Pediatric Intensive Care Hospitalization: Sibling Experience

Karla Abela

University of Texas Health Science Center at Houston-Cizik School of Nursing

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PEDIATRIC INTENSIVE CARE HOSPITALIZATION: SIBLING EXPERIENCE

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN
NURSING THE UNIVERSITY OF TEXAS
HEALTH SCIENCE CENTER AT HOUSTON CIZIK SCHOOL OF NURSING

BY
KARLA M. ABELA, PhD(c), MSN, RN, CCRN-K, CPN

MAY, 2020
To the Dean for the School of Nursing:

I am submitting a dissertation written by Karla M. Abela and entitled "Pediatric Intensive Care Hospitalization: Sibling Experience." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing.

Geri LoBiondo-Wood, Ph.D., RN, FAAN
Committee Chair

We have read this dissertation and recommend its acceptance:

[Signatures]

Accepted
Dean for the School of Nursing
Acknowledgements

I am forever grateful for the guidance and support provided to me by the faculty and staff of the School of Nursing. My confidence in my ability to do research has grown tremendously over the years because of the willingness of others to push me along the path. Every meeting with Dr. Wood ended with a feeling of renewed excitement about my research. With her constant encouragement and coaching, I always walked away feeling like I can accomplish the next milestone. She was my coach in personal and professional matters; I feel prepared to grow my program of research because of her. Dr. Casarez’s and Dr. Kaplow’s gentle guidance developed my ideas and made me more passionate to study the stories of the children I serve in my practice. Every faculty and staff member at the School of Nursing that nudged me in the best direction – I only hope to be as influential and inspiring to others as they all have been to me.

I am deeply humbled to have received the generous support of the American Nurses Foundation and the Southern Nursing Research Society. This study would not have been successful without their funding.

To all of my colleagues who inspire me every day to look for new opportunities to care for our patients and their families: Thank you for believing in me. I cherish all of our conversations and your words of support. I could not have completed this program without the support of my husband and my three boys. They inspire me daily to help other families who are not as fortunate to have our health, support system, and love for one another. I am reminded of the importance of family, and I am thankful for their unconditional love.
Abstract

Prior research on the impact of pediatric intensive care unit (PICU) hospitalization on families have been predominantly focused on the parents, yet siblings who visit the ill child in the PICU environment remain understudied. The aim of this study was to describe the experiences of 9- to 17-year-old siblings of acutely critically ill or injured children. A generic qualitative approach using one-to-one interviews, observations, and clinician notes was used to gain an understanding of the experience of siblings who visited the PICU. Qualitative analytic methods were used to analyze the data. The findings from 16 siblings (mean age 6.3 years) indicated that visiting their critically ill sister or brother in the PICU can be emotionally distressing. Three major themes and nine subthemes were identified from the data. Predominant sibling stressors include: Pre-illness stressors, ICU environment, parent stressors, appearance of ill child, and uncertainty. Siblings coped by distraction, praying, reflecting on their bond with the ill child, and accepting support from close friends, family members, and the community. Sibling physical, emotional, and social health were impacted. Siblings experienced fear, worry, and hope while visiting their critically ill sister or brother in the PICU. Future research should fully incorporate the sibling perspective when designing interventions to mitigate the effects of PICU visitation on healthy children.

Keyword: pediatric intensive care unit, family, sibling
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Summary of Study

The research protocol "Pediatric Intensive Care Hospitalization: Sibling Experience" was approved by the Baylor College of Medicine Institutional Review Board and by the Committee for the Protection of Human Subjects (CPHS) of The University of Texas Health Science Center at Houston on September 3, 2019. The experiences of parents of critically ill children have been previously examined yet the impact of the hospitalization on the healthy sibling is unknown. The aims of this generic, qualitative study was to describe the experience of 9-17 year old siblings of critically ill or injured children during their visit to the pediatric intensive care unit (PICU). Recruitment began on September 4, 2019 and ended on January 24, 2020. One-to-one interviews with siblings were conducted. Interviews were audio- and video-recorded. Siblings were also observed during their visit with the ill child. Data saturation and redundancy were reached at 16 siblings. One protocol amendment was submitted and approved by the IRB. The approved amendment allowed for the recruitment of siblings of PICU patients who have been in the PICU for ≥ 2 days. Eligibility criteria was modified to length of stay ≥2 days from ≥ 7 days in order to capture the experience of siblings of children across the range of severity of illness.

Interview transcripts were coded, analyzed, and reviewed by the committee. Three major themes and nine subthemes were identified. Siblings shared stressors related to the ICU environment, the appearance of their brother or sister, the uncertainty of the situation, and their parents' stress. Coping strategies utilized by the siblings included distraction, reflection on sibling
relationship, social support, and spirituality. The sibling experienced emotions such as fear, worry, sadness, and guilt. Siblings felt supported by their immediate family members, friends, and local community. Siblings shared being excluded in information-sharing and decision-making with the clinical team.

Findings indicated that siblings felt supported by their immediate family members, friends, and local community. Siblings shared being excluded in information-sharing and decision-making with the clinical team.

Findings indicated that siblings The findings revealed a significant albeit weak correlation between uncertainty and health literacy. Education level was a significant predictor of uncertainty and health literacy. Significant differences in uncertainty levels were found through the different phases of the pancreatic cancer experience. Sample homogeneity restricted inferences and generalizability on effects of race/ethnicity. A manuscript was written describing the background and significance of the research questions along with methods, results, and implications for future research. Appendices A-I contain supplemental information from the study including the IRB and CPHS approval documents, MDACC protocol and IRB-approved amendments, study consent form, study instruments, and human subjects research training certificates.
PEDiatric intensive care hospitalization: sibling experience

A dissertation proposal submitted in partial fulfillment of the requirements for the degree of doctor of philosophy in nursing University of Texas health science center at Houston Cizik school of nursing

By Karla M. Abela, MSN, RN, CCRN-K, CPN

June, 2019
Specific Aims

Pediatric critical care units have become more inclusive of families, yet the impact of critical illness or injury on healthy sibling visitors is not known. Adoption of family-centered care delivery models in pediatric intensive care units (PICUs) has resulted in open visitation guidelines inclusive of all family members, but knowledge about the unintended consequences of increased sibling presence at the bedside is lacking (Foster, Mitchell, Young, Van, & Curtis, 2018; Hagstrom, 2017; Meert, Clark, & Eggly, 2013). Hospitalization of a child in the PICU has been associated with the development of chronic psychiatric disorders in parents after discharge from the PICU (Foster et al., 2018; Stremler, Haddad, Pullenayegum, & Parshuram, 2017). Although the effects of pediatric acute critical illness and injury on the parents have been assessed, the experience of healthy children who visit their critically ill or injured siblings in the PICU has not been described. Currently, no standardized approaches are used to prepare siblings for their PICU visit. Therefore, there is an urgent need to describe the sibling's perception of acute critical illness or injury and the PICU hospitalization. Not meeting this need potentially places the sibling at risk for subsequent negative psychological, physical, and social outcomes (e.g., acute stress disorders, post-traumatic stress disorder, impaired social functioning) (Terp & Sjostrom-Strand, 2017) and increases the overall burden of critical illness and injury on the family unit (Coa & Pettengill, 2011).

The overall objective of this study is to describe the experience of the sibling of a child admitted to a PICU for acute critical illness or injury. The
rationale that underlies the proposed research is that once the sibling experience has been described, quantitative studies can be conducted to further explore concepts and ultimately develop and evaluate interventions to prepare the sibling for a visit to the PICU. This study will be conducted in the largest PICU in the United States that cares for a diverse patient population. This study will seek to answer the following research question: What is the experience of the sibling(s) who visits an acutely critically ill or injured child? The specific aim of this study is to describe the experience of 9- to 17-year-old children visiting an acutely critically ill or injured brother or sister in the PICU.

Although the burden of critical illness or injury on the family unit has been described, siblings of acutely critically ill or injured children in the PICU are understudied. Family-centered care delivery models within the pediatric critical care environment have allowed healthy children to visit the ill child, yet the exposure of healthy children to potentially traumatizing experiences associated with sibling hospitalization is not well understood. This research will lead to an understanding of the experiences of siblings during the PICU hospitalization. At the conclusion of this study, the findings will provide insight into the needs, stressors, coping strategies, and overall impact on the well-being of siblings of acutely critically ill or injured children in the PICU.

Significance

Despite calls for increased sibling presence in the PICU (Davidson et al., 2016; Meert, Clark, & Eggly, 2013; Rozdilsky, 2005), the effects of the intensive care hospitalization on siblings are not well understood. Sights and sounds in the
PICU environment (Aamir, Mittal, Kaushik, Kashyap, & Kaur, 2014; Coa & Pettengill, 2011; Colville & Gracey, 2006; Colville et al., 2009; Dahav & Sjostrom-Strand, 2017; Majdalani, Doumit, & Rahi, 2014; Pooni, Singh, Bains, Misra, & Soni, 2013; Terp & Sjostrom-Strand, 2017) and witnessing medical procedures (Aamir et al., 2014; Colville et al., 2009; Jee et al., 2012; Pooni et al., 2013) are significant stressors for parents of critically ill or injured children. Parents of critically ill or injured children who require admission to the PICU experience a range of negative physical, emotional, and psychological responses that may be identifiable as early as 24 hours after admission and may persist years after PICU discharge (Colville & Pierce, 2017; Ehrlich et al., 2005). As a result, parents develop symptoms of anxiety (Bronner et al., 2009; Needle, O’Riordan, & Smith, 2009; Stremler, Haddad, Pullenayegum, & Parshuram, 2017), depression (Bronner et al., 2009; Stremler et al., 2017), post-traumatic stress disorder (Bronner et al., 2010), and psychiatric distress (Ehrlich et al., 2005). The impact of children’s critical illness or injury on their parents is well documented, but the experience of healthy siblings is unknown.

Two studies reflectively assessed siblings’ response to critical illness or critical injury. McMahon, Noll, Michaud, and Johnson (2001) assessed depressive symptoms, self-concept, and behavior in siblings (N=11) of children with traumatic brain injury post-PICU hospitalization. Kleiber, Montgomery, and Craft-Rosenberg (1995) conducted a qualitative study to learn about the information needs of siblings of children in the PICU (N=8) and neonatal intensive care unit (N=2) during
admission. Neither of these studies sought to learn about the experiences of siblings visiting the PICU. To date, a qualitative account of the siblings’ experiences within the PICU remains undescribed.

Siblings who visit their sister or brother in the PICU are exposed to the same sights and sounds in the PICU as their parents; therefore, siblings may be at risk for developing similar negative reactions. Although siblings are exposed to the PICU environment and bear witness to the pain and suffering of the critically ill or injured child and their parents, the impact of hospitalization in the PICU on the sibling is not well understood. Therefore, the sibling experience, as told by the sibling, must be explored.

This study will focus on the experiences of siblings of acutely critically ill or injured children. *Acutely critically ill or injured children* are those with no known history of PICU hospitalization or chronic illnesses. Unlike siblings of chronically ill children or those with prior PICU admission, siblings of acutely critically ill or injured children have not been exposed to the chronic stressors that are inherent in chronic illness (Hamlett, Pellegrini, & Katz, 1992), and they have had no prior exposure to the PICU environment that may have impacted their reactions to critical illness or critical injury.

A previously identified theoretical framework will be used in the present study to provide direction during data collection (Corbin & Strauss, 2008). The family adjustment and adaptation response (FAAR) model (Figure 1) describes how a family or family member may respond to daily hassles and crisis situations using available resources and existing capabilities. To complement the data that
will emerge from the sibling interviews, the FAAR model (Patterson, 1988) will be adapted to provide direction in the development of the interview questions that will be used during the initial phase of data collection. Initial questioning will seek to identify the stressors, strains, coping strategies, and support needs of the siblings. The researcher will remain open to new concepts that are not included in the FAAR model. Concepts that are in the FAAR model that do not fit the data will be abandoned (Corbin & Strauss, 2008).

Figure 1. Family Adjustment and Adaptation Model.

The proposed research is expected to contribute to the understanding of the experience of the acutely critically ill or critically injured child’s sibling by describing the healthy sibling’s experience. Attainment of the study objective will lead to further testing of relationships between identified concepts, subsequent testing of methods to identify clinically important difficulties or factors that may influence untoward effects in siblings, and, later, testing of interventions to prevent or mitigate negative effects of critical illness or critical injury on the sibling.
Innovation

The opportunity for siblings of acutely critically ill or critically injured children to visit the PICU is supported by the literature, yet an understanding of the impact of this opportunity is missing. Given the recent inclusion of siblings into the PICU environment, this study will provide insight into the siblings' experience during the ICU admission. This insight may lead to the development of tested interventions to prepare siblings for a visit to the PICU.

Approach

Introduction. The experience of siblings of acutely critically ill or critically injured children is unknown. The objective of this study is to describe the experience of siblings of an acutely critically ill or critically injured children, as told by the siblings. Qualitative methods will be utilized to learn about the siblings’ experiences in the PICU. An understanding of the siblings’ experiences will be developed using data collected from interviews, observations, and field notes. The justification for this approach is that no prior studies describing the experiences of siblings during a visit to the PICU have been conducted. Variables that may explain the siblings’ experiences from the perspective of the sibling, must first be identified. It is my expectation that after achieving this aim, a deeper understanding of the overall impact of PICU hospitalization on siblings will be gained.

Design. This study will use a generic, qualitative approach in which one-to-one interviews, observations, and clinician notes will be analyzed to help
identify concepts and themes described by siblings of acutely critically ill or injured children.

**Setting and Sample.** The study site will be conducted within a 693-bed, level 1 trauma-designated, academic freestanding children’s hospital in the southwest United States. The hospital system consists of a main facility in the Texas Medical Center, two community hospitals, and primary care and urgent care facilities. The facility is ranked number four overall in the country by *U.S. News & World Report* (2018). Children admitted to acute care patient units are grouped by pediatric subspecialty: pulmonology, endocrinology, gastrointestinal transplant, gastroenterology, surgery, trauma, neurology, neurosurgery, hematology, oncology, bone marrow transplant, cardiology, and women’s services. The facility has three intensive care areas: neonatology, cardiovascular, and general pediatric (study site).

The study setting is an 84-bed PICU with an average daily census of 67. The PICU team cares for children 3 days to 18 years old with a variety of critical illnesses and injuries. Children are admitted to any one of the surgical, medical, or transitional ICUs, depending on their diagnosis and acuity. Common diagnoses include respiratory failure, sepsis, pulmonary hypertension, status epilepticus, solid organ transplant, liver failure, and trauma. Children are also admitted to the surgical ICU for postoperative recovery.

Parent presence at the bedside is encouraged 24 hours a day, 7 days a week. After being screened by a child life specialist, siblings 3 years and older may visit the ill child in the PICU for two 30-minute periods per day.
The study sample will comprise children 9-17-years old who are the siblings of children hospitalized ≥ 7 days. This is approximately the age when a sibling is able to examine his/her experiences in response to the PICU admission and willing to share his/her experiences with an interviewer (Morse, 1991). This is also the age period of cognitive development when the child is able to think of two, sometimes opposing, emotions simultaneously (Fischer & Bullock, 1984). Based on the investigator’s experience, 7 days from admission to the PICU is when the family may be able to recall and reflect on the events surrounding admission. Thus, the impact of the PICU admission can be comprehensively assessed. Other inclusion criteria include the absence of a developmental delay as reported by a parent and ability to speak and understand English.

Siblings of children with a chronic illness or a history of PICU hospitalization and siblings of actively dying or deceased children will be excluded from this study. Sibling reactions to the current PICU admission may be affected by chronic stressors associated with chronic illness, malignancies, and previous PICU hospitalization (Hamlett, Pellegrini, & Katz, 1992; Woodgate, Edwards, Ripat, Rempel, & Johnson, 2016). Similarly, siblings of actively dying children, defined as hours or days from imminent death with declining physiologic functions (Hui et al., 2014), and bereaved siblings (Brooten & Youngblut, 2017; Russell et al., 2018) have unique experiences related to grieving and death.

Initial sampling will begin via a purposive sampling technique to identify siblings who are information-rich based on the investigator’s clinical experience (Patton, 1990; Sandelowski, Holditch-Davis, & Harris, 1992). Information-rich
subjects are those from whom the investigator can learn the most (e.g., siblings who may have witnessed medical procedures being performed on the ill child) from (Patton, 1990). Theoretical sampling will follow, whereby emerging data and concepts from ongoing analysis will be used to identify subjects who may best contribute to an understanding of the sibling’s experience (Corbin & Strauss, 2008; (Moser & Korstjens, 2018). As new data emerge and a line of inquiry is evident, new participants will be recruited, and interview questions will be amended. As this is a generic qualitative study, informational redundancy and data saturation are expected to be reached between 20 and 30 participants (Moser & Korstjens, 2018).

**Procedures.** After approval from the Institutional Review Board is obtained, participants will be recruited using two methods: 1) a flier with information regarding the study will be posted in the family lounge outside of the PICU, and 2) the investigator will screen all patients currently in the PICU daily. An automated daily report of admitted PICU patients with who have been hospitalized for \( \geq 7 \) days will be sent to the investigator’s email address. The investigator will review the electronic medical record to further screen for chronic conditions and malignancies. The clinical team will be consulted to determine if patient is actively dying. Parents of patients who have been hospitalized \( \geq 7 \) days that do not have chronic conditions, and are not actively dying will be approached for further screening. All effort will be made to approach families of patients who meet inclusion criteria outside of the patient’s room. If parents are not available
outside of the patient’s room, a time to discuss the study in a nearby consult room or in the family lounge will be negotiated with the parent(s).

Parental consent will be obtained for eligible siblings. Parents will be informed that siblings will be interviewed in the absence of the parents. Parents will be given the opportunity to consent for their child (sibling) to be audio- and video-recorded or audio-recorded only. Assent will be obtained from the sibling. A copy of the parental consent and sibling assent forms will be given to the family. After obtaining parent consent and sibling assent, the parent(s) will be asked to complete a demographic questionnaire for the sibling prior to the interview.

A time to conduct the interview will be negotiated with the parent and sibling. If a sibling is to visit at a later date or time, the parent will be given the investigator’s contact information so that the parent can notify the investigator when the sibling visits.

Participant observations will be performed during the sibling’s visit to the PICU, immediately before the interview. Broad descriptive observations will be made noting the sibling’s response to people and the environment including emotions and nonverbal cues. More focused and selective observations will be made as needed (Spradley, 2016).

The interview will be conducted in a private consult room within the PICU but away from the patient’s room. One-on-one interviews will be conducted with each sibling participant using the grand tour approach. Probing questions will be used as data emerge. The interview guide may be modified as the series of
interviews progress. Interviews will be audio-recorded or audio- and video-recorded, and then transcribed by a professional transcription service. The investigator will view video-recorded interviews and note observations in a journal. The research team will clarify interpretations with the sibling, parent(s), or clinical team members as needed.

The interview guide including probing questions (Appendix B) will be based on the concepts of meaning, demands, and capabilities of the FAAR Model (Patterson, 1988). The questions will be used to explore the stressors, daily hassles, demands, and coping strategies related to the PICU visit, as perceived by the sibling. Key questions will include the following: (a) Tell me about your brother or sister’s illness; (b) Tell me what it’s like to visit your brother/sister in the hospital room; (c) Tell me about what you would be doing right now if your family wasn’t in the hospital; (d) When you visit your brother or sister, do you need help from your parents or the nurses/doctors with anything?; (e) Do you have any worries or concerns about your brother/sister?; and (f) Tell me about the people and things that you think really helped you and your family while your brother or sister is here. The full protocol for approaching and interviewing the parent(s) and sibling is provided in Appendix C. In addition, demographic data will be collected on all participants (see Appendix D).

Clinician notes in the ill child’s medical record will also be reviewed for any references to the sibling’s experience during the visit to the PICU. All observations will be recorded via field notes. Recruitment and data collection will continue until data saturation/redundancy is reached.
**Analysis Plan.** Data analysis will begin after the first interview and will occur after each subsequent interview. Two cycles of coding will be performed during analysis.

During the first cycle, initial, in vivo, and process coding methods will be used concurrently. Initial or open coding involves breaking down and categorizing the data (Corbin & Strauss, 2008) into tentative parts (Saldana, 2016). In vivo coding uses the actual words of the child, providing the investigator a deeper understanding of her or his experiences. Process coding will be used to code behaviors and actions described in the field notes and, observed during the interview. Process codes will also be used to identify potential relationships between concepts identified in the data (Saldana, 2016).

During the second cycle, focused coding will be used to categorize data, axial coding to reorganize and link the categories, and theoretical coding to identify a central theme (Saldana, 2016). During focused coding, data will be organized into categories and subcategories. These categories will be compared across other interviews to assess transferability. Axial coding involves linking the categories developed during focused coding, developing more elaborate concepts. These concepts will then be linked further during theoretical coding to develop assertions or a theory (Saldana, 2016). Data will be managed using ATLAS.ti, a qualitative data analysis and research software (ATLAS version 8 Windows, 2018).

Interview transcripts will then be analyzed using Linguistic Inquiry and Word Count (LIWC), a computer text analysis program that analyzes the style
and content of written or spoken text to evaluate the psychological state of the writer or speaker (Tausczik & Pennebaker, 2010). Using LIWC to evaluate word use, the investigator may gain insight into the child’s emotional state, social relationships, and attentional focus, which can indicate how the sibling may be processing their visit in the PICU.

Triangulation and comparison of data from field notes, interviews, and clinician notes will ensure deeper, generalizable findings (Crabtree & Miller, 1999; Green & Thorogood, 2014). Analytical memos noting insights, analytic decisions, and personal reflections will be kept during data analysis and reviewed by the investigator and dissertation committee members periodically. A compilation of codes will be kept as a record of emergent codes and will be reviewed by the investigator and the dissertation committee members as coding progresses. These processes facilitate reflexivity, extraction of meaning from the data, and communication between the investigator and the dissertation committee members (Saldana, 2016).

**Study Limitations.** Parents or legal guardians, may be interested in the study but hesitant to have the sibling participate in the study because the family’s current situation may be too distressing. In this case, alternative dates and times for the sibling interview will be offered to the parent or legal guardian.

Due to the unpredictable nature of patient admissions to the PICU, siblings who are identified as information-rich or those who may contribute to an emerging concept or theme, may not be available to be recruited. For example, a child who required cardiopulmonary resuscitation and now extracorporeal
membrane oxygenation (ECMO) may not be present during the study period. In this case, the investigator will hold on this line of inquiry and proceed with subsequent interviews until an opportunity to recruit from such a family arises.

The sample for this study is comprised of siblings who are 9-17 years old, and English-speaking. Siblings who are younger than 9 years old or older than 17 years old may have a different perception of their experiences in the PICU. Similarly, while the demographics of the PICU patient population and their families is diverse, it is possible that non-English speaking siblings may experience the PICU hospitalization differently than English-speaking siblings. Future studies within the investigator’s research trajectory will explore the experiences of siblings of various ages, developmental stages, and cultures/languages.

**Ethical Considerations**

**Potential Discomfort.** The sibling may experience uncomfortable emotions such as fear, sadness, and anger during the interview. The investigator will remind the sibling that she or he may: a) pause and take a break during the interview, b) return to the room with the parent(s) and reschedule for another time, or c) withdraw from the study. The sibling will be assured that pausing or withdrawing from the study will not affect the care of the ill child. After returning to the room, the parent(s) and sibling will be offered a visit from the Child Life Specialist.

**Risk for loss of confidentiality.** There is a potential risk for loss of confidentiality should the sibling disclose information that may indicate severe
distress, potential presence of mental health issues, or risk of self-harm during the one-to-one interviews. During the consent and assent process, and prior to the interview, the investigator will disclose that relevant interview data may be disclosed should the investigator determine that the sibling is at-risk for self-harm.

If the child is experiencing signs and symptoms of anxiety, depression, anticipatory grief, or if the investigator becomes concerned about the mental health of the sibling, a brief conference with the parent(s) will be requested by the investigator immediately upon completion of the interview. During the conference, the investigator will provide the family with the contact information for the hospital’s Trauma and Grief Center, where the sibling(s) can be evaluated further by the clinicians in the Trauma and Grief Clinic.

Siblings who are at imminent risk for self-harm will be escorted back to the patient’s room immediately after the interview. The parent(s) and the sibling will be referred to the Emergency Center within the hospital for further evaluation and care. Only data relevant to the concern will be shared with the parent(s)/legal guardians, social worker, and providers.

**Facilitate Coping.** The one-to-one interviews will provide the siblings with the opportunity to discuss their feelings and concerns with the investigator. Siblings may feel relief at the conclusion of the interview and they may feel better prepared to cope with future stressors. They may also have a better understanding of their support network, thus enhancing their coping resources.


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Appendix A

Eligibility Screening Form
To be completed daily: This screening form is to be completed for all patients that meet inclusion criteria.

**DATE:**

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*Note: a. PICU LOS is determined using the report generated from the electronic medical record. Patients with an ICU LOS ≥ 7 days will be included in the report. b. Children who are actively dying are hours or days from imminent death with declining physiologic functions.*
Appendix B
Interview Guide
1. **Tell me about what you know about your brother or sister’s illness?**
   a. What have you heard about why your brother or sister is in the hospital?
   b. Where did you hear that from?
   c. What do you think that means [being sick]?
   d. How does that make you feel?
   e. How do you feel when your mom or dad is here with your brother or sister?

2. **Tell me what it’s like to visit your brother/sister in the hospital room.**
   a. How did it make you feel to see your brother/sister in the hospital room?
   b. What did you see/hear/smell/touch? How did these make you feel?
   c. Tell me about what your brother or sister’s hospital room looked like?
   d. What did your brother or sister look like? Is this different from how they usually look? How did that make you feel?
   e. Other people have told me that the tubes and lines are scary. How do these make you feel?

3. **Tell me about what you would be doing right now if your family wasn’t in the hospital.**
   a. How does it make you feel to not be doing these things?

4. **When you visited your brother or sister did you need help from your parents or the nurses/doctors with anything?**
   a. Other kids have needed things like food, a place to stay, or things keep them busy. Tell me about what things you needed.
   b. Other kids have said that they needed someone to talk to about their feelings. Did you need to talk to someone during your visit?
   c. How did it make you feel when you weren’t able to get these things?
   d. What are some things that you needed from your mom or dad? From other family members? From the people that worked in the PICU?

5. **Do you have any worries or concerns about your brother/sister?**
   a. Do you have any questions about what’s happening to your brother/sister or what the doctors and nurses are doing?

6. **Let’s talk about things that made you feel good or people that helped you and your family while your brother or sister is in the hospital. Tell me about the things that you think really helped you and your family while your brother or sister is here.**
   a. What was that like?
   b. Who/what helped you the most? What did they do that was helpful to you and your family?
   c. Tell me about things that you wish you got help with.
Appendix C

Protocol
1. The screening form in Appendix A will be used to screen families for eligibility. The screening form will be stored in a locked filing cabinet in the investigator’s office. The investigator’s office is within an office suite accessible only by the nursing leadership team. The investigator’s office door within the office suite is locked.

2. The investigator will review patient lists in the electronic medical record for floors 9 through 12 in the PICU daily. Information regarding length of stay and presence of chronic conditions or malignancies will be determined.

3. The investigator will contact the bedside nurse or provider to inquire if the patient is actively dying.

4. If the patient meets LOS criterion, does not have a chronic condition or malignancy, and is not actively dying, then the parent will be approached for further screening.

5. The investigator will preferably approach the parent(s) outside of the patient room to participate in the study. The parent(s) will be asked about the following inclusion criteria:

   a. presence of a sibling who is 9-18 years old,
   b. patient without history of previous PICU admission,
   c. sibling understands and speaks English,
   d. sibling is not developmentally delayed
   e. sibling visit to the PICU is planned

6. Families that meet the inclusion criteria will be consented to participate in the study.

   a. The investigator will ask the parent(s) to meet in a consult room or parent lounge.
   b. Information about the study purpose and procedures will be provided to the parent(s).
   c. The parent(s) will be asked to sign the consent form.
   d. A copy of the consent form will be given to the parent(s).

7. Consent forms will be stored in a locked filing cabinet in the investigator’s office.

8. After parental consent is obtained, a time to observe and interview the sibling during the visit to the PICU will be negotiated.

9. A parent will be asked to complete a demographic questionnaire (Appendix E) at the time of consent. The demographic questionnaire will be stored in a locked filing cabinet in the investigator’s office.

10. A participant code will be assigned at the time of the interview, and will be noted on the demographic questionnaire. The 4-character participant code will be assigned as follows:

    a. First character - first letter of city of birth,
    b. Second character - first letter of month of birth,
    c. Third character - last digit of year of birth,
    d. Fourth character - first letter of PICU patient’s first name

11. During the time of the PICU visit, the investigator will obtain sibling assent prior to observing the sibling in the patient’s room.
12. The investigator will record field notes in a study journal. The study journal will be kept in a locked filing cabinet in the investigator’s office.

13. The parent will be informed of the location of the consult room and the approximate time that the interview will conclude. The sibling will be escorted to the consult room for the interview.

14. The investigator will conduct the interview.

15. Upon conclusion of the interview, the sibling will be escorted back to the patient’s room and a gift card will be given to the parent(s).
Appendix D

Demographic Questionnaire
This questionnaire is to be completed by a parent after consenting to participate in the study.
Participant Code: ____________________
Sibling gender (please circle): Male Female
Sibling age: __________
Sibling race (please circle): White Hispanic Non-Hispanic Black Asian Other
Letter to the Editor

Dear Dr. First,

I am writing to you in regards to a manuscript we have prepared entitled *Pediatric Intensive Care Hospitalization: Sibling Experience*. The paper describes the findings of a descriptive, qualitative study conducted to explore the experience of siblings visiting a child admitted to the pediatric Intensive Care Unit (ICU). The impact of visiting a critically ill brother or sister has not been studied. Our findings indicate that siblings are physically, socially, and psychologically impacted by stressors in the PICU environment, the appearance and acuity of the sibling, the uncertainty of critical illness, and perceptions of parental stress.

I believe the manuscript is relevant for PEDIATRICS as the siblings of children admitted to the PICU are exposed to stressors that are unique from the general, non-intensive care environment. Our findings can be used to further suggest areas of study in this population including the testing of interventions to support this vulnerable population.

We would appreciate your thoughts if you might consider this work for publication. If so, we would be more than happy to submit.

Thank you for your consideration,

Karla Abela PhDc, MSN, RN, CCRN-K, CPN
University of Texas Health Science Center at Houston, Cizik School of Nursing
Pediatric Intensive Care Hospitalization: Sibling Experience

Introduction

Pediatric critical care units have become more inclusive of families, yet the impact of critical illness or injury on healthy sibling visitors is not known. Adoption of family-centered care delivery models in pediatric intensive care units (PICUs) has resulted in open visitation guidelines inclusive of all family members, but knowledge about the unintended consequences of increased sibling presence at the bedside is lacking (Foster, Mitchell, Young, & Curtis, 2019; Hagstrom, 2017). Hospitalization of a child in the PICU has resulted in negative physical, psychological, and social impacts in parents (Abela, Wardell, Rozmus, & Wood, 2020). Although the effects of pediatric acute critical illness and injury on the parents have been assessed, the experience of healthy siblings who visit their critically ill or injured siblings in the PICU has not been described.

Despite calls for increased sibling presence in the PICU (Davidson et al., 2017; Meert, Clark, & Eggly, 2013), the effects of the intensive care hospitalization on siblings are not well understood. Sights and sounds in the PICU environment and witnessing medical procedures are significant stressors for parents of critically ill or injured children. Parents may develop symptoms of anxiety, depression, and post-traumatic stress disorder. Parents reported symptoms of anxiety (23.4% - 60%) (Bronner et al., 2009; Needle, O’Riordan, & Smith, 2009; Stremler, Haddad, Pullenayegum, & Parshuram, 2017), depression (15.6% to 50%) (Bronner et al., 2009; Stremler et al., 2017), and 30.3% met criteria for PTSD (Bronner et al., 2010). The impact of children’s critical illness or
injury on parents is documented, but less is known about the experience of healthy siblings (Abela et al., 2020). Siblings who visit in the PICU are exposed to the same sights and sounds in the PICU as their parents, bearing witness to the pain and suffering of the critically ill or injured child. Furthermore, some siblings may not have the cognitive capacity to fully understand what is happening to their brother or sister. Siblings therefore, may be at risk for developing similar negative reactions as their parents. Since the impact of hospitalization in the PICU on the sibling is not well understood, the sibling experience, as told by the sibling, must be explored. The specific aim of this study was to describe the experience of 9- to 17-year-old children visiting an acutely critically ill or injured brother or sister in the PICU.

This study sought to answer the following research question: How do 9- to 17-year-old siblings of acutely critically ill or injured children admitted to the PICU perceive their experience? *Acutely critically ill or injured children* are those with no known history of PICU hospitalization or chronic illnesses. Unlike siblings of chronically ill children or those with prior PICU admission, siblings of acutely critically ill or injured children have not been exposed to the stressors inherent in chronic illness (Hamlett, Pellegrini, & Katz, 1992), and have no prior exposure to the PICU environment that may impact their reactions to critical illness or critical injury.

The Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988) was used to provide direction for this study (Corbin & Strauss, 2008). The FAAR Model (Figure A1) delineates how a family or family member
may respond to daily hassles and crisis situations using available resources and existing capabilities. To complement the data that would emerge from the sibling interviews, the FAAR model was adapted to provide direction for the development of the interview questions used during data collection.

**Methods**

**Design.** This study used a generic, qualitative design. This approach was selected in order to explore the sibling's perspective of their experience during their visit to the PICU. The study aims to understand the sibling's response to the stressors they experienced related to the ill child's hospitalization.

**Setting and Participants.** After approval from the Baylor College of Medicine Institutional Review Board was obtained, siblings were recruited from an 84-bed PICU in the Southwest United States that cares for children 3 days to 18 years old with a variety of critical illnesses. At the study site, parent presence at the bedside is encouraged 24 hours a day, 7 days a week. Siblings 3 years and older may visit the ill child in the PICU for two 30-minute periods per day after being screened by a Child Life Specialist. Siblings were recruited based on a purposive sampling technique in which information-rich siblings were selected based on the PI's clinical experience (e.g., siblings who may have witnessed medical procedures being performed on the ill child) (Corbin & Strauss, 2008; Patton, 1990; Sandelowski, Holditch-Davis, & Harris., 1992; Moser, 2017). As data collection and analysis progressed, themes began to emerge in the data. Theoretical sampling was used to refine differences and similarities between the groups.
Written informed consent was obtained from the parent or legal guardian if an English-speaking sibling who was 9-17 years old, was planned to visit the PICU. Other inclusion criteria include: Sibling is not developmentally delayed and patient does not have a chronic illness or history of PICU hospitalization. Siblings of children with a chronic illness or a history of PICU hospitalization and siblings of actively dying or deceased children were excluded as sibling reactions to the current PICU admission may be affected by chronic stressors associated with chronic illness, malignancies, and previous PICU hospitalization (Hamlett et al., 1992; Woodgate, Edwards, Ripat, Rempel, & Johnson, 2016). Siblings of actively dying children, defined as hours or days from imminent death with declining physiologic functions (Hui et al., 2014), and bereaved siblings (Brooten & Youngblut, 2017; Eaton Russell et al., 2018) who have unique experiences related to grieving and death were also excluded.

Data Collection. Participant demographic data was collected from the parent prior to the interview using a demographic questionnaire (Appendix B). If possible, siblings were observed during their visit to the ill child’s bedside to study their response to people and the environment, including emotions and nonverbal cues. All observations were recorded using field notes. The interviews were conducted in a private room within the PICU. The grand tour interviewing approach was used with probing questions as data emerged. All interviews were audio- and video-recorded, and transcribed. Clinician notes in the ill child’s medical record were reviewed for any reference to the sibling.
**Interview Guide.** The interview guide was based on the FAAR Model’s (Patterson, 1988) concepts of meaning, demands, and capabilities. Open-ended questions were aimed at exploring stressors, daily hassles, demands, and coping strategies related to the PICU visit, as perceived by the sibling. Key questions are included in Appendix C. As the interviews progressed, the interview guide was modified to explore relevant topics that arose.

**Procedure.** Participants were recruited using an IRB-approved flyer posted in each of the family lounges and at the Welcome Desk of each ICU. The patient list in the electronic medical record was screened daily for patients who have been in the PICU \( \geq 2 \) days and who did not have a chronic illness or previously diagnosed cancer. The eligibility screening form is included in Appendix D. The assigned bedside nurse of patients who met the length of stay and illness criteria was then consulted about the status of the patient. Families of patients who were not actively dying or bereaved were approached for the study. Families were screened further to determine if any 9 to 17-year old siblings who were developmentally appropriate, and English-speaking were expected to visit the PICU. The study was explained in detail to parents and siblings of eligible families. Written informed consent was obtained from the parents or legal guardians. A date and time to interview the sibling(s) was negotiated with the parents or legal guardians. Parents of siblings who did not meet inclusion criteria were thanked for their time and reminded of services available to all PICU families (e.g. Chaplain support).
The PI observed siblings during their visit in the room, if possible, followed by a one-to-one interview. Siblings were interviewed without their parent, by the PI, in a private consult room close to the patient room. Siblings were provided developmentally-appropriate toys and activities during the interview for comfort. Interviews lasted approximately 20-30 minutes and parents were given a $15 gift card for the sibling’s participation.

**Qualitative Analysis.** Data analysis began after the first interview and after each subsequent interview. Two cycles of coding were performed during analysis. During the first cycle, initial, in vivo, and process coding methods were used concurrently to reduce and categorize the data into tentative parts (Corbin & Strauss, 2008; Saldana, 2016). In vivo coding was used to record the child’s actual words, providing the investigators a deeper understanding of the child’s experiences. Process coding was used to code behaviors and actions described in the field notes and observed during the interview. Process codes were also used to identify potential relationships between concepts identified in the data (Saldana, 2016).

During the second cycle, focused, axial, and theoretical coding were used to further categorize and organize the data into categories, sub-categories, eventually leading to more elaborate concepts (Saldana, 2016). These categories were compared across other interviews to assess transferability. Data were managed using ATLAS.ti, a computer assisted qualitative data analysis software.
Data from field notes, interviews, and clinician notes were compared and triangulated to ensure deeper, generalizable findings (Crabtree & Miller, 2000; Green & Thorogood, 2018). Analytical memos and reflexive notes were made during data analysis and reviewed by the investigator and dissertation committee members periodically. A compilation of codes was kept as a record of emergent codes and were reviewed by the investigator and the dissertation committee members as coding progressed. These processes facilitated reflexivity, extraction of meaning from the data, and communication between the investigator and the dissertation committee members (Saldana, 2016).

Findings

Sixteen siblings of 10 children hospitalized in the PICU participated. Of the participants, 56% were female and 69% non-White (African American – N=3, Hispanic – N=5, Asian – N=3). Patient mean LOS was 6.3 days (SD=4.1); all but one was an unexpected admission to the PICU. Patient diagnoses included respiratory failure, newly diagnosed cancer, traumatic brain injury, stroke, sepsis, cellulitis and cardiac arrest. Families were of mixed structures. Sibling characteristics are described in Table 1 (Appendix E).

Analysis revealed nine subthemes that are nested within three main themes. The main themes are: 1) Stressors, 2) Coping, and 3) Sibling experience. An explanatory model using these themes and subthemes was developed to gain a better understanding of the sibling's experience in the PICU in Figure 1 (Appendix F).
Stressors. Participants described five main stressors experienced during their brother or sister’s hospitalization. These stressors were: Pre-illness stressors, ICU environment, appearance of ill child, uncertainty, and parental stress. Data revealed that these stressors did not occur in isolation. For example, a sibling may experience fear from what they observed in the PICU environment and from how their brother or sister appeared.

Pre-Illness stressors. Siblings shared stressors that existed prior to their brother or sister’s critical illness. These included coping with their parents’ divorce, another sibling or family member’s death, and starting in a new school. Two participant shared examples of existing stressors:

“I've actually been this way since my brother got locked up so I'm kinda used to me breaking down out of time, you know, out the blue.” (O.J., female, age 17)

“We had another, we had, our mom had another daughter but she passed awhile ago... And, our step-dad also passed, so we were already kinda in a hole and then that happened.” (A.L., male, age 14)

ICU Environment. Siblings were asked about what they saw, heard, and smelled during their visit to the PICU. None of the siblings reported any memorable smells however, all siblings shared seeing machines, pumps, monitors and hearing their associated sounds. A sibling visiting the PICU for the first time spoke about her first impression of the patient rooms,

“I feel like what was scary, like all the machines and all the medicine he was taking. Like, there was a machine with all his like, medicine and stuff
on there. So that made me kinda nervous. And there was like, all the
stickers and all the like, stuff on there and all the doctors around. And
pretty much just machines and stuff and a tube...all I remember is like, a
couple doctors in there. My mom and me crying. A lot of machines.” (M.P.,
female, age 10)

Several participants described their response to hearing other patients in addition
to the machines,

“I don't know what it is, the machines around her... Like, I sometimes hear
it at night... I like, I see doctors, with their patients and like, they're very
little they're like, babies, you know. And like, you could hear them
crying...sometimes at night screaming. And it's just like, it's, it's really hard
'cause I know like, my sister's not the only one because you can hear it
outside her doorway too.” (J.R., female, age 17)

In response to seeing an urgent situation in the PICU, a sibling shared her
physical response:

“...then like I thought I was gonna like faint, like low key.... like, my head
was feeling really light and my vision was like getting really spotty...”

(E.N., female, age 17)

**Appearance of Ill Child.** Seeing their brother or sister in the PICU caused
a variety of emotions among the sibling participants. Emotions ranged from
happiness, sadness, fear, guilt, and apprehension. Siblings interviewed during
their first visit described the experience as shocking and surreal:
“...I felt like it was all a dream. Like, it was like, none of it was real. Like, I just looked at her, I was like that's really my sister. But I feel like I wasn't- it was just not real." (J.R., female, age 17)

“Well, when I saw him I just broke down. Like, it's just hard seeing him like that when he's always doing something stupid, causing trouble somewhere and then you see him like that." (S.H., male, age 15)

Two siblings shared their feelings about seeing different pieces of equipment on each of their sisters,

"... it's like this machine that goes through her and it like circulates her blood...you could like see the blood and that was kinda weird and then she has two tubes in her so that was really weird...she also has tubes in her legs I think, so that was just...I didn't like the tubes....it was just like all the stuff sticking in her, it was just like kinda creeping me out." (K.M., female, age 11)

"...it makes me feel depressed and stuff, about her sitting in the room with a tube in her throat." (L.D., female, age 12)

One sibling saw his sister in bed, not moving. He was tearful when he stated,

"Oh, my god, like, oh, she's so ... I can't express how ... uh, when I look her, like, she always happy and she's fine. And now she is in a bed." (B.S., male, age 15)

Other siblings who had visited their brother or sister in a more critical state before the time of the interviews occurred felt that their brother or sister was getting
better either because there were fewer tubes or the ill child didn’t appear as uncomfortable. One sibling described progress as:

“…the other time…, you can hear her, you can hear when she breathes, like you can hear the boogers, like in her nose…but now you can hear her uh, breathing normally.” (G.V., male, age 11)

One sibling expressed two opposing emotions about seeing his brother,

“I felt, uh, different types of emotions, I felt happy and also felt sad, ’cause I was going to see him, but I was going to see him like that, like with the mask and everything.” (A.S., male, age 11)

**Uncertainty.** All participants experienced uncertainties regarding: a) where they will be staying for the night, b) the ill child’s health status, and c) whether or not the ill child will recover to their previously healthy state. These uncertainties led siblings to worry about their own and their families’ futures, their sibling’s survival beyond the PICU, and how they will cope with changes in family functioning. Unexpected admissions required families in the sample to rapidly make arrangements for the healthy siblings’ care. This was also evident in notes written by social workers, who conducted psychosocial assessments on several of the families in the sample. Participants reported staying with various friends and family members sometimes not knowing where they will be sleeping for the night. One sibling shared,

“…we were staying with our aunt and then the day before that we were with our cousin. And, then I think those are the only, yeah, those are the
only days we were here. But, today, our mom's trying to figure it out...”
(A.L., male, age 14)
"...it's a lot go through my mind, like, before the doctors can even say anything, so many things run through my minds. It's like you trying to run at one point, like, you doing a race and then you try to pick up something at the same time and you can't grab it. You just continue running. That's what it feels like. A lot be going through my mind." (N.R., female, age 14)

Because the PICU patient's condition often fluctuates from moment to moment, siblings quickly learn that news about their brother or sister can change dramatically from one time to the next. The condition in which they left their sibling may not always be the condition to which they return. Siblings learned about updates regarding their brother or sister's clinical status mostly by listening to conversations between their parents and clinicians or other adults. Siblings were not consistently included in information-sharing or decision-making, thus leading to uncertainties regarding their brother or sister's progress. Several participants expressed how they worry when they are about to receive an update,

“I scared they'll give us bad news. Um, I be like, God please just give us good news. I don't want to...no more bad news than what cancer... what they said about cancer. I just want to hear good news, good news.” (N.R., female, 14)

Siblings also worry about the uncertainty of their sibling's future. All participants expressed worry about the ill child dying, but one sibling expressed worry about how critical illness will impact his brother in the long term,
“... is he going to have trouble, uh, like growing up. Not just right now as a baby but toddler, a kid and-Um, is he going to be like, not less like, um, is he gonna need help when, when doing things?” (A.S., male, age 11).

Not receiving information about their brother or sister increased the uncertainty for some siblings,

“I don't like just sitting there and not knowing what's going on.”

(C.G., male, age 9)

**Parental stress.** Participants described seeing their parents in a state that they have never witnessed before. Siblings voiced that although their parents did not share their emotions with them, their worries, physical stress, and desperation for a cure was evident. Siblings reported seeing their parents’ exhibit emotions they have never seen before from the time of diagnosis and lasting throughout the hospitalization. A participant described his reaction to seeing his father cry in response to the illness,

“I've never seen him cry and this is the first time I've ever saw my dad cry....it made me really, really sad hearing that he was crying because he doesn't cry...I was like, dang, this is serious. He's crying. Like, I've never, ever, ever seen him cry ever.”  (A.L, male, age 14)

Another participant whose mother stayed in the hospital for long hours noted the impact of hospitalization on the physical health her parents and the disruption to family routines,

“I know my mom doesn't get a lot of sleep because the beeping, the machines and....So I know she doesn't get much sleep at all and I think it's
just stressful. And my dad with like running back and forth all the time, it's a long drive back and forth...he works too so it's just a lot of stress overall...it's upsetting." (K.M., female, age 11)

And after receiving a grim prognosis from the clinical team, a sibling witnessed his parents’ reaction,

“My parents just... they're in a state where they're very desperate for anything. Like, my dad, he was trying to get them to like do any medicine...He wanted to try anything." (S.H., male, age 15)

**Coping**

Siblings described coping strategies that fit into four subthemes. These subthemes were: Reflection on sibling relationship, distraction, social support, and spirituality. Similar to the stressors experienced by the siblings, coping strategies did not occur independently of one another. Coping strategies offered the sibling respite, distraction, and hope. Strategies were accessed by the sibling or provided for them by a friend, clinician, family member, or the community. Coping strategies were accessed as a result of an experience with a stressor, or support was provided to the sibling thus impacting his or her experience. This is from a sibling whose community organized assistance with meals for the family:

“...our friends started like, the meal train and then we have some other close friends like when my dad can't make it back and we've had to go somewhere for the night, we've had some friends that we go stay at their
house and they like feed us for a couple days, we've done that like twice”
(K.M., female, age 11)

Similarly, siblings who were provided information about the PICU environment, the equipment, and how their brother or sister may look described feeling prepared (and thus less shocked) for the PICU visit.

“I asked my dad why he had those little, like some sort of liquid, in his cheek, and why he had so many things in his arm….He told me that the wet stuff was some residue of the mask, or some bandaids, that he had on…. It's like, it's not like scary, like, oh my God, he's, he's going to die…”
(A.S., male, age 11)

“Mama told me that there was a 90% chance that it wasn't a t- that it wasn’t cancerous and it was r- really probably benign…But that, uh, but makes me happy about it. And also knowing that this is almost over.”
(W.T., female, age 9)

Or, a sibling may have established coping mechanisms to which they turn to during difficult situations,

“So, what I do is I stop stressing and pray. It's not gonna come right away. It's not. It's gonna take some time. We’re on His time but, yeah, it's gonna come…I know she suffering and all that but she, afterwards she gonna be good.” (O.J., female, age 17)

“I vent to my friends…And they try to help me through this….I just text them.” (S.H., male, 15)
Reflecting on the Sibling Relationship. Siblings in this sample shared that they often thought about their relationship with the ill child to cheer themselves up. They described happy moments they shared with their brother or sister. They thought about those times to momentarily reflect on their bond. As a result of their reflection some siblings expressed gaining a deeper understanding of their relationship with the ill child, as a result of the hospitalization. One sibling shared a story about play time with his sister,

“…play hide and to seek. It's her favorite game. She's a really good hider (laugh).” (C.G., male, age 9)

Another sibling reflected on how special her relationship is with her sister,

“Like, we do everything together... Like, we're really strong together and it's like, you know, since she's not here with me all the time it's just like, you kinda lose that part from you, you know?” (J.R., female, 17)

Distraction. Siblings often turned to their friends, social events, or electronic devices to divert their attention away from distressing situations. Other distraction strategies included: Sharing emotions with their close friends, attending school events, dancing, listening to music, and looking at pictures on their smartphones. Others turned to social media. A sibling shared,

“I can dance and then forget about everything. I could be at a game, forget about everything. All of that. So that's a relief.” (O.J., female, age 17)

The relief felt from these distractions were temporary as illustrated by the following exemplar from a sibling who attended homecoming while her sister was in the PICU,
“You know, get your mind off things. But you know, as soon as you come home you just feel it again.” (J.R., female, age 17)

**Social Support.** Siblings were happy with the amount of support their families had received during the hospitalization. Types of support reported by siblings included: assistance with meals, sleeping accommodations, transportation to and from school, transportation to and from the hospital, and fundraising. One sibling described how her mother’s workplace and co-workers supported the family,

"…it's nice that mama’s job gives her, gives her stuff. Random people and people from my mama’s job, they, they nice enough, they gave a $50 gift card." (L.D., female, age 12)

Siblings were supported by immediate and extended family members, community members, and peers from school. For the majority of the sample, support began soon after hospitalization. One sibling reported that the family had not yet shared the news of the illness with others by the time of the interview.

Some siblings felt supported by the clinical team, especially Child Life Specialists (CLS). These siblings received preparation prior to entering the PICU. CLS orientation to the PICU included an explanation of their sibling’s illness, medical play to illustrate procedures and equipment, and a brief discussion of what to expect to see and hear in the PICU environment. One sibling described the result of her visit with a CLS,

"I saw the Child-Life Nurse person lady, um and she kinda explained what's happening and like all the, what all the beeping and machines are
and what...Kinda explained them, so... Yes, it did help because kinda like she explained the machine stuff and that did help....Because it wasn't so much of like a shock walking into the room, like I kinda knew about the machinery that was gonna be in there when I walked in. So it wasn't as like shocking when I walked in." (K.M., female, age 11)

In contrast to the support provided by the CLS, sibling communication with other clinicians like nurses and physicians was less purposeful. Siblings reported hearing bits of information from the periphery or while a procedure was occurring,

“...um, so most of the time they just pull our mom on the side and tell her, like, what they going to do..."." (N.R., female, age 14)

“They didn't tell me, they told my mama. But she don't really have time, you know, breaking everything down to me like talking about it. Um. I know like, you know, the top of it. I know some of it deal with blood pressure, deal with like all her vitals, um. Yeah, that's really about it.” (O.J., female, age 17)

“...they explained what happened, but then, um, wh- when it happened it was like really serious, so like, like we heard what the news was, and me and my brother were in shock.... I think they're getting him like an ER or whatever it's called, and then tomorrow they're going to take another one, ... right now he's brain dead, so then t- they're taking a few like scans, and tomorrow they're going to take one more, and if he's still brain dead, he's gone.” (D.A., female, age 9)
**Spirituality.** Siblings prayed to God for their brother or sister's recovery. Siblings shared that they prayed at the time of hearing about the illness, before receiving updates from the medical team, and any changes in clinical status. Prayer comforted siblings during times of distress,

"...every time I would wake up I would go ... Especially wake up like, a parent and I'll ask them like, ‘Would you pray with me?’ And they would. So it made me feel a little bit better, praying." (M.P., female, age 10)

**The Sibling Experience**

At the core of the model was the sibling experience. The sibling’s experience during their visit to the PICU was influenced by stressors associated with the hospitalization of their brother or sister. Siblings described physical and emotional responses to these stressors including loss of sleep, feeling faint, shock, fear, worry, and sadness. The PICU hospitalization also impacted the sibling’s social life. Siblings reported being absent from school, having an increased number of chores and responsibilities at home, and missing social events at school and with friends. Some siblings had a very close relationship with the hospitalized child and they discussed feeling lonely with the sudden loss of their usual companion or playmate.

“... [patient's name] not home, and she's funny, like, she's... she gonna make you laugh at any time, like, you at your downest point...sitting down watching TV with her, doing homework. Playing around, wrestling, goofing around, stuff like that. All that's changed, because she’s not home.” (N.R., female, age 14)
Siblings coped using a variety of resources including participating in activities that distracted them from the stressors, receiving community and extended family support for lodging, meals, and transportation, thinking about their relationship with their ill brother or sister, and praying to God. As a result, siblings reported feeling happy, supported, and less worried. Although most of the coping strategies utilized by siblings in the sample provided temporary relief, these coping strategies made siblings feel hopeful.

“I actually don't think there's anything that we haven't gotten from relatives, or, and friends…. It makes me feel, blessed.” (K.M., female, age 11)

“I feel really supported….we ordered Incredible shirts and masks. And so I gave …some of the masks to my class and we all took a picture for [patient's name] and sent to him…. (W.T., female, age 9)

Siblings distracted themselves by attending homecoming, dances, and other social events at school, watched television, spent time outdoors, played games on their mobile devices, and browsed through social media. Support from close friends and family members was very helpful for the siblings in the sample,

“Well, my friends are just helping me but there's like a lot of people that are just helping my parents and they like bring food, give support, pray for him.” (S.H., male, age 15)

**Discussion**

Qualitative methods were used to explore the experiences of siblings who visited a brother or sister in the PICU. Three major themes with nine subthemes emerged from the data. The findings highlighted that the sibling’s physical,
emotional, and social health are impacted by the stressors associated with the hospitalization of a brother or sister in the PICU. Siblings were found to use a combination of coping strategies to manage negative experiences associated with the PICU hospitalization. For organizations seeking to adopt a family centered care delivery model in which sibling presence and engagement are encouraged, the sibling’s perspective is key to understanding the impact of critical illness to the family unit.

Two previous studies reflectively assessed siblings’ response to critical illness or critical injury (Kleiber, Montgomery, & Craft-Rosenberg, 1995; McMahon, Noll, Michaud, & Johnson, 2001). Investigators discovered that severity of injury was significantly associated with lower self-concept and more symptoms of depression in siblings (McMahon et al., 2001), and that siblings acquired most of their information about the illness and the ICU environment mainly from their parents (Kleiber et al., 1995). Parents in Kleiber et al.’s (1995) reported a lack of confidence in their ability to provide information to their healthy children which may have resulted in information that was not always fully understood by the siblings.

Although the present study did not measure levels of self-concept or depression, siblings in the sample reported feeling deep sadness and grief. Parents in the present study were also the primary providers of information to the siblings. The type of information provided was similar to those identified by Kleiber et al. (1995), including reason for the hospitalization, descriptions of the equipment, and descriptions of the ill child. Findings indicated that this
information was not well understood by siblings, leading to worry and fear. Neither study (Kleiber et al., 1995; McMahon et al., 2001) sought to learn about the experiences of siblings visiting the PICU.

Before the current study, an account of the siblings’ experiences within the PICU remained undescribed. This study highlighted the range of emotions that siblings feel during the hospitalization of a brother or sister in the PICU. Sibling health was impacted by critical illness or injury and clearly, effects of hospitalization lasted throughout the PICU stay, well beyond the initial visit to the bedside. The explanatory model (Appendix E) highlights the stressors and coping strategies reported by siblings in this sample. Most notably, all siblings were distressed by the uncertainties associated with critical illness. These siblings were not active recipients of information in the PICU.

Similarities and differences between siblings in this study and those in studies conducted among siblings of chronically ill children or children with cancer were found. Similar to siblings of children with cancer (Yang, Mu, Sheng, Cheng, & Hung, 2016) and chronic illnesses (Deavin, Greasly, & Dixon, 2018), siblings in the present study expressed the desire for complete information about their sibling’s illness. Siblings had a fragmented understanding of their brother or sister’s illness during the initial hospitalization and diagnosis that may have led to worry, fear, and uncertainty about the future. Understanding of the illness and the hospital experience however, gradually improves for siblings of children with cancer or chronic illnesses as they become more knowledgeable and involved in the care of their brother or sister (Deavin et al., 2018; Yang et al., 2016). Due to
the nature of the hospitalization, siblings in this sample did not have the opportunity to gain a deeper understanding of the illness. In most cases, they had only a few days to make sense of the information they could gather due to frequent changes in the ill child’s clinical status, infrequent visits, and degree of information shared by the parents.

Siblings of children with a chronic illness may be resentful and jealous of the amount of time parents spent caring for the chronically ill child (Deavin et al., 2018). There may also be changes in the sibling relationship that may be due to changes in the ill child’s cognitive status (Deavin et al., 2018). Also related to the amount of time and attention given to the child with cancer, the siblings may feel neglected at home, sometimes developing an estranged relationship with the ill child over time (Yang et al., 2016). In contrast, siblings in this study reported a desire for all of the attention to be focused on the treatment of the critically ill child, some even discussing their attempts to be strong and independent so as not to detract their parents’ attention away from the ill child.

With progressive exposure to their sick brother or sister’s experiences, siblings of children with cancer eventually mature and adapt to their new roles within the changed family unit (Yang et al., 2016). Siblings of children with chronic illnesses have a similar experience of developing new roles within the family and learning new coping skills. Over time, they have become specialists of their brother or sister’s condition, taking on additional responsibilities in the family (Deavin et al., 2018). Because the families in the PICU were still in the acute phase of the initial hospitalization, and changes to family life occurred suddenly,
the siblings in the present study’s sample may not have adjusted to the critical illness. The emotions displayed by the siblings during the visit and the interviews indicated that they were still processing the crisis.

Findings regarding social support and a need for distraction mirrored those of siblings of chronically ill and pediatric cancer patients. Most siblings found a temporary distraction from their chaos by reaching out to peers for support. Siblings of children with cancer and chronic illnesses (Nabors & Liddle, 2017) were provided access to hospital or Ronald McDonald House peer support groups throughout treatment and after hospitalization while the siblings in our sample relied on their friends and family members. Play activities or information provided by Child Life Specialists or other clinicians helped siblings in the current study cope with the stress of visiting the PICU. The importance of preparing siblings entering the PICU with information about the PICU environment was evident in the findings, and were consistent with literature (Nabors & Liddle, 2017; Yang et al., 2016), promoting the adoption of Child Life Services.

Limitations

This study was conducted at a single institution with English-speaking families. The experience of this sample may not be representative of siblings who speak a different language. However, the sample was comprised of various races and family structures, reflective of the population typically admitted to TCH. The purposive sampling strategy ensured clinical diversity, and theoretical sampling allowed for a deeper understanding of each theme identified. Finally, the sample was comprised mostly of siblings of patients unexpectedly admitted
to the PICU. Their experiences may have been more pronounced than those of siblings of patients who were planned to be hospitalized. The sibling of the scheduled admission however, shared similar experiences than the rest of the sample.

**Implications for Practice**

Clinicians caring for critically ill children should acknowledge the presence of the healthy sibling in the PICU, and recognize the impact of the hospitalization beyond the parents. Since siblings are impacted beyond the initial admission, sibling support should not be limited to orientation to the PICU. Services such as Child Life, social work, or psychological trauma and grief support should be made available to the family throughout the ill child’s stay in the PICU. Communication to the family about the PICU and the ill child should include developmentally-appropriate information to meet the information needs of the sibling. Existing family support programs can be strengthened by addressing the stressors and associated needs identified in this research. Within these programs, parents can be educated to recognize the impact of these stressors on their healthy children. Parents can be engaged in developing standardized programs aimed at preparing a sibling for the sights and sounds of the PICU. Organizations may also consider adopting social media applications that facilitate peer support programs to provide emotional and informational support to visiting siblings.

**Implications for Research**

The findings of this study provide a starting point in understanding the impact of critical illness and visiting the PICU on a healthy sibling. Cross-
sectional and longitudinal studies should be conducted to examine the short- and long-term influence of stressful sights, sounds, and events experienced by the sibling during critical illness, on their physical, social, and psychological health. Coping strategies used by siblings in this study can be further explored to investigate potential benefits to the sibling. The influence of spirituality on the sibling’s emotional health for example, can be determined. Differences in emotional well-being between siblings who pray to a higher being versus those that do not can be identified. Furthermore, there may be specific factors that can be identified, that place siblings at greater risk for developing deleterious health effects as a result of the PICU hospitalization. There may be siblings that have a greater number of existing stressors prior to the hospitalization that may exacerbate negative responses to the stress of the PICU visit. Identification of high-risk siblings and associated factors may eventually lead to the development of tested interventions to prevent or mitigate negative effects of critical illness or injury. There is also an opportunity to develop and test the effectiveness of support services developed to support high-risk siblings during the hospitalization and beyond discharge. Finally, technological solutions can be explored as a mechanism to facilitate peer support programs focused on the psychosocial needs of the sibling.

Conclusions

Findings from this study provide insight into the needs, stressors, coping strategies, and overall impact on the well-being of the siblings of acutely critically ill or injured children in the PICU. Although siblings appear to be coping well with the hospitalization, they may be experiencing distress internally. Family-centered care delivery models within the
pediatric critical care environment have allowed healthy children to visit the ill child, yet the exposure of healthy children to potentially traumatizing experiences was not well understood until the present study. Currently, no standardized approaches are used to prepare siblings for their PICU visit and organizations who are seeking to develop strategies to mitigate the impact of hospitalization on siblings may be under-resourced. Not meeting this need potentially places the sibling at risk for subsequent negative psychological, physical, and social outcomes (e.g., acute stress disorders, post-traumatic stress disorder, impaired social functioning) and increases the overall burden of critical illness and injury on the family unit.
References


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https://doi.org/10.1097/PCC.0b013e3181a706c9


https://doi.org/10.1016/j.pedn.2017.01.012

Appendix A

Family Adjustment and Adaptation Response Model (Patterson, 1988)
**Figure 1.** Family Adjustment and Adaptation Response Model (Patterson, 1988).
Appendix B

Demographic Questionnaire
This questionnaire is to be completed by a parent after consenting to participate in the study.

Participant Code: ____________

Sibling gender: Male Female

Sibling age: __________

Sibling race: White Hispanic Non-Hispanic Black Asian Other
Appendix C

Interview Guide
1. **Tell me about what you know about your brother or sister’s illness?**
   d. What have you heard about why your brother or sister is in the hospital?
   e. Where did you hear that from?
   f. What do you think that means [being sick]?
   g. How does that make you feel?
   h. How do you feel when your mom or dad is here with your brother or sister?

2. **Tell me what it’s like to visit your brother/sister in the hospital room.**
   a. How did it make you feel to see your brother/sister in the hospital room?
   b. What did you see/hear/smell? How did these make you feel?
   c. Tell me about what your brother or sister’s hospital room looked like?
   d. What did your brother or sister look like? Is this different from how they usually look? How did that make you feel?
   e. Other people have told me that the tubes and lines are scary. How do these make you feel?

3. **Tell me about what you would be doing right now if your family wasn’t in the hospital.**
   a. How does it make you feel to not be doing these things?
4. When you visited your brother or sister did you need help from your
parents or the nurses/doctors with anything?
   a. Other kids have needed things like food, a place to stay, or things
      keep them busy. Tell me about what things you needed.
   b. Other kids have said that they needed someone to talk to about
      their feelings. Did you need to talk to someone during your visit?
   c. How did it make you feel when you weren’t able to get these
      things?
   d. What are some things that you needed from your mom or dad?
      From other family members? From the people that worked in the
      PICU?

5. Let’s talk about things that made you feel good or people that helped
   you and your family while your brother or sister is in the hospital.
   Tell me about the things that you think really helped you and your
   family while your brother or sister is here.
   a. What was that like?
   b. Who/what helped you the most? What did they do that was helpful
      to you and your family?
   c. Tell me about things that you wish you got help with
Appendix D

Eligibility Screening Form
To be completed daily: This screening form is to be completed for all patients who meet study criteria.

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*Note:* a. PICU LOS (Length of stay) is determined using the report generated from the electronic medical record. All patients with a hospital LOS ≥ 2 days will be screened for inclusion criteria. b. Presence of chronic conditions or malignancies are identified using the hospital problem list of the electronic medical record. c. Children who are actively dying are hours or days from imminent death with declining physiologic functions.
Appendix E

Characteristics of PICU Sibling Sample
Table 1

*Characteristics of PICU sibling sample (N=16)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. (%)</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
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<tr>
<td>Male</td>
<td>7 (44)</td>
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<tr>
<td>Female</td>
<td>9 (56)</td>
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<tr>
<td><strong>Race</strong></td>
<td></td>
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<tr>
<td>White</td>
<td>5 (31)</td>
</tr>
<tr>
<td>African American</td>
<td>3 (19)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5 (31)</td>
</tr>
<tr>
<td>Asian</td>
<td>3 (19)</td>
</tr>
<tr>
<td><strong>Current age (years), mean (SD; range)</strong></td>
<td>12.5 (3.0)</td>
</tr>
<tr>
<td><strong>Patient LOS (days) at time of interview, mean (SD; range)</strong></td>
<td>6.3 (4.1)</td>
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<tr>
<td><strong>Child life preparation prior to visit</strong></td>
<td></td>
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<tr>
<td>Yes</td>
<td>9 (56)</td>
</tr>
<tr>
<td>No</td>
<td>7 (44)</td>
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<tr>
<td><strong>First PICU visit prior to interview</strong></td>
<td></td>
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<tr>
<td>Yes</td>
<td>5 (31)</td>
</tr>
<tr>
<td>No</td>
<td>11 (69)</td>
</tr>
</tbody>
</table>
Appendix F
Explanatory Model of Sibling Experience in PICU
Figure 1. Explanatory model of the sibling experience in the PICU
Appendix G

Human Subjects Approval Letter
September 3, 2019

KRISANNE GRAVES
BAYLOR COLLEGE OF MEDICINE
PEDIATRICS: EMERGENCY MEDICINE

H-45846 - PEDIATRIC INTENSIVE CARE HOSPITALIZATION: SIBLING EXPERIENCE

APPROVAL VALID FROM 9/3/2019 TO 7/10/2020

Dear Dr. GRAVES

The Institutional Review Board for Human Subject Research for Baylor College of Medicine and Affiliated Hospitals (BCM IRB) is pleased to inform you that the research protocol and consent form(s) named above were reviewed and approved by Expedited procedures on 9/3/2019 by Board 3.

The study may not continue after the approval period without additional IRB review and approval for continuation. You will receive an email renewal reminder notice prior to study expiration; however, it is your responsibility to assure that this study is not conducted beyond the expiration date.

Please be aware that only IRB-approved informed consent forms may be used when written informed consent is required.

Any changes in study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact the research participants' safety or willingness to continue in your study.

The BCM IRB is organized, operates, and is registered with the United States Office for Human Research Protections according to the regulations codified in the United States Code of Federal Regulations at 45 CFR 46 and 21 CFR 56. The BCM IRB operates under the BCM Federal Wide Assurance No. 00000286, as well as those of hospitals and institutions affiliated with the College.

Sincerely yours,

[Signature]

FLOR MUNGOI-RIVAS, M.D.
Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals

https://brain.bcm.edu/esp/1/report/human/approvals/esp?protocol=3957678&title_code=0
Appendix H

Recruitment Flyer
Does your child in the Pediatric ICU (PICU) have a brother or sister?

Brothers and sisters of children admitted in the PICU are being recruited to take part in a research study. We want to understand the experience of their visit to the PICU.

He or she may be able to participate if he or she:

- Is 9- to 17-years old
- Is not developmentally delayed
- Speaks and understands English

AND

The child in the PICU:

- Has been in the ICU for at least 7 days
- Does not have any chronic illnesses or cancer diagnosed before this PICU hospitalization
- Has not been hospitalized in the PICU in the past

For more information or to participate, you can contact:

Karla Abela, PhD(c), MSN, RN, CCRN-K, CPN
UT Health Science Center Cizik School of Nursing
Email: kmabela@texaschildrens.org
Phone: 832-301-6212

IRB Approval #: H-45846
Approval date: September 3, 2019
Appendix I

Informed Consent
CONSENT FORM
Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals
Pediatric Intensive Care Hospitalization and Sibling Experience
H-45846- PEDIATRIC INTENSIVE CARE HOSPITALIZATION: SIBLING EXPERIENCE

Concise and Focused Presentation
We are conducting a study to understand the sibling PICU visit experience better so that in the future we may be able to prepare the healthy sibling to spend time with the ill child.

We would like to interview your child. Participation is strictly voluntary. You or your child may choose to stop participating in the study at any time without changing the care of your child. Potential risks of participation are limited, but could be loss of confidentiality or our questions may make your child feel uncomfortable. Before the interview begins, your child will be told that she or he can stop the interview at any time. Your child will be told that if the interviewer becomes concerned for your child during the observation or interview, then the interviewer will speak with you and the critical care doctor about obtaining additional support for your child.

Background
On this form, the word you may refer to you or to your child. You are invited to take part in a research study of visiting child siblings of patients in the Pediatric Intensive Care Unit. Please read this information and feel free to ask any questions before you agree to take part in the study.

Prior research that has examined the effect of spending time in a pediatric intensive care unit (PICU) on families have been mostly focused on the parents, yet healthy brothers and sisters who visit the ill child are exposed to the same possibly upsetting situations and conditions. In these studies, parents experience a range of physical, social, and mental issues that may continue to exist for years beyond discharge from the PICU. Ways to prepare the healthy brother or sister to spend time with the ill child, how much time spent is spent in the room, and follow-up after the visit are not done the same way every time. If brothers and sisters are permitted to visit the PICU, current methods to prepare brothers and sisters for the visit may differ depending on individual hospital and local unit policies. Even with the negative reactions that brothers and sisters may have related to their PICU visit, the effect of their visit is unknown.

Purpose
The purpose of this study is to describe the experiences of 9- to 17-year-old siblings who visit their brother or sister who is admitted to the PICU for a serious illness or injury.

Procedures
The research will be conducted at the following location(s):
Baylor College of Medicine and TCH, Texas Children’s Hospital.

The investigator will review the medical record of your child (the patient) for notes written by other PICU team members that refer to a sibling visit.

The investigator will interview the patient’s brother or sister, and observe his or her visit with the patient. The interview will last approximately 30 minutes, away from any parents or guardians. The interview will be audio- and video-recorded. Your child will be asked questions about what they have seen, heard, felt, or any concerns they may have had during their visit with their brother or sister.
CONSENT FORM
Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals
Pediatric Intensive Care Hospitalization and Sibling Experience

H-45346- PEDIATRIC INTENSIVE CARE HOSPITALIZATION: SIBLING EXPERIENCE

Should your child experience distress during the interview, she or he may choose to pause or stop at any time. If your child becomes incoherent we may refer you and your child to the Trauma and Grief Center for further evaluation or other hospital resources for support, at your expense. If the investigator becomes concerned for your child's immediate safety (threats of self-harm) a referral to the Emergency Center will be made, at your expense.

All materials resulting from the interview and observation will be protected behind encrypted, password-protected networks and locked physical spaces.

Clinically Relevant Research Results
The investigator may refer you and your child to the Trauma and Grief Center for further evaluation or other hospital resources for support. If the investigator becomes concerned for the child's immediate safety (threats of self-harm) a referral to the Emergency Center will be made.

Sharing and Future Research Studies with Identifiable Private Information
Your identifiable private information or identifiable biospecimens collected as part of this research, even if the identifiers are removed, will not be used or distributed for future research studies.

Research related health information
Authorization to Use or Disclose (Release) Health Information that Identifies You for a Research Study

If you sign this document, you give permission to people who give medical care and ensure quality from Baylor College of Medicine and TCH: Texas Children's Hospital to use or disclose (release) your health information that identifies you for the research study described in this document.

The health information that we may use or disclose (release) for this research includes:

- Information from health records such as diagnoses, progress notes, medications, lab or radiology findings, etc.
- Demographic information (name, D.O.B., age, gender, race, etc.)
- Photographs, videotapes, and/or audiotapes of you

The health information listed above may be used by and or disclosed (released) to researchers, their staff and their collaborators on this research project, the Institutional Review Board, Baylor College of Medicine, and TCH: Texas Children's Hospital.

Use or Disclosure Required by Law
Your health information will be used or disclosed when required by law.

Your health information may be shared with a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability and conducting public health surveillance, investigations or interventions.

Approved from September 03, 2019 to July 10, 2020
Chair Initials: F. M.
CONSENT FORM
Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals
Pediatric Intensive Care Hospitalization and Sibling Experience

H-46846  PEDIATRIC INTENSIVE CARE HOSPITALIZATION: SIBLING EXPERIENCE

Baylor College of Medicine and TCH: Texas Children’s Hospital are required by law to protect your health information. By signing this document, you authorize Baylor College of Medicine and TCH: Texas Children’s Hospital to use and/or disclose (release) your health information for this research. Those persons who receive your health information may not be required by Federal privacy laws (such as the Privacy rule) to protect it and may share your information with others without your permission, if permitted by laws governing them.

Please note that the research does not involve treatment. Baylor College of Medicine and TCH: Texas Children’s Hospital may not condition (withhold or refuse) treating you on whether you sign this Authorization.

Please note that you may change your mind and revoke (take back) this Authorization at any time. Even if you revoke this Authorization, researchers, their staff and their collaborators on this research project, the Institutional Review Board, regulatory agencies such as the U.S. Department of Health and Human Services, Baylor College of Medicine, and TCH: Texas Children’s Hospital may still use or disclose health information they already have obtained about you as necessary to maintain the integrity or reliability of the current research. If you revoke this Authorization, you may no longer be allowed to participate in the research described in this Authorization.

To revoke this Authorization, you must write to: Karla Abela
6651 Main St, Houston, TX 77030
kabela@texaschildrens.org
832-301-0212

This authorization does not have an expiration date. If all information that does or can identify you is removed from your health information, the remaining information will no longer be subject to this authorization and may be used or disclosed for other purposes.

No publication or public presentation about the research described above will reveal your identity without another authorization from you.

Potential Risks and Discomforts
This study poses limited risk to its participants. We will be careful to keep her or his information confidential however, there is always a small risk of unwanted or accidental disclosure. The interviewer will not share your child’s individual responses with others outside of the research team unless your child shares information that may indicate that she or he may be at risk for hurting themselves or others, or if the interviewer is concerned about the presence of a mental health issue. In this case, the interviewer will discuss the need for a psychological evaluation with you and the critical care doctor.

There is also a risk that the questions may make your child feel uncomfortable. Before the interview begins, your child will be told that she or he can stop the interview at any time. Your child will be told that if the interviewer becomes concerned for your child during the observation or interview, then the interviewer will speak with you and the critical care doctor about obtaining additional support for your child.
CONSENT FORM
Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals
Pediatric Intensive Care Hospitalization and Sibling Experience

H-45646- PEDIATRIC INTENSIVE CARE HOSPITALIZATION: SIBLING EXPERIENCE

Study staff will update you in a timely way on any new information that may affect your decision to stay in the study. There is a small risk for the loss of confidentiality. However, the study personnel will make every effort to minimize these risks.

Potential Benefits
You will receive no direct benefit from your participation in this study. However, your participation may help the investigators better understand how brothers and sisters of children hospitalized in the PICU feel about the hospitalization and their visit with the hospitalized child.

Alternatives
You may choose to not participate in this study.

Subject Costs and Payments
You will not be asked to pay any costs related to this research.

Parents of participants will receive a $15 Target gift card upon completion of the interview.

Subject’s Rights
Your signature on this consent form means that you have received the information about this study and that you agree to volunteer for this research study.

You will be given a copy of this signed form to keep. You are not giving up any of your rights by signing this form. Even after you have signed this form, you may change your mind at any time. Please contact the study staff if you decide to stop taking part in this study.

If you choose not to take part in the research or if you decide to stop taking part later, your benefits and services will stay the same as before this study was discussed with you. You will not lose these benefits, services, or rights.

The investigator, KRISANNE GRAVES, and/or someone he/she appoints in his/her place will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury related to the research, you may speak with a member of the study staff: Karla Abela at 832-301-6212 during the day and after hours.

Members of the Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals (IRB) can also answer your questions and concerns about your rights as a research subject. The IRB office number is (713) 798-6970. Call the IRB office if you would like to speak to a person independent of the investigator and research staff for complaints about the research, if you cannot reach the research staff, or if you wish to talk to someone other than the research staff.

Approved from September 03, 2019 to July 10, 2020    Chair Initials: F. M.
CONSENT FORM
Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals
Pediatric Intensive Care Hospitalization and Sibling Experience

H-45846- PEDIATRIC INTENSIVE CARE HOSPITALIZATION: SIBLING EXPERIENCE

If your child is the one invited to take part in this study you are signing to give your permission. Each child may agree to take part in a study at his or her own level of understanding. When you sign this you also note that your child understands and agrees to take part in this study according to his or her understanding.

Please print your child’s name here __________________________
CONSENT FORM

Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals
Pediatric Intensive Care Hospitalization and Sibling Experience

H-45846: PEDIATRIC INTENSIVE CARE HOSPITALIZATION: SIBLING EXPERIENCE

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Subject ________________________________ Date ________________

Legally Authorized Representative
Parent or Guardian ________________________________ Date ________________

Investigator or Designee Obtaining Consent ________________________________ Date ________________

Witness (if applicable) ________________________________ Date ________________

Translator (if applicable) ________________________________ Date ________________

Approved from September 03, 2019 to July 10, 2020 Chair initials: F. M.
Appendix J
Publication
Impact of Pediatric Critical Illness and Injury on Families: An Updated Systematic Review

Karla M. Abela, MSN, RN, CCRN-K, CPN*, Diane Wardell, Ph.D., RN, WHNP-BC, Cathy Rozmus, Ph.D., RN, FAAN, Geri LoBiondo-Wood, Ph.D., RN, FAAN

The University of Texas Health Science Center at Houston, School of Nursing, United States of America

Abstract

Problem: PICUs (PICU) that have adopted family-centered care models welcome families to the critically ill child’s bedside to partner with clinicians in decision-making and the provision of care. The aim of this review was to synthesize the evidence on the impact of critical illness and injury on families of children admitted to the PICU to identify research needs in pediatric critical care.

Eligibility criteria: This systematic review included quantitative and qualitative studies that examined the experiences of families of children admitted to a PICU published between 2005 and 2019.

Sample: 33 articles were selected for inclusion in the final analysis after screening those identified by searches in CINHAL, PubMed, PsychInfo, and reference lists of included publications.

Results: Main parental stressors included the sights and sounds within the PICU, child acuity, changes in family functioning and parenting role, and uncertainty of the child’s outcome. The most common need of parents was to be well-informed. Psychological, physical, and social impact of hospitalization were experienced by parents from days after admission to years after discharge. Spirituality was identified as a coping mechanism in half of the studies.

Conclusions: Parent experience negative effects of the ill child’s admission to the PICU and to PICU exposure.

Implications: Careful consideration of the impact of the PICU admission on family members of critically ill or injured children is needed when implementing family-centered care strategies. Future research on other family members including the health of sibling needs to be conducted.

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Background

The experience of the child and family in the pediatric intensive care unit (PICU) environment is unique. Advances in technology used in the PICU such as extracorporeal life support, noninvasive ventilation, and noninvasive diagnostic and monitoring techniques extend the survival of children with life-threatening conditions (Namachivayum et al., 2010). Also, the adoption of core concepts of family-centered care (FCC), dignity and respect, information sharing, participation, and collaboration (Institute for Patient– and Family-Centered Care [IPFCC], n. d.) in PICUs have allowed for 24-h presence of parents and other family members (Meert, Clark, & Eggy, 2013). PICUs have adopted an FCC care model that welcome parents and family members to the bedside of their critically ill child, encouraging active participation in the child’s care to promote coping and healing. Despite the benefits of FCC in the PICU, evidence on adverse family outcomes as a result of increased family presence and involvement in the ICU is limited (Davidson et al., 2017).

* Corresponding author.
Email address: karla.abela@uth.tmc.edu (KM. Abela).

In a systematic review, Shudy et al. (2016) described the impact of pediatric critical illness and injury on families. In their review of 115 studies, Shudy et al. (2016) identified stressors that family members were exposed to during PICU admission, with changes in the parental role during the child’s hospitalization as the major source of stress for parents (Shudy et al., 2016). The needs most commonly cited by parents included honest information regarding their child’s medical status and the ability to participate in the child’s care, maintain family cohesion, and receive quality care for their child (Sibling (N = 7) needs reflectively assessed months to years after the PICU admission included information, family cohesion, hospital visitation, and distraction from the current situation.

Studies that assessed the psychological impact of PICU admission on families reported that mothers developed psychological distress and psychiatric disorders such as anxiety, depression, and post-traumatic stress disorder (PTSD) at admission and after discharge (Shudy et al., 2006). In terms of the physical impact of PICU admission, both mothers and fathers reported experiencing fatigue, low energy, malaise, headache, irritability, and interrupted sleep and meal patterns. Critical illness affected parental roles and relationships within the family after PICU...
Curriculum Vitae
Karla M. Abela, MSN, RN, CCRN-K, CPN
6651 Main St., Houston, TX 77030
832-824-5933
kmabela@texaschildrens.org

EDUCATION

Ph.D. Nursing  University of Texas Health Science Center at Houston, Cizik School of Nursing, Houston, Texas  Expected completion 5/2020

Master of Science in Nursing  University of North Carolina at Chapel Hill, Chapel Hill, North Carolina  5/2013

Diploma in Nursing  Humber College of Applied Arts and Technology, Toronto, Ontario, Canada  12/ 2003

LICENSE & CERTIFICATION

Registered Nurse - Texas  Active - Expires 2/28/2020

Certified Critical Care Nurse (CCRN-K)  Active  American Association of Critical Care Nurses  1/2015 – 12/2020

Certified Pediatric Nurse (CPN)  Active  Pediatric Nursing Certification Board

BLS for Healthcare Provider  Active  American Heart Association

PROFESSIONAL EXPERIENCE

Texas Children’s Hospital  Assistant Director of Clinical Practice  9/2017 - Present

Texas Children’s Hospital  Clinical (Nurse) Specialist  4/2015 – 9/2017

Texas Children’s Hospital  Patient Care Manager, Pediatric Intensive Care Unit  8/2014 – 4/2015

Duke University Hospital  Nurse Manager, Pediatric Intensive Care Unit, Pediatric Procedural Unit  5/2011 – 7/2014

Duke University Hospital  Educator, Pediatric Acute Care Units  2/2008 – 5/2011

Duke University Hospital  Clinical Nurse, Pediatric Hematology/Oncology and Intermediate Care Unit  11/2006 – 2/2008

HONORS & AWARDS

Innovations in Fellowship Education  American Thoracic Society  2016

GRANTS

Research Grants

Evaluation of a Workplace Violence Against Nurses Program, Texas Department of State Health Services, Program Director, $179,979, March 1, 2020 – October 1, 2021 (inclusive)

Pediatric Intensive Care Hospitalization: Sibling Experience, American Nurses Foundation, Principal Investigator, $4,914, Sept. 1, 2019 – Aug. 31, 2020 (inclusive)

Other Funded Projects Including Contracts for Service

Moving and Grooving: Incentive Based Mobility Program, Children’s Miracle Network, Program Director, $1000, 2008

Normalizing the Pediatric Intensive Care Unit Environment, Kids Care Grant, Duke University Hospital, Program Director, $3500, 2012


Color Changing Alcohol Wipe, New England Pediatric Device Consortium, Inventor, $10,000, 2016-2017

Bead Mindful in the Pediatric Intensive Care Unit, Philanthropic funds, Texas Children’s Hospital, Program Director, $8750, 2017-2018

PUBLICATIONS

Peer Reviewed Publications


Non-Peer Reviewed Publications


Peer Reviewed Abstracts


PRESENTATIONS

International


response events: Characteristics, outcomes, and quality improvement. Poster presentation at the 2016 World Congress on Pediatric Intensive and Critical Care, Toronto, Canada.


National


(2013, October) Preventing Central Venous Access Device-Related Bloodstream Infections in Pediatrics, Podium presentation at the Annual Infusion Nurses Society Conference


Regional/State


Abela, K., Acorda, D., Cain, C. & Gibbs, K. (2016). Relationship of food insecurity to sociodemographic characteristics in hospitalized children in Texas. Poster presentation at the University of Texas Health Science Houston Research Day. Houston, TX.


PROFESSIONAL SERVICE

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<tr>
<th>Organization</th>
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<td>Southern Nurses Research Society</td>
<td>State Liaison</td>
<td>October 2019 – Present</td>
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Professional Memberships

American Nurses Association

American Association of Critical Care Nurses

Sigma Theta Tau

Filipino Nurses Association