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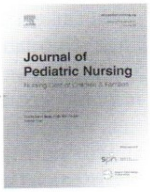

Siblings' experience during pediatric intensive care hospitalization

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ABSTRACT

Purpose: The impact on children who visit an ill sibling in the pediatric intensive care unit (PICU) is unknown. The aim of this study was to describe the experiences of siblings of acutely critically ill or injured children hospitalized in the PICU.

Design and methods: A qualitative approach using one-to-one interviews was conducted to gain an understanding of the experience of 9- to 17-year-old children who visited their siblings in the PICU. Thematic analysis was used to develop a description of the experiences of the siblings.

Findings: Sixteen siblings (mean age, 12.5 years) indicated that visiting their critically ill sister or brother in the PICU can cause negative reactions. The data revealed two major themes within the overall sibling experience—stressors, coping—and nine subthemes. Predominant sibling stressors included pre-illness stressors, the PICU environment, the appearance of the ill child, uncertainty, and parental stress. Siblings coped mainly via distractions, social support, and spirituality and by reflecting on the sibling relationship. Support from friends, family members, and the community was reported to be helpful.

Conclusions: Siblings visiting the PICU may experience a broad range of physical, emotional, and social responses.

Practice implications: Future research should fully incorporate the sibling perspective when designing interventions to mitigate the potentially distressing effects of PICU visitation on the family.

Introduction

The adoption of the family-centered care approach (Institute for Patient and Family Centered Care, n.d.) in pediatric intensive care units (PICUs) has resulted in open visitation inclusive of all family members. Open communication and collaboration between healthcare members and families are valued, and families are considered partners in decision-making and care. In many PICUs, parents, siblings, extended family members, and friends are encouraged to visit and interact with the ill child. Families and patients are invited to participate in interdisciplinary rounds, participate in daily care, and partner with clinicians in health-related decision-making. While PICUs can vary in size and scope, neonates, children, and young adults who require intensive monitoring and treatment are usually hospitalized in a critical care setting. For visitors unfamiliar with the PICU clinical environment, the experience may result in negative responses. Varying degrees of family support can be provided to the child depending on their illness. A child's appearance may also be significantly altered depending on their illness and the type of care they are receiving. Depending on the PICU's physical layout, it is possible that visitors may witness distressing situations. The physical, psychological, and social impacts of children's critical illness or injury on parents are well-documented (Abela et al., 2020). However, knowledge about such effects on siblings present at the bedside is lacking (Abela et al., 2020; Foster et al., 2019; Hagstrom, 2017).

Sights and sounds in the PICU environment, the appearance of their child, the uncertainty of the outcome of the illness, and disruption to their daily life, are significant stressors for parents of critically ill or injured children (Abela et al., 2020). Parents may develop symptoms of anxiety, depression, and post-traumatic stress disorder 24 h after PICU admission to months after hospital discharge (Bronner et al., 2010; Bronner, Kayser, Knoester, Bos, Last, and Grootenhuis, 2009; Needle et al., 2009). Coping mechanisms to manage the effects of stressors related to hospitalization such as using available social networks, prayer, and mindfulness techniques have also been explored among parents (Abela et al., 2020). Siblings who visit the PICU are exposed to the same sights and sounds like their parents, and some siblings may not have the cognitive capacity to fully understand what their brother or sister is experiencing. The responses of siblings of children with chronic illnesses including cancer have been studied extensively (Deavin et al., 2018; Havill, Flemin, & Knafl, 2019; Yang et al., 2016). Yet, only two studies (Kleiber et al., 1995; McMahon et al., 2001) have been published

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about siblings of critically ill children. These studies examined the siblings' information sources (McMahon et al., 2001), and self-confidence and depression (Kleiber et al., 1995) but did not characterize the sibling response to the PICU visit. Sibling stressors related to the hospitalization, resulting outcomes, and coping mechanisms remain unknown. Siblings visiting the PICU, therefore, may be at risk for developing negative reactions similar to those of their parents. The purpose of this study was to describe the experience of children visiting an acutely critically ill or injured sibling in the PICU.

The Family Adjustment and Adaptation Response (FAAR) Model (Fig. 1) (Patterson, 1988) was used to guide the approach of this study. The FAAR Model describes the work that families must do during crisis situations in terms of demands, meaning, and capabilities. Adjustment or adaptation by families depends on their ability to balance the demands of daily life and the stressors associated with their current situation, with available capabilities or resources (Patterson, 1988).

Methods

Design

A descriptive qualitative approach comprising one-to-one interviews was used to explore the siblings' experience during their visits to the PICU. This approach was used to learn about the siblings' observations and reflections of the whole experience of critical illness (Percy et al., 2015). We sought to summarize their experiences as they sensed them, using a theoretical framework to guide the development of the study but maintaining flexibility in the case that the data illustrate otherwise (Sandelowski., 2000).

Setting and participants

The Institutional Review Board process included a review of proposed strategies to prevent distress to the subjects. A plan was established to provide immediate evaluation and support for a child who reported thoughts of distress and self-harm during the interview including a referral to the Trauma and Grief Center located at the site. After approval was granted by the Institutional Review Board, siblings were recruited from an 84-bed PICU that cared for children with various critical illnesses. Parent presence at the bedside was encouraged, and siblings could visit in the PICU. As per unit protocol and whenever available, a Child Life Specialist met with the sibling prior to the PICU visit to provide an initial orientation to the environment. Child Life Services are also consulted during end-of-life situations.

Siblings were purposively sampled from the scheduled and unscheduled admission groups. From these groups, the study team sampled patients of various ages with varying severity of illness, diagnoses, appearance based on the number of indwelling catheters and tubes, and family structure (e.g., single parent, multiple siblings).

Siblings were included if they spoke English, were 9–17 years old, planned to visit the PICU, and were not developmentally delayed as reported by the parents. Siblings of children with a chronic illness may have unique experiences (Hamlett et al., 1992; Woodgate et al., 2016); therefore, this population was excluded. Siblings of children who were actively dying, defined as hours or days from imminent death with declining physiologic functions (Hui et al., 2014), were deceased (Eaton Russell et al., 2018; Brooten & Youngblut, 2017), or had a history of PICU hospitalization were also excluded.

The patient census was screened daily by the principal investigator (PI) for families who met the inclusion criteria. The research team consulted the bedside clinical team prior to approaching the family. Written informed consent was obtained from the parent or legal guardian of each participant. Participants were provided information about the study purpose and methods. Assent was obtained from the sibling immediately prior to the interview.

Data collection

Participant demographic data such as age and gender were collected from the parent prior to the interview. Interviews were conducted in a

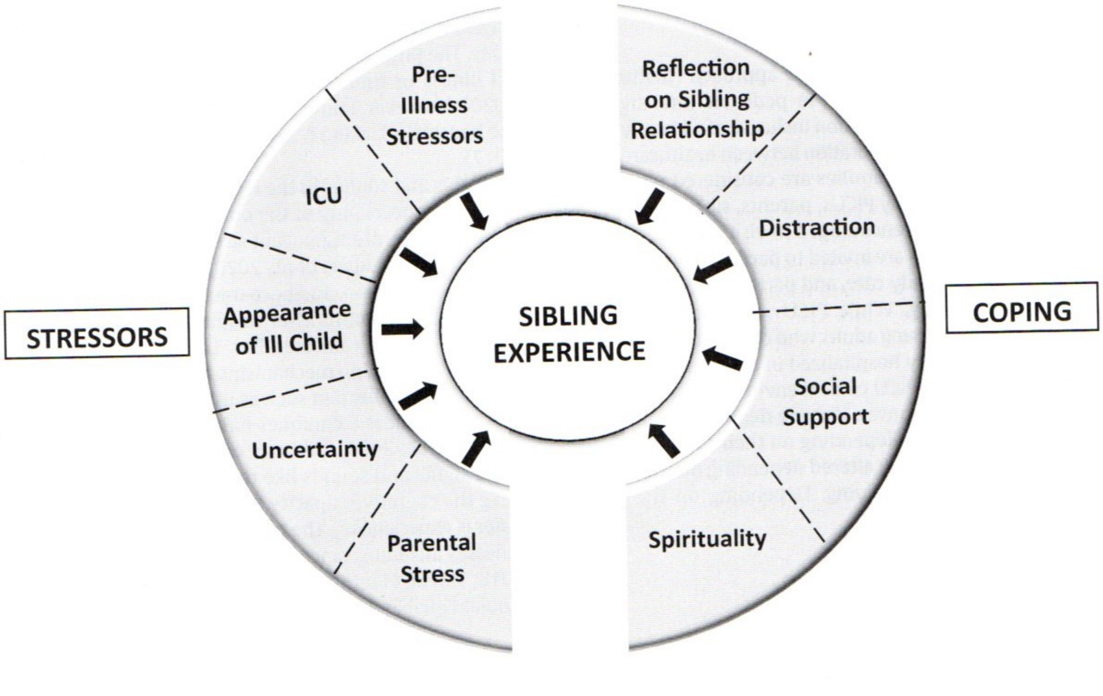

Fig. 1. Model of sibling experience in the PICU.

private room within the PICU. Siblings from the same family were interviewed separately. All interviews were audio- and video-recorded and transcribed by a professional transcription service. Clinician notes referring to the sibling(s), if present in the electronic medical record, were also reviewed by the PI.

The interview guide was based on the Family Adjustment and Adaptation Response model's (Patterson, 1988) concepts of meaning, demands, and capabilities (Table 1). This model describes the family's effort to maintain balance, using their capabilities and resources to meet their demands or stressors. As the sample was comprised of school-aged children and adolescents, the study team considered that there may be participants that may be unable to understand the questions or fully express the meaning of their feelings. Thus, directive and non-directive interviewing styles were used (Morrison & Flegel, 2018). A non-directive interviewing technique, using open-ended questions was initially used to allow the child to freely express their thoughts and emotions. Open-ended questions were aimed at exploring stressors, daily hassles, demands, and coping strategies related to the PICU visit, as perceived by the sibling. As the interviews progressed, direct, probing questions were asked to explore relevant topics that arose and to further elicit a description of the participant's feelings (Cox Rutter & Holbrook, 1988). Siblings were informed that they could ask to stop or pause the interview should they feel any discomfort or distress.

Play during interviews with children is known to allow the child to distance themselves from the emotions associated with the current situation, allowing them to speak freely about their feelings with an adult (Morrison & Flegel, 2018). To develop rapport with the sibling and to decrease potential anxiety about the interview, developmentally appropriate activities and toys such as coloring books, stuffed animals, and 3-D puzzles were made available to the sibling throughout the interview. Siblings were invited to select a toy or activity that they would like to play with while the interview was conducted. Interviews lasted approximately 20–30 min.

Qualitative analysis

Data were managed using ATLAS.ti (Scientific Software Development GmbH, version 8). Qualitative data analysis was conducted following Braun and Clarke's (2006) phases of thematic analysis. Inductive thematic analysis of the data was conducted to gain detailed accounts of the siblings' experiences (Braun & Clarke, 2006; Vaismoradi et al., 2013). Three research team members (KA, RC, and GW) reviewed transcripts independently to familiarize themselves with the data. Data analysis and the development of an initial codebook began after the first interview and continued after each subsequent interview. Data were initially categorized into broad categories such as stressors, impact, and coping. Data were further categorized into smaller subthemes (e.g. pre-illness stressors) as data collection and analysis progressed, and as patterns in the data emerged. Patterns across the dataset such as repeated exemplars describing uncertainty related to the illness became the themes and subthemes resulting from the study.

Table 1
Interview guide.

1. Tell me about what you know about your brother or sister's illness?
2. Tell me what it's like to visit your brother/sister in the hospital room.
3. Have you ever face-timed with your brother/sister while she/he is in the hospital?
4. What's important for you to know about your brother/sister right now?
5. Tell me about what you would be doing right now if your family wasn't in the hospital.
6. When you visited your brother or sister did you need help from your parents or the nurses/doctors with anything?
7. Do you have any worries or concerns about your brother/sister?
8. Tell me about the things that you think really helped you and your family while your brother or sister is here.

Analytical memos and reflexive notes were made during data analysis and periodically reviewed with the record of emergent codes by the team members (Saldaña, 2016). The research team met regularly to discuss the coded data, generate and refine themes, and resolve differences. Data from field notes, interviews, and clinician notes were compared and triangulated to ensure deeper, generalizable findings (Crabtree & Miller, 2000; Green & Thorogood, 2004). Data collection and analysis continued until data saturation and redundancy were reached at 16 participants. Saturation was deemed to have been met when the study team observed repetition in the data and no new themes or subthemes related to the sibling experience could be identified (O'Reilly & Parker, 2013).

Findings

Participants

Sixteen siblings of 10 PICU patients participated (Table 2). Of those, 56% were female, 69% were non-White, and one was the sibling of a scheduled admission to the PICU. Patient diagnoses included respiratory failure, newly diagnosed cancer, traumatic brain injury, stroke, sepsis, cellulitis, and cardiac arrest. The participants were from a variety of family structures, including single-parent families and stepfamilies. Sibling and patient characteristics are described further in Table 3.

Themes

Under the overarching theme of sibling experience, thematic analysis revealed two components—stressors and coping—and nine subthemes. An explanatory model using these themes and subthemes was developed to gain a better understanding of the siblings' experience (Fig. 1).

Sibling experience. At the core of the conceptual model is the siblings' experience during the PICU visit. Siblings' experience during their visit to the PICU was influenced by stressors and coping strategies associated with their siblings' hospitalization. Participants described their physical and emotional responses to stressors, including loss of sleep, feeling faint, shock, fear, worry, and sadness. The PICU hospitalization also impacted the participants' social life. Participants reported being absent from school, having extra chores at home, and missing social events with friends. Several participants shared that they completely stopped extracurricular activities so that they could focus their energy on their family. Family routines were disrupted by the hospitalization, thus siblings were often left under the care of extended family members or friends. Where and with whom the siblings ate and stayed for the night varied from day to day. Some participants reported a close relationship with the hospitalized sibling and discussed

Table 2
Summary characteristics of PICU sibling sample (N = 16).

Characteristic	No. (%)
Gender	
Male	7 (44)
Female	9 (56)
Race	
White	5 (31)
African American	3 (19)
Hispanic	5 (31)
Asian	3 (19)
Current age (years), mean (SD)	12.5 (3)
Patient length of stay (days) at time of interview, mean (SD)	6.3 (4.1)
Number of siblings of planned PICU admissions	1 (6)
Number of siblings of unplanned PICU admissions	15 (94)
Child Life preparation prior to visit	
Yes	9 (56)
No	7 (44)
First PICU visit prior to interview	
Yes	5 (31)
No	11 (69)

Table 3
Participant and patient characteristics.

Participant	LOS	Age (yrs)	Gender	Race	Family structure	Diagnosis (Patient)	Expected (E) vs. unexpected (U) admission	Appearance (patient)	CLS consult before visit?	First visit[a]?
1	7	11	M	Hispanic	Mother, father, patient has twin sister, older brother, younger sister	RSV bronchiolitis	U	NIV, sedated	N	Y
2	7	17	F	Hispanic	Parents are divorced, patient is younger sister of subject	Stroke	U	HFNC, central line, jaundiced, unable to move/speak	N	N
3	14	12	F	African American	Mother, step-father, patient has 3 sisters, 1 brother	Lymphoma, HLH	U	Intubated, arterial line, multiple drips	N	N
4	14	14	F	African American					N	N
5	14	17	F	African American					N	N
6	8	11	F	Caucasian	Mother, father, patient has a younger sister and younger brother	HLH	U	HFNC, jaundiced, central line	Y	Y
7	4	14	M	Caucasian	Mother, father, step-mother, patient has 2 step-brothers, younger sister, older brother	Stroke, intracranial hemorrhage	U	Intubated, EVD, art line, multiple drips, EEG leads	Y	N
8	4	10	F	Caucasian					Y	N
9	7	17	F	Asian	Mother, father, patient has 1 older sister	Flu, sepsis	U	Intubated, art line, multiple drips, HFOV	N	N
10	4	9	M	Caucasian	Mother, step-father, patient has 1 younger sister	Cellulitis, post-op debridement	U	NC, negative pressure drain, PIVs	Y	N
11	2	9	F	Caucasian	Mother, father, patient has 1 older sister	Brain tumor resection	E	NC, PIVs	Y	Y
12	3	15	M	Hispanic	Mother, father, patient has 1 older brother, younger sister	RSV bronchiolitis	U	Intubated, multiple drips	N	N
13	2	9	F	Asian	Mother, father, patient has 1 older brother, younger sister	Intracerebral hemorrhage, herniation	U	Intubated, EVD, multiple drips, warmer, arterial line, EEG monitoring	Y	N
14	2	15	M	Asian					Y	N
15	4	11	M	Hispanic	Mother, father, patient has 8 siblings, participant is oldest sibling	RSV Cardiac arrest	U	Intubated, sedated, infant warmer	Y	Y
16	4	9	M	Hispanic	Mother, father, patient has 8 siblings, participant is second oldest sibling				Y	Y

Note. LOS=Patient length of ICU stay at time of interview; CLS=Child Life Specialist; RSV = Respiratory Syncytial Virus; NIV=Non-invasive ventilation; HFNC = High-flow nasal cannula; HLH = Hemophagocytic lymphohistiocytosis; EVD = External ventricular drain; EEG = electroencephalogram; HFOV=High-frequency oscillatory ventilation; NC=Nasal cannula; PIV= Peripheral intravenous catheter.

[a] Sibling's first visit to the PICU at time of the interview.

feeling lonely with the sudden loss of their usual companion or playmate.

> "...She can make you laugh at any time... at your downest point... Playing around, wrestling, goofing around, stuff like that. All that's changed, because she's not home." (Female, age 14).

Stressors. Participants described experiencing five main stressors: pre-illness stressors, the PICU environment, the patient's appearance, uncertainty, and parental stress. Data revealed that these stressors did not occur in isolation. Participants reported experiencing several stressors concurrently. For example, a sibling may experience stress from the PICU environment and from their sibling's appearance.

Pre-illness stressors. Participants shared stressors that existed prior to their siblings' critical illness. These included coping with their parents' divorce, grieving another family member's death, and starting a new school. One participant shared a personal stressor unrelated to her sister's hospitalization, "I've actually been this way since my brother got locked up, so I'm kind of used to me breaking down out of time, you know, out the blue." (Female, age 17) Another sibling shared, "We had another, we had, our mom had another daughter but she passed a while ago... And, our step-dad also passed, so we were already kinda in a hole and then that happened." (Male, age 14)

PICU environment. Participants were asked about their impression of the PICU; the people, the rooms, the machines, the various sounds, and smells they noticed during the PICU visit. Siblings saw and heard other patients and families in the PICU, either while walking past a doorway or through windows. Seeing and hearing other families caused sadness and fear among the siblings: Siblings saw various healthcare workers going in and out of their brother or sister's room, often engaging with the parents only. A sibling shared,

> "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." (Female, age 17).

Those visiting the PICU for the first time reported their amazement at the size of the room and the view from the patient's window. None reported any memorable smells; however, all participants reported seeing and hearing machines, pumps, and monitors. Participants reported that they were unfamiliar with the machines and the different sounds that the machines made. They described the beeping or alarming of machines, pumps, and monitors as 'scary'. One recalled feeling lightheaded from witnessing an urgent situation unfold in her sister's room. During this particular event, several clinical team members rushed into her sister's room in response to monitor alarms. Another sibling described what she saw in the room,

> "I feel like what was scary...all the machines and all the medicine he was taking...there was a machine with all his ... medicine and stuff on there. So that made me kind of nervous. And there was ... all the stickers and all the ... stuff on there and all the doctors around...just

> machines ... and a tube...all I remember is ... a couple doctors in there. My mom and me crying. A lot of machines." (Female, age 10).

Appearance of the ill child. Disease and treatment of critical illness may cause the appearance of the ill child to change. The child may be unconscious, they may look swollen, their skin may be discolored, they may have lost limbs due to complications or trauma, and they may have many tubes and wires inserted into their body. Seeing their ill sibling in the PICU caused a variety of emotions among the participants: happiness, sadness, fear, guilt, and apprehension. A sibling described how he felt when he saw his brother, "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." (Male, age 15)

Participants interviewed during their first visit described the experience as shocking and surreal. They described distress associated with seeing the equipment attached to their siblings, some becoming tearful at the sight. One recalled,

> "... it's like this machine that goes through her and it ...circulates her blood...you could...see the blood and that was kind of 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 ...all the stuff sticking in her, it was just like kind of creeping me out." (Female, age 11).

Those who had visited their sibling in a more critical state before the interviews felt that their sibling was getting better because the ill child either had fewer tubes or did not appear as uncomfortable.

Uncertainty. All participants experienced uncertainties regarding where they would be staying for the night, the ill child's current health status, and whether the ill child would fully recover. These uncertainties led participants to worry about their own future, their sibling's survival beyond the PICU, and how they would cope with changes in family functioning. Unexpected admissions required families to rapidly arrange for the healthy siblings' care. This was also evident in notes written by clinicians who conducted psychosocial assessments of several families in the sample.

Because PICU patients' conditions often fluctuate, siblings learned that news about the patient can change dramatically and frequently. The condition in which they left their sibling may not always be the condition to which they return. One sibling likened her thoughts about her sister's illness to running a race,

> "...It's a lot go through my mind...before the doctors can even say anything, so many things run through my mind. It's like you're trying to run at one point, you're 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 is going through my mind." (Female, age 14).

Not receiving information about their sibling increased uncertainty for some participants. They received updates regarding their sibling's clinical status mainly by listening to conversations between their parents and clinicians or other adults. The participants were not consistently included in information sharing or decision making. Several participants expressed how the uncertainty just before receiving an update led them to worry about the ill child's progress. Participants also worried about the uncertainty of their siblings' future, including the potential for death and long-term loss of function. A sibling shared her worry about receiving news, "I'm scared they'll give us bad news... God, please just give us good news. I don't want to...no more bad news.... I just want to hear good news..." (Female, 14) Another sibling shared his concern for his brother's future health, "...is he going to have trouble, uh, like growing up. Not just right now as a baby but toddler, a kid and...is he going to be like, not less like, um, is he gonna need help when, when doing things?" (Male, age 11).

Parental stress. Participants described seeing their parents in a state they had never witnessed. A sibling described seeing his parent cry, "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. "(Male, age 14) Although their parents did not necessarily share their emotions verbally, their worries, physical stress, and desperation for a cure were evident. Participants saw their parents' sadness and fear when they received distressing clinical news. One participant described the stress he saw in his parents, "My parents just... they're in a state where they're very desperate for anything...My dad, he was trying to get them to...do any medicine...He wanted to try anything." (Male, age 15)

The impact of the hospitalization on the parents' physical health and disruptions to family routines were also reported by siblings. One participant shared how staying in the hospital had affected both of her parents,

> "I know my mom doesn't get a lot of sleep because the beeping, the machines...So I know she doesn't get much sleep at all, and I think it's just stressful. And my dad ...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." (Female, age 11).

Coping. Participants described coping strategies that fit into four subthemes: reflection on the sibling relationship, distraction, social support, and spirituality. Participants coped in various ways, including thinking about their relationship with their ill sibling, participating in activities that distracted them from the stressors, receiving community and extended family support for lodging, meals, and transportation, and praying to God. Similar to the stressors experienced by the participants, coping strategies were not reported in isolation. Coping strategies provided the participants with respite and hope. Strategies were either sought out by the participants because of a stressful experience or independently provided by a friend, clinician, family member, or community.

Reflection on the sibling relationship. Participants shared that they often thought about their relationship with the ill child to cheer themselves up, including thinking about shared happy moments. They expressed that by reflecting on these moments, they gained a deeper understanding of their relationship. One participant described her relationship with her sister, "... we do everything together...we're really strong together and... since she's not here with me all the time... you kind of lose that part from you, you know?" (Female, 17)

Distraction. Participants often turned to their friends, social events, or electronic devices to divert attention away from distressing situations. Participants attended homecoming and dances, watched television, went outdoors, played video games, and browsed social media. Other distraction strategies included dancing, listening to music, and looking at pictures on their smartphones. A sibling described what she did do distract herself, "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." (Female, age 17) The relief felt from these distractions, however, was temporary. While these strategies allowed the participants to tune out distressing thoughts and emotions, feelings associated with reality returned immediately after the distraction stopped. One participant described this temporary relief, "You know, get your mind off things. But you know, as soon as you come home, you just feel it again." (Female, age 17)

Social support. Participants were happy with the support their families received, including assistance with meals, sleeping accommodations, transportation to and from school and the hospital, and fundraising. Participants were supported by immediate and extended family members, community members, and peers from school. For most, support began soon after hospitalization. A participant reported, "...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." (Female, age 12) Support from close friends and family members was very helpful for the participants in the sample, "Well, my friends are just helping me but there's ...a lot of people that are just helping my parents and they bring food, give support, pray for him." (Male, age 15) Another sibling described the support her family received, "...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" (Female, age 11)

Some participants felt supported by the clinical team including clinical social workers, spiritual care providers, and especially the child life specialist. Prior to entering the PICU, these participants had a child life specialist orientation that 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. A participant described her experience with a child life specialist,

> "I saw the child life lady...and she kind of explained what's happening and...what all the beeping and machines are...kind of explained them...Yes, it did help because...she explained the machine stuff and that did help...Because it wasn't so much of...a shock walking into the room...I kind of knew about the machinery that was going to be in there when I walked in. So it wasn't as...shocking when I walked in."
>
> [(Female, age 11)]

As a result of the support they received, siblings reported feeling happy, supported, and less worried. "I actually don't think there's anything that we haven't gotten from relatives, or, and friends.... It makes me feel blessed." (Female, age 11) Although most of the coping strategies used by the participants in the sample provided temporary relief, these coping strategies made them feel hopeful.

In contrast, participants' communication with other clinicians such as nurses and physicians was less purposeful. They reported hearing bits of information from the periphery or while a procedure was occurring. One participant shared that she often was not a direct recipient of information, "...most of the time they just pull our mom on the side and tell her...what they're going to do..." (Female, age 14)

Spirituality. Participants shared that they prayed when they heard about their siblings' illness, before receiving updates from the medical team, and after any changes in clinical status. Prayer comforted participants during times of distress, giving them hope that their sibling would recover. One participant reported that she prayed more now than she ever did,

> "I do a lot of prayer, because I know God can help me through this. Only God can, not the way man can. God can help us more. He can make you feel good, you know, inside. You pray and you continue praying. It's just every day you want to wake up, you pray, I pray God...pray to God that my sister come home today or I pray to God...so God helps me through this."
>
> [(Female, 14)]

Another sibling shared what she did whenever she had trouble sleeping, "...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." (Female, age 10).

Discussion

The themes identified in this study illustrate the key elements experienced by siblings who visited a single PICU. Findings from this study suggest that a sibling's health may be impacted by the stressors associated with an ill child's hospitalization in the PICU. While the participants were not direct recipients of medical care or active caregivers of the patient, in varying degrees, all were affected physically, socially, emotionally, and spiritually by the critical illness and their visit to the PICU. Study participants used coping mechanisms to manage negative experiences associated with PICU hospitalization. Without guidance from their parents or other adults, they used their belief in a higher being to make sense of and cope with stressors. Participants actively sought out counsel from friends and extended family as their time allowed, and they turned to technology and social media to redirect their thoughts away from the current crisis. Particularly helpful for participants in the study was having access to a mobile device or gaming console, as a means to connect and communicate with others. Despite the presence of nurses, providers, and child life specialists in the PICU, and the availability of clinical social workers, spiritual care providers, and sibling support programs in the area surrounding the study site, families relied heavily on close relatives and their community for sibling support. Their reasons for not accessing available services for support are unknown.

Two previous studies reflectively assessed siblings' response to critical illness (Kleiber et al., 1995; McMahon et al., 2001). Neither study, however, sought to learn about the stressors, coping strategies, and experiences of siblings visiting the PICU. Parents were the primary source of information for siblings in the study by Kleiber et al. (1995) despite the parents' reported lack of confidence in their ability to provide information to their healthy children. Parents in the present study were also the primary sources of information to the siblings. The type of information provided to the siblings was similar to that identified by Kleiber et al., including the reason for the hospitalization, descriptions of the equipment, and descriptions of the ill child. The findings of the present study suggest that while well-meaning, this information was not well understood by siblings, which may have led to worry and fear.

This study highlighted the range of emotions that children may feel during the hospitalization of a sibling in the PICU. Due to the nature of critical illness and the ill child's changing health status, siblings' emotions fluctuated from happiness to fear within hours to days. This may be an expected finding given the timing of recruitment and data collection; interviews were conducted during the first few days or weeks of hospitalization in the PICU, typically a time of instability for a newly admitted patient. Although the present study did not measure levels of anxiety or depression, participants reported feeling worry and deep sadness. As found in previous studies of parents of critically ill children (Abela et al., 2020), all participants were distressed by the uncertainties associated with critical illness. The present study suggests that the effects of the visit may last beyond the initial date of PICU hospitalization.

The findings of this study were compared to findings from studies conducted among siblings of chronically ill children and children with cancer (Deavin et al., 2018; Havill et al., 2019; Yang et al., 2016). Similarities included the siblings' desire for complete and accurate information about the ill child's illness. 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 (Havill et al., 2019). In contrast, the participants in this study did not have the opportunity to gain a deeper understanding of the illness, perhaps due to the brief and episodic nature of the PICU hospitalization. In most cases, participants 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 the degree of information shared by the parents.

Participants in this study desired 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. In contrast, siblings of children with a chronic illness or cancer (Havill et al., 2019) may experience resentment of the family life changes associated with the illness.

With progressive exposure to their sick siblings' experiences, siblings of children with chronic illnesses and cancer eventually mature and adapt to their new roles within the changed family unit (Deavin et al., 2018; Havill et al., 2019; Yang et al., 2016), some becoming specialists of their brother's or sister's condition (Yang et al., 2016). As the families in the PICU were still in the acute phase of the initial hospitalization, and changes to family life occurred suddenly, the participants in the present study may not have yet adjusted to the critical illness. Their emotions 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 participants 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 peer support groups throughout treatment and after hospitalization, while the siblings in this sample relied on their friends and family members. The importance of preparing siblings with information about the PICU environment was evident in the findings and consistent with literature (Deavin et al., 2018; Nabors & Liddle, 2017), thereby promoting the adoption of child life services.

Limitations

PICUs in different regions vary in size, scope, and appearance. It is possible that siblings who visit these environments may have different experiences. This study was conducted at a single institution with English-speaking families. However, the sample comprised various races and family structures, reflective of the population typically admitted to the study site. The purposive sampling strategy ensured clinical diversity; however, other factors such as the frequency and duration of the PICU visit, consultation with a child life specialist, and other patient or family characteristics may have contributed to the sibling experience. Because this study was conducted during the acute phase of critical illness, the long-term impact of the hospitalization and PICU visit were not explored. Finally, the sample comprised mostly siblings of patients unexpectedly admitted to the PICU. Their experiences may have been more pronounced than those of siblings of patients whose hospitalization was planned. The sibling of a patient who was a scheduled admission, however, shared similar experiences with the rest of the sample described in the study.

Implications for practice

For organizations seeking to adopt a family-centered care delivery model in which sibling presence at the bedside and engagement in care are encouraged, the sibling's perspective is key to understanding the impact of critical illness to the family unit. Clinicians caring for critically ill children should acknowledge the presence of the healthy sibling and recognize the potential impact of the hospitalization on their health. As siblings may be impacted beyond admission, sibling support should be made available to the family throughout the ill child's hospitalization. Support should extend beyond the initial visit or end-of-life situations, and should be offered by all clinicians who interact with the family in an organized, planned manner. Communication and education about the PICU and the ill child should include developmentally appropriate information that is in the style and language that would be best understood by the ill child's sibling. The clinical team can designate a consistent person to communicate any updates regarding the plan of care with the sibling. Additionally, existing family support programs can be strengthened by addressing the stressors and associated needs identified. Parents and siblings 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 and communication with the hospitalized child.

Implications for education

Programs aimed at providing clinicians with an introduction to the patient- and family-centered care approach should include specific content related to the sibling impact of visiting the PICU. Clinical team members would benefit from learning about potential negative reactions to visiting the PICU. In addition, clinicians can be equipped with strategies and resources to prevent or mitigate negative reactions. Teaching methods such as simulation or role playing may help clinicians become more comfortable with engaging family members of varying developmental ages in conversation. Potential simulation objectives may include engaging children of different developmental ages in discussion, explaining routine PICU care to children, recognizing a distressed sibling, and providing anticipatory guidance to parents regarding potential sibling impacts of the PICU visit.

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. The FAAR Model by Patterson (1988) was used to develop the study and the interview guide however, a new model was derived from the findings. Further research to explain the relationships between identified categories is needed. For example, the short- and long-term influence of stressful sights, sounds, and events experienced by the sibling during critical illness, on mental health outcomes should be examined. Exploration of developmentally-appropriate coping strategies that may be beneficial to the sibling is also needed. Additionally, the influence of spirituality on the sibling's emotional health, for example, may be an important area of future research. There is also an opportunity to develop and test the effectiveness of services to support siblings during the hospitalization and beyond discharge. Finally, technological solutions (e.g., web-based support groups) can be explored as a mechanism to facilitate peer support programs focused on the psychosocial needs of the sibling.

Researchers planning to study children and their families in the PICU should address ethical considerations early during the study design stage. Families and children in the PICU potentially are experiencing a significant amount of distress at the time of recruitment and data collection; additional strategies are needed to ensure that no further distress resulting from study activities occurs. In most PICUs, parents are encouraged to be active participants in care and decision-making. Patient care or interdisciplinary rounds occur at varying times of the day and night in the PICU. It is also possible that families may have received upsetting news regarding the ill child's clinical status prior to the study team member's visit. Collaboration with the clinical team is important to identify the most appropriate time to approach families.

Parents and children may be hesitant to decline participation in a study. During the consent process, researchers must emphasize that the care and management of the ill child will not be impacted by participation or non-participation in the study. This is particularly important if any of the study team members are also members of the clinical team.

Parents may also need some additional time to read the consent form. Parents may be experiencing disruption in sleep and meal schedules due to the hospitalization, and they may be actively providing care to the ill child. Researchers should consider the potential concern and worry the parents may have for the wellbeing of the healthy child participating in an in-person, private interview. If possible, privacy for the participant and proximity to the parent can be balanced by selecting a space that is easily accessible to the parent (e.g., a room close to the ill child's bed space). Careful attention should be given to providing the participant with a comforting and calming environment.

Conclusions

Findings from this study provide insight into the needs, stressors, coping strategies, and overall impact on the well-being of siblings of acutely critically ill children in the PICU. Although siblings may appear to be coping well with the hospitalization, they may be experiencing distress internally. Family-centered care delivery models within the

PICU environment have allowed healthy children to visit the ill child, yet the exposure of healthy children to potentially traumatizing experiences related to having a sibling in the ICU was not well-understood until the present study. Currently, no standardized approaches are used to prepare siblings for their PICU visit, and organizations seeking to develop strategies to mitigate the psychological impact on siblings may be under-resourced. Not meeting this need potentially places the sibling at risk for subsequent negative psychological, physical, and social outcomes and increases the overall burden of critical illness and injury on the family unit.

Contributors' statement page

Dr. Abela conceptualized and designed the study, designed the data collection instruments, collected data, carried out the analysis, drafted the initial manuscript, and revised the final submission.

Dr. Casarez conceptualized and designed the study, designed the data collection instruments, supervised data collection and analysis, carried out the analysis, and reviewed and revised the manuscript.

Dr. Kaplow conceptualized and designed the study, designed the data collection instruments, and reviewed and revised the manuscript.

Dr. Wood conceptualized and designed the study, designed the data collection instruments, supervised data collection and analysis, carried out the analysis, drafted the initial manuscript, and reviewed and revised the manuscript.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Disclosures

The authors have nothing to disclose.

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