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Family Centered Pediatric Nursing Care: State of the Science

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Family centered care (FCC) has been adopted as a philosophy of care for pediatric nursing (American Nurses Association and Society of Pediatric Nurses, 2003; Lewandowski & Tesler, 2003). Providing FCC means that the clinician incorporates into caregiving the knowledge and conviction that family is the constant in children's lives, children are affected by and affect those with whom they have relationships, and, by including families in care processes, children will receive higher quality care. Formally adopting FCC as the philosophy of care for pediatric nursing serves to provide a framework for pediatric nurses to take on the responsibility and the goal to care for infants and children in ways that not only support and promote physical health but that support and promote the healthy emotional and psychological development that occurs in the context of the family (Blake, 1954; Knafl, Cavallari, & Dixon, 1988). The purpose of this paper is to examine the current state of pediatric nursing research related to FCC and to propose directions for future study. Other specialties within nursing, as well as other health care disciplines, have adopted a family centered approach to providing care. Examination of possible similarities and differences in the perspectives toward and approaches to studying FCC among other groups is beyond the scope of this paper.

Background

Historically, hospitalized children in the early half of the twentieth century were cared for exclusively by health professionals and visitation by parents was either extremely restricted (Frank, 1952) or completely prohibited (Alsop-Shields & Mohay, 2001). Attitudes and practice began to change in the 1950s and 1960s largely due to the work of Bowlby (1953), who demonstrated serious emotional, psychological, and developmental consequences of separation between mother and child, and to the work of Robertson (1958), who focused specifically on direct observations of hospitalized children, documenting child behavior changes associated with separation from the mother. As a result of their work, attitudes began to change and articles appeared in the nursing literature advocating not only increased visiting hours, but allowing the mother to room-in with her child (Frank, 1952; Hohle, 1957; Morgan & Lloyd, 1955). These changes in practice and policy were supported and made more compelling with the publication of seminal research demonstrating that hospitalized toddlers cared for in institutions allowing mothers to room-in were significantly less likely to experience serious emotional and behavioral problems after discharge when compared with toddlers cared for in institutions with restricted visitation (Fagin, 1966). Although the focus of Fagin's study was limited to effects of the mother's presence, she concluded that changes in the roles and attitudes of nurses when a child was hospitalized were needed with the goal of "encouraging the mother to become a participant in the hospital experience" (Fagin, p. 69).

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The earliest description of the multiple components of family centered pediatric nursing care was provided by Florence Blake in her comprehensive proposal for improving health care services delivered to children and families (1954). The proposal focused on addressing the psychosocial, as well as physical, needs of children and families and included attending to the relationship of children with their families. Blake emphasized that nurses must make a deliberate effort to establish a relationship with parents that fostered understanding of parents' as well as children's needs concerning adapting to illness and hospitalization. Blake's focus was on significant changes in the philosophy and practice of educating pediatric nurses, but recognized other aspects of health care that would need to be addressed for successful adoption of this new philosophy. These included changes in hospital practices so parents could stay with and care for their hospitalized child, provision of home care services for sick children who could safely be cared for at home, and education of staff nurses and other hospital personnel. The components of care described in Blake's proposal included many of the components currently associated with FCC, such as caring for the child in the context of family, facilitating parent participation in care, identifying and supporting family strengths, caring for children within the context of their development, providing information to children and families, recognizing that each family is unique, and designing health care that is flexible and responsive to families.

These components of family centered pediatric care were examined by nurse leaders from a large metropolitan children's hospital in several articles providing a comprehensive overview of the practice of FCC and its clinical application (Beatty, 1972). Of special importance was the discussion of implementation of this philosophy of care in a large institution (Luciano, 1972). This relatively early work demonstrates the leadership of pediatric nursing in valuing, committing to, and working toward implementation of this philosophy of nursing practice.

A formal, multidisciplinary definition of FCC for children and families came in response to professional and parental concerns about the approach to health care for children with special health care needs, a population that was rapidly growing as a consequence of improved medical and technological care (Shelton, Jeppson, & Johnson, 1987). Discontent with traditional approaches to health care delivery prompted the formation of a multidisciplinary task force composed of professionals and parents and charged with the task of defining FCC. The seminal definition of FCC produced by this task force was published by the Association for the Care of Children's Health (ACCH) in 1987 (Shelton et al.) and has been further examined and clarified (Shelton & Stepanek, 1994). The eight elements of FCC according to this definition are:

1. Incorporating into policy and practice the recognition that the family is the constant in a child's life, while the service systems and support personnel within those systems fluctuate.
2. Facilitating family/professional collaboration at all levels of hospital, home and community care: care of an individual child; program development, implementation, evaluation, and evolution; and policy formation.
3. Exchanging complete and unbiased information between families and professionals in a supportive manner at all times.
4. Incorporating into policy and practice the recognition and honoring of cultural diversity, strengths, and individuality within and across all families, including ethnic, racial, spiritual, social, economic, educational, and geographic diversity.
5. Recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide developmental, educational,

emotional, environmental, and financial supports to meet the diverse needs of families.

6. Encouraging and facilitating family-to-family support and networking.
7. Ensuring that hospital, home, and community service and support systems for children needing specialized health and developmental care and their families are flexible, accessible, and comprehensive in responding to diverse family-identified needs.
8. Appreciating families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support (p. vii).

The core of this definition of FCC is the relationship between families and health professionals. In this relationship, families are considered full partners in the provision of health care to children. In order to provide this type of care, professionals must have an attitude and practice of respect, collaboration, and support, and health care systems must provide support for staff, adequate facilities, innovative and accessible services, and opportunities for family participation on policy and facility decision-making boards.

ACCH has continued its work in advocating for improved care for children and their families. FCC is currently funded as a National Center by the Bureau of Maternal and Child Health (<http://www.familycenteredcare.org>). FCC, as defined by these elements, was mandated legislatively as an expectation of service delivery for children with special health care needs in the Maternal and Child Health Block Grant Amendments in the Omnibus Budget Reconciliation Act of 1989 (P.L. 101–239), the Individuals with Disabilities Education Act (P.L. 101–476), the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 101–496) and the Mental Health Amendments of 1990 (P.L. 101–639) (Johnson, Jeppson, & Redburn, 1992). Furthermore, it has been suggested as the standard for all children and families who enter the health care system (Ahmann & Johnson, 2000).

The concept of FCC as practiced by pediatric nurses has been analyzed based on published literature. In one analysis, pediatric nursing support for FCC consistent with the ACCH was found to have evolved over time beginning with an emphasis on parental involvement in care, moving to describing partnership between parents and nurses, and finally promoting provision of care to the family as a unit (Coyne, 1996). In another analysis of the literature, two approaches of pediatric nurses toward FCC were identified (Hutchfield, 1999). The first was based on respect and cooperation with the family with the nurse working in partnership with them. The second was less collaborative with the nurse determining the extent of the family's involvement and caregiving. In a more recent concept analysis, FCC as practiced in neonatal intensive care units (NICU) was described using five defining characteristics: (1) "a respectful coalition between the health care team and the family with the goal of including the family in the decision-making and care of their infant," (2) open communication between health care provider and family with a particular focus of the health care provider "actively seeking to understand the perceptions and concerns of families," (3) being aware of and supporting family strengths, (4) "accepting individuality and diversity," and (5) "recognizing the family as experts in the care of their child." (Malusky, 2005, p. 27).

In summary, the philosophy of care that was first described in the 1950s has gradually been introduced into practice and a formal description has been developed by a multidisciplinary group that promotes application in all settings in which children receive care. Professional nursing associations have adopted FCC as the basis of pediatric nursing practice, and there is evidence that the meaning of FCC within the nursing profession is consistent with FCC as defined by ACCH. Knowledge of the focus and findings of pediatric nursing research in FCC

will be helpful in evaluating the level of success in providing this type of care to children and families in various health care settings as well as identifying critical areas for future research.

Methods

To examine the current state of pediatric nursing research in FCC, a literature search was conducted entering the terms “family centered” or “family centred” in the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed. The CINAHL database indexes journals from the fields of nursing and allied health and includes all English language nursing journals. PubMed is a comprehensive database developed at the National Library of Medicine within the National Institutes of Health, and indexes thousands of national and international biomedical journals. The search terms were further limited to studies of children 18 years of age or younger and published between 1995 and 2006 to reflect the most recent research in pediatric populations.

Abstracts from the articles retrieved in the initial search were reviewed. The final sample was limited to articles meeting the following criteria: (a) a nurse must have been first author, (b) the article must have been a research report, not a case study, instrument development project, or quality improvement project, (c) and the research must have been conducted in a developed country, to reduce confounding of results from the more recent adoption of FCC in developing countries. The resulting 30 articles were read and organized by the description of the sample being studied: nurses, families, or both. Each article was then reviewed using the framework of the elements of FCC as defined by ACCH (Shelton & Stepanek, 1994).

State of the science related to FCC

The sample of 30 papers will be reviewed in three sections: researcher observations of parent-nurse interactions, research examining the perspective of parents or family caregivers, and research examining the perspective of health professionals.

Observations of parent-nurse interactions

Participant observation was used to explore the relationship between nurses and parents of well children aged birth to three years hospitalized with an acute illness (Rowe, 1996). Nurses were clearly the “insiders” or “hosts” while parents were viewed by nurses as “visitors” (p. 105–106). Both held themselves responsible for the child’s care, yet this was not discussed between nurse and parent. Three types of relationships were identified. In the first, and most common, a parallel relationship was described in which the parent and the nurse worked side by side, complementing each other’s care, yet conducting it independently. Still, lack of collaboration or a sense of partnership between nurse and parent was illustrated by the nurses’ perspective that “parents were not part of the daily planning but were useful for relieving the pressure of time by bathing or feeding their child” (p. 103). In a second, less common, type of relationship, described as cooperative, the parent and the nurse cooperated in care with some negotiation of roles, yet the nurse controlled and directed the activities. Finally, no partnership or collaboration was present in a type of relationship described as excluding, in which the nurse undermined the role of the parent by taking over the child’s care, with parents described by the observers as “bystanders” (p. 104). The author concludes that changes in the relationship between nurses and parents will occur only if the nurse initiates and facilitates such a relationship.

In a second observational study, little evidence was found that the philosophy of FCC was incorporated into the care of infants and families in a neonatal intensive care unit (NICU; Fenwick, Barclay, & Schmied, 1999). Nurses directed and managed the infant’s care, even when the care did not require technologic skill, with little role negotiation between nurse and

parent. Slightly more positive (47%) than negative (37%) communication patterns were identified, and 16% included both positive and negative components. Positive patterns included evidence of support for the mother, friendliness, and included engagement of both participants. Negative patterns demonstrated nurses' efforts to "exert their authority, establish expertise, and demonstrate their own power in the relationship" (p. 61). Within positive communication patterns, only 6% were described as egalitarian, in which both partners were observed to have equal status. These interactions were described as relationship building and occurred when nurses and mothers shared life experiences. Interactions with mothers by nurses were on the whole task oriented or providing information with little evidence of nurses working to assist parents in developing a relationship with their infant and preparing to assume caregiving.

Perspectives of parents or family caregivers

This group of papers will be discussed in three sections: how parents or family caregivers perceived the caregiver-nurse relationship, how parents or family caregivers perceived the value and provision of FCC, and intervention studies examining the effect of FCC on children or families.

Caregiver-nurse relationship—The majority of research in which caregivers' perspectives were examined focused on FCC as a relationship of respect and collaboration between families and health professionals. Parents of children hospitalized with cancer described characteristics of staff nurses with whom they had or had not developed a relationship in which caregiving and decision making were shared (Romaniuk & Kristjanson, 1995). The relationship was influenced by several factors, including the way in which the nurse approached the practice of nursing, staffing levels, and the quality of working relationships between physicians and nurses. Parents valued their positive relationships with nurses and wanted to be involved in their child's care. In another study, parents reported that having a positive relationship with nurses in which rapport was developed and care of the child was shared was not enough to be considered collaborative as long as the nurse was perceived as maintaining control of the relationship (Espezel & Canam, 2003). The parents' definition of collaboration was not reported.

In a study of mothers of infants in an NICU, mothers actively sought out and worked toward collaborative relationships with their baby's health professionals (Hurst, 2001). This was difficult because, in order to succeed at this, mothers needed to work to increase their position of authority in the face of the power differential accorded health professionals in the institution (i.e., the health professionals controlled the provision of care to their infant and the interactions between mothers and health professionals). Mothers reported numerous barriers to their attempts to develop a partnership with nursing staff, including lack of adequate staffing which limited time for communication and sharing of information, experiencing multiple caregivers which limited the ability of the mother to develop rapport with individuals, and mothers' fears that their own actions would negatively impact the quality of care their infants received. They also reported that their attempts to develop a partnership were either not recognized or were misunderstood as questioning the competence of the professional staff.

Parents' needs related to the parent-nurse relationship when their child was hospitalized in a pediatric intensive care unit (PICU) were examined in two studies. In the first, ambiguity of health-related family boundaries (i.e., uncertainty about responsibilities for caregiving), was explored (Tomlinson, Swiggum, & Harbaugh, 1999). Parents experiencing high levels of family boundary ambiguity were interviewed to elicit nursing interventions most supportive of maintaining family integrity. Interventions deemed useful were those that: (a) supported family normalcy, (b) respected the rights of families, (3) employed open, honest communication, and (d) included families in daily planning. In the second study of parents

with children hospitalized in PICU, parents were asked to share their perceptions of nurses' caregiving behaviors (Harbaugh, Tomlinson, & Kirschbaum, 2004). Nursing behaviors supportive of family integrity and family functioning were seen by parents as those that complemented and facilitated the critical parental behaviors of nurturance and vigilance: "giving affection and caring, and watching and protecting" (p. 170).

Two studies went beyond measuring parental perceptions to measuring the effect on the parent of the parent-health professional relationship. The FCC element of acknowledging and respecting the pivotal role of the family in the life of the infant was examined with mothers of infants with Down syndrome (Van Riper, 1999) and mothers of infants in the NICU (Van Riper, 2001). Mothers who reported positive relationships with health professionals also reported higher levels of well being and more satisfaction with care than mothers not reporting positive relationships with health professionals.

Perception of the value and provision of FCC—Several investigators examined the value caregivers placed on the elements of FCC and the extent to which caregivers perceived that they actually received FCC. Galvin et al. (2000) surveyed 193 parents of hospitalized children to determine the importance placed on the elements of FCC and the frequency of observing these elements of care. Survey items were grouped conceptually into three areas of FCC: respect, collaboration, and support. Items ranking highest in importance included feeling like a parent rather than a visitor (respect), knowing who to call for help after discharge (collaboration), and believing staff is familiar with the care needs of the patient (support). Items ranked highest in occurrence included feeling welcomed (respect), feeling prepared for discharge (collaboration), and feeling staff understood the parent's need to stay hopeful (support). The item ranked lowest in both importance and occurrence was staff willingness to understand cultural or religious beliefs (respect). Hispanics rated the importance of collaboration and support items lower than other racial groups (African-American, Caucasian, and other), and parents who had been in the United States less than five years ranked the importance of all three conceptual areas as lower.

Perceptions of family caregivers that aspects of FCC were provided differentially based on race were found in two studies examining urban families of American Indian descent. In both studies, families thought they were not respected or understood and believed they were treated less well because of their cultural background (Garwick, Jennings, & Theisen, 2002; Rose & Garwick, 2003). Differences in perceived provision of FCC were also found in a study of parents of hospitalized children (Young et al., 2006b). Parents of toddlers and preschoolers reported significantly less satisfaction with communication and were less likely to perceive the nurses as being sensitive to parents' needs when compared with parents of infants and parents of children over age 5 years.

In one study, the adequacy of providing FCC was examined by asking 63 culturally diverse family caregivers of school-aged children with chronic physical health conditions to identify how health care services could be improved (Garwick, Kohrman, Wolman, & Blum, 1998). The recommendations, which did not differ between cultural groups, revealed major gaps in provision of this type of care. Family caregivers reported a need to: (a) improve accessibility and availability of health care services, (b) improve training of health care professionals, families, and the general public in caring for children with chronic conditions, and (c) decrease barriers to available services and programs.

Interventions—Four studies were found in which interventions to implement specific aspects of FCC were tested. Two focused on outcomes of family involvement in care. In one study, incorporating the family into the care of their premature infant through the provision of family-centered, developmentally supportive care was examined in a sample of 114 infants

assigned to receive either the intervention or standard care in the NICU (Byers et al., 2006). No differences in parental satisfaction or in infant physiologic measures (heart rate, respiratory rate, and oxygen saturation) were found between groups. However, behavioral stress cues were significantly lower in the intervention group. In a second study, parental participation in care was examined in a small sample of mothers of children with cancer (Evans, 1996). Five mothers trained to administer intravenous antibiotics to their hospitalized child reported less anxiety, improved coping, and feeling more in control.

The remaining two intervention studies included one based in the NICU and one in a community setting. In the first, parents with infants in the NICU reported benefits of parent support programs, including facilitation of greater parent participation in infant care and improvement in communication with health professionals (Hurst, 2006). In the second, a community-based intervention of a comprehensive asthma education program for over 500 low income Latino children and their families was tested that incorporated the FCC elements of family participation in educational programs, support groups, and a community advisory board (Lewis, Lewis, Leake, Monahan, & Rachelefsky, 1996). Significant reductions were found in number of physician visits, percentage of children hospitalized, and percentage of children requiring emergency care.

Perspectives of health professionals

The perspective of health professionals was the focus of numerous studies. Nurses were found to have reservations about providing FCC. Ten NICU nurses were interviewed about their experiences in transitioning from a traditional model of nursing care to a family centered model of providing developmentally supportive care (Heerman and Wilson, 2000). Although the nurses reported positive responses to facilitating a relationship between a mother and her infant, negative feelings of being intimidated by parents and of losing control and power were also expressed. Difficulties in delivery of FCC were also described in a study of hospital-based pediatric nurses (Paliadelis, Cruickshank, Wainohu, Winskill, & Stevens, 2005). Nurses believed that family members should be involved in the care of a hospitalized child, but found it difficult to implement in practice, largely because of conflicting beliefs about their role as a nurse, including: (a) nurses are the experts, (b) nurses have the legal responsibility to care for the children, and (c) nurses need to assess parents' abilities before allowing their participation. Reluctance to provide care based on principles of FCC was again demonstrated in a study of decision making about parental presence during invasive procedures in the pediatric intensive care unit (Jefferson & Paterson, 2001). The decision about parental presence was made by the health professional and depended upon that individual's goal, which was most often "to perform a procedure with maximal efficiency and minimal disruption" (p. 17) and only rarely to support the parent-child relationship, two goals seen as mutually exclusive.

Differences in attitudes towards parent participation in care were found in a sample of 256 pediatric health care providers including nurses, physicians, respiratory therapists, and nursing assistants (Daneman, Macaluso, & Guzzetta, 2003). The majority (51%) of respondents were nurses. No differences in attitudes were found between nurses and physicians. Although respondents valued the benefits of parents participating in routine tasks such as feeding, there was less support for allowing parents to visit whenever they wished and for doing things normally done by health care providers, such as giving medications, even when the parent normally gave those medications at home. Health care providers working on specialty units and those with higher levels of education had higher scores in support of parental participation.

Differences in attitudes were also revealed in a small qualitative study of empowerment of parents by acute care pediatric nurses (Valentine, 1998). Empowerment in the context of FCC was described by the authors as a shifting in the balance of power between health care professionals and families wherein the health care professional supports and enables the family

to maintain their parental role of advocating for, caring for, and making decisions involving their child's health and well-being. Although all nurses were knowledgeable about the theoretical basis for empowerment of parents, experienced nurses had a more positive attitude about the abilities of parents to participate in their child's care and were less threatened by negotiating this change of traditional roles than nurses with less experience. Additionally, nurses identified hospital culture and working environment as factors in affecting their ability to effectively empower parents in caring for their hospitalized child.

Differences in perception of provision of FCC were found among hospital-based pediatric nurses (Young et al., 2006a). More experienced nurses, nurses with more education, nurses with children under five years of age, and nurses whose own children had been hospitalized were significantly less likely to agree that nurses were sensitive to parents' needs. Communication with parents was identified as the key component in negotiating roles, and was also identified as needing improvement. A large majority of these nurses perceived that parents did not know what was expected of them.

Differences in perceptions of provision of FCC were also found between health care systems. Varying degrees of provision of FCC to pediatric patients were reported by staff members of nine emergency departments in nine states (Eckle & MacLean, 2001). The sites most supportive of FCC were those in which the culture supported inclusion of families, educational programs were offered to the staff, and specific competencies related to FCC were mandated.

Finally, the difference between health professionals' perceptions of the importance of the elements of FCC and actual practice of these elements was examined in five studies. Two of these studies included nurses along with other health professionals (Bruce et al., 2002; Letourneau & Elliott, 1996). The remaining three specifically examined nurses' perspectives (Bruce & Ritchie, 1997; Caty, Laroque, & Koren, 2001; Petersen, Cohen, & Parsons, 2004). Each of these studies used the Family-Centered Care Questionnaire (Bruce & Ritchie). This 45-item instrument included assessment of each of the eight elements of FCC described by Shelton and Stepanek (1994) as well as one additional element added by the Izaak Walton Killam children's Hospital FCC Committee (as cited in Bruce & Ritchie, 1997) to account for the importance of a supportive work environment. The findings were consistent: nurses and other health care providers reported perceptions that all of the elements of FCC are necessary for working with children and families, but did not consistently incorporate these elements into their practice. Ratings of perception and practice varied on a number of characteristics. The importance of the elements was rated significantly higher among health professionals with higher educational levels (Letourneau & Elliott), among health professionals in administrative or teaching positions (Bruce & Ritchie; Bruce et al.; Letourneau et al.) and among nurses working in pediatric or pediatric intensive care units when compared with nurses working in the NICU (Petersen et al.). There was closer agreement between the perceived importance of the elements of FCC and actual practice of the elements of FCC in individuals with these characteristics: (a) nurses with less experience (Petersen et al.), (b) nurses with more education (Bruce & Ritchie), (c) nurses with more participation in continuing education (Caty et al.), (d) nurses working in staff positions when compared to nurses working in administrative or teaching positions (Bruce & Ritchie), and (e) health care professionals in older age groups (Bruce & Ritchie; Letourneau & Elliott).

Summary and Future Directions

The nursing literature focused on research of FCC over the past decade reflects support for the elements of FCC as described by Shelton and Stepanek (1994). Families value and expect a relationship of partnership with health professionals. Nurses support the concept of FCC but experience difficulty in implementing this philosophy of care in practice.

FCC is multi-faceted, requiring a variety of approaches to adequately study both its effectiveness and its implementation. Several strengths in these studies were identified. As a group, all eight elements of FCC as defined by Shelton and Stepanek (1994) were examined and included families and health professionals working with infants and children with a wide range of ages and with varying diagnoses. Both mothers and fathers, as well as non-parent primary caregivers, were included as participants in most of these studies. These studies provided a rich description of the significance of FCC to families particularly in the NICU, the PICU, families of children with chronic illness, and families of children hospitalized with cancer as well as descriptions of experiences of health professionals in adopting and implementing this philosophy of care. However, many areas of research related to outcomes and delivery of FCC remain undeveloped.

One weakness of this group of studies was that the primary setting for the research was tertiary care. Other care settings such as primary care offices, home health care agencies, public health departments, and community health centers need to be more thoroughly examined.

There was a limited focus on outcomes in this group of studies, being examined in just 6 of the 30 studies. Outcomes examined were parental well being or psychological functioning (Evans, 1996; Hurst, 2006; Van Riper, 1999; 2001), parental satisfaction with care (Byers et al., 2006), infant physiologic and behavioral responses (Byers et al.), and health care utilization (Lewis et al., 1996). Only four of the studies addressing outcomes were intervention studies (Byers, et al.; Evans; Hurst; Lewis et al.). Additional research is needed to examine outcomes of FCC on families, children, and health care professionals. These outcomes may include the effect of family experiences with FCC on parental self-esteem, psychological well being, self confidence, competence in making health care decisions, and caregiving competence; the effect of FCC on patient outcomes, such as length of stay, health care utilization, and physical health status; and the effect of practicing FCC by health professionals on length of employment, job satisfaction, and turnover rates.

There is evidence in these studies that there are differences in perceived provision of FCC based on culture (Galvin et al., 2000; Garwick et al., 2002; Rose & Garwick, 2003) and age of the child (Young et al., 2006b). These differences are supported in the non-nursing literature. Less educated mothers, unmarried mothers, and Spanish speaking mothers were less likely to score high on provision of FCC in primary care practices (Bethell, Reuland, Halfon, & Schor, 2004), and the reported provision of FCC decreased as poverty increased, was reported less frequently among non-Hispanic blacks and non-Hispanic other races than with non-Hispanic whites, and was reported less frequently with families of adolescents than with families of children under the age of five years (Strickland et al., 2004). There is also evidence in earlier literature that there are differences in perspective toward FCC between families with acutely ill children and families with chronically ill children (Knafl et al. 1988). This difference has neither been explained nor examined further. The identification of differences in perspectives of FCC related to cultural identity, socioeconomic background, and the child's age or health condition is essential to more clearly identify the issues involved.

Differences among nurses in the extent to which they agree with and incorporate FCC into their practice were also found. The results of these studies indicate that nurses working in specialty units, nurses with more education, and nurses with less experience were more able to practice in agreement with their perceptions of the importance of FCC. Additional research is needed to further identify subgroups of nurses who have particular difficulty in practicing FCC.

Several barriers to implementing FCC were identified by health care professionals in these studies, including lack of skills in communication, role negotiation, and developing

relationships (Bruce & Ritchie, 1997; Caty et al., 2001; Valentine, 1998); lack of time (Paliadelis et al., 2005), negative attitudes, including feeling threatened, fearful of losing role, feeling intimidated (Valentine; Heerman & Wilson, 2000; Paliadelis et al.); and lack of support within the health care system and from other health care disciplines (Bruce & Ritchie; Heerman & Wilson; Petersen et al., 2004). A deeper analysis is needed to address specific problems and issues within the individual and within the practice environment that serve as barriers to FCC.

On an individual level, the extent to which nurses embrace FCC in their own practice may be influenced by experiences as a student (Bridgeman, 1999; Hartrick, 1998). It is only relatively recently that traditional nursing education models have moved from a child-centered approach to a family-centered approach and from nurse-led care to the concept of working in partnership with patients as clients (Pridham, Broome, & Woodring, 1996). Socialization into this type of role begins during the educational program and continues in the context of practice and institutional policy. Standards and guidelines for the education of nurses in caring for children, including the principles of FCC, have been developed (Pridham et al.). The extent to which these standards have been adopted by schools of nursing is not known. Even when FCC is included in the curriculum, students report a large gap between the theory of FCC and actual practice in the clinical settings (Bridgeman).

Research is critically needed to develop and test strategies to support student nurses and graduate nurses in collaborating with parents in providing FCC. One of the strategies that could be developed and tested as an intervention is to adapt the concept of transformation of participation (Rogoff, 1998) as a model within which nurses can provide FCC to families. In the context of nursing education and practice, this approach would conceptualize nurses and family members as “mutually engaged individuals [who] collaborate in reaching goals” (Rogoff, p. 698). In this model, collaboration is defined as “interactions in which participants’ roles are complementary or with some leading and others following, supporting, or actively observing.” (Rogoff, p. 723). Other strategies may include utilizing parents and other family members in the educational curriculum and staff development seminars, offering programs to enhance skills in interpersonal communication; assisting nurses in recognizing and building on family strengths; and changing the terminology used in the curriculum and in the institution to be more family centered (e.g., identifying parents and family members as caregivers, not visitors). Developing and testing interventions using these and other strategies will move the nursing profession forward in successfully adopting this philosophy of care.

The level to which nurses embrace FCC in their own practice may also be influenced by the environment in which they work (Eckle & MacLean, 2001; Valentine, 1998). There is much to learn about institutional supports essential to successful implementation of FCC. Research is needed examining outcomes in family satisfaction, parent-professional communication, child health, and parent-child relationships in facilities with differing (a) amounts of space for caregivers at the infant or child’s bedside, (b) flexibility of visiting policies, (c) adequacy of staffing, (d) opportunities for staff education in FCC, (e) and expectations for staff competency in FCC.

Conclusion

FCC has appropriately been adopted as a philosophy of care for pediatric nursing. The concept has evolved from allowing parents to visit their hospitalized child to welcoming parents as full participants in partnership with health professionals. Current research has demonstrated that families value and desire FCC and that nurses agree with this philosophy. It is disheartening to note that more than fifty years after Blake first set forth the essentials of FCC (1954), pediatric nurses continue to struggle with providing this type of care. This gap between what is perceived as important and what is actually practiced marks an area of frustration and dissatisfaction for

both families and clinicians. The research to date provides a solid foundation for the next step: to move forward in conducting research focused on assisting nurses in implementing this basic philosophy of practice in all settings and situations in which children receive health care.

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