Parents’ and Nurses’ Perceptions of Patient-and-Family Centered Care and the Impact of the Nurse-Patient Relationship

by

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Abstract

In a healthcare system where patients are defined as consumers and consumers have a choice, hospital leaders have begun to recognize that good service is as important as excellent clinical care. In the United States, consumers go to a hospital expecting good clinical care, they return because they were treated well. Hospitals are looking at ways to improve care beyond the clinical and see patient-and-family centered care (PFCC) as one avenue to achieve this goal. The focus on relationships and partnership that PFCC emphasizes opens the door to honest dialogue between the patient/family and the caregiver laying the foundation for a long-term relationship. Through a literature review essential elements of PFCC and associated barriers and enablers are identified. This project also includes a discussion of the relationship between PFCC literature and theoretical writing about caring practices in nursing. Finally recommendations for the implementation of PFCC within an organization are derived from an exploration of the literature surrounding nurse and parent perceptions of PFCC.
Parents’ and Nurses’ Perceptions of Patient-Family Centered Care and the Impact of the Nurse-Patient Relationship

The discipline of nursing has been described as both an art and a science. The science of nursing can be understood as the acquisition of knowledge and application of skill, whereas the art of nursing, while having no single definition, involves human-to-human interaction and the transformational experience that occurs in the nurse-patient relationship (Idzak, 2007). The American Nurses Association (ANA) defines nursing as “the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response and advocacy in the care of individuals, families, communities, and populations” (ANA, 2012). The ANA further describes the difference between nursing and other health care professions as the nurse’s focus on being attuned to the whole person and not just the disease. The ANA’s Code of Ethics defines the obligations and duties of every individual that enters the nursing profession (Code of Ethics, 2010). Within the Code of Ethics, the nurse-patient relationship is addressed stating “the nurse establishes relationships and delivers nursing services with respect for human needs and values, and without prejudice” (p. 3).

Patient-and-family centered care (PFCC) is an approach to care where the patient and family are seen as equal partners in care and decision making, bringing with them their own expertise (Institute for Patient & Family Centered Care, 2010). This approach to care purports the centrality of the patient and has at its heart the importance of a caring, therapeutic relationship between nurse and patient/parent. It encompasses both the art and science of nursing. The intent of PFCC is to involve patients and families in decisions that affect their own health as well as policies, programs and staff day-to-day interactions potentially leading to better
health outcomes, wiser allocation of resources and greater patient and family satisfaction. PFCC was developed in response to the negative experiences of patients and families with the “traditional” way that care has been organized in hospitals.

Over many years I have witnessed the vulnerability of our patients and families, and the trust that parents place in the health care team. I have always been awed by their willingness to put their most sacred possession, their child, in our hands, and am honored to accept the responsibility. As a bedside nurse I have been able to direct my practice in a collaborative, respectful, and trusting manner. Through my roles as preceptor, mentor and leader, I have been able to influence the practice of others. When I moved away from the bedside I began to see that not all nurses practiced in this manner and I began to question why. It was during my time as coordinator of the nurse internship program that I became increasingly aware that many nurses were focusing on the completion of tasks and skills without consideration of the value of relationships. While this practice may be more common in new graduate nurses, what was concerning was the action of preceptors and other senior nurses in perpetuating this approach to practice. One nurse told me about her conflict with spending time with a patient whose family was unable to visit regularly. The patient found it comforting to have her hands and feet rubbed with lotion so the nurse took the time to do this. Meanwhile her co-workers were becoming angry as they could not find her anywhere and judged her to be “not helpful” or a “team player”. Unfortunately, the nurse manager, while in agreement that this patient care work was also important, validated that it was more important to help others with their tasks so that no one had to work overtime. This perceived lack of support from the manager was similarly described in the literature with nurses reporting that PFCC was not always given priority when confronted with limited resources and supportive personnel (Coyne, O’Neill, Murphy, Costello, & O’Shea,
This one example demonstrates the complexities of actually achieving the goal of PFCC. It is not enough to just say, “this is what we’re going to do now”. PFCC requires a transformational culture change that requires close examination of the barriers and a willingness to address the tough issues. Within my own organization, PFCC has been identified as an organizational goal; however, little has been done to examine the potential increase in resources necessary for the direct caregiver to meet this goal.

**Project Scope and Intent**

Through a review of PFCC literature, the overall intent of this project was to explore the perceptions of pediatric nurses and parents of hospitalized children in order to gain an understanding of the essential elements of PFCC and to identify recommendations to assist in the implementation of PFCC within my institution. The specific objectives of this project include: 1) identification of the essential elements of PFCC in a comprehensive literature review, 2) a discussion of the relationship between the PFCC literature and theoretical writing in caring practices in nursing, and 3) from the literature, the identification of the enablers and barriers for the implementation of PFCC with the goal of identifying recommendations for PFCC implementation in my current work context.

**Current Practice Context**

The last 17 years of my nursing career have been spent at a large (559 bed) tertiary non-profit, children’s hospital that provides care for children 0-18 years of age. It is affiliated with a major medical school and is the primary site for pediatric training in a variety of medical specialties. The hospital provides services in over 50 sub-specialties including cardiology, hematology, oncology, neurosciences, infectious disease, and trauma. It is a Level I pediatric trauma center providing care for children from across Texas as well as from neighboring states.
Additionally, it is a major site for pediatric nursing education and is affiliated with several area nursing programs providing both undergraduate and graduate clinical experiences.

**Theoretical Framework**

My approach to nursing practice has always been grounded in the belief that caring plays an integral role in the healing process. Nursing theorist Jean Watson refers to caring as the “essence of nursing practice” (Neil, 2002, p. 147). She provides a postmodern perspective for transpersonal caring that illustrates the validity of the nurse-patient relationship (Watson, 2008). In this relationship both nurse and patient are affected by each other’s actions and choices (Wills, 2002). In pediatric nursing, the formation of a relationship with the patient’s family could be considered critical. Watson (2008), states that a person’s family “best provides the relationship and environment necessary for the development of one’s need for affiliation” (p. 185). She describes the need for affiliation as “the human need that comes closest to revealing the core of our humanity and humanness” (p. 180). A strong relationship with the child’s family is essential as the family is the child’s main source of comfort and support. In PFCC this relationship becomes a partnership whereby the nurse and parent work collaboratively.

Another approach to practice that focuses on the nurse-patient relationship is relational nursing. Relational practice is described by Hartrick Doane as “a humanely involved process of respectful, compassionate, and authentically interested inquiry into another [and one’s own] experiences” (as cited in Doane & Varcoe, 2005, p. 200). It requires that nurses give up knowing and certainty, or their role as expert, and take up a position of uncertainty, approaching each situation, patient and family as unique. These theoretical or conceptual approaches to nursing practice align with the core concepts of PFCC and will provide the foundation for exploration in
the literature of the connection between caring practices and PFCC. This exploration will help to establish recommendations for practice within my organization.

**Methodology**

The aim of this project is to examine the literature to identify the essential elements of PFCC and the enablers and barriers to implementation resulting in recommendations for PFCC practice within my institution. While there are several types of written research reviews (Polit & Beck, 2008), a comprehensive review was utilized in this paper as a method to summarize research around the implementation of PFCC and the perceptions of parents and nurses. A literature review was conducted through accessing the University of Victoria’s library database system.

Utilizing data bases including Medline, CINAHL and Ebsco host, I began a search with a date range of ten years using the broad search terms of “family-centered care” and patient-and family-centered care”. This search strategy provided a vast amount of literature (greater than 4900 and 2000 articles respectively). The search was then limited by selecting documents written in the English language with the inclusion of older research as it related to demonstrating ongoing trends and themes. The search was further refined through identifying key words relative to my area of focus for this project. Key terms included: implementation of FCC and the hospitalized child, essential elements of FCC implementation, essential characteristics of FCC, parent perception of PFCC, nurses’ perceptions of PFCC, parents role in care of hospitalized child, implementation of PFCC in pediatric hospitals, and nurse attitudes towards PFCC. I further narrowed the search by looking explicitly at articles that addressed the perceptions held by nurses about the inclusion of parents/family in care and decision-making, and at the perceptions held by parents on how they view their role as well as the role of the nurse.
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The search was additionally narrowed to focus on the perceptions of PFCC held by pediatric nurses and the perceptions of PFCC held by parents of hospitalized children. I excluded literature that focused on pediatric and neonatal intensive care areas as these practice areas are beyond the scope of this project. This resulted in the identification of 20 articles.

Inclusion of high quality articles is integral to the development of an excellent literature review. In order to ensure the quality of articles utilized, throughout the literature search I selected articles that were published in peer-reviewed journals and excluded articles that, while providing corroborating stories from nurse and parents, were based solely on author opinion. Quantitative and qualitative research studies were included in order to provide a range of available perspectives on PFCC. Articles from North America and international sources were also included to provide a wide representation of available research. Articles were further selected based on research purpose and setting, specifically, research that aimed to explore parent nurse interactions as they relate to PFCC within the context of an acute care setting, unit or ward.

Through review of the reference lists in the selected articles, I identified authors who had conducted multiple studies related to PFCC over a period of time. Some of these articles were included for both an historical perspective and for relevance to the specific subject matter. Similarly, I concurrently, reviewed reference lists from selected organizations, specifically the Institute for Patient-and- Family Centered Care (IPFCC) website. The IPFCC website includes a comprehensive list of research literature and other resources related to PFCC and pediatrics. This list of 50 plus articles was also reviewed by first eliminating articles published prior to 1993. Next I reviewed this list utilizing the same criteria as mentioned previously regarding exclusion of literature focused on pediatric and neonatal intensive care areas. Ultimately I
included three articles that met the criteria of being high quality peer reviewed research articles.

In addition to this overall search strategy I utilized a more targeted sub-analysis of the literature specific to addressing the potential problems or barriers and enablers related to PFCC implementation. I refined this search using my previously described inclusion criteria about the pediatric setting and key words related to PFCC implementation. I selected high quality peer reviewed articles and excluded literature that was primarily disease specific or focused on pediatric or neonatal intensive care. Again, crosschecks were made between literature accessed through the data base search with the resources identified through accessing the IPFCC website.

In summary, 11 peer-reviewed articles (see Appendix A) were selected which met the inclusion and exclusion criteria. These articles range from Espezel & Smith’s (1990) classic article on role negotiation between nurses and parents to articles primarily focused on parental and nurse perceptions of PFCC. Having reviewed the research methodologies of each of the articles I am confident that I have included high quality research and classic works that will be suitable to address each of my project goals.

The articles were then reviewed for the identification of essential elements of PFCC as well as for barriers and enablers to implementation of the PFCC. Secondly, findings from the literature review were considered in relation to caring practices and the nurse-patient relationship. Specifically, Watson’s Philosophy and Science of Caring (2008) as well as Doane & Varcoe’s (2005) work on relational practice were used to explore the relevance of caring and therapeutic relationships between nurses, patients and families and PFCC implementation. A limitation within this methodological approach exists in the elimination of PFCC literature from pediatric and neonatal intensive care, as there has been significant progress in PFCC implementation in these areas. The inclusion of this literature may have provided additional
elements to PFCC implementation as well as potential barriers, enablers and recommendations.

**Findings**

I will begin the review of the literature by providing a historical context of PFCC. I will then discuss the three essential elements I identified in the literature. Some of these elements were explicitly named within a study but I also grouped similar themes found across studies. Next I will discuss the relationship between the PFCC literature and theoretical writing in caring practices in nursing. Finally, I will review the barriers and enablers to the implementation of PFCC I identified in the literature.

**Historical Context of PFCC**

The idea of family-centered care (FCC) emerged in North America in the late 1960s and had gained strength by the mid-1980s, particularly in the United States (MacKean, Thurston & Scott, 2005). Within the context of caring for children with disabilities, the family-centered agenda was advanced by the passage of “The Education of the Handicapped Act Amendments” of 1986 particularly related to Part H of the Act which recognized the importance of collaborating with families through incorporation of their goals and priorities in maximizing the health and development of their handicapped children (Johnson, 2000). Mandating an “Individualized Family Service Plan” as an essential component of services “created opportunities for families to collaborate in meaningful ways in service delivery and evaluation as well as to serve in policy and program development at local, state, and national levels” (Johnson, 2000, 137). In 1987, Surgeon General Dr. C. Everett Koop launched a National Agenda for Children with Special Healthcare Needs, which established family-centered, community-based, coordinated care as the standard for care for these children. For the first time, significant numbers of parents were invited to participate with healthcare professionals, researchers, and
public policy makers at a national meeting sponsored by the federal Bureau of Maternal and Child Health; a major step towards partnership with families (Koop, 1987).

The Institute for Patient-and-Family-Centered Care (IPFCC) was founded in 1992 by a group of health professionals and parents who had been leaders in the family-centered care movement of the 1980s. They came from diverse backgrounds--hospitals, state and local health agencies, and community programs. The term family-centered care was originally used; however, PFCC is used more commonly today as it includes the patient as part of the collaborative team. The IPFCC was known as the Institute for Family Centered Care until 2010 when it formally changed its name to the Institute for Patient-and-Family Centered Care. IPFCC serves as a central resource for those individuals and organizations interested in the development of a PFCC environment. PFCC has been defined by the IPFCC (2010) as “an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers” (IPFCC, Frequently Asked Questions section, p. 1). At the heart of PFCC are core concepts that were developed by the IPFCC. The core concepts identified as key components of a PFCC approach to care are (IPFCC, 2010, p.1):

1. Dignity and Respect- Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

2. Information Sharing- Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
3. Participation - Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

4. Collaboration - Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Shelton, Jeppson & Johnson (1989) wrote a classic article that is frequently cited within the PFCC literature and identified some key attributes as being equally important to PFCC. These attributes include: acknowledging the family as constant in the child’s life; parent/professional collaboration; acknowledging family differences and coping skills; parent-to-parent support and age and developmentally individualized care. Through critical examination of the literature I was able to identify common themes that encompassed the numerous elements essential to PFCC as identified by healthcare professionals and families. These essential elements included: two-way communication, partnership, and caring/relationship building.

**Element I: Two-way and Respectful Communication**

The significance of communication to PFCC is emphasized in the guiding principle of information sharing which calls for the provision of complete and unbiased information with patients and families. Sharing information is necessary in order for families to effectively participate in care and decision-making. This significance was supported by findings in a study by Espezel & Canam (2003) and again by Coyne et al. (2011). All of these authors describe the necessity of clear communication between parents and the multidisciplinary team in order to clearly define expectations, help determine care needs and develop mutually agreed upon goals.
In the absence of clear communication, misunderstandings may occur leading to conflict and alienation of the patient and family from the care team and the decision making process.

In contrast to a collaborative two-way approach to communication and information sharing, some nurses use an instructive, unidirectional approach where the nurse gives information to the parent (Brown & Ritchie, 1990). While this unidirectional patient education approach may have been more evident 20 or more years ago, it still exists in practice today as nurses deliver information they feel is relevant as opposed to identifying the learning needs of both the patient and family. Time constraints may be one possible reason for this approach as nurses revert to one-way communication when feeling the pressure of trying to get more done in less time. Two-way communication and the time spent to assess a family’s needs and level of understanding may be considered luxuries or unrealistic expectations by some nurses. However, two-way communication and information sharing has been linked to effective parent/professional collaboration (Bruce, Letourneau, Ritchie, Larocque, Dennis, & Elliott, 2002).

In a study of parental perceptions of PFCC, (Young, McCann, Watson, Pitcher, Bundy & Greathead, 2006), parents reported that giving and receiving information regarding their child’s care was a high priority. As one parent stated, “communication is the key”. Young et al., found the majority of parents indicated that they felt the nursing staff kept them informed; however, there were specific examples given of communication breakdown that indicated an inconsistency between caregivers (nurses) as to the amount and frequency of communication provided.

Parents within my own practice setting have told me that they felt that some nurses were more open with the sharing of information than others. Some nurses have also expressed a reluctance to share complete information with the family using reasons such as wanting to
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protect them or not wanting to enter into conversations in which they were not prepared to answer questions. Reluctance could be related to uncertainty as to what the provider has shared or plans to share with the family, and fear of overstepping their intent. This reluctance may also be attributed to the nurse’s lack of confidence with the delivery of evidence-based information. Results reported by Hughes (2007) suggest that nurses and parents differ in their perception of the nurse’s ability to teach new skills, however both agreed that sufficient information about the skills were given verbally as well as in writing. The author proposes that this finding suggests that nurses value the importance of empowering the parents, which differs from findings by other researchers who identified the nurse’s role as a gatekeeper as a contributing factor in the breakdown in the provision of PFCC (Brown & Ritchie, 1990; Kirk, 2001; Paliadelis et al., 2005; Ygge et al., 2006).

The role of the nurse as a gatekeeper in what information is communicated to families is considered in several studies. Health care providers spoke about the importance of their roles as information-givers emphasizing the importance of providing enough information so that parents could “feel empowered around making decisions for care for their child” (MacKean, et. al., p. 78). Of note here is the idea of providing “enough” information, which might suggest that nurses are acting as gatekeepers by tailoring information to the learner’s readiness, even in the act of empowerment. As identified earlier in this discussion, Ygge, Lindholm & Arnetz (2006) suggest that while nurses have identified that providing information is important, some nurses also feel that it is their responsibility to decide what information is important for the parents to receive. Nurses described their responsibility for providing information and support to families in order to help them understand the illness process and understand the impact of the disease on both child and family (Bruce et al., 2002).
The ability to communicate effectively can be a difficult skill to learn (MacKean et al., 2005). MacKean and colleagues describe communication and its association with family-centered care as a relational competency. The authors identified that health-care providers with good communication skills were open and honest, direct and informative, valued parents’ input, and listened carefully.

Patient education and information sharing are two examples of communication that occur between nurse and patient-parent that can be done in ways that are empowering or not empowering. Another aspect of communication often overlooked by nurses and other healthcare professionals is the simple task of introductions. In the study by Young et al. (2006), most parents identified that they knew which nurse was caring for their child on each shift; however there was inconsistency amongst the nurses. The importance of this information was highlighted by comments such as, “I didn’t even know my son’s nurse’s name except when I saw it on her ID badge” (p. 6). The simple act of introducing oneself and the role played on the care team can decrease confusion for parents who may not be able to differentiate who amongst the care team is a nurse. Lack of communication, miscommunication and the nurse’s role as gatekeeper of information may negatively impact the development of a trusting, collaborative relationship between parent and nurse.

Element II: Partnership and Collaboration

PFCC calls for partnership between the patient, his or her family and the healthcare team. Partnership involves cooperation and the development of strong relationships between people working together for the same purpose. While parents and nurses might agree that they are both working towards a common purpose, a full partnership is not always present and may be difficult to achieve. PFCC differs from traditional models of care that are based on
the premise that the healthcare professional is the ‘expert’ in all aspects of care delivery (Institute for Patient & Family Centered Care, 2010). In these professionally centered models of care, the focus of the healthcare provider is on assessing and formulating a plan based on perceived needs of the patient. Input from the patient is given little value and the patient is seen as a unit of intervention; someone we do things to and for (Shields, Pratt, Davis, & Hunter, 2007). Although the well being of the child is at the forefront of the nurse’s mind, some nurses believe that as the “expert” they know better and therefore nurses practicing from this perspective are often non-inclusive of the parents (Paliadelis et al., 2005). The level of parental participation in care and decision-making is often at the discretion of individual nurses, which can serve as a barrier to effective implementation of PFCC. In contrast, PFCC focuses on collaborative relationships and decision-making. Collaboration and its importance to PFCC were specifically mentioned in five of the eleven studies. Other terms used that directly related to collaboration included role negotiation and partnership (Callery & Smith, 1991 & Young et al., 2006).

Brown & Ritchie (1990) described nurses as being gatekeepers to the parental role; a role where they exerted control over parents of hospitalized children. Nurses stated overtly, “they set limits on parental behaviors and that they supervised and assessed parents and the care they provided” (p. 32). Although this study is 20 years old, this attitude persists in my setting today. Families that serve on a family advisor council in my organization have shared that they felt as though they were in fishbowls, constantly being assessed and judged as parents and caregivers. Susan Kirk (2001) conducted a grounded theory study that echoed these observations of nurses’ control over parental involvement in care. Kirk found that the nurse determined the level of parental involvement in the care of their sick children. These situations often lead to a struggle for control as parents attempt to assert themselves as the primary caregiver, and thus, serve as
another barrier to effective implementation of PFCC. In the absence of collaboration, these power struggles continue and may adversely affect the care of the child.

MacKean et al. (2005) in a study examining the conceptualization of PFCC, found that parents placed a high value on healthcare providers who sought and valued their input, provided useful information, invited them to be collaborative, listening to them, and valued their perspective and knowledge. A key aspect in partnership development and collaboration is the negotiation of caregiving roles. In the nurse-parent relationship, the balance of power favors the nurse. The hospital is the nurse’s territory, where the nurse has more control over both environment and information. The parent is away from home “turf” and is immersed in a stressful environment experiencing uncertainty, anxiety and loss of control (Callery & Smith, 1991).

While there exists a desire for increased parental participation in care, there is no consensus about how far that participation should extend. Nurses in a study by Coyne et al. (2011), identified the importance of assessing the needs of the parents and children and then consulting with the parents in the negotiation of care. Nurses agreed that parents should be engaged at the level they choose and not that the nurse dictates. This practice is congruent with the guiding principle of participation (IPFCC, 2008); however Coyne and colleagues also acknowledged that some nurses did not fully involve parents. Further because nurses hold the balance of power, it falls to them to take the steps necessary to relinquish total control (Callery & Smith, 1991). Nurses who feel threatened by the family’s knowledge are more apt to limit parental involvement and are less likely to encourage participation in the delivery and planning of care. There must exist a willingness by both parties to enter into partnership. Bruce et al. (2002) described parent-professional collaboration as the least agreed upon facet of PFCC and
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the least practiced. They agree that collaboration requires relinquishing of control on the part of
the healthcare professional and also add that working collaboratively with parents necessitates
trust and risk taking. Their study also affirmed the importance of communication and
information sharing as necessary to the effective implementation of PFCC.

Hughes (2007) suggested that in order to for a therapeutic relationship to be formed, nurses need to change their role as “dominant expert” and patients (parents) need to move beyond being a “passive recipient of care” (p. 2342). There appears to be general consensus amongst authors that the interaction between nurse and parent greatly influences the quality of children’s healthcare (Espezel & Canam, 2003; MacKean et al., 2005, Shields et al., 2006 &Ygge, et al., 2006). In order to help ensure the best possible outcomes, a collaborative partnership must exist between the nurse and parents. Espezel & Canam (2003), state that the establishment of rapport is a “precondition to engaging in collaborative behavior” (p. 35). Rapport suggests empathy, relationship and understanding, which are woven throughout all of the identified themes or essential elements. Rapport, an important part of communication, is integral to partnership and collaboration and is established through the development of a trusting, caring relationship where both parent and child feel valued and cared for in a genuine way.

Element III: Caring and Relationship Building

From the perspective of the parents, a key aspect of establishing rapport is the nurse’s “demonstration of interest in learning about the child’s conditions and in the child as an individual” (Espezel & Canam, 2003, p. 36). The study by Espezel & Canam (2003) identified that one aspect of rapport building involved nurses and parents spending time together in order to feel comfortable with each other. More contact translated to better rapport. While rapport is deemed an important element of PFCC by parents (Espezel & Canam, 2003; Galvin et al., 2000;
MacKean et al., 2005; Miceli & Clark, 2005), nurses rarely speak about their interactions and relationships with children or their parents (MacKean et al., 2005). MacKean and colleagues found that nurses spoke more about their roles as “information-giver and comparatively less about their role as a caring person, collaborator, and helper” (p. 78). The idea that these roles are not mutually exclusive raises a question; have we lost our ability to demonstrate caring in our daily work? Caring as a relational competency was described by parents as encompassing being compassionate, respectful and providing care in a personalized way (MacKean et al., 2005).

Demonstration of caring can take many forms. Miceli and Clark (2005) in a retrospective study that reviewed parent satisfaction surveys and made recommendations for improvements in pediatric care, found that caring encompassed staff sensitivity to the many inconveniences faced by families and addressing emotional and spiritual needs. This study sought to outline the greatest opportunities for improving the experience for patients and families in the inpatient setting from the parent’s perspective. Survey respondents reported that they came to the hospital expecting proficient clinical care but what makes the experience fundamentally different is the act of caring. The top three areas for improvement that had the highest correlation to overall satisfaction included: improving staff sensitivity to the inconvenience that hospitalization can cause, improving the degree to which hospital staff address the family’s emotional and spiritual needs, and improving the response to parents’ concerns and/or complaints. These researchers noted that improved responses to parents’ concerns could only occur if nurses are willing to hear and parental feedback is sought and respected.

Nurses, for the most part, see themselves as caregivers and protectors of both patient and family. However, when caring for sick children the nurse may take on a more maternal role shifting away from a place of empathy and empowerment. The nurse may provide the physical
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Aspects of care; administering medications, performing treatments, providing for comfort, but neglect the emotional aspects of caring such as empathetic listening, support, and simply being present. Providing collaborative PFCC becomes even more complex when nurses in their capacity as care givers, understand their role as protecting parents from unpleasant news or events. Nurses may describe these events as caring for the entire family, that is, they believe they were implementing PFCC (Corlett & Twycross, 2006 & Paliadelis et al., 2005). The disconnect that exists between nurses’ and parents’ perceptions of caring and PFCC is perhaps one reason why relationships do not form. In the absence of a caring relationship between nurse-patient-parents, a void between physical and emotional caregiving may occur.

The essential elements found within the literature, communication, partnership and relationship building are interwoven. Effective communication and a good relationship are needed for successful partnership and collaboration. A therapeutic partnership is grounded in a caring relationship. A caring relationship assists the nurse to establish a healing environment.

**PFCC and Caring Practices**

In order to understand the significance of PFCC to nurse-patient and nurse-parent relationships, an exploration of PFCC as it relates to caring practices within nursing is important. In 1979, Jean Watson’s Nursing: The Philosophy and Science of Caring provided the foundation for her evolving work on caring. This book outlines the structure for her “Theory of Human Caring: Ten Carative Factors”, and identifies the essential aspects of caring in nursing. Watson has stated that without caring, “nurses may not have been practicing professional nursing but instead were functioning as technicians or skilled workers” (Watson, 2008). In the 2008 revised version of this book, Watson addresses the formal research on caring outlining the outcomes of caring and noncaring relationships as described by Swanson (1999). Swanson’s meta-analysis
showed that patients who experienced caring had positive outcomes including emotional and spiritual well being, enhanced healing and enhanced relationships with others. The consequences of noncaring included feelings of fear, humiliation, being out of control, alienation, helplessness and vulnerability. An important aspect of this meta-analysis was the inclusion of the outcomes for nurses. Nurses who practiced caring experienced a personal and professional sense of satisfaction, a love of nursing, and the ability to live out their own philosophy. Conversely, nurses who did not engage in a caring relationship with patients experienced feelings of being hardened, depressed, oblivious, frightened, brittle and worn down. These findings serve to demonstrate the critical aspects of caring in practice for patients and nurses alike.

In considering the three common themes that emerged as essential to PFCC through review of the literature, as identified by both healthcare professionals and family members, the importance of two-way and respectful communication, partnership and collaboration, and caring and relationship building can also be found throughout Watson’s description of the Ten Carative Factors and her later evolution of Caritas Nursing (2008). In this later work, Watson once again brought to light the idea that nursing needs to commit to a model of professional caring-healing that goes beyond the “conventional medicalized-clinical routines and industrial product-line view of nursing” (p.32). It is Watson’s belief that without a caring framework, nursing will lose its humanity.

Two of the Carative Factors specifically refer to the act of caring and relationship building; cultivation of sensitivity to oneself and others and the development of a helping-trusting relationship. In Caritas Nursing, these evolved into the deepening of one’s own self-awareness and spiritual practice and the development and sustenance of a helping-trusting, authentic caring relationship (Watson, 2008). The development of one’s own spiritual practice is
really about moving beyond ego. In PFCC this is central to treating patients and families with dignity and respect as we ask ourselves; whose needs are being met, mine or that of the patient and family? Whose best interests are affected by my decisions and actions? Within the literature this practice is illustrated in the “assignment” of tasks and responsibilities by nurses to parents. For the most part, parents agree that they should be involved in the basic care of their child, but at the same time believe that the nurse must include them in setting expectations from the beginning (Bruce et al., 2002; Young et al., 2006). In the study by Paliadelis et al. (2005), nurses’ beliefs were centered on empowerment issues where control over what parents could do rested with the nurse. The need for control over the environment is based on the perception of nurses that they must fill the role of expert and protector (Callery & Smith, 1991; Palisadelis et al., 2005).

At the heart of PFCC is the belief that the patient’s family is integral to the healing process (IPFCC, 2008). They are essential to the healing environment. The creation of a healing environment that is supportive and protective is identified as one of Watson’s Carative Factors. By ensuring that family, as identified by the patient, is welcomed, included and treated as a vital part of the care team, nurses are creating the environment that Watson describes. Within this environment exists the need for open communication and exchange of knowledge. Watson’s Caritas Factors underline this, specifically, “engaging in genuine teaching-learning experiences within the context of a caring relationship” (p.31). Watson further describes this practice as moving toward a coaching role instead of the usual delivery of information. Once again, the practical application of coaching in daily practice can be challenging due to the increased time required. Simply delivering information may be faster despite the potential for less than optimal outcomes (i.e. not understanding discharge teaching which could lead to readmission).
Watson places much emphasis on relationship building and how it is often “taken for granted, not even recognized, or attended to in professional practice” (Watson, 2008, p.101). She further describes how emotions affect an interpersonal relationship and the ability to communicate effectively, to listen, and build rapport. It is important to understand the impact of emotion on both the patient and caregivers, and its value in building and sustaining a trusting, caring relationship. Often nurses believe that they are providing empathetic care but patients and families do not always perceive this. Families’ interpretations of caring and concern may be linked to the nurse’s demonstration of interest in their child, their willingness to share information about themselves, and time spent listening (Espezel & Canam, 2003; MacKean et al., 2004). Patient/family satisfaction surveys from within my own organization confirm the importance of parental perceptions of caring. The questions about “friendliness of the nurse” and “the nurse was caring” are often scored low which can be puzzling to the nurses who believe that they demonstrate caring at all times. One possible explanation for this disconnection could be related to differences in parental and nursing expectations. According to Watson (2008), this negative reaction can hinder or disrupt the relationship building process, which calls for openness and acceptance, especially in difficult moments.

While Watson’s work is centered on the idea that the act of caring and relationship building are critical to outcomes for both patients and nurses, Doane and Varcoe (2005) raise the idea that while good relationships may enhance care, seeing them as a means to end is problematic. They identify these problems with the assumption that the nurse is in control of the relationship, the nurse drives the relationship and the worth of the relationship is obscured. The authors argue that in a health promoting relationship the family and nurse must work together on the relationship. They further highlight the idea that if the nurse drives the
relationship; the results may focus on the nurse’s concerns and commitments rather than those of the family (Callery & Smith, 1991; Palisadelis et al., 2005). Doane and Varcoe go on to state that in order for the relationship to be meaningful, the nurse must believe in the importance of caring relationships as part of the healing process and not just in the value of what it can produce (i.e. compliance, ease in ability to complete tasks in a timely manner etc.). Nurses have identified lack of time as a barrier to their ability to form relationships with parents. Doane and Varcoe (2005) address this perceived barrier stating, “relational practice is not just a matter of whether you have time to form relationships but rather how you live the relational time you have” (p. 180). In my observance and experience this concept is foreign to many nurses, especially inexperienced ones. I have observed the missed opportunities that Doane and Varcoe describe in the moments for engagement that exist during medication administration, taking vital signs, or while performing assessments. These authors also stress that a caring relationship is grounded in dignity and respect, and includes information sharing, participation and collaboration. Watson (2008), Doane & Varcoe (2005) help provide a theoretical framework upon which to better understand the importance of the patient, and by extension, the family, to the healing process. These theorists encourage the nurse to be self-aware and attentive to what he or she brings to the nurse-patient relationship. The relationship is affected by our own “situatedness” which in turn affects what we see, listen for, hear and how we respond (Doane and Varcoe, 2005). This attention to self is at the core of Watson’s work and it is through understanding these foundational concepts that one is able to see the connectedness to the PFCC principles. In the absence of self-awareness and self-caring, the ability to provide care that is patient-and-family centered proves to be challenging.

**Barriers and Enablers to the Implementation and Practice of PFCC**
As described thus far, the three common themes of two-way and respectful communication, partnership and collaboration, and caring and relationship building that were identified as essential to PFCC, are at the very heart of the art of nursing and are rooted in human interaction and the experiences surrounding the nurse-patient relationship. It would seem then that their implementation and integration into everyday nursing practice would be simple, but unfortunately, this is not the case. The next goal of this project was to identify barriers and enablers to the implementation of PFCC into practice.

Nurses and other healthcare professionals have identified numerous barriers that impact their ability to deliver care in a PFCC approach. Paliadelis et al., (2005) explored pediatric nurses’ perceptions of how they involve families in the care of their children during hospitalization. The authors, using interviews with nurses, identified barriers and constraints to the implementation of PFCC that included staff shortages, time constraints, and heavy workloads. Nurses cited all of these barriers as major factors in impacting their ability to give sufficient time to each family stating, “in a very busy ward it’s easier to do it yourself…it’s a timeframe thing “ (p. 35). Other studies directly or indirectly identified lack of time or resources as barriers to PFCC (Bruce et al. 2002; Brown & Ritchie, 1990; MacKean et al., 2005).

Paliadelis et al. (2005) identified additional constraints to the provision of family centered care including: a) lack of structure or guidance about how to implement family-centered care, b) poor communication between nurses and parents, c) the nurses’ need to be seen as “the expert”, d) nurses and parents lack of confidence in their respective roles and e) nurses and parents lack of understanding of their roles and role negotiation.

Similarly, Bruce et al. (2002) reported that nurses identified a lack of education related to understanding the concept of FCC and the need for additional skills for interpersonal
relationships including negotiating and clarifying parental and professional roles. Nurses identified the need for education specifically related to caring for families and for the inclusion of practical knowledge about how to enact the concepts of PFCC. Furthermore, the skills necessary for PFCC, such as communication and conflict management, also have been identified as areas for additional education. These learning needs concur with my experiences where nurses have shared that their reluctance to address concerns and “get involved” with families is based on a lack of ability to deal with conflict when it arises.

Conflict between nurse and parent can occur when a nurse’s need to exert the expert role clashes with the parents’ knowledge and expertise regarding their child and his or her response to illness and hospitalization. For example, Brown & Ritchie (1990) reported that nurses often don’t “invite” families to be present during painful procedures because they believe it would be too upsetting for the parent and therefore upset the child further. They seem to be unaware that parents have a very different understanding of their role and “what is best for their child” (p.32). Paliadelis et al. (2005), highlight this differing opinion of involvement in care in the discussion of empowerment issues as nurses made statements like “skilled nursing jobs should be done by the nursing staff….and the unskilled jobs like bathing and changing, left to the parents” (p.34); “nurses just go and do things because sometimes nurses know best and kids are better with nursing staff than they are with their parents”(p.34). Failure to recognize parental expertise can be a contributing factor to the ambiguity in role expectations between parent and nurse as each struggle to determine how to carry out their assigned or traditional responsibilities.

The lack of understanding of parental needs was also identified in the qualitative study by Brown & Ritchie (1990). The need for respite from caring for a sick child was condemned by some nurses, “they put the child in the playroom and then go out for a few hours to socialize
more than anything with other parents….they miss the point of why they should be there” (p. 33). At the same time other nurses commented on the importance of addressing parental needs as illustrated by one nurse’s statement, “They have to eat. Some don’t leave the kid’s side. A couple of cases…the parent was more of a nuisance to us, hanging around the desk and annoying us” (p. 33). Here, nurses felt it was appropriate for parents to leave when they were being annoying to the nursing staff, but described it as genuine concern for their welfare.

These sentiments were echoed by parents in a descriptive survey conducted by Young, McCann, Watson, Pitcher, Bundy, & Greathead (2006). The primary aim of this study was to describe parents’ perspectives of their involvement in their child’s care, in relation to negotiation of care. Young et al reported that parent comments included feelings of guilt for taking a break and leaving the bedside. These feelings led them to stay at the bedside without a break, ultimately neglecting their own needs. In pediatrics, the family often requires as much emotional care and support as the child. Providing care for the parent of a hospitalized child is a hidden part of a nurse’s work (Callery, 1997). The ability to communicate and build caring relationships is vital to establishing an effective partnership between the nurse, the child and the family.

This review of the literature clearly identified the essential elements or the “ideals” of PFCC and also documented the complexities and challenges of actualizing PFCC. These challenges exist within the essential elements of communication, partnership and caring/relationship building. These challenges and differing perceptions can create tension in the nurse-patient-parent relationship and be a barrier to two-way communication and collaborative partnerships. The lack of time as a perceived barrier to PFCC implementation is evident in the literature in relationship to provision of information such as education and care planning. According to the literature time pressures can also affect the development of relationships as the
ability to develop rapport is related to the amount of time the nurse spends with the family. Recognizing and respecting the specific needs of children and their families can also be difficult when attempting to implement best practices as nurses are challenged to individualize care and involve parents in the planning and decision-making process.

Several studies discussed the nurses’ difficulties in providing PFCC due to a lack of knowledge related to communication and conflict management skills, (Brown & Ritchie, 1990; Bruce et al. 2002; MacKean et al. 2005; Paliadelis et al. 2005). These skills are essential to the development of effective, collaborative relationships between nurse and parent; however, they are also skills that are often found to be lacking in organizations that do not facilitate good organizational communication. While it is accepted that an organizational culture change is needed for effective PFCC implementation, many organizations continue to function in a paternalistic environment, thus creating a barrier to providing the education and support for healthcare providers to be successful in cultural transformation. What is evident in the literature is that while nurses may believe in the PFCC concept, its application in practice can be difficult.

While the identification of barriers is an important first step in the implementation process, the task of removing these barriers is not a simple one; furthermore, reliance on the removal of barriers does not guarantee successful implementation.

In addition to the identification of barriers within the literature, several studies also addressed items that enable effective PFCC implementation. These enablers are also situated within the three identified essential elements of two-way and respectful communication, partnership and collaboration and caring and relationship building. Coyne et al. (2011) discussed the need for improved communication strategies and educational training for nurses and other members of the healthcare team as important in order to assist in the provision of
“understandable, unbiased and timely information” (p.2567). Coyne et al. also identified the provision of more resources to aid in communication as an important factor in enhancing PFCC. Such resources include teaching rooms for families and teaching resources such as written information in multiple languages. Bruce et al. (2002) also identified the importance of conflict resolution as a necessary skill in effective communication.

Providing clarity to what role the parent plays in the provision of care and decision-making is a factor that enhances the ability of nurses to collaborate effectively (Brown & Ritchie, 1990; Espezel & Canam, 2003; Ygge et al., 2006). The development of unit-based guidelines helps the nurse and parent understand that the role of the parent might change according to the type of care required. Bruce et al. (2002) further describes the importance of interdisciplinary collaboration and coordination of care as enablers to PFCC. In order to gain trust, members of the interdisciplinary team must work to ensure that information provided is consistent. An identified strategy that has proven effective in this regard is interdisciplinary team conferences that are inclusive of the parents (Bruce et al., 2002).

As previously described, time is a necessary component to the establishment of rapport; an important step in the development of a caring relationship between nurse and parent. Managerial and organizational understanding and support for time spent with families is critical to PFCC implementation (Coyne et al., 2011). Appropriate staffing levels and a skill mix that considers the needs of the patients and families aid in ensuring “optimal delivery” of PFCC (p. 2569). Organizations that establish policies that promote PFCC provide nurses with a framework from which they can work and guide their practice. Policies and guidelines grounded in PFCC aid in creating consistency in nursing practice across an organization thereby promoting trust as patients/parents move through the system (Coyne et al., 2011 & Paliadelis et al., 2005).
The provision of education on PFCC principles and the incorporation of families into organizational committees are two additional enablers to PFCC. Representation of healthcare professionals and parents on committees or advisory groups promotes collaboration and enables parents and professionals to gain understanding and appreciation of each other’s roles, knowledge and expertise, which can lead to increased collaboration, effective partnerships and relationship building (Bruce et al., 2002; Coyne et al., 2011; Espezel & Canam, 2003; Hughes, 2007).

**Recommendations for PFCC Implementation**

A critical next step in the implementation of PFCC within an organization is the identification of current strengths and threats to implementation. First, which of the identified barriers exist? Within my own organization the primary barriers include all of those identified in the literature; lack of time, staffing shortages, lack of education/understanding related to PFCC, and lack of skills related to communication, role negotiation and conflict resolution. While removal of these barriers will not ensure successful PFCC implementation, ignoring their existence will certainly impede it. Organizational commitment to implementation of PFCC principles is essential. Organizations that are serious about adopting PFCC provide needed resources and ensure that parents have the opportunity to provide feedback and participate in institutional change processes, perhaps by conducting focus groups or forming a patient/family advisory council. Several strategies identified in the literature as enablers to PFCC are included in my organization’s multi-strategy approach.

**Education**

The best approach in addressing each of the barriers is to do so in a methodical way. The logical first step would be to educate staff on PFCC and its advantages to patient outcomes. The
findings of a 2001 study involving nurses working on pediatric units found that those who had participated in continuing education sessions on FCC were more likely to practice the elements than those who had not (Caty, Laroque, & Koren, 2001). Education cannot however consist only of classroom style of delivery. It must include the opportunity for discussion so that staff can voice their concerns and fears. The need for continuing education on PFCC principles and the related skills of communication, relationship development and conflict resolution were identified repeatedly within the literature as enablers to PFCC (Brown & Ritchie, 1990; Bruce et al. 2002; Coyne et al., 2011).

What we have come to realize within my own organization is that PFCC implementation is a culture change that will need to happen over time. Additionally, in order to be successful, we need to start with smaller groups, units/departments; trying to enculturate over 5000 employees at once is a monumental task and according to the IPFCC can hinder progress (Johnson et al., 2008). The first opportunity that exists to start “planting the PFCC seed” is in new employee orientation (NEO). By presenting these principles early, the organization is laying a foundation for quality and service that will enhance the overall patient-family experience. New employee orientation also provides the opportunity to include families who have had experience in the health care system (Johnson et al.) enabling them to share stories that illustrate the impact of PFCC practices. These types of presentations allow the organization to demonstrate the connections between PFCC and quality of care for the employee. This has been an area of strength within my organization as key leaders within Human Resources and the Learning Institute have worked to incorporate PFCC principles throughout NEO. PFCC is further described in Clinical Orientation that is attended by employees who provide direct patient care including nurses, respiratory care practitioners, and patient care technicians.
Two-way and Respectful Communication

As described by Coyne et al. (2008) education of staff must also include content, tools and techniques surrounding communication and conflict resolution skills. It is here that a unit by unit or a departmental approach would work best. My team started this work almost three years ago as we began working on one particular unit to make improvements. As I identified previously in the literature, communication is key in the nurse-patient/parent relationship. The first step in helping nurses to understand the importance of two-way communication is to educate them on the principles of PFCC with initial emphasis on information sharing, participation and dignity and respect. Once this foundation has been established, helping the staff to identify opportunities for improved communication is an important next step.

As described previously, the inclusion of families in multidisciplinary care conference is one strategy that promotes trusting, collaborative relationships between parents and the healthcare team as well as providing an environment for two-way respectful communication. Similar strategies include nurse-to-nurse report at the bedside with family inclusion, rounding at the bedside with the physicians and inclusion of patients and families in care plan development. Within my organization nurses have described inclusion of families in care plan development as “telling them” or “keeping them informed” about the plan. After working with families, nurses have realized that truly including families meant that parent’s goals were an important part of the plan. An important communication skill identified as an enabler to PFCC is conflict resolution. Within my organization work has begun in this area with the use of actual scenarios experienced by nurses. These scenarios are used to role-play how to deal more effectively with conflict in order to preserve the relationship between nurse and parent. Work done to date on one unit has demonstrated a significant improvement in patient satisfaction scores as well as other quality
indicators including decreased peripheral intravenous infiltrates, decreased blood stream infections and a decrease in the number of codes outside of the intensive care unit. Nurses have also reported an increase in their own satisfaction related to communication and collaboration with families. The positive outcomes demonstrated on one particular unit have provided both a template for other units as well as evidence that this approach works thereby gaining approval from the chief nursing officer to move forward in other areas. While this approach has been successful, it is important to remember that it is just one step in the journey to truly implementing PFCC. It is also important to note that in order to be successful, communication skill building must be embraced by nurses (Brown & Ritchie, 1990; Coyne et al., 2011).

**Selection**

In order to truly create a PFCC culture, the organization needs to embed PFCC principles into its values and action plans. While education can provide a foundation upon which current employees can build, an important step must include ensuring that new employees possess the competencies required for successfully enacting the PFCC guiding principles. Brown & Ritchie (1990) identified that the exploration of the relationship between the characteristics of the nurse, their beliefs about PFCC and the kind of care they provide can help identify nurses that may or may not be willing to change their approach to care. Hiring nurses who have a belief system grounded in PFCC can help to mitigate potential issues that arise with nurses who are unable and/or are unwilling to adjust behaviors and attitudes. This crucial step begins with the selection and hiring process and ends with performance management. The first steps have been taken in this process with the identification of behavioral competencies that are in alignment with the PFCC principles that are also congruent with service and quality. For example, information sharing, dignity and respect are PFCC principles that have been shown to be associated with
providing good service and high quality (source). Competencies that are incorporated into the interview process include: patient relations, building trusting relationships and a customer focus (Byham, 1998) In addition to hiring nurses and other employees that possess these attributes, the organization must move to include these values into performance management, including annual reviews, as well as in staff development opportunities (Coyne et al., 2011).

**Collaborative Partnership**

As stated previously, simply educating staff, or even hiring new staff that possess the essential competencies or behaviors is not enough to change a culture. While a foundation is laid, the lack of resources, whether they are time or people cannot be fixed overnight and realistically, may be a barrier that cannot be overcome. In today’s healthcare climate in the United States, state and federal budgets have made this an even more difficult task as cuts to Medicaid have direct impact on a hospital’s operating budget. Budget restrictions, rising healthcare costs and the impact to PFCC implementation are an issue outside of the United States as well (Bruce et al., 2002; Coyne et al., 2011). The impact of recent state budget cuts have pushed my organization into budget recovery, where everyone is working to try and lower costs, including not filling open positions and not adding new ones. So, how then do we ensure that PFCC becomes part of the culture and part of the way that we interact with patients and families every day?

For the nurse or individual health care professional, the simply stated but not simply executed solution is to truly put patients and families at the center of all aspects of care delivery. As described previously, role negotiation between nurse and family is an important barrier that needs to be addressed in order to establish a healthy, caring partnership. An important part of this process identified previously as an enabler to enhancing PFCC is creation of written standards and guidelines that describe the ideal role of parents, based on the unique needs of their children
as well as the family. An example of how this could be implemented within my own organization is on the pulmonary unit. Patients on this unit who have new tracheostomies and are ventilator dependent require care that initially is beyond the capabilities of parents. Parents are often fearful of even touching their children. At this stage, nurses become the primary caregiver providing all aspects of physical care of the child. As the child’s condition improves, parents can slowly start to take on more of the caregiver role such as changing diapers, bathing and feeding. This “transfer of responsibility” continues to move from nurse to parent as the child improves to eventual discharge home. At each step in this process the role of the nurse and the parent waxes and wanes enabling the parents to be able to fully care for the child at home upon discharge. A written description of this process, respective roles and rationale would provide a beneficial foundation from which both nurse and parent could work thereby establishing a common base upon wish to develop a therapeutic relationship.

**Time Constraints**

Staffing shortages and time constraints are two barriers that present the biggest challenges to the implementation of PFCC elements. Balancing workloads and evaluating the process for patient assignment are two areas that must be addressed in order to prevent further strain on the nurse-parent relationship (Paliadelis et al., 2005). Decreased staffing numbers in conjunction with increased workloads lead to greater reliance on parents to provide care that otherwise would be done by the nurse. Operationalizing PFCC does not translate into “training parents to assume more responsibility for their child’s care and care management” but instead calls for a collaborative approach where roles are mutually negotiated (MacKean et al., 2005). An approach to help ease the workload of nurses within my organization is aimed at care delivery re-design. The re-design is aimed primarily at identifying tasks normally provided by
the nurse and sharing them with other members of the care team, specifically, patient care technicians and respiratory therapists. Through delegation and assignment of tasks such as vital signs, answering alarms etc. the hope is that the nurse will have more time to spend engaging with the families in meaningful ways, one example would be providing teaching. Reassignment of these tasks may however unknowingly present a barrier to relational practice. However, nurses would no longer be able to utilize this time to engage parents in meaningful ways that aid in relationship building. Emphasis must then be placed on helping nurses to recognize the opportunities that do exist for engagement in every seemingly insignificant moment. As resources are stretched and nurses are asked to do “more with less,” the institution must recognize the negative impact this can have on the provision of PFCC.

**Summary and Conclusion**

Browning (2003), in the Initiative for Pediatric Palliative Care, makes reference to patients and families being forced into the world of healthcare against their will; like being suddenly whisked away to a foreign land. When they enter this foreign land they are confronted with language (medical), customs and traditions that are unknown to them. They try desperately to become accustomed to this new world, learn the language and respect the customs and traditions. They do so because they have a great deal at stake, the health of their child. Parents look to nurses as advocates in navigating the world of healthcare.

In the world of pediatrics caring relationships that develop between nurse and patient and extend to the patient’s family are vital to the healing process. In order to optimize the healing process these relationships must be built on a foundation of trust, respect, collaboration and honest communication. The guiding principles of PFCC provide a framework in which organizations can establish and maintain an environment that supports and adopts the expectation
that families are an integral part of the care team. Application of these principles and the essential elements identified in this paper; communication, partnership and collaboration, and caring and relationship building, should be carried out in such a way as to be mindful of the barriers that exist. A well-developed plan must include incorporation of these elements and principles into all aspects of organizational values, from the selection, hiring and, orientation of new employees to the education of current employees. In order for a plan to be successful, nurses must be willing to be introspective and make needed changes regarding their own views and attitudes concerning the importance of interpersonal relationships and the role of parents as partners. These changes can only be made with the support of leadership at all levels within the organization. Leaders must also be prepared to answer the questions and challenges that may arise as healthcare professionals and families move along on the PFCC journey. What must be kept in mind is that the creation of a PFCC culture is not a destination; organizations do not arrive and then stop. Instead, they must continually evaluate the environment for opportunities to expand this practice and constantly challenge themselves to keep moving forward.

The literature reviewed within this paper provides the knowledge needed in order to move forward with putting PFCC into practice. In over 20 years of working in healthcare systems where processes are often focused on the needs and convenience of the institution rather than the needs of patients and families, I have continued to believe in the centrality of the patient and family in the provision of quality nursing care. The relationships that I have developed with patients and their families are what I value the most as a nurse.
Parents’ and Nurses’ Perceptions

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multisite study of health professionals’ perceptions and practices of family-

Pittsburgh, PA. Check format


## Appendix A

### Theme identification

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<thead>
<tr>
<th>Citations and authors</th>
<th>Research Problem identified</th>
<th>Method</th>
<th>Findings</th>
<th>Identified themes</th>
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<tbody>
<tr>
<td>3. Bruce, B., Letourneau, N., Ritchie, J., Larocque, S., Dennis, C., &amp; Elliott,</td>
<td>Determine the differences in health professionals’ perceptions and practices of</td>
<td>Multisite survey, total sampling of non nurses and random sampling of</td>
<td>Significant differences were demonstrated between healthcare professionals’</td>
<td>Collaboration, information sharing, parental support (caring)</td>
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<td>M.R. (2002). A multisite study of health professionals’ perceptions and practices of family-centered care. <em>Journal of Family Nursing, 8</em>(4), 408-429</td>
<td>family centered care (FCC) and examine factors that influence those perceptions and practices.</td>
<td>nurses.</td>
<td>perceptions and practices of FCC at the three sites. While advances have been made in understanding the key elements of FCC, implementation remains difficult.</td>
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<td>4. Callery, P. &amp; Smith, L. (1991). A study of role negotiation between nurse and the parents of hospitalized children. <em>Journal of Advanced Nursing, 16</em>, 772-781.</td>
<td>Exploration of role negotiation between parents and nurses.</td>
<td>Critical incident technique was used and nurses were asked describe two incidents: one where they felt the parent wanted more involvement and one where they wanted less.</td>
<td>Categories were identified as encouragement, explanation, and negotiation. There were differing views between nurses and parents on whose responsibility it was to negotiate care.</td>
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Role negotiation, collaboration, parental support (caring) | Respect, collaboration, support. |
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<th><strong>Parents’ and Nurses’ Perceptions</strong></th>
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<td><strong>Pediatric Nursing, 26(2), 625-32.</strong></td>
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<td>Examination of hospital staff perceptions of parental involvement in children’s hospital care.</td>
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<td>Describe parents’ perspectives of their involvement in their child’s daily care, particularly in relation to negotiation of care.</td>
<td>Cross-sectional descriptive survey given to parents upon discharge.</td>
<td>Parents value a family-centered approach to caring for their child. Open and effective communication and acknowledgment and utilization of parents’ knowledge were identified as necessary for success.</td>
<td>Communication, role negotiation, family presence/participation</td>
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| 10. Coyne, I., O’Neill, C., Murphy, M., Costello, T., & O’Shea, R. Report nurses’ perceptions and practices of Family-Centred Care |
|---|---|---|---|
| Qualitative study using open-ended questions | Two core themes identified: components of FCC and enhancing FCC. | Role negotiation, participation in care, communication |