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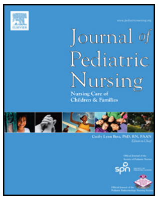

Family-Centered Care From the Perspective of Parents of Children Cared for in a Pediatric Intensive Care Unit: An Integrative Review

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ABSTRACT

Problem: The Institute for Patient- and Family-Centered Care's (IPFCC) definition of family-centered care (FCC) includes the following four core concepts: respect and dignity, information sharing, participation, and collaboration. To date, research has focused on the provider experience of FCC in the PICU; little is known about how parents of children hospitalized in the pediatric intensive care unit (PICU) experience FCC.
Eligibility Criteria: Articles were included if they were published between 2006 and 2016, included qualitative, quantitative, or mixed methods results, related to care received in a PICU, and included results that were from a parent perspective.
Sample: 49 articles from 44 studies were included in this review; 32 used qualitative/mixed methods and 17 used quantitative designs.
Results: The concepts of respect and dignity, information sharing, and participation were well represented in the literature, as parents reported having both met and unmet needs in relation to FCC. While not explicitly defined in the IPFCC core concepts, parents frequently reported on the environment of care and its impact on their FCC experience.
Conclusions: As evidenced by this synthesis, parents of critically ill children report both positive and negative FCC experiences relating to the core concepts outlined by the IPFCC.
Implications: There is a need for better understanding of how parents perceive their involvement in the care of their critically ill child, additionally; the IPFCC core concepts should be refined to explicitly include the importance of the environment of care.

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Introduction

The Institute for Patient- and Family-Centered Care (IPFCC) defines family-centered care (FCC) as encompassing four core concepts: respect and dignity, information sharing, participation in care and decision-making, and collaboration between patients, families, and the healthcare team (www.ipfcc.org). In pediatrics, respect and dignity encompass how the child and the child's family are treated; information sharing involves communicating with and making information available to patients and families in formats they understand. Participation entails including the family in decision making and the child's care at the level the family chooses, and collaboration comprises partnering with families to improve policy, programs, and infrastructure. As an approach to care, the goal of FCC is to improve patient and family satisfaction and care outcomes; FCC has the potential to influence health care delivery at levels ranging from social and institutional policies to daily interpersonal interactions with staff and family (www.ipfcc.org).

Partnerships between families and the health care team are essential in pediatrics where children are often unable to self-report symptoms or treatment preferences due to their developmental stage or health status. Thus, parents are charged with communicating on the child's behalf, necessitating that parents be included in their child's care. Additionally, parents are most often responsible for the child's care after discharge, making critical that they are involved in care and decisions during the child's hospitalization to aid in the transition to home. Multiple professional organizations have released statements stressing the importance of adopting FCC as a policy in the pediatric hospital environment (e.g., The Institute of Medicine, 2001; American Academy of Pediatrics, 2003, 2012; American Nurses Association, 2008, 2015); however, the extent to which FCC as defined by the IPFCC is enacted in pediatric critical care units (PICU) is largely unknown. To inform understanding of FCC in pediatric intensive care, an integrative literature review was performed; this paper reports on the findings.

Background

As a mode of care delivery, FCC is relatively new in the care of pediatric patients and families. As recent as the mid-20th century children

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were cared for in hospital wards with no or minimal visitation allowed from family members. Parents of children with chronic health conditions and key advocacy groups joined together to bring about change and prioritized FCC in the late-20th century (Johnson, 1990). Slowly the care of hospitalized children has shifted to a more family-centered model; however the PICU has been slow to adopt these standards (Butler, Copnell, & Willetts, 2013; Foglia & Milonovich, 2011).

The introduction of FCC in pediatric settings was intended to change how providers interact with families and care for hospitalized children. Based on FCC principles, the family is central to the child's health and pediatric care should focus on partnership with the family (Just, 2005). These ways of interacting can be challenging in PICUs which have traditionally limited family visitation, involvement in direct care, and decision-making (Kuo et al., 2012). Published first-hand accounts of parents who have had children treated in a PICU illustrate poor implementation of the core concepts of FCC as envisioned by the IPFCC (Merk & Merk, 2013; Wills & Wills, 2009).

While others have examined FCC implementation in pediatric environments including the PICU, these syntheses have focused on healthcare professionals' experiences and perspectives rather than those of parents. Given that parents are the voice, advocate, and caregiver for their child including during critical pediatric illness, their perspective is critical to understanding FCC implementation in the PICU. The overall purpose of this review was to examine parents' perspectives on and experiences with implementation of the FCC core concepts in the context of having a child in the PICU.

Aims

The primary aim of this integrative review (Whittemore & Knafl, 2005) was to examine the extent to which published research articles concerning parent perspectives on their involvement in their child's care in a PICU demonstrate implementation of the four core concepts of FCC. Secondary aims were to determine if the definitions of these four concepts require refinement or expansion to incorporate parental perspectives and experiences, and whether the evidence suggests additional core concepts reflecting parents' perspectives on FCC.

Methods

Search Method

The searches were guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA: Moher, 2009). Search strategies were developed by the first author (CH) in consultation with a research librarian. The databases searched between July and October 2016 included: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica Database (Embase), PubMed, and PsycINFO. To be included in this review, reports had to be available in English, published between January 1, 2006 and October 31, 2016, include qualitative, quantitative, or mixed methods results, relate to the PICU, and include results of parental perspective via parent report regarding PICU care. To reflect the most recent research on FCC in the PICU and ensure timeliness and clinical relevance, the literature search was limited to reports published within the last 10 years. Articles that included other care environments or reports of healthcare professionals' experiences were included only if the parent report and PICU environment were distinguishable among the results. Excluded were first-hand accounts, editorials, and other works that were not primary research.

Search terms included PICU, pediatric intensive care unit, family-centered care, parent, collaboration, decision-making, participation, and information. Keywords and Medical Subject Heading (MeSH) terms were customized to the database searched. Additionally, truncation of words was used when appropriate to reflect syntax and search rules common to individual databases (Havill et al., 2014).

Search Outcome

Refer to Fig. 1 for search outcomes.

Quality Appraisal

The first author critically appraised the retained articles using the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011), a tool designed to assess the methodological quality for systematic reviews that contain qualitative, quantitative, and mixed methods studies. An article could score 0, 25, 50, 75, or 100% based on how many assessment items the article addressed. No articles were excluded based on poor quality; for individual quality scores see Table 1.

Data Abstraction and Synthesis

Data were extracted from included reports using an extraction template structured to summarize results related to each FCC core concept as outlined by the IPFCC, as well as evidence for refining core concepts definitions and/or adding concepts not previously explicated as central to FCC. The first author (CH) extracted data from the remaining articles using the template, and then either the second (KK) or third author (SS) reviewed the abstractions for completeness and conceptual fit. The authors met to review and resolve data extraction discrepancies.

Results

Table 1 summarizes the articles included in this integrative review. The IPFCC core concepts respect and dignity, information sharing, and participation were evident in the reports of parent perspectives; collaboration was mentioned just once in the implications section of one article. An additional review finding was the impact of the physical and cultural environment of the PICU on the parents' perception of FCC implementation. In the following sections we discuss our findings based on each IPFCC core concept, the need for FCC model refinement, and parent report of whether implementation of the FCC core concepts was met in the PICU.

Respect and Dignity

The IPFCC defines respect and dignity as “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” (www.ipfcc.org). We operationalized this core concept as results addressing “how patients and their families are treated”. Themes included perceptions of the PICU physical and cultural environment and expressions of compassion and support from providers.

Perceptions of the PICU Physical and Cultural Environment

A common theme throughout the research reports was the PICU environment and how it impacted parents' experiences. Although not explicitly mentioned in the definitions of any core concept, the PICU environment (e.g., patient room, overall unit, waiting room) was experienced by parents as conveying respect and dignity for the family and their situation and, attempts to preserve dignity through attention to the child and parents' privacy and emotional decompression, or lack thereof.

The structural layout of PICUs ranges from open units where patient spaces are separated only by curtains, semi-private room units that house 2–4 patients, and private room units. Parents identified aspects of each layout that contributed to their comfort or discomfort. Parents interpreted rooms that were clean and comfortable (Abuqamar, Arabiat, & Holmes, 2016), close by waiting rooms (Sturdivant & Warren, 2009), and availability of telephones and lockers (Meert, Briller, Schim, & Thurston, 2008) as indicators of respect. For parents,

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