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Assessment of Organizational Readiness: Parent Advisory Councils in a Children's Hospital within a Hospital

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REVIEW, APPROVAL AND ACCEPTANCE

The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Assistant Dean for MSN and DNP Studies, on behalf of the program; we verify that this is the final, approved version of the student's DNP Project including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Suzanne R. Springate, Student

Dr. Nora Warshawsky, Advisor

Final DNP Practice Inquiry Project Report

Assessment of Organizational Readiness:

Parent Advisory Councils in a Children's Hospital within a Hospital

Suzanne R. Springate, BSN, RN

University of Kentucky

College of Nursing

Spring 2015

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Dedication

This body of work is dedicated to William Roger Springate, III, my husband of 31 years, who passed on to another dimension of life on July 9, 2012. His illness enriched our lives, his perseverance and laughter made us humble, and his influence—“Suzanne, promise me you will finish your DNP when I am gone...” are the reasons I am a DNP candidate.

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Over the course of the last five years, I have experienced professional growth and a renewed sense of purpose because of these people—my advisors and mentors:

- Dr. Nora Warshawsky, PhD, RN, CNE, my DNP committee chair and academic advisor. Dr. Warshawsky's dedication to the pursuit of excellence and academic success transformed me from a clinician to a clinical scholar.
- Dr. Sharon J. Barton, PhD, RN, PCNS-BC from the Children's Hospital of Philadelphia, a member of my committee and my long-standing clinical mentor. Dr. Barton was the inspiration for my post-baccalaureate work and I have been honored to have her steady and astute guidance along this journey.
- Dr. Leslie Scott, PhD, APRN, PNP-BC, CDE, a member of my committee who has been influential in both my clinical practice and my academic pursuits.
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I would also like to thank my children, Hunter, Trevor and Caitlin, my sister Frances, and some special friends: my running buddies, the Dunns and the Baumgartners for always asking me to join in on the fun, and for always understanding that the pursuit of my DNP meant I could rarely come out and play!

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Capstone Overview

The term patient-centered care is used broadly to describe a model of care, an approach to provider—patient relationships and as a means of achieving better patient outcomes.

Organizations often claim patient-centered care as their practice model and yet the defining characteristics and defining attributes are not readily agreed upon by health care providers.

My pediatric colleagues are quick to point out that patient-centered care has its roots in “family centered care” historically linked to the maternal-child care setting.

It was the 1960’s work of John Bowlby on maternal-child attachment that set the foundation for family-centered care and the model became strongly associated with the care of child-bearing women and children—especially children with special needs. Then, in the late 1980’s, the Picker Institute coined the term “care through the eyes of the patient” and patient and family centered care was proposed as a model of care across the lifespan and in all care settings. Soon thereafter, qualitative measurement of patient satisfaction with care began. The question remained: what makes up a culture of patient and family centered care? What are the elements of family centered care best practices in the inpatient pediatric clinical setting?

In the fall of 2013, I had the honor of spending time with my colleague, Dr. Sharon J. Barton at the Children’s Hospital of Philadelphia (CHOP), the number one ranked children’s hospital in the nation. Recognized for being at the leading edge of family centered care, CHOP has a clearly defined mission statement that is inclusive of parents as full partners in care along the continuum from individual care episode to strategic planning and policy development. My goal was to observe and experience nursing practice in an established culture of family centered care. One of the most impressive things I learned while there was that CHOP has identified over 100 events where patient harm was prevented due to their partnerships with parents.

The focus of my work was a children's hospital within a hospital (CHWH) at one of the fastest growing academic medical centers in the United States. In this children's hospital, a culture of family centered care was not well developed as part of the mission statement or strategic vision and evidence of a family centered care culture was not readily apparent. Thus, my *academic challenge* was to discover "what is family centered care and how is it described in the literature?" My *practice challenge* was to assess the current state of family centered care and to close the gap between current state and best practice in this CHWH.

My first manuscript, *Family Centered Care in the Inpatient Pediatric Setting: A concept Analysis*, sought to examine the phenomenon and answer the question "what are the defining characteristics for a culture of FCC?" My second manuscript and practice inquiry project, *An Assessment of Organizational Readiness: Integrating Parents into Formal Roles in a Children's Hospital within a Hospital* assessed organizational readiness for integrating parent advisors into the culture of the CHWH. My third manuscript, *Parent and Family Advisory Councils: An Implementation Guide for a Children's Hospital within a Hospital* was developed to facilitate the complex endeavor of integrating parents as advisors in the CHWH.

Manuscript 1

Family Centered Care in the Pediatric Inpatient Setting: A Concept Analysis

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Abstract

This article explores family centered care (FCC) in the inpatient pediatric setting (IPS). The author reports the results of an extensive literature search and identifies defining attributes, antecedents, and consequences of FCC in the IPS. Using Donabedian's model, antecedents are reported as structures and processes; consequences as outcomes of the model of care (Donabedian, 1997). The author reports on existing evidence to support FCC as a model in the IPS, and challenges the nurse leader to further examine outcomes and applicability in today's health care environment. The importance of concept analysis and establishing an evidence base for practice is presented.

Keywords: family centered care, inpatient, pediatrics

Family Centered Care in the Pediatric Inpatient Setting: A Concept Analysis

Introduction

Concept analysis is a means of examining the structure and function of a phenomenon (Walker & Avant, 2011). Identifying defining attributes of a concept is essential if we use the concept to create models for nursing practice and patient care (Walker & Avant, 2011). The concept of family-centered care (FCC) has been used to describe models of care, an approach to patient-provider interactions, as a means of achieving better outcomes for individual patients, and has been linked to financial and organizational efficiency and growth.

The history of FCC began with a negative tone in the 1950's. Viewpoints expressed in nursing literature ranged from hostility toward parents (Aubuchon, 1958) to being supportive of their presence while doubting benefit to the child's health (Forres, 1953). Pediatric health care providers viewed the family as counterproductive to the care of hospitalized children. In both nursing and physician literature the belief that parents, particularly mothers, impeded the recovery of the hospitalized child was published (Shields, 2010). In the late 1950's to early 1960's, the work of John Bowlby appeared. Bowlby described the nature of attachment and negative outcomes resulting from separation of mother and baby. His observations and theories culminated in the foundation for family centered care in the pediatric setting (Bowlby, 1958).

The term "patient centered medicine" first appeared in health care literature as early as 1969, when Balint, Ball, & Hare (1969) published an article addressing the training of medical students. In 1988, the Picker Institute (Picker) was the first to use the term "patient centered care" (Conway et al., 2006). Picker gathered qualitative data from patients and families in an attempt to define "high quality of care" through the eyes of the patient and family (Conway et al., 2006). Throughout the 1960's to 1980's FCC was typically used in reference to child-

bearing women and children, particularly children with special needs and technologically dependent children (Conway et al., 2006). Over time, the term patient and family centered care came to be associated with collaboration between health care providers, patients and their families at all levels of decision making and in all care settings (Conway et al., 2006).

The Institute for Patient and Family Centered Care (IPFCC, 2010) defines FCC as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.” Discussions with physicians and nurses at a children’s hospital within a hospital revealed the following perceptions of attributes of family centered care:

- Family participation in physician rounds
- Encouraging parents to participate in the care of their hospitalized child
- Providing a place for parents to sleep and rest
- Providing a kitchen for parents to select snacks/refreshments for their child

Though much is written about the importance of FCC as a preferred model of care, the defining characteristics in the inpatient pediatric setting are not readily agreed upon by health care providers.

The “How” and “Why” of a Decision to Analyze FCC in the Pediatric Inpatient Setting

Family-centered care as the model for health care delivery is widely used in pediatrics (Shields, 2010). The IPFCC challenges us to include patients and their families in everything we do: policy making, program development, facility design, and communication standards (“Institute for Patient and Family Centered Care,” 2010). A family centered care environment shifts the standard doctor/nurse driven model of care to a model where the family is integrated into every aspect of the care episode. This includes decision making, establishing a treatment

plan, and providing care to the patient to the extent the family chooses (Ahmann & Johnson, 2001). FCC leads to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction ("Institute for Patient and Family Centered Care," 2010). In spite of recommendations and varying levels of support for and understanding of FCC, the defining attributes in a pediatric inpatient setting are not well documented. In addition, there is evidence to suggest that integration of the core values of FCC is lacking in the practice of pediatric inpatient nurses (Curley, Hunsberger, & Harris, 2013). Though widely described as an organizational model of care, there is little agreement regarding essential components for successful implementation (Shields, Pratt, & Hunter, 2006). The need to identify the defining elements and create a common understanding among health care providers, especially among nurses in leadership roles, is essential to the implementation and evaluation of FCC. The aim of this paper is to analyze the concept of family centered care in the inpatient pediatric setting (IPS).

Attributes of Family-Centered Care in the Inpatient Pediatric Setting

Walker & Avant (2011) suggest that identifying the attributes most frequently associated with a concept is essential to being able to recognize and differentiate the phenomenon from other like concepts or philosophies. A thorough search of literature was performed using the search engine Cumulative Index of Nursing and Allied Health Literature (CINAHL). The key words included "family centered care," "inpatient," and "pediatric". Ninety-eight articles were returned. Articles were included if family centered care was described as a model of care in developed countries, articles written in English, and other than seminal articles, published within the last 15 years. A total of 18 articles were included in the analysis.

General Attributes and Common Characteristics of FCC

All articles reviewed referenced definitions proposed by the IPFCC (2010) and the Institute for Healthcare Improvement (IHI, 2010). The IPFCC lists the defining attributes of FCC as:

- Collaborative relationships
- Partnerships between family and caregivers
- Patient as the source of control
- Recognition of the family as the constant in the patient's life
- Caring for the whole family.

FCC is referred to as care through the eyes of the patient ("Picker," n.d.), a philosophy of care (Harrison, 2010), an "ideal model of care," (Shields & Tanner, 2004, p. 189), and an "innovative approach to planning, delivery, and evaluation of healthcare" (IPFCC as cited in Moretz, 2010, p. 168). Care that is planned around the whole family (Shields, 2010), based on the family as the constant in the child's life (Harrison, 2010), and recognition that all members of the child's family are recipients of care (Shields et al., 2006) are phrases commonly used to describe FCC in the inpatient pediatric setting. Other, less common descriptions of FCC in the pediatric inpatient setting were relationships that promote empowerment (Titone, Cross, Sileo, & Martin, 2004), and negotiated care (Shields & Tanner, 2004).

FCC in the Inpatient Pediatric Setting (IPS)

In the IPS, FCC may promote professional growth in the bedside nurse as he/she practices the skills needed to navigate reciprocal, therapeutic relationships with the family of the hospitalized child (Curley et al., 2013). Parents of hospitalized children value nurses who are perceived to care, give affection, and are watchful and protective of the patient (Harrison, 2010).

Pediatric nurses, who convey that the parent and family of the patient are full partners in care, create a care environment where the parenting role is sustained and nurtured. These behaviors increase the parent's confidence and competence in making health care decisions on behalf of their child (Harrison, 2010). When the pediatric nurse fails to develop a therapeutic partnership with the family (i.e.: FCC) of the hospitalized child, parents may perceive the nurse as the gatekeeper of knowledge and options for participation in the care of their child (Shields et al., 2006). Strategies for the pediatric nurse to consider when practicing FCC include using "we language" to demonstrate respect for the nurse-parent relationship and actively negotiating a nurse-parent partnership (Ahmann & Dokken, 2012, p. 233). The inpatient pediatric nurse must hone his/her practice to include specific behaviors that support the defining attributes of FCC. These include developing meaningful partnerships with parents/family in the care of the child through negotiation or by actively initiating parent participation as a full partner in care.

Development of a Model Case for FCC in the IPS

Creating an exemplary model of FCC in the IPS helps demonstrate the nature of the concept through an illustration containing each of the essential attributes (Walker & Avant, 2011). By creating an example of the concept in the purest form, a litmus test against which one can measure FCC in an inpatient pediatric care environment is developed. A model case, illustrating the nurse's role in FCC in an IPS is described below:

Upon admission of a child with a long-term chronic illness, the nurse meets the patient and mother in their hospital room and sits down to listen and record the mother's impression of what has brought them to the inpatient unit. She asks the mother about the child's home routine, how the sibling's schedules fit into the care of the chronically ill child, and how this hospitalization is going to impact the mother's role in caring for her family. When the physician team arrives, the mother and nurse are asked to provide information about the child's current state of health, and the mother is asked if she has anything to add, understands the plan, and if the plan of care is acceptable to her. The nurse and mother review the plan of care and the nurse asks the mother for which components of the plan of care she wants to be responsible and what she prefers the nurse to manage. The mother wants to manage the child's meals, bathing, and play-time and

asks the nurse to assist with linen changes and all medication management. The mother wants to be present during any potentially painful or traumatic care episodes. The child's home routine includes after school play with his siblings prior to their homework, the nurse and mother discuss planning the child's tests and treatments to ensure that sibling play time is maintained. Since the mother is the primary provider for her family, she relates to the nurse that she must spend some time each day working to maintain enough hours to keep an active insurance policy and to pay her bills. The nurse and mother plan for a child life specialist to spend time with the child each day when the mother goes to work and picks up the other children from school. The mother's support system includes a friend who helps with the children at home, and the mother has asked the friend to help her during this hospital stay. The nurse arranges for the family friend and mother to alternate staying with the child every other night so the mother can continue to provide some continuity with her sick child and her children at home. The nurse uses "we language" indicating that the care of the hospitalized child is a collaboration between the mother and the nurse.

In this scenario, the nurse and mother form a collaborative relationship and become partners in the care of the hospitalized child. The nurse recognizes and supports the mother as the source of control and promotes maintenance of the "family as the constant" in the child's life by arranging care episodes to support family routine and by including the family friend in the hospital plan of care. Caring for the whole family is displayed in this model of FCC in the IPS.

Concept Analysis

When performing a concept analysis, identifying antecedents and consequences helps to further distinguish the attributes of the concept. Antecedents and consequences are not the same as attributes. Antecedents are precursors to the concept while consequences occur as a result of the existence of the concept (Walker & Avant, 2011).

Antecedents of FCC in the IPS

In the IPS, antecedents are the structures, (e.g.: policies and caregiver competency) and processes (interventions) that support FCC. Structural antecedents identified in the literature include a staffing ratio supportive of the time required to partner with the family. Adequate time for development of healing relationships and negotiation of roles is essential if FCC is to take place (Shields, 2010). An environment that promotes physical comfort including nutritional

support, spiritual support, distraction and entertainment are structural antecedents to FCC (Balik, Conway, Zipperer, & Watson, 2011). Family resource centers are highlighted across the literature as antecedents to FCC. The resource center provides information consistent with health literacy principles, a place of respite from the care environment, and an opportunity to seek support from parents in similar situations (Balik et al., 2011). An organizational mission, vision, and values coupled with leaders who demonstrate a commitment to FCC across the continuum of care are foundational structural antecedents in the IPS (Balik et al., 2011 and Ahmann & Johnson, 2001).

In the literature, consistently mentioned process antecedents include:

- Collaborative relationships (Curley et al., 2013), (Conway et al., 2006), (Harrison, 2010), (Titone, Cross, Sileo, & Martin, 2004)
- Partnerships between family and caregivers (Balik, Conway, Zipperer, & Watson, 2011), (Ahmann & Dokken, 2012), (Shields & Tanner, 2004), (Moretz, 2010)
- Patient as the source of control (Balik et al., 2011), (Conway et al., 2006)
- Recognition of the family as the constant in the patient's life (Harrison, 2010), (Shields et al., 2006), (Titone et al., 2004)
- Caring for the whole family (Shields, 2010), (Shields et al., 2006)

Though not identified in the literature as nursing specific, it was readily apparent to the author that caregiver skills including communication and specific, evidence based interventions to promote partnerships are essential antecedents to FCC. The role of the bedside pediatric nurse and his/her nursing knowledge and communication skills, lead to an ability to promote a healing partnership with the child and family. These competencies are clearly essential antecedents to FCC in the IPS. Pediatric nurses must be able to:

- communicate and negotiate collaborative roles with parents, allowing and supporting the parent to participate in care at the level the parent is comfortable
- use language that is supportive of and promotes a parent/nurse partnership
- share information in an unbiased way
- explain and apologize if things go wrong.

Consequences of FCC in the IPS

If FCC exists within the IPS, specific outcomes or consequences will be observed as a result. Consequences may be grouped into FCC outcomes for the parent/child, the inter-professional team, and the organization. Perhaps the most important consequence of FCC is the competency and confidence that a parent gains in their role to care for their sick child both in the hospital and upon discharge (Curley et al., 2013). Families who are in full partnership in the inpatient setting are better capable of managing their medical condition and are more likely to seek health care if needed post-hospitalization. They are less stressed and often experience less negative financial impact related to the family member's illness (Balik et al., 2011). Children of parents who participate actively in patient rounds are discharged sooner and experience fewer medical errors while hospitalized (Conway et al., 2006).

Consequences for nursing staff in a FCC environment include staff rating working with parents as highly as they rated working with children (Shields, 2010). Nurses perform work that is value added to the patient and family, and eliminate work that is not value-added to the care episode and nurse-family partnership (Balik et al., 2011). When FCC exists, nurses have time, education and tools to develop communication and negotiation skills to help parents assume the role of care partner. The result is an increase in overall nurse satisfaction and engagement in the work of caring for the patient and family (Shields et al., 2006 and Harrison, 2010).

FCC consequences for the organization include improved clinical, financial, and service outcomes. An organization whose philosophy and model of care is FCC can expect improvement on patient satisfaction surveys, positive movement on employee engagement surveys, a reduction in length of stay, and an increase in new patients. All of these measures are linked to an organization's financial health, referral base and reputation within the community it serves (Balik et al., 2011 and Conway et al., 2006).

Measuring FCC in the IPS

There are many "versions" of FCC in the IPS. FCC is used as the model of care in free-standing children's hospitals, co-located children's hospitals and on pediatric units within a full service community hospital. Evidence clearly linking FCC to measurable outcomes in the literature is inconclusive. Some present the point that if FCC is the model of care, patient's likelihood to recommend scores will be positively affected (Balik et al., 2011 and Conway et al., 2006) while others purport that there is no level 1 or level 2 evidence that FCC works as a model of care and cannot be effective in today's environment of dramatically reduced length of stay (Shields, 2010). As a model of care in the IPS, perhaps process measurements such as 100% of patients have a care plan that has evidence of parent participation in planning and 100% of all family education materials meet health literacy guidelines (Balik et al., 2011), coupled with a long term evaluation of the psychosocial impact of the hospitalization on the child and family might be more appropriate metrics to utilize in measuring FCC outcomes. Harrison (2010) suggests that the outcomes and metrics directly linked to FCC in the IPS are underdeveloped and challenges the pediatric nursing community to increase our understanding of the impact of FCC on:

- parental self-esteem and confidence/competence in navigating the health care environment
- patient outcomes and length of stay
- practicing professionals and length of employment and job satisfaction

Summary and Conclusion

FCC is frequently espoused as the model of care in the pediatric care setting.

Understanding the concept of FCC, antecedents and consequences is essential for the advanced practice nurse leader whose practice setting includes children and families. An adaptation of Donabedian's model for quality improvement provides a snapshot view of FCC, antecedents and consequences (Donabedian, 1997). See Figure 1 below.

Concepts are essential to theory construction in nursing (Walker & Avant, 2011).

Advanced practice nurses in the inpatient pediatric setting must be able to fully describe and measure family centered care as an evidence based, model for practice. Walker and Avant (2011) challenge us to examine the concept, those elements of practice that must be present to support the concept and the anticipated outcomes if we are to successfully implement or embrace a concept in our practice environment. Essential II of the essentials of doctoral education for advanced nursing practice challenges the doctoral prepared nurse leader to develop and evaluate care delivery approaches that support current and future patient population needs (Chism, 2010). If we, as pediatric nurse leaders, continue to use FCC as the model of care for IPS, it is our obligation to:

- Increase level 1 and level 2 evidence to support FCC as an effective model of care (Harrison, 2010)
- Know and understand the antecedents of FCC

- Promote a workplace where the antecedents to FCC exist without fail, including time required by the bedside nurse for development of nurse-family partnerships
- Support the education and skill set acquisition for effective communication that promotes partnering with parents, supporting the parent role, and understanding that the family is the constant in the child's life and that we as caregivers are the "visitors" (Harrison, 2010, p. 4)

It is incumbent upon the pediatric nurse leader to understand the antecedents of FCC and promote the implementation of the structures and processes that support FCC with executive leadership of one's organization. Most importantly, as nurse leaders, we must evaluate scientifically the presence and outcomes of family centered care. Family centered care has been a proposed model of care for over a half century. In today's changing healthcare environment many potential barriers to developing meaningful partnerships with parents in the inpatient setting exist. Some of these include:

- reduced length of hospital stay
- focus on cost containment and nurse productivity targets
- the prevalence of families impaired by drug and alcohol abuse
- the increasing frequency of family inflicted non-accidental trauma

These obstacles pose a challenge to the existing FCC model. How can we, as nurse leaders create an environment of care where nurses have the skill set to practice family centered care regardless of the obstacles? It is our leadership responsibility as members of the health care community to determine if the concept can be fully implemented and if FCC as a model of care produces the outcomes that we have traditionally expected.

Antecedents (Structures & Processes)

- Sharing of knowledge/information sharing
- Dignity and respect
- Recognizing and capitalizing on family strengths
- Recognizing and respecting ways of coping
- Parent advisors members: executive, unit based, and service line councils
- Parents participate in rounds
- Parent and family advisors members: planning and process improvement committees
- Patients and families involved in program design and change

Family Centered Care

- Collaborative Relationships
- Partnerships between families & caregivers
- Family as source of control
- Family is the constant in the patient's life
- Caring for the whole family

Consequences (Outcomes)

- Parent confidence and competence in caring for their child
- Families seek health care when needed post-hospitalization
- Families are less stressed and have a reduced financial burden due to their child's illness
- Decreased length of stay
- Child experiences fewer medical errors
- Staff rate working with parents highly
- Staff perform value added work
- Nurses have time, education and tools to partner with family
- Improved clinical outcomes
- Improved financial outcomes
- Improved patient satisfaction scores
- Positive employee engagement scores

Figure 1. Family Centered Care: Antecedents and Consequences (Adaptation of Donabedian's Model for Quality Improvement (Donabedian, 1997))

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Manuscript 2

An Assessment of Organizational Readiness: Integrating Parents into Formal Roles in a
Children's Hospital within a Hospital

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Abstract

Background: A children's hospital within a hospital (CHWH) in the Midwest region of the United States established a strategic goal to become the preferred provider for children in the region. Outcomes in patient and family experience had fallen short of established organizational expectations. Recognizing that parent advisors are an essential component of patient and family centered care, the strategic plan called for integrating parents into formal, advisory roles.

Purpose: The purpose of this practice improvement project was to perform an assessment of organizational readiness to incorporate parents into formal advisory roles at this CHWH.

Methods: A cross-sectional survey design was used to measure indicators of organizational readiness: 1) an analysis of the current state of patient and family centered care (PFCC) 2) an analysis of stakeholder attitudes and beliefs about incorporating parents as advisors.

Results: A score of five for each question on the PFCC Organizational Self-Assessment Tool indicates an organization's culture is consistent with best practice organizations. Assessment of the current state of PFCC in this CHWH resulted in only five of eleven domains on the PFCC Self-Assessment Tool having a mean score >3 . However, 83.7% of all stakeholders responded in support of integrating parents into formal advisory roles. These results suggest that the CHWH is in the *contemplative stage* of organizational readiness (Prochaska, Norcross, & DiClemente, 1994).

Conclusion: Stakeholders in this CHWH recognize knowledge gaps regarding PFCC culture in their organization. They are confident their individual clinical practices are supportive of PFCC, yet recognize that integrating parents into formal advisory roles will require adoption of complex organizational changes in this CHWH.

Keywords: Patient and Family Centered Care; Family Centered Care; Parent Advisors; Patient and family advisors; Readiness assessment; IPFCC survey instrument

An Assessment of Organizational Readiness: Integrating Parents into Formal Roles in a
Children's Hospital within a Hospital

Background

Leaders at a 143 bed children’s hospital within a hospital (CHWH), part of a fast growing academic medical center in the Midwest, set a strategic goal to become the preferred provider of pediatric care in the region. The strategic plan calls for the incorporation of parents into advisory roles including quality, safety, and service initiatives. Patient experience scores have failed to meet the organizational goal for “likelihood to recommend” and when compared to other children’s hospitals within academic medical centers, the hospital’s percentile ranking is below the 50th percentile (Press-Ganey, 2014).

A patient and family centered care (PFCC) environment, including the integration of patients and families as advisors, leads to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction with care (Conway, 2008; Institute of Medicine [IOM], 2001). Unless parents are formally integrated into this CHWH, the organization may not be able to meet its goal of serving as the preferred regional provider of care to children.

This CHWH’s current state of PFCC and readiness to integrate parents into formal roles had not been formally assessed. Organizational structures and attitudes to support parents as advisors were evaluated through a gap analysis with the goal of determining the current state of readiness to integrate parents into this CHWH

There are reports that differences in pediatric outcomes between freestanding children's hospitals and children's hospitals within a hospital exist and have been linked to resource adequacy (Cimotti, Barton, Gorman, Sloane, & Aiken, 2014). A gap analysis of family centered

care practices at a nationally recognized free-standing children's hospital in the Northeastern United States and this CHWH was performed in October, 2013 by the primary investigator (PI). For the purpose of informing the gap analysis policies were reviewed, interviews conducted with parent advisors and hospital staff, and observations of staff-family interactions were accomplished. The parent advisors were formally hired as hospital staff and were integral to daily activities of the caregivers, patient safety culture, policy development, and program planning at the nationally recognized children's hospital. In contrast, there were no formal advisor roles for parents in the CHWH.

The purpose of this practice inquiry project was to perform an assessment of organizational readiness to incorporate parents into formal advisory roles at this CHWH.

Literature Review

Throughout the 1960's to 1980's family centered care (FCC) was typically used in reference to child-bearing women and children, particularly children with special needs and technologically dependent children (Conway et al., 2006). FCC as a model for health care delivery is widely used in pediatrics (Shields, 2010). A PFCC environment shifts the standard provider driven model of care to a model where the family is integrated into every aspect of the care episode. This includes clinical decision making, establishing a treatment plan, and providing care to the patient to the extent the family chooses (Ahmann & Johnson, 2001).

Over time, the term *patient and family centered care* came to be associated with collaboration between health care providers, patients and their families at all levels of decision making and in all care settings (Conway et al., 2006). The Institute for Patient and Family Centered Care (IPFCC) challenges health care leaders to include patients and their families in

every aspect of care planning and delivery: policy making, program development, facility design, and communication standards (Institute for Patient and Family Centered Care, 2010).

A qualitative study published in 2011, by Luxford, et al, examined facilitators and barriers to PFCC in eight health care organizations with reputations for improving the patient and family's experience of care. The most extensive incorporation of patient and families was reported by inpatient facilities. Five of the organizations reported engaging patients, families, and their caregivers as an essential facilitator for improving the delivery of PFCC (Luxford, Safran, & Delbanco, 2011). Engaging families in organizational decisions including employee interview panels and medical executive committees was prevalent. Patients and families were engaged in advisory committees, represented on the board of trustees, and were members of quality improvement committees (Luxford et al, 2011). Challenges to changing the culture of an organization to support patient and family centered care are clustered around transforming professional identities, rethinking established communication methods, and altering physician and nurse practice patterns (Baker, 2014).

Baker (2014) identified three crucial components for engaging patients and families:

1. Recruiting and preparing patients and family members as advisors and team members
2. Engaging, coaching and supporting staff to work with patients and families as team members on committees, panels and as partners in care
3. Ensuring leadership has the appropriate competencies, strategic vision, and commitment to support engagement of patients and their families at the micro and macro system levels.

It is estimated that 50% of health care organization change efforts do not succeed because of a failure to identify readiness for change among stakeholders (Smith & Donze, 2010).

Assessment of readiness is best established before implementation efforts and can be evaluated in terms of culture, infrastructure and resources (Smith & Donze, 2010).

“Measuring readiness is a systematic analysis of an organization’s ability to undertake a transformational change process” (Health Resources and Services Administration [HRSA], 2015). Change management experts recognize organizational readiness for change as a critical precursor to successful implementation and adoption of complex changes in the health care environment (Weiner, 2009). Change within health care organizations may impact the sense of psychological safety, control, and identity of those providing care to patients (Weiner, Amick, & Lee, 2008). Readiness for change can be described in terms of the beliefs, attitudes, and intentions of stakeholders who must implement and or participate in the change (Armenakis, 1993).

Prochaska describes readiness for change in six stages: precontemplation, contemplation, preparation, action, maintenance and termination (Prochaska, Norcross, & Diclimente, 1994). *Precontemplation* is the stage of resistance to change. In the *contemplation* stage, those anticipating change struggle to understand the problem and causes of the problem. During this stage, a search for solutions for improvement is undertaken. People in the contemplation stage of change readiness are thinking about the issue and potential solutions yet are typically not ready to take action. In the *preparation* stage stakeholders are committed to action, but have not resolved their ambivalence about moving forward with the change. The *action* stage is characterized by modifications in behavior, confrontation of fears, and activities that require commitment of time and energy. During the *maintenance* stage, the focus is on prevention of a return to the prior state. Maintaining cultural change is a long, ongoing, and critically important process. The *termination* phase is the ultimate goal. A return to the former organizational culture

or state is no longer a threat when an organization reaches the termination phase of change readiness (Prochaska, et al, 1994).

Integrating parents into the fabric of the operations and strategic vision of a children's hospital is one of the essential elements of a culture committed to family centered care (Johnson et al., 2008). An increasing body of evidence suggests that incorporating families into advisory roles is positively linked to patient outcomes, reducing health care costs, reducing medical errors and medical litigation, increased patient and staff satisfaction, and improved family/self-advocacy (IOM, 2001; Johnson et al., 2008; Johnson, Abramson, & Shelton, 2009; Shields, 2010). Engagement of caregivers and leadership—the stakeholders—within an organization is essential for successful integration of patients and families (Baker, 2014). Implementing evidence based practice changes requires that stakeholders have the necessary knowledge, skills, resources and support to be successful (Smith & Donze, 2010). Therefore, this practice inquiry project seeks to address the following:

- Specific Aim 1: Determine the gap between the current state of PFCC compared to best practices established by the IPFCC
- Specific Aim 2: Describe stakeholder attitudes toward formally incorporating family advisors into the organization and operation of the CHWH
- Specific Aim 3: Describe thematic differences in survey responses among three stakeholder groups.

Methods

Design

This practice inquiry project used a cross-sectional survey design. An electronic survey was developed to assess organizational readiness of key stakeholder groups; specifically, nurses,

physicians, and leaders. This project was reviewed and approved by the University of Kentucky institutional review board. Participation was voluntary and anonymous. Documentation of consent was waived and completion of the survey by the participants indicated their consent to participate.

Sample

Participants were recruited from the CHWH *Children's Services* service line. The stakeholders were divided into groups based on their primary professional role:

- Professional bedside nurses (n = 52; 32% response rate)
- Attending physicians (n= 23; 28.8% response rate)
- All members of Children's Services operational leadership/management (n=11; 68.8% response rate)

Data Collection

Data were collected with a questionnaire that was developed and administered using Qualtrics® (Provo, UT), a web-based survey management system. Since the PI was well known to all potential participants, an administrative assistant sent an invitation and three reminder emails on behalf of the PI using group distribution lists for each stakeholder group over an eight week period.

Instruments

PFCC Self –Assessment Tool

The current state of PFCC was assessed using *The Patient- and Family-Centered Care Organizational Self-Assessment Tool (PFCC Self-Assessment Tool)*(IPFCC, 2013). The *PFCC*

Self-Assessment Tool was designed to assess the current state of PFCC in an organization against the “leading edge of practice” (*PFCC Self-Assessment Tool*, 2013, p. 1).

The *PFCC Self-Assessment Tool* is comprised of eleven domains considered to be the essential elements of family centered care. Each domain is made up of 2-6 questions that are designed to evaluate the current state of the essential element of PFCC within the organization. Each question was rated using a 5-point Likert scale with an additional option of “*do not know.*” A rating of five indicates the organization is performing at the leading edge of PFCC as recommended by the IPFCC. The survey is designed to identify organizational strengths and weaknesses and provide the basis for an action plan to improve patient and family partnerships. The “*do not know*” response indicates a knowledge gap regarding the element of PFCC and a need for further education and discussion (*PFCC Self-Assessment Tool*, 2013).

Checklist for Attitudes Survey

Attitudes for PFCC were assessed using *A Checklist for Attitudes about Patients and Families as Advisors (Checklist for Attitudes)*. The *Checklist for Attitudes* was designed to explore attitudes, promote self-reflection and spark discussion prior to integrating patients and families into an organization’s culture (*Checklist for Attitudes*, 2010). The *Checklist for Attitudes* survey instrument identifies facilitators and barriers to partnering with patients and families. Stakeholders were asked to answer questions in the “*clinical interaction*” and “*organizational level*” domains of the survey instrument. A response of “*yes*” was coded as *one* and a “*no*” response as *zero*. A score of *one* indicates attitudes supportive of partnering with patients and families (*Checklist for Attitudes*, 2010).

In addition, participants were asked to indicate their overall support for integrating parents as advisors by answering *yes or no* to the question: “I would support integrating parents

into formal roles in our hospital,” The final, open-ended question invited participants to provide comments.

Data Analysis

Data analyses were conducted in SPSS® version 15 (IBM, Armond, NY) with an alpha level of 0.05. An examination of assumptions revealed a normal distribution. Data for each domain on the PFCC Self-Assessment Tool were combined across all stakeholder groups and descriptive analysis, including means and standard deviations or, frequency distributions were used to summarize subscale scores. Answers of “do not know” were removed from the dataset prior to further evaluation. One-way analysis of variance (ANOVA) was completed to determine if a statistically significant difference between stakeholder’s mean scores existed. When the ANOVA identified significant differences in subscale scores between groups, post-hoc analysis was conducted.

A Chi-Square test for differences among the three stakeholder groups was performed to determine the proportion answering yes, and if there were differences among each of the three stakeholder groups for each question on the “Checklist for Attitudes” survey.

Results

PFCC Self –Assessment Tool

Table 1 presents a descriptive analysis by domains of all stakeholder responses (N=86) to the PFCC Self –Assessment Tool. Mean scores range from 1.83 in the “*Advisors*” domain to 3.59 in the “*Care Support*” domain as compared to a score of five representing the state of family centered care in best practice organizations. Table 2 presents descriptive statistics of the current state of PFCC by *individual questions* and % “*do not know*” for all stakeholders. Table 2 is sorted from greatest to least percent of “*do not know*” responses. The percent “*do not know*”

range from 0.00% to 43.12% for the questions “*families are actively involved in care planning and transitions*” and “*clinician email access from the patient/family is encouraged and safe*” respectively.

Figure 1 presents PFCC organizational readiness domains in rank order. The domains approaching five are areas of strength related to organizational readiness in the CHWH. The domains approaching one may serve as barriers to fully implementing a family centered care culture and the integration of parents into formal roles.

Figure 2 represents a mean score comparison by stakeholders for the domains where a significant difference among groups was shown on the post-hoc analysis (p -value <0.05). The three domains with significant differences among stakeholder groups were:

Leadership/Operations, Advisors, and Personnel.

Table 3 presents the results of a one way ANOVA and significant differences ($p < 0.05$), among stakeholder groups for the *Leadership/Operations, Advisors, and Personnel* domains. Nurses had significantly higher mean scores compared to physicians ($p = 0.034$) and leaders ($p < 0.001$) within the *Leadership/Operations* domain while there was no significant difference between physicians and leaders ($p = 0.06$). The *Personnel* domain reveals a significant difference between nurses and leaders ($p = .001$). Nurses mean scores were highest (2.96), with physicians scoring 2.39 and leaders having the lowest mean scores for the personnel domain (1.71). There was no significant difference between nurses and physicians or physicians and leaders for the personnel domain. In the Advisors domain, nurses mean scores were again significantly higher than the physicians ($p = 0.04$) and leadership ($p = .022$) while the physicians and leaders groups showed no significant differences.

Checklist for Attitudes Survey

There was minimal variability in the responses among stakeholder groups on the IPFCC “*Checklist for Attitudes*” survey. There were no significant differences between stakeholder groups and the percent of respondents who answered “yes” were the majority within each group. The lowest scoring item was “*I believe patients and families can look beyond their own experiences and issues*” having a 70.9% “yes” response rate. The highest ranking question was “*I encourage patients and family members to participate in decision-making about their care*” with 100% of all stakeholder groups responding “yes” (See Table 4).

Qualitative Comments

There were a total of 14 comments across all stakeholder groups. Within each stakeholder group, there was at least one comment of support for integrating parents into formal roles in the CHWH. Evidence of unfamiliarity with the elements of PFCC was captured in the nursing and physician groups through comments such as “I can’t imagine how a parent would be used in the orientation process for new staff” and “One thing we need to be careful of is not to take all family comments and turn on the providers and put them in a defensive position.” Expressions of concern for parents driving professional practice and the difficulties encountered when attempting to partner with challenging families came from both physician and nurse groups. Within the physician groups, there were comments identifying patient care units where a PFCC culture is more prevalent than other units. The only trend identified across all groups was support for a PFCC culture and integration of parents.

Discussion

The process of gap analysis was used to determine the CHWH state of readiness to integrate parents as advisors, an essential element of PFCC. Results of the gap analysis of the

current state of PFCC in the CHWH were compared to a freestanding nationally recognized children's hospital and the IPFCC best practice recommendations for integrating parents into formal roles. The data suggest that the CHWH is in the contemplation stage of change readiness (Prochaska et al., 1994).

With a rating of five indicating the organization is performing at the leading edge of PFCC, only five of eleven domains resulted in a mean score > 3.0 on the *PFCC Self-Assessment Tool*. The highest scoring domains were the domains of *Care Support* and *Care*. There is evidence that stakeholders have a lack of knowledge about the elements of PFCC and the importance of parents as advisors as indicated by ten out of thirty-nine questions where “do not know” responses were >30% (See Table 2).

The qualitative comments provided additional insight into the stakeholders' beliefs and attitudes and where they lie on the continuum of understanding and practicing PFCC. The stakeholder's comments reflect the importance of distinguishing “family directed care” from PFCC where the professionals and families have roles and obligations in development of mutually beneficial partnerships. However, it is important to note in spite of a knowledge gap about PFCC key elements, 83.7% of all stakeholders responded in support of integrating parents into formal advisory roles (see Table 4).

PFCC Self-Assessment Tool

It is not surprising that the PFCC domains of *Care Support* and *Care* ranked highest by the stakeholder groups. The elements included in these two domains reflect the care provided by physicians and nurses and supported by leaders through policy development and resource allocation. Pain management, patient/family activation of rapid response systems and family presence during rescue events are elements of care to which physicians, nurses, and leadership

share a common commitment to best practice standards and are a source of professional pride. The domains of *Quality Improvement*, *Personnel* and *Advisors* had a “do not know” response rate >30% for more than half of the questions within each domain. The mean scores for these three domains were < 3 on the five point scale. In the contemplative stage of change readiness, stakeholders may understand the importance of partnering with families, but not be ready to fully embrace the concept of PFCC as a mutually beneficial partnership between providers and families. The absence of parents in formal roles may also contribute as a driver of knowledge gaps and mean scores on this scale.

With the exception of the domains of *Leadership*, *Personnel* and *Advisors*, differences among the stakeholder groups’ evaluation of the current state of PFCC were non-significant. The *Leadership/Operations* domain seeks to evaluate organizational current state of PFCC in relation to commitment, measurement, accountability and inclusion of patients and families in development of policies, procedures and governance. Nurses rated *the Leadership/Operations* domain significantly higher than did physicians and leaders with *p-values* of .034 and .000, suggesting that nurses have greater confidence in organizational support for PFCC than do physicians and leaders themselves. None of the questions within the *Leadership/Operations* domain had a response of “do not know” $\geq 30\%$, which may indicate that the respondents felt they had enough knowledge to rate the specific question of PFCC against best practice organizations. Nursing’s focus on a new nursing practice model, seeking Magnet® designation and improving patient experience scores may have contributed to the nurses’ rating of *Leadership/Operations* domain higher than physicians and leaders. A recent emphasis on communication strategies to support development of mutually beneficial nurse-parent partnerships is likely to have influenced the answers documented by nurses as well.

Physician comments gave some insight into the mean score of 2.75 for the *Leadership/Operations* domain. Perceived variances in PFCC across specific patient care units, perceived lack of operational support for families with language barriers, and an expression of lack of trust regarding investigation of family complaints suggested there is a lack of confidence that adequate resources and support for a PFCC culture exist.

Clear statements of commitment to PFCC, patient-family partnerships, policies, procedures and supportive guidelines fall under the areas of leadership responsibility and accountability. These foundational components of PFCC were areas of focus for CHWH leadership at the time of survey launch. Also, at the broader organization level, including the adult hospital and ambulatory services, clarity of aim regarding integration of parents and families was under development. CHWH Leaders' anticipation of executive leadership's formal expression to integrate patients and families into advisory roles, coupled with the burden of responsibility to create a culture supportive of PFCC may have contributed to the leader group's mean score of 1.98 in the *Leadership/Operations* domain. This domain mean score and leader qualitative comments were consistent with Prochaska's (1994) contemplative stage of change readiness in the Leaders stakeholder group.

The *Personnel* domain on the PFCC Self-Assessment Tool seeks to evaluate how integrated are patients and families into selection, orientation and evaluation of hospital personnel. This domain was another area where significant differences existed between nurses and leaders. As the drivers of significant changes related to accountability and changes to performance evaluations to be inclusive of family centered care, leaders have a greater understanding of the current state and gaps to achieving the CHWH long term goals for PFCC. The nurses recently experienced changes in expectations for practice and accountability in

relation to patient experience. Changes included the addition of patient experience as a performance metric on the nurse's annual evaluation. The changes in expectations for nurses coupled with the leaders serving as drivers of the change, most likely accounted for the significant difference in stakeholder perception of current state in the *Personnel* domain.

The *Advisors* domain was the lowest ranking domain across all stakeholders with the mean scores of the three questions ranging from 1.60 – 2.02. The *Advisors* domain measures the existence of patients and families in advisory roles including hospital committees, safety rounds, and advisory councils. The only question within the *Advisors* domain where a response of “do not know” was < 30% was “*Patients/ Families participate in quality and safety rounds.*” A recent quality improvement initiative by the acute care nursing shared governance council was the implementation of bedside handoffs that include patients and parents in the exchange of knowledge and safety checks. The interpretation of this question by nursing staff may have accounted for higher mean score and the significant difference between nurses and physicians within the *Advisors* domain. Qualitative comments from nurses ranged from “*adding patients and families on planning and quality and safety levels would be fantastic*” to “*patients and families should not direct the actions of nursing and physicians.*” Comments from the leaders group included “*for us to succeed and compete, it is imperative we engage with the people we serve at all phases*” and “*we must courageously bridge our gaps in understanding their [the family's] experience and gain from it.*” This wide range of perception of current state and knowledge regarding PFCC highlights areas of opportunity and provides focus for action planning prior to integrating parents into the culture of this CHWH.

Checklist for Attitudes Survey

Priorities for improving health care quality in the current age of consumerism will be set by all stakeholders including patients and families (Kizer, 2001). Attitudes and expectations about health care have changed in recent years with patients and their families increasingly being interested in clinical performance and treatment outcomes (Kizer, 2001). Health care quality problems are widely known and as a result consumers of health care are challenging the traditional roles of physicians and nurses as the gatekeepers of knowledge and decision making (Conway, 2008). Understanding healthcare providers' beliefs and attitudes about partnering with patients and families is central to determining readiness for incorporating parents into advisory roles in this CHWH.

It is interesting that 100% of all respondents answered “yes” to the question “*I encourage patients and families to speak freely*” while only 76.7% of respondents believe “*that the perspectives and opinions of patient, families and providers are equally valid in planning and decision making at the program and policy level.*” These two questions suggest that although stakeholders respect the opinion of families in clinical interactions, not everyone is convinced of the value of including the opinions and perspectives of family at the organizational level. Also, the question “*I believe patients and families can look beyond their own experiences and issues*” resulted in the lowest mean score across all stakeholder groups.

With a majority (83.7%) of stakeholders in support of integrating parents into formal roles, the Checklist for Attitudes Survey reveals homogeneity of beliefs about partnering with patients and families across all three stakeholder groups. In spite of this general consensus, a readiness to act was not apparent in the Checklist for Attitudes Survey results; another indicator that stakeholders are in the contemplative phase of readiness for change (Prochaska et al., 1994).

Successful integration of parents will require substantial examination of the attitudes of stakeholders and development of time sensitive and specific action plans prior to integration of parents into this CHWH culture.

Limitations

This practice inquiry project had several limitations which may affect overall outcomes. First, the combined response rate was 33.5% for all stakeholder groups. The lowest response rate, 28.8%, was the physician group with the leaders group responding at the highest rate of 68.8%, and nurses responding at a rate of 32.2%. A 40% response rate has been indicated as necessary to reliably assess nursing unit work environments (Kramer, Schmalenberg, Brewer, Verran, & Keller-Unger, 2009). In a study by Willis, Smith and Lee (2013), repeatedly contacting physicians to improve response rates had little effect on data distribution and non-response bias and that the majority of analyzed variables remained the same. (Willis, Smith, & Lee, 2013).

Next, nurses may have been influenced in their responses because nursing leadership was driving family centeredness as an important nursing practice issue. In addition, a focus on developing mutually beneficial partnerships with families, and education and support for dealing with difficult families was in progress at the time of survey launch.

Another factor which may have impacted the survey responses was a change in organizational structure affecting nurses, leaders, and physicians. Changes in reporting structures and established collaborative interdisciplinary partnerships within the CHWH took place within six months of survey launch. Though difficult to accurately assess the impact, these factors may have affected survey responses for each group of stakeholders.

Perhaps the most important limitation of this assessment was that parents were not surveyed. It will be essential to measure parent perception of the PFCC environment before and after the integration of parents and should be considered prior to developing the implementation plan.

Implications for Clinical Practice

The findings from this assessment of organizational readiness to integrate parents into formal advisory roles have implications for advancing evidence based practice and PFCC in this CHWH. Integrating patients and families as advisors at the organizational level is critical to advancing the current state of PFCC including improvements in quality and safety. Expectations for changes in clinical practice patterns and challenges to current beliefs and attitudes of stakeholders may impact integration of parents as advisors into the culture. With 83.7% of all stakeholders in favor of parents as advisors in the CHWH, implementation plans must focus on the identified knowledge gaps and attitudes that may prove to be barriers. Recognition that stakeholders are in the *contemplative phase* of readiness for change suggests that stakeholders need more time, opportunities to express their concerns and fears, and episodes of facilitated visioning of a CHWH culture where parents are full partners in care.

A proposed implementation plan should include:

1. Executive leadership sets a clarity of aim to integrate parents and families into the culture on an organization wide scale (including adult hospital and ambulatory services) (J. Conway, personal communication, March 10-11, 2015)
2. Determine leading and lagging indicators/outcome metrics for successful integration of parents into formal roles

3. Develop a timeline and a process for evaluating and communicating progress toward integrating parents as advisors
4. Prepare CHWH nurses, physicians and leaders to work with parents as advisors through education and open discussions of perceived facilitators and barriers
5. Identify CHWH stakeholder champions to serve as early adopters of parents as advisors and lead the culture change
6. Develop formal feedback and problem solving sessions for nurses, physicians, leaders
7. Develop criteria and recruitment guidelines to identify potential parent advisors
8. Identify a CHWH administrative support professional for parent advisors
9. Identify opportunities to engage parent advisors in the CHWH
10. Orient parent advisors to privacy expectations, role of the parent advisor
11. Coach parent advisors regarding how and when to tell their story (Agency for Healthcare Research and Quality [AHRQ], 2008).

Conclusion

Readiness for integrating parents as advisors in terms of the beliefs, attitudes, and intentions of stakeholders was assessed. Findings included:

- Key stakeholders in the organization expressed support for integrating parents as advisors
- Gaps were identified in the CHWH current environment and environments supportive of PFCC culture
- Knowledge gaps were reported by stakeholders regarding PFCC culture while they expressed the belief that their individual clinical practices supported PFCC.

The data indicated that all stakeholder groups are in the contemplative stage of organizational readiness for integrating parents into formal roles (Prochaska et al., 1994). Both qualitative and quantitative data indicate stakeholders are striving to fully accept parents as full partners in care, and envision parent partnerships positively impacting the CHWH culture. Future planning for successful integration of parents as advisors should address the elements of PFCC gaps in knowledge and provide opportunities for all stakeholders, to collectively examine their current beliefs and attitudes. Facilitated discussions among stakeholders and national experts in PFCC should be considered as a tactic to move stakeholders toward the preparation and action phases of organizational readiness.

Integration of parents as advisors will require adoption of complex changes in this CHWH including adjustments to work flow, decision making, communication patterns, and potentially staffing and resource allocation. This assessment of organizational readiness provides the critical first step toward reaching the CHWH's vision to be the preferred provider of pediatric care in the region.

Table 1. Descriptive statistics of organizational readiness by Domains: All stakeholders (N=86) *except* those answering “do not know”

Domain	Mean (SD)
Leadership	3.03 (1.18)
Mission	3.39 (1.08)
Advisors	1.83 (1.02)
Quality Improvement	2.48 (1.20)
Personnel	2.64 (1.13)
Environment/Design	2.23 (1.04)
Information/Education	2.77 (1.11)
Diversity & Disparities	3.04 (1.10)
Charting & Documentation	1.93 (1.11)
Care Support	3.59 (0.97)
Care	3.52 (0.99)

Table 2. Descriptive statistics of organizational readiness by individual questions. Sorted in descending order from greatest to least percentage: “I don’t know.” All stakeholders (N=86)

Domain	Element of family centered care—Individual Questions	Mean (SD)	% I don’t know
Information / Education	Clinician email access from PATIENT/FAMILY is encouraged and safe	1.96 (1.061)	43.12
Quality Improvement	PATIENT/FAMILIES are part of the team that attends Institute for HealthCare Improvement, National Patient Safety Forum and other national meetings	1.46 (1.034)	40.48
Environment And Design	PATIENT/FAMILY participate fully in all clinical/hospital design projects	1.61 (0.940)	36.47
Personnel	PATIENT/FAMILY participate on interview teams, search committees	1.60 (1.116)	33.73
Quality Improvement	PATIENT/FAMILIES participate in quality, safety, and risk meetings	1.61 (1.039)	33.33
Quality Improvement	PATIENT/FAMILY are active participants on task forces, QI teams	1.54 (0.927)	32.14
Advisors	PATIENT/FAMILY serve on hospital committees	1.59 (1.044)	31.76
Diversity & Disparities	Navigator programs for minority and underserved patients	2.20 (1.186)	31.40
Personnel	PATIENT/FAMILY welcome new staff at new employee orientation	1.50 (1.112)	30.95
Advisors	Patients and families are members of advisory councils	1.61 (1.000)	30.59
Information / Education	PATIENT/FAMILY serve as educators/faculty for clinicians and other staff	2.07 (1.250)	28.24
Diversity & Disparities	Careful collection and measurement; race / ethnicity / language	3.06 (1.296)	25.58
Leadership / Operations	Patient/Families included in policy, procedure, program and guideline development, Governing Board activities	2.27 (1.296)	22.35
Advisors	PATIENT/FAMILY participate in quality and safety rounds	2.02 ((1.234)	22.35
Care Support	Patients receive updated medication history at each visit	3.51 (1.233)	21.18
Charting and Documentation	Patient and family are able to chart	1.28 (0.709)	20.00
Diversity & Disparities	Educational materials at appropriate literacy levels	3.13 (1.187)	19.77
Care	PATIENT/FAMILY listened to, respected, treated as partners in care	3.51 (1.098)	18.82
Quality Improvement	PATIENT/FAMILY voice informs strategic / operational aims/goals	2.55 (1.240)	16.47

Personnel	Expectation for collaboration with PATIENT/FAMILY is in job descriptions & performance reviews	3.28 (1.385)	15.48
Domain	Element of family centered care—Individual Questions	Mean (SD)	% I don't know
Quality Improvement	PATIENT/FAMILIES are interviewed as part of walk-rounds	3.31 (1.307)	15.29
Information / Education	Web portals provide specific resources for PATIENT/FAMILY	3.15 (1.709)	15.29
Environment And Design	Environment supports patient and family presence and participation as well as interdisciplinary collaboration	2.47 (1.179)	14.12
Information / Education	PATIENT/FAMILY have access to / encouraged to use resource rooms	3.07 (1.284)	14.12
Mission, Vision, Values	Patient/Family “friendly” Patient Bill of Rights and Responsibilities	3.23 (1.222)	12.94
Charting and Documentation	PATIENT/FAMILY have full and easy access to paper/electronic record	2.33 (1.329)	11.76
Care Support	PATIENT/FAMILY find support, disclosure, and apologies with error and harm	3.28 (1.177)	10.59
Care Support	PATIENT/FAMILY are able to activate rapid response systems	3.64 (1.344)	10.59
Quality Improvement	Staff/physicians have the skills and are supported in PATIENT/FAMILY centered care practice	2.96 (1.163)	9.41
Care Support	Family presence allowed/ supported during rescue events/codes	3.62 (1.165)	8.24
Leadership / Operations	Clear statement of commitment to Patient and family centered care and patient-family partnerships	3.40 (1.27)	5.88
Mission, Vision, Values	Patient and family centered care included in Mission, Vision, and/or Core Values	3.49 (1.119)	4.71
Leadership / Operations	Explicit expectation, accountability, and measurement of patient and family centered care	3.04 (1.232)	3.53
Care Support	Families are members of the care team, not visitors, with 24/7 access	3.48 (1.209)	3.53
Diversity & Disparities	PATIENT/FAMILY provided timely access to interpreter services	3.18 (1.170)	3.49
Care	PATIENT/FAMILY engage with clinicians in collaborative goal setting	3.33 (1.221)	2.35
Care Support	Families can stay, join in rounds & change of shift report	3.83 (1.177)	1.19
Care	Pain is respectively managed in partnership with patient and family	3.69 (1.075)	1.18
Care	Actively involve families in care planning and transitions	3.56 (1.128)	0

Figure 1. CHWH PFCC organizational readiness domains in rank order as compared to best practice organizations

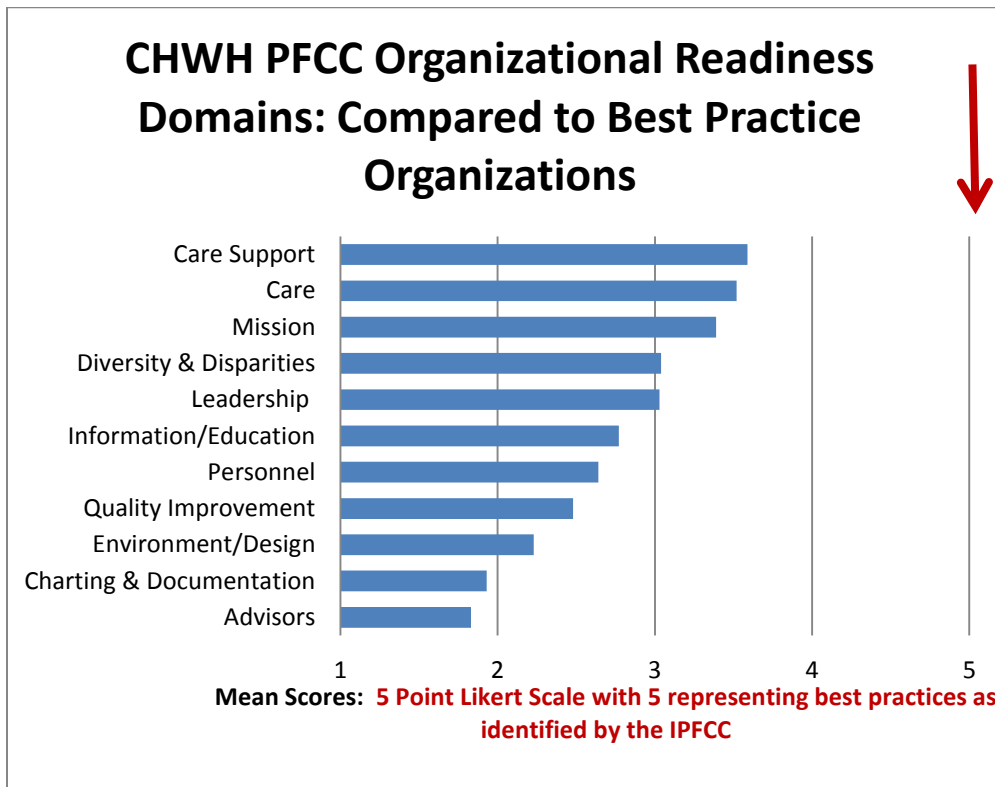


Figure 2. Comparison of mean scores for domains where a significant difference between stakeholder groups was identified.

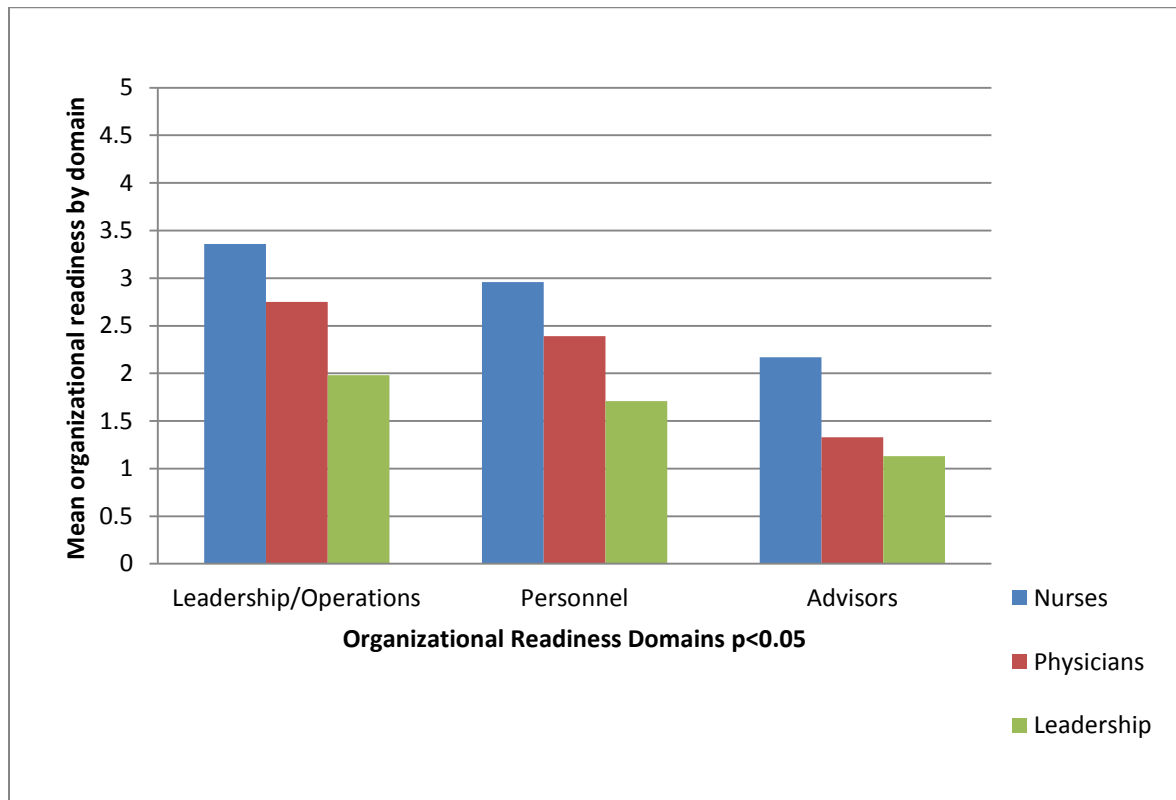


Table 3. Multiple Comparisons—LSD (Least Significant Difference)

Dependent Variable	I - J		Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
	Group I	Group J				Lower Bound	Upper Bound
Leadership/Operations	Nurses	Physician	.608*	.282	.034	.05	1.17
		Leaders	1.377*	.362	.000	.66	2.10
	Physician	Nurses	-.608*	.282	.034	-1.17	-.05
		Leaders	.769	.406	.062	-.04	1.58
	Leaders	Nurses	-1.377*	.362	.000	-2.10	-.66
		Physician	-.769	.406	.062	-1.58	.04
Advisors	Nurses	Physician	.841*	.279	.004	.28	1.40
		Leaders	1.041*	.326	.002	.39	1.69
	Physician	Nurses	-.841*	.279	.004	-1.40	-.28
		Leaders	.200	.378	.599	-.56	.96
	Leaders	Nurses	-1.041*	.326	.002	-1.69	-.39
		Physician	-.200	.378	.599	-.96	.56
Personnel	Nurses	Physician	.567	.275	.042	.02	1.11
		Leaders	1.244	.391	.001	.54	1.94
	Physician	Nurses	-.567	.275	.042	-1.11	-.02
		Leaders	.677	.392	.088	-.10	1.46

Table 4. “Checklist for Attitudes” about Partnering with Patients and Families-- % YES

Attitudes	Total Sample	Nurses	Physicians	Leaders
	% yes	% yes	% yes	% yes
In each clinical interaction:				
I believe that patients and families members bring unique perspectives and expertise to the clinical relationship	97.7	96.2	100.0	100.0
I encourage patients and families to speak freely	100.0	100.0	100.0	100.0
I listen respectfully to the opinions of patients and family members	96.5	98.0	100.0	100.0
I encourage patients and family members to participate in decision-making about their care	100.0	100.0	100.0	100.0
I encourage patients and family members to be active partners in assuring the safety and quality of their own care	98.8	100	95.7	100
At the organizational level:				
I consistently let colleagues know that I value the insights of patients and families	84.9	88.2	82.6	81.8
I believe that patients and families can play an important role in improving patient safety and quality within the organization	96.5	96.1	100.0	100.0
I believe in the importance of patient and family participation in planning and decision-making at the program and policy level	82.6	84.0	82.6	90.0
I believe that patients and families bring a perspective to a project that no one else can provide	93.8	92.0	100.0	100.0
I believe patients and families can look beyond their own experiences and issues	70.9	72.5	65.2	90.0
I believe that the perspectives and opinions of patients, families, and providers are equally valid in planning and decision-making at the program and policy level	76.7	78.4	65.2	100.0
*I would support integrating parents into formal roles in our hospital	83.7	82.8	90.9	100.0

(*This is a supplemental question—not associated with the IPFCC survey instruments)

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Manuscript 3

Parent and Family Advisory Councils: An Implementation Guide for a Children's Hospital

within a Hospital

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Parent and Family Advisory Councils: An Implementation Guide for a Children's Hospital
within a Hospital

Introduction

Prochaska, Norcross, and Diclimente (1994) describe the stages of organizational readiness for change as *precontemplation*, *contemplation*, *preparation*, *action* and *maintenance*. *Precontemplation* is the stage of resistance to change and the *contemplation* stage finds the organization struggling to understand the change and need for change. Organizations in the contemplation stage of change readiness think about the issue and potential solutions yet are not ready to take action. In the *preparation* stage there is a commitment to action, but persistent ambivalence about moving forward with the change. The *action* stage is characterized by modifications in behavior, confrontation of fears, and activities that require commitment of time and energy. During the *maintenance* stage, the focus is on prevention of a return to the prior state. Reaching the *termination* phase is the ultimate goal where a return to the former organizational culture or state is no longer a threat (Prochaska et al., 1994).

Patient and family engagement in healthcare can be multidimensional; ranging from participating in direct care, organizational design, governance and policy making (Carmen et al., 2013). Engaging patients and families has been deemed an imperative component of the United States' health care system redesign, and quality of care improvement initiatives (Institute of Medicine [IOM], 2001). Engaging patients and families as advisors leads to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction with care (Conway, 2008). The integration of parents into formal roles in children's hospitals ranges from parent advisors who are fully benefitted and salaried members of the health care team to parents who volunteer their time as parent advisors (Springate, 2015).

Background & Significance

The results of an organizational readiness assessment to integrate parents into formal advisory roles at a children's hospital within a hospital (CHWH) in the Midwest United States, revealed clinicians and leadership to be in the *contemplation* stage of readiness for change (Prochaska, et al). There was an absence of parents as advisors at the time of the organizational readiness assessment. This CHWH is part of a fast growing academic medical center in the Midwest, and is striving to become the preferred provider of pediatric care in the region. The strategic plan calls for the incorporation of parents into advisory roles including quality, safety, and service initiatives (Springate, 2015). To move beyond the *contemplation stage* of readiness will require education, opportunities for clinicians and leadership to express their concerns and fears, and episodes of facilitated visioning of a culture where parents are full partners in care (Springate, 2015).

Guidelines for development of patient and family advisory councils (PFAC) are prolific. The Institute for Patient and Family Centered Care (IPFCC), Agency for Healthcare Research and Quality (AHRQ), Institute for Healthcare Improvement (IHI), the American Hospital Association (AHA) and many other organizations publish suggestions and road maps for developing patient and family advisory councils (<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ahi.org/>; (<http://www.aha.org/>). To support this CHWH as it strives to integrate parents into the fabric of the organization, an implementation guide including structure, process, and outcome evaluation was developed. This implementation guide is a compilation/adaptation of best practice guidelines and recommendations from the IPFCC, AHRQ, and the AHA. The guide is tailored to the current CHWH culture and the *contemplation* stage of readiness for acceptance and integration of PFACs (Prochaska et al., 1994). Feedback

from parents whose children are patients at the CHWH was collected and the Parent/Family Advisory Council member application was revised accordingly.

Recommendations

To successfully implement the PFAC, executive leadership must set a firm agenda and clarity of aim to integrate patients and families into the culture organization-wide (J. Conway, personal communication, March 10-11, 2015). Next, adequate time and preparation of the stakeholders: clinical staff, leadership, and parent advisors must be allowed for effective advisory council development. The proposed timeline with strategies and tactics may need adjustment based on how quickly the stakeholders enter the *action stage* of organizational readiness (Prochaska et al., 1994). Facilitated discussions among stakeholders and national experts in PFCC should be considered as a tactic to move stakeholders toward the preparation and action phases of organizational readiness (Springate, 2015).

Summary

Parent/Family advisory councils are an essential element of an organization committed to quality improvement (IOM, 2001). Incorporating the parent and family perspective in this CHWH culture may require adoption of complex changes including adjustments to work flow, decision making, communication patterns, and potentially staffing and resource allocation. The accompanying implementation guide and supporting documents are designed to facilitate the development of formal Parent/Family advisory councils in this CHWH.

Parent & Family Advisory Councils: Implementation Guide for CHWH

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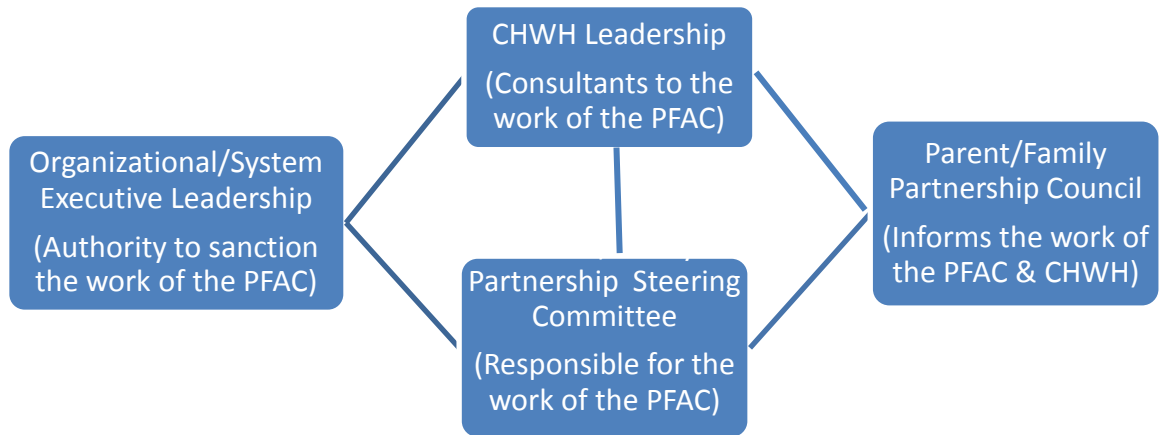
Strategy/Tactics & Timeline: Integrating Parents into Formal Roles in a CHWH

	QTR 1 20XX	QTR 2 20XX	QTR 3 20XX	QTR 4 20XX	QTR 1 20XX
Assess staff/physician readiness using IPFCC ¹ Current State and Attitudes survey	X				
Present results of survey, open forum with PFCC ² experts: Determine stage of readiness*		X			
*The stage of readiness for integrating parents into the CHWH may require adjustments to this timeline					
Educational opportunities and open forum dialogue to examine attitudes and beliefs/ prepare staff & physicians for parental presence in the organization			X		
Establish governance, organizational structure and proposed budget for Parent Partnership Council		X			
Develop position description and onboard parent partnership council coordinator		X			
Convene a steering committee: group of staff members, leadership and family members to guide the integration of parents			X		
Establish guidelines for selection of parents to serve as advisors/committee members		X			
Seek input from staff/physicians/parents about potential parent candidates		X			
Develop interview guide and screening tools for parent selection		X			
Collaborate with volunteer services regarding onboarding, HIPAA training		X			
Develop and implement a “how to tell your story” orientation program for parents and		X	X	X	
Create communication standards to keep involvement of parents top of mind for process/quality improvement, organizational changes		X	X		
First Parent Partnership Advisory Council Meeting					X**
Parent Partner Presents at Nursing Orientation					X**
Parent Partner attends Child Life Staff Meeting					X**
Parent Partner attends Nursing Council					X**
Evaluation of Partnership Council by steering committee & council members; program adjustments				X	
**denotes pre-meeting and debriefing to take place with the parent partnership council coordinator and selected members of steering committee					
Parent Partner(s) attend CHWH monthly quality and safety meeting—18 -24 months after parent partnership council launch					
Evaluation of expansion of program with executive leadership—18 – 24 months after parent partnership council launch					

¹Institute for Patient and Family Centered Care

²Patient and Family Centered Care

PARENT/FAMILY ADVISORY COUNCIL ORGANIZATIONAL/GOVERNING STRUCTURE & REPORTING RELATIONSHIPS



Essential to the success of any Patient and Family Advisory Council is a clear vision and directive from executive leadership. A children’s hospital within a hospital is subject to special challenges related to the sharing of resources, being seen as an integral yet separate component of the health care system, and competition/benchmarking with free standing children’s hospitals where children are the sole focus (Cimotti, Barton, Gorman, Sloane, & Aiken, 2014).

This proposed matrix reporting structure outlines the governing structure of the Parent/Family Partnership Council.

Parent/Family Advisory Council: Organizational Structure

The core concepts of Patient and Family Centered Care (PFCC) are:

- Dignity and Respect
- Information Sharing
- Participation
- Collaboration (Institute for Patient and Family Centered Care; www.ipfcc.org)

Kentucky Children's Hospital is committed to advancing the culture of PFCC. A patient and family centered care environment, including the integration of patients and families as advisors, leads to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction with care (Conway, 2008; Institute of Medicine [IOM], 2001).

Parent/Family advisory councils do not generally need complex organizational structures, however, clear cut operating principles are recommended for success (Webster & Johnson, 2000). The following organizational structure is designed to serve as the initial structure for a children's hospital within a hospital (CHWH) and may need to be adapted based upon the organization's current state of readiness to integrate parents/family members into formal advisory/partnership roles.

GOAL/PURPOSE

The Parent/Family Advisory Council advises the CHWH administration and clinical leadership on patient needs and hospital priorities from a family perspective. Members may participate in hospital-wide decision-making processes, and are a valuable resource for educating families and employees about family-centered care. Members may also serve on hospital committees that influence patient care.

The Parent/Family Advisory council serves to help the CHWH to reach the strategic goal of being the preferred provider of care to children in this region.

COUNCIL SIZE

Family members/staff representatives should be represented on the council at a ratio 2:1 respectively. Over time, the ratio of family members to staff representatives should gradually increase, with the goal of family members having a substantial majority of representation on the council. A membership of 15 members is considered optimal to ensure diversity among council members and attendance that represents a quorum of family/parent partners.

PARENT/FAMILY MEMBER COMPOSITION of the council should reflect the population served:

- Parents, guardians, grandparents, foster families, single parents, step-parents
- Diversity with respect to culture, race, religion, age, income, education

- Chronic versus acute illness
- Families experiencing loss (recommend that these families participate > 6 months after the loss of their child)

STAFF/PHYSICIAN MEMBER COMPOSITION

- Nurse and Physician leader
- Nursing Practice Council Chair
- Manager, Office of Patient Experience
- Parent/Family Advisory Coordinator
- Guests may attend to ask for input from Parent/Family Partners or at the request of the Parent/Family Advisory council to provide information

MEMBERSHIP TERMS AND ATTENDANCE

Continuity of membership is imperative for the success of the Parent/Family Advisory Council. Initially, members will be asked for a one year commitment with the option of staying for a second year. Partners who choose to leave after the first year will be replaced using the standard selection process.

After two years, Partners must rotate off the council, but may move on to other opportunities for Parent/Family Partners. The goal for the council is to maintain one half of the Parent/Family Partners every year for continuity of effort and purpose.

Council meetings must have a quorum of Parent/Family partners to facilitate optimal discussion and proposed action. Members are asked to attend 80% of regularly scheduled council meetings.

RESPONSIBILITIES OF COUNCIL MEMBERS:

- Be willing to listen to differing views
- Respect the viewpoints of others
- Look beyond one’s individual experience and reach out broadly to other patients, families, staff and community members
- Be committed to improving the care for all patients and family members

COMPENSATION and REIMBURSEMENT for EXPENSES

Parent/Family Partners will be reimbursed for parking expenses and provided with a \$10 gasoline gift card for every hour of travel time for council meetings. Refreshments and/or a meal will be provided at council meetings depending on time of day.

OFFICERS and COMMITTEES

The Parent/Family Advisory Council will have the following council officers:

- Co-Chairs: Two family members will serve as co-chairs of the council

- Facilitator: The Parent/Family Advisory Coordinator will serve as the facilitator for the group
- Recorder: Staff/Physician member. Minutes are recorded via standard template and provided to Council Facilitator within 3 days of the council meeting for processing and distribution

BY-LAWS

Once formed, the Parent/Family Advisory Council should collaboratively develop by-laws that address:

- Procedures for election of officers
- Guidelines for setting council meeting agendas
- Meeting times and frequency
- Communication guidelines/channels for communication
- Maintaining confidentiality of issues
- Guidelines of authority

Once developed, the by-laws should be voted on by the council and then reviewed and approved by the Patient/Family Advisory Council Steering Committee and Hospital Administration.

Adapted from (Webster & Johnson, 2000)

Proposed Budget (Estimated) for Parent/Family Advisory Council

	Estimated Cost
1. Salary & Benefits for Parent/Family Partnership Coordinator	
Grade 11 Position Salary Mid-range	\$ 66,352
Benefits	\$ 19,905
SUBTOTAL	\$ 86,257
2. Recruitment of Parents/Family Partners Administrative Costs	
Direct mail, brochures, office supplies	\$ 5,000
Background Checks, Drug Screens 15 people @ \$30 each	\$ 450
Vaccinations/Screenings 15 people at \$100	\$1,500
SUBTOTAL	\$ 6,950
3. Food/Refreshments for Council Meetings	
10 meetings/year--25 people @ \$10/person	\$ 2,500
	\$ -
	\$ -
SUBTOTAL	\$ 2,500
4. Reimbursement of Expenses for Parent/Family Partners	
Parking	\$ 2,000
Gas Cards at \$10 card for every 1 hour of travel for 15 parent partners	\$ 3,000
	\$ -
SUBTOTAL	\$ 5,000
TOTAL	\$ 100,707

***The proposed budget is intended to spark discussion and determine the level of organizational support for the Parent/Family Advisory Council. Budgets for Patient and Family Advisory Councils range from Patient/Parent Advisors who are hospital staff members with full salary and benefits to councils where Patient/Parent Advisors do not receive any reimbursement for participating.**

Parent/Family Advisory Council Coordinator Position Description*

DEPARTMENT: Office of Patient Experience (OPE)

SUPERVISOR'S TITLE: Manager, Patient Experience

PURPOSE OF POSITION: To provide leadership and support for educational and programmatic activities that integrate adult family members into the culture of Kentucky Children's Hospital (KCH). Identify and coordinate ways in which adult family members can contribute to the mission and values of the KCH. Serve as administrative support and liaison for family partners/family advisory council between KCH and OPE leaders and staff.

MAJOR JOB RESPONSIBILITIES:

1. Plan and facilitate the KCH Parent/Family Advisory Council (PFAC) meetings:
 - a. initiate agenda
 - b. ensure minutes and agenda are distributed in timely manner
 - c. facilitates regular FPC meetings in unbiased, professional manner ensuring that the goals and objectives of the council are met.

2. Assists with overall function of the KCH Parent/Family Advisory Council (PFAC):
 - a. recruit and interview candidates for FPC as needed
 - b. assist with planning and orientation of new FPC members
 - c. Assist with matching family members to hospital wide committees and programs as requested by KCH medical staff, leadership and front line team members.

3. Provides psychosocial, educational and leadership support for Family Advisors
 - a. Serve as an on-site resource and support for families and staff
 - b. Direct, supervise, and support personal and professional growth of FPC members
 - c. Connect patients and families with appropriate hospital support and resources as appropriate
 - d. Function as liaison among patients, families, and staff to facilitate information exchange including how to effectively "tell one's story"
 - e. Facilitate communication among families and health care members to support integration of family partners into the quality, safety, service and efficiency strategies of the KCH

4. Communicate with and educate hospital personnel regarding patient and family centered care and the role of the Parent/Family Advisory Council in a family centered care culture
 - a. Serve on designated University and public committees with the purpose of providing a broad consumer perspective
 - b. Promote the availability and progress of the FPC to administration, staff, students, and faculty via meetings, presentations, publications, and correspondence
 - c. Report family-determined challenges and concerns to KCH and OPE leadership, staff & faculty

- d. Facilitate open communication so that families and professionals feel free to express themselves and work collaboratively to design, implement and evaluate improvement efforts

REQUIRED SKILLS: Exceptional verbal, written, interpersonal and customer service skills required. Ability to relate to diverse age and demographic backgrounds. Sound understanding of concepts of Family Centered Care. Demonstrated organizational, problem solving and negotiation skills. Capable of working with a diverse family population. Able to adapt to unique situations. Demonstrates an independent work initiative

EDUCATION/WORK EXPERIENCE: Adult family member of a child who is currently or has been a patient at KCH. A sound understanding of medical terminology, experience with public speaking, presentations, and group facilitation strongly preferred.

Previous work with volunteers preferred.

High School diploma required with additional educational preparation strongly preferred.

Adapted from (AHA; AHRQ; IHI; IPFCC)

(<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ihl.org/>; <http://www.aha.org/>).

Selecting a Parent Advisory Council Coordinator: Considerations *

Selection of the Parent/Family Advisory Council Coordinator should be conducted with the following in mind: To be successful, the person selected as the Coordinator should be someone who has a passion for patient and family centered care. Ideally, this person will have experience working with parents and their children, facilitating parent groups, and collaborating with hospital leadership.

Use the following guidelines to frame your selection of the Parent Advisory Coordinator:

- Understands the importance of mutually beneficial partnerships between parents and hospital staff
- Able to balance parent perspective and staff/physician perspectives
- Able to listen respectfully to differing opinions and share different points of view
- Positive and supportive of the mission of the hospital
- Has experience helping children and their families cope in challenging circumstances
- Able to communicate differences of opinion in a positive, constructive manner
- Able to influence using emotional intelligence skills
- Interacts well with many different kinds of people
- Able to work in partnership with others.
- Is well-respected by senior leadership and their peers

Adapted from (AHA; AHRQ; IHI; IPFCC)

(<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ihl.org/>; <http://www.aha.org/>).

Parent/Family Advisory Council Coordinator Interview Guide *

1. We would like to hear about your experiences working with children and their parents/families. Can you tell us about a specific time that you were able to make a difference for a parent and their child?

We know that it is not always easy to relate to some families. Can you tell us about a specific time that you had difficulty understanding family dynamics or coping skills?

2. The ability to influence others is an important quality in healthcare culture. Can you tell us about a time when you were able to influence others to consider a point of view that was different from their own?

3. Have you ever been a member of a community group like the PTA (parent teachers' association), online or face to face support groups? Tell us about your best experience as a member of that group.

Given the chance, what would you change about that group?

4. Tell us about your experience working with physicians, nurses and hospital leadership.

5. Tell us why you are the best candidate for this position.

If you can accomplish one thing while serving as the Parent/Family Advisory Council Coordinator, what would you want it to be?

6. What questions do you have for us?

Adapted from (AHA; AHRQ; IHI; IPFCC)

**(<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ihl.org/>;
(<http://www.aha.org/>).**

Parent Advisory Council Coordinator: Interview Feedback *

Selection of the Parent/Family Advisory Council Coordinator should be conducted with the following in mind: To be successful, the person selected as the Coordinator should be someone who has a passion for patient and family centered care. Ideally, this person will have experience working with parents and their children, facilitating parent groups, and collaborating with hospital leadership.

Candidate's Name _____ **Date of interview** _____ **KCH**
Team Member _____

Rate the candidate on your perception of their ability to:

Quality	I have concerns (1)	Will be fine with support/development of skills (2)	Candidate is ready to actively contribute to and guide our work (3)
Understands the importance of mutually beneficial partnerships between parents and hospital staff (Family Centered Care)			
Able to balance parent perspective and staff/physician perspectives			
Able to listen respectfully to differing opinions and share different points of view			
Positive and supportive of the mission of the hospital			
Has experience helping children and their families cope in challenging circumstances			
Able to communicate differences of opinion in a positive,			

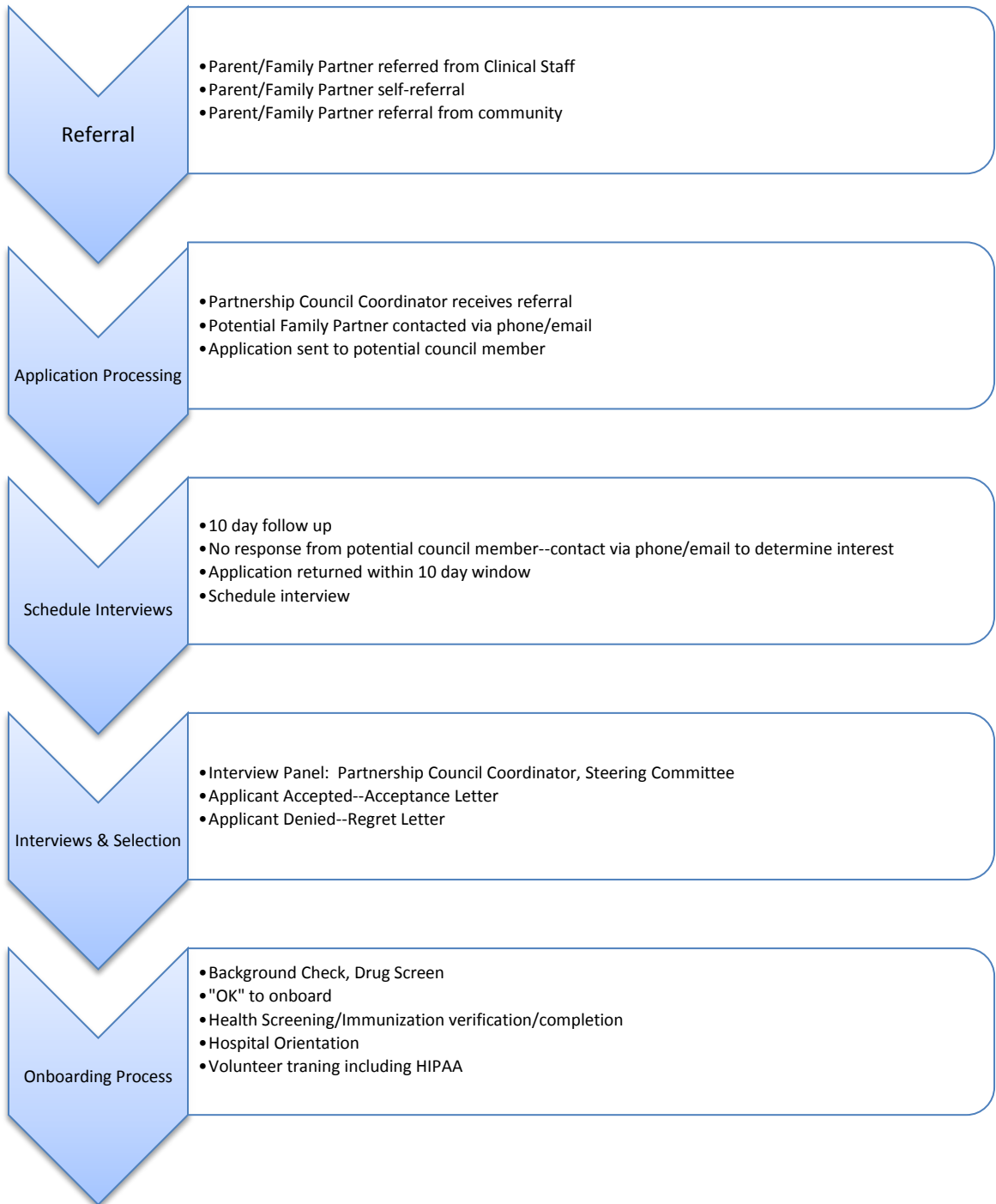
Quality	I have concerns (1)	Will be fine with support/development of skills (2)	Candidate is ready to actively contribute to and guide our work (3)
constructive manner			
Able to influence using emotional intelligence skills			
Interacts well with many different kinds of people			
Able to work in partnership with others.			
Is well-respected by senior leadership and their peers			
<i>SUBTOTAL PER COLUMN</i>			
TOTAL SCORE =			

Comments:

Adapted from (AHA; AHRQ; IHI; IPFCC)

**(<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ihl.org/>;
(<http://www.aha.org/>).**

Parent/Family Partner Selection/Hiring Process Flow



PLEASE NOTE: This process may take up to 2 months to complete

Parent/Family Advisory Council Application*

Date: _____

Name: _____
Last First
MI

Address: _____ City: _____ State: _____

Zip: _____

Home Phone: _____ Work Phone: _____ Cell Phone: _____

Email: _____

Do you prefer: (*circle one*) mail phone email text

The following questions will help us get to know you better:

1. When was your care experience at UK HealthCare Kentucky Children's Hospital, Clinic or Outpatient visit?

(Check all that apply)

- 6 months or less ago
- 6 months to 1 year ago
- 1 year to 2 years ago
- 2 years to 3 years ago

2. Which areas of service provided care for you or your family members? (*Check all that apply*)

- Pediatric Emergency Department
- General Pediatrics Clinic
- Pediatric Specialty Clinic
- Outpatient Services
- Children's Sedation & Procedure Unit
- Operating Room
- Rehabilitation Services (PT/OT/Speech)
- Pediatric Surgery clinic
- Laboratory Services
- Radiology
- Echo
- Kentucky Children's Hospital Inpatient (KCH)

3. The last time your child was cared for at KCH - how many days did he/she stay? (*Check one*)

- 1 or less days
- 2-5 days
- 5-10 days
- 10 or more days

4. SKILLS & INTERESTS Please describe any personal or professional experiences you have that will benefit the Parent/Family Advisory Council? Example: Concerned parent, PTA member, Girl Scout leader, fundraiser, coach, etc.

5. We recognize that our parent/family partners have busy lives. How much time are you able to commit to being a parent/family partner? A minimum of 2 hours per month are required to participate, and we also suggest a 6 month commitment for all parent/family partners. (Check one)

- 2 hours per month
- 2-3 hours per month
- 3-4 hours per month
- 4 plus hours per month

6. We are looking for all kinds of participation: (Check all areas of interest)

- Interview:** Participate in a one-time interview about your healthcare experience.
- Reviewer:** Review informational materials for patients and family members.
- Story Sharing:** Share your healthcare experience(s)
- Improvement Teams:** Join a hands-on team to improve an organizational issue. Actively participate as a team member, working closely with KCH staff. You would be representing the patient or family perspective.

Please tell us about...

1. One good experience you had when you were in our care

2. One challenge your family faced when you were in our care

3. One thing you would like to see improved for all families who receive care from us

10. Please put an 'X' in the Day(s) and Time(s) you are available for us to contact you to further discuss this opportunity

	Monday	Tuesday	Wednesday	Thursday	Friday
Mornings					
Afternoons					
Evenings					

Adapted from (AHA; AHRQ; IHI; IPFCC); Revisions based on Parent Feedback

**(<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ihi.org/>;
<http://www.aha.org/>).**

Selecting a Parent Advisory Coordinator: Considerations *

Selection of the Parent/Family Advisory Council Coordinator should be conducted with the following in mind: To be successful, the person selected as the Coordinator should be someone who has a passion for patient and family centered care. Ideally, this person will have experience working with parents and their children, facilitating parent groups, and collaborating with hospital leadership.

Use the following guidelines to frame your selection of the Parent Advisory Coordinator:

- Understands the importance of mutually beneficial partnerships between parents and hospital staff
- Able to balance parent perspective and staff/physician perspectives
- Able to listen respectfully to differing opinions and share different points of view
- Positive and supportive of the mission of the hospital
- Has experience helping children and their families cope in challenging circumstances
- Able to communicate differences of opinion in a positive, constructive manner
- Able to influence/strong emotional intelligence skills
- Interacts well with many different kinds of people
- Able to work in partnership with others.
- Is well-respected by senior leadership and their peers

Adapted from (AHA; AHRQ; IHI; IPFCC)

**(<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ihl.org/>;
(<http://www.aha.org/>).**

Parent/Family Advisory Council Coordinator Interview Guide *

1. We would like to hear about your experiences working with children and their parents/families. Can you tell us about a specific time that you were able to make a difference for a parent and their child?

We know that it is not always easy to relate to some families. Can you tell us about a specific time that you had difficulty understanding family dynamics or coping skills?

2. The ability to influence others is an important quality in healthcare culture. Can you tell us about a time when you were able to influence others to consider a point of view that was different from their own?

3. Have you ever been a member of a community group like the PTA (parent teachers' association), online or face to face support groups? Tell us about your best experience as a member of that group.

Given the chance, what would you change about that group?

4. Tell us about your experience working with physicians, nurses and hospital leadership.

5. Tell us why you are the best candidate for this position.

If you can accomplish one thing while serving as the Parent/Family Advisory Council Coordinator, what would you want it to be?

6. What questions do you have for us?

Parent/Family Partners: Interview Feedback Form*

Selection of charter members of the Parent/Family Advisory Council (PFAC) should be conducted with the following in mind: To be successful, the *initial* Family Advisory Council must be comprised of members who are balanced in their health care view/opinions.

Candidate's Name _____ Date of interview _____ KCH
 (PFAC) Team Member _____

Rate the candidate on your perception of their ability to:

Quality	I have concerns (1)	Will be fine with support/development of skills (2)	Candidate is ready to actively contribute to and guide our work (3)
Able to listen to differing opinions and share different points of view.			
Able to listen to differing opinions and share different points of view.			
Positive and supportive of the mission of the hospital.			
Share insights and information about their experiences in ways that others can learn from them.			
Able to see beyond their own personal experiences.			
Shows concern for more than one issue or agenda			
Respect the perspectives of others			

Quality	I have concerns (1)	Will be fine with support/development of skills (2)	Candidate is ready to actively contribute to and guide our work (3)
Speak comfortably in a group			
Able to interact well with many different kinds of people			
Able to work in partnership with others			
Tally of item scores			
TOTAL SCORE =			

Comments:

Adapted from (AHA; AHRQ; IHI; IPFCC)
 (<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ihl.org/>;
 (<http://www.aha.org/>).

Parent/Family Partner: How to tell your story...things to consider

Your experience may help others, but sometimes reliving past experiences, especially when they are about your child, may cause you to experience strong emotions. Before you agree to tell your story, think about the following questions.

- What am I willing to share?
- What is too private to share?
- Is my family and my child “OK” with what I am about to share?
- How could telling my story help another parent/child/health care team member?
- What could my story teach the audience?
- What are the three most important messages I want to get across
- If I have had negative experiences that are still very hurtful or bothersome, will I be able to share about these experiences in a balanced, constructive manner?

Before agreeing to share your story, be sure to ask:

- Where and when do you want me to speak?
- Who will I be speaking to?
- How long do I have to tell my story
- Is there a specific part of my story that you want me to focus on?
- Should I allow time for questions?
- If the event is out of town, will there be reimbursement for travel expenses?

And always remember...If you don't know the answer...feel comfortable and confident to say “I don't know.”

Adapted from: (Abraham, Ahmann, & Dokken, 2013)

Parent/Family Advisory Council Evaluation

(Choose One) I am a: Parent/Family Partner _____ Staff Partner _____

Please choose the number that best describes how you rate each question below. With 1 being “strongly disagree” and 5 being “strongly agree.” N/A means “does not apply to me.”

Question	1	2	3	4	5	N/A
Parent/Family Partners and Staff Partners						
Overall I am satisfied in my role as a Parent/Family Partner						
The content of COUNCIL meetings is interesting to me.						
COUNCIL meetings are productive and valuable use of my time						
Meetings are frequent enough to meet the need						
The meeting time is convenient						
My opinions are listened to and valued						
The Parent/Family Partnership Council Coordinator is available to me						
I am involved with the work of the COUNCIL to the degree that I would like.						
My expectations of the mission and work of this council were accurate.						
Presenters to the COUNCIL come to listen to and apply the council’s perspective on their work.						
The COUNCIL has the resources it needs to accomplish its mission of promoting family-centered care.						
I learn things from the COUNCIL meetings that help me understand how the hospital works.						
I learn things from the COUNCIL meetings that help me understand how to help the hospital change and improve.						
The hospital actively listens to and applies lessons learned from family experiences and suggestions						
I was adequately oriented to the work of the council and the expectation of me as a patient and family advisory						
Staff Partners Only						
The content of COUNCIL meetings is relevant to what I do						
I learn things from COUNCIL meetings that help me promote family centered care where I work						
I was adequately oriented to the work of the council and expectations of me as a staff advisor						

The COUNCIL’s greatest strengths are:

The COUNCIL’s greatest challenges/my recommendations for improvement are:

Adapted from (AHA; AHRQ; IHI; IPFCC) (<http://www.ipfcc.org/>; <http://www.ahrq.gov/>; <http://www.ahrq.gov/>; <http://www.ahi.org/>; (<http://www.aha.org/>).

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DNP Capstone Conclusion

Over the course of achieving my doctorate in nursing practice, I have come to a greater understanding of the phenomenon of patient and family centered care (PFCC)—the antecedents that must be present to support the practice of patient and family centered care and the patient outcomes that can be achieved. I have been able to observe PFCC in a nationally recognized free-standing children’s hospital and compare it to the CHWH setting. An assessment of the current state of readiness to integrate parents into the CHWH practice environment was accomplished and an implementation guide and tool kit to help move the organization beyond the contemplative stage of change readiness was developed.

Academic pursuit is without merit if the results do not affect the care of patients. Florence Nightingale tells us: “In dwelling upon the vital importance of sound observation, it must never be lost sight of what observation is for. It is not for the sake of piling up miscellaneous information or curious facts, but for the sake of saving life and increasing health and comfort” (Nightingale, 1859, p. 70).

Thus, the transfer of knowledge of this work is the most important outcome. My first manuscript has been accepted for publication pending revisions by the Journal of Pediatric Nursing and the practice inquiry project was highlighted by Mr. Jim Conway (formerly from the IHI and IPFCC) at our academic medical center’s patient safety week earlier this year. The implementation guide and tool kit is serving as a road map for a collaborative effort between the CHWH and the health care system’s Office of Patient Experience for the development of parent advisory councils to serve in the children’s hospital.

Integrating parents into formal roles has support from all stakeholders within the CHWH. This body of work lays the groundwork for achieving the CHWH goal of being the regional

provider of choice for the care of sick children. The impact this work has on patient safety, outcomes and parent engagement across the continuum of care will serve as the most important indicators of success.

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