Nursing Framework (Appendix D), guided this exploration of nurses and parents of hospitalized children perceptions about engagement of SDM within the pediatric hospital setting. Essential in this adapted version is the consistent focus on the competencies that were the basis of the development of the SDM-Q-9 tool (Elwyn, Edwards, Kinnersley, & Grol, 2000). The measures in use of this tool provided the basis for the framework as well as application and adaptation of the tool for use in this study focused on parents and children in decision making situations. Two of the components that comprise the “Care Processes” section of the original model were the focus of this study: (1) Working with Patient Preferences, Beliefs and Values and (2) SDM. Six concepts are needed for there to be a focus on patient preferences and values and SDM within healthcare processes. The six concepts that support the implementation of SDM

within a system that focuses on patient preferences and values include: communication, collaboration, clarity, consensus, choice, and respect. These concepts were noted frequently in the literature (Brinkman et al., 2013; Légaré & Witteman, 2013; McCormack & McCance, 2006; Wiley, Westbrook, Greenfield, Day, & Braithwaite, 2014) and are represented in the instruments used to measure SDM in this study.

### **Summary of Dissertation Chapters**

Chapter 2 outlines the current state of the science related to SDM in the pediatric setting. The purpose of this literature review was to critically review the peer-reviewed literature related to the concept of SDM, patient preferences and values, clinical practice guidelines, and SDM in pediatric healthcare. Chapter 3 describes the process of adapting SDM tools used in the adult setting to SDM tools used in the pediatric setting with nurses and parents of hospitalized children. For purposes of this study, the adult and physician focused tools: SDM-Q-Doc (Scholl et al., 2012a; Scholl et al., 2012b); SDM-Q-9 (Kriston et al., 2010) were adapted and titled Pediatric Shared Decision Making-Q-Nurse (PSDM-Q-Nurse) and Pediatric Shared Decision Making -Q-Parent (PSDM-Q-Parent) with author permission changes were made in language, content, and identification of care issues identified by parents and nurses. Following the adaptation process of the SDM tools, a cognitive interview process was implemented to clarify the tool with pediatric nurses and parents of hospitalized children. Modifications were then made to the tools based on nurse and parent feedback.

Chapter 4 summarizes the findings of two-phases of the three-phase study using a mixed methods approach in which the SDM tools previously adapted for pediatric nurses and parents of hospitalized children was implemented and evaluated (Appendix E, Figure 3; Appendix F, Figure 4). In the initial quantitative phase (Phase 2), the adapted SDM tools were administered to nurses and parents of hospitalized children. Nurses were recruited by email invitation and postings on participating units. Nurses could complete the instruments via online or paper format. Parents were approached individually invited to participate in the study. Results indicated consistency in positive perceptions of SDM components among nurses caring for pediatric patients and parents of pediatric hospitalized patients.

The qualitative portion of this study (Phase 3) engaged nurses in either focus group or one-on-one interviews to better understand their perceptions on SDM. Themes of communication and team approach were noted in analysis of participant responses. The importance of clear messages that would lead to a better understanding of directions and messages provided to the parent from the nurse was discussed. In addition, feelings of empowerment and ability to decrease the occurrences of mixed messages were also noted as important to the communication nurses and parents engage in when care initiatives for the child were initiated. Sub-themes were noted in the analysis of participant responses in relation to communication.

Clarity in all messages provided to the parent and from nurse to nurse was noted as important in the issue of communication. The importance of avoiding conflict was

discussed as key to effective communication in the clinical setting. Empowerment was noted as important in the nurse's communication with parents to encourage their participation in the child's care and in conversation with physicians and nurses. The need for consistency in communication with parents was noted in the nurse's responses to study issues presented to them during interview sessions. A team approach was a second theme noted in the analysis. Participants noted the importance of working together as a nurse and parent team to make the best decisions for the child's care.

As clarity was noted within the theme of communication, participants also acknowledged it as an important sub-theme in working as a team – it was critical to be clear when working together to make the decision that would best address the child's care issues. Within team approach a sub-theme of collaboration was noted. Nurses voiced the importance of collaborating with parents as critical to decision making and in achieving a goal of providing the highest level of care for the hospitalized child.

Perceptions, also noted as a sub-theme, was verbalized by nurses concerned about how parent(s) would feel about the relationship and ability to work together for the child's best interest.

Each of these themes and sub-themes focused on application to nursing practice and interactions between parents and pediatric nurses in the hospital setting. Voices of the nurses support the concepts within the Person and Family Centered Nursing Framework (Appendix D) of communication, collaboration, and clarity with parents. In addition, the concepts of choice in the framework supports the need for parents to be offered choices, when possible, in making decisions. Among team work and in decision making, it is often critical for consensus among the team members to occur for care needs to be met.

Chapter 5 provides a synthesis of findings from chapters 2-4. An examination of perception of SDM is explored with nurses caring for children as well as parents of children hospitalized in a pediatric setting. Results of qualitative and quantitative findings are discussed including ideas for future research, interconnectedness of major concepts and meaning of participant voices. Finally, research, education, and practice implications derived from the dissertation as a whole are explored.



## CHAPTER II: UNDERSTANDING SHARED DECISION MAKING: A LITERATURE REVIEW

### **Introduction**

Chapter Two outlines the current state of the literature in shared decision making (SDM) among nurses caring for hospitalized children and parents of hospitalized children. Today's healthcare environment is focused on safety and quality. To attain quality, practices must be based on evidence. Initially, research utilization provided a mechanism for researchers to implement study findings. One important issue was the time from study completion to publication of the findings for actual use in practice. The average time from completion to publication was identified as 10-12 years, resulting in the potential for the implementation of irrelevant research findings. The evidence-based practice (EBP) movement began as a means to more quickly implement and evaluate clinically-relevant research. Early work by Archie Cochrane M. D. (1973), founder of EBP, identified the need for study findings related to a person's health be shared with not patient and others. The Cochran Database of Systematic Reviews was thus formed which provides healthcare workers and the public with the resources to make evidence-based healthcare decisions. Additional work was developed by Sackett (1996) when he described EBP as the integration of individual clinical expertise and the best external evidence available for use in decision making. EBP is explained as the conscientious and judicious use of current best evidence along with clinical expertise and patient and family

preferences to make decisions related to one's healthcare (Coffey, McCarthy, McCormack, Wright, & Slater, 2007; DiCenso, Guyatt, & Ciliska; 2000, 2002, 2005; Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000; Sigma Theta Tau, 2010).

Evidence-based practice (EBP) is defined as the integration of research findings, clinician expertise, and patient-centered focus on preferences and values (Melnik & Fineout-Overholt, 2015). The EBP component of patient preferences and values includes shared-decision making (SDM). The evidence-based movement across healthcare initially focused on medicine rather than overall healthcare (Sackett et al., 1997). Throughout the 1990s, the EBP momentum spread to other disciplines including nursing.

In 2001, the U.S. Institute of Medicine announced that patient-centeredness was one of the six goals for healthcare improvement. Patient-centeredness may be a means to address deficits in health systems in response to specific patient needs, preferences, and values. Berwick (2009) proposed a definition of patient-centered care as “the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care” (Berwick, 2009, pg. 560). Berwick also identified three maxims of patient-centeredness: “the needs of the patient come first,” “Nothing about me without me,” and “Every patient is the only patient” (pg. 560).

For these maxims to be included in everyday care processes at the individual or systems level, healthcare professionals and those supporting the professionals need to

understand the concept of patient-centeredness and its critical nature in the implementation of evidence-based care.

McCormack and McCance (2006) developed a framework for patient-centered care in nursing entitled “The Person-Centered Nursing Framework.” This framework includes four constructs: prerequisites, the care environment, person-centered processes, and expected outcomes (Appendix D). These constructs were used to frame the analysis of four studies in a meta-synthesis exploring person-centeredness (McCormack, Karlsson, Dewing, & Lerdel, 2010).

Findings aligned with the work of Berwick where patient-centeredness is a concept needing further examination in healthcare. A patient-centered approach requires interactions and communication between the patient/family and the healthcare provider. This interaction may provide the most opportune time for the patient/family to become engaged in care processes through shared decision making. Shared decision making (SDM) can be defined as: “an approach whereby practitioners and patients communicate around decisions, referring to the best available evidence and deliberating upon the consequences of each option” (Légaré et al., 2010, pg. 555).

Nurses play a central role in ensuring that quality care occurs consistently within the healthcare system. Direct care nurses provide care and form relationships with patients and families based on the interaction and communication that is critical for providing competent care. Nurses are the professionals most frequently at patients' bedsides. The "Transforming Care at the Bedside" initiative set a goal to increase the time nurses spend in direct care to 70% (Robert Wood Johnson, 2014). Spending time at the bedside engaged in dialogue and education with patients' positions nurses to actively engage patients and families in SDM. The purpose of this literature review was to critically review the peer-reviewed literature related to the concept of SDM in light of patient preferences and values, decision aides, clinical practice guidelines, and shared decision making in pediatric healthcare.

### **Shared Decision Making**

Légaré et al. (2011) noted that SDM, as a process, is critical to the success of healthcare providers obtaining informed consent and those same providers working within a system that supports patient-centered care. Charles, Gafni, and Whelan (1997) defined four key principles of the SDM process: 1) at least two people must be involved (patient/provider), 2) information must be shared, 3) consensus must be built about the preferred treatment, and 4) a treatment plan must be mutually agreed upon.

Benefits noted through engagement in SDM include decreased health care costs, patients exhibiting greater satisfaction, collaboration, and positive outcomes (Joosten, DeFuentes-Merilla, deWeert, Sensky, van der Staak, & deJong, 2008; Stevenson, Cox,

Britten, & Dundar, 2004; Wennberg, Marr, Lang, O'Mallye & Bennett, 2010). Despite improved outcomes with SDM, patients are not always involved in making decisions. The dearth of patient engagement has been noted to be due to healthcare providers' lack of engaging patients in the decision-making process. Additional issues related to the lack of engagement include: patient's level of certainty, concern for initiating a treatment, an organization's readiness and support through available resources. These resources may include presence of evidence-based tools and education/knowledge of SDM (Ellen, Leon, Bouchard, Lavis, Ouimet, & Grinshaw, 2013; Elwyn et al., 2005; Fraenkel, 2011; Goss, Fontanesi, Mazzi, Del Piccolo, Rimondini, & Zimmerman, 2007).

### **Patient Preferences and Values.**

Evidence based practice encompasses more than use of evidence alone. It also includes working with patients and families in addition to nurse's use of their own expertise. In addressing the inclusion of patient preferences and values, care must focus on options patients may be provided followed by discussion and agreement on decisions to implement interventions needed in the care processes (Melnyk & Fineout-Overholt, 2015). Callum et al. (2001) presented an example of how nurses may approach a patient with leg ulcers and clarified that nurses do not "simply" treat the leg ulcer; they care for the person with the leg ulcer. To accomplish this, nurses must understand the concept of patient preferences and values and their impact on decision-making.

Dirkson et al. (2013) referred to a broad definition of patient preference as "the value attached by patients to (aspects of) health and healthcare" (pg. 5). To understand

the patient/family preferences and values a partnership must be formed. This partnership is with the healthcare professional that has the knowledge and skills to enter into a partner relationship. Communication is a key factor in the building of a relationship. Awareness of non-verbal cues and focused listening of the patient/family are crucial when developing a response. It is critical that the response be respectful and focused on their wishes, values, and preferences (Hain & Sandy, 2013).

Among breast cancer patients, research has shown that the patient's selection of the surgeon is viewed as the single most helpful source of information and that their opinions are regarded as having the strongest impact on the patient's treatment decision (Raupach & Hiller, 2002; Mazur, Hickman, Mazur, & Mazur, 2005; Oskay-Ozcelik et al., 2007; and Lee et al., 2010). Frongillo, Feibelman, Belkora, Lee, and Sepucha (2013) found an association between the type of breast cancer surgical treatment recommendations and the amount of SDM that occurred during the interaction. Results showed that patients were not receiving a balanced view of the options nor were patients asked about their preferences. This leads to concerns that patients were not receiving adequate information for shared decision making to occur.

A concept analysis on partnership of healthcare professionals and patients within the context of professional-provider relationship identified components of a partnership: antecedents, partnership attributes, and consequences of the partnership (Hook, 2006). Walker and Avant (2005) described antecedents as events or incidents that happen prior to the formation of the relationship. One aspect of an antecedent is reflection. Self-

reflection on the part of the healthcare professional may affect their approach to the patient.

Specifically, instead of viewing the patient as a person who will receive information and make decisions based on the professionals' approach and information (paternalistic approach), the patient will be entered into a partnership where the patient is considered an "expert" in their own care (Holman & Lorig, 2000). Hook (2006) described an approach that included patient empowerment, improved health outcomes such as enhanced self-management, and appropriate use of resources all leading to decreased healthcare costs.

### **Decision Aids.**

Decision aids are evidence-based resources for addressing patient-parent-clinician communication to ensure that: "patients and parents receive standardized information on the pros and cons of the medically reasonable options in a way that can be easily understood;" "patient and parent preferences are elicited about important trade-offs among the various options" and "the option selected is congruent with the families' well-informed preferences" (Cincinnati Children's Hospital Medical Center, 2017).

Specifically, a decision aid is used to inform patients about available treatments, along with potential benefits, risks and costs during clinical encounters. Potential outcomes in the use of decision aids include increased patient knowledge of available treatments, greater patient participation in decision-making, and improved patient health status and quality of life.

Brinkman et al. (2013) examined the effect of decision aide use by physicians with parents of children newly diagnosed with attention-deficit/hyperactivity disorder and found that their decision aid intervention increased shared decision making with parents. Specifically, time spent in the office visit was not increased when treatment options were discussed, and parents had a better understanding of the options available for their child's care.

### **Clinical Practice Guidelines.**

An alternate strategy to promote interaction and engagement of parents in SDM is with evidence-based clinical practice guidelines (Medves et al., 2010). Evidence-based practice guidelines are developed to address patient issues and assist in guiding care. One of the goals of practice guidelines is to recommend best practices for managing specific diseases for improved outcomes. Clinical guidelines for breast cancer care emphasize the importance of patient's preferences in selecting treatments (IOM, 2001).

Rabetoy and Bair (2007) surveyed 300 clinical nephrology nurses to gather initial data on nephrology nurses' awareness of the Renal Physicians Association (RPA) & American Society of Nephrology (ASN) *Shared decision-making in the appropriate initiation of and withdrawal from dialysis guideline*. Results showed that in the workplace, 8% had a copy of the guideline in the workplace, 48% claimed no copy in the workplace, and 44% did not know if there was a copy of the guideline. In addition, few nurses were aware of the guideline being used to guide patient care. Hager, Loprinzi, and Stone (2013) conducted retrospective chart reviews of a long-term care facility's



residents to describe outcomes of a diabetes care program based on evidence-based guidelines. Findings revealed the need for continued work in the application of evidence-based guidelines in long-term care.

Medves et al. (2010) concluded from a systematic review of guideline dissemination that more research is needed to understand how teams and practitioners can affect knowledge translation and dissemination of evidence-based guidelines. In addition, findings supported the need for healthcare professionals to be given information on the importance of practicing from an evidence base.

Berman (2008) found that nurses' implementation of a clinical practice guideline for educational anticipatory guidance interventions for ear pain led to an 80% decrease in ear pain related emergency department visits, 40% decrease in urgent care visits, and 28% decrease in regular-hours primary care office visits. By engaging parents in their child's care and empowering them to make decisions on their child's ear pain, improvements in healthcare outcomes netted a savings of \$50 per child.

In the pediatric population, Montgomery and colleagues (2013) identified key points in the implementation of clinical practice guidelines in Type 1 diabetes with the primary focus on children hospitalized with Type 1 diabetes. Key points included the importance of developing clinical practice guidelines (CPGs) to guide nurses in evidence-based practice to identify at-risk children while encouraging optimal care and referrals to appropriate health care providers (Montgomery et al., 2013).

Another example is that of a chronic condition which requires the implementation of an evidence-based clinical practice guideline is asthma. To provide children and families dealing with asthma best options in care to promote healthy children, National Heart, Lung and Blood Institute (NHLBI, 2007) developed guidelines for the management of asthma. These guidelines provide recommendations for medication, activity, education, monitoring and alterations in treatment strategies based on a body of evidence. Within the guidelines there are opportunities for patients and parents to make choices in care through interaction with healthcare providers.

### **Shared Decision Making in Pediatric Healthcare.**

Recent studies and interest has emerged for SDM in the pediatric population (Table 1). Fiks and colleagues (2010) found that households with children who reported greater difficulty accessing care by telephone were less likely to engage in SDM. Knopf, Hornung, Slap, DeVellis, and Britto (2008) described the congruence of decision-making preferences of adolescents with chronic illnesses and their parents. Forty-six percent of adolescents and fifty-three percent of parents preferred the passive or a paternalistic model of shared decision making. Passive decision-making focuses on the physician assuming the authoritative role in the decision-making process. The physician or healthcare provider tells the patient about the treatment plan without the patient or parent's input or choice within the plan of care (Knopf et al., 2008).

Higgins (2001) analyzed preferences of parents for their level of involvement in cardiac transplantation issues. Results of this prospective ethnographic study revealed

that the style of parental decision-making varied from making an independent, autonomous decision to favoring an authoritarian, paternalistic choice. Coyne et al. (2014) through a qualitative study found that healthcare professionals and parents controlled the process of SDM while the children's accounts revealed that they held a minimal role in making decisions about their own care.

Hong et al. (2016) focused on describing parental level of decisional conflict and decisional regret in making decisions related to an otoplasty procedure for their child. In addition, the study explored the relationships of decisional conflict and regret to perceptions of SDM. Findings revealed that parents' involvement had varied perceptions of the degree of SDM when involved in discussions to move forward with the procedure. Hong et al. (2016) concluded that efforts should focus on inclusion of parents in decision making processes.

Lipstein, Brinkman, and Britto (2012) addressed parents' treatment decisions and what is known regarding the decisions parents make related to their child's care. Findings of a narrative review that consisted of 52 descriptive qualitative studies revealed that a variety of influences existed on both parent preferences and parental decision making. Specific findings revealed that most parents preferred an active role in decision making and their preferred role was based on a collaborative approach versus an autonomous or paternalistic approach (Gagnon & Recklitis, 2003; Pyke-Grimm, Degner, Small, & Mueller, 1999; Zwaanswijk, Tates, vanDulmen, Joogerbrugge, Kamps, & Bensing, 2007).

Pyke-Grimm, Degner, Small, and Mueller (1999) found that decision-making preferences were stable over time; however, Angst and Deatrick (1996) and McKenna, Collier, Hewitt, and Blake (2010) reported that situations affect the stability of parental decisions. For example, parents and providers may have different ideas about each person's involvement in the child's care.

Parental involvement also varies based on the setting in which decision making occurs. In outpatient settings there tends to be inconsistent decision-making roles for parents; whereas, in inpatient settings parental participation and interest in decision making was more consistent (Cox, Smith, & Brown, 2007; Tarini, Christakis, & Lozano, 2008). Findings from Lipstein, Brinkman, and Britto (2012) identified the following themes in the literature: parents' role in decision making, influences on parent decision making, parents' perspectives on the physician's role and parent/child decision-making interactions. Specifically, the authors identified the theme of "parents' role in decision making" which focuses on parent's preference for an active role in making decisions. Within the theme of 'influences on parents' decision making the authors found that decisions were influenced by prior hospitalizations of the child and level of parent and caregiver involvement in the child's care. Additional influences affecting parent involvement included the amount of information provided by providers, emotional and familial factors, faith and personal beliefs.

## Discussion

Review of the shared decision making (SDM) literature revealed a focus on healthcare providers, primarily adult physicians and adult patients. Application of SDM within the healthcare setting is an expectation between healthcare providers and patients (O'Grady & Jadad, 2010). Although the literature has historically focused on physician and adult patients, the expectation for quality care also includes pediatric patients, parents and nurses who care for children.

Table 1 lists 16 SDM studies reviewed in this manuscript categorized by target population of physicians and children, multidisciplinary care providers, nurse and parent, and those only gathering data from a parent and/or child. While studies included both inpatient and outpatient settings, none of the studies specifically explored SDM between parents and nurses in an acute care setting. Nurses were considered part of the team in studies reviewed by Lipstein, Brinkman and Britto (2012) and Medves et al. (2010) and in studies of specific health conditions (Montgomery et al., 2013; Rabetoy & Blair, 2007). Other studies only addressed SDM in light of physician and parent/child interactions (Brinkman et al., 2013; Cox, Smith & Brown, 2007; Hong et al., 2016; Tarini, Christakis, & Lozano, 2008). The only study specifically focused on nurse/parent SDM occurred in a primary care site (Berman, 2008). Lipstein, and colleagues (2012) recommend that future studies explore interventions to improve parental ability to make treatment decisions. It is critical for future studies to focus on how to improve SDM between point-of-care acute care nurses and parents.

## Conclusions

Shared decision making is an approach “where patients and healthcare providers collaborate to formulate a treatment decision that is based on the most up-to-date evidence, while at the same time considering the patient values and preferences” (Hong et al., pg. 39, 2016). Much of the literature reviewed in this manuscript focused on physicians and how they use decision aides and SDM interventions when working with patients to make care decisions (Brinkman et al., 2013; Wyatt et al., 2013). The literature is limited related to nurse’s individual involvement in SDM with parents as well as their contribution to multi-disciplinary care decisions.

Changes were identified in the role parents play in SDM, regardless if they are working with nurses or physicians. Studies published between 2008 and 2012 revealed a shift from a paternalistic approach to an active approach in making decisions related to their child’s care. This finding has implications for healthcare providers when engaging patients and families in care decisions. Healthcare providers, including nurses, need to be cognizant of the more active role parents are taking in decisions regarding their child’s care. For patient preferences and values, specifically, between pediatric nurses and parents of hospitalized children within the EBP paradigm to be addressed, parents and healthcare providers must engage in SDM. The extent of the literature addressing engagement of nurses and parents of hospitalized pediatric patients in SDM is limited, thereby supporting the need for additional research in the area of parents of hospitalized children and pediatric nurse interactions in SDM.

Table 1

*Participants and Site of Shared Decision Making Studies*

Authors	Participants	Site
<b>Physician and Parent/Child Focus</b>		
Brinkman et al. (2013)	15 parents of children newly diagnosed with attention-deficit/hyperactivity disorder. 7 general pediatricians from convenience sample of 5 practices.	Pediatric practices
Hong et al. (2016)	65 parents of children participating in surgical consultation for otoplasty.	Academic otolaryngology clinic
Cox, Smith, & Brown (2007)	2 Otolaryngology surgeons 101 children's acute care visits (parent and child) Up to 15 physicians	Pediatric Primary Care Acute care setting
Tarini, Christakis, & Lozano (2008)	130 parents of children admitted to a general pediatric medical unit of a tertiary care referral center	Pediatric hospital & regional medical center
<b>Multidisciplinary Focus</b>		
Lipstein, Brinkman, & Britto (2012)	Parents: 212 Physicians: 68 Nurses: 3 Chaplains: 4 Health care Providers: 40 Families: 34 Children: 337	Inpatient and outpatient academic health care centers
Coyne, Amory, Kiernan, & Gibson (2014)	20 children (aged 7-16 years), 22 parents, 40 healthcare professionals (20 nurses, 16 doctors, 4 allied health professionals))	Hematology Oncology Unit in Ireland
Montgomery et al.	2 Diabetes Nurse Practitioners	Diabetes Center

Authors	Participants	Site
(2013)	1 Endocrinology Physician 1 Pediatric Nephrologist	
Medves et al. (2010)	Systematic review of SDM team approach with number of participants based on either studies or professional healthcare providers: <ul style="list-style-type: none"> <li>• 81 studies involved physicians</li> <li>• 80 studies involved nurses</li> <li>• 23 pharmacists</li> <li>• 15 dietitians</li> <li>• 12 respiratory therapists</li> <li>• 12 physiotherapists</li> <li>• 9 social workers</li> <li>• 3 occupational therapists</li> <li>• 73 studies had both physicians and nurses</li> </ul>	Inpatient and Outpatient settings
<b>Nurse and Parent Focus</b>		
Rabetoy & Bair (2007)	50 Nurses <ul style="list-style-type: none"> <li>• 37 Clinical nephrology nurses</li> <li>• 13 Nephrology NPs</li> <li>•</li> </ul>	Survey via mail
Berman (2008)	Nurses in primary care clinic Parents of children with signs and symptoms of ear pain	Primary Care setting
<b>Surveys/Large dataset analysis of Parents regarding SDM</b>		
Fiks et al. (2010)	1,397 children with ADHD 2,738 children with asthma	2002-2006 Medical Expenditure Panel Survey (MEPS) full year consolidated data files
Knopf, Hornung, Slap, DeVellis, & Britto (2008)	82 adolescents 62 parents	Pediatric chronic illness subspecialty clinics
Higgins (2001)	24 parents of 15 children	2 comprehensive



Authors	Participants	Site
		healthcare institutions in Northern California
Gagnon & Recklitis (2003)	118 parents of pediatric oncology patients	Pediatric oncology clinic in a comprehensive cancer center
Pyke-Grimm, Degner, Small, & Mueller (1999)	A convenience sample of 58 custodial parents of children with cancer	Large metropolitan university teaching hospital
Zwaanswijk, Tates, vanDulmen, Joogerbrugge, Kamps, & Bensing (2007)	Seven patients (aged 8–17), 11 parents, and 18 survivors (aged 8–17 at diagnosis)	University oncology wards
Angst & Deatrick (1996)	First study: Twenty children with cystic fibrosis (aged 7 to 11 years); both parents of each child (40 parents) Second study: Eight children undergoing scoliosis surgery (aged 7 to 11 years); at least one parent/child (8-16 parents)	Secondary Data analysis; acute care settings
McKenna & Collier, Hewitt, & Blake (2009)	50 mothers and 16 fathers responsible for 58 children	Pediatric Oncology Unit

## CHAPTER III: ADAPTATION OF TWO SHARED DECISION MAKING INSTRUMENTS BASED ON PERSPECTIVES OF PEDIATRIC NURSES AND PARENTS OF HOSPITALIZED CHILDREN

### **Introduction**

Care on in-patient hospital units is provided by nurses who play a central role in ensuring that quality care occurs consistently. Direct-care nurses provide care and form relationships with patients and families based on the interaction and communication that is critical for providing competent care. The “Transforming Care at the Bedside” initiative set a goal to increase the time nurses spend in direct care to 70% (Robert Wood Johnson, 2014). Spending time at the bedside engaged in dialogue and education with patients and families optimally positions nurses to actively engage in shared decision making (SDM) processes that are a cornerstone of supporting person-centered, high-quality healthcare outcomes. Shared decision making has been referred to as a process, a conceptual framework, a theoretical construct (Arcuri, Montagnini, Clavi, & Goss, 2013), and an action analysis (Wolf, 2001).

Impact on healthcare costs through engagement in SDM has been discussed as a potential benefit to patients and families (Wennberg, Marr, Lang, O’Malley, & Bennett, 2010). Other benefits include patients exhibiting greater satisfaction, collaboration, an

improved outcomes when involved in decision making in their preferred ways (Stevenson, Cox, Britten, & Dundar, 2004; Joosten et al., 2008).

There are a variety of variables that influence patients' decisions related to healthcare needs. Variables can include personal preferences, support from healthcare providers, engagement of significant others, finances, location of services being provided, transportation and goals for their healthcare outcomes. Regardless of the variables, it is imperative for healthcare providers to remember that patients may prefer to make a decision on their own, while other patients may want family involvement in making their decision. Providing care with a focus on variables that impact care decisions can increase the likelihood of patients receiving care consistent with their preferences. (Hubner et al., 2018).

In the hospital setting, there is growing interest in SDM with parents of hospitalized children. Lipstein, Brinkman, and Britto (2012), through a narrative review of 52 qualitative studies, addressed parents' treatment decisions and what is known regarding the decisions parents make related to their children's care. Findings revealed that inpatient decisions made by parents with physicians were influenced by prior hospitalizations and level of involvement in each child's care, information from providers, emotional and familial factors, faith, and personal beliefs. Other studies have reported that most parents prefer an active role in decision making and their preferred

role was a collaborative approach instead of an autonomous or paternalistic approach (Gagnon & Recklitis, 2003; Pyke-Grimm, Degner, Small, & Mueller, 1999; Zwaanswijk et al., 2007).

Tarini, Christakis, and Lozano (2007) conducted a study to determine parent participation in medical decision making during their child's hospitalization and its association with parental self-efficacy. Results focused on medical decision making showed a strong association between past hospitalization of a child and an increase in parent participation. Parents with less than a high school education showed a trend toward less participation in comparison to parents with a completed college education. In addition, parents who were younger in age and had experienced a child's prior hospitalization appeared to be more involved in the care of their child during hospitalization. Additional findings showed that parents with scores in the middle and highest self-efficacy quartiles focused on SDM for their child's care had greater odds of participating in medical decision making.

In making decisions there are several approaches or processes that one could implement: SDM, problem solving, or problem resolution. SDM is a key component of patient-centered healthcare. It is a process in which clinicians and patients work together to make decisions and select tests, treatments, and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values (Berry, 2012). *A definition of problem solving is the process of recognizing a problem, defining it, identifying alternative plans to resolve the problem, selecting a plan, organizing steps*

of the plan, implementing the plan, and evaluating the outcome (Miller-Keane, 2003). Problem resolution is a multistep process for responding when concerns arise. Use of problem resolution involves both problem-solving and mediation processes. This process is used in the academic settings when a concern in some part of a student's education experience has not been resolved directly by the parties involved. Although used mostly in the academic setting, this is applicable for use in clinical settings when decisions need to be made regarding a child's care. A key difference between SDM, problem solving, and problem resolution is in the description of SDM as a process. The process includes clinicians and patients working together to address concerns. Following success in addressing patient and clinician concerns, it is imperative to arrive at a solution in order for decisions to be made, implemented and evaluated as part of the decision making process.

Despite improved outcomes with SDM, parents of hospitalized children are not always involved in making decisions about their children's healthcare. This lack of engagement can be related to variables such as healthcare providers not encouraging parents to be engaged in the decision making process; low level of parental comfort with making decisions and concern for initiating a treatment; and the organization's readiness, support, and availability of resources such as evidence-based tools along with education about and knowledge of SDM (Ellen et al., 2013; Elwyn et al., 2005; Fraenkel, 2011; Goss et al., 2007; Légaré, & Witterman, 2013).

For meaningful engagement in SDM to occur, it is imperative to understand how parents of hospitalized children and nurses providing care to hospitalized children perceive their engagement in SDM. Nurses may need to self-reflect on their interactions with parents, how or to what degree they engage parents and perhaps most importantly what their knowledge level is with regard to SDM. Understanding parent and pediatric nurse involvement in care decisions requires adapting and assessing instruments to measure perceptions of SDM. Therefore, this study engaged parents and nurses in discussions about adapted SDM instruments through use of a qualitative approach known as “cognitive interviewing.”

### **Cognitive Interviewing.**

In gathering data from participants using self-report instruments, it is important to obtain valid and reliable responses. Cognitive interviewing is a method to iteratively pretest and refine self-report instrument items using small numbers of participants who have similar characteristics to populations for which the instrument is intended to be used in future research (Wills et al., 2011). Cognitive interviewing provides data on identifying and correcting problems with survey questions. Beatty and Willis (2007) define cognitive interviewing “as the administration of draft survey questions while collecting additional verbal information about the survey responses, which is used to evaluate the quality of the response or to help determine whether the question is generating the information that its author intends” (pg. 288). The most common application of cognitive interviewing was described by Beatty and Willis (2007) as the

administration of draft survey questions while collecting additional verbal information about the survey responses. This process can then be used to evaluate the quality of the response or to help determine whether the question(s) are generating the information that its author intends.

### **Measurement of Shared Decision Making**

Measuring perceptions of SDM with instruments specifically designed to address decision making between nurses and parents in the inpatient pediatric setting is critical to understanding SDM-during-care processes. A review of the published literature of measurement instruments pertaining to SDM identified 37 studies. Thirty-one (83.78%) of these studies addressed interactions between physicians and adult patients both in acute and chronic settings. Instruments focused on outcomes for adult inpatient settings in relation to SDM addressed length of stay, repeat visits to the emergency department, and patient flow in outpatient settings (Berman, 2008; Stevenson et al., 2004; Lipstein, Brinkman & Britto, 2012; Truglio-Londrigan, 2013).

Of the remaining six studies of measuring instruments pertaining to SDM, two focused on nursing/medical students or nurses (5.4%). One study addressed bereaved family members, two studies focused on parents of children with critical illnesses, and one study addressed children's health status. None of the studies focused on parents/children addressed SDM between acute care nurses and parents of children on pediatric medical–surgical inpatient units. To better understand engagement in SDM of parents of hospitalized children and their nurses in the inpatient clinical setting, it is

critical that reliable and valid measurement tools focused on perceptions about engagement in SDM in the pediatric inpatient setting be developed, validated, and readily accessible for use. The purpose of this study, therefore, was to evaluate and adapt existing reliable and valid SDM instruments for use in the pediatric inpatient setting with parents of hospitalized children and with nurses providing care to hospitalized children.

### **Adaptation of the SDM-Q-9 and SDM-Q-DOC**

Two instruments were identified for adaptation in the pediatric inpatient setting for use in measuring the SDM of parents and nurses providing care to hospitalized children: The Shared Decision Making -Questionnaire-9 (SDM-Q-9) (Kriston, Scholl, Hölzel, Simon, Loh, & Härter, 2010) and the Shared Decision Making-Questionnaire-DOCTOR (SDM-Q-DOC) (Scholl, Kriston, Dirmaier, Buchholz, & Härter, 2012b). These tools were originally developed for use with adult patients and physicians (Table 2).

Elwyn's model of competencies for involving patients provided the theoretical framework for the development of the tools. Additional theories from general psychology, social psychology, and decision analysis also supported tool development (Simon et al., 2006).



Table 2

*SDM-Q-9 & SDM-Q-DOC: Original Language for Use in Adult Settings*

<b>Item</b>	<b>SDM-Q-9 (Adult patient perspective)</b>
Opening Statement	Please indicate which health complaint/problem/illness the discussion was about.
Opening Statement	Please indicate which decision was made.
Item 1	My doctor made clear that a decision needs to be made.
Item 2	My doctor wanted to know exactly how I want to be involved in making the decision.
Item 3	My doctor told me that there are different options for treating my medical condition.
Item 4	My doctor precisely explained the advantages and disadvantages of the treatment options.
Item 5	My doctor helped me understand all the information.
Item 6	My doctor asked me which treatment option I prefer.
Item 7	My doctor and I thoroughly weighed the different treatment options.
Item 8	My doctor and I selected a treatment option together.
Item 9	My doctor and I reached an agreement on how to proceed.
<b>Item</b>	<b>SDM-Q-Doc (physician perspective)</b>
Opening statement	Please indicate which health complaint/problem/illness the discussion was about.
Opening statement	Please indicate which decision was made.
Item 1	I made clear to my patient that a decision needs to be made.
Item 2	I wanted to know exactly from my patient how he/she wants to be involved in making the decision.
Item 3	I told my patient that there are different options for treating his/her medical condition.
Item 4	I precisely explained the advantages and disadvantages of the treatment options to my patient.
Item 5	I helped my patient understand all the information.
Item 6	I asked my patient which treatment option he/she prefers.
Item 7	My patient and I thoroughly weighed the different treatment options.
Item 8	My patient and I selected a treatment option together.
Item 9	My patient and I reached an agreement on how to proceed.

The SDM-Q-9 is a nine-item patient-report instrument for measuring SDM in clinical encounters (Kriston, Scholl, Hölzel, Simon, Loh, & Härter, 2010). The SDM-Q-Doc is an adapted tool from the SDM-Q-9 to measure physicians' perspectives in the SDM process in the clinical setting (Scholl, Kriston, Dirmaier, Buchholz, & Härter, 2012b). Although the SDM-Q was developed for use in an adult clinical setting, it has been adapted to address the SDM between healthcare providers and the patient in three separate studies resulting in consistent psychometric testing (Simon et al., 2006; Kriston et al., 2010; Scholl, Kriston, Dirmaier, Buchholz, & Härter, 2012a). These results provide support for further adaptation of the SDM-Q tools for use in other settings, such as nurses working in an acute care pediatric setting with families of hospitalized children.

Both the SDM-Q-9 and the SDM-Q-DOC contain nine items with responses on a six-point Likert scale ranging from “completely disagree,” “strongly disagree,” “somewhat disagree,” “somewhat agree,” “strongly agree,” to “completely agree.” A raw total score between 0 and 45 is calculated by summing the scores of all items. The total raw score is transformed by the following formula to create a sum score that ranges from 0 to 100:

$$\text{SDM Score} = (\text{Raw Score} * 20) / 9$$

This process assumes that the extent of SDM is additive, therefore, a higher SDM-Q-9 score represents higher perceived SDM. The SDM-Q-9 has shown to have high internal consistency reliability in a sample of primary care patients with a Cronbach's alpha of

0.94 and corrected-item-total correlations above 0.7 (Kriston, Scholl, Hölzel, Simon, Loh, & Härter, 2010; Scholl, Kriston, Dirmaier, Buchholz, & Härter, 2012b).

Examination of structure invariance of the scale supported a unidimensional factor structure (Glass, Wills, Holloman, Olson, Hechmer, Miller, & Duchemin, 2012; Scholl, Kriston, Dirmaier, & Härter, 2012b; Wills et al., 2011). The SDM-Q-Doc was tested in clinical encounters with physicians and found to have a high level of acceptance based on a 93% survey completion rate.

Researchers found the instrument feasible to administer to physicians and that physicians completing the instrument responded in a timely manner. Item intercorrelations ranged from .132 to .744 with a mean of .443. The confirmatory factor model loadings exceeded .4 for 7 of the 9 items with the remaining two items loadings were .278 and .383 showing that items were substantively associated, yet non-collinear. Strong internal consistency was noted with a Cronbach's  $\alpha$  of .88. Factor analysis confirmed a unidimensional structure in a German sample (Scholl et al., 2012b), which was replicated by Wills et al. (2011) in a U.S. sample.

Few studies to date have explored the perceptions of SDM among nurses who provide care to hospitalized children and parents of hospitalized children. To fill this gap in existing knowledge and measurement tools, the purpose of this study was to adapt and evaluate two SDM instruments, SDM-Q-9 and SDM-Q-Doc, for translation to the pediatric setting (PSDM-Q- Parent; PSDM-Q-Nurse) and use with parents of hospitalized children and nurses providing care to hospitalized children.

## **Methods**

### **Design.**

A cognitive interviewing approach was used to better understand how participants perceived the wording and meaning of the items as a basis for further refining the wording of the items in the instruments. This understanding then serves as a basis for further refining the wording of the items in the instruments. Permission was obtained from the author, Dr. Isabelle Scholl, to adapt the SDM instruments by changing “doctor” to “nurse.” Institutional Review Board (IRB) approval was obtained from both the academic institution and the pediatric care hospital setting where research was conducted.

### **Instrument.**

The SDM-Q and SDM-Q-DOC were adapted by changing the language of “doctor” to “nurse,” and “patient” to “patient’s parent.” The instruments were retitled the Pediatric SDM-Q-Parent (PSDM-Q-Parent) and the Pediatric SDM-Q-NUR (PSDM-Q-NUR) (Table 3). In addition, Item 3 of the PSDM-Q-NUR was changed from “his/her medical condition” to “his/her child’s medical condition.”

The initial version of the SDM-Q-DOC instrument by Scholl et al. (2012b) consisted of language focused on the physician (SDM-Q-Doc). This instrument began with the physician being asked to identify an issue in which the physician would consult with a patient that addressed a health complaint/problem/illness. Following identification of an issue to be addressed, the physician provided information on the instrument as to which decision in collaboration with the patient was made.

As the tool was focused on the adult patient and physician, alterations needed to be made in the tool for the present study. To best represent the nurse and parent interaction, changes were made to the instrument for the instrument to focus on nurses. The language was changed to: “In answering the questions please address a situation where you spoke with a parent in making a decision about their child’s care.” Nurses were then asked to “describe the situation in which a decision was made.” This was followed by the nurse being asked to describe the decision.

Language was revised for the patient version of the instrument developed by Scholl (2012) to represent the parent of the hospitalized child. The SDM-Q-9 asked the patient to “please indicate which health complaint/problem/illness the consultation was about” and “please indicate which decision was made.” Changes made to better represent the parent SDM-Q-PARENT included an initial statement, “In answering the questions, please address a situation where you spoke with a nurse in making a decision about your child’s care.” The parent was then asked to “describe the situation in which a decision was made.”

In order to address the open-ended statements, the parent was instructed to identify a situation in which he/she had worked together with the nurse to make a decision and to use the situation as a reference point as he/she answered the questions. Likewise, the nurse was also instructed to identify a situation in which he/she had worked together with the parent where a nursing care decision was made and to use that situation as a reference point as he/she answered the questions. The situations identified by the

nurse and the parent were independently obtained from nurses and parents on the identified units and were not matched based on reference situation (i.e., the nurse and parent could have responded to the survey instruments based on the same or different situations).

The revised SDM tools (Appendix G) provide language used in the instruments for both the nurse and parent. The revisions (Table 4) based on nurse and parent input focused on decision making in relation to situations identified by a nurse and parent. Revisions were based on feedback regarding clarity in identification of a situation requiring a decision to be made for the hospitalized child, clarification of terms used in the original tools for adult subjects to be applicable for use in the pediatric setting, and clarification in the directions for completion of the survey instrument.

Table 3

*Tool Refinement: Parent and Nurse Input*

<b>Item</b>	<b>PSDM-Q-Parent</b>
Opening Statement	In answering the questions, please address a situation where you spoke with a nurse in making a decision about your child’s care. Please describe the situation in which a decision was made.
Opening Statement	Please describe the situation that was made.
Item 1	My nurse made clear that a decision needs to be made.
Item 2	My nurse wanted to know exactly how I want to be involved in making the decision.
Item 3	My nurse told me that there are different options for treating my medical condition.
Item 4	My nurse precisely explained the advantages and disadvantages of the treatment options.
Item 5	My nurse helped me understand all the information.
Item 6	My nurse asked me which treatment option I prefer.

<b>Item</b>	<b>PSDM-Q-Parent</b>
Item 7	My nurse and I thoroughly weighed the different treatment options.
Item 8	My nurse and I selected a treatment option together.
Item 9	My nurse and I reached an agreement on how to proceed.
<b>Item</b>	<b>PSDM-Q-NUR</b>
Opening statement	In answering the questions, please address a situation where you spoke with a parent in making a decision about their child's care. Please describe the situation in which a decision was made.
Opening statement	Please describe the decision that was made.
Item 1	I made clear to my patient's parent that a decision needs to be made.
Item 2	I wanted to know exactly from my patient's parent how he/she wants to be involved in making the decision.
Item 3	I told my patient's parent that there are different options for treating his/her child's medical condition.
Item 4	I precisely explained the advantages and disadvantages of the treatment options to my patient's parent.
Item 5	I helped my patient's parent understand all the information.
Item 6	I asked my patient's parent which treatment option he/she prefers.
Item 7	My patient's parent and I thoroughly weighed the different treatment options.
Item 8	My patient's parent and I selected a treatment option together.
Item 9	My patient's parent and I reached an agreement on how to proceed.

Table 4

*Original and Revised Language to SDM Instruments*

<b>Item</b>	<b>Original Language</b>	<b>Revised Language</b>
	<b>SDM-Q-9</b>	<b>PSDM-Q-PARENT</b>
Opening Statement	Please indicate which health complaint/problem/illness the discussion was about.	Please describe the situation in which a decision was made.
Opening Statement	Please indicate which decision was made.	Please describe the decision that was made.

<b>Item</b>	<b>Original Language</b>	<b>Revised Language</b>
Item 1	My doctor made clear that a decision needs to be made.	My nurse made clear that a decision needs to be made.
Item 2	My doctor wanted to know exactly how I want to be involved in making the decision.	My nurse wanted to know exactly how I want to be involved in making the decision.
Item 3	My doctor told me that there are different options for treating my medical condition.	My nurse told me that there are different options for treating my child's medical condition.
Item 4	My doctor precisely explained the advantages and disadvantages of the treatment options.	My nurse precisely explained the advantages and disadvantages of the treatment options.
Item 5	My doctor helped me understand all the information.	My nurse helped me understand all the information.
Item 6	My doctor asked me which treatment option I prefer.	My nurse asked me which treatment option I prefer.
Item 7	My doctor and I thoroughly weighed the different treatment options.	My nurse and I thoroughly weighed the different treatment options.
Item 8	My doctor and I selected a treatment option together.	My nurse and I selected a treatment option together.
Item 9	My doctor and I reached an agreement on how to proceed.	My nurse and I reached an agreement on how to proceed.

<b>Item</b>	<b>SDM-Q-Doc</b>	<b>PSDM-Q-NUR</b>
Opening statement	Please indicate which decision was made.	Please describe the decision that was made.
Item 1	I made clear to my patient that a decision needs to be made.	I made clear to my patient's parent that a decision needs to be made.
Item 2	I wanted to know exactly from my patient how he/she wants to be involved in making the decision.	I wanted to know exactly from my patient's parent how he/she wants to be involved in making the decision.
Item 3	I told my patient that there are different options for treating his/her medical	I told my patient's parent that there are different options for treating his/her child's



<b>Item</b>	<b>Original Language</b>	<b>Revised Language</b>
	condition.	medical condition.
Item 4	I precisely explained the advantages and disadvantages of the treatment options to my patient.	I precisely explained the advantages and disadvantages of the treatment options to my patient's parent.
Item 5	I helped my patient understand all the information.	I helped my patient's parent understand all the information.
Item 6	I asked my patient which treatment option he/she prefers.	I asked my patient's parent which treatment option he/she prefers.
Item 7	My patient and I thoroughly weighed the different treatment options.	My patient's parent and I thoroughly weighed the different treatment options.
Item 8	My patient and I selected a treatment option together.	My patient's parent and I selected a treatment option together.
Item 9	My patient and I reached an agreement on how to proceed.	My patient's parent and I reached an agreement on how to proceed.

### **Setting and Sample.**

The setting was a single-site pediatric hospital in the mid-west region of the United States with an inpatient bed capacity of 155. The sample included: (1) six pediatric nurses from the hospital setting who provided bedside care to hospitalized children (aged 0–11 years) admitted to an inpatient unit and (2) six parents of children aged 0–11 years hospitalized on an acute care inpatient unit. Parents were purposefully selected to be representative of the stages of growth and development: Two parents of infants and young toddlers (birth–2 years), two parents of preschoolers (2–5 years), and two parents of school-age children (5–11 years).

Inclusion criteria for the parent of the hospitalized child included biological parent or legal guardian, English speaking, admission of a child 0–11 years of age to an acute care inpatient unit. Exclusion criteria included non-English speaking parent with a child greater than 11 years of age, admitted with a chronic medical condition, tracheostomy, dependent on a home ventilator, and anxiety disorder or other diagnosed mental health condition.

Parents who were identified by nursing staff as in acute distress were excluded. Inclusion criteria for pediatric registered nurses includes: direct provider of care at the bedside for the parent and child aged 0–11 years of age. An incentive of a \$10.00 VISA gift card was provided to each nurse and parent for their participation in the study. Six nurses and six parents completed the questionnaire and interviews.

### **Procedures.**

**Parent participants.** Nurse Managers and Clinical Nurse Specialists on each of the units were asked to identify potential participants based on situations occurring on the unit. Following identification of parents who met the inclusion criteria, parents were approached by the principal investigator (PI) and introduced to the study. An information sheet was provided to each parent explaining the study and directions for completion. Completion of the instrument implied participant consent.

Parents were told that their participation in the study was voluntary and that nonparticipation would not affect the care provided to their child. Once the parent agreed to participate in the study, they were asked to think about a situation that they had with a

nurse within the last two days that required a decision to be made regarding their children's care. The researcher left the room after the parent identified a situation, leaving the parent to complete the instrument.

Following participant completion of the instrument, each participant was engaged in a cognitive interviewing session, lasting up to 20 minutes. This session occurred either in the patient's room or in an empty room on the unit with the door closed and with only the participant and researcher present for the interview. To promote consistency in the process and following the parent's completion of the questionnaire, scripted probes (Appendix H) were used as a basis for the cognitive interview that was conducted between the investigator and the participant.

The overall goal of the interview was to ascertain the ability of a participant to understand the tool as well as to identify specific aspects of the individual items that might need revision to support improved clarity. Probing questions via a feedback form (Appendix I) were asked that addressed each item on the questionnaire in relation to (1) difficulty in answering the item, (2) the meaning of each SDM term specific to the item, and (3) suggestions for improvement in the wording of the item. Interview notes were recorded during the discussion. At the completion of the interview, the researcher collected the completed instrument and provided the parent with the incentive for participation.

**Nurse participants.** Nurses working on an acute care inpatient unit who met the inclusion criteria were approached to participate. Parallel to the procedure employed with parents, an information sheet was provided to each nurse explaining the study. Nurses were told that their participation in the study was voluntary and that nonparticipation would not affect their employment. Once the nurse agreed to participate in the study, the nurse participants were instructed to think about a situation that they had with a parent within the last two days that required a decision to be made regarding a child's care. The researcher then left the area while the nurse completed the instrument. After the instrument was completed, the participant was engaged in the cognitive interviewing session in a room on the clinical unit with a closed door. During this session, lasting up to 20 minutes, a one-on-one interview using scripted probes was conducted as previously described. At the end of the interview, the participant was provided with their incentive.

#### **Data Management and Analysis.**

The focus of the analysis was qualitative in nature and focused on understanding the ability of a participant to understand the tool as well as to identify specific aspects of individual items that might need revision to support improved clarity. Each participant's responses were reviewed and any suggested changes to items on the instrument were critically analyzed. Parent perceptions of the SDM instruments were recorded on a "Feedback Form – PSDM – Q-PARENT." Notes were taken by the PI based on the parents' answers to each question regarding items for which there appeared to be

insufficient understanding of the conceptual meaning of an item and/or lack of clarity of wording of an item. At the end of the interview the feedback form and the parent's completed instrument were paired together for further analysis by the researcher, placed in a closed envelope, and placed in a locked box located in the researcher's locked office. The same process was implemented by the researcher with the nurses during the cognitive interviewing session for feedback on the PSDM-Q-NUR instruments.

Upon parent and nurse completion of the SDM instruments, an initial review of the data was conducted by the study PI. The results were presented to members of the researcher's dissertation committee for further discussion and interpretation. Changes to the instruments were made based on consistency of feedback from nurses and parents for refinement of individual survey items and feedback on open-ended questions. For example, for Question 6, the initial language: "My nurse precisely explained the advantages and disadvantages of the treatment options" was changed to "My nurse explained the advantages and disadvantages of the nursing care options for my child." A final review by the researcher and dissertation committee members regarding revisions guided the final changes made to the PSDM-Q-PARENT and PSDM-Q- NUR instruments.

## **Results**

Results were based on parent and nurse responses to the PSDM questionnaires. The situations parents, both mothers and fathers, and nurses identified are described, followed by a description of changes to the language of the PSDM-Q-PARENT and the PSDM-Q-NUR as suggested by nurses and parents.

### **Parent Identification of Shared Decision Making Situations.**

The decision making situations parents identified were medications, need for antibiotics prior to surgery, gastrointestinal issues, pain, treating fever. A specific situation involved a parent being aware that the child needed antibiotics prior to surgery and was concerned because the child was to leave for the operating room in 10 minutes and had not yet received the antibiotics. The resolution, after talking to the nurse, involved an agreement between the nurse and parents that the antibiotics would be administered in the pre-op area so as not to delay the surgery. A second issue as described by a parent of a child with a distended belly: "I was concerned about my child's distended belly and having issue with bowel movements." The resolution to the situation included the nurses listening to the parent's concerns, and consulting with medical personnel. Following a discussion, options with respect to the distended abdomen included: (1) suppository to possibly relieve the distention or (2) obtaining an initial x-ray to determine the cause of the distension, the parent, nurse and medical personnel agreed that the best method of addressing the child's distended belly would be an order for the abdominal x-ray. This order was written and the x-ray was obtained.

After testing was completed and the results were obtained, the patient was ordered to receive a rectal suppository. Another parent stated: “my son was screaming in pain and I didn’t know what to do.” In talking with the nurse “we decided to up his medicine from every 3 hours to every 2 hours. The nurse kept us informed on all his medicines and what was needed to be done about his appendix.”

A parent voiced concern when her child was “running a fever and I did not know whether he could/should wear a blanket – he was cold but running a fever and crying for his blanket. Due to the fever, we could not put his blanket on him.” “We worked with the nurse who got us a baby blanket and we placed the blanket on his feet and he was happy with that.” This parent shared her discussion with the nurse about a possible option of her child having a blanket placed over some part of his body. Following the discussion, it was deemed acceptable to have a blanket on the child. The nurse discussed where the blanket could be placed due to the child’s elevated temperature. The nurse provided a couple of options and the mother chose to have the blanket placed on the child’s feet. Placing the blanket just on the feet calmed the child and impacted the mother in a positive way of having the opportunity to work with the nurse in making the decision.

Another situation involved attempts at searching for fluids that were appropriate for the child and specific fluids that the child would accept. The parent reported that the nursing staff provided different choices that were appropriate for the child’s condition.

A variety of situations were shared by parents regarding decision making with healthcare providers, primarily nurses. These situations aided in revision of the tool for applicability in the pediatric healthcare setting. Parent voices are important based on familiarity of their child and then through collaboration with the nurse the goal of providing quality care and achieving parent satisfaction assist in the delivery of quality care processes during stressful situations.

### **Nurse Identification of Shared Decision Making Situations.**

Nurse-reported examples of situations with respect to providing care and requiring the need for a decision included: reinsertion of an intravenous line (IV) for antibiotics, use of asthma care program protocol and medication administration at home, available resources for parent upon discharge, weaning of morphine with use of a non-narcotic pain medication for patient pain, reward system for patient not cooperating with administration of pain medication, and use of positive reinforcement for complaints of pain.

One situation involved a child's IV becoming dislodged while receiving IV antibiotics. This child was to be discharged soon and the options related to IV medication administration included: restarting the IV, administration of an intramuscular (IM) antibiotic or administer oral antibiotics that the patient would receive for 2 weeks after discharge. The resolution included "parents, residents and I making a decision to give the IM antibiotic."



Another situation involved a nurse consulting with parents about the best way to administer an oral medication. The decision that needed to be made by the parents was “whether they wanted me [nurse] to give it or if they wanted to, and how often, if it is an as needed (PRN) medication.” “The parent decided to let me [nurse] give the medication, and it was determined that it was best to give the medication at this time, even though the child didn’t want to.”

A third situation involved the pediatric nurse and mother of a child having concerns about the patient’s abdomen being distended with no bowel movement for several days. “The mother and I discussed whether to continue with the current treatment of Miralax or consult the doctor for further treatment. We decided to consult the doctor for further treatment.”

Another opportunity for SDM to occur was when a child was admitted to the Asthma Care Program with an additional diagnosis of Rhinovirus. The child was progressing, treatments had been spaced to every six-hour intervals and was ready to be discharged on an asthma care protocol. “I asked the mother if she felt comfortable managing the change in treatment at home or if she had any concerns.” After discussions and teaching, the child went home and the mother assumed care using the Asthma Action Sheet and the physician’s number as resources should she have any questions.

One pediatric nurse described a situation where “mom and I were discussing trying Tylenol for pain and weaning the Morphine. Our decision was made to use Tylenol with Morphine for breakthrough pain.” One final situation as described by a

nurse was the child not cooperating in taking oral pain medication. “Based upon the child’s pain, something needed to be done. A decision was made to use positive reinforcement to engage the child’s participation. A reward was selected to be administered to the patient. It was important to maintain a therapeutic level of medication on the patient, it was important to have interaction between the parent and I to complete our common goal of pain control.”

### **Responses to PSDM-Q Items.**

To identify clarity and understanding of the questions on the SDM tool, three questions were asked by the researcher: (1) any difficulty in answering the item, (2) understanding the meaning of each SDM term specific to the item, and (3) suggestions for improvement in the wording of the item. Appendix H and I display the specific feedback on the three probing questions asked of the participants regarding their ability to understand and complete the instrument. Overall, nurses and parents recommended minor changes in the language. Both groups stated that the instrument wording was understandable and addressed the issue of participation in the child’s care. One of the main changes was based on feedback of changing “choice” to “option.” For example, a child does not have a choice about whether or not to take a medication but there could be options about how the child takes the medication. The use of “option” then provided the parent, child, and nurse an opportunity to engage in discussions regarding what would be best for the child. An additional change focused on the use of “nursing decision” to clarify to parents that actions are based on nursing care and not medical care.

### **Parental Responses to the PSDM-Q-Parent Items.**

Parents provided feedback regarding use of words to promote more clear understanding of parent perceptions about SDM (Table 5). Findings revealed the need to review all nine items to clarify differences between nursing care and medical care. Parents overall identified themes in relation to use of the words “choice,” “child’s condition,” and “treatment.” Parents commented on the need for simplifying the wording used within items: need to make clearer “identification of nursing versus medical care” and clarity in use of the language “focus on use of nursing care.”

### **Nurse Responses to the PSDM-Q-NUR Items.**

Nurses provided feedback regarding use of words to promote clear understanding of nurse perceptions about SDM (Table 6). Findings revealed the need to review all nine items to clarify differences between nursing care and medical care although nurses had minimal suggestions for change. The one change in language that was common in both nurses’ and parents’ responses were the use of the word “choice.”

### **Parent and Nurse Interview Responses.**

Situations identified by both parents and nurses provide an understanding of the type of issues that occur within nursing care processes. In interviewing each nurse and parent, each situation was clearly stated and resolved in a way that included sharing of the decision and ending with positive outcomes. The use of the instruments and adaptation continues to be in alignment with the Person Centered Nursing Framework (McCormack & McCance, 2006) and the Person Centered Nursing and Family

Framework (adapted 2011) from McCormack and McCance (2006) The component of the framework: Care Processes that includes SDM and Person-Centered Outcomes, specifically, involvement with care is supported by the feedback from parents. The parents involvement with decision making aligns with a focus on Person-Centered Outcomes for the child and parent in the pediatric healthcare setting.

Parents and nurses were asked one final question, if there was anything they would like to share that was not on the questionnaire. Parent responses included helpfulness of the nurse in answering questions, better understanding of care needed for their child's diagnosis, and sharing of information regarding medications. Nurse responses noted that SDM was "not just about the parent-nurse-child, but also included physicians and interns and that the entire team should be involved in decision making."

### **Discussion**

Implications of the findings related to instrument item wording focused on clarification in use of the term "nursing care options." This refinement in wording provided clarity in the type of care decisions that nurses and parents would collaborate about for the child. In the findings saturation was achieved in wording and input from parents of the hospitalized child and pediatric nurses. This study has resulted in adapted SDM study instruments appropriate for use in acute care pediatric situations to assess SDM with nurses and parents working collaboratively in making care decisions for the child. Updates to the instruments resulted in the final version of the PSDM- Q-PARENT and PSDM-Q-NURSE ([www.sdmq9.org](http://www.sdmq9.org)).

Future use of the instruments will provide data to determine the reliability, validity, and applicability of the tools for use with pediatric nurses involved in the care of children and their families. Limitations of this study include a small sample size and participants limited to one acute care pediatric facility. Future research related to the SDM measures will need to include a larger population of both parents and nurses. In addition, pediatric patients of varying ages and diagnoses should also be included in future research. When conducting future studies, the science of decision making in nursing would benefit from a specific identified situation that both the nurses and parents focus on when answering the SDM tools. An additional limitation of this study was the lack of participant demographic data. A decision was made to not collect demographic data due to the focus of the study on the adapted instruments and not on the participant responses. Future studies will need to collect nurse and parent demographic data.

### **Conclusions**

This study successfully adapted two SDM instruments focused on pediatric nurses providing care to children in acute care facilities and parents of these hospitalized children: PSDM-Q-PARENT and PSDM-Q-NURSE. The final adapted instruments reflect the changes suggested by nurse and parent participants. The additions provided clarity in the describing the type of decision that was to be made between the parent and nurse, specifically, related to whether the decision was a medical or nursing decision. This change also helped to clarify whether or not the decision was within the scope of nursing practice.

To support the continued development of SDM practice in healthcare, clinicians and researchers need valid and reliable instruments to measure SDM to improve care and outcomes for hospitalized children and their families. Issues of concern, collaborative efforts, and resolutions related to care issues by parents of hospitalized children and pediatric nurses who provide care to hospitalized children need to be addressed on a consistent basis. The results of this study will guide the development of subsequent studies to explore pediatric nurses' and parents' perceptions of engagement in SDM with respect to hospitalized children.

## CHAPTER IV: ANALYSIS OF PARENT AND NURSE PERCEPTIONS ABOUT SHARED DECISION MAKING: UNDERSTANDING DATA AND PERSPECTIVES

Shared decision making (SDM) consists of healthcare providers, patients and families working collaboratively to arrive at a plan of care for the patient. Berwick (2009) described patient-centeredness as a dimension of health care that involves significant shifts in control and power of those involved in care processes. The shifts involve movement of control and power from those who administer care to those who receive care. Légaré et al. (2011) noted that SDM is critical to support collaboration between the healthcare provider and the patient and family.

Intervention studies using decision aides have been conducted in both inpatient and outpatient settings and have focused on providing support for patients and families making care decisions (Brinkman et al., 2013; Degner & Sloan, 1992; Gillies, Skea, Politi, & Brehaut, 2012; Kremer & Ironson, 2008). Patient decision aides are tools that help people become involved in decision making by making explicit the decision that needs to be made, providing information about the options and outcomes, and by clarifying personal values. They are designed to complement, rather than replace, counseling from a health practitioner (<https://decisionaid.ohri.ca/>, 2017). Decision aides use a shared, informed approach to clinical decision making. Increased patient

knowledge of available treatments, greater patient participation in decision-making, and improved patient health status and quality of life are potential outcomes of decision aids (Scholl et.al. 2017). Brinkman and colleagues (2013) used decision aides in the outpatient setting while addressing parental involvement with medication issues regarding their child. The intervention provided information to the parents allowing them to be better informed about treatment options decisions in collaboration with their physician.

Results showed that the use of the decision aides and interaction between the parent and physician did not increase duration of the outpatient visit. Smith, Cheater, Bekker, and Chatwin (2013) investigated parent and health professionals (nurses and physicians) shared decision making during the diagnosis of suspected shunt malfunction in acute hospital admissions. Findings from their mixed methods study revealed that both parents and health professionals perceived effective collaboration in arriving at the patient's diagnosis. However, the health professionals found it difficult to integrate the parent's expertise into the decision-making processes.

Studies with parents and children regarding SDM have primarily been conducted in outpatient settings (Brinkman et al., 2013; Wiering et al., 2015). Valenzuela et al. (2014) examined perceptions of SDM in caregivers of youth with Type 1 diabetes and healthcare providers (pediatric endocrinologist, nurse practitioner, or nurses) in clinic or primary care settings. Overall findings suggest that youth of caregivers who perceived greater input in sharing decisions may show health benefits related to self-care and glycemic control. Hong, Gorodzinsky, Taylor, and Chorney, (2016) described the level of decisional conflict and decisional regret that parents experienced when considering otoplasty for their child. Shared decision making was measured between parents



surgeons. One of the study outcomes reported that parents had less decisional conflict and decisional regret after the surgery due to more involvement in decision making prior to the surgery than those parents with less involvement. Uhl, Fisher, Docherty, and Brandon (2013) interviewed parents whose children were on an inpatient hospital unit to describe their care experiences as well as identify strategies to improve their experiences with family- centered care. Themes of “apprehending reality, engaging adversity, and advancing forward” were noted (pg. 121).

Aarhun and Akerjordet (2014) conducted an integrative review on parental participation in decision-making in pediatric healthcare services that included inpatient, outpatient, and community services. Eighteen studies were identified with three emerging themes: relational factors and interdependence, personal factors and attitudes, and organizational factors. Parents indicated they participated in SDM about their child’s care to varying degrees and they would like to participate more, but few opportunities were provided. Findings also revealed that parents felt pressured to make decisions and identified a lack of negotiation during the decision-making process.

Professionals’ identified that it was important to involve parents in decision making; however, parent involvement was impacted by how clearly the parent voiced an interest to the healthcare provider about participating in making care decisions. Communication became a focus of the findings. How well the healthcare provider identified opportunities for shared decision making with parents, quality of the parent and

healthcare provider relationship, and professionals' competence were all identified as important qualities of the parent-health professional relationship and parent role in decision making (Aarhun & Akerjordet, 2014).

Personal factors and attitudes was the second theme associated with parental participation in decision-making identified by Aarhun and Akerjordet (2014). Studies showed that some parents wanted to be involved in decision making but did not want to assume the responsibility of making the decision (Pyke-Grimm et al., 2006); whereas, other parents relied solely on the physician to make the decision (Pyke-Grimm et al., 2006, Young et al., 2006). Parent-health professional relationships were discussed by parents as characterized by mutual trust and respect, a two-way process focused of communicative and relational competencies, provider technical knowledge, experience and working collaboratively as being important for decision making between parents and professionals (Alderson, 2006; Fiks et al., 2011; Mackean et al., 2005; Pyke-Grimm et al., 2006;).

Organizational factors, the third theme identified by Aarhun and Akerjordet (2014), was characterized by time constraints in preparing parents to participate in decision making, availability of resources such as telephone communication, email access to the healthcare provider, cost of care, and transportation (Alderson et al., 2006; Young et al., 2006; Fiks et al., 2010; Fiks & Jimenez, 2010). In addition, short hospital stays,

lack of routines that included parents in decision making, and the lack of community resources for care after hospitalization impacted parental engagement in decision making (Alderson et al., 2006; Ellberg et al., 2010; Kirk, 2001; Miceli & Clark, 2004).

Légaré et al. (2011) noted that SDM is critical to support collaboration between the healthcare provider and the patient and family. However, there is little understanding in how to address, implement and evaluate the effectiveness of SDM within a healthcare system. Healthcare systems often lack the support needed to effectively and collaboratively engage in shared decision making and to coordinate patient care issues. Barriers include high staff turnover, lack of human resources, lack of consistency in how decision making is described, supported, and agreed upon by parents and healthcare providers, as well as the lack of available standardized tools for measuring effectiveness of SDM (Légaré et al., 2011). Participants noted that nurses have the insight and perceptions into patient and family needs. In addition, nurses were portrayed as very capable of anticipating what will be needed based on their insight, intuition and experiences in the care of children and families.

To date, few studies have been conducted where pediatric nurses and parents of hospitalized children on an acute care inpatient unit provide their thoughts, perspectives, or perceptions of engagement in SDM during care processes. Hubner, Feldman & Huffman (2018) conducted an initial study that designed a tool to assess parent engagement in SDM in an outpatient setting. The goal of the study was to understand and adapt as needed clinical tools that could motivate parent engagement in SDM related

to treatment decisions. Corlett and Twycross (2006) identified inconsistencies in the degree of nurse's willingness to allow parents to participate in decisions regarding their child's care. This mixed-methods study addressed perceptions of shared decision making of pediatric acute care nurses and of parents of hospitalized children.

### **Purpose**

The purpose of this study was to provide insight into the perceptions of parents and pediatric nurses providing care to hospitalized children about engaging in SDM at the bedside. The following aims and research questions (RQ) were addressed:

**Aim 1.** To quantitatively determine perceptions of engagement in the shared decision making processes by pediatric nurses caring for hospitalized children and their parents.

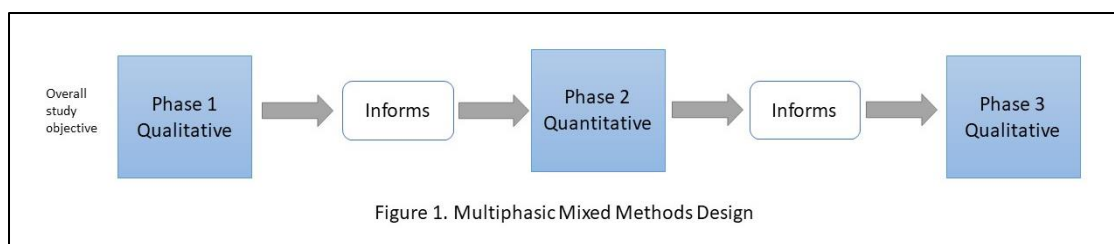
- RQ1. How do pediatric nurses caring for hospitalized children perceive their engagement in SDM processes?
  - *RQ1a.* What is the extent of differences in shared decision making based on nurse demographic factors?
- RQ2. How do parents of hospitalized children perceive their engagement with pediatric nurses in SDM processes?
  - *RQ2a.* What is the extent of differences in shared decision making based on parent demographic factors?

- RQ3. What is the extent of agreement between perceptions of pediatric nurses and parents of hospitalized children in SDM?

**Aim 2.** To qualitatively explore pediatric inpatient nurses' perceptions of their engagement in SDM processes.

## METHODS

A multiphase, mixed methods design (Figure 1) addressed the study aims and research questions (Cresswell & Plano, 2011).



This phase was based on preliminary work in which cognitive interviewing with parents and pediatric nurses providing care to hospitalized children was used to adapt two SDM instruments (Scholl, 2012a) for use in the pediatric inpatient setting (See Chapter 3). The results of Phase 1 led to an adaptation of the survey instruments that were then used in this present phase. A descriptive, quantitative design measured pediatric nurses' and parents' perceptions of engagement in SDM during the care of their hospitalized child (Quantitative Phase 2).

Findings were then shared with pediatric nurses in either one-to-one interviews or focus groups to obtain their perspective on pediatric nurse and parent responses to both survey results and qualitative inquiry (Qualitative Phase 3). This design allowed for the interpretation of the qualitative results in elucidating the quantitative results.

Triangulation of quantitative and qualitative findings from the different sources provided the ability to explore agreement between nurses and parental perceptions of engagement in shared decision making (Creswell & Plano, 2011). The study was approved by the Institutional Review Board (IRB) of both the academic and practice institutions.

### **Setting**

The setting for the study was a single site pediatric hospital in the southern region of the United States with an inpatient bed capacity of 263. The institution offers both inpatient and outpatient services. Five acute care units' participating in the study included pediatric patients with the following healthcare problems: neurology, respiratory, orthopedic, oncology and general care.

### **Quantitative Phase 2: Perceptions of SDM by Parents and Nurses**

#### **Sample.**

The sample for the quantitative phase included: (1) a convenience sample of 51 pediatric nurses who provided bedside care to hospitalized children, aged 0-11 years, admitted to an inpatient unit, and (2) convenience sample of 52 English-speaking parents (biological or legal guardian) of children aged 0-11 years hospitalized. Inclusion of younger children, rather than adolescents, ensured that parents and pediatric nurses were

engaged in making care decisions (Brinkman et al., 2013). Use of a guideline stating the need for five subjects per questionnaire item yielded a minimum of 45 nurse and 45 parent participants based on five subjects per nine questionnaire items.

### **Instruments.**

The instruments used in this study, PSDM-Q-NUR and PSDM-Q-PARENT, were adapted, with author permission, from the original questionnaires: the SDM-Q-9 and SDM-Q-DOC. The original questionnaires were based on patients and physicians in the adult setting. The SDM-Q-9 is a 9-item patient-report instrument for measuring SDM in clinical encounters (Kriston, Scholl, Hölzel, Simon, Loh, & Härter, 2010). The SDM-Q-Doc is an adapted tool from the SDM-Q-9 measuring physician's perspectives in the SDM process in clinical encounters (Scholl, Kriston, Dirmaier, Buchholz, & Härter, 2012b).

The wording for the SDM-Q-DOC was kept as similar to the original patient version (SDM-Q-9) as possible to minimize any differences in item interpretation between physician and patients (Scholl et al., 2012b). The SDM-Q-9 has shown to be reliable with a Cronbach's  $\alpha$  of 0.94 and SDM-Q-DOC Cronbach's  $\alpha$  of .88.

The PSDM-Q-NUR and the PSDM-Q-PARENT used in this study are parallel instruments each consisting of three sections: 1) two open-ended statements asking parents and pediatric nurses to identify a situation where they made a decision regarding the child's care, 2) nine survey items, and 3) one open-ended statement requesting any

further comments. The nine survey items (Table 5) requested that participants respond to statements regarding interactions the parent had with their pediatric nurse or interactions the nurse had with the parent on care issues and decisions needing to be made for the child. All statements related to how the parent or pediatric nurse viewed their interactions when making decisions about nursing care while the child was in the hospital setting.

Overall, statements focused on treatment options, involvement or interaction between the pediatric nurse and parent, explanations, and agreement on a care decision. Response options for each survey item include a six-point Likert scale: 1=completely disagree, 2=strongly disagree, 3=somewhat disagree, 4=somewhat agree, 5= strongly agree, and 6=completely agree. The Cronbach's alpha for the PSDM-Q-NUR was 0.948 and for the PSDM-Q-PARENT was 0.972.

Demographic data were collected from both parent and pediatric nurse participants. Items on the Parent Demographic Questionnaire include parent participants' sex, marital status, educational level, age of child hospitalized, type of insurance coverage, and a main reason for the child's hospitalization. The Pediatric Nurse Demographic Questionnaire included the following items: role in the healthcare team, length of time in position, highest educational degree, and number of years as a registered nurse, shift usually worked, employment status, sex, race, and certifications.



Table 5

*PSDM-Q-Parent and PSDM-Q-NUR Survey Items*

<b>Item</b>	<b>PSDM-Q-Parent</b>
Opening Statement	In answering the questions, please address a situation where you spoke with a nurse in making a decision about your child's care. Please describe the situation in which a decision was made.
Opening Statement	Please describe the situation that was made.
Item 1	My nurse made clear that a decision needs to be made
Item 2	My nurse wanted to know exactly how I want to be involved in making the decision.
Item 3	My nurse told me that there are different nursing care options for caring for my child.
Item 4	My nurse explained the advantages and disadvantages of the nursing care options for my child.
Item 5	My nurse helped me understand all the information.
Item 6	My nurse asked me which nursing care option I prefer.
Item 7	My nurse and I went over the different nursing care options.
Item 8	My nurse and I selected a nursing care option together.
Item 9	My nurse and I reached an agreement on how to proceed.
<b>PSDM-Q-NUR</b>	
Opening statement	In answering the questions, please address a situation where you spoke with a parent in making a decision about their child's care. Please describe the situation in which a decision was made.
Opening statement	Please describe the decision that was made.
Item 1	I made clear to my patient's parent that a nursing care decision needs to be made.
Item 2	I wanted to know from my patient's parent how he/she wants to be included in making the nursing care decision.
Item 3	I told my patient's parent that there are different nursing care options for caring for his/her child.
Item 4	I explained the advantages and disadvantages of the nursing care options to my patient's parent.
Item 5	I helped my patient's parent understand all the information.
Item 6	I asked my patient's parent which nursing care option he/she prefers.
Item 7	My patient's parent and I went over the different nursing care options.
Item 8	My patient's parent and I selected a nursing care treatment option together.
Item 9	My patient's parent and I reached an agreement on how to proceed.

## **Data Collection: Quantitative Phase 2**

*Pediatric Nurses.* For the quantitative phase of the study an invitation to participate was sent to all pediatric nurses on the identified units via email. Flyers and contact information were also posted on each unit involved in the study. The instrument packet, consisting of the PSDM-Q-NUR questionnaire and nurse demographic questionnaire, was available to nurses electronically via a link to Survey Monkey® and in hard copy paper format. Information was provided to each participant concerning the purpose of the study, length of time to complete the questionnaires, and a statement stating that their participation was voluntary. The hard copy format of the survey was available on each of the identified units in a place agreed upon by unit leadership and the researcher. Upon completing the hard copy of the instruments, the pediatric nurse participant placed the documents in an envelope addressed to the researcher, sealed the envelope, and placed it in a locked box designated for study documents located on the unit at a place deemed appropriate by unit leadership. Locked boxes were checked twice weekly by the researcher to remove sealed envelopes. All data were kept in a locked drawer of a locked file cabinet. Data collection continued until at least 50 pediatric nurses completed the questionnaire. Incentives for nurses completing the survey consisted of lunch and dinner delivered to the unit with the highest number of survey completions by nursing staff.

**Parents.** Collecting data from the parents of the hospitalized child began at the same time as data collection with the nurses. Staff nurses, nurse managers, assistant nurse managers, and clinical nurse specialists on each of the units were consulted for parents who, based on situations occurring on the unit, would not be available or interested in completing the questionnaires (e.g., child has had a “bad day”, parents received concerning information regarding their child’ health).

Parents (biological or legal guardian) were approached by the researcher, informed of the study and invited to participate once it was determined that each person met the inclusion criteria. An information sheet was provided to each parent containing information about the purpose of the study, length of time to complete the questionnaires and a statement stating that their participation was voluntary. If the parent voiced an interest in participating in the study a questionnaire packet containing the Parent Demographic questionnaire and the PSDM-Q-PARENT questionnaire was provided to the parent. Parents were asked to complete the Parent Demographic questionnaire and PSDM-Q-PARENT questionnaire via a pencil/pen and paper format. An envelope with the researcher’s name accompanied the questionnaire and demographic form. The researcher left the room before the parent completed the questionnaires. Once the parent completed the demographic form and PSDM-Q-PARENT questionnaire, he/she placed the documents in a sealed envelope and kept the envelope in the room until the researcher returned to obtain the sealed envelope. The researcher returned to the patient’s room within 30 minutes of leaving the room or at a time agreed upon by the parent and

researcher to obtain the sealed envelope. If the parent was not finished completing the questionnaire, the researcher returned as a time agreed upon by the parent and investigator.

Completed questionnaires were kept in a locked drawer of a locked file cabinet. Data collection continued until at least 50 parents completed the surveys. Incentive for parents consisted of a \$10.00 voucher for use in the healthcare facilities cafeteria.

**Data Management and Analysis.** All quantitative data were entered into SPSS 24 without links to personal identifiers and kept in a password protected file on a computer requiring log-in username and password. Demographic data and survey items from the PSDM-Q-PARENT and PSDM-Q-NUR were analyzed with descriptive statistics (frequencies, including mean, standard deviation, median, mode, minimum, and maximum). The extent of differences in shared decision making based on nurse and on parental demographic factors was analyzed using ANOVA F-statistic.

Data from parents and nurses were analyzed separately. For parent responses, groups were formed for each question, based on specific demographic characteristics. Marital status, for example, had the groups “married” and “single, divorced, or widowed.” Means and variances were calculated for both of those two groups. By partitioning the variance, it was possible to examine the effect of belonging to that group.

For the parent responses, groups were formed separately for:

- sex of the child (male/female),
- type of insurance (public/private),

- level of education (anything up to technical degree/4-year degree/more than 4-year degree),
- age of child (birth-5 years/ 6-11 years),
- parent sex (male/female).

For the pediatric nurse responses, groups were formed separately for:

- nursing certification (yes/no),
- shift worked (day/night),
- employment status (full time/part time),
- nurse role (staff nurse/nurse educator/nurse practitioner/clinical nurse specialist),
- highest level of nursing education (MSN/BSN/ADN),
- length of time in nursing (0-5 years/more than 5 years)

To have a valid ANOVA result, the following assumptions were checked for accuracy: independence of cases, normality of underlying distribution of trait and homogeneity of variance. To avoid a Type 1 error, a p-value of 0.01 or smaller was considered statistically significant.

### **Qualitative Phase: Voices of Pediatric Nurses**

Following completion of quantitative data collection and analysis, qualitative data collection was employed to better understand nurse's perceptions of their engagement in SDM with parents of hospitalized children using a basic interpretative qualitative design.

This design was used with the purpose of “generating understanding” (Stenbacka, 2001, p. 551). Survey results were used to form discussion points for nurse interviews during individual interviews and small focus groups.

**Sample.**

Data for the qualitative phase were collected from a convenience sample of pediatric nurses who met the inclusion criteria of: Registered Nurse, English speaking, and worked on one of the five targeted hospital units. Participant availability was based on each nurse’s assigned work schedule. Twelve nurses participated in either a one-on-one or small focus group session. Two groups of nurses, total of twelve, with five who participated in focus group interview sessions and seven participated in individual interview sessions.

**Instruments.**

The interview questions were carefully constructed to be open-ended, clear, appropriately sequenced, and supportive of the group process and response maximization (Krueger, 1998). The successive interview questions consisted of: 1) an opening question (similar to an “ice-breaker” question, designed to allow everyone to respond quickly and without undue effort), 2) an introductory question, 3) key questions, and 4) ending questions. Key questions addressed nursing practice, nurses’ familiarity with SDM, nurses’ experiences with SDM, and how clinical nursing decisions were made in the practice setting.

Aggregate findings from the quantitative data were shared with pediatric nurse participants who had the opportunity to respond to findings from the quantitative study and provide additional comments. Participants were asked to anonymously complete a short demographic questionnaire containing descriptive items of sex, type of nursing education, years at current position, unit currently employed, shift usually worked, current role on healthcare team, years worked as RN, certification, and race/ethnicity.

### **Recruitment and Data Collection.**

Each member of the unit leadership of the five participating units was initially contacted to discuss the qualitative data collection and inform them of the researcher's upcoming presence on the unit to begin recruitment. Each unit nurse leader then sent an email to their staff that included a recruitment letter and flyer. The flyer was also posted in areas deemed appropriate by the unit leader. Once a participant contacted the principal investigator for further information and interest in participating, a brief overview of the study was presented, and potential participants were screened for inclusion criteria. If the potential pediatric nurse participant met the criteria, indicated an interest in participating in the study, and had no additional questions, the date and time of focus group (FG) sessions was provided to the participant. If the participant was not able to attend a FG, a time for an individual interview was scheduled.

Nurse participants were also recruited by the researcher making direct contact with nurses while on the study units. The study was explained, information about the incentive and appointments were made with the interested nurses based on their

availability. Participants were contacted by telephone or email as a reminder of the date, place, and time of the individual interview or FG. Contact information of each nurse participant was kept (in a locked file cabinet) to conduct member checking after obtaining and conducting analysis of participant voices. An information sheet describing the study, the methods used to keep their responses anonymous, and how the data would be reported was provided to the participants at the beginning of each individual interview or FG session. The interview locations were chosen to be easily accessed and within close proximity to the nurse's patient population should the nurse be needed in an emergency situation.

FG and individual interview sessions lasted approximately sixty minutes. All interviews were conducted by the researcher who greeted participants as they arrived, confirmed eligibility (using inclusion criteria as screener), and oriented participants to the facility. The interview/FG sessions began by welcoming the participant(s), reviewing the purpose of the study and the FG topic, stating the ground rules, including reinforcing the potential risks of breach of confidentiality and participants' rights regarding actions they can take to minimize breach of confidential information and to not answer any question that they were not comfortable answering. Written informed consent was then obtained.

Participants were then asked to complete the short anonymous demographic form. Once the demographic forms were completed a digital recorder was placed between the interviewer and the interviewee(s) and the interviewer began recording the FG/interview. During the interview, a structured, systematic format was followed for each interview/FG



and notes were recorded. This structured record allowed the researcher to record key points in such a way that an outline of the summary was read to the participants at the end of the interview. The summary provided a credibility check that key points had been noted, and a means of allowing participants to briefly reflect on what was said and add additional thoughts that may have emerged after hearing the summary.

At the conclusion of the interviews, the interviewer presented a brief summary of the main points of the discussion and solicited participants' comments to the summary. A small token of appreciation was then presented to each participant consisting of a \$6.00 voucher to be used in the hospital cafeteria, a bottle of water, snack bar, and a banana.

### **Data Management and Analysis**

Data from both the quantitative and qualitative approaches were used in the analysis of the study findings. Qualitative comments were compared to quantitative findings related to parents' and pediatric nurses' perceptions of SDM. Caring for hospitalized children is important for pediatric nurses to understand not only data that presents correlations and consistency across findings, but also the voices of nurses who provide care on a daily basis. This is important in planning care processes for all children and their families in the pediatric setting, at the time of discharge and in follow-up appointments. Data were combined based on consistent information obtained from participants in both the qualitative and qualitative phases of the study.

Processes were kept consistent throughout both the quantitative and qualitative phases. In the qualitative phase, after the interview, the quality of the recording were verified, all tapes and written notes were properly labeled with the date and number of the interview session (R. A. Krueger & Casey, 2009). All interview transcriptions and tapes were kept in locked drawer in a locked cabinet.

Digital sound files from the digital recorders were saved onto a password protected site accessible only to the researchers. Any identifiers (e.g., names) were electronically removed and the de-identified file was saved. Verbatim transcriptions were prepared by an experienced transcriptionist with numbered lines of text and wide margins. Transcripts were then uploaded into Dedoose qualitative analysis software for coding by two members of the research team (LL, BP). After team members coded the transcript, those transcripts were compared for agreement. Any discrepancies in the transcripts as coded were resolved through discussion.

Data reduction through coding began on a line-by-line basis, using phrases as the analytic unit. This detailed analysis generated working hypotheses, suggesting the direction of future coding and FG/interview questions. Subsequent analysis then moved to the paragraph (collective responses to a particular question) as the unit of analysis. An open coding procedure assigned conceptual labels to individual phenomena discerned from phrases and later from paragraphs in the transcripts (Strauss & Corbin, 1998).

**Data display.** After the open coding process, related conceptual labels were grouped into themes and patterns, with attention to the context and dimensions of the emerging themes or patterns. Emergent themes and patterns were grouped into a summary of the FG or interview, so that each FG or interview was fully represented in a condensed mode.

**Data interpretation.** Meaning was drawn from the displayed data using techniques of constant comparison (Strauss & Corbin, 1998) across summaries and through clustering of summaries. The iterative process of constant comparison facilitated the discovery of new analytic patterns, new working hypotheses, and revisions of procedures or questions. Central phenomena that emerged through the constant comparative process were combined into a descriptive narrative.

Interpretation of the findings included a description of the researchers check for accuracy (validity) and credibility (reliability) within the qualitative research process. Qualitative validity refers to the researcher's check for accuracy of the findings through the use of certain procedures. Qualitative reliability refers to the consistent approach the researcher takes across different researchers and different projects (Creswell, 2014).

### **Validity.**

**Trustworthiness.** In qualitative research the term "trustworthiness" refers to "validity" in the conduct of a study. An idea of discovering truth through measures of reliability and validity is replaced by "trustworthiness" (Golafshani, 2003), with is "defensible" (Johnson, 1997, p. 82) and establishes confidence in the findings (Lincoln &

Guba, 1985). Johnson (1997, p. 283) discusses the possibility that if the quality of the research is related to generalizability of the result that this may lead to an increase in the validity or trustworthiness of the research. In this study, participant voices of both nurses and parents of hospitalized children did provide confidence in the findings. This confidence leads to an increase in the trustworthiness of participant perceptions of SDM between nurses and parents of hospitalized children.

**Rigor.** Rigor within qualitative research relates to exploration of subjectivity, reflexivity and the social interaction of interviewing; whereas, in quantitative research rigor can be approached by recognizing that there is a quantitative bias in the concept of rigor (Golafshani, 2003). This study explored the subject of SDM with parents and nurses caring for pediatric patients as well as the social interaction of interviewing pediatric nurses to hear their voices related to SDM in the pediatric care setting.

**Member checking.** Member checking allowed the researcher to determine the accuracy of the findings, descriptions or themes by taking the findings back to the participants (Creswell, 2014). A follow-up individual interview phone call was conducted with a random selection of three nurse participants to obtain member checking. Study findings from the major themes of communication, team approach, resources and education were provided to nurse participants. Examples of statements from pediatric nurses related to each theme were provided to the participants. Discussions led to participants' comments being included in participants' responses that were consistent and supportive of nurse responses related to SDM with parents.

For example, in relation to communication and resources, member checking discussions focused on the importance of resources for interpreting discharge and medication instructions to all parents. Comments in support of team approach were clear in discussions. Additionally, discussions focused on the importance of all healthcare services always being available, including weekends, for comprehensive pediatric care to be provided based on a team approach.

**Rich, thick description.** Detailed descriptions or the presentation of varying perceptions of themes provided the participants a realistic and richer understanding of the findings. This type of representation provides the audience with a sense of being in the setting with shared experiences. Thick description also allows for transferability of the findings with a solid framework for comparison. Descriptions of this study's findings are presented in the detailed thematic approach (Creswell, 2014).

**Bias.** Researcher self-reflection is a key step in providing the reader with an open and honest approach to the study findings. Self-reflection included the researcher's interpretation of the findings considering her background as a pediatric nurse (Creswell, 2014).

**Peer debriefing.** This included identifying a person (peer debriefer) who could review and ask the researcher about the study allowing for the study to resonate with people other than the researcher. In this study, a person familiar with the concept of SDM reviewed the study from a distinct perspective other than the researcher (Creswell, 2014). The peer debriefer and researcher discussed the approach used by the researcher

in asking the interview questions, process of analysis of participant voices, and development of themes within the data collected. No concerns were raised by the peer-debriefer.

**External auditor.** The external auditor, unfamiliar to the study, yet experienced in qualitative research methods, reviewed the study. The review was conducted in order to provide the researcher with an objective assessment of the accuracy of the de-identified transcription, relationship of data to research questions, and the level of data analysis. The external auditor served as an independent researcher who conducted the audit of this completed study to enhance the validity of the research (Creswell, 2014). The external auditor reviewed the study and identified that there were no issues related to the conduct of the qualitative phase of the study.

### **Reliability**

**Transcript checks.** Checking of transcripts provides identification of mistakes made during transcription. The transcripts were checked twice by the investigator. No errors were found in the transcription process (Creswell, 2014).

**Drift.** Checking for a drift assures that there will not be a shift in the meaning of the codes assigned during the coding process. Constant comparison of the data and codes was conducted during the coding process (Creswell, 2014).

**Code cross-check.** Intercoder agreement was conducted to assure that two coders are in agreement on whether another coder would assign the same or similar code. There was approximately eighty percent agreement in consistency with the findings of nurses who participated in this study (Miles & Huberman, 1994).

## **RESULTS**

### **Quantitative Phase: Perceptions of SDM by Parents and Nurses**

#### **Participants.**

Nurses (N=52) participating in this phase were primarily female (98%), Caucasian (98%), and baccalaureate prepared (71.4%). Most of the participants in the quantitative phase were staff nurses (77.6%), worked full-time (77.6%), and worked on day shift (55.1%). Approximately half (49%) had been an RN for five years or less. Less than half of the nurse participants (42.9%) indicated they had achieved specialty certification (Table 6).

Parent participants (N=51) were primarily female (66.7%), married (64.7%), and had at least a high school education (96.1%). Parents indicated they were either insured by Medicaid (47.1%) or by private insurance (47.1%). Most of the hospitalized children were males (64%) and were 5 years old or younger (64.7%). The majority of parents (63.3%) indicated their child was hospitalized due to respiratory concerns or surgery (Table 6).

Table 6

*Pediatric Nurse and Parent Participant Demographic Characteristics, Quantitative*

*Phase 2*

Characteristic	N (%)
<b>Pediatric Nurse participants (N=52)</b>	
Sex	
Female	48 (98.0)
Male	1 (2.0)
Race/ethnicity	
White	49 (98.0)
Other	1 (2.0)
Education	
Masters' degree	3 (7.1)
Baccalaureate degree	31 (73.8)
Associate degree	8 (19.1)
Nursing Role	
Staff nurse	31 (77.6)
Assistant nurse manager	4 (8.2)
Nurse manager	4 (8.2)
Charge nurse	1 (2.0)



<b>Characteristic</b>	<b>N (%)</b>
Clinical nurse specialist	1 (2.0)
Patient navigator	1 (2.0)
Full or part-time employment	
Full-time	38 (77.6)
Part-time	10 (20.4)
Per diem	1 (2.0)
Shift usually worked	
Day shift	27 (55.1)
Night shift	16 (32.7)
Weekend shift	5 (10.2)
Other	1 (2.0)
Years an RN	
Less than 1 year	5 (10.2)
1-3 years	12 (24.5)
4-5 years	7 (14.3)
6-10 years	8 (16.3)
11-15 years	3 (6.1)
>15 years	14 (28.6)
Certification as an RN	

<b>Characteristic</b>	<b>N (%)</b>
Yes	21 (42.9)
No	28 (57.1)
<b>Parent Participants (N=51)</b>	
<b>Sex</b>	
Female	34 (66.7)
Male	17 (33.3)
<b>Marital Status</b>	
Single	14 (27.5)
Married	33 (64.7)
Divorced	3 (5.9)
Other	1 (2.0)
<b>Education</b>	
Less than high school diploma	2 (3.9)
High school diploma	21 (41.2)
Technical education	3 (5.9)
Associate degree	6 (11.8)
Bachelor's degree	11 (21.6)
Graduate degree	5 (9.8)
Other	3 (5.9)

<b>Characteristic</b>	<b>N (%)</b>
<b>Insurance</b>	
Medicaid/Passport	24 (47.1)
Private insurance	24 (47.1)
Other	1 (2.0)
Both Medicaid/Passport & private insurance	2 (3.9)
<b>Hospitalized Child</b>	
<b>Sex</b>	
Female	18 (36.0)
Male	32 (64.0)
<b>Age</b>	
Birth to 5 years	33 (64.7)
6-7 years	8 (15.7)
8-11 years	10 (19.6)
<b>Reason for hospitalization (per parent)</b>	
Breathing condition	17 (34.7)
Surgery	14 (28.6)
Stomach or intestinal condition	5 (10.2)
Nerve condition	1 (2.0)
Accident	1 (2.0)

Characteristic	N (%)
Other	11 (22.4)

### **Pediatric Nurses Perceptions of SDM.**

Overall, nurses indicated that they either strongly or completely agreed that they were engaging parents in shared decision making in response to the nine-item PSDM-Q-NUR survey (item means range: 4.78 to 5.17) (Table 7). The highest mean scores were for Items 4 and 5. Item 4 addressed the nurse explaining the advantages and disadvantages of nursing care options while Item 5 related to the nurses' ability to help parents understand all the information that has been provided to the parent. Mean scores for Items 1 and 3 were rated the lowest. Item 1 focused on clarity with the patient's parent that a nursing care decision needed to be made. Item 3 related to nurses informing parents that there were different nursing care options for their child. Percentages of responses for Items 4 and 5 are displayed in Figures 1 and 2, showing that although the means scores were higher, there were nurses who did disagree with how they worked with parents in making decisions.

Table 7

*Pediatric Nurse Responses to the PSDM-Q-NUR (N=52)*

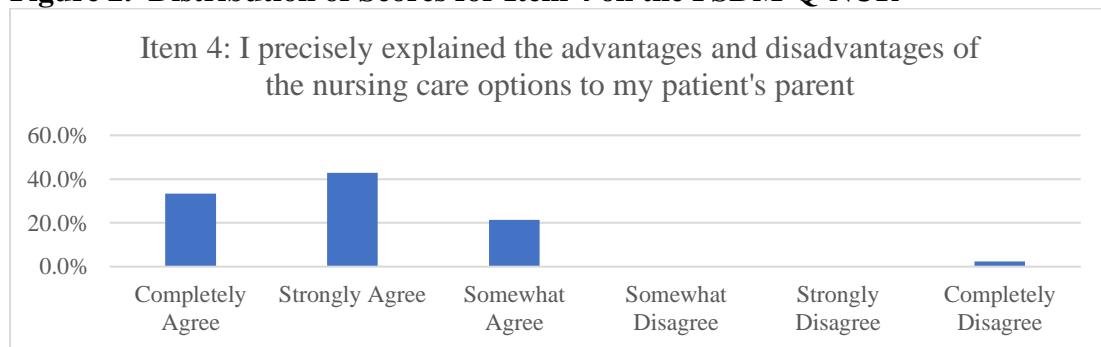
Survey Item	M (SD)	Median	Mode	Minimum	Maximum
1. <u>I made clear to my patient's parent that a nursing care decision needs to be made.</u>	4.79 (1.2)	5	5	1	6
2. I wanted to know exactly from my patient's parent how he/she wants to be involved in making the nursing care decision.	4.95 (0.94)	5	5	1	6
3. <u>I told my patient's parent that there are different nursing care options for caring for his/her child.</u>	4.78 (1.11)	5	5	1	6
4. <i>I explained the advantages and disadvantages of the nursing care options to my patient's parent.</i>	<b>5.02 (.98)</b>	5	5	1	6
5. <i>I helped my patient's parent understand all the information.</i>	<b>5.17 (0.91)</b>	5	5	1	6
6. I asked my patient's parent which nursing care option he/she prefers.	4.98 (1.07)	5	5	1	6
7. My patient's parent and I	5.0 (.98)	5	5	1	6

Survey Item	M (SD)	Median	Mode	Minimum	Maximum
went over the different nursing care options.					
8. My patient's parent and I selected a nursing care option together.	4.8 (.98)	5	5	1	6
9. My patient's parent and I reached an agreement on how to proceed.	5.0 (0.99)	5	5	1	6

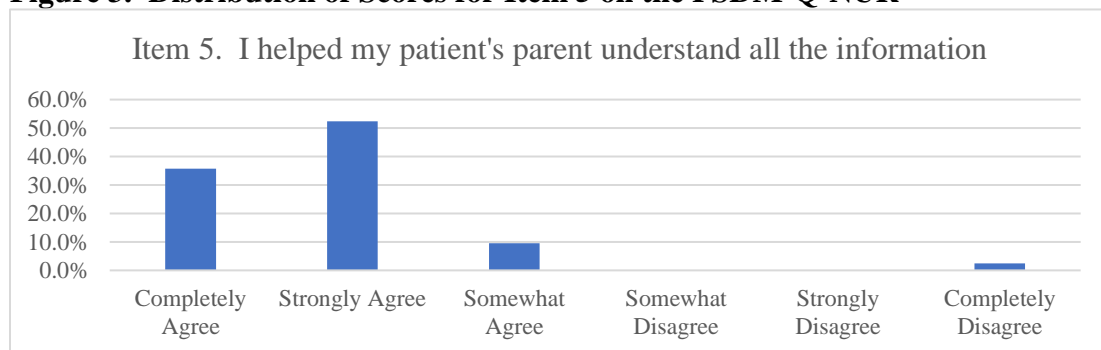
SD=Standard Deviation

Note: **Bolded** items indicate highest mean scores; Underlined items indicate lowest mean scores.

**Figure 2. Distribution of Scores for Item 4 on the PSDM-Q-NUR**



**Figure 3. Distribution of Scores for Item 5 on the PSDM-Q-NUR**



### **Differences in pediatric nurses' perceptions of SDM based on demographic factors**

Individual descriptors identified the nurses' roles, length of time in the position, unit employed, educational level, years of practice, shift worked, sex, race, ethnicity, and certification. There were no statistically significant differences in nurses' perceptions of SDM based on any of the demographic factors. For item 4, "*I precisely explained the advantages and disadvantages of the nursing care options to my patient's parent*" nurses working full-time had higher scores ( $p=.022$ ) than did nurses working part-time, but with  $p\leq.01$ , the item did not reach statistical significance.

### **Parental Perceptions of SDM**

Parent mean responses to the nine PSDM-Q-PARENT survey items ranged from 4.64 to 5.06 (Table 8). The highest scoring items were Items 2 and 5 (designated in bold in the table). Item 2 focused on the nurse wanting to know how the parent, wanted to be involved in making the nursing care decision. Item 5 addressed the nurse helping the parent understand all the information that was provided to the parent. Items 7 and 8 had the lowest means scores in response to the PSDM-Q-PARENT survey items. Item 7 relates to the nurse and parent discussing the different nursing care options. Item 8 focused on the nurse and parent working together to select a nursing care option for the child.

Table 8

*Parental Responses to the PSDM-Q-PARENT (N=53)*

<b>PSDM-Q-PARENT</b> Survey Items	M (SD)	Median	Mode	Minimum	Maximum
1. My nurse made clear to me that a nursing care decision needs to be made.	4.85 (1.40)	5	6	1	6
2. <i>My nurse wanted to know how I want to be involved in making the nursing care decision.</i>	<b>5.00</b> <b>(1.28)</b>	5	6	1	6
3. My nurse told me that there are different nursing care options for caring for my child.	4.80 (1.53)	5	6	1	6
4. My nurse explained the advantages and disadvantages of the nursing care options for my child.	4.84 (1.51)	5	6	1	6
5. <i>My nurse helped me understand all the information.</i>	<b>5.06</b> <b>(1.38)</b>	5	6	1	6
6. My nurse asked me which nursing care option I prefer.	4.80 (1.65)	5	6	1	6
7. <u>My nurse and I went over the different nursing care options.</u>	4.64 (1.69)	5	6	1	6
8. <u>My nurse and I selected a nursing care option together.</u>	4.74 (1.51)	5	6	1	6
9. My nurse and I reached an agreement on how to proceed.	4.96 (1.53)	5	6	1	6



### **Differences in parents' responses on the PSDM-Q-Parent by demographic factors**

Parental responses to the PSDM-Q-Parent were compared by parental demographics. There were no significant differences in parent demographic factors and their responses to the PSDM-Q-Parent items with regards to respondents' sex, education, health insurance, child's sex, age, reason for hospitalization, number of children in home.

### **Comparison of SDM Item Responses by Parents and Pediatric Nurses**

Comparison of mean scores for parallel items on PSDM-Q-Parent and PSDM-Q-NUR are presented in Table 9. Mean scores for parent respondents were higher than parallel items for pediatric nurse respondents for the following items: Clarity that a nursing care decision needed to be made (Item 1); parents desired involvement in making the nursing care decision (Item 2); and parent awareness that there are different nursing care options that can be made for their child (Item 3). Nurse respondents had higher mean scores for the following items: Explaining advantages and disadvantages of the nursing care options (Item 4); understanding information presented to the parent (Item 5); and selecting options together with the parent and ability to reach an agreement on how to proceed (Item 8). Differences between mean scores for parent respondents and mean scores for nurse respondents revealed the largest difference was 0.36 for Item 7 in which nurse respondents had higher mean responses related to reviewing different nursing care options. The smallest differences between mean responses for parent and nurse respondents was for Item 3 - Parent awareness that there are different nursing care options that can be made for their child.

Table 9

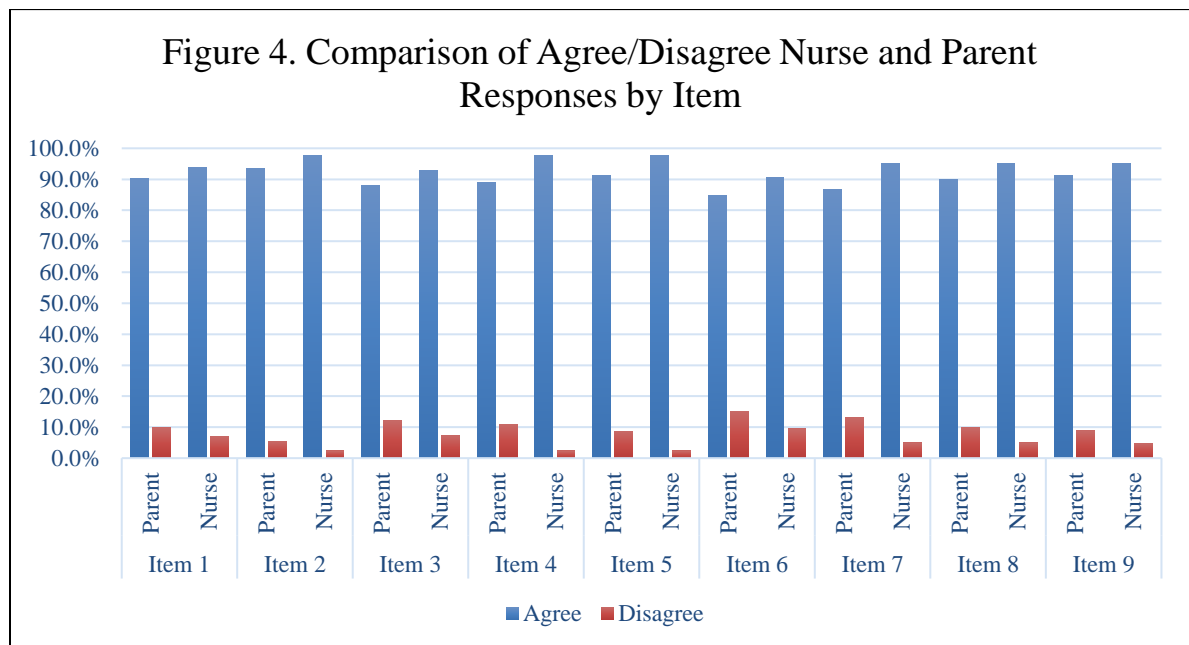
*Comparison of Means in SDM of Pediatric Nurses and Parents*

SURVEY ITEMS	Parent Mean Response	Nurse Mean Response	Difference in means
1. My nurse made clear to me that a nursing care decision needs to be made.	<b>4.85*</b>		0.06
1. I made clear to my patient's parent that a nursing care decision needs to be made.		4.79	
2. My nurse wanted to know how I want to be involved in making the nursing care decision.	<b>5.00*</b>		0.05
2. I wanted to know from my patient's parent how he/she wants to be involved in making the nursing care decision.		4.95	
3. My nurse told me that there are different nursing care options for caring for my child.	<b>4.80*</b>		0.02
3. I told my patient's parent that there are different nursing care options for caring for his/her child.		4.78	
4. My nurse explained the advantages and disadvantages of the nursing care options for my child.	4.84		0.18
4. I explained the advantages and disadvantages of the nursing care options to my patient's parent.		<b>5.02*</b>	

SURVEY ITEMS	Parent Mean Response	Nurse Mean Response	Difference in means
5. My nurse helped me understand all the information.	5.06		0.11
5. I helped my patient's parent understand all the information.		<b>5.17*</b>	
6. My nurse asked me which nursing care option I prefer.	4.80		0.18
6. I asked my patient's parent which nursing care option he/she prefers.		<b>4.98*</b>	
7. My nurse and I went over the different nursing care options.	4.64		0.36
7. My patient's parent and I went over the different nursing care options.		<b>5.00*</b>	
8. My nurse and I selected a nursing care option together.	4.74		0.06
8. My patient's parent and I selected a nursing care option together.		<b>4.80*</b>	
9. My nurse and I reached an agreement on how to proceed.	4.96		0.04
9. My patient's parent and I reached an agreement on how to proceed.		<b>5.00*</b>	

**\*=higher mean response**

To further address the extent of agreement between parents and nurses, the responses were dichotomized as either Agree or Disagree and graphed (Figure 3). The response options of: completely disagree, strongly disagree and somewhat disagree were dichotomized as “disagree”. The response options of: completely agree, strongly agree and somewhat agree were dichotomized as “agree”. While over 80% of parents and nurses agreed with the statements, there were some differences in the perceptions with over 10% of parents disagreeing, as follows: Item 3 (*My nurse told me that there are different nursing care options for caring for my child*; 12.1%), Item 4 (*My nurse explained the advantages and disadvantages of the nursing care options for my child*; 11%), Item 6 (*My nurse asked me which nursing care option I preferred*; 15.2%), and Item 7 (*My nurse and I went over the different nursing care options*; 13.2%). The option of “disagree” selected by nurses did not exceed 10%.



### Qualitative Phase 3 Results: Perspectives of Pediatric Nurses

**Participants.** Twelve nurses providing care to children and their families in a pediatric setting participated in the qualitative phase of this study. Nurses who participated were from units that represented the services of oncology, gastroenterology, respiratory, cardiac, neurology, and orthopedics. All participants were female, white, and worked full-time. Most participants (67%) were baccalaureate-prepared, staff nurses (67%), and worked day shift (83.3%). Half of the participants had over 15 years' experience as an RN, the remaining had worked 10 years or less (Table 10).

Table 10

*Pediatric Nurse Participant Demographic Characteristics, Qualitative Phase*

Characteristic	N (%)
<b>Pediatric Nurse participants (N=12)</b>	
Sex	
Female	12 (100.0)
Male	0 (0)
Race/ethnicity	
White	12 (100.0)
Other	0 (0)
Education	
Masters' degree	2 (16.7)
Baccalaureate degree	8 (66.7)

<b>Characteristic</b>	<b>N (%)</b>
Associate degree	2 (16.7)
<b>Nursing Role</b>	
Staff nurse	8 (66.7)
Assistant nurse manager	1 (8.3)
Clinical nurse specialist	1 (8.3)
Other (educator/clinical coordinator)	2 (16.7)
<b>Full or part-time employment</b>	
Full-time	12 (100.0)
<b>Time in position</b>	
New hire up to 10 years	7 (60.0)
11-15 years	5 (40.0)
<b>Shift usually worked</b>	
Day shift	10 (83.3)
Night shift	2 (16.7)
<b>Years an RN</b>	
1-3 years	1 (8.3)
4-5 years	3 (25.0)
6-10 years	2 (16.7)

Characteristic	N (%)
11-15 years	0 (0.0)
>15 years	6 (50.0)
Certification as an RN	
Yes	10 (83.3)
No	2 (16.7)

### **Themes.**

Two main themes were identified from two focus group and interview sessions with pediatric nurses: Communication and Team approach. Each theme and sub-theme will be discussed and exemplar quotes provided. The first theme of communication included the following sub-themes: 1) commitment, 2) conflict, 3) clarification, 4) collaboration, 5) consistency, 6) cognition, 7) people skills, 8) perception, and 9) empowerment. The second theme of team approach was comprised of the sub-themes: 1) parents/caregivers and child together in decision making, 2) nurses and parents/caregivers have clear understanding of the issue, and 3) expectations. Voices of nurses related to care issues with parents of hospitalized children is captured via additional comments and responses (Appendix J).

**Theme 1– Communication.** Communication as discussed by pediatric nurse participants related to interactions between parents and healthcare providers as essential for engagement in SDM. Nurses voiced concerns about their ability to clearly discuss important care issues with parents that included a sufficient amount of time for engaging

in education regarding the child's health status and language barriers. Nurses discussed resources available to help parents understand issues of concern, discharge instructions and identified when parents did not understand instructions due to language barriers. Identification of these issues provides avenues for dialogue and clearer understanding of strategies that may need to be implemented in the setting to assure clarification is in the forefront of nurse's thoughts and actions for patient and provider safety.

Different views about communication existed among the participants. Some pediatric nurses viewed communication as a usual part of their work with patients and families while others viewed it as beyond "usual care." Participants noted a variety of communication strategies used as well as varying amounts of time needed to engage in shared decision-making. Identifying strategies that can be helpful to both the parent and to nurses may involve a pediatric nurse spending more time with a family that perhaps takes time away from the care provided to another child and family. Addressing communication strategies, time, and activities that are a usual part of work were noted in the sub-themes of: 1) commitment, 2) conflict, 3) clarification, 4) collaboration, 5) consistency, 6) cognition, 7) people skills, 8) perception, and 9) empowerment.

**Sub-theme: Commitment.** Working with families requires an approach that incorporates caring and thought related to the needs of the child. Implementation of interventions for the child and family integrates the caring approach and a dedication to providing quality care for the patient and family as exemplified in the following quote.



*Talking and teaching; it's not additional time. Instead of talking about the weather or the UK basketball game, we could be talking about the medication and arranging home care or whatever they might need. Have you watched your 'get well' network videos? Let's go ahead and put that on.*

**Sub-theme: Conflict.** Nurse participants identified situations that addressed conflict, as well as discussions about strategies to minimize conflict in communication situations with parents. In one situation the nurse was to administer a medication and although there are varying modalities for administration of the medication, due to particular circumstances, the child could only receive the medication via one modality. In the following quote, the nurse referred to the issue of options in care when in there were not such option, thus the chance for conflict between the nurse and parents.

*And with conversations comes conflicts. So, if I don't tell you about the medication, let you decide whether you need pain meds in IV or oral, then I'm just going to wait for you to ask for something and I'll say, "Well, this is your best option." So, it's really not an option. It's a request. "Well, since we waited so long, we got to go with the IV." So yeah, there were no options. So that's the first thing that stuck out for me.*

*Between doctors, parents, nurses, and attending physicians—even between the attending physician and residents sometimes you get totally different—consults, especially when a kid gets tons of---because there's so many people coming in and out of that room. And then there's so many different orders written. And they're like, "Well, this doctor said this. And this doctor said that. This doctor said 'don't do this,' but this one said we can." So communication is huge.*

*I think it gets more difficult when you have subspecialties and specialties that are weighing in too that are not present all the time every day. I think that sends a little bit of mixed messages, or sometimes they want to change the plan, but they don't always communicate that with the other team members. And I think that complicates things sometimes, but definitely the rounding and family-centered rounds where they participate and are present and encouraged to ask a question has been huge.*

**Sub-theme: Clarification.** Nurses voiced concerns about the need to clarify care issues with parents prior to discharge and during the child's hospitalization. One nurse verbalized attempts to clarify issues related to parent's smoking:

*I talk to families for a little bit, and sometimes I spend over an hour talking to them and teaching, you realize that they're still smoking in the home or they only give this medicine when the child has an issue.*

In another conversation related to smoking cessation a nurse discussed issues related to smoking with the parents. This situation related to a nurse working with parents of a child with asthma. As part of the child's care the nurse was providing the following education related to the effects of smoke on children with asthma.

*I have to do sometimes smoking cessation with them, especially with the asthma and the bronchiolitis population, kind of encouraging the families to break those bad habits that they have that's important to their child's ongoing care. So I try to tell them - I understand how hard this is. It's like myself having to give up M&Ms – that kind of thing, it puts them at ease but lets them know that I recognize that this is something that I'm asking them to do that's not easy, that I appreciate that situation that I'm putting them in, but still for the health of their child it's important. You can't just ease away from it. I think some people do, they'll say to the families. "You really should think about stopping smoking" and the families will say, "I'm not going to stop." And so, they drop it, but I think we need to go forward with some of that, trying to encourage them to break those habits.*

**Sub-theme: Collaboration.** Collaboration between nurses and parents was considered important in achieving success when addressing child care concerns in the pediatric hospital setting. Parents and nurses working together involves communication

between nurses providing care and health care providers responsible for achieving outcomes.

*Some do; some don't. They sit back and they're somewhat timid. And they're not in their element, and we are comfortable in this environment, and so they're afraid to ask when they have questions. They don't know that they have options. Now with skin care, when we have a child that comes in that has like a chronic—a CP child, and we're worried about turning and positioning, we'll ask the families. And on most kids, I think we do a great job. We'll say, not just with skin care but all care, feeding and everything, "How do you do this at home? What's your feeding schedule?" That kind of thing. We try to mimic as much as we can what they do at home to make it easier for them to go back home and everything stays on the same schedule. So, I think we probably do a better job with that patient population and incorporating the family into care and getting their opinion and trying to keep them a big part of our team more so than our families that are in and out, which more and more of our children are quick links to stay. And when you're only in the hospital for a day and a day and a half, it's hard to develop rapport and to get all the info in.*

*I had a patient that came in, it was a suicide kid, and the team wanted her to go to the pediatric medical unit. . Well, she had an outpatient psychiatrist, so her mom just wanted to see him the next day. And so, they had our psychologist come talk to her, and he thought she needed to go to a psychiatric unit rather than go home. Well, the mom wasn't for that. So, I explained to her what the psychiatric unit could do for her daughter and that they do a lot of group therapy and it would probably be better for her because she tried to hurt herself. She can tell her that she's not going to hurt herself, but she might still. And they thought that was best and that she should probably do what the doctor thinks. The doctors came back too, but she ended up going to the pediatric medical unit.*

**Sub-theme: Consistency.** Nurses discussed the need for consistent communication between parents, nurses, physicians and additional healthcare team members. Participants raised concerns over mixed messages given to parents when they were asking about plans of care.

*But from my approach, you just have to keep an open mind. You have to try your best and listen and have the doctors in there and talk to them, because it is this team approach. We have to try to stay on the same plate.... It takes time and it takes effort and your attitude about things and openness with the groups. We all need to be included so we can be on the same plate. So that we hear as nurses what the doctors are telling the families when their questions come up later in the day, and we can reinforce what was said during rounds. I think that's helpful for families to hear it a second, a third time; anxious, they're tired. I think I like to make them feel at ease.*

**Sub-theme: Perception.** Interpretation of a situation may be based on one's experiences in school, work, and life. Communication is important in understanding one's experiences, especially for those who have been involved in care decisions. Nurses explained that parents' thoughts about them and their thoughts about parents, accurate or inaccurate, may impact communication and decision making in the health care settings. Perception of a situation may also be based on previous experiences within a healthcare setting.

*Well, I went to an intervention, we're in the room—I just think it goes back to communication. And they're in the room, providing care, and I don't think they're talking as much as they need to and incorporating the families into that. Now you know, unit A is trialing bedside report. And I really think that's where we need to go, and that would probably clear up that discrepancy because you do incorporate the family into your bedside report. So, they know exactly—so they would be participating in bedside report in the multidisciplinary rounds. So, there's two opportunities in a 24-hour period that the families, the parents at the bedside, know what's going on, what the plan is for the night, what labs, what we're waiting on, what we're expecting for discharge, all that kind of stuff. So, I see that as an intervention that can fix this perception problem, but I really think it's more of a communication.*

**Sub-theme: Empowerment.** Nurses often voiced the gratification they felt from engaging in the process of decision making in interactions with parents. Empowerment was exemplified in the ability to make shared-decisions regarding care issues, helping parents arrive at decisions they were comfortable with for their child's care, and discussions that led to the most positive outcome for the child and family. One nurse stated *"I think it's very gratifying to be able to talk with families and make that decision together. That's awesome."* Another noted:

*I find it very empowering if I'm involved at the very beginning because then you can set the pace. I've had patients where I've become involved after the process has already started.... So, let's say if we have a new diagnosis family and maybe they've been here for two weeks and I become their nurse for the first time after two weeks. I feel awkward at that point because the stage has already been set for a level of communication. And I'm just jumping on board at the point in time. So that's an awkward situation. But if I can be involved from the beginning, let's say if I take care of them the first days of their admission, then I can really feel like—I don't want to say I own the process, but at least I'm instrumental in the type of communication that's carried on. I think as nurses we get that communication class just as a prerequisite for our core classes in nursing school. It's never really focused on as far as therapeutic communication in the real-life healthcare setting.*

In this study, communication was identified as a major theme by pediatric nurse participants who engaged parents in decision making. Participants also identified challenges to the engagement of parents in decision making. Communication was identified as an essential for supportive, safe, and collaborative care between a parent and healthcare providers. Pediatric nurse participants noted that communication took time to engage parents. Clear communication requires the ability to provide clear directions and

messages and to understand parents and their needs. When engaging in shared decision making, nurses noted that communication improved, thus, leading to a feeling of empowerment and a noticeable decrease in the incidence of mixed messages.

**Theme 2 - Team approach.** Team approach was the second theme generated from the interviews. Pediatric nurse participants indicated that nurses and families viewed working together as a team was not only valuable, but essential to achieve the best outcomes for their child. Pediatric nurses discussed the importance of the parent and child working together with the nurse in making care decisions. Parents, the child, and the pediatric nurse working together provides a team approach that aids in promoting the best possible decision-making situation within the hospital setting. Participants discussed expectations related to shared decision making not only of parents, but also members of the healthcare team.

Nurse participants noted that addressing expectations – either by the parent, or by the nurse – was a component of the team approach to SDM. Within “team approach” the following sub-themes were identified: parents/caregivers and child together in decision making, nurses and parents/caregiver have a clear understanding of the issue, and expectations.

**Sub-theme: Parents/Caregivers and child together in decision making.**

Decision making may involve individuals or a group of two or more people. Pediatric nurses caring for children and their parents make decisions based on discussion and agreement amongst the care team, the child, and the parents.

In the following situation, the issue of care and how best to implement an intervention to decrease the risk of harm and pain were discussed.

*Yeah, I've had a patient that's been in with abdomen, he's had a dressing on his abdomen for a month, so it's tape that's removed every single day. And some doctors come in and just yank off the tape and others—and so we had a discussion yesterday how we were going to address using—because he still has a dressing on his abdomen and discussing ways we can take off the tape using adhesive remover, taking it off very gingerly and maybe just doing a different dressing and using an ace bandage. It was the patient, and he's 9 and the parents, what other way we can do this. And that worked out. It was family, patient, and nursing making a decision.*

The following situation focused on the decision-making abilities of hospitalized children and teenage patients. The discussion addressed the ability of a child, their maturity in making decisions, experiences they may have had in making care decisions for themselves or in collaboration with their parents.

*I think of like maybe we have a teenage patient so they're able to make decisions, but they obviously aren't old enough to sign their own consent yet or whatever. So, I think of that, like them being able to talk with their parents and giving their own opinion about their healthcare even though they're technically not old enough to actually be in complete charge of their own care.*

*Engage the parents in that care, and if the child is old enough, the child also, so that they feel like they're a part of the decision making. And it's not just me saying "you're going to this and this and this, and you have to take this med, and you have to—" whatever. So, I think if you make it interesting and knowledgeable at the same time and give the child a choice when you can—*

**Sub-theme: Nurses and parents/caregivers have clear understanding of the**

**issue:** Clarity in decision making is imperative for all members of the healthcare team.

Nurses work closely with parents/caregivers in arriving at decisions on care issues.

Clarity and understanding are key to parental/caregiver involvement in decision making

regarding their child's health and wellness. In many situations, parents may perceive mixed messages regarding the care or plan of care their child is to receive from the healthcare staff. This is reality in healthcare settings and of the expectation of parents with the health care teams.

*The parents feel like sometimes they're not all on the same page or they're not all talking to each other, or this one said this, and that one said that and now I'm confused because now you're saying something else as a nurse. And when that happens, if I'm not clear what they're saying or asking about and if it's not something that the nurse told me in shift report that I can say, "well, I think you're referring to this; let me clarify it," my first thought is to always say, "I wasn't here on day shift, so I'm not sure what those doctors told you, but I would be glad to call the resident that's here right now and see if they can clarify any of that for you."*

The following is an ideal situation that could occur with any pediatric patient, parent and nurses.

*Between the parents, and then one of the reasons why—they come and grab us for nursing rounds. And so, it's the nurse, the team, and the parents together, and then they can bounce off ideas. And so, it's three different entities that at that moment come together as one to talk about plan of care, what's working, what's not working, what else we can do, different tasks, procedures, education, all this stuff.*

Situations occur when a child needs care regardless of the events that had recently occurred – for example, the lack of sleep. Negotiation is needed within situations between pediatric patients, their parents and the nurse caregivers

*A couple of things I could think about would be mouth care for prevention of mucositis. Well, maybe parents don't want to do the mouth care because their child was sick all day, and they're finally asleep for the first time in six hours or something, and they want to forego the mouth care. So at that time, I'll be like, "I understand. Sleep's really important and I agree. But this mouth care is really important. You don't want to give any opportunity for infection or breakdown of*



*their mucosal lining. So, I just want you to hear me that it's really important. So, if your child should wake up, please call out and I'll come in and do mouth care." Or whatever. This is a really simple example. Baths are another thing that falls in the cracks a lot. Parents get absent minded about the hygiene of their child and I don't think it's deliberate; they just get—it's just one of those things that gets swept under the rug. It really does come down to us saying, "Hey, listen, have you given your child a bath in the past three days?" We really need to be doing.*

**Sub-theme: Expectations.** Providing care based on established plans can lead pediatric nurses to expected actions and outcomes for the child and family. This also allows for families to expect a certain level of care and achieve quality outcomes. However, expectations need to be realistic for the nurse, child and parents. The following situation related to pediatric nurses teaching parents about their child's discharge expectation and confirming that they understand the information for safe care to be provided at home.

*They're supposed to be able to teach back, show back. And they're supposed to be able to tell you what you told them because we had a family, it wasn't my patient, but just in this last week when the nurse was going over the discharge paperwork, and the nurse asked the dad to sign his name, but he didn't know where to sign his name because he didn't know how to read. So she gave him written info, teaching info, but she just realized that "oh, my god, he's not going to be able to read what I just gave him." So teach back, show back was like he didn't understand a word you said.*

The following situation is focused on discussions about discharge instructions and the exploration of alternative interventions that will fit within the home environment yet achieve the desired outcome.

*To me SDM in the pediatric world in the until I work on is that the nurse and the parents and even the patient if they're old enough to understand and know what's going on work together to meet the needs of that patient. That doesn't mean they do what the nurses or doctors say. We educate them as to the doctor's orders, their plan of care, and how we have to try to achieve it, but then they give us the input "Oh no, my [son or daughter] can't do it this way; can we try it this way?" But you work together to achieve the outcome, which is great.*

The pediatric nurse described, in the following quote, the importance of the parent in providing care to avoid future hospitalizations.

*I do think the parent is an integral part in the care of the child and keeping them out of the hospital. So, I like to make sure that we included them in conversation., Also, that we talk to them at a level they understand, eye contact to make them feel a part of it and important, that kind of thing.*

Pediatric nurse participants indicated that nurses and parents/caregivers need to have a clear understanding of the healthcare issues for which decisions will be made. A lack of communication among healthcare providers may impact time to treatment when addressing patient and family care needs. A concern identified in qualitative interviews was the lack of clarity among nurses, physicians, and parents of pediatric patients while in acute care hospital settings. A team approach includes clear communication and collaboration among all team members who are identified as part of the care team within the pediatric inpatient setting. Therefore, a team approach would be critical to the success of outcomes for children and their families.

## Discussion

The purpose of this mixed methods study was to explore perceptions of nurses providing care to hospitalized children and perceptions of parents of hospitalized children on SDM. A quantitative survey (Phase 2) provided findings related to how parents and nurses engage in making shared decisions about a child's care in the hospital setting. Qualitative interviews (Phase 3) with nurses providing care to hospitalized children identified two themes that further enhance and explicated the SDM process with parents as perceived by participating nurses. Together, qualitative and quantitative study results provided insight into how nurses and parents perceived SDM concerning a child receiving inpatient care.

Key findings from the Phase 2 survey indicated that participating nurses either strongly or completely agreed that they were engaging parents in shared decision making in response to the nine PSDM-Q-NUR items. Parents who completed the PSDM-Q-PARENT survey identified that nurses wanted to know how parents preferred to be involved in making the nursing care decisions. In addition, parents indicated that nurses were active in helping the parent understand the information provided to them about their hospitalized child. Nurse's voices from the qualitative interviews revealed two primary themes related to SDM between inpatient point-of-care bedside nurses and parents of hospitalized children: communication and team approach. Communication and a team approach were identified by nurses as critical to nurses and parents working together to assure shared decisions were made for the child's care. These findings align with both the

framework used to support this study: Person and Family-Centered Nursing Framework (adapted from McCormick, Karlsson, Dewing & Lerdel, 2010) and the work of Berwick introducing the concept of patient-centeredness (Legare et al, 2010).

Analysis of the items in the SDM-Q-NUR and the SDM-Q-PARENT revealed consistency in the average responses by parents and by nurses for five of the nine items (Items 1, 2, 3, 8, & 9). The majority of these items (1, 2, & 3) focused on the nurse interacting and communicating with parents by asking for information from the parent in relation to care issues for the child or providing such information to the parent. These items provide direct answers requiring less time and discussion for a decision to be made. The items with the largest differences in mean scores (Items 4, 6, & 7) focused on communicating about detailed interventions or more complex decisions that may require additional discussions between the nurse and the parent. These SDM-Q-NUR/PARENT items required not only additional discussions, but also provision of clear and accurate information and the use of problem solving skills to assist the parent in making decisions that work best for their child and themselves. In the present study, parents did not provide feedback on the length of the study – no complaints on the amount of time it took to complete were noted. Few parents stated that the most challenging part of completing the tool was identifying a situation involving a “nursing” intervention. Once they identified an intervention that involved them communicating with a nurse, the tool was not difficult or too time consuming to complete.

Similarly, Smith, Cheater, Becker, and Chatwin (2013) investigated parent-professional SDM during the diagnosis of a child's suspected shunt malfunction. Their mixed methods study found that parents and healthcare professionals focused on problem solving versus actual decision-making. Smith et al. also reported barriers with parents in relation to communication based on the amount of time needed for a decision and the environment in which discussions could occur. Findings from the Smith et al. study align with the differences noted in this study related to answers of questions based on level of involvement and complexity in making decisions. The issue of a medical intervention as compared to a nursing intervention was the challenge for parents. Situations varied in their level of complexity.

Nurses interviewed in the qualitative phase of this study identified communication and a team approach critical as they worked with parents in making care decisions for their child integral to success in engagement. Muething et al. (2007) discussed that the introduction of the rounding team members to those involved in the patient's room was a key component to improving communication with parents. In this study, prior to the investigator introducing herself to the family or parent, the non-verbal behavior of parents was noted. These were one of caution and uncertainty until the investigator introduced herself and the reason for her presence in their child's room. In addition, Muething et al. (2007) discussed the importance of making families feel they were truly

partners in the care-giving process. In this study, communication was a major theme for nurses and parents. Nurses viewed the importance of spending time with the child's parents as a vital component of communication.

In addition to communication, "team approach" was an identified theme. For a team approach to be effective, Muething et al. (2007) discussed the need for team efficiency to allow for family involvement. Strategies identified by Muething et al. included family members as active participants in decisions made during care rounds allowing for all members of the team to be aware of and comfortable with the treatment plan. Muething et al. also found that teaching, which occurred while in the child's room, was beneficial not only for members of the team but also for parents' present during rounds. Langley et al. (1996) similarly found that each encounter could lead to later discussions and teaching moments with the patient and family.

The current study identified similar responses by nurses. Nurses discussed specific engagement with parents in the child's room. One nurse noticed a heightened anxiety level of the parent in relation to making a care decision. She took the parent out of the room and for a walk down the hall quietly discussing the situation, the child's perspective and addressed the parents' concerns and fears. This provided an opportunity for the parent to open-up and the parent was then able to make a decision that was appropriate for the child and agreeable by both nurses and the parent.

Nurses interviewed in this study raised the issue of collaboration. Similarly, Smith et al. (2013) investigated parent-professional SDM during the diagnosis of suspected shunt malfunction in an acute care hospital experience. Two themes identified by Smith et al. include establishing cause for illness symptoms and involving parents in care planning. Smith et al. study focused on parents' and professionals' perceptions of collaboration and practices of health care professionals that enabled or hindered effective collaboration in SDM efforts. In this study, collaboration was identified as essential between parents and nurses for the child to receive the best care possible through the nurse and parent working together in decision making.

Overall findings suggest that there is a relatively large body of SDM research that includes multiple types of care settings and research completed with adults and their views on SDM. However, a key gap in the research knowledge is in relation to pediatric contexts. This study contributes to the body of knowledge focused on parental perspectives of SDM with nurses and nurses engaging parents and pediatric patients in SDM. Quantitative results showed few differences in how parents and nurses viewed engagement in SDM, Qualitative results provided key areas in need of change for SDM to occur in a consistent and clear manner within the health care settings.

### **Limitations**

Limitations to the study include a small sample size of parents and pediatric nurses in both the qualitative and quantitative phases of the study. Second, parents and pediatric nurses were from one pediatric healthcare system, thus limiting the

generalizability of the results to other pediatric settings. Third, this study focused on pediatric nurses and parents of pediatric patients; therefore, the findings are only applicable to these participants (Truglio-Londrigan, 2013). Fourth, the interviews were conducted with five of the nurses on duty and during their hospital shift. If their assigned patients needed an intervention that could have caused an interruption within the question and answer time leading to possible gaps in information collected. Fifth, the tool used for measuring the quantitative data was an adapted tool used only during this study. A fifth limitation is that racial/ethnic data were not collected on parental participants in Phase 2. While a diverse group of parents participated in Phase 2, specifics related to parental racial/ethnicity were not collected.

### **Recommendations for Future Research**

Recommendations for future research findings from this study will guide researchers in the refinement of the SDM-Q-NUR and SDM-Q-PARENT shared decision-making instruments. Further testing is needed to assess the validity and reliability of the SDM-Q-NUR and SDM-Q-PARENT instruments. Replication of the study enrolling pediatric nurses and parents of pediatric patients in other settings, such as pediatric emergency departments or intensive care units would provide an opportunity to assess SDM in different settings. Replication of the study in the home care environment would provide a chronic care setting different from the present acute care setting. Including pediatric patients who are tech-dependent in the hospital setting as well as patients in a Neonatal Intensive Care Unit or Pediatric Intensive Care Unit would provide



healthcare providers with a perspective different from the patients and parents of hospitalized children in less acute care environments. Assessing SDM of a healthcare team that included pediatricians, and other healthcare providers (e.g., respiratory therapy, physicians) using these tools is also warranted. Future efforts to build on the results of this study may also want to include: integration of decisional conflict and decisional regret in the SDM process with parents and healthcare providers; style of parent decision making as either independent, autonomous as compared to authoritarian, paternalistic or an active and collaborative role as compared to autonomous or paternalistic approach. Findings from this study provides a foundation to build upon as interdisciplinary teams work towards providing care that is inclusive of all people involved in the decisions.

### **Conclusions**

SDM continues to be an emerging concept with patients and healthcare providers. Existing tools that measure SDM among adult patients and physicians, however, are inappropriate for use with pediatric nurses and parents of hospitalized children. No tools were available that quickly measured SDM among parents/caregivers of hospitalized children and nurses providing care to hospitalized children, therefore existing tools were adapted and successfully implemented. A mixed methods study was conducted to address SDM between nurses and parents of children hospitalized in an acute care setting. Findings showed that parents and nurses have similar perceptions of working together to address the child's care. Qualitative findings of pediatric nurse interviews revealed two major themes: communication and team approach. Nurses discussed the importance of

communication in providing care to children and families. Specifically, nurses voiced concerns about their ability to have clear discussions regarding the importance of care issues with parents. In addition, nurses discussed resources available to help parents understand language barriers, discharge instructions, and care issues.

Communication also involves team members and their approach to interventions related to children and parents in an acute care hospital setting. Team approach may be critical to successful care outcomes. Each member of the team provides specific input into the care of the patient and their parents based on their expertise. In addition, team members provide specific information and recommendations in relation to the child's plan of care. It is imperative that communication between team members and among teams occurs for successful care to be provided to each child and their parent.

## CHAPTER V: SYNTHESIS AND CONCLUSIONS

The overall purpose of this dissertation has been to identify perceptions of shared decision making (SDM) among parents of hospitalized children and nurses providing care to children in the hospital setting. Specifically, this dissertation has served to (1) explore the concept of SDM within the pediatric population among parents of hospitalized children and nurses who provide care to hospitalized children; (2) provide a critical review of the literature focused on SDM, nurses, and parents of hospitalized children; (3) adapt adult-focused SDM instruments for use in the pediatric setting; and (4) understand the perceptions of nurses who provide care to hospitalized children along with the thoughts of the parents of hospitalized children and then offer recommendations about working collaboratively to provide quality care to those children.

### **Synthesis of Findings and Implications**

Understanding the perceptions of both the nurses and the parents of pediatric patients regarding SDM was explored through literature, parent verbal and written comments, and nurse verbal and written comments. The initial literature review addressed the Evidence-Based Practice (EBP) paradigm. EBP focuses on three content areas: clinical expertise, literature, and patient preferences and values.

A theoretical framework that supported this work in engaging parents in the care of their hospitalized children is the “Person-Centered Framework” (McCormack & McCance, 2006) (Chapter 2). This framework includes four constructs: prerequisites, the care environment, person-centered processes, and expected outcomes (Appendix C). A patient-centered approach requires interactions and communication between the patient/family and the healthcare provider. This interaction may provide the most opportune time for the patient/family to become engaged in care processes through SDM. SDM can be defined as “an approach whereby practitioners and patients communicate around decisions, referring to the best available evidence and deliberating upon the consequences of each option” (Légaré et al., 2010, pg. 555). Use of the Person-Centered Framework supports the practice of SDM within the work of nurses caring for children and their families in an inpatient healthcare setting, making decisions together as the children’s needs are met.

The Person-Centered Framework provided guidance on further exploration into parents’ and nurses’ engagement in decision making related to the children’s care. To better understand this approach to healthcare, appropriate measurement tools are essential. Few instruments existed that specifically focused on interactions between parents and nurses in an acute care setting. Instruments focused on adult patients were then adapted to address this gap (SDM-Q-9; SDM-Q-DOC) (Kriston, Scholl, Hölzel, Simon, Loh, & Härter, 2010; Scholl, Kriston, Dirmaier, Buchholz, & Härter, 2012b). These instruments were adapted specifically for parents and nurses providing care to a child in an acute care pediatric setting (PSDM-Q-Nurse; PSDM-Q-PARENT). Cognitive

interviews were completed with parents of children (N=6) and nurses providing care to children (N=6) in an acute care setting. The cognitive interviews identified several areas in need of revision, primarily use of language common to parents and clarity in some of the verbiage. Nurses indicated that the meaning of specific items related to patient care required greater clarity. After the suggested modifications were made, the tools were implemented in a regional academic pediatric hospital with nurses on medical-surgical units and parents of children on those units. Quantitative findings revealed both differences and agreement among nurse and parent data in completion of the SDM instruments. The smallest differences between mean responses of parents and nurses was for Item 5, which measured parent awareness that there are different nursing care options available for their children. The extent of agreement between parents and nurses in their responses were dichotomized as either *agree* or *disagree*. Over 80% of parents and nurses *agreed* with the all of the items on both tools. However, there were some differences in the percentage of disagreements, with over 10% of parents *disagreeing* with the following items:

- *My nurse told me that there are different nursing care options for caring for my child,*
- *My nurse explained the advantages and disadvantages of the nursing care options for my child.*
- *My nurse asked me which nursing care option I preferred.*
- *My nurse and I went over the different nursing care options.*

In contrast, there were no items on the PSDM-Q-Nurse with which over 10% of the nurse participants *disagreed*.

Following analysis of quantitative data, qualitative interviews were conducted with nurses in the pediatric setting. Two major themes from voices of the nurses were identified: communication and team approach. Overall, findings indicate the need for clarity in communication efforts within SDM.

### **Literature Findings and Implementation**

**Instrument Adaptation.** Beatty and Willis (2007) define cognitive interviewing “as the administration of draft survey questions while collecting additional verbal information about the survey responses, which is used to evaluate the quality of the response or to help determine whether the question is generating the information that its author intends” (pg. 288). The most common application of cognitive interviewing as described by Beatty and Willis (2007) was the administration of draft survey questions while collecting additional verbal information about the survey responses. This process can be used to evaluate the quality of the response or to help determine whether the question(s) are generating the information that its author intends (Chapter 3). To date, no prior studies have used the technique of cognitive interviewing to adapt SDM measurement tools for the pediatric inpatient setting and for populations of parents and nurses in this setting. Therefore, this study has focused on addressing this gap in the literature.

Instrument developers of the SDM tools have focused on their use in adult healthcare settings. The SDM-Q-9 (Kriston, Scholl, Hölzel, Simon, Loh, & Härter, 2010) and the SDM-Q-DOC (Scholl, Kriston, Dirmaier, Buchholz, & Härter, 2012b) were developed for adult/physician interactions. For the tools to be used with parents and nurses in the pediatric setting required adaptation. The tools were adapted by experts in pediatric nursing and in the use of SDM tools. Following adaptation, the tools were administered to parents and nurses in a pediatric inpatient setting. Findings identified the need for changes to be made to items to enhance clarity and understanding for use in the clinical setting. In addition to adaptations to specific items, the titles were changed to PSDM-Q-NUR and PSDM-Q-PARENT. Further adaptation was completed based on input from 12 participants (six nurses and six parents) who completed the tools and provided critical feedback on clarity and understanding (Chapter 3). Although the adaptation of the instruments provided valuable data regarding SDM between parent and nurses, future use of the instruments will provide additional data related to reliability, validity, and applicability for use with all healthcare professionals. In addition, future research related to the SDM tools also includes the need for replication with a larger population of both parents and nurses.

### **SDM among Nurses and Parents of Hospitalized Children**

SDM is a key component of patient-centered healthcare. It is a process in which clinicians and patients work together to make decisions and select tests, treatments, and care plans based on clinical evidence that balances risks and expected outcomes with

patient preferences and values (Berry, 2012). Charles, Gafni, and Whelan (1997) defined four key principles of the SDM process: (1) at least two people must be involved (patient/provider), (2) information must be shared, (3) consensus must be built about the preferred treatment, and (4) a treatment plan must be mutually agreed upon. Berwick (2009) used these principles in working with patients and families and reminds healthcare workers to approach patient care issues with “nothing about me, without me.”

In addition, Berwick (2009) described patient-centeredness as a dimension of healthcare that involves significant shifts in control and power of those involved in care processes. These shifts allow the focus of the healthcare provider to be working with the patient and family. This focus allows providers to address issues and possible interventions that are needed to arrive at specific care decisions.

Aarhun and Akerjordet (2014) found that parents indicated they participated in SDM about their children’s care to varying degrees and would like to participate more, but few opportunities were provided. Findings also revealed that parents felt pressured to make decisions and identified a lack of negotiation during the decision-making process. Professionals identified the importance of involving parents in decision making; however, parent involvement was impacted by how clearly the parent voiced an interest to the healthcare provider about participating in making care decisions. Communication became a focus of the findings.



In the current study, 50 parents completed the PSDM-Q-PARENT, and 50 nurses completed the PSDM-Q-NUR in order for researchers to explore perceptions of SDM processes in the acute pediatric healthcare setting. Nurses and parents were asked to identify a situation in which they worked with each other in making a decision regarding the child's care. Personal factors and attitudes were themes associated with parental participation in decision making identified by Aarthun and Akerjordet (2014). In this study, neither parental personal factors nor attitudes appeared to impact their completion of the PSDM-Q-PARENT.

Légaré et al. (2011) reported barriers to parents' and healthcare providers' engagement in SDM as high staff turnover; lack of human resources; lack of consistency in how decision making is described, supported, and agreed upon by parents and healthcare providers; and the lack of available standardized tools for measuring effectiveness of SDM. Nurses did not indicate these as barriers on the PSDM-Q-NUR. However, qualitative interviews/focus group discussion with nurses did reveal that time, staffing, and inconsistency in implementation of SDM between nurses and families were concerns.

Consistent with the work of Aarthun and Akerjordet (2014), communication was a theme by nurses discussing SDM. Voices of the nurses discussed the importance of communication and collaboration in executing care and decision making during care processes. Other researchers described the importance of mutual trust and respect as a

two-way process focused on communicative and relational competencies, provider technical knowledge, experience, and working collaboratively for SDM between parents and professionals (Mackean et al., 2005; Alderson, 2006; Pyke-Grimm et al., 2006; Fiks et al., 2011).

### **Policy and Practice Implications**

Within the healthcare arena, policy drives practice. Policy development may be implemented on a national level or at the point-of-care setting. This dissertation has focused on the practice of SDM at the point-of-care. Policy developers and point-of-care healthcare providers continue to question if practice is consistent with best evidence and how to implement evidence that improves and sustains outcomes. Implementation of Evidence-Based Practice (EBP) process has been shown to have significant implications on national healthcare issues. Examples include (1) a positive impact on patient safety through the development of policies and procedures, (2) decreased costs through implementation of interventions that decrease length of stay, (3) increased revenue for organizations by applying process changes that increase patient flow, and (4) increased staff and patient satisfaction through consistent care based on guidelines (Cook, 1998, Jennings & Loan, 2001, Porter-O'Grady & O'Malloch, 2006, Sigma Theta Tau, 2010).

Addressing the many issues within healthcare must be approached from an evidence perspective that includes the voices of those involved in providing care, the patient, and families of those receiving care. Findings from this study may provide guidance for the pediatric acute care setting on areas for improvement in administration

of care processes. Listening to and understanding nurses' responses to the interview questions reflected the need for adequate time in the workday to engage in timely communication with patients and families. Nurses voiced the need for teaching and educating parents regarding their children's care. They identified that having the time to educate parents and develop clear plans of care are critical to the effectiveness of the information provided to the parent and child. Pediatric hospitals and medical centers that base nursing practices on a shared governance model would be an ideal setting to engage nurses in discussions about integration of SDM into daily practice.

Discussions about integration of SDM should be driven by point-of-care nurses in collaboration with nursing management for decision making, implementation, and evaluation of outcomes. The need for systems to facilitate the initiation and sustainability of a culture where discussing options with parents and patients is critical in assuring quality patient care.

### **Research Implications**

Additional studies that explore SDM in the pediatric healthcare settings are needed, including ones in which the SDM-Q-PARENT and SDM-Q-NURSE are implemented in a variety of settings to assess the validity and reliability of the instruments. Psychometric testing of the tools should occur with administration in a variety of settings including outpatient, clinics, and homecare.

Future qualitative studies are also warranted to elicit further clarity of the two identified themes in this study: communication and team approach. Additional themes and subthemes may be unearthed if a broader sample of nurses are included. Similarly, interviews with parents and other healthcare providers (e.g., physicians, respiratory therapists) may yield new insights.

Outcomes of studies focused on SDM within hospital settings can be adapted to multiple other settings that would promote partnerships, team approaches, and engagement of those by whom decisions are being made. Examples include health departments and urgent care settings as well as all care units within healthcare institutions focused on providing the best care for patients and families.

### **Summary**

In this dissertation, the concept of SDM has been explored in a mixed-methods approach through the use of cognitive interviewing as adult-focused SDM tools were adapted for inpatient nurse pediatric encounters, completion of quantitative SDM instruments by nurses and parents of pediatric patients, and by listening to the voices of nurses through focus groups and one-on-one interviews. The SDM instruments used in this study were adapted to address the population of interest for this study: nurses providing care to children hospitalized in a pediatric setting and the parents of the children hospitalized in the pediatric setting. Initial feedback via cognitive interviewing regarding the adapted SDM-Q-NUR and SDM-Q-PARENT was the need for clarification

in items focused on the child's care. Nurses and parents provided alternate wording that did not change the intent of the questions and thus were incorporated into the final version of the SDM-Q-NUR and the SDM-Q-PARENT.

Findings from the quantitative phase of this study that included nurses' and parents' completion of the SDM-Q-NUR and SDM-Q-PARENT identified areas of agreement and disagreement related to care issues and communication about decisions regarding the child's care. A subsequent qualitative phase using focus groups and one-on-one interview sessions with pediatric nurses elicited the themes of communication and team approach as critical to the implementation of SDM. Together, the data and participant voices provided information for implementation of SDM in the clinical settings. Additional studies using the revised tools are needed in continuing to identify areas of strength and weaknesses within SDM in the care of children in the pediatric setting.

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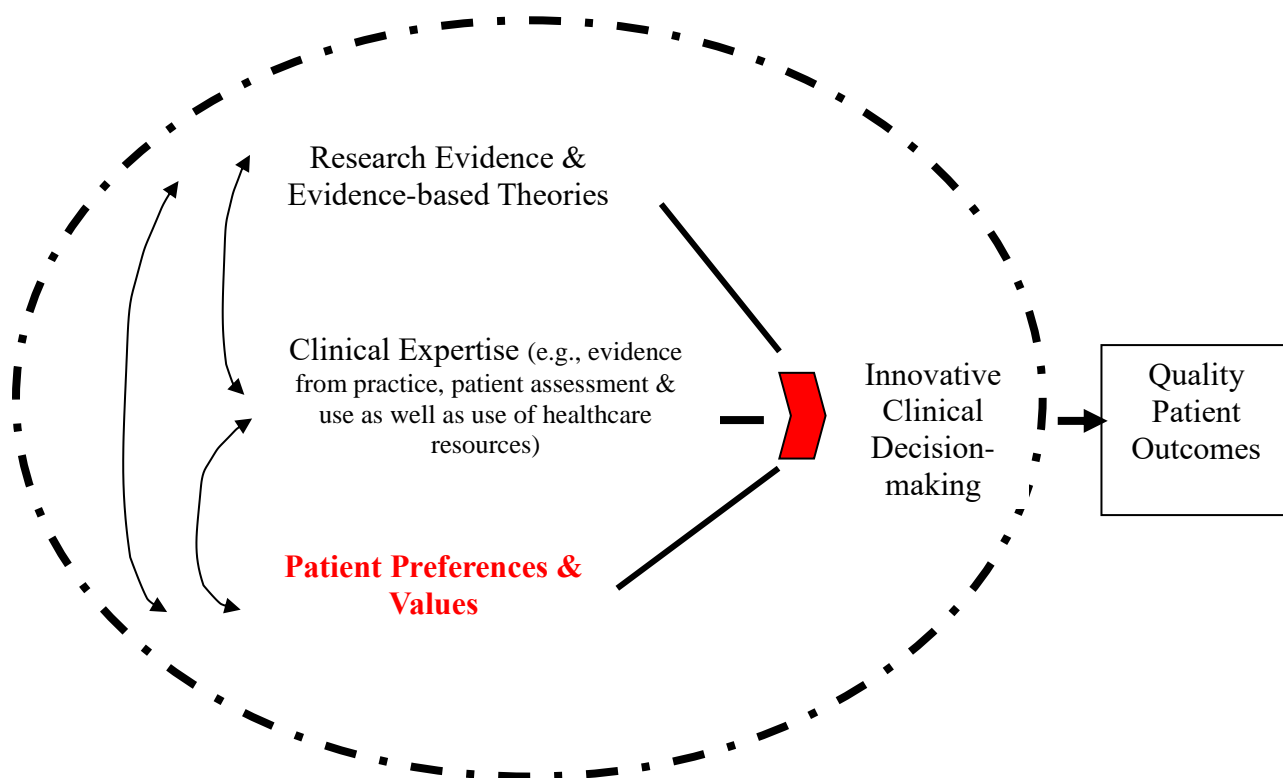
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Appendix A: The Conceptual Framework to Support the EBP Paradigm

EBP Organizational Culture



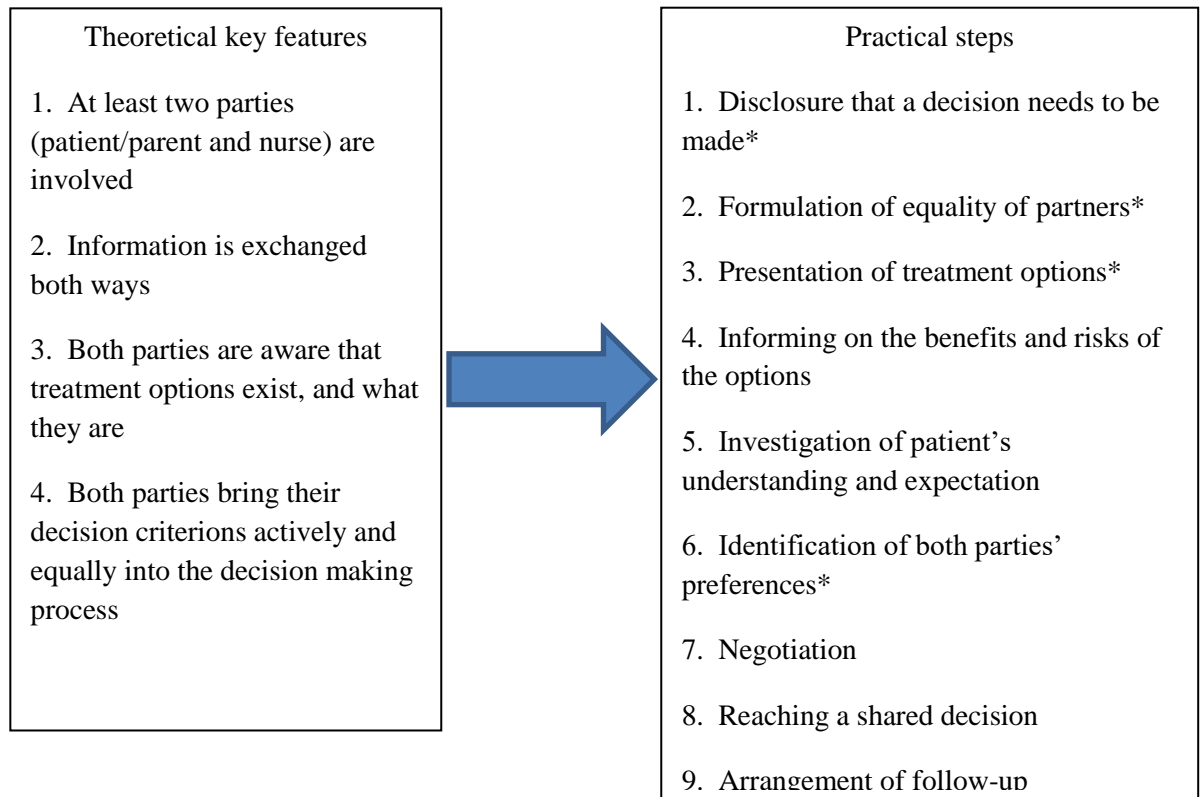
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The Context of Caring allows for individualization of the patient-provider relationship  
Melnyk, B. & Fineout-Overholt, E. (2011). *Evidence-based practice in nursing & healthcare. A guide to best practice*. Philadelphia: Lippincott Williams & Wilkins.

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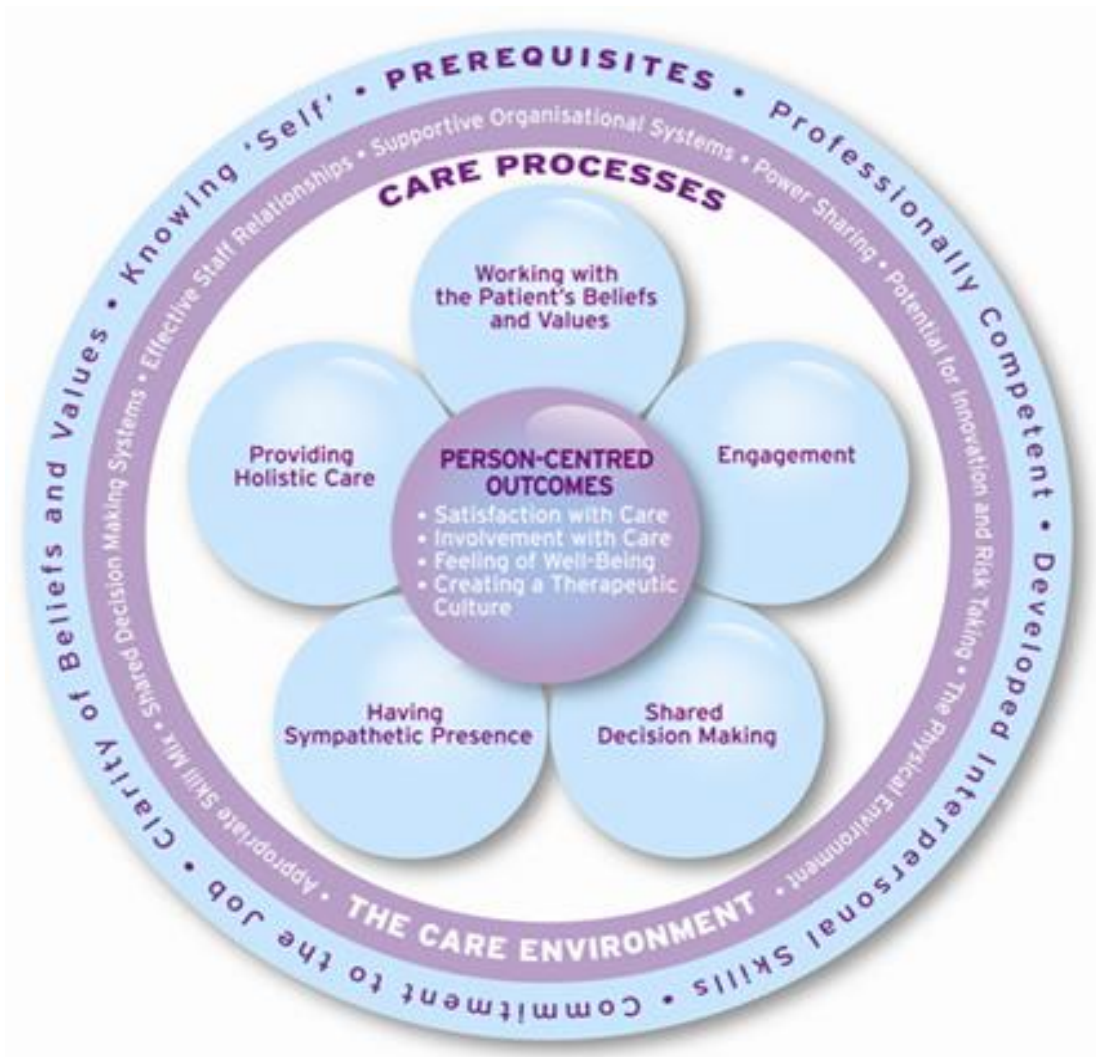
## Appendix B: Theoretical Framework: Process Model of Shared Decision Making

\*Steps, which could not be covered sufficiently by the original instrument (SDM-Q)



(Kriston et al., 2010)

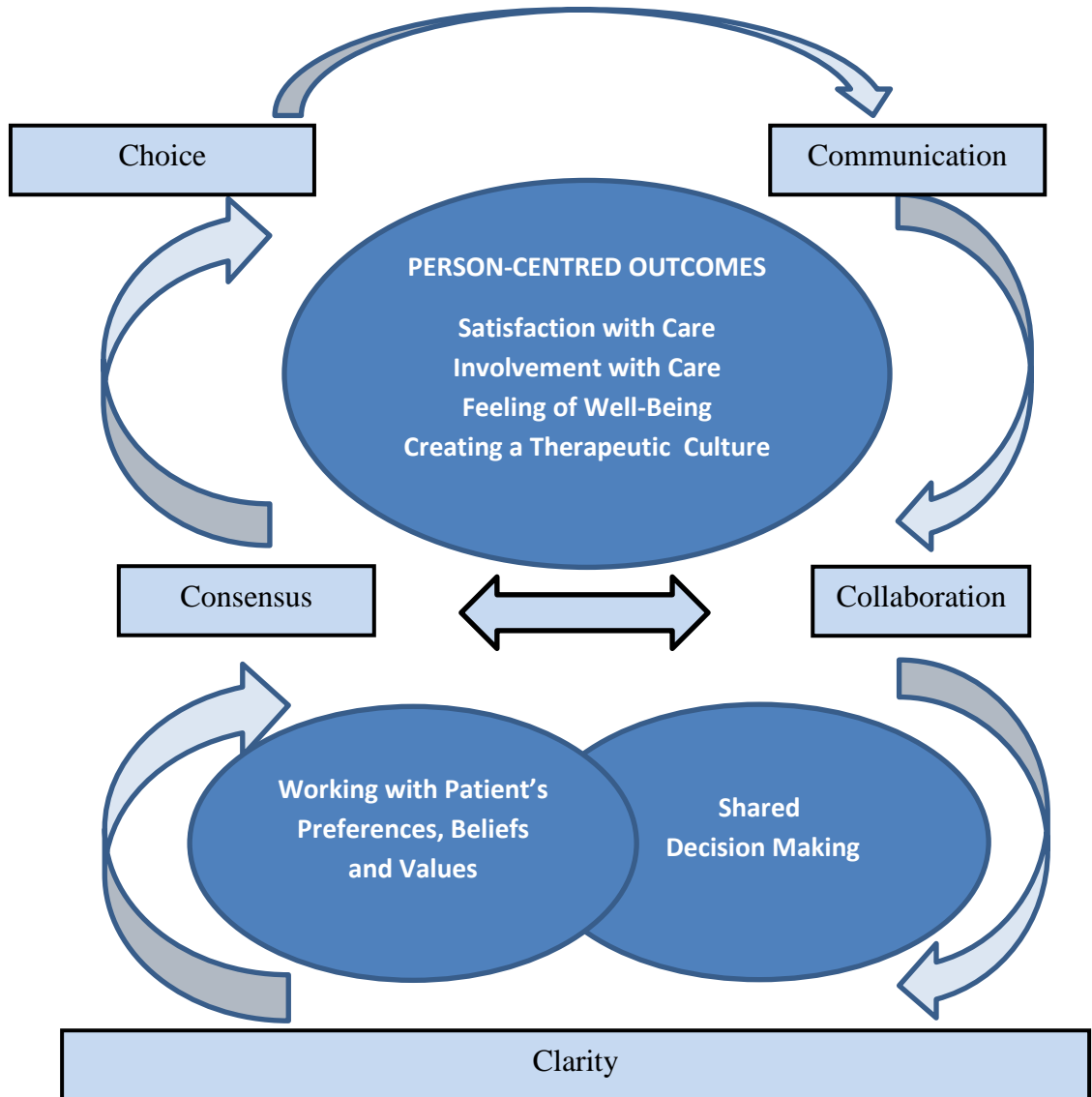
## Appendix C: Person-Centered Nursing Framework



(McCormack & McCance 2006)



Appendix D: Person and Family-Centered Nursing Framework

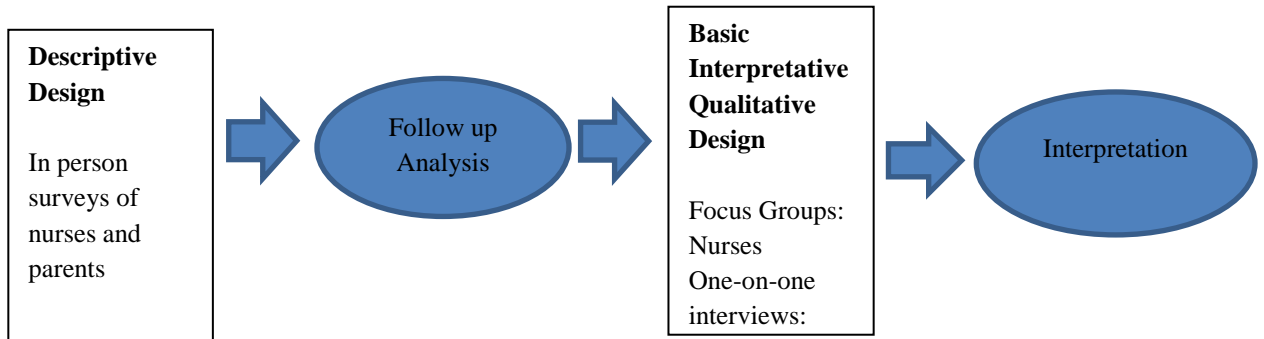


## Appendix E: Sequential Explanatory Design



(Creswell, 2003; Creswell & Plano Clark, 2011)

Appendix F: Application to Proposed Study



## Appendix G: Revised Shared Decision Making Tools

### Pediatric Shared Decision Making Questionnaire-PARENT (PSDM-Q-PARENT) A 9-item Shared Decision Making Questionnaire

In responding to the statements below, please think about a situation where you spoke with your child's nurse in making a nursing care decision about your child's care. One example could be a discussion about options of times for visitors to visit.

1. Describe a situation in which you spoke with your child's nurse about making a nursing care decision about your child's care.

1. Describe the decision that was made:

Nine statements related to the decision-making in the above-mentioned situation are listed below. For each statement please indicate how much you agree or disagree.

<b>3.</b>	<b>My nurse made clear that a nursing care decision needs to be made.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>4.</b>	<b>My nurse wanted to know how I want to be involved in making the nursing care decision.</b>					
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>5.</b>	<b>My nurse told me that there are different nursing care options for caring for my child.</b>					
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>6.</b>	<b>My nurse explained the advantages and disadvantages of the nursing care options for my child.</b>					
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>7.</b>	<b>My nurse helped me understand all the information.</b>					
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>8.</b>	<b>My nurse asked me which nursing care option I prefer.</b>					
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>9.</b>	<b>My nurse and I went over the different nursing care options.</b>					
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>10.</b>	<b>My nurse and I selected a nursing care option together.</b>					
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>11.</b>	<b>My nurse and I reached an agreement on how to proceed.</b>					
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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 July 2016, adapted by L. Long (School of Nursing, University of Louisville).  
 Adaptation of the original "9-Item Shared Decision Making Questionnaire (SDM-Q-9)".  
 Authorized by Martin Härtel & Bettine Schell (University Medical Center Hamburg-Eppendorf, Germany).

**Pediatric Shared Decision Making Questionnaire-NURSE (PSDM-Q-NUR)**  
A 9-item Shared Decision Making Questionnaire

In responding to the statements below, please think about a situation where you spoke with a parent in making a nursing care decision about their child's care. One example could be a discussion about route and type of medication to administer.

Describe a situation in which you spoke with a parent about making a nursing care decision about their child's care.

Describe the decision that was made:

Nine statements related to the decision-making in the above-mentioned situation are listed below. For each statement please indicate how much you agree or disagree.

<b>1. I made clear to my patient's parent that a nursing care decision needs to be made.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>2. I wanted to know from my patient's parent how he/she wants to be involved in making the nursing care decision.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3. I told my patient's parent that there are different nursing care options for caring for his/her child.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>4. I explained the advantages and disadvantages of the nursing care options to my patient's parent.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>5. I helped my patient's parent understand all the information.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>6. I asked my patient's parent which nursing care option he/she prefers.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>7. My patient's parent and I went over the different nursing care options.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8. My patient's parent and I selected a nursing care option together.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>9. My patient's parent and I reached an agreement on how to proceed.</b>	completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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July 2016, adapted by L. Long (School of Nursing, University of Louisville).  
Adaptation of the original "9-Item Shared Decision Making Questionnaire (SDM-Q-9)".  
Authorized by Martin Hürler & Isabelle Schell (University Medical Center Hamburg-Eppendorf, Germany).

## Appendix H: Clarity and Understanding - Parent Responses

Original Item	Findings	Parent Recommendations for Final version
3. My nurse made clear that a decision needs to be made.		My nurse made clear that a nursing care decision needs to be made.
a. How hard was it to answer the question?	(a) 1 parent: the question was not clear 1 parent: question about involvement in the nurse-mom initiated decision 3 parents: issue was not hard or difficult to identify 1 parent: question was not clear;	
b. What does the term “decision” mean to you?	(b) 1 parent: means “choice” 3 parents: they had a “choice” 1 parent: we have to do this 1 parent: have the say to tell how feel and meds. to use 1 parent: what is best - come up with what works for patient;	
c. How could the wording of this question be improved?	(c) 1 parent: change “decision” to “choice in treatment” 1 parent: simplify work to “choice” 4 parents: “no change” x 4 parents.	

<p>4. My nurse wanted to know exactly how I want to be involved in making the decision.</p>	<p>My nurse wanted to know how I want to be involved in making the nursing care decision.</p>
<p>a. How hard was it to answer the question?</p>	<p>(a) 5 parents: “not hard,” “easy” 1 parent: hard due to plan of care is made due to diagnosis;</p>
<p>b. What does the term “involve” mean to you?</p>	<p>(b) 5 parents: part of care; do things with baby – help in care; being with--; being right there in the middle; parents decide work together 1 parent: keep parents informed-allow options;</p>
<p>c. How could the wording of this question be improved?</p>	<p>(c) 5 parents: no change; no change 1 parent: simplify.</p>
<p>5. My nurse told me that there are different options for treating my child’s medical condition.</p>	<p>My nurse told me that there are different nursing care options for caring for my child.</p>
<p>a. How hard was it to answer the question?</p>	<p>(a) 1 parent: “kind of” 2 parents: difficult due to clear plan in place; difficult-nurse telling options but child’s condition deteriorating 2 parents: not hard;</p>
<p>b. What does the term “options” mean to you?</p>	<p>(b) 1 parent: different types of diagnosis 2 parents: choice; choices; you can pick different things; different choices to make better;</p>
<p>c. How could the wording of this question be improved?</p>	<p>(c) 1 parent: change condition to treatment 4 parents: no change; no change; no change; no change 1 parent: simplify – use less wording.</p>

<p>6. My nurse precisely explained the advantages and disadvantages of the treatment options.</p>	<p>My nurse explained the advantages and disadvantages of the nursing care options for my child.</p>
<p>a. How hard was it to answer the question?</p>	<p>(a) 6 parents: not hard; first a choice then no choice, not hard; completely agree surgery or not; not hard;</p>
<p>b. What does the term “advantages” and “disadvantages” mean to you?</p>	<p>(b) 3 parents: pros/cons/good/bad; good/not good; pro/con, good for pt./what does not work 1 parent: pluses/minuses 3 parents: what works, what will improve, will help child in the long run/what would negatively affect in the future;</p>
<p>c. How could the wording of this question be improved?</p>	<p>(c) 5 parents: no change; no change; no change; no change; no change 1 parent: simplify.</p>
<p>7. My nurse helped me understand all the information.</p>	<p>No change</p>
<p>a. How hard was it to answer the question?</p>	<p>a) 6 parents: not hard; not hard; not hard; not hard; not hard; not hard;</p>
<p>b. What does the term “information” mean to you?</p>	<p>(b) 6 parents: facts related to care; everything that is going on; detail; literature/someone tells you what is going on; everything the parent needs to know about the situation; to inform;</p>
<p>c. How could the wording of this question be improved?</p>	<p>(c) 5 parents: no change; no change; no change; no change; no change 1 parent: ?shorter, ?simplify.</p>



8. My nurse asked me which treatment option I prefer.	My nurse asked me which nursing care option I prefer.
a. How hard was it to answer the question?	(a) 4 parents: not hard; not hard; not hard; easy to answer 2 parents: yes it was hard, no options; hard due to no choice;
b. What does the term “prefers” mean to you?	(b) 6 parents: what would I like; preference; what would you rather--/what do you want; which one do you choose/which is better; better for child/rather not---; preference;
c. How could the wording of this question be improved?	(c) 4 parents: no change 2 parents: literacy issue with “prefers”-change to: option I would like; what way of care.
9. My nurse and I thoroughly weighed the different treatment options.	My nurse and I went over the different nursing care options.
a. How hard was it to answer the question?	(a) 3 parents: easy; not hard; not hard 3 parents: hard – difficult to answer; hard; somewhat hard – nurses are different – some explain, others do not;
b. What does the term “weighed” mean to you?	(b) 5 parents: choice; sort out options; looked at options – advantage/disadvantage; pros and cons with treatment; selection 1 parent: difficult to answer;
c. How could the wording of this question be improved?	(c) 5 parents: change weighed to reviewed; simplify; use different terms; change “weighed” to “preferred”; change “weighed” to “thought out” 1 parent: no change.

10. My nurse and I selected a treatment option together.	My nurse and I selected a nursing care option together.
a. How hard was it to answer the question?	(a) 6 parents: easy to answer; not hard- no choices for care; easy to answer but no option for care; not hard; not hard; not hard;
b. What does the term “selected together” mean to you?	(b) 6 parents: both agreed upon; agreement/standard of care; coming up with joint decision; pick; nurse and I discussed – both agreed on option best for child; both parties;
c. How could the wording of this question be improved?	(c) 6 parents: no change; no change; simplify; no change; no change; no change.
11. My nurse and I reached an agreement on how to proceed.	No change
a. How hard was it to answer the question?	a) 5 parents: easy; not hard; not hard; not hard; not hard 1 parent: difficult;
b. What does the term “agreement on how to proceed” mean to you?	(b) 6 parents: further the care; dad and nurse on same page – “do it”; solution to care; how to move forward; both agree that child gets treatment and keep it going; consensus or going forward;
c. How could the wording of this question be improved?	(c) 5 parents: no change; no change; no change; no change; no change 1 parent: how to proceed.

## Appendix I: Clarity and Understanding - Nurse Response

Item	Findings	Nurse Recommendations
3. I made clear to my patient's parent that a <b>nursing care</b> decision needs to be made.		I made clear to my patient's parent that a nursing care decision needs to be made.
a. How hard was it to answer the question?	(a) 5 nurses: easy; easy; not hard; not hard; easy 1 nurse: vague, dependent upon method to make decision: control, satisfaction, positive reinforcement;	
b. What does the term "decision" mean to you?	(b) 1 nurse: agreement between all, have to do 1 nurse: choice about care 1 nurse: something needs to be done or said when a problem arises 1 nurse: to make a choice between doing one thing or another 1 nurse: have to commit to an answer; 1 nurse: coming together for a common goal to implement a common outcome for both parties.	
c. How could the wording of this question be improved?	(c) 5 nurses: no change; no change; no change; no change; no change 1 nurse: specific if asking relevance to procedure, overall goal or medical base.	
4. I wanted to know exactly from my patient's parent how he/she wants to be involved in making the <b>nursing care</b> decision.		I wanted to know from my patient's parent how he/she wants to be included in making the nursing care decision.
a. How hard was it to answer the question?	(a) 5 nurses: not to hard; easy; not hard; not hard; not hard	

	1 nurse: appropriate – something to do in patient centered rounds;	
b. What does the term “involve” mean to you?	(b) 6 nurses: to include; how much do you want to participate; how much a person has to say in making a decision; be included in making decision; have to make a decision-parent; participation from parent or therapeutic decision making – goal-specific or broad;	
c. How could the wording of this question be improved?	(c) 5 nurses: no change; no change; no change; no change 1 nurse: to know how and what extent to be involved; 1 nurse: more specific – from what standpoint.	
5. I told my patient’s parent that there are different nursing care options for caring for his/her child medical condition.		I told my patient’s parent that there are different nursing care options for caring for his/her child.
a. How hard was it to answer the question?	(a) 4 nurses: easy; easy; not hard; not hard 1 nurse: difficult due to diagnosis 1 nurse: somewhat, depends on medical – sometimes no choice, i.e.: surgery sedation protocol;	
b. What does the term “options” mean to you?	(b) 5 nurses: different choices; different choices for care; choices – different to make decision; choices 1 nurse: treat this way or that; parent – choices.	
c. How could the wording of this question be improved?	(c) 4 nurses: no change; no change; no change; no change 1 nurse: due to diagnosis, option not valid 1 nurse: depends upon what looking for- sometimes not negotiable.	

<p>6. I precisely explained the advantages and disadvantages of the <b>nursing care</b> treatment options to my patient's parent.</p>	<p><b>I explained the advantages and disadvantages of the nursing care options to my patient's parent.</b></p>
<p>a. How hard was it to answer the question?</p>	<p>(a) 6 nurses: not hard; easy; not hard; not hard; not difficult; easy;</p>
<p>b. What does the term "advantages" and "disadvantages" mean to you?</p>	<p>(b) 6 nurses: bonus – good/harm; good comes/bad comes; benefits/risks of different treatment options; pro/con; plus/minus of staying or going home; pro, positive outcome, starting point, positive health/risk;</p>
<p>c. How could the wording of this question be improved?</p>	<p>(c) 6 nurses: no change, already easy to understand; no change; no change; no change; no change; no change.</p>
<p>7. I helped my patient's parent understand all the information.</p>	<p><b>No Change</b></p>
<p>a. How hard was it to answer the question?</p>	<p>(a) 6 nurses: not hard - also depends upon who and what referring to, i.e.: nurse, physician; easy; not hard; not hard; not hard; not hard;</p>
<p>b. What does the term "information" mean to you?</p>	<p>(b) 1 nurse: general knowledge; all things need to know to make a choice  1 nurse: full detail  1 nurse: situation  1 nurse: education/treatment plan materials, learning topics, many different forms, research;</p>
<p>c. How could the wording of this question be improved?</p>	<p>(c) 4 nurses: no change; no change; no change; no change  1 nurse: treatment plan instead of "information"</p>

	1 nurse: more specific as to what type of information referring to – relevance to specific person i.e.: RN, MD.	
8. I asked my patient’s parent which <b>nursing care</b> treatment option he/she prefers.		<b>I asked my patient’s parent which nursing care option he/she prefers.</b>
a. How hard was it to answer the question?	(a) 6 nurses: easy, easy, not hard, easy, not hard; not hard – if choices to create optimal health;	
b. What does the term “prefers” mean to you?	(b) 5 nurses: likes, want to do; which would be better; chooses the best choice; what person likes; what they would like us to do; like, dislike, choice 1 nurse: comfortable with treatment plan, providing home care, confident they can do treatment;	
c. How could the wording of this question be improved?	(c) 5 nurses: no change; no change; no change; no change; no change. 1 nurse: “plan for care” instead of “treatment plan”.	
9. My patient’s parent and I thoroughly weighed the different treatment options.		<b>My patient’s parent and I went over the different nursing care options.</b>
a. How hard was it to answer the question?	(a) 6 nurses: easy; easy; not hard; not hard; not hard; not hard; not hard, parent involvement and if parent agrees from beginning – what are options-nursing advocacy;	
b. What does the term “weighed” mean to you?	(b) 6 nurses: compare, see what is better; thought through pros and cons; risk/benefit; discuss pros and	

	cons; discussed; look at all options, limitations, maximum potential considered;	
c. How could the wording of this question be improved?	(c) 4 nurses: no change; no change; no change; no change 1 nurse: change “weighed” to “discussed” and “decided” 1 nurse: if applicable to patient, not a lot of change.	
10. My patient’s parent and I selected a nursing care treatment option together.		My patient’s parent and I selected a nursing care treatment option together.
a. How hard was it to answer the question?	(a) 6 nurses: easy; easy; not hard; not hard; not hard; not hard – find common ground;	
b. What does the term “selected together” mean to you?	(b) 4 nurses: collaborate; talked through it and determine what was best for both of us; collective decision agreed upon decision 1 nurse: weigh pros and cons, which work for her 1 nurse: chose; decision, finalized;	
c. How could the wording of this question be improved?	(c) 5 nurses: no change; no change; no change; no change; no change 1 nurse: change “selected together” to “choose a plan of care or chose to--.	

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11. My patient's parent and I reached an agreement on how to proceed.

No change

- a. How hard was it to answer the question? (a) 4 nurses: easy; easy; not hard; not hard  
1 nurse: not valid - nurse cannot make decision to proceed; 1 nurse: may not have reached an agreement but have to move forward-challenging;
- b. What does the term "agreement on how to proceed" mean to you? (b) 1 nurse: decision  
3 nurses: understanding of best treatment option and clear; both know what next steps are; obvious – difficult" same like mind"  
1 nurse: decided  
1 nurse: contract;
- c. How could the wording of this question be improved? (c) 4 nurses: no change; no change; no change; no change  
1 nurse: change to "prefer to proceed not how we can do it"; 1 nurse: reached an "understanding" – understand why but parent does not agree.
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Appendix J: Participant Voices in Shared Decision Making

THEME	SUBTHEME	PARTICIPANT VOICES
<b>Communication</b>	Clarity	<p>“Nurses spend time, provide clarification and encourage education activities in order for parents to better understand their child’s care.”</p>
	Avoiding Conflict	<p>“Yeah, cuz it’s not a good feeling when you walk in and tell a parent something and they’re like, “But this doctor said the opposite of that,” but you have no idea they said that to the parents cuz they didn’t communicate it”.</p> <p>“Or you go in and they’re eating a cheeseburger, and you’re like, “Uh, you’re supposed to be NPO.”</p> <p>“The doctor told us we could eat.” Yeah, and then they put the order in, so then you have to page them, and then they get, you know.”</p>
	Empowerment	<p>“You’re stressed you’re in the hospital. They come in, they have a quick agenda that they want to get out the door to see the next patient. So that way you make sure that all of your needs are met and you’ve got all of your questions answered while they’re here with you. Write them down and take a quick—I always say “Take a look at the list when you’re done and make sure they’ve answered everything that you have.” Because inevitably they will walk out of the room, and they will start asking you those questions, and you cannot answer them.”</p> <p>“If you really feel like this is the wrong path, then we need to let someone know. Or you need to let the doctors know ‘my kid doesn’t normally act this way; this is weird for them.’”</p> <p>“I love the new diagnosis family. I love talking with them and educating them on the process and</p>

		listening to them and just helping them walk this new journey. And that's how I define it is you are at the beginning of a new journey that you didn't know you were going to take in this life. So we're just going to take it one day at a time, and sometimes one minute at a time"
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	Consistency	<p>"They say they're not told the same thing consistently. So the communication becomes in even nursing care "I'm your nurse, I'll be bringing the meds," and then the aide comes in: "I'm your aide, and I'll be doing blah, blah, helping you with your bath. Do you want to give your child a bath? Or do you want me to?" And to me, that's the extent of nursing care, other than "I'll be doing vital signs. Do you want to—" I don't know that the nurses actually say, "Your child will be less fearful if you provide the home care as a bath and feeding."</p> <p>"I feel like everyone just needs to be on the same page."          "Yeah Communication is key—key"</p>
<b>Team Approach</b>	Clear Understanding	Engage the parents in that care, and if the child is old enough, the child also, so that they feel like they're a part of the decision making. And it's not just me saying "you're going to this and this and this, and you have to take this med, and you have to—" whatever. So I think if you make it interesting and knowledgeable at the same time and give the child a choice when you can—
	Nurse, parent and child together in decision making	I think of like maybe we have a teenage patient so they're able to make decisions, but they obviously aren't old enough to sign their own consent yet or whatever. So I think of that, like them being able to talk with their parents and giving their own opinion about their healthcare even though they're technically not old enough to actually be in complete charge of their own care.

		<p>We actually had to meet him and see what his concerns were and help her get better by Dad's way as much as we could let him make some decisions in her care. "Well, we can get up after she takes a nap, after lunch" or whatever. Let him make those decisions. So I think we worked together to come out with a solution, and he was happy and he said, "OK, I think we're ready to get up.</p> <p>So you gotta meet them where they're at and listen. A couple of things I could think about would be mouth care for prevention of mucositis. Well, maybe parents don't want to do the mouth care cuz their child was sick all day, and they're finally asleep for the first time in six hours or something, and they want to forego the mouth care. So at that time, I'll be like, "I understand. Sleep's really important and I agree. But this mouth care is really important. You don't want to give any opportunity for infection or breakdown of their mucosal lining. So I just want you to hear me that it's really important. So if your child should wake up, please call out and I'll come in and do mouth care." Or whatever. This is a really simple example. Baths are another thing that falls in the cracks a lot. Parents get absent minded about the hygiene of their child and I don't think it's deliberate; they just get—it's just one of those things that gets swept under the rug. It really does come down to us saying, "Hey, listen, have you given your child a bath in the past three days?" We really need to be doing.</p>
	Expectation	<p>Encourage doctors to participate.</p> <p>To me SDM in the pediatric world in the until I work on is that the nurse and the parents and even the patient if they're old enough to understand and know what's going on work together to meet the needs of that patient. That doesn't mean they do what the nurses or doctors say. We educate them as to the doctor's orders, their plan of care, and</p>

		<p>how we have to try to achieve it, but then the give us the input “Oh no, my [son or daughter] can’t do it this way; can we try it this way?” But you work together to achieve the outcome, which is great.</p> <p>When I think of SDM I think of the physician, the nurse, the family—at the bedside discussing a plan of care.</p> <p>Since I’ve worked here for—I lose track of the years 16-ish years, we didn’t always do the family-centered rounding. And I started off on night shifts. So when I say “that’s recent,” it’s probably been several years that we’ve been doing that. But I think that helps; it keeps everybody on the same page. Plus, being a teaching hospital, when they round it’s like a huge team. And at least they’re going in all at once, all together and they try to have the nurse at the bedside if it’s possible with the parents. So you have the whole team”.</p> <p>“I do think the parent is an integral part in the care of the child and keeping them out of the hospital. So I like to make sure that we included them, that we talk to them at a level they understand, eye contact to make them feel a part of it is important, that kind of thing.”</p>
	Collaboration	<p>“I also talk to the social workers about there are some insurances that will give us the info whether the family is actually has been getting their meds like they said”.</p> <p>“I had a patient that came in, it was a suicide kid, and the team wanted her to go to the psychiatric unit. Well, she had an outpatient psychiatrist, so her mom just wanted to see him the next day. And so they had our psychologist come talk to her, and he thought she needed to go to the unit rather than go home. Well, the mom wasn’t for that. So I explained to her what the psychiatric unit was about and that they do a lot of group therapy and it would probably be better for her cuz she tried to</p>

		<p>hurt herself. She can tell her that she's not going to hurt herself, but she might still. And they thought that was best and that she should probably do what the doctor thinks. The doctors came back too, but she ended up going to the psychiatric unit.”</p> <p>“And to make them feel for that 5 minutes that they are my only patient, that they are my concern, and I'm not worried about getting into the next room unless it's an emergency. I think that really sets the tone because then they're like coming back and saying, “Oh, I forgot to ask you this,” or “They never told me this on day shift,” and “what time did you say that med—.” So it's kind of like if you give them the little plan of care for the next 12 hours—they're not necessarily going to remember everything you say of course—but to just let them know that you're there for them and you'll be in every hour to check the IV or every 2 hours if it's a saline lock. We all carry cell phones on us, and we have a wipe off board that we write our name on there and our cell phone numbers are on there and let them know that the residents are here all night if they think of anything else later that they have a question about—just not to hesitate to ask. Cuz I think the only bad question is one that you don't ask. There's no stupid question because if you don't ask it, then you're not going to get an answer”.</p>
	Perception	<p>“Hey, the care you're getting, this is why we're doing it.” so maybe they are thinking they're involved in discussing yes or no, we're going to do this. And it's just we're telling them that this is the care you're getting because this is why you need it. So maybe their perception that they should be involved on the decision but really nursing, we're not involved in the decisions”.</p>

CURRICULUM VITAE

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**A. Education**

<u>Institution</u> <u>Degree</u>	<u>Location</u>	<u>Dates</u>	
School of Nursing PhD University of Louisville	Louisville, Kentucky	Expected graduation Spring 2018	
Arizona State University Master's EBP Certificate Health Innovation	Tempe, Arizona College of Nursing and Cincinnati, Ohio	8/2006-8/2007	Post-
College of Nursing M.S.N.	Cincinnati, Ohio University of Cincinnati	9/1985-6/1987	
College of Allied Health B.S.N and Nursing Eastern Kentucky University	Richmond, Kentucky	8/1976-5/1980	

**B. Academic Appointments**

8/2017-Associate Director, Online and Hybrid Program: Accelerated Bachelor of Science in Nursing: Xavier University; Cincinnati, Ohio

7/2012-9/2017 Instructor of Clinical Practice: The Ohio State University; Columbus, Ohio

1/2011-6/2012 Clinical Instructor: Wright State University; Dayton, Ohio

8/2010-12/2010 Lecturer: University of Louisville; Louisville, Kentucky

9/1998-6/2004 Assistant Professor Clinical Nursing: University of Cincinnati; Cincinnati, Ohio

9/1992-6/1997 Clinical Instructor: University of Cincinnati; Cincinnati, Ohio

8/1988-5/1992 Assistant Professor of Nursing: Northern Kentucky University; Highland Heights, Kentucky

8/1987-7/1988 Nursing Instructor: School of Nursing Deaconess Hospital; Cincinnati, Ohio

### **C. Other employment**

3/2006-12/2010 Director, Evidence-Based Practice: Cincinnati Children's Hospital Medical

Center; Cincinnati, Ohio

9/2005-5/2006 Consultant: Orbis, Inc.; Fisher, Indiana

12/2003- 12/2010 Clinical Nurse Specialist/Evidence-Based Practice: Cincinnati Children's

Hospital Medical Center; Cincinnati, Ohio;

6/1997-9/1998 Clinical Nurse Specialist/Otolaryngology/Airway Management: Cincinnati

Children's Hospital Medical Center; Cincinnati, Ohio

5/1992-8/1993 Staff Nurse/ Clinical Nurse I: Cincinnati Children's Hospital Medical Center;

Cincinnati, Ohio

3/1990-6/1991 Totsaver CPR Monitor: Good Samaritan Hospital; Cincinnati, Ohio

2/1985-2/1990 Staff Nurse/ ICU/SDU: Cincinnati Children's Hospital Medical Center; Cincinnati, Ohio

11/1984-1/1985 Staff Nurse/NICU: Good Samaritan Hospital; Cincinnati, Ohio

8/1981-10/1984 Staff Nurse/Rotating Charge: Kosair Children's Hospital; Louisville, Kentucky

6/1980-7/1981 Staff Nurse/ Medical Surgical Unit: Fayette County Memorial Hospital;

Washington Court House, Ohio

**D. National Board Certification(s) and state RN Licensure(s)**

Ohio License: Reg. #21-16-9320

**E. Professional Memberships and Activities**

Sigma Theta Tau – Beta Iota Chapter

Member: 2006-2015

Sigma Theta Tau, Beta Iota Chapter, Awards and Scholarship -2006-2007, 2009

Sigma Theta Tau, Iota Zeta Chapter, Member 2015

Society of Pediatric Nurses

Ohio River Valley Chapter – member-at-large, 2007, 2009

Ohio Chapter- member, 2012, 2013, 2014, 2015

National Nominating Committee – member, 2009, 2010 (elected)

National Conference Planning Committee- member, 2010, 2011, 2012

Co-chair National Conference – 2012-2013



Chair National Conference – 2013-2014

National League for Nursing – Member, 2011

Presenter for the 1994 American Nursing Review; University of Cincinnati, June 1994

Consultation for July, 1993, Children's Hospital Medical Center Nursing Grand Rounds

## **F. Honors and Awards**

Lambda Sigma Honorary

- Eastern Kentucky University

Nursing Honor Society

- Eastern Kentucky University

Collegiate Pentacle Honorary

- Eastern Kentucky University

Sigma Theta Tau International Honor Society of Nursing

- Beta Iota Chapter

Excellence in Clinical Teaching Award

- University of Cincinnati

Golden Key Honor Society

- University of Louisville

## **G. Committees and Services**

### a. University/Organization

Xavier University – Nursing Faculty Organization- member - 2017

The Ohio State University – Task force for Integration of EBP into curriculum – Leader – 2012

Cincinnati Children's Hospital Medical Center – Evidence Federation – co-leader – 2006 - 2008

Cincinnati Children's Hospital Medical Center – Nurse Residency Steering Committee-member

2006 - 2008

Cincinnati Children's Hospital Medical Center – A6 South Microsystems Development/High

Reliability Team – member – 2005, 2006

Cincinnati Children's Hospital Medical Center – Divisional Nursing Research and Evidence-

Based Practice Council, member- 2005, 2006

Cincinnati Children's Hospital Medical Center – A6 South Nursing Research Council, AdHOC

member – 2004 - 2006

University of Cincinnati – Decanal Review Committee – Member – 2002

Children's Hospital Medical Center – CHMC Faculty Committee AdHOC Task Force  
(Development of Faculty Competencies) – Member – 1995 - 1996

Children's Hospital Medical Center – Planning Committee December 1994 Nursing Grand

Rounds – Member – 1994

Children's Hospital Medical Center – Planning Committee National Pediatric Critical Care

Conference – Co-Chairperson 1994 - 1996

Children's Hospital Medical Center – Faculty Service Committee Ad HOC Task Force (Student

Placement) – Member – 1993 - 1995

Northern Kentucky University Department of Nursing, Associate Degree Faculty Search  
Committee – Chairperson - 1990-1991

b. School of Nursing

University of Cincinnati – Curriculum Task Force – Member - 2002

University of Cincinnati – Curriculum Committee – Member – 2002

University of Cincinnati – Representative to Cincinnati Children’s Hospital Medical  
Center

Service Committee – Member – 2001 - 2004

University of Cincinnati – Admission and Progression – Member – 1999

University of Cincinnati – Affirmative Action Committee – Member – 1998-2000

University of Cincinnati – 1996 Senior Class Co-Advisor – 1995-1996

University of Cincinnati – Department Head Review Committee Member – 1994-1995

University of Cincinnati – Undergraduate Admissions and Student Progress Committee –  
1993 -

1996

University of Cincinnati – Curriculum Nursing Process Ad HOC Committee – Member –  
1993 -

1994

University of Cincinnati – Student Grievance Committee – Member – 1992 - 1994

Northern Kentucky University Department of Nursing, Resource Committee – Member –  
1990-

1991

Northern Kentucky University Department of Nursing, Professional Development  
Committee –

Member 1988 - 1989

Northern Kentucky University Department of Nursing, Associate Degree Student Development

And Concerns Committee – Member 1988 - 1989

Children's Hospital Medical Center Research Interest Group Member – 1988 - 1991

c. Community Service

Cincinnati Center for Developmental Disorders – Child Find Subcommittee of Hamilton County

Early Intervention Collaborative – Member – 1993 - 1995

Cincinnati Center for Development Disorders – Hamilton County Early Intervention Collaborative – Member – 1993 - 1995

## **H. Journal Editorial Boards, Advisory Councils, Peer Reviewer of Manuscripts**

Manuscript Review Panel: Pediatric Nursing Journal, 2006 - 2011

## **I. Teaching**

### Undergraduate

Nursing Advancement: Evidence-based Practice: RN to BSN Students; The Ohio State University: Online. Fall 2012; co-lead, 160 students; Fall 2013, course lead, 160 students Online; Fall 2014, course lead, 150 students; Fall 2015, course lead, 130 students

Cultural Competency: RN to BSN Students; The Ohio State University: Online, Fall 2016, 60

students; Online, Spring 2017, 30 students

Evidence-based Practice for the Graduate Nurse: MSN Students; The Ohio State University:

Online, Fall 2016, 30 students; Spring 2017, 60 students.

Nursing Care of Childrearing Families: Undergraduate senior and graduate students; Wright

State University; Winter 2011; 120 students for lecture; 16 clinical students

Community Nursing: Undergraduate senior students; Wright State University; Winter 2011;

16 clinical students.

Interdisciplinary Professionalism: Undergraduate senior; University of Cincinnati

Winter 2004; 40 students

Foundations of Nursing II: Undergraduate sophomore; University of Cincinnati

Spring 2004; 100 students

Foundations of Nursing I: Undergraduate sophomore; University of Cincinnati

Winter 2004; 100 students

Transition to Professional Practice; Undergraduate senior; University of Cincinnati

Spring 2000; coordinated clinical placement of 200 students

Health Patterns A: Undergraduate junior; University of Cincinnati; spring

2001 - 2004; clinical 16 students/quarter

Health Patterns I, II, III: Undergraduate junior; University of Cincinnati; winter 1999;  
clinical,

16 students/quarter

Health Assessment Lab: Undergraduate junior; University of Cincinnati; fall

1998 – 1999, 2001 - 2003; clinical 16 students/quarter

Professional Practicum: Undergraduate junior; University of Cincinnati; fall 1998;  
clinical,

16 students/quarter

Role Transition: Undergraduate senior; University of Cincinnati; spring 1994; winter 1995/1996; 50 students

Nursing Care of Children: Undergraduate freshman; Northern Kentucky University; Academic Year 1992 - 1993; 120 students lecture; 16 clinical students

Nursing Care of Adults: Undergraduate freshman; Northern Kentucky University; Spring 1989, 199 - 1992; 16 clinical students

Nursing Care of Adults and Children: Undergraduate freshman; Northern Kentucky University

Fall 1989, 1991 - 1992; 120 students-lecture

Foundations of Nursing I: Undergraduate freshman; Northern Kentucky University; Fall 1988, 1990 - 1991; 16 clinical students.

### Graduate

Evidence-based Nursing: Transforming Clinical Practice – Graduate, The Ohio State University, Fall 2012, 30 students; Fall 2013, 30 students; Fall 2014, 30 students

Evidence-based Practice and Nursing Scholarship – Graduate, The Ohio State University, Online

Spring 2013, 40 students; Spring 2014, 40 students; Spring 2015, 40 students; Spring

2016, 40 Students; Fall 2016, 30 students; Spring 2017, 60 students

Nursing Research Application and Utilization: Graduate: Wright State University; Spring 2012;

Online; 24 students

Nursing Research Application and Utilization: Graduate; Wright State University; Spring 2011;

21 students

Evidence-Based Nursing: Graduate online; University of Louisville; Fall 2010; 17 students

Nursing Care of Children: Graduate clinical; University of Cincinnati; Summer 1995;

16 students

## **J. Abstracts and Presentations**

### **a. Podium Presentations: National/International Meetings**

2013 – Presenter - Long, L., Melnyk, B.M., & Gallagher-Ford, L.

(November, 2013). Integrating Evidence-based Practice throughout the Academic Curriculum. Celebrating Early Signs of Transition to a Fully Integrated EBP Curriculum: Spring Flowers. *42nd Biennial Sigma Theta Tau International Convention.* Indianapolis, IN.

2013 – Presenter - Long, L., Gallagher-Ford, L. & Buck, J. (November, 2013). Walking the Talk: Using Evidence to Create an Extraordinary EBP Education Program. Asking the Tough Question: Are We Teaching EBP the Best Way Possible? Re-Inventing Our Own Wheel. *42<sup>nd</sup> Biennial Sigma Theta Tau International Convention.*

Indianapolis, IN.

2013- Presenter - Long, L.E. & Brewer, T.L. (November, 2013).

An Exploration of Contextual Factors Impacting Nurses Implementation of



Evidence: Readiness, Beliefs, Skills and Needs. *42nd Biennial Sigma Theta Tau International Convention.* Indianapolis, IN.

2011- Presenter - Long, L. 12<sup>th</sup> Annual Evidence-Based Practice Conference – Preconference

(invited speaker) - Organizational Culture & Evidence-Based Decisions: Influencing

National, Regional and Organizational Policy. June 2011. Phoenix, Arizona.

Presentation entitled: Understanding Systems to Lead an Evidence Culture.

2011- Presenter - Long, L. 12<sup>th</sup> Annual Evidence-Based Practice Conference – Preconference

(invited speaker) – Organizational Culture & Evidence-Based Decisions: Influencing

National, Regional and Organizational Policy. June 20. Phoenix, Arizona.

Presentation

entitled: Policy and Evidence: Making a Difference in Healthcare.

2011-Presenter - Long, L. 12<sup>th</sup> Annual Evidence-Based Practice Conference

Be a Transformer: Your Role in Leading Evidence-Based Practice

& Health Policy. June 9-10, 2011. Phoenix, Arizona. Presentation entitled:

Making a Difference with Multisystem Mentoring.

2011-Presenter - Long, L, & Brewer, T. Society of Pediatric Nurses

Annual Convention. Pediatric Nurses: Leaders in Making Health Care Safe for

Children and Families. March 2011. Las Vegas, Nevada. Presentation entitled:  
An Evidence-Based Literature Synthesis: Length of Stay and Incidence of  
Rebound in Term Infants with Hyperbilirubinemia.

2010 – Presenter - Morrison, C., & Long, L.E. 11<sup>th</sup> Annual National/International  
Evidence-

Based Practice Conference-Translating Research into Best Practice with  
Vulnerable

Populations – The Role of Technology in Advancing Evidence-Based Care. June  
2010.

Phoenix, Arizona. Presentation entitled: Evidence-Based Practice Project:  
Peripheral Chemo Vesicant Administration.

2009- Presenter - Long, L.E., & Huth, M.M. Sigma Theta Tau National Conference.

November, 2009. Indianapolis, Indiana. Presentation entitled: Engaging Staff  
Nurses in

Evidence at the Point of Care.

2009 – Presenter - Long, L.E., & Giambra, B. National Hemophilia Foundation: 61<sup>st</sup>  
Annual

Meeting, Building Bridges. October, 2009. San Francisco, CA. Presentation  
entitled:

Validating Social Work Strategies Through Evidence-Based Practice.

2009 – Presenter - Long, L. E., & Huth, M. M. Society of Pediatric Nurses 19<sup>th</sup> Annual

Convention: Embracing Children: Our Most Valuable Resource. Atlanta, Georgia.

Presentation entitled: Strategies to Engage Staff in Evidence at the Point of Care.

2008 – Presenter -Burkett, K., Huth, M., & Long, 9<sup>th</sup> Annual National/International Evidence-

Based Conference 2008. February 2008, Phoenix, Arizona. Presentation entitled:

A

Process to Evidence-Base Policies and Procedures: What Does it All Mean?

2008 – Presenter - Long, L. 9<sup>th</sup> Annual National/International Evidence-Based Conference 2008.

February 2008, Phoenix, Arizona. Presentation entitled: An EBP Project: Effect of an

Educational- Behavioral Intervention Program on Parent Satisfaction and Staff EBP

Beliefs and Implementation.

2008 – Presenter - Long, L. & Brewer, T. 9<sup>th</sup> Annual National/International Evidence-Based

Conference 2008. February 2008, Phoenix, Arizona. Presentation entitled: Theory.

Evidence and Guidelines: Strategies for Integrating Evidence into the Care of the Pediatric Patient and Family.

2006 – Presenter – Long, L. Tenth Anniversary, Panamericana Univerisdad International

Congress,. Mexico City, Mexico. September 8 and 9, 2006. Presentation  
entitled:

“Good, Better, Berst: Use of Evidence in Practice”.

2004 – Presenter – American Association of Colleges of Nursing Baccalaureate Conference.

Sunny Isles, Florida, November 10-13, 2004.

b. Podium Presentations: Local/Regional Meetings

2007-Presenter- Long, L., Brewer, T. & Pansing, J. Navigating

Educational Waters: Health Professionals Working Together to Bridge Education and Outcomes. Covington, Kentucky. May 2007.

Presentation entitled: Who Moved Our Cheese? Competency Evaluation of Change, Teamwork, Evidence-Based Practice and Critical Thinking.

2007- Presenter- Burkett, K., Long, L. & McGee, S. PNP

Seminar class, University of Cincinnati, College of Nursing. May 2007.

Presentation entitled: Good, Better, Best: Use of Evidence in APN Practice.

2006 - Presenter – Burkett, K, Long, L. & McGee, S. APN

Conference: The Future of the APN: Linking Clinical Experts and Clinical

Scholars through Evidence-Based Practice. Cincinnati, Ohio. November 2006.

Presentation entitled: Good, Better, Best: Use of Evidence in APN Practice.

2005 – Presenter – Long., L. Nursing Notes: Children’s Hospital

Medical Center, Cincinnati, Ohio. February 8, 2005. Presentation entitled: A

Journey towards Evidence-Based Practice.

1988 – Presenter – Continuing Education Offering, Pediatric Nursing Care. Saint Elizabeth Medical Center, Edgewood, Kentucky.

1987 – Presenter – Continuing Education Offering, Children and the Importance of Play.

Saint Elizabeth Medical Center, South Unit, Edgewood, Kentucky

1987 – Presenter – Primary Care Nursing. Saint Elizabeth Medical Center, South Unit, Edgewood, Kentucky.

1987 - Presenter – Pediatric Code Blue. Saint Elizabeth Medical Center, South Unit, Edgewood, Kentucky.

1986 - Presenter – Continuing Education Offering, Physical Assessment I and II. Saint

Elizabeth Medical Center, South Unit, Edgewood, Kentucky.

1981 - Presenter - Spiritual Care and the Nurses Role. Department of Public Health,

Washington Court House, Ohio

Poster Presentations: National/International Meetings

2010-Presenter- Long, L.E., Giambra, B., McGee, S., & Meier, M.

Society of Pediatric Nurses 20<sup>th</sup> Annual National conference. April

2010. Orlando, Florida. Poster entitled: Mentoring Healthcare

Providers through the Maze of EBP.

2008 – Presenter - Long, L. E., Burkett, K., McGee, S., &

- Huth, M. M. 15<sup>th</sup> National Evidence-Based Practice Conference. April 2008, Coralville, Iowa. Presentation entitled: Promotion of Safe Outcomes: Incorporating Evidence into Policies and Procedures.
- 2007 – Presenter - Brewer, T. & Long, L. Sigma Theta Tau International Nursing Honor Society, Vienna, Austria. July 2007. Presentation entitled: Empowering Nurses to Integrate Evidence-Based Practice at the Bedside.
- 2007 – Presenter - Johnson, K., Long, L., Tierney, C., Beiting, M. & Switzer, M. Society of Pediatric Nurses 17<sup>th</sup> Annual Convention: Expanding the Possibilities. Milwaukee, Wisconsin. April, 2007. Presentation entitled: An Evidence-Based Practice Project: Subcutaneous Aspiration.
- 2007 - Presenter - Long, L., McGee, S. & Burkett, K. Society of Pediatric Nurses 17<sup>th</sup> Annual Convention: Expanding the Possibilities. Milwaukee, Wisconsin. April, 2007. Presentation entitled: An Evidence-Based Workshop: Does it make a difference?
- 2007-Presenter- Johnson, K., Long, L., Tierney, C., Beiting, M. & Switzer, M. 8<sup>th</sup> Annual Evidence-Based Practice Conference. Translating Research into Best Practice with Vulnerable Populations. Phoenix, Arizona. February, 2007. Presentation entitled: An Evidence-Based Practice Project: Subcutaneous Aspiration.
- 2007-Presenter - Long, L., McGee, S. & Burkett, K. 8<sup>th</sup> Annual Evidence-Based Practice Conference. Translating Research into Best Practice with Vulnerable Populations. Phoenix, Arizona. February,

2007. Presentation entitled: An Evidence-Based Workshop: Does it make a difference?

2003 – Presenter – Poster accepted for American Association of Colleges of Nursing

Baccalaureate Conference. San Antonio, Texas, November, 2003

1996 – Presenter – Poster accepted for National Pediatric Critical Care Conference –

Pediatric Critical Care Innovations in Nursing Practice: Strategies for Today and Tomorrow. Cincinnati, Ohio, April 11-12, 1996. Poster

Their Presentation of Research entitled: Parental Participation in the Care of Critically Ill Child.

Poster Presentations: Local/Regional Meetings

2015 –Presenter-Poster presentation. Long, L. & Polivka, B. Midwest Nursing Research

Society, Indianapolis, Indiana. April 2015. Use of Cognitive Interviewing in the

Testing of Two Pediatric Shared Decision Making Instruments.

2014- Presenter-Poster presentation. Long, L., Polivka, B. Midwest Nursing Research

Society, St. Louis, Missouri. March, 2014. Determining Readiness of Nurses and Organizations in the Development of an Evidence-based Culture.

2011- Presenter-Poster presentation. Egbert, A., Lincicome, A., Elam, A. Shinkle, M.,

& Long, L. Society of Pediatric Nurses Annual Conference, Las Vegas,



Nevada. March, 2011. Presentation entitled: Maintaining a Full House  
for  
Research Involvement among Float Pool Nurses.

2007 –Presenter- Poster presentation. Long, L., McGee, S. & Burkett, K. .  
Nursing

Research Poster Day, Cincinnati Children’s Hospital Medical Center.

June, 2007. Presentation entitled: An Evidence-Based Workshop:  
Does it make a difference?

2007- Presenter- Poster presentation. Long, L., Alexander, A. Sigma Theta Tau  
International Annual SONK Consortium Conference: The  
Professional’s Contract with Society: A Commitment to Health and  
Safety. Sharonville, Ohio. March, 2007. Presentation entitled:

Searching the Evidence: Best Nursing Practice for Children with  
Cellulitis.

2006– Presenter– Poster presentation. Johnson, K., Long, L., Tierney, C., Beiting,  
M.,

Switzer, M. 14<sup>th</sup> Annual Northwest Indiana Nursing Research  
Conference – New Dimensions in Nursing Research: Impacting  
Patient Outcomes through Research. Merrillville, Indiana. November,  
2006.

Presentation entitled: An Evidence-Based Practice Project:  
Subcutaneous Aspiration.

2006 - Presenter- Poster presentation. The Ohio State University, Quest for  
Excellence

Conference. Dublin, Ohio. September 26, 2006. Poster entitled:  
Who Moved Our Cheese: Competency Evaluation of Change, Team  
Work, Evidence Based Practice, and Critical Thinking.

2005 – Presenter – Poster accepted for Research Day. Cincinnati Children’s  
Hospital

Medical Center, Cincinnati, Ohio. February 8, 2005. Poster entitled:  
Searching the Evidence: Best Nursing Practice for Children with  
Cellulitis.

2005 – Presenter – Poster accepted for Research Day. Cincinnati Children’s Hospital

Medical Center, Cincinnati, Ohio. February 8, 2005. Poster entitled:  
Revitalization of a Unit-Based Nursing Research Council

1988 – Presenter – Eighth Annual Research in Nursing Conference, College of Nursing

and Health, University of Cincinnati, Cincinnati, Ohio. April 18, 1988. Poster Presentation of Research, Parental Interest in Participating in the Care of Their Ill Child in the Pediatric Intensive Care Unit.

## **M. Publications, Book Chapters, Monographs and Textbooks**

### a. Peer-reviewed

1. Melnyk B. M. & Fineout-Overholt, E. (2015). **Chapter Contributor, first author:**

*Evidence-based Practice in Nursing & Healthcare. A guide to Best Practice.*  
3<sup>rd</sup>

edition. Chapter 7, 171-181.

2. Melnyk, B.M., Gallagher-Ford, L., **Long, L.E.**, & Fineout-Overholt, E. (2014). The

Establishment of Evidence-based Practice Competencies for Practicing Registered Nurses and Advanced Practice Nurses in Real-World Clinical Settings: Proficiencies to Improve Healthcare Quality, Reliability, Patient Outcomes, and Costs. *Worldviews on Evidence-Based Nursing*, 00.00, 1-11.

3. **Long, L.E.** & Brewer, T. (2011). Evidence-Based Policy in the New Organizational

Paradigm Part 1. *Journal of Pediatric Nursing*, 26(4). 385-387.

4. **Long, L.E.** & Brewer, T. (2011). Evidence-Based Policy in the New Organizational

Paradigm Part 2. *Journal of Pediatric Nursing*, 26(5). 507-510.

5. **Long, L.E.**, McGee, S., Kinstler, A. & Huth, M. (2011). Aligning the Forces of

Magnetism to Achieve Exemplary Professional Practice. *Journal of Pediatric*

*Nursing*, 26(2). 108-113.

6. **Long, L.E.**, Burkett, K. & McGee, S. (2009). Promotion of Safe Outcomes:

Incorporating Evidence into Policies and Procedures. *Nursing Clinics of North*

*America*, 14(1). 57-70.

7. Finkelman, A. & Kenner, C. (2007). **Chapter contributor.** *Teaching IOM. Implications of the Institute of Medicine Reports for Nursing Education.* Maryland: ANA.

8. Brehm, B., Breen, P., Brown, B., **Long, L.**, Smith, R., Wall, A., & Warren, N. (2006).

An Interdisciplinary Approach to Introducing Professionalism. *American Journal of Pharmaceutical Education.* 70(4).

9. **Long, L.E.** (2003). Stress in families of children with sepsis. *Critical Care Nursing*

*Clinics of North America,* 15. 47-53.

b. Non peer-reviewed/interviews/media

2009-Interview-Research by Nurses Improves Care. *2009 Nursing Annual Report: The*

*Journey Continues.* Cincinnati Children's Hospital Medical Center.

2007-Interview-Implementing Evidence-Based Practice in Work Environments. ASU

*Nursing. Innovations in Clinical Practice and Community Partnerships.* College

of Nursing and Health Innovation. Arizona State University.

## **N. Invitational Speaking Engagements**

### a. National

2010- Presenter (invited) - Key Note address. Long, L.E., Morgan, B.J., Siegle, L., & Morrison, C. Sigma Theta Tau, Zeta Alpha Chapter Spring Conference. April 2010. Chattanooga, Tennessee. Presentation entitled: Systems and Strategies: Engaging Point of Care Staff in Evidence Evaluation.

2015- Long, L.E., & Brewer, T.L. (September). "Nursing Evidence-Based Practice: Improving the Quality of Pediatric Care." Children's Hospital of Orange County. Orange, CA.

2015-Brewer, T.L. & Long, L.E. (September, 2015). "Nursing Evidence-Based Practice: Asking the Question, Finding the Evidence." EBP Scholars Program, Children's Hospital of Orange County. Orange, CA.

### b. Regional

2014-Presenter (invited) - Brewer, T.L. & Long, L.E. Research Louisville. Louisville, Kentucky. September, 2014. Presentation titled: Super Hero Evidence: Does Your Literature Have the Strength to Support your Practice Change. Louisville, KY.

2017-Presenter (invited) - Brewer, T.L. & Long, L.E. Research Louisville. Louisville, Kentucky. September, 2017. Presentation titled: Bridging the Gap and Busting through Barriers: Implementing Evidence into Nursing Practice. Louisville, Kentucky.

## **O. Funded Research**

2017-Co-Investigator: Sigma Theta Tau International Honor Society, Small Grants,

“Faculty

and Employer Perceived Importance of Quality and Safety Competencies for

Newly

Graduated Registered Nurses,” \$4219.00 (PI: Dr. Ellen Fineout-Overholt).

2016-Co-Investigator: Institute for Integrated Healthcare, College of Nursing and Health

Sciences the University of Texas at Tyler. “Employers’ and Faculty’s Perceived

Importance of Quality and Safety Competencies (EFQSC) for Newly Graduated

Registered Nurses, “\$1440.00 (PI: Dr. Ellen Fineout-Overholt).

2012-Co-Investigator: “Interdisciplinary Faculty Beliefs and Organizational Readiness  
for

Curricular Integration of Evidence-based Practice” Research Initiation Grant

Wright

University Office of Research and Sponsored Programs \$9320. (PI: Dr. Tracy

Brewer)

## **P. Unfunded Research**

2011-Principal Investigator: “An Exploration of Contextual Factors Impacting Nurses

Implementation of Evidence: Readiness, Beliefs, Skills and Needs”, Dayton

Children's Medical Center, Dayton, Ohio.

2012-Principal Investigator: "Nurses' Experiences with Implementation of Evidence-Based

Practice in Improving Outcomes", 2012, Dayton Children's Hospital Medical Center,

Dayton, Ohio.

2014-Co-Principal Investigator: "Cognitive Interviewing in the Testing of Two

Pediatric Shared Decision Making Instruments", (Doctoral Dissertation in process)

2014, University of Louisville.

2014-Co-Principal Investigator: "Perceptions of Nurses and Parents of Hospitalized Children

About Engagement in Shared Decision Making", (Doctoral Dissertation in process)

2015, University of Louisville.