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# What Impact Do Hospital and Unit-Based Rules Have Upon Patient and Family-Centered Care in the Pediatric Intensive Care Unit?

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Patient and family-centered care (PFCC) is the foundation for pediatric healthcare. The existence of hospital rules can, however, impact the extent to which PFCC is delivered. This qualitative, grounded theory study identified the existence of explicit and implicit rules in a pediatric intensive care unit, all of which negatively affected the family's ability to receive care that was attentive to their needs. The rules also placed the registered nurse in the challenging position of serving as rule enforcer and facilitator of PFCC. Further work is needed to explore how to adapt the hospital environment to better meet families' needs.

## Background

AS THE NUMBER of children in the United States with complex chronic conditions (CCC) grows, so too does our understanding of their unique care needs and the daily challenges faced by family members as they provide this care. An extensive body of literature now exists that defines and describes this group of children (Feudtner, DiGiuseppe, & Neff, 2003; Gordon et al., 2007; Harrigan, Ratliffe, Patrinos, & Tse, 2002; Srivastava, Stone, & Murphy, 2005) and that identifies the unique challenges they and their families face in navigating the healthcare system and engaging in life in the "normal" world (Kirk, Glendinning, & Callery, 2005; Ray, 2002; Reeves, Timmons, & Dampier, 2006; Rehm & Bradley, 2005a, 2005b). The literature that has accumulated over the past 25 years has contributed to improvements in care for these children and their families, but it has also raised questions about current care delivery systems and identified gaps in our knowledge base. Among the most significant of those gaps is how to help HCPs develop the skills necessary to build strong working relationships with families, thereby promoting optimal care for some of our most vulnerable children.

Patient and family-centered care (PFCC), a model that recognizes the family as expert in the care of their child and that seeks to establish and maintain a partnership between family and provider, is the gold standard in pediatrics and is widely accepted as the philosophy of care upon which optimal pediatric healthcare practice is built. Professional organizations and government agencies have endorsed

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PFCC, and it has become an established part of the curriculum in programs that train future pediatric providers (American Academy of Pediatrics, 2012; American Nurses Association, 2008). The following components are generally considered to be key elements of the PFCC model: respect for family preferences; flexibility and customization of care; honest information sharing to promote participatory decision-making; collaboration across all levels of the healthcare delivery system; and a strengths-based approach to working with patients and families (American Academy of Pediatrics, 2012; Institute for Patient and Family-Centered Care, 2010; Jolley & Shields, 2009; Malusky, 2004; Mikkelsen & Frederiksen, 2011; Shields et al., 2012). Despite widespread acceptance of the concepts of PFCC, implementation has remained a challenge in pediatric healthcare settings, with families reporting widely disparate experiences in the quality and family-centeredness of the care they receive (Balling & McCubbin, 2001; Davies, Baird, & Gudmundsdottir, 2013; Graham, Pemstein, & Curley, 2009). The inpatient, acute care setting has historically not provided optimal PFCC and has particularly struggled with the PFCC concepts of respect for family preferences and flexibility and customization of care. Traditional practices such as visitation restrictions and family exclusion from care planning and the rounding process have limited the extent to which PFCC was achieved (Meert, Clark, & Eggly, 2013; Uhl, Fisher, Docherty, & Brandon, 2013). Children with CCC and their families are the ones most in need of this type of care, and a failure to engage the family in a partnership and to recognize the expertise that they have regarding the care of their child can have detrimental effects upon the family and can result in unnecessary, wasteful, and potentially harmful care.

Yet, some families do experience care that acknowledges and respects the expertise they bring; there are healthcare providers who embrace the concept of PFCC and consistently incorporate it into their practice (Davies et al., 2013). Efforts to improve the quality of care for children, particularly for those with CCC, must focus on these providers, understanding how they engage with families and how they operate within the busy and complex context of the modern healthcare environment. The pediatric intensive care unit is a natural setting in which to explore interactions with such providers because it is a high-stress, high-stakes environment with rapidly-evolving care situations necessitating frequent and, at times, complex communication with families. Further, a large percentage of the patients who receive care in the PICU are children with CCC (Edwards et al., 2012; Namachivayam et al., 2012).

The data presented in this paper are one component of the analysis from a qualitative, grounded theory study, the overall goal of which was to identify best practices in parent/nurse interactions in the pediatric intensive care unit (PICU) setting for the parents of children with CCC. Some of the strongest themes from the data centered around the existence and enforcement of rules in the PICU and the implicit rules, or social norms (Bicchieri, 2006), that guided practice in that environment. Emerging from these themes was an understanding of the ways in which the model of PFCC, as currently conceptualized, fails to adequately account for the context in which parent/nurse interactions are occurring and the ways in which existing social norms may run counter to the goal of delivering optimal PFCC. This paper adds to the existing literature by exploring these two important contextual factors that challenge the delivery of PFCC in the inpatient setting. Although context is implicit in the existing model of PFCC, the model may need to more fully explicate these factors in order to for PFCC to be fully actualized in pediatric healthcare settings.

## Methods

This grounded theory study had, as its foundation, the sociological theory of symbolic interactionism, which posits that meaning is central to understanding human behavior and that it is a social product, derived from a person's interactions with others. Social interaction is therefore central to the creation of meaning, and social researchers are thus charged with studying and understanding how and why interactions occur and the meanings individuals derive from those interactions (Blumer, 1969; Hall, 1987; Strauss, 1993). Grounded theory and symbolic interactionism have been described as a “theory/methods package” (Clarke, 2005, p. 4) because of grounded theory's emphasis on understanding interaction, social processes, and interpretation of meaning. Accordingly, this study sought to understand interactions, processes, and the creation of meaning for the parents of children with CCC and nurses in the PICU.

A single PICU in a large, urban teaching hospital in the western United States served as the data collection site, and the first author was the sole data collector. Approval from the local institutional review board was obtained prior to the start of data collection, and guidelines for the ethical conduct of research were followed throughout the study process. Eligibility criteria for parents included: age greater than 18 years, English-speaking, and being the parent of a child with a CCC who was currently admitted to the PICU and who had an expected length of stay in the PICU of at least 7 days. Parents who agreed to participate allowed the investigator to observe their interactions with healthcare providers from the child's room in the PICU at various times over the course of a week. Near the end of that week, parent participants also engaged in a single, in-depth interview that asked questions about their experiences with healthcare providers while in the PICU. Conducting the interview while the child was still hospitalized in the PICU provided parents with an opportunity to report and to reflect in “real time” on their experiences and may have helped to highlight some of the day-to-day concerns that would be lost in a more traditional retrospective interview. Parents were invited to begin the discussion by describing their child, including a brief summary of their child's illness and their past experiences in the healthcare system. During the course of the observations and