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### Title

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### Permalink

<https://escholarship.org/uc/item/8nk1218x>

### Journal

Nursing Research, 65(2)

### ISSN

0029-6562

### Authors

Baird, Jennifer  
Rehm, Roberta S  
Hinds, Pamela S  
[et al.](#)

### Publication Date

2016-03-01

### DOI

10.1097/nnr.0000000000000135

Peer reviewed



Published in final edited form as:

Nurs Res. 2016 ; 65(2): 142–150. doi:10.1097/NNR.000000000000135.

## Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit

**Jennifer Baird, PhD, MSW, RN,**  
Boston Children's Hospital, Boston, MA

**Roberta S. Rehm, PhD, RN, FAAN,**  
University of California, San Francisco School of Nursing

**Pamela S. Hinds, PhD, RN, FAAN,**  
Children's National Medical Center, Washington, DC

**Christina Baggott, PhD, RN, PNP-BC,** and  
Stanford University Pediatric Oncology, Palo Alto, CA

**Betty Davies, PhD, RN, FAAN**  
University of Victoria School of Nursing, Victoria, BC Canada

### Abstract

**Background**—Parents of children with complex, chronic conditions report a desire for continuity of care, but relatively little is known about the ways in which nursing continuity of care occurs and the extent to which it is delivered in the inpatient setting.

**Objectives**—The objective of this analysis, which arose from a study on best practices in parent/nurse interactions in the pediatric intensive care unit (PICU), was to explore the delivery of continuity of nursing care in the PICU from the perspective of both parents and nurses.

**Methods**—A qualitative, grounded theory study using situational analysis was conducted with seven parents, and 12 nurse participants from a single PICU. Data sources included in-depth interviews, observation, and organizational written materials. Data were coded and analyzed using memoing and situational and positional maps to highlight emerging themes, context, and positions within the data.

**Results**—Parents repeatedly endorsed a desire for continuity of nursing care, wanting to ensure that the bedside nurse valued their child as an individual and understood the complexities of the child's care regimen. Nurses understood this need but faced both contextual and personal

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Corresponding Author: Jennifer Baird, PhD, MSW, RN, Boston Children's Hospital, 300 Longwood Avenue, Boston, MA 02115 (jennifer.baird@childrens.harvard.edu).

**Jennifer Baird, PhD, MSW, RN,** is Research Fellow, Boston Children's Hospital, Boston, MA.

**Roberta S. Rehm, PhD, RN, FAAN,** is Associate Professor, University of California, San Francisco School of Nursing.

**Pamela S. Hinds, PhD, RN, FAAN,** is Director, Nursing Research and Quality Outcomes, Children's National Medical Center, Washington, DC.

**Christina Baggott, PhD, RN, PNP-BC,** is Clinical Research Nurse Practitioner—Pediatric Oncology, Stanford University Pediatric Oncology, Palo Alto, CA.

**Betty Davies, PhD, RN, FAAN,** is Professor Emeritus, University of Victoria School of Nursing, Victoria, BC Canada.

The authors have no conflicts of interest to report.

challenges to achieving continuity, including fluctuations in staffing needs, training demands, fear of emotional entanglement, and concern for missed learning opportunities.

**Discussion**—Continuity of nursing care is highly valued by parents of children with CCC in the PICU, but significant barriers to optimal delivery exist within the current critical care environment. Mechanisms for supporting nurses to deliver continuity of care are needed, as are alternative ways to help parents feel that all nurses caring for their child have the knowledge necessary to deliver safe and compassionate care.

### Keywords

child; chronic illness; continuity of care; pediatric intensive care unit

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Children with complex chronic conditions (CCC) are those with a health condition expected to last greater than a year (unless death occurs) that involves one or more organ systems, and requires care from specialty providers and likely hospitalization in a tertiary care center (Feudtner, DiGuseppe, & Neff, 2003). These children comprise a significant portion of the patient population and account for an even higher percentage of resource use at most children's hospitals in the United States (Simon et al., 2010). The complexity and severity of these patients' health conditions necessitate frequent interactions with the healthcare system, and coordination of care to ensure the effective and efficient transfer of information among a potentially large team of providers.

Parents of children with CCC consistently report a desire for continuity of care for their child across the care continuum. They value the individualized care that familiar providers deliver, and they have confidence in the quality of care provided by those who know their child best (Carter, Cummings, & Cooper, 2007; Espezel & Canam, 2003; Fisher & Broome, 2011). The care these parents are seeking is described by Haggerty and colleagues (2003) as relational continuity, or the development over time of trusting relationships between patients/families and individual care providers. Existing literature on the care of this population of children has emphasized the importance of relational continuity in the outpatient setting, citing the benefits to the child and family of care coordination through mechanisms such as the medical home (Hamilton, Lerner, Presson, & Klitzner, 2013; Turchi et al., 2009). However, relatively little attention has been given to the ways in which relational continuity occurs and the extent to which it is delivered in the inpatient setting, during periods of diminished health status, or disease exacerbation.

Relational continuity of care may be of particular relevance in the pediatric intensive care unit (PICU), given the changing nature of the patient population being served in this setting over the past 30 years (Namachivayam et al., 2010). Medical and technological advancements have shifted the composition of patients receiving care in the PICU, such that greater than 50% of these patients may have a diagnosis that qualifies as a CCC. These patients have longer lengths of stay and increased mortality than children with either noncomplex chronic conditions or with no chronic condition (Edwards et al., 2012; Namachivayam et al., 2012). They are also likely to have specialized care regimens that are best managed by a small group of providers with whom parents can develop rapport and collaborate to ensure optimal care for their child. As a result of the significant amount of

time that nurses spend coordinating and managing at the bedside, they are in a unique position to affect the continuity of care that a child and family receive while in the PICU.

Although limited, there is an emerging body of literature that has attempted to explore the phenomenon of relational continuity in pediatric inpatient settings. These studies have confirmed parental interest in and desire for continuity of care (Epstein, Miles, Rovnyak, & Baernholdt, 2013; Heller & Solomon, 2005); attempted to map continuity and its relationship to parent satisfaction using network analyses (Gray et al., 2010); and assessed the extent to which relational continuity of nursing care can be linked to patient outcomes (Siow, Wypij, Berry, Hickey, & Curley, 2013). Interestingly, Siow and colleagues (2013) failed to demonstrate a positive impact of relational continuity of nursing care on patient mortality, but this may be the result of confounding by indication that could not be adequately controlled for in the available data and is a finding in need of further exploration. Collectively, the available evidence suggests that parents highly value continuity of care, but relatively little is known about how nurses perceive relational continuity of care or what barriers exist to its delivery in the inpatient setting. This article contributes to the literature by addressing both of these issues.

## Methods

### Design

A qualitative study using situational analysis—a postmodern conceptualization of grounded theory informed by ethnographic methods (observation, interviews, and analysis of written materials)—was conducted to conceptualize best practices in the interactions that occur between nurses and the parents of children with CCC who are hospitalized in the PICU. The data described in this paper describe and problematize continuity of nursing care as a key element of these best practices and are one component of the analysis from this larger study.

Another component of this study has been published previously (Baird, Davies, Hinds, Baggott, & Rehm, 2015). The analysis reported in Baird et al. (2015) focused on identification of explicit and implicit rules in a PICU that affected receipt of care attentive to family needs and placed registered nurses in the position of serving as “rule enforcer” and facilitator of patient and family-centered care.

### Setting and Ethical Considerations

A single PICU in an urban, academic medical center in the western U.S. served as the site of data collection, and the first author collected all of the data. The first author also worked part time in the unit where data collected and, therefore, had insider status that allowed her access to the research setting and potential participants. This information was disclosed to all participants during the introduction to the study and again during the informed consent process, and the first author explicitly avoided approaching families for whom she had provided care prior to their participation in the study to avoid a sense of obligation to participate. Institutional Review Board approval was obtained prior to initiation of the study, and guidelines for the ethical conduct of research were upheld throughout the research process.

## Participants

Parents who were greater than 18 years of age, English speaking, and who had a child with a CCC with an anticipated length of stay of at least seven days were eligible to participate. They were informed that the purpose of the study was to understand best practices in parent/provider interactions in the PICU via interview and observation with both parents and nurses. The definition of CCC developed by Feudtner and colleagues (2003) was utilized to determine child eligibility. Nurses who worked in the PICU and who were identified as having a good relationship with the recruited families were also invited to participate in a single in-depth interview.

## Procedures

Parents of a child with a CCC who agreed to participate allowed the investigator to observe as they interacted with nurses who entered their child's room; these observations occurred in two-hour blocks at varying times of the day over the course of a week. At the conclusion of the week, a single in-depth interview was conducted with each parent. Recruitment of parents continued until saturation was achieved. During the course of the observations and through the interview process, parents identified one or two nurses who had cared for their child and with whom they felt they had developed a good relationship. These nurses were invited to participate in a separate in-depth interview, and all nurses who were approached to participate consented to do so. In order to achieve theoretical saturation, additional key informant nurses from the PICU also participated in one-on-one interviews. All interviews were transcribed verbatim by a professional transcription service and verified by the interviewer. Additional data were gathered from observation periods on the unit, during which time the investigator sat at each of the units' two central nurses' stations to observe workflow, patterns of movement, and formal and informal communication amongst hospital staff and visitors to the unit. Data collection additionally included participation in unit meetings and examination of relevant documents, including nursing care policies and educational and informational materials distributed to parents during the course of their child's stay in the unit.

## Data Analysis

As conceptualized by Clarke (2005), situational analysis provides qualitative researchers with a set of tools that help generate an understanding of the impact of context on complex social processes. Situational analysis de-emphasizes the reduction of data to a single core concept and focuses on "theorizing" rather than theory production. Given the complex nature of communication in the emotionally charged, high-stakes PICU environment, situational analysis provided an appropriate framework for data analysis. Studies using situational analysis begin the analytical process in much the same way that traditional grounded theory studies do—with coding of data. Accordingly, data analysis began with open coding of the transcribed interviews and observation field notes. The frequency of the code "continuity" in the early stages of coding helped to highlight this concept as one of critical importance to both parent and nurse participants, and it therefore became a focused area of discussion in subsequent interviews. Initial codes were later clustered into groups with similar themes, and memos about these themes helped to clarify emerging ideas and to

point to areas of conceptual weakness, where either more information (in the form of additional data) or more analysis was needed (Charmaz, 2006).

Constant comparative analysis (Corbin & Strauss, 2008) was ongoing throughout the analytical process. The data, first in raw form and later as codes, were compared and contrasted to highlight similarities and differences in meanings and practices. This analysis was particularly useful for highlighting differences in interpretations of continuity between parents and nurses, and helped to emphasize the problems surrounding delivery of continuity of care within this PICU setting. Organizational written documents (guidelines, policies, and educational materials) that addressed themes identified in the interview and observational data were reviewed to help clarify the institutional mandates under which healthcare providers were operating, and provide insight into the culture of the organization and its impact upon both parents and nurses. These texts were coded, and the codes were integrated into the existing coding structure that was established from analysis of the interviews and observation field notes. In an effort to better understand the context in which continuity of care was occurring and clarify spoken and unspoken positions in the data, situational maps and positional maps (Clarke, 2005) were constructed. These maps use the developed codes from previous stages of analysis to help highlight the highly contextual nature of interactions between parents and healthcare providers, and illustrate the complexity of the environment in which care was occurring. Situational maps attempt to capture the full scope of the process under study by first listing, and then categorizing, all relevant actors and elements of the process. Positional maps are used to identify and name positions in the data by constructing a conceptual continuum and identifying points along the continuum that are represented in the data. This activity helps to highlight both dominant and absent positions, and encourages questions about why certain positions are absent, underrepresented, or otherwise hidden. For example, positional maps representing the continuum of the concept of continuity were constructed for both parents and nurses. Parents who rejected the concept of continuity were absent in the data, lending support for the argument that parents consider continuity a best practice for nursing care delivery in the PICU.

To ensure rigor in the research process (Tobin & Begley, 2004), findings were discussed with members of the research team at various points throughout the analytical process. These discussions helped to advance the analysis by highlighting alternative explanations, challenging biases in the analysis, and identifying areas in need of further development (Whittemore, Chase, & Mandle, 2001).

## Results

A total of seven parents (five mothers and two fathers, all the parents of different children) and 12 nurses (all female) participated. Basic demographic information about these participants is found in Tables 1 and 2. Continuity quickly emerged as an issue of primary importance to both parents and nurses. Interviews with both groups indicated that continuity for PICU patients and families was inconsistently achieved, and that there was confusion among both parents and nurses about the continuity process. The following sections will highlight the discrepancy in perceptions between the two groups and the structural influences impacting delivery of continuity, which in turn will help to highlight why

continuity is inconsistently achieved in this setting. In this unit, “continuity” referred to the creation of a list of nurses who have cared for a patient and family, and who connected well with that family such that they were willing to continue providing care in the future. The list, which was a preprinted form, had spots both for parents to indicate nurses with whom they felt they connected and for nurses to indicate their willingness to serve on the continuity list for the child and family. When there was agreement between the two parties (parent and nurse), the nurse’s name became a part of the continuity list. These lists were maintained in a binder for reference by the charge nurse when nursing assignments were being made for the upcoming shift. Some charge nurses were more attentive to use of the lists than others, resulting in the inconsistency noted by both parents and nurses.

There was not a standard method for introduction of the continuity list to parents. Information about continuity was not, for example, included in the welcome packet that parents received upon admission to the unit. Exclusion of this topic from the welcome packet was a deliberate choice, as it was felt that continuity lists were not appropriate for every patient admitted to the unit. Any nurse could initiate a continuity list for a particular patient and family, and this most often occurred when the nurse either felt that the family could benefit from consistent nursing care, or when the nurse had established a connection with the family and wanted to continue working with them during the course of the child’s stay in the PICU. No one nurse or group of nurses assumed responsibility for organization and maintenance of the continuity lists once they were created. This lack of ownership meant that establishing and providing continuity was simultaneously everyone’s and no one’s responsibility, and it contributed to a sense of confusion about the process, which in turn fostered a lack of commitment to the goal of ensuring continuity for patients and their families.

### Parent Perceptions

Parent participants spoke frequently about the importance of continuity for their child’s care, often in the context of a desire for individualized care that was specifically tailored to meet the child’s unique needs and characteristics. This concept was captured in the related codes of “knowing my child” and “individualizing care.” Continuity was a mechanism by which this individualized care could be delivered because the longer that a nurse had cared for the child, the better he or she knew the child’s unique history, special traits, and customized care regimen. Having the child cared for by a nurse who was familiar to the parent created a sense of relief, as the parent could relax and trust that the child was receiving good care. In contrast, parents felt the need to remain vigilant when encountering a new nurse and to provide detailed information about the child, with the goal of ensuring that this new nurse was adequately prepared to care for the child.

... From like the first day you get to know them, they’re understanding your child —I know the first day’s a little shaky with every ... I’ll say, “Let me tell you exactly what’s been going on, because I’m not sure if you know everything. So [from] a mother’s perspective, you want them to know everything about my child; this is where we started, and this is where we’re at now. And then as the days go on ... it’s like, ‘Oh, the nurse has got it.’ [Participant M100]



Unfortunately, several of the parents had the experience of inconsistent nursing care, which created frustration when it happened frequently. Constantly meeting new nurses also required more effort on the part of the parent, who was already likely to be under a significant amount of stress due to the child's critical illness and uncertain health status.

It's a little frustrating when it's like a new nurse every day and they don't really get to know [Child] as well ... our nurse last night, she'd never had [Child] before, and most of the time, well lately, actually, it's been nurses that don't have her and then they'll have her for a day or two. After the second or third day it's fine because they're used to [Child] and I'm used to them, but it's just, you kind of just want the same people sometimes. It's tough because they, it takes so long for them to catch up on what's going on, whereas if it's just one or two days [the nurse has] been gone, it's a little easier ... [Participant M200]

Failure to provide continuity for a patient and family could ultimately undermine the trust that a parent had in the nurses caring for his or her child, as happened for one father:

... And the nurses switch off [referring to the assignment of a new nurse] every other day, so each one doesn't know what's going on. Every time they'd switch off on a nurse, it was me explaining what was going on, why they were doing this. I felt like I was basically the educator, telling them what to do. It got to the point where I was just hands on with everything, changing his diapers, changing his bed sheet, doing the suction thing ... [Participant F500]

The continuity list process was an additional source of frustration for some of the parents. When asked if her child had a continuity list, one mother laughed and stated that she had created one, but that it had been lost. She went on to say that it did not really matter because the list was not adhered to in a consistent manner. Another mother commented that her daughter was rarely cared for by the nurses on the continuity list, despite requests and inquiries on her part of the charge nurses who were responsible for making nursing assignments.

### Nurse Perceptions

There was significant variability in the commitment of the nurse participants to providing continuity of care to patients and families in the PICU. This variability did not map consistently to years of nursing experience, such that the midrange and experienced nurses were just as likely to have concerns about continuity as the newer nurses. Support for continuity was not a dichotomous "yes or no" answer, but rather occurred along a continuum, with some nurses expressing more support for the concept than others. For example, several of the nurses identified the mutual benefits of continuity, citing the ease with which care can be provided when the nurse is familiar with a child and that child's routine.

I think [continuity] makes a huge difference for the families and for the nurses, because especially with our really intricately detailed and fine-tuned care patients, you know how they prefer things and their family doesn't have to explain again, 'Actually, we really want the dressing this way' or, you know, those little things. So it just makes the day very natural and smooth. [Participant RN404]



Many of the nurses, however, expressed at least some concern about the concept of continuity. They identified a belief in the value of continuity for the families, but had reasons why they personally preferred to either not to be on a continuity list or to limit the number of times they were assigned to care for a particular patient and family. One reason cited was the need for variability in patient assignments. This group of nurses valued caring for a wide variety of patients and was concerned that serving on a continuity list would limit their exposure to different types of patients, or cause them to miss out on caring for a patient requiring complex ICU care. Technical skill acquisition and maintenance was an important focus for these nurses.

The only thing I [don't] like about continuity ... it stops your learning almost, because you're dealing with the same diagnosis, the same meds, the same everything, and so you get good at picking up subtle clues, that kind of stuff, but as far as progressing, I feel like it's better to have a variety of patients ... I don't think I want to be on anyone's continuity list because I want a variety of assignments. Unless the patient is really challenging ... then I would like to be on the continuity list because then I could keep up with the challenges and not have to worry about the ... frazzled feeling, because I know this patient ... and that would be good.  
[Participant RN402]

Another downside to continuity was the possibility of emotional entanglement: They worried that the relationship with the family could become "messy," that they would cross professional boundaries, or that they wouldn't be able to take a break from caring for the child and family when the need arose. One nurse indicated that continuity lists promoted the placement of nurses onto "pedestals," and she worried about "falling from the pedestal" and becoming a disappointment to the family. Another nurse stated:

With our chronic kids, I always end up really close to the families, just maybe because they're here for so long and I always have them. I don't know if that's easier with your communication or it makes it more difficult because you get in a relationship with them and then you want to filter what you're saying because you don't want to ruin the relationship. I feel like you get a friendship and that feels like, okay, now that we have this nice relationship, I don't want to say anything that's going to make you mad or hurt your feelings. I feel like it becomes more difficult that you would think. It's not easier. I think it's more difficult because you almost feel a connection and you don't want to hurt them because it hurts you.  
[Participant RN203]

### **Structural Influences on Continuity**

Observation of care delivery in the unit, along with informal conversations and review of staffing procedures, confirmed what parents had reported. There was inconsistent attention given to continuity, such that at times it was achieved and at other times it was significantly lacking. During observation sessions with the parents, which occurred at varying times over the course of a week, it was rare to see the same nurse on two consecutive days. There were several reasons for this lack of continuity. First, there was confusion amongst the staff (in particular the less-experienced nurses) about who was responsible for establishing and maintaining the continuity list, the appropriate timing of introduction of the list, and whether

it was nurse- or parent-driven. The lack of an identifiable guideline or policy about continuity meant that there was significant inconsistency and no authoritative source to consult for assistance when questions or concerns arose. Second, there were often competing staffing priorities, some of which took precedence over delivery of continuity to a particular patient or family. In a unit that trains a large number of nurses annually, the learning needs of new staff members were a constant source of concern. New graduate nurses, of which there were up to 20 per year, received 12 weeks of orientation. Discussions with charge nurses revealed that significant effort was taken to ensure that they received exposure to a wide variety of experiences and types of patients, even if that meant assigning an unfamiliar nurse orientee and his or her preceptor to the patient and family. Also, fluctuations in unit census necessitated either the canceling or reassignment of nurses to alternative duties—both of which had the potential to disrupt a family’s continuity. This accounted for several of lapses of continuity identified during observation sessions with families. Finally, there was significant scheduling flexibility for the nursing staff, such that it was not unusual for the nurse to work nonconsecutive days during the course of the week, limiting the continuity that a patient/family could achieve. Of note, two of the nurses interviewed indicated that they attempt to counteract this scheduling concern by deliberately scheduling themselves for consecutive days. They both felt it benefitted the patients and families to have the same nurse for up to three days in a row. This deliberate scheduling was not, however, observed to be a regular behavior among the nurses in the unit. Review of health system policies and guidelines related to the care of patients and families yielded no reference to the term “continuity,” which suggests that continuity was seen as an informal “nicety” and not as a standard of care.

## Discussion

These findings suggest that families’ desire for continuity of care competed with existing structures of care in the PICU environment to create a continuity process that worked only intermittently, providing an inconsistent continuity experience for children and their families. As nurses interfaced with the existing structure, they experienced confusion about how and when to provide continuity to patients and families. They also learned that avoidance of participation in the continuity process yielded enhanced opportunities for learning and variety in care assignments and could help to ensure emotional self-preservation. Thus, nurses contributed to the inconsistency in the continuity process, despite their awareness of the importance of continuity to patients and families.

The origins of the discrepancy between parental desire for continuity of care and the ability of nurses to provide this type of care are likely multifactorial. Nursing care in the PICU occurs in a complex and rapidly evolving environment that is focused on the provision of life-sustaining therapies and rapid stabilization of the critically ill child (Epstein & Brill, 2005); all of which may, at times, take precedence over relationship development and concern for relational continuity of care. Skill development was of primary importance in this PICU. Frequent reference was made to the skill mix of the nurses on a given shift, and significant attention was paid to matching patients with nurses who had the skill set necessary to provide optimal care. The skills of concern were, however, technical and not interpersonal. There were competency checklists for each of the technical skills that the

nurse was expected to perform, but relatively little oversight or instruction on how best to interact with patients and their families. This emphasis on technical skill was part of the culture of the unit, such that the nurses were socialized to identify as critical care nurses and to be concerned about acquisition and maintenance of skills. It was therefore acceptable to offer “exposure to a variety of patients” or “building my skills” as reasons for a nurse not to join patient continuity lists. Co-occurring with this emphasis on skill development was the frequent hiring and training of new staff members. The effort to provide learning experiences for these staff, at times, took precedence over continuity and again reiterated that the focus in the PICU was on technical skill delivery.

This focus on teaching and skill acquisition was not, of course, entirely misplaced. It was important that the nurses within the PICU had the skills necessary to care for critically ill children, and new staff members had to be trained to adequately staff the unit. The problem arose when the focus on skill mix and skill acquisition became so important as to overshadow the needs of the patients and families whom the nurses are there to serve, and when the discourse about skills is so accepted that nurses are unwilling or unable to provide the type of care that they know families want and need.

Also overlooked in this emphasis on acquisition of critical care nursing skills is that the care of long-term, chronically, critically ill children requires an additional skill set—one that is equal parts technical and interpersonal (Russell & Simon, 2014). Nurses caring for this growing population of children must be adept at providing care to patients with complex conditions and a high level of technology dependence, but they must also have the ability to work with families who face a unique and often ongoing set of challenges. These families often present to the PICU with expertise in caring for their child, and they want that expertise to be honored and valued (Graham, Pemstein, & Curley, 2009; Reeves, Timmons, & Dampier, 2006), something best done by a set of caregivers who can provide consistent care. Additionally, these families are often in the PICU because of a health crisis that may represent a worsening of their child’s condition, and they are likely to be dealing with the grief and loss associated with such an event. The nurse caring for these families must therefore be equipped not only to provide excellent technical care, but also to attend to the psychosocial needs of individuals who are likely to have experienced a multitude of traumatic events in the relatively short course of their child’s life and who face daily struggles related to their child’s care (Caicedo, 2014). Care of these children and their families, therefore, does require a highly skilled nurse, but the emphasis placed on acquisition of traditional critical care nursing skills may not fully prepare PICU nurses for the challenges they will encounter in caring for the current PICU population—which includes a significant proportion of children with CCCs. This mismatch between skill sets may also account for the high levels of nursing turnover observed in this unit; nurses who do not feel as though their skills are being adequately utilized, or who do not feel they have the right skill set for a particular practice environment, may be more likely to be dissatisfied with their job and seek alternate work environments.

Nurses’ concerns about emotional entanglement is perhaps the most troubling reason cited for not engaging in continuity and speaks to a larger issue of how nurses interact with and connect with patients and families, as well to the support nurses receive when working over

extended periods of time with a population of long-stay, chronically, critically ill patients. The focus on technical skill development overlooks the fact that these skills are being performed in the context of highly charged, emotional family situations that play out over extended periods of time in the PICU. The concern that relationships with the family will become messy or burdensome to the nurse indicates that these nurses lack the tools necessary to authentically engage with patients and families without becoming overinvolved or crossing professional boundaries. Nurses may lack both the training and institutional support necessary to optimally care for both these families and for themselves, and avoidant behavior can be one mechanism by which they cope with these challenging situations. This does a disservice to the patient and family, and it creates a dilemma for the nurse who knows that the family needs consistent care, but does not have the training or support necessary to meet the family's needs.

### Limitations

This study has several limitations. It was conducted entirely within a single PICU and therefore, reflects, only the opinions and experiences of the parents and staff members within that unit. It is likely that continuity of care is delivered differently in PICUs around the U.S., and it also, therefore, possible that the challenges to continuity identified within this paper are unique to this particular practice setting. Additionally, the sample of nurses interviewed was relatively homogenous: All of the nurse participants were female, and all but one were Caucasian. This homogeneity, while not reflective of the population of nurses in the county in which this data was collected, is reflective of the population of nurses employed in this particular PICU. It is likely, however, that the beliefs and opinions of male and/or non-Caucasian nurses are not adequately reflected in this analysis. The ethnicity of parents in this study is also not reflective of the country's population, and it is, therefore, possible that some viewpoints are overrepresented while others are underrepresented. The impact that these discrepancies have upon the issue of continuity of nursing care in the PICU is not known; further research on the topic is needed.

The first author's insider status could also be considered a limitation. This status afforded her access to both parent and nurse participants and enabled her to easily obtain all necessary documents and materials. It may, however, have also impacted the way in which she viewed and understood processes and procedures within the unit, creating an additional level of bias that an outsider to the environment would not have possessed. The research team remained attentive to this insider's status during the course of the analysis and attempted to review and reflect upon the findings with this status in mind.

### Conclusions

In spite of these limitations, the findings from this study indicate that delivery of the continuity of care desired by patients and families is a significant challenge for the field of pediatric nursing. The approaches taken thus far to address this concern have not adequately met the existing need. Given the current design of inpatient nursing care delivery, including the dominance of 12-hour work shifts and three-day work weeks, attempts at achieving continuity of care that are dependent on individual nurses may not be feasible. The existing focus on relational continuity of care may need to shift instead to an emphasis on

informational continuity, ensuring that the information that parents consider most critical for providers to understand about their child's care is communicated consistently among nurses, and that all providers have an understanding of not only the child's current clinical status, but also of the broader history and context of care and of the family's priorities. In doing so, nurses may help to create the continuity families are seeking by ensuring a safe environment in which every nurse who encounters the child and family is armed with the knowledge necessary to deliver the care families are seeking. Additional studies are needed to explore how best to facilitate this informational continuity of care, and to understand if this shift in focus helps to ensure high-quality, consistent care for patients and families while also attending to the needs of the nurses caring for them. This study likewise highlights the need for additional support for the emotional work of nursing. Nurses caring for families facing the ongoing crisis of their child's complex, chronic condition need a forum to review and reflect on their interactions with families, and they need to receive support, guidance, and education about how best to manage challenging family dynamics and their own emotions when working with such families. Methods for delivering this type of support should be identified and tested, again, with the goal of improving both care for patients and families and the work experience of nurses caring for them.

The work of caring for children with CCC and their families in the PICU is challenging and in need of focused attention—with particular focus given to the ways in which continuity of nursing care is delivered. Mechanisms are needed for meeting parents' stated desire to receive care from a knowledgeable group of nurses who understand and respect the unique attributes of their child's care, while at the same time attending to nurses' needs and the realities of current care delivery systems. Awareness of and adaptation to the context in which care is delivered will be the key to development of workable solutions that ultimately better meet the needs of children with CCC and their families.

## Acknowledgments

The authors acknowledge that the research described in this article was funded by an individual National Research Service Award from the National Institute for Nursing Research, Grant No. NIH-5F31NR012093, and an Institutional National Research Service Award from the Agency for Healthcare Research and Quality, Grant No. AHRQ-5T32HS00063-21.

The authors gratefully acknowledge Irwin Weiss, MD, Professor of Pediatrics, David Geffen School of Medicine at UCLA, for his assistance in the completion of this study.

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TABLE 1

## Parent Characteristics

Characteristic	<i>n</i>	(%)
Age of parent		
20–29	4	(57.1)
30–39	2	(28.6)
40–49	0	(0)
>50	1	(14.3)
Age of child (years)		
< 1	2	(28.6)
1–5	2	(28.6)
6–10	2	(28.6)
11–15	1	(14.3)
Parent gender		
Female	5	(71.4)
Male	2	(28.6)
Parent race		
White	5	(71.4)
Unidentified	2	(28.6)
Parent ethnicity		
Hispanic	5	(71.4)
Non-Hispanic	2	(28.6)
Parent education level		
Bachelor's degree	1	(14.3)
Some college	3	(42.9)
High school	3	(42.9)
Child's gender		
Male	4	(57.1)
Female	3	(42.9)
Child's primary condition		
Gastrointestinal	3	(42.9)
Genetic disorder	2	(28.6)
Seizure disorder	1	(14.3)
Heart disease	1	(14.3)

Note. *N* = 7. From Baird et al. (2015). Copyright Elsevier, Inc. Used with permission.

TABLE 2

## Nurse Characteristics

Characteristic	<i>n</i>	(%)
Age (years)		
20–29	6	(50.0)
30–39	3	(25.0)
40–49	1	(8.3)
50–59	1	(8.3)
> 60	1	(8.3)
Gender		
Female	12	(100.0)
Male	0	(0.0)
Race		
White	10	(83.3)
Black	1	(8.3)
More than one race	1	(8.3)
Ethnicity		
Hispanic	0	(0.0)
Non-Hispanic	12	(100.0)
Nursing education (highest)		
MSN	1	(8.3)
BSN	9	(75)
Associate	2	(16.7)
Experience (years)		
<2	4	(33.3)
2–5	3	(25)
6–10	2	(16.7)
11–20	0	(0)
>20	3	(25)

Note. *N* = 12. From Baird et al. (2015). Copyright Elsevier, Inc. Used with permission.