

THE EXPERIENCE AND PERCEPTIONS OF SIBLINGS OF PEDIATRIC
INTENSIVE CARE UNIT PATIENTS: A QUALITATIVE STUDY

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DEDICATION

For my husband, Vernon, who has been my steadfast supporter since we were teenagers; for my parents, who had that role before him; and for my sisters and brothers, who have always taught me about the importance of sibling relationships in life.

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ABSTRACT

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Over 200,000 patients are admitted into pediatric intensive care units (PICU) annually in North America, exposing families to extreme psychosocial stressors and adverse outcomes. While previous research has shown PICU patients and their parents experience post-traumatic stress disorder, few studies have addressed post-PICU outcomes in siblings and siblings' voices of their own experience are absent from the literature.

The purpose of this study was to understand the experiences of school-aged and adolescent siblings, ages 6 to 17 years, whose brother or sister experienced admission to a PICU due to a critical illness or injury. Interpretive phenomenology was used to gain an in-depth understanding of the experiences and perceptions of the lived experiences of siblings of PICU patients.

Seven participants were identified from a list of families whose child was in the PICU at Dell Children's Medical Center within the past 2 years and discharged from the hospital for three months or longer. Families were screened for the presence of siblings in the household and for additional inclusion and exclusion criteria before being approached for to participate in the study. Those families meeting criteria received a study information letter and follow up phone call inviting them to participate and providing

contact information for the researcher if they wanted to receive further information on the study.

Data collection consisted of demographic information to describe the sample and semi-structured interviews to address the research questions. Interviews were conducted either face-to-face prior to the COVID-19 pandemic or by videoconference during the pandemic, and audio recorded and then transcribed word-for-word. Data analysis and interpretation utilized Colaizzi's methodology and Merleau-Ponty's *Phenomenology of Perception* (2012). Four themes emerged from the data: What I Remember; What I Felt; What Helped; and What's the Same and What's Different.

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CHAPTER I

INTRODUCTION

Focus of Inquiry

Hospitalization of a child dramatically affects the entire family, including the healthy siblings of the patient. Family-centered care initiatives in recent years (Davidson et al., 2017; Meert et al., 2013) have promoted family presence at the bedside and family involvement in care in both acute care settings and intensive care units, but knowledge of interventions to prepare siblings to visit has not kept pace with these efforts. Early studies with siblings of hospitalized children identified categories of concern that include separation from hospitalized siblings, worry about the sibling, and fear about the outcomes of the sibling's illness or injury and that the expressed needs of well siblings include information about their brother or sister (Kleiber et al., 1995; Lewandowski, 1992; Rozdilsky, 2005). Recent work (Bronner et al., 2010; Colville & Pierce, 2012; Nelson et al., 2019; Stremmler et al., 2017) in the pediatric intensive care unit (PICU) has demonstrated the psychosocial effects of PICU hospitalization on patients and their parents, but siblings of critically ill children have received almost no attention in the literature.

Statement of Purpose

The purpose of this study was to explore the lived experience of school aged and adolescent siblings of PICU patients and the perceptions of the sibling relationship

following discharge from the hospital. Through semi-structured individual interviews, siblings described their experiences of their brother or sister's PICU hospitalization and their perceptions of the sibling relationship following hospital discharge.

Rationale for the Study

Nearly 90% of the Western population have a sibling (Milevsky & Heerwagen, 2013). Research has shown the benefits of having a close sibling bond, including enhanced psychological and emotional health (Milevsky, 2005), and the role of siblings in navigating childhood and learning social interaction is well established (Akerlund, 2017). Positive sibling bonds may have a buffering effect on the development of adverse outcomes, promoting mental health and life satisfaction, and may compensate for a lack of positive peer relationships (Portner & Riggs, 2016). Changes in sibling relationships over time, especially during life transitions such as moving from adolescence to emerging adulthood, occur along a typical trajectory, with fewer conflicts and greater closeness and support (Portner & Riggs, 2016).

While not all sibling relationships may be considered warm or supportive, the sibling relationship is nonetheless one of the most enduring relationships that humans experience. Disruptions in the sibling relationship due to separation, trauma, or life-altering events can impact the social and emotional development of children. A life-threatening illness or injury requiring PICU hospitalization and the associated long-term outcomes represents a significant event in a family and may result in disruption of relationships and lead to long-term outcomes. While researchers have investigated the

experiences of siblings of children hospitalized for acute and chronic conditions, the unique experiences of siblings of PICU patients remains unexplored.

Philosophical Underpinnings

Phenomenology

The phenomenological movement in philosophy marked a departure from positivist thought, rejecting the position that knowledge can only be derived from empirical observations. Edmund Husserl, considered the pioneer of phenomenology, introduced the concepts of phenomenological intuiting, whereby phenomena are contemplated and explored, and phenomenological reduction, whereby previous ideas of a phenomenon are suspended, and a fresh perspective gained through critical analysis (Husserl, 2017). Through phenomenological intuiting and phenomenological reduction, Husserl proposed a radical transformation of the approach to scientific inquiry. As an epistemology, phenomenology emphasizes the role of experience and perception in knowledge development. Assumptions of phenomenology include the concept of knowledge as socially constructed and therefore continually developing; that knowledge can be gained from experience, art, and science; all research is inherently biased; knowledge about family worlds is epistemologically important; meaning in everyday life is significant; and meaning of events varies from person to person (Boss et al., 1996).

Merleau-Ponty's Phenomenology of Perception

Influenced by Husserl, Maurice Merleau-Ponty furthered phenomenological thought through his work relating knowledge to the body, experience, and the perceived world. Merleau-Ponty's Phenomenology of Perception emphasizes the role of the body in

experience and perception as the primary sources of knowledge, describing humans as embodied beings who experience phenomena and gain knowledge through the body. His tenet of embodiment holds that we are beings situated within the world, experiencing the world through our bodies, especially through perception (Merleau-Ponty, 2012). The body is the individual's point of view and is itself the knowing subject (Merleau-Ponty, 2012; Polifroni & Welch, 1999). Perception is engaged and embodied knowledge of the world and is our primary means of experience and source of knowledge. In its application to research, Merleau-Ponty's *Phenomenology of Perception* requires an interpretive or hermeneutic approach, as it focuses on interpretation to understand experience within the context of the lifeworld.

Throughout his work, Merleau-Ponty focused on children and their experiences and perceptions. In addition to his extensive philosophical work, he held a position as lecturer in child psychology and pedagogy at the Sorbonne University of Paris from 1949 to 1952 (Welsh, 2010). His lectures during this time build on the tenets in his previous works *Phenomenology of Perception* and *The Primacy of Perception* to further develop his philosophy of children's perceptions and experiences (Merleau-Ponty, 2010; Welsh, 2010). Merleau-Ponty held that perceptions and relationships are a "structuring of the child's experience" (Merleau-Ponty, 2010, p. 241) and that a child's perception of his role within the family arises from perceptions. Thus, the child's sense of self and identity are heavily influenced by family relationships, life events, and the child's perception of those events and their outcomes.

As a research methodology, phenomenology is concerned with the study of individual's subjective experiences and perceptions (Butts & Rich, 2018).

Phenomenological research aims to describe a type of experience as it was lived, interpret a type of experience relevant to context, or analyze the form of a type of experience (Smith, 2013). The interpretive phenomenology approach to a research problem seeks information that places the lived experience in the context of the lifeworld; these descriptions would include details of the activities, interactions, time, and experiences of the body (Lopez & Willis, 2004). An example of this approach is looking at the lived experience of informants in a research study and their viewpoint of the phenomena to gain understanding of how others may experience the same phenomena.

Very little is known about the experience of siblings of PICU patients and how these experiences shape family relationships; the individuals living this experience are the best informants of the phenomenon. These questions can only begin to be answered by analyzing the data provided by these informants. Phenomenological research and Merleau-Ponty's philosophy provide a means to highlight the perception of the individuals and gain understanding of meaning within the context of their experience. By first exploring this phenomenon, we can work toward improving how siblings are involved in and learn about their brother or sister's care and support the family in transitioning from the intensive care environment and into post-hospital life.

Summary

This chapter discussed the increased need and importance of investigating the sample population of PICU siblings, the purpose and rationale for this study, why it is

needed, and the philosophical orientation and assumptions that underpin the study, Merleau-Ponty's Phenomenology of Perception. Merleau-Ponty emphasized perception as the primary source of knowledge and wrote extensively on children's perceptions of the world in shaping their development and identity. Children define themselves through family relationships and their role within the family; life events influence the child's sense of self and traumatic events may disrupt the relationships that are foundational to development. Using interpretive phenomenology to capture informants' descriptions of their experiences and perceptions of having a sibling hospitalized in the PICU and the effect on the sibling relationship is needed to gain understanding of this phenomenon.

CHAPTER II

REVIEW OF THE LITERATURE

More than 230,000 children and adolescents are admitted to the PICU annually in the United States (Watson & Hartman, 2014) and the number of PICU beds in the US increased 43% from 4,135 to 5,908 between 2001 and 2016 (Horak et al., 2019). It is anticipated that 1,000,000 children will be hospitalized in the PICU over the next decade (Watson et al., 2018). Children are admitted to the PICU for planned surgery for complex health conditions, acute illness or injury, or acute exacerbations of complex chronic conditions (Society of Critical Care Medicine, 2019). The length of stay is longer than seven days for greater than 35% of PICU patients, and more than 40% of patients require mechanical ventilation (Society of Critical Care Medicine, 2019). Children with complex chronic conditions, defined as “chronic conditions in ≥ 2 organ systems, a progressive condition associated with decreased life expectancy, malignancy, or technology dependence” comprise 53% of PICU admissions and consume 75% of PICU resources (Chan et al., 2016, p. 198).

The successful treatment of children with critical illness or injury has significantly decreased mortality rates in the PICU population over the past three decades to 3–5% (Namachivayam et al., 2010), but with an ensuing increased morbidity following PICU admission (Pollack et al., 2014); the rate of comorbid conditions in critically ill children was reported at 41% in 2006 (Odetola et al., 2010). A greater number of children leave

the PICU facing a complicated post-ICU course and extended need for follow up treatment. With this change in the PICU patient population, the focus of the critical care community has shifted to include optimization of outcomes in survivors of critical illness or injury and their families (Choong et al., 2018; Colville et al., 2009; Davidson et al., 2012; Manning et al., 2018; Merritt et al., 2018; Needham et al., 2012).

In 2012 two taskforces created by the Society of Critical Care Medicine identified and described outcomes in adult patients and families as including physical, cognitive, mental health, and social domains; these outcome experiences were conceptualized as Post Intensive Care Syndrome (PICS) and Post Intensive Care Syndrome—Family (PICS-F; Davidson et al., 2012; Needham et al., 2012). The psychosocial sequelae of PICU admission on the family reflect that admission to PICU exposes families to extreme stressors, including separation (Hagstrom, 2017). Studies have demonstrated that heightened maternal anxiety post-PICU is predictive of heightened child anxiety (Lopes-Junior et al., 2018; Rennick et al., 2014), and that 17% to 62% of children and 13% to 35% of parents experience post-traumatic stress disorder (PTSD) following PICU admission (Lopes-Junior et al., 2018). Current work in pediatrics has focused on PICU patients and their parents, with a paucity of studies addressing the experiences of siblings of PICU patients; these primarily reflect parent or other adult-report (e.g., teacher or child life specialist) information on sibling functioning (Hagstrom, 2017; Merritt et al., 2018; Terp & Sjöström-Strand, 2017). Tunick et al. (2013) reported on pediatric psychology critical care consultation reasons and identified assistance with child coping to PICU-related stress along with parent and family support as the most common reasons for

psychology referrals, accounting for 40% of referrals. However, only 6.9% of all referrals were for support for a sibling (Tunick et al., 2013).

Manning et al. (2018) conceptualized the outcome experiences of PICU patients and families as Postintensive Care Syndrome- pediatric (PICS-p), which recognizes the role of siblings in the family as an interdependent unit and includes outcomes in the domains of physical, cognitive, emotional, and social health. Published literature reviews on the current state of knowledge of post-ICU outcomes in children and their families reflect that the experience and needs of siblings represents a key gap in knowledge (Shudy et al., 2006; Watson et al., 2018). Literature search of academic databases located only two studies that captured self-report data from PICU siblings (Carnevale, 1999; Manning et al., 2017).

Hospitalized children with serious or life-threatening illness or injury (e.g., sepsis, respiratory failure, burn injury, trauma, spinal cord injury, or traumatic brain injury), and those identified as having a complex chronic condition (e.g., diabetes, spina bifida, cystic fibrosis, cancer, or progressive neuromuscular disease) have frequently experienced admission to the PICU, suggesting that siblings of these patients may have similar experiences to siblings of PICU patients and that, research in these siblings may inform understanding of the experience of PICU siblings of PICU. The purpose of this literature review is to synthesize the published literature on outcomes in school age and adolescent siblings of children hospitalized in the PICU or who have experienced a serious or life-threatening injury or illness using the described domains of PICS-p: physical, cognitive, emotional, and social health.

Conduct of the Literature Review

This systematic review was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher et al., 2009). A systematic search of the literature was conducted using the databases Academic Search Premiere, Child Development & Adolescent Studies, CINAHL, Health Source: Nursing/Academic Collection, MEDLine, PsycARTICLES, Psychology and Behavioral Sciences Collection, and SocINDEX. Search terms used were: “outcomes” AND “siblings” AND “pediatric” AND “hospital*”; “siblings” AND “hospitalization”; “sibling*” AND “intensive care”. Additionally, PubMed was searched using MeSH terms “adolescent, hospitalized” OR “child, hospitalized” AND “siblings”; and “intensive care unit, pediatric” AND “siblings”. The search was limited to the 21-year period from 1999 to 2020, coinciding with the first availability of comparative data for benchmarking PICU outcomes (Epstein & Brill, 2005), English language, and peer reviewed publications. The reference lists of identified articles were hand searched to find relevant articles not identified by database searches. See Figure 1, PRISMA Flow Diagram Search Results.

Included articles were English language, peer reviewed, primary research reports that addressed experiences and psychosocial outcomes of siblings from the siblings’ perspective and that utilized data collection methods that included data gathered directly from the siblings. Articles were excluded that used siblings as a control or comparison group in a study, that focused on end-of-life or sibling death, that reported outcomes from

only the parent or other adult's perspective, utilized parent-report data only, or that focused on neonatal or adult patients or adult siblings, and any gray literature.

Results

Thirty-one studies were identified examining self-reported experiences and outcomes in school age and adolescent siblings of children with serious or life-threatening illness or injury; 14 quantitative, 15 qualitative, and one mixed methods. One study author identified the method as mixed method, qualitative dominant; this study is counted as qualitative for this review (Lehna, 2010). For studies utilizing both parent- and sibling-report data, only findings germane to the sibling's self-report data are included in this review. See Table 1, Summary of Literature of Children with Siblings with Life-threatening or Critical Illness or Injury.

Table 1*Summary of Literature of Children with Siblings with Life-threatening or Critical Illness or Injury*

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Pit-ten Cate and Loots (2000)	mixed method	to investigate experiences of brothers and sisters with physical disabilities	43 siblings (ages 10 – 19 years) of a child with spina bifida, cerebral palsy, or multiple impairment	-most stressful situations identified by siblings (for CRI-YF completion) included illness or hospitalization; siblings used all coping strategies at an average level c/t norm group -siblings reported difficulties communicating with their brother/sister; most siblings worried about the future and the health of their brother/sister; they acknowledge their parents' attempts at equal treatment even though the parents are not always successful	-Study sample may not reflect diversity of all families within population -Self selection of participants -Over representation of two-parent families -Participant families had a higher education level than the population norm -Trustworthiness established through interview and analysis techniques -saturation achieved with sample -Quantitative instruments have established reliability and validity
Akhtar et al. (2012)	Qualitative; interpretive phenomenological	to examine the experiences of healthy children of siblings with pediatric spinal cord injury	8 participants between the ages of 7 and 18 years	three main themes were identified: life interrupted; what about me?; and my safety net	-Small sample size of heterogeneous participants -Self selection of participants -Possible over representation of two parent families -Data analyzed using Interpretive Phenomenological analysis (IPA) -saturation achieved with sample

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Bellin at al. (2008)	Qualitative; content analysis	To describe the sibling's experience of living with a brother or sister with spina bifida	155 siblings of a child with spina bifida	Four domains captured the lived experiences of siblings of youths with SB: the rewards and consequences of SB; the journey toward acceptance of SB; the emotional climate of siblings; the qualities of the social environment of siblings	-lack of demographic diversity -Participants responses were written, relying on ability of participant to express themselves this way -lack of opportunity for follow up or probing questions -Data analyzed using Content Analysis; -Lincoln & Guba's criteria for trustworthiness cited -saturation achieved with sample
Bugel (2014)	Qualitative; phenomenology	to describe and understand the experience of being a well school-aged sibling of a child recovering from a traumatic injury	Seven school aged siblings ranging in age from 8 to 12 years	Two major themes emerged: changes and constants siblings expressed needs regarding communication and individual identity	-Single interviews were conducted with each participant -limited sibling diagnoses may not represent all trauma -Van Manen's method of analysis used -Detailed description of trustworthiness using Lincoln & Guba's criteria -saturation achieved with sample
Bugel (2018)	Qualitative; phenomenology	to uncover principle themes inherent in the experience of school age siblings of children with a	Seven school age (8 to 12 years) siblings of children who suffered burn injury	four main themes (compassion; a difficult experience; changes; and constants) and three overarching meta themes (sadness, empathy, altruism); the most prevalent and strongest theme was compassion	-limited demographic (age) -Van Manen's method of analysis used -Detailed description of trustworthiness using Lincoln & Guba's criteria -saturation achieved with sample

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
		severe traumatic injury			
Carnevale (1999)	Qualitative; phenomenology	to examine the experience of families with a critically ill child	10 families, 4 months to 5 years following critical illness; nine siblings ages 5 – 22 years	The central phenomenon of the study is trying to recapture our previous lives; experiences of siblings were described as ‘what about me?’ siblings expressed sentiments of isolation and relative insignificance; children both missed their sibling and resented the disproportionate amount of attention the sick child received	-self selection of participants -limited demographics -Detailed description of trustworthiness using Lincoln and Guba’s criteria -saturation achieved with sample

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
D'Urso et al. (2017)	Qualitative; thematic analysis	to explore the experiences of siblings of children diagnosed with cancer	six siblings of children diagnosed with cancer	Main themes: difficult emotions, strengthened relationships, and personal development. Siblings experienced a range of difficult emotions throughout the cancer trajectory as well as experiencing remarkable changes in their lives, including increased empathy and resilience, improved family relationship, disrupted routine, increased responsibility and perceived changes in the ill child	-Research could have been more robust by using triangulation -Use of “survivor” label may have bias participant response -Data analyzed using Thematic Analysis -Methodological rigour described using Tobin and Begley (2004) -saturation achieved with sample
Fleitas (2000)	Qualitative; thematic analysis	to examine the response of siblings to complex illness and disability and offer a thematic distinction between the stresses they experience and the competencies they acquire	comments from siblings gathered through two venues: notes shared in response to an invitation on a website, and comments from children visiting hospitalized brothers or sisters	themes depicted are stress (responsibility, loneliness/resentment, fear, jealousy, guilt, sadness, embarrassment, and confusion) and resilience (lessons learned, independence, altruism)	-self selection of participants -convenience sample -lack of structured interview guide -saturation not addressed -Data analysis and trustworthiness not described

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Hilkner et al. (2019)	Qualitative; narrative inquiry	to compile perceptions of siblings of children hospitalized due to chronic disease	four siblings (ages 7 – 17 years) of children hospitalized for chronic diseases	Four categories of results were identified: coping with the sibling's disease; family restructuring; experiences resulting from the siblings' hospitalization; and experiences of exclusion.	-small sample -Analysis using Bardin's content analysis -Trustworthiness addressed through use of Consolidated criteria for Reporting Qualitative research (COREQ) -saturation achieved with sample
Hollidge (2001)	Qualitative; thematic analysis	to investigate the psychological experience of well children living in the same household as child siblings with diabetes	28 well siblings of patients between the ages of 8 and 12; parent report data on measures of anxiety and depression	personal coping resources correlated significantly with healthy siblings' duress responses	-self selection of participants from one clinic; limited representation -lack of single parent families -Qualitative findings triangulated with parent-report data on standardized instruments -saturation achieved with sample
Lehna (2010)	Qualitative; life story process	to understand, primarily from the sibling perspective, the effect of a child's major burn injury on his or her sibling	participants from 22 family cases and 40 individuals; siblings were ages 4 to 11	The central thematic pattern was normalization. Two components of normalization were described: areas of normalization and the process of adjustment	-Noted that participants were not very talkative -interviews conducted by telephone -length of time between interview and hospitalization may have been too long per author -Narrative analysis used -Detailed description of trustworthiness using Lincoln and Guba's criteria -saturation achieved with sample

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Manning et al. (2017)	Qualitative; content analysis	to report the findings from a multiple-stakeholder consultation event that aimed to identify the priorities for services and research with CYP and families who have survived childhood critical illness	eight children and young people (CYP) aged 7 to 15 who were critical care survivors or their siblings; parents and adult caregivers	future services, interventions and research must be holistic and family-centered; priorities focused on initiatives to optimize the lives and longer-term functional and psychosocial outcomes of PICU survivors; lack of support for siblings needs to be addressed.	-limited demographics -homogeneity of illness categories -Data analyzed using inductive content analysis -Transferability of findings addressed -saturation achieved with sample
Nabors et al. (2017)	Qualitative; thematic analysis	to examine the perceptions of children with illnesses and their siblings using a play interview	Eight siblings ranging in age from 3 to 12 years	Themes indicated resilience in child functioning for both patients and siblings Brothers and sisters of children with chronic illness could experience loneliness; a more common report was a strong desire to help and be a support for a sibling with an illness	-Questions did not address negative emotions -findings could be strengthened through triangulation with interviews from parents and medical team -Content analysis was used -detailed description of member checking provided -Trustworthiness addressed using Lincoln and Guba's criteria -saturation achieved with sample

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Prchal and Landolt (2012)	Qualitative; content analysis	To describe the experiences of siblings of pediatric cancer patients in different areas of life in the first half-year after the cancer diagnosis	7 siblings of pediatric cancer patients ages 11 – 18 years	23 categories of experience were identified. In all areas, siblings reported difficulties but also identified important resources	-all siblings were older than patient -Time lapse since diagnosis was large -serial interviews might capture more comprehensive data -Mayring's content analysis was used -Findings subjected to peer checking -saturation achieved with sample
Sloper (2000)	Qualitative; content analysis	To capture siblings' perceptions of their experience at 6 and 18 months after their siblings' cancer diagnosis	64 siblings ages 8 to 16 years of children with cancer	Themes reported were losses and gains. Siblings reported losses in their own lives: attention, family routine, certainty and security, and companionship of the ill child. Gains included closer family relationships, increased independence, or understanding and compassion, and increase in family and social activities. Supportive relationships were reported to be important resources.	-only siblings closest in age to patient included -Analysis subjected to peer checking -Trustworthiness criteria not addressed -saturation achieved with sample
Woodgate (2006)	Qualitative; content analysis	To describe findings on interpreting and understanding siblings' perspectives of the childhood	30 siblings (age 6 to 21 years) of children with cancer	Three themes relating to a different way of being in the family were identified: committing to keeping my family together, being present, and enduring sadness	-wide age range of subjects -lack of cultural diversity -Data analyzed using constant comparison -Study author indicates Lincoln and Guba's criteria used to enhance rigor -saturation achieved with sample

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
		cancer trajectory			
Alderfer et al. (2003)	quantitative	To investigate whether adolescent siblings of childhood cancer survivors experience posttraumatic stress (PTS).	78 adolescent siblings of adolescent cancer survivors	49% of subjects reported mild PTS and 32% indicated moderate to severe levels.	-subjects were drawn from an intervention study, indicating an increased willingness to participate in research -demographic differences between groups -use of self-report instruments
Alderfer and Hodges (2010)	quantitative	To determine if family-school partnerships are of value in meeting the mental health needs of siblings of children with cancer.	161 siblings (ages 8 to 18) of children with cancer and one of their parents; teachers for 51 of the children	Reports by siblings did not indicate greater rates of anxiety or depression, but over half experience moderate to severe cancer-related posttraumatic stress symptoms. Siblings also scored in the impaired range for social competence. School-based support is important and potentially protective.	-lack of comparison group -cross-sectional method does not support longitudinal findings

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Barrera et al. (2004)	quantitative	To examine the role that emotional social support plays in the psychological adjustment of siblings of children with cancer.	two groups of siblings of children being treated for cancer: siblings referred for behavior problems ($n = 47$) and a comparison group of non-referred siblings ($n = 25$).	Siblings who reported more social support endorsed significantly fewer symptoms of depression, anxiety, and fewer behavior problems. High level of social support appears to play a protective role in psychological adjustment of siblings of pediatric cancer patients.	-use of specific social support instrument limits generalizability -limited demographics -small sample size
Bellin et al. (2009)	quantitative	To explore the relationships between select individual, family, and peer factors and sibling adjustment	224 adolescent (age 11 to 18 years) sibling/parent dyads [parent data on clinical and demographics only]	Attitude toward spina bifida, family satisfaction, sibling warmth & conflict, and classmate & close friend support were strongly associated with self-concept, prosocial behavior, and behavior difficulties	-recruitment strategy may have resulted in selection bias -lack of comparison group -cross sectional methodology limits inference of longitudinal findings

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Coban et al. (2017)	quantitative	To investigate PTSD and HRQoL in siblings (donor and non-donor) of pediatric BMT survivors and PTSD in their mothers, compared to healthy controls	35 siblings (ages 8 to 14) and their mothers and 35 healthy peers and their mothers	Both children and mothers in the study group obtained significantly higher PTSD rates than the healthy peer control groups. Children in the study group also reported significantly poorer HRQoL than the control group in all scales. There was a significant negative correlation between siblings' and mothers' PTSD scores and siblings' PedsQL scores, indicating that PTSD symptoms in siblings and mothers led to impairment in siblings' HRQoL or vice versa	-Cross sectional design -small sample size -only siblings closest in age to patient included
Gursky (2007)	quantitative	To test the effect of child life specialists providing deliberate educational intervention to siblings of hospitalized children, based on their developmental and cognitive level	Siblings age 6 to 18 years of hospitalized children; 25 in intervention group and 25 in control group	Siblings who received educational interventions had significantly lower anxiety levels after interventions compared to siblings to who did not receive interventions.	-small sample size -lack of attention control for control group

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Hamama et al. (2008)	quantitative	to investigate healthy children's responses to a sibling's cancer and its aftermath with particular scrutiny toward stress factors (role overload), duress responses (anxiety and psychosomatic complaints) and coping resources (self control and self efficacy)	100 healthy siblings ages 8 – 19 years of a child with cancer	Siblings' stress (role overload) correlated significantly with their duress response stress factor correlated significantly with one of their personal resources: greater SC was linked with lower role overload personal coping resources correlated significantly with healthy siblings' duress responses greater SC was linked with milder anxiety	-lack of control group -Use of self-report measures

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Houtzager et al. (2005)	quantitative	To assess psychosocial adjustment in siblings of pediatric cancer patients by obtaining both self-reported and parent-proxy-reported information on siblings' social-emotional well-being, and to compare these respondents and assess correspondences and differences.	83 siblings (aged 7–18) of pediatric cancer patients at 1 month post diagnosis; 57 siblings 24 months later	greater SC was linked with milder anxiety	-small subgroups stratified by age -questionnaires were mailed out to families -limited reliability of one instrument in some domains
Kaplan et al. (2013)	quantitative	to explore cancer-related posttraumatic stress reactions in siblings of children with cancer including prevalence, common symptoms,	125 children between the ages of 8 and 17 with a sibling with cancer, diagnosed 4 to 38 months prior to the study	Over half the sample scored in the moderate to severe range for PTS and 22% fulfilled criteria for PTSD; over 60% reported arousal symptoms, PTS symptoms frequently interfered with functioning and co-occurred with anxiety and depressive symptoms. Gender and age-related patterns were not found	-data collection exclusively by questionnaire -heterogeneity of sample in regard to treatment status -unable to compare groups based on whether patient was on or off treatment

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
		comorbidity with anxiety and depression, and gender and age related patterns			
Labay et al. (2004)	quantitative	To examine relationships between empathy, illness concepts, sibling relationship variables, and psychological adjustment among siblings of children with cancer.	29 healthy siblings and 14 children on active treatment for ALL, AML, and non-Hodgkin's lymphoma	Healthy siblings did not exhibit increased rates of behavior problems, but did display more social and academic difficulties. Empathy was a significant predictor of externalizing and total problems.	-small sample size --use of single instrument for outcome -lack of comparison group

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
Lobato et al. (2005)	quantitative	to evaluate the impact of a family-based group intervention for young siblings of children with CI/DD	43 healthy siblings (ages 4 – 7 years) of children with chronic illness/developmental disability (CI/DD) and their parents	sibling knowledge of CI/DD and sibling connectedness increased significantly; sibling perceptions of self confidence increased from pre to post treatment	-lack of control group -limited demographics in sample
McMahon et al. (2001)	quantitative	To assess depressive symptoms, self-concept, and behavior in non-affected siblings of children with severe traumatic brain injury (TBI)	12 siblings (ages 9 to 21) of patients admitted to inpatient rehab following TBI and case controls randomly selected from sibling's classmates	No statistical differences were found between siblings and their classmates 3 to 18 months after injury; poorer functional outcomes in child with TBI correlated with lower self concept and more symptoms of depression in siblings	-small sample size -cross-sectional design
Prchal and Landolt (2012)	quantitative	to evaluate the effectiveness of a two-session psychological intervention for siblings of newly diagnosed pediatric cancer patients	30 siblings age 6 to 17 years	siblings assigned to the intervention group including medical information, promotion of coping skills and a psychoeducational book for parents showed better psychological well-being, had better medical knowledge, and reported receiving social support from more people. The intervention had no effect on	-timing of intervention to early time after diagnosis --small sample --author developed measures with limited psychometric testing -use of screener in ages below established validation -lack of lower SES families

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
				posttraumatic stress symptoms and anxiety	
Sambuco et al. (2012)	quantitative	to determine predictors of self-esteem and behavioral outcomes among siblings of children with traumatic brain injury	39 siblings closest in age to a child who sustained moderate to severe TBI	significantly reduced self esteem but no evidence of behavioral difficulties were found in siblings; sibling self esteem did not correlate with any other study variables' behavioral outcome correlated with sense of social support, knowledge about TBI and injured child behavior	-small sample size -use of knowledge assessment that lacks psychometric testing -cross-sectional design -lack of control group
Swift et al. (2003)	quantitative	to evaluate long-term outcomes for siblings of children with traumatic brain injury (TBI) and to identify factors that	64 siblings (ages 7 – 18 years) of children with a severe or moderate TBI and 39 control siblings of children with an ortho injury	participants were an average of 4 years post injury More negative sibling relationships were found in families of children with TBI than ortho injuries behavior problems in children with TBI predicted both sibling relationships and sibling behavior problems	-length of time since injury -lack of baseline data on sibling relationship -lack of uninjured control group -subject attrition

Author/Year	design	study purpose	participants	Key Findings	Qualitative Rigor Study Limitations
		predict these outcomes			

Level of Evidence

Level of evidence was assessed using the Johns Hopkins Nursing Evidence-Based Practice Model (JHN EBP; Dang & Dearholt, 2017). The JHN EBP identifies three levels of evidence, with Level I representing the strongest or highest level, and Level III the weakest or lowest level. Level I includes experimental and randomized control studies, Level II includes quasi-experimental studies, and Level III includes non-experimental and qualitative studies. All studies included are classified as Level III evidence with the exception of Gursky (2007) and Lobato and Kao (2005), both of which are Level II quasi-experimental studies.

Risk of Bias

No studies included for review identified potential bias from financial support or funding sources. Common risks of bias include small sample sizes, use of purposive sampling strategies, and self-selection bias of participants. Risk of bias across studies relates to the limited number of participants and diagnosis categories identified as a serious or life-threatening condition.

Rigor

Evidence of Lincoln and Guba's (1985) criteria for trustworthiness was used to assess the rigor of qualitative studies. Findings from qualitative and quantitative studies are presented using a segregated design in which separate syntheses are undertaken, then the findings integrated to reflect complementarity (Polit & Beck, 2017). This approach is appropriate when the different study paradigms address research questions that are "different but connected" (Polit & Beck, 2017, p. 665). Themes were identified in studies

through a process of reading and re-reading studies and categorizing findings. Patterns were identified within study findings, and ultimately themes emerged.

The exploration of experiences both informs and complements the objective outcomes assessed through quantitative methodologies. For qualitative studies, common themes were identified which were then categorized based on definitions presented in the study report. This involved relabeling themes from the original studies. For quantitative studies, common findings amongst studies identified were categorized based on outcome domains of social health, emotional health, cognitive health, and physical health (Manning et al., 2018).

Focus of Inquiry

Findings from Quantitative Studies

The outcome domains identified in the PICS-p framework are physical, cognitive, social, and emotional and mental health (Manning et al., 2018). These domains are applicable to the quantitative findings in siblings of children with serious or life-threatening illness or injury as they reflect the categories of outcomes measured through these studies. Few studies have examined the physical or cognitive outcomes in siblings, most studies identified examined social outcomes, followed by emotional health outcomes.

Physical Health

Physical outcomes were measured through Health Related Quality of Life (HRQoL) subscales in the identified studies (Coban et al., 2017; Houtzager et al., 2005). These researchers identified significantly lower HRQoL in the physical subscale domain

(Coban et al., 2017) and reports of physical and motor problems at 1 month and 24 months following their siblings' diagnosis (Houtzager et al., 2005).

Cognitive Health

Cognitive outcomes are described as executive function, memory and attention (Manning et al., 2018; Needham et al., 2012). No identified studies reported specific diagnostic measures of these outcomes in siblings, but Alderfer and Hodges (2010) found that increased levels of parental support measured on the self-report Child and Adolescent Social Support Scale (CASSS) were associated with better school performance and fewer symptoms of attention problems on the Child Behavior Checklist (CBCL). Other studies report use of the CBCL in siblings (Barrera et al., 2004; Houtzager et al., 2005; Labay & Walco, 2004; Sambuco et al., 2012; Swift et al., 2003) but do not address attention problems as an outcome.

Emotional Health

Outcomes in emotional and mental health include traumatic stress responses, depression, anxiety, and complicated grief (Manning et al., 2018; Needham et al., 2012). The identified studies reported rates of post-traumatic stress (PTS), an early traumatic stress response, in siblings ranging from 49% (Alderfer et al., 2003, p. 283) to 60% (Kaplan et al., 2013, p. 209). Post-traumatic stress disorder (PTSD), which develops later than PTS, was found in 22% (Kaplan et al., 2013, p. 209) to 34% (Coban et al., 2017, p. 4) of siblings. Kaplan et al. further reported that PTS symptoms interfered with functioning for 75% of participants (p. 209) and co-occurred with anxiety and depression symptoms. Development of stress disorders and other emotional and mental health

diagnoses impair function and quality of life. Coban et al. (2017) reported significantly lower HRQoL in psychosocial function subscales of siblings; McMahon et al. (2001) reported lower self-concept and more symptoms of depression in siblings whose brother or sister experienced poorer functional outcomes following life-threatening brain injury. Hollidge (2001) reported moderate to high levels of anxiety in well siblings, significant internal stressors, and that anxiety in well siblings affected self-concept. Hamama et al. (2008) found that siblings' role overload correlated significantly with anxiety and psychosomatic complaints. Mitigating factors examined include educational interventions, associated with lower anxiety (Gursky, 2007); empathy for the sibling, a predictor of decreased externalizing and total problems (Labay & Walco, 2004); greater perceived self- confidence, self-efficacy and self-control (Hamama et al., 2008; Lobato & Kao, 2005); and knowledge about the injury, a contributor to behavioral outcomes (Lobato & Kao, 2005; Sambuco et al., 2012).

Social Health

Social outcomes in children were most often measured using the social competence subscale of the CBCL, which includes subscales of activities, social relationships, and school performance (Labay & Walco, 2004) and measures of sibling relationships as an indicator of social support (Barrera et al., 2004; Swift et al., 2003). Consistent among findings were low social competence scores (Alderfer & Hodges, 2010; Gallo & Szychliniski, 2003; Labay & Walco, 2004) and increased negative effect on sibling relationships (Swift et al., 2003). Social support was associated with fewer symptoms of depression, anxiety, and fewer behavior problems (Barrera et al., 2004);

self-concept, prosocial behavior, and behavior difficulties (Bellin et al., 2009); and is identified as contributing to more positive behavioral outcomes (Sambuco et al., 2012). Additionally, Lobato and Kao (2005) found that sibling connectedness increased following a family-based group intervention that addressed sibling knowledge.

Findings from Qualitative Studies

Consistent with quantitative studies reviewed, identified qualitative studies focused primarily on emotional health and social health; no identified studies described physical health or cognitive health as siblings' self-reported experiences. Themes emerging from the patterns identified in qualitative studies are pervasiveness, needs, social health, emotional health, and normalization.

Pervasiveness

The theme of pervasiveness encompasses the impact of the illness or injury on multiple aspects of the siblings' lives, including day-to-day life and special occasions or plans (Bellin et al., 2009; Prchal & Landolt, 2012; Woodgate, 2006). Siblings described this as an unwanted intrusion (Akhtar et al., 2012), a loss of routine (Bugel, 2018; Sloper, 2000), and as life revolving "around siblings' illness" (D'Urso et al., 2017, p. 307). Many siblings reported they assumed additional responsibilities around household duties and chores, altering previous routines and impacting all areas of family life (D'Urso et al., 2017; Prchal & Landolt, 2012; Sloper, 2000).

Needs

Siblings expressed that it is important to them that they are acknowledged and validated in their experiences (Bellin et al., 2008; Bugel, 2018), and that they are part of

their brother or sister's care (Sloper, 2000; Woodgate et al., 2012). Siblings expressed the need for information (Bugel, 2018; D'Urso et al., 2017; Prchal & Landolt, 2012; Sloper, 2000) to help make sense of the situation and understand the implications for their own lives. Siblings expressed a sense of loss of identity in the family (Bugel, 2014; Woodgate et al., 2012) and need for self-identity, validation, their own position in the world, and confirmation of their importance (Akhtar et al., 2012; Bugel, 2018; Manning et al., 2017). Finally, siblings identified the need for acknowledgement of their emotions and experiences, the need for parents to understand the extent of their sadness, and support for processing emotions and achieving normalization (Akhtar et al., 2012; Bellin et al., 2008; Manning et al., 2017; Nabors & Liddle, 2017; Woodgate et al., 2012).

Emotional Health

The experience of having a seriously ill or injured brother or sister generates a wide range of emotions for well siblings. The emotional complexity experienced by siblings was described by one sibling as "the emotional roller coaster" (Bellin et al., 2008, p. 204). Siblings expressed feeling guilt, jealousy, embarrassment, worry, loneliness, and sadness throughout their experiences (Bellin et al., 2008; Bugel, 2018; D'Urso et al., 2017; Fleitas, 2000; Hilkner et al., 2019; Hollidge, 2001; Prchal & Landolt, 2012; Sloper, 2000; Woodgate et al., 2012). Jealousy was most often associated with feelings of competition for parents' attention and gifts given to the sick child (Bellin et al., 2008; Carnevale, 1999; Hollidge, 2001; Prchal & Landolt, 2012). Siblings felt guilt over not being able to do more for their brother or sister (Fleitas, 2000; Woodgate et al., 2012), and for remaining healthy while their brother or sister endured illness or injury

(Bellin et al., 2008; Hollidge, 2001; Woodgate et al., 2012). Siblings also expressed worry over their own health as well as their brother or sister's (Hollidge, 2001; Pit-ten Cate & Loots, 2000; Sloper, 2000). Finally, siblings expressed deep sadness over their brother or sister's illness or injury and their need to endure treatment (Bugel, 2018; Hollidge, 2001; Woodgate et al., 2012).

Social Health

The family is the primary social support unit for the younger school age child, while older school age children and adolescents view friends, school and activities outside the family with increasing importance. In the theme of social health, family relationships, school, peers, and other adults were identified by siblings as both supports and stressors.

Family Relationships. Family relationships were described as a source of strength and support (Bellin et al., 2008; Pit-ten Cate & Loots, 2000) during illness and treatment. Siblings expressed a strong desire to keep their family together (Woodgate, 2006), and described increased cohesion of family bonds and increases in purposeful planning of family activities (Bellin et al., 2008; D'Urso et al., 2017; Fleitas, 2000; Prchal & Landolt, 2012; Sloper, 2000).

Sibling Relationship. The sibling relationship emerged as an important theme for siblings in describing their experiences. Many siblings expressed their relationship with their siblings as supportive or protective, with feelings of responsibility and a desire to be there for their sibling (Bellin et al., 2008; Carnevale, 1999; Hollidge, 2001; Nabors & Liddle, 2017; Woodgate et al., 2012). A positive perspective on the experience was the

perceived strengthening, increased closeness, or warmth of the sibling relationship (Bellin et al., 2008; Bugel, 2018; D’Urso et al., 2017; Hilkner et al., 2019; Lehna, 2010; Sloper, 2000).

School. School and its associated activities provided an additional source of social support, as it was identified as a consistent environment (Bugel, 2018), a sanctuary (Akhtar et al., 2012), and a diversion from the illness or injury (Prchal & Landolt, 2012), but also as a source of stress as siblings faced questions from classmates and problems with school work owing to disruption in routines and distraction due to thinking about their brother or sister’s illness (Prchal & Landolt, 2012).

Peers. Siblings described peer relationships as a source of support and comfort (Bellin et al., 2008; Sloper, 2000) and as a means to process their own emotions (Sloper, 2000). Engaging in their own interests and activities provided a means of coping with their brother or sister’s illness for many (Sloper, 2000).

Other adults. A common finding amongst siblings was the importance of relationships external to the nuclear family, including extended family, teachers, and other supportive adults. Siblings described increased involvement with other adult caretakers (Akhtar et al., 2012; Bugel, 2018; D’Urso et al., 2017; Hilkner et al., 2019) and the role of other adults as integral to emotional processing (Sloper, 2000).

Normalization

Normalization refers to minimizing impact on daily living or the process of regarding a person or circumstance as no different than others. Siblings expressed a desire for normalization in their lives (Akhtar et al., 2012; D’Urso et al., 2017; Lehna,

2010; Prchal & Landolt, 2012), as well as the importance of the sibling relationship and not treating their brother or sister differently as important parts of normalization (Akhtar et al., 2012; Bellin et al., 2008).

Comparison of parent report and child self-report data

Across both quantitative and qualitative studies, findings of discordance between parent-report and child self-report data were noted. Barrera et al. (2004) identified the importance of obtaining both parental reports and child self-reports in relation to their finding of differences between parent perceptions of anxiety and social support and child and adolescent self-report measures. Houtzager et al. (2005) reported that siblings of children with cancer experience a more serious burden from the illness than is perceived by the parents. Guite et al. (2004) reported discordance between sibling and parents reports on the sibling perception questionnaire, with parents reporting more sibling adjustment problems than children. Lobato and Kao (2005) described parent report of sibling behavioral functioning as remaining within normal range pre and post interventions, while the sibling self-report measures showed increased behavioral functioning problems between the time points. These discrepancies in report point to both interfamily dynamics and the need for siblings' voices of their own experiences to be the primary source of data. Parents who find their attention divided may not have the capacity to assess and support the well siblings in the family.

Summary of Literature Review

The importance of siblings in the family unit and of sibling relationships in emotional and social development is well established. When a child is hospitalized for a

serious or life-threatening illness or injury, the family dynamics and sibling relationship are disrupted. Recent work in intensive or critical care settings has identified that hospitalization in PICU settings has long-term effects on patients and families. Conceptualized as PICS-p, these identified sequelae impact physical, cognitive, emotional, and social health. The findings from this review reveal that siblings of children with serious illness or injury experience changes across these health domains related to their brother or sister's illness or injury and their hospital experiences.

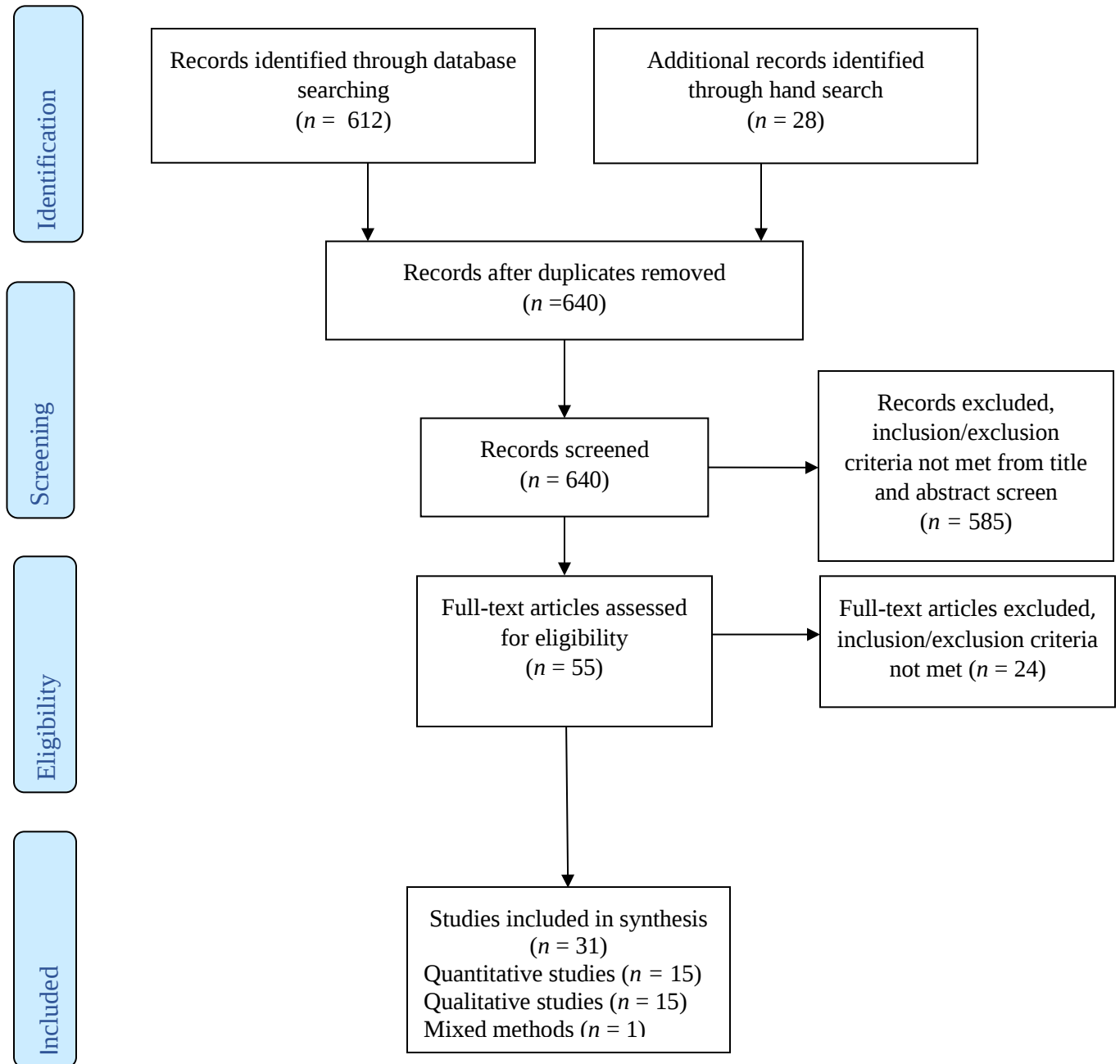
Quantitative studies identified examined social and emotional health outcomes in siblings of children with serious or life-threatening injury or illness more often than physical or cognitive outcomes. This represents a clear gap in comprehensive assessment of sibling outcomes identified in pediatric literature. In terms of social outcomes, identified studies clearly demonstrate low social competence scores associated with anxiety, depression, and behavior problems. Emotional and mental health findings demonstrate siblings frequently experience traumatic stress responses, including PTS and later PTSD, which are associated with decreased function and lower quality of life. Siblings further experience increased anxiety and depression, affecting self-concept. These outcomes may be mitigated by emotional processing, educational intervention, and knowledge about the illness or injury.

Qualitative findings revealed themes of pervasiveness, needs, social health, emotional health, and normalization. These themes integrate with and inform the findings from quantitative approaches, as siblings self-identified many of the objective findings measured. Social supports, emotional processing, normalization, and sibling relationships

were identified as both stressors and strengtheners by siblings. The adjustment to the pervasiveness of the illness or injury as touching all aspects of life suggests a level of stabilization for siblings in transitioning to a life that is different than before their siblings' illness or injury. Finally, the siblings' identified needs for validation, acknowledgment, information and education, and support for processing and adjusting reflect the findings of emotional and mental health outcomes measured.

Figure 1

PRISMA Flow Diagram



CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

An interpretive phenomenological study design was used to examine the experiences and perceptions of siblings of PICU patients. This population has remained unstudied in the exploration of post-discharge outcomes of PICU patients and families; phenomenology is an appropriate approach when little is known about a topic (Creswell & Poth, 2018; Polit & Beck, 2017). Very little is known about the experience of siblings of PICU patients, and the individuals living this experience are the best informants of the phenomenon. Semi-structured interviews conducted either face-to-face or through a videoconference platform with audio-only recording captured participants' own voices to provide insight into their lived experiences and perceptions.

Setting

Participants in this study had a sibling that was a patient in the PICU at Dell Children's Medical Center of Central Texas (DCMC), located in Austin, Texas. DCMC, a Level 1 trauma center and regional referral center for a 46-county area, has 248 licensed beds, including 24 PICU beds. The PICU admits approximately 1,300 patients annually and treats a mixed medical-surgical population. Once recruited for the study, the data collection interviews took place at a location chosen by the participant and their family, either at the participant's home (two participants), in a public park (two participants), or by videoconference platform with the participant in their home (three participants).

Participants

The population of interest in this study was school aged and adolescent siblings (ages 6 to 17 years) of children who had been hospitalized in the PICU for life threatening or critical illness or injury. This study utilized purposive sampling of potential participants from families whose child was hospitalized in the PICU at DCMC. Purposive sampling was used to select participants who were the best informants for the study (Polit & Beck, 2017). Enrollment and data collection continued until saturation of themes was achieved. The use of key informants to address a particular phenomenon of interests resulted in an expected small sample size, which is frequently fewer than 10 participants in phenomenological studies (Creswell & Poth, 2018; Polit & Beck, 2017).

A list of patients admitted to the PICU during the study time period was generated from the hospital's HealtheAnalytics (HeA) database, a part of the electronic medical record (EMR) system used at DCMC. Families whose child experienced a PICU admission and had been discharged from the hospital for at least three months were screened for presence of siblings in the household and additional inclusion and exclusion criteria as noted below before being approached for study participation. Additionally, clinicians working with families in the PICU the researcher with names of potential participants for screening and recruitment. Inclusion and exclusion criteria for participants were:

Inclusion Criteria:

- Age ≥ 6 years and ≤ 17 years
- Sibling of PICU patient discharged ≥ 3 months prior to interview date

- Able to complete interview
- Parent or legal guardian provides permission/consent for participation
- Participant provides assent to participate

Exclusion Criteria:

- Sibling (PICU patient) did not survive hospitalization or died since discharge
- Non-English speaking
- Developmental delay, cognitive impairment or speech pathology that prevents participation in the interview process
- Family involvement with Child Protective Services

Recruitment took place through invitation letter with follow up phone call and through clinician referral. Those families identified through the patient list provided by the health analytics department and meeting criteria received a study information letter inviting them to participate and providing contact information for the researcher so that they could receive further information on the study (see Appendix A, Invitation to Participate Letter). One week after the first letter, a second letter was sent if the family did not respond to the initial invitation letter. One week after the second letter, families received a phone call to verify letter receipt and ask whether they would like to hear more about the study or if they would like to participate. If a family declined further information or participation during the phone call, no further contact was made. If the family member indicated interest, an appointment was scheduled to complete the informed consent, assent, and the interview. In families in which there was more than one

eligible sibling, siblings were interviewed per the parent and participants' expressed desire, resulting in two participants from two families in the study.

Healthcare professionals working at the bedside with families in the PICU, including nurses, chaplains, child life specialists, and social workers, were informed of the study, its purpose, and participation requirements and asked to either share the investigator's contact information with families with whom they have continued contact, or ask the family for permission for the researcher to contact them about the study. After receiving names of potential participants, the researcher called the family to explain the study purpose and activities. If the family wished to proceed with participation, an appointment was scheduled to complete informed consent, assent, and the interview. See Appendix B, Telephone Script.

Families interviewed in person were asked where they wanted the interview to take place. Two families chose their home, and one family chose a local park. At the agreed upon time and place, the researcher reviewed the parental permission and consent document and the participant assent document. Any questions were answered, and appropriate signatures obtained prior to the interview. Families recruited for videoconference interview during the COVID-19 pandemic received an email with the consent and assent forms attached. These forms were reviewed with the parent and participant before the interview and a signed copy returned by email to the researcher prior to the interview. All participants and families received copies of the consent and assent documents to retain for their information.

Human Research Subjects Considerations

The Seton Institutional Review Board (SIRB) in Austin, Texas approved this study under expedited review as the primary IRB of record, and the Texas Woman's University Institutional Review Board in Houston, Texas approved the study under an Institutional Authorization Agreement (IAA) with the SIRB.

Potential Risks

One standard risk in studies with children or conversations with parents about their children is acquiring information about familial child abuse or neglect. If this information was acquired, it would have been reported to Child and Family Protective Services. All consent forms provided information regarding the legal requirement to report concern for child abuse. For this study, there were no reports of abuse or neglect.

The participants of this study were asked to discuss potentially traumatic events to describe their experiences and perceptions. Discussion of these events has the potential for psychological risk, as even in the absence of acute stress disorder or post-traumatic stress disorder such discussion can be upsetting to participants. The researcher has experience in having difficult or emotionally challenging discussions with children and families. If the participant demonstrated signs of psychological distress, the researcher was prepared to provide a referral to a behavioral health service provider for further counseling, with a clear explanation to the family that this is a resource referral only, and any services provided were not covered by the researcher, the study, DCMC, or TWU. For this study, there were no reported issues or discomforts and no referrals were made.

Participants were at risk of loss of time through study participation. This risk was mitigated through scheduling interviews on days and at times that are convenient for the participant. Participants were informed of expected time needed to complete the study activities. The interview process could have been fatiguing for some participants. This was mitigated through scheduling the interviews at times best for the participant. Participants were informed that they could take breaks if needed and could stop the interview at any time without consequence. No participants expressed fatigue or the need to stop participation.

Loss of confidentiality was an additional risk of this study. This risk was mitigated through use of study ID numbers, securing of hard copy data in locked cabinets and offices, and use of password protected computers for entry and analysis of electronic data. Audio recordings were maintained in password protected computer files and deleted following study completion. Hard copy data were destroyed by shredding following study completion.

Potential Benefits

There were no direct benefits to participants or their families. Participants may have benefited from discussing their experiences and engaging in age-appropriate self-reflection as a result, but the researcher explained clearly that the study procedures are in no way meant to serve as therapy in any form.

Participants received a gift card to a local store in the amount of \$10.00 as compensation for their time. Parents received a gift card to a local store in the amount of \$15.00 for their time and transportation related to their child's participation.

The benefit of this study to society is the potential for providing better care to children and families experiencing a PICU admission through understanding of the participants' experiences and the potential of the study findings to inform the design and testing of interventions to support children and families in the PICU.

Data Collection

Data collection for this qualitative study consisted of demographic information and semi-structured interviews. Demographic information was recorded on a paper form that was coded and contained no identifying information. Demographic data was collected to capture the age, race, ethnicity, and gender of the PICU patient and sibling, length of PICU and hospital stay, diagnosis category for patient admission, and time since PICU and hospital discharge; these data describe the study sample. See Appendix C, Demographic Data.

Participants completed a semi-structured interview with the researcher in which they were asked about the experience of having a sibling in the PICU, and their perceptions about their relationship with their sibling following discharge from the hospital. Interview questions using a phenomenological approach guided the participant in describing their experiences and perceptions beginning with "What was it like for you when [sibling] was in the PICU?" Appendix D, Interview Schedule provides an overview of sample interview questions mapped to the research questions. Participant interviews lasted between 25 minutes and 1 hour.

Data for this study was collected through audio recordings and field notes. Five audio recordings were transcribed by the researcher word-for-word, including pauses and

audible activity during the interview; two interviews were transcribed using Trint audio transcription software, an International Standards Organization (ISO) information security management certified, encrypted transcription program (Trint, 2021) and edited by the researcher for accuracy and redaction of names. Following interviews, the PI completed field notes coded with the same study ID used on the demographic form. Field notes captured elements of the setting, participant non-verbal communication, and researcher thoughts and impressions during the interview.

Data Analysis

Qualitative data analysis followed the method described by Colaizzi (1978).

Colaizzi's method of data analysis consists of seven steps:

1. Reading and rereading the transcripts
2. Highlighting and extracting significant statements
3. Identifying and formulating the meanings of significant statements
4. Organizing the clusters of themes from the groupings of identified meanings
5. Comparing the themes to the original descriptions to validate the clusters and to examine discrepancies
6. Integrating the theme clusters into a description of the essential structure of the phenomenon
7. Validate the descriptive statement of the essential structure with select experts and revise if necessary

Scientific Rigor: Qualitative Controls

Scientific rigor in qualitative research relies on qualitative controls to establish trustworthiness of study findings (Polit & Beck, 2017). Munhall (2012) identifies four criteria for trustworthiness: credibility, or truth value; transferability, or applicability; dependability, or consistency; and confirmability, or neutrality. The criteria for trustworthiness in this study is met through utilization of accepted qualitative methods of data collection and data analysis, as described by Lincoln and Guba (1985).

Credibility

Credibility ensures the truth value or believability of study findings. The utilization of prolonged engagement and member checks demonstrate that the data collected reflect accurate identification and description of participants. Prolonged engagement involves the investment of sufficient time to learn and explore the phenomenon, identify and minimize distortions, and build trust with participants (Lincoln & Guba, 1985). The researcher explained to participants the importance of their role in understanding the experience and perceptions of siblings and allowed the participants to take the time they needed to describe their experience and respond to interview questions. By establishing rapport and allowing participants to express their experience through their own thoughts and words, the investigator engaged participants in telling their truth of their experiences. The investigator engaged in member checking by reflecting the participants' words back or asking for clarification throughout the engagement to ensure that the expressions and meaning are understood and accurately capture the participants' perceptions.

Transferability

The criterion of transferability, or ability to transfer study findings to other groups, is facilitated through provision of “thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility” (Lincoln & Guba, 1985, p. 316). Thick description is provided through quotations in the participants’ own words illustrative of identified themes and as exemplars of their experiences and perceptions of being a sibling of a PICU patient and their relationship with their brother or sister following hospital discharge. These themes and quotations are extracted directly from the participants’ own words, allowing readers of the findings to reach conclusions regarding transferability.

Dependability

Through dependability, the researcher accounts for stability of the data through changing conditions of data collection and understanding. Lincoln and Guba (1985) identify the technique of inquiry audit in addressing this criterion. An inquiry audit involves evaluation of the investigator’s process and product of the research by an external auditor. The auditor reviews the investigator’s methods and records in determining the dependability of the study. The process of this study, including identification and recruitment of participants, field notes, and journals, were carefully documented as an ongoing process throughout the study, thereby providing an audit trail for evaluation of dependability.

Confirmability

Confirmability is concerned with the neutrality of the data and the study findings as a product of the data. Confirmability may be established through the same audit trail created for dependability to establish that findings are grounded in the data (Lincoln & Guba, 1985). A sampling of findings is traced back through the audit trail to the data, establishing clear and consistent linkages. The use of a confirmability audit in this study establishes confirmability.

The additional use of a reflexive journal, in which the investigator records “a variety of information about self and methods” (Lincoln & Guba, 1985, p. 327), supports all criteria of trustworthiness. The reflexive journal is updated frequently to include the schedule of the study, a personal diary to reflect one’s own values and insights, and a methodological log to record decisions and rationales (Lincoln & Guba, 1985). This journal, kept by the investigator throughout the study, further enhances trustworthiness.

Pilot Study

A pilot study was conducted to test study methodology and explore preliminary findings. Following approval by the SIRB and IAA with the TWU IRB, pilot study participants were recruited using the described strategy. A total of four siblings (2 males, 2 females; ages 6 to 9 years) from three families participated in face-to-face, one-on-one interviews that were recorded and transcribed verbatim by the researcher. Analysis using Colaizzi’s method revealed emerging themes of What I Remember, What I Felt, What Helped, and What’s the Same and Different. Study conclusions are the disruption of a PICU hospitalization to family functioning and sibling interactions, the expressed needs

of siblings for information about and contact with the PICU patient, and siblings described perceived changes in the sibling relationship following PICU hospitalization. Understanding the sibling experience is key for the healthcare team to support families during PICU hospitalization and through the transition to post hospital life. Through these findings, the researcher affirmed the methodology of the study as feasible and identified the need for further study to expand these findings and inform practice in the PICU setting.

CHAPTER IV

ANALYSIS OF DATA

This purpose of this phenomenological study was to explore the experiences and perceptions of siblings of PICU patients. Semi-structured interviews with participants from a purposive sample were conducted, audio recorded, and transcribed. Guided by the philosophy of Merleau-Ponty and using Colaizzi's method of qualitative analysis, interviews were analyzed, and codes and themes identified. The results provide a description of the experience, perceptions, and meaning of the lived experience of children ages 6 to 17 whose sibling had been a PICU patient. This chapter provides a description of the sample, setting, and themes that emerged from the data.

Description of the Sample

The total sample consisted of seven children from five families. Four participants completed interviews face-to-face and three participants completed videoconference interviews in accordance with COVID-19 pandemic restrictions. Three additional families had agreed by phone to participate in videoconference interviews but failed to respond to further phone or email contact; these missed appointments occurred before the final two interviews.

Participants ranged in age from 6 years to 16 years and their siblings ranged in age from 5 years to 14 years. Two participants identified as Black/Non-Hispanic; one

identified as White/Hispanic; and four participants identified as White/Non-Hispanic.

Four participants were female and three were male; the siblings who had been PICU patients were six males and one female. Three participants were older than their siblings, three were younger, and one was a twin. Diagnosis category/reason for admission to the PICU was two medical, one surgical, one surgical-cardiac, and one surgical-neuro.

Length of PICU stay ranged from 3 days to 5 ½ weeks, and hospital length of stay from 5 days to 3 months. Time since discharge ranged from 3 ½ months to 12 months. See Table 2, Participant Characteristics.

Table 2

Participant Characteristics

Participant age and gender	Race/Ethnicity	Sibling age and gender	Sibling diagnosis category	PICU length of stay	Hospital length of stay	Time since hospital discharge
9 yr F	White, non-Hispanic	5 yr M	Medical	3 ½ weeks	7 weeks	8 months
7 yr M	Black/ non-Hispanic	7 yr M	Surgical	3 days	4 weeks	3 ½ months
9 yr M	Black, non-Hispanic	7 yr M	Surgical	3 days	4 weeks	3 ½ months
6 yr F	White, Hispanic	7 yr M	Surgical-cardiac	5 ½ weeks	6 weeks	5 months
16 yr M	White, non-Hispanic	7 yr F	Medical	3 days	5 days	9 months
10 yr F	White, non-Hispanic	14 yr M	Surgical-neuro	2 weeks	3 months	12 months
13 yr F	White, non-Hispanic	14 yr M	Surgical-neuro	2 weeks	3 months	12 months

Findings

Data saturation was achieved at a sample size of seven participants. This is consistent with published phenomenological studies with children that explore health and medical phenomena and enrolled sample sizes of five participants, two of whom were siblings (Mikkelsen, 2018), six participants (Mant et al., 2018; van Manen, 2015), seven participants, including two sets of siblings (Finch & Gibson, 2009), seven participants (Yap et al., 2020), and 10 participants (Israelsson-Skogsberg et al., 2019). The lived experience of PICU siblings reflect what they remembered, felt, found helpful when their brother or sister was in the PICU, and what they perceive as changed or unchanged following their sibling's discharge home. Participants described events leading to hospitalization, what happened while they were there, and when their sibling came home from the hospital. When describing their experiences, participants expressed common feelings of sadness, separation, and being scared but feeling happiness when their family was reunited after discharge. Things that helped were visiting the PICU patient, getting information, maintaining connection, helping, and other adults. Exploration of how the sibling relationship was affected by the PICU admission revealed the participant's thoughts about things they do with their sibling and as a family, their time together, and what they notice as different about their brother or sister and their family. These experiences and perceptions clustered into four themes: What I Remember, What I Felt, What Helped, and What's the Same and What's Different. See Table 3, Significant statements, Codes, and Themes.

Table 3

Significant Statements, Codes, and Themes

Significant Statements	Codes	Themes
<i>The neighbors in front of us picked us up from school...they said everybody sit on the couch...and then they said your brother is at the hospital right now. It was pretty hard for me.</i> <i>[I remember] the throwing up, the screaming, the blood.</i> <i>It seemed weird because he had to get surgery and I had to go to school for Monday, Tuesday, Wednesday, Thursday. And Friday.</i> <i>Our mom packed early because she woke me up and said let's go downstairs and wake up grandma and then we did. We got [brother] ready. He never knew that he was gonna go to the hospital.</i> <i>I remember at first – it didn't seem real...just like it wasn't happening. And then after trying to talk to her, like it like really sunk in.</i> <i>[At the hospital there was] a toy section with lots of toys and [second sib] and me</i>	Physical symptoms Going to the hospital While they were there The hospital environment When they came home	What I remember

*got to play there while he was in the PICU.
On the weekends.*

*Whenever we first got there, [I could]
...just kind of like talk to her, hold her
hand...*

*...my grandpa woke me up and I thought
that the screams [were] in my dream...he
told me we have to go to the hospital.*

*And I didn't think [brother] was going to
have surgery...And then the nurse was not
sugarcoating anything. She was like your
brother had a really bad brain injury so
you might be here for a while.*

*It was a different kind of room and a
different kind of doorways.*

*Then my brother gets carried out and his
eyes are rolled back into his head, like not
walked out, like two people are holing on to
his feet, two people holding on to his arms.
I had a really, really bad feeling that it was
not going to be fine.*

*I remember in the car ride, my mom was
telling us what happened, and she told us
she didn't know how long he was going to
be there.*

*He was talking different, though, when he
had stuff in his nose.*

<i>Some of them [doctors/nurses] were my friends.</i> <i>[While he was there] we went to summer camp, go swimming, watch TV.</i> <i>[brother] had to go to the bathroom and he got up and he was in a diaper. And I was like, oh! ... I didn't expect him to be like screaming at people, or like in a diaper.</i> <i>[in the PICU], he was on so much medicine where he kind of like would just cuss at people because he didn't know how to process things.</i> <i>I got to come out of school early because [brother] was coming home and I wanted to celebrate him coming out of the hospital.</i> <i>My mom drove him back home and then I was really excited to see him and he was really happy. We did a group hug!</i> <i>After brother got better. And he started being himself again...during the summer my family would take walks or picnics downtown and bring our dog...and just let her run around. And it made me really happy to normal stuff as a family.</i>		
<i>And it was pretty hard when I couldn't give my mom and dad loves and stuff. I couldn't</i>	Separated Alone	What I felt

<i>go back in the room and give [brother] loves until three weeks later.</i> <i>...sometimes I...just wanted to have one person to hold on to and to just stay with me. And I didn't want them to ever leave, and that was usually my mom.</i> <i>I just felt like I want to be alone and I don't want to do anything...during that time I couldn't find the feel good emotions. I could just feel alone.</i> <i>I was pretty sad on the first day when I got back [to school].</i> <i>It [seeing brother] was kind of hard. I got scared.</i> <i>And then, um, every day on Tuesday or Thursday or Monday, I would leave school and go see a therapist.</i> <i>I'm like really upset and I have no idea what's going on....I'm really sad at this point.</i> <i>And so I'm really, really scared because I love him a lot and I don't want anything to happen to him.</i> <i>My mom [came] home for a little bit...and I, I'm so grateful to see her. It's been like three, two days and I haven't seen her...</i>	Sad Scared Anxious Stressed	
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<i>...when [brother] was in the PICU... it was kind of hard because. Like I didn't get to see them as much. It's sad because I'm always used to coming home and seeing my mom.</i> <i>I was really, really upset. I couldn't see them any more. I was mad that this was happening to me and my brother and my family. And sometimes I would just get kind of frustrated whenever people would kind of like try and take their place.</i> <i>[being apart from brother] felt really upsetting because I, he always made me laugh. So it's kind of hard being away from him. But when he was in PICU like, that's when it was really hard.</i> <i>Because I love him but it was just so hard seeing him like that.</i> <i>I'm trying to be happy and optimistic, but I'm really, really hurting.</i> <i>...then I just broke into tears and I was just like, please bring my brother back to me, And everyone was like, she's not OK. I'm like, I'm not OK.</i> <i>I was really excited, but I was also really scared. He did not look like my brother at</i>		
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<i>all. I genuinely was not really ready for the experience. I really was upset...the PICU was really scary.</i> <i>It was like very weird whenever you put stuff in somebody else's nose, nose it feels a little weird when, when they talk and when they see their family.</i> <i>Well, it was weird because we were separated because he had to go to the hospital and I had to go to school and it was, like, so weird that we had to.</i> <i>Whenever I left I said I'll be right back when its Saturday and Friday and Sunday. He was crying because I had to leave. [I felt] sad.</i> <i>[I felt sad] because he wasn't at home and [I missed him]</i> <i>I actually started crying after that because I didn't want my brother to go. I got really scared.</i> <i>I'd only have one parent every night [we had to] live with [our] grandparents for three months, only one parent a day.</i> <i>I remember thinking that the machines were all enemies and that they were just like killing my brother.</i>		
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<i>I was still really sad ... I felt like I wasn't a part of anything anymore.</i> <i>So I felt like my parents didn't trust me anymore with this. And it made me really sad...because they didn't tell me, like really anything until it had happened.</i> <i>I was scared and I was, I didn't know what to do.</i> <i>...it was pretty scary...just the uncertainty of everything, just the not quite knowing what's going on or what's going to happen.</i>		
<i>I couldn't stop looking at him.</i> <i>I helped him...open the playdoh box. And [brother] had a target thing in the hospital and a basketball hoop.</i> <i>I helped the doctors take stuff off of him.</i> <i>[I helped] change his diaper. I would sometimes like hold him down when he didn't want a shot.</i> <i>It (visiting) felt good. Like I would bring something for him to play with.</i> <i>I was at the hospital the majority of the time, actually.</i>	Visiting Helping my sibling Helping the hospital staff Getting information about him Friends "normal stuff" Other adults	What helped

<i>...somebody came in close to the end of the time that I was there and, um, kind of explained everything and what would happen in the months to come. Um...just gave me like a general walkthrough of what she was going through and what we were gonna do to help her and stuff like that.</i> <i>So it really did help me for the nurses to keep on [talking to me].</i> <i>I had so many questions and that was all adding on to my anxiety...</i> <i>I wanted to know what was going on.</i> <i>[at school] they offer me breaks... and just talk and sit down if I need it.</i> <i>My dad and my mom took me to a nurse. And she kind of told me everything...what was going on and how long he might have stayed there and what was going to happen...it kind of helped me cool down a little bit and calm down, because now some of my questions have been answered.</i> <i>And then my parents started opening up a little more to me and about the surgeries and everything.</i> <i>And then once the nurse explained to me that the machines were actually helping my brother and helping him stay alive, that</i>		
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<i>helped me so much more because now I knew that all the machines there weren't bad.</i> <i>[I felt] happy to see him.</i> <i>[We watched a movie] and we had a lot of fun because there was a blue couch and that's my favorite kind of color and my brother's favorite kind of color.</i> <i>[I would] watch the doctors to see what he's doing, to see what they're doing to [brother].</i> <i>[Child Life Specialist] had this little dog, a stuffed animal, that she put like a feeding tube on it and showed us like the body part that he got his IVs and his feeding tube. She taught us about them.</i> <i>My mom [explained things to me].</i> <i>And my teacher, um, last year said if you need anything, um, just tell me. If you need to step out into the hallway, it's okay, you can.</i> <i>The doctors that were my friend and my brother and my Mom and Dad [helped me]. And my mom's friend. Or our uncle.</i>		
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<i>My grandma came over here to stay with me. It was really fun. I got to sleep down here in my mom's room with her.</i> <i>...my grandparents came and picked us up. And they basically were just like out parents for quite a while.</i> <i>[My mom] was like, why don't you make a recording for him, to and I can play it for him. And so it became a daily thing...I made a video for him every day he was in PICU.</i> <i>My friends were really understanding, like, I probably wouldn't have had such a good experience without them.</i> <i>So I go to school for like half a day and told my teacher about what happened so she was being real nice...</i>		
<i>Things are the same. I play with him, eat next to him, and that's it.</i> <i>We play. And sometimes when it's still not morning we still play.</i> <i>We, like, hang out and we play more together.</i> <i>He's still in therapy but, um, he is doing great with therapy and he's running faster than he was when he got out of the hospital.</i>	Things we do School Time together Family activities Increased closeness Personal growth Physical changes	What's the Same and What's Different

<i>He's still kind of slow from running and he's still kind of slow walking.</i> <i>[at school] He has his wheelchair still because his legs still gets tired.</i> <i>[At school] we have different homeworks and we have different classes.</i> <i>My brother has a page [website] that my Mom posts stuff on it. Like pictures, words that she wants to talk about, that's all.</i> <i>Sometimes he would go to grandma's in Houston and we would have baseball games. And that's it.</i> <i>He was in the hospital for a very long time and they had to put him in a wheelchair.</i> <i>Her diet, for sure. Um, the level of—how do I describe this?—like, like how much we watch her. She can't really go anywhere alone.</i> <i>We tend to do more things now...so we go outside and do, we play more basically.</i> <i>He had to relearn how to read. And like, how to walk and move and talk and everything.</i> <i>Everything was just kind of piecing back together after it broke apart.</i>		
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<i>We're more close...our family's just we've now organized things more and helped out and talk to each other more.</i> <i>After...we got closer and I started being more kind to people</i> <i>We've [brother and I] gotten so much closer after...because, like he went through some traumatizing stuff...it's like every little moment counts.</i> <i>I think we've [family] become really even more close.</i>		
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What I Remember

All seven participants described when they found out their brother or sister was in the hospital or going there, and some details of the precipitating illness: “The neighbors in front of us picked us up from school...and then they said your brother is at the hospital right now”; “Our mom packed early because she woke me up and said let’s go downstairs... We got [brother] ready. He never knew he was going to the hospital”; [I remember] “the throwing up, the screaming, the blood”; “I remember at first—it didn’t seem real...just like it wasn’t happening”; “Then my brother gets carried out and his eyes are rolled back into his head.... I had a really, really bad feeling that it was not going to be fine”.

Six participants describe continuing some routine activities while their brother or sister was in PICU: “School was the same for me. I only cut the day in half...the first day I went to school”; “we went to summer camp, go swimming, watch TV” but with disruptions: “It seemed weird because he had to get surgery and I had to go to school”; “... it was really hard because I had to tell all the kids in my class”; “And then every day on Tuesday or Thursday or Monday I would leave school and go see a therapist”.

Five participants emphasized discharge from the hospital and coming home as cause for happiness: “I got to come out of school early because [brother] was coming home and I wanted to celebrate him coming out of the hospital”; “My mom drove him back home and then I was really excited to see him and he was happy. We did a group hug!”; “After [brother] got better...and he started being himself again...my family would take walks...and it made me really happy to do normal stuff as a family”.

What I Felt

All seven participants expressed feeling sadness at their sister or brother's illness and hospitalization: "sad because he wasn't there and I missed him"; "Whenever I left...he was crying because I had to leave. I felt sad"; "I was pretty sad on the first day when I got back [to school]"; "I'm like really upset and I have no idea what's going on...I'm really sad at this point"; "I actually started crying after that because I didn't want my brother to go"; "...then I just broke into tears and I was just like please bring my brother back to me. And everyone was like, she's not OK. I'm like, I'm not OK".

Along with and contributing to feelings of sadness, six participants expressed a sense of separation from their sibling and family: "And it was pretty hard when I couldn't give my mom and dad loves and stuff. I couldn't go back in the room and give [brother] loves until three weeks later"; "Well it was weird because we were separated because he had to go to the hospital"; "I was still really sad...I felt like I wasn't a part of anything anymore"; "...during that time I couldn't find the feel good emotions. I could just feel alone"; "I'd only have one parent every night [we had to] live with our grandparents for three months, only one parent a day"; "It's sad because I'm always used to coming home and seeing my mom.... And sometimes I would get frustrated whenever people would kind of like try and take their place."; "So it's kind of hard being away from him. But when he was in the PICU like, that's when it was really hard"; "I just wanted to have one person to hold on to and to just stay with me. And I didn't want them to ever leave, and that was usually my mom".

Finally, all participants reported feeling scared by the hospital environment: “It was kind of hard. I got scared”; “It was like very weird whenever you put stuff in someone else’s nose, nose it feels a little weird when, when they talk and when they see their family”; “It [seeing brother] was kind of hard. I got scared.”; “I was scared and I was, I didn’t know what to do”; “...it was pretty scary...just the uncertainty of everything...”; “And I’m really, really scared because I love him a lot and I don’t want anything to happen to him.”; “I remember thinking that the machines were all enemies and that they were just like killing my brother.”; “...the PICU was really scary”.

What Helped

All participants expressed that visiting or communicating with their sibling, helping with care, getting information, and other adults helped them with their experience. The need to visit and see their brother was expressed by many as a positive experience: “It felt good. Like I would bring something for him to play with”; [I felt] “happy to see him”; “we had a lot of fun because there was a blue couch and that’s my favorite kind of color and my brother’s favorite kind of color”; “I was there the majority of the time, actually” as was maintaining connection with their sibling: “I made a video for him every day he was in PICU”; “...she let [brother] talk on the phone, and then...she let me talk on the phone. And then [brother] was saying a lot of stuff and then he couldn’t stop talking”. Helping their sibling or helping hospital staff care for their sibling also emerged as a positive experience: “I helped him...open the playdoh box”; “I would help change his diaper”; “I helped one of the doctors take things off of him”; “I could like read to her...I could feed her ice...that kind of thing”.

All seven participants identified getting information, either directly or indirectly, about their sibling as important: “I had so many questions”; “[Child Life Specialist] had this little dog, a stuffed animal, that she put like a feeding tube on it and showed us like the body parts that he got his IVs and his feeding tube. She taught us about them”; [I would] watch the doctors to see what he’s doing, to see what they’re doing to [brother]”; “My mom explained things to me” [about the equipment]; [Most helpful was] somebody came in ...and kind of explained everything and what would happen in the months to come”; [a nurse] “kind of told me everything...what was going on and how long he might have stayed there and what was going to happen”; “So it really did help me for the nurses to keep on [talking to me]”; “...it would be nice to just kind of know what was going on”; “when she told me, it helped me kind of cool down a little bit and calm down, because now some of my questions have been answered”; “I wanted to know what was going on”.

The importance of other adults both within and outside the family as helpers was identified by six participants: “my teacher last year said if you need anything, just tell me. If you need to step out into the hallway, it’s okay, you can”; “The doctors that were my friend and my brother and my Mom and Dad [helped me]. And my mom’s friend. Or our uncle”; “My grandma came over to stay with me. I go to sleep down here in my mom’s room with her”; “...my grandparents came and picked us up. And they basically were just like our parents for quite a while”; “I...told my teacher about what happened so she was being really nice”; [at school] “they offer me breaks to go sit with the assistant principal and just talk and sit down if I need it”.

What's the Same and What's Different

In regard to the sibling relationship after hospital discharge, participants described how they spend time with their sibling and family, what is the same as before hospitalization, and what they notice as different about their sibling and how they interact. Some day-to-day activities were described by all participants as the same: “I play with him, eat next to him, and that’s it” but seeming to carry more significance “We play. And sometimes when it’s still not morning we still play”; “We tend to do more things now...so we go outside and do we play basically”; “it’s like every little moment counts”. How things are at school was important to five participants: “He has his wheelchair still because his legs still gets tired”; “We have different homeworks and we have different classes”.

Physical changes are noted as impacting interactions for five participants: “He’s still in therapy but, um, he is doing great with therapy and he’s running faster than he was when he got out of the hospital. He’s still kind of slow from running and he’s still kind of slow walking”; “He had to relearn how to read. And like, how to walk and move and talk and everything”; ...the level of...like how much we watch her. She can’t really go anywhere alone”. Lastly, six participants identified changes in family activities and how the sibling and family relationships are after PICU: “My brother has a page [website] that my Mom posts stuff on it. Like pictures, words that she wants to talk about, that’s all”; “Sometimes we would go to grandma’s in Houston and we would have baseball games. And that’s it”; “We’ve just gotten so much closer because...like, he went through some traumatizing stuff”; “we’re more close...our family’s just—we’ve organized things more

and helped out and talk to each other more”; “I think we’ve [family] become really even more close”; “Everything was just kind of piecing together after it broke apart”.

Summary of the Findings

The experience of having a sibling in the PICU and its effect after hospital discharge was described by participants through a range of memories, emotions, expressed needs, and noted changes in sibling and family relationships. Participants described their memories of the precipitating event or illness that led to their sibling’s PICU admission, their thoughts and feelings during that time, and their perceptions of events. The experience of their sibling being in the PICU generated feelings of sadness, separation, and being scared. These emotions contributed to a strong need for information expressed by all participants; seeing, communicating with, and staying connected to their hospitalized sibling is noted as an important help during their experience. Other identified helps were participating in their sibling’s care, and the support of other adults, both in and outside the family, in the absence of parents. Finally, participants described engaging in familiar activities and the relief of having normal activity with their siblings and family but noted the increased awareness of meaning in the ordinary and described closer family and sibling bonds after PICU hospitalization.

CHAPTER V

SUMMARY OF THE STUDY

The limited literature on siblings of PICU patients primarily relies on adult-reported data and includes siblings in the context of the family experience but not as individuals experiencing a unique phenomenon. Existing sibling studies focus on those whose brother or sister has experienced a serious or life-threatening illness or injury, but do not include the specific experience of the PICU setting. The purpose of this study was to gain an in-depth understanding of the experiences and perceptions of siblings of PICU patients. This chapter provides a summary of the study and discusses findings related to the available literature on siblings of children with serious or life-threatening illness or injury as a surrogate population due to the paucity of literature on siblings of PICU patients. Conclusions, implications for practice, and recommendations for further research are additionally presented.

Summary

An interpretive phenomenological approach was used to explore the experience and perceptions of siblings of PICU patients. Families whose child had been in the PICU at Dell Children's Medical Center were identified through medical record screening and recruited through invitation letter, clinician referral, and phone calls. Seven school aged and adolescent children, ranging in age from 6 years to 16 years, from five families agreed to participate in the study, completing one-on-one interviews, either face-to-face

(pre COVID-19 pandemic) or through videoconferencing platform (during COVID-19 pandemic). The participants' words were recorded, transcribed, and interpreted using Colaizzi's method of qualitative analysis. The interpretation and identification of themes was used to answer the research questions:

1. What is the lived experience of having a sibling hospitalized in the PICU?
2. What is the perception of the sibling relationship following hospital discharge for the brother or sister of a PICU patient?

Discussion of the Findings

The first research question was explored through participants recounting their experiences and memories of their sibling going to the hospital, time while their sibling was in the PICU, and their emotions and perceptions of their interactions with healthcare professionals, parents, and others during hospitalization. School-age and adolescent siblings in this study shared their experiences and perceptions in terms of what they remembered, how they felt, and how they were affected. Siblings recounted detailed memories of their brother or sister becoming ill or leaving for the hospital and of their experiences visiting the hospital. They identified examples of what helped them emotionally and practically while their brother or sister was hospitalized and described changes following hospital discharge.

In the school-age group (6 to 9 years old), children have less capacity for abstract thought and describe events in concrete terms, although they become less egocentric and begin to consider others' thoughts and feelings (Piaget & Inhelder, 1969). Adolescents (12 years and older) have increased capacity for abstract thoughts and have moved into

formal operations, gaining the ability to think symbolically and hypothetically; they often wonder about and seek the reasons behind things (Piaget & Inhelder, 1969). These differences in development are demonstrated in their memories and perceptions, although the experiences remain consistent across the age groups. Interpreting their described experiences to identify commonalities provides a framework for building the knowledge base to inform support of siblings and families in PICU.

Siblings described their memories of going to the hospital, visiting the hospital and coming home through significant events. Studies with siblings of hospitalized non-PICU patients revealed the impact of the illness or injury on multiple aspects of the siblings' lives (Bellin et al., 2008; Prchal & Landolt, 2012; Woodgate, 2006), suggesting that these memories reflect a broad impact of events and disruption of routine (Bugel, 2018; Sloper, 2000). One participant recalled a thunderstorm while in the car on the way to visit her brother for the first time: "I saw lightning and thunder and I was like a little scared because I thought that it was going to freak me out". On further probing, this participant identified the storm and not the impending visit as what scared her, but this demonstrates the link between concrete events and emotions in children's minds. Need for acknowledgment of emotions and experiences and support for emotional processing is an identified need in studies with non-PICU siblings (Akhtar et al., 2012; Manning et al., 2017; Woodgate et al., 2012) and is exhibited in the experiences of with PICU siblings.

Siblings expressed emotions of sadness, separation, and fear. Experiences that led to these feelings include being away from their siblings, parental absence during hospitalization, and not knowing what was happening to their brother or sister or how

long they would be in the hospital. Similar findings in siblings of children with spina bifida (Bellin et al., 2008), children with traumatic injury (Bugel, 2018), diabetes (Hollidge, 2001), and cancer (D’Urso et al., 2017; Prchal & Landolt, 2012; Sloper, 2000; Woodgate, 2006) support this experience. The need for information about and contact with their brother expressed by PICU siblings mirrors findings in non-PICU siblings (Bugel, 2018; D’Urso et al., 2017; Prchal & Landolt, 2012; Sloper, 2000) as a means to make sense of their experience and its implications for their own lives.

The role of other adults in sibling experiences as caregivers, emotional support and as a constant that helped maintain routine and normalized experiences emerged in participants’ experiences. This finding is consistent with those of non-PICU siblings, for whom a common finding was the importance of relationships external to the nuclear family, including extended family, teachers, and other supportive adults. Siblings described increased involvement with other adult caretakers (Akhtar et al., 2012; Bugel, 2018; D’Urso et al., 2017) and the role of other adults as integral to emotional processing (Sloper, 2000).

The second research question addresses the impact of PICU hospitalization on the sibling relationship. This relationship is described by participants as both the same and different. While participants depicted routine activities—playing, meals, hanging out—as the same as before hospitalization, they also note differences in their brother or sister and how the family interacts. Notably, physical differences, such as activity tolerance or new comorbidities, are recalled as differences. Among siblings of non-PICU patients, physical changes were identified as a component of normalization, a return to treating their brother

or sister as no different than others (Akhtar et al., 2012; Bellin et al., 2008). While PICU siblings were aware of physical limitations such as need for assistive devices, loss of function in some areas, and being easily fatigued, they tended to describe these as challenges their sibling was overcoming rather than as ongoing burdens.

Siblings reflected on how their brother or sister's hospitalization has impacted family dynamics after hospital discharge, identifying shifts in the family's priorities as focused on the needs of the post-PICU patient. Changes in the family such as the creation and maintenance of a website by a parent and the decrease in travel to a relative's house were described. These changes represent disruptions in family functioning that may have larger implications as the family system adapts. Findings among siblings of children with serious or life-threatening illness or injury included the description of life revolving "around siblings' illness" and that routines and other aspects of family life were impacted by the illness (Bugel, 2018; D'Urso et al., 2017; Prchal & Landolt, 2012; Sloper, 2000). Increased parental support was associated with better school performance and fewer symptoms of attention problems in siblings of non-PICU patients (Alderfer & Hodges, 2010), and parental support may emerge as a concern in PICU siblings over time.

A shared experience among participants is the perception that sibling and family bonds are stronger following PICU hospitalization, and that there is new importance to time spent together, indicating that some post traumatic growth may result from their experience. This is consistent with findings among siblings of non-PICU patients who described their relationship with their siblings as supportive or protective with a desire to be there for their sibling (Bellin et al., 2008; Carnevale, 1999; Hollidge, 2001; Nabors &

Liddle, 2017; Woodgate et al., 2012); others described a perceived strengthening, increased closeness, or warmth of the sibling relationship (Bellin et al., 2008; Bugel, 2018; D’Urso et al., 2017; Hilkner et al., 2019; Lehna, 2010; Sloper, 2000). Lobato and Kao (2005) identified interventions that addressed sibling knowledge as increasing sibling connectedness, which aligns with the expressed need of PICU siblings for information about and connection with their brother or sister during PICU hospitalization. Support that includes developmentally appropriate knowledge and allows siblings to maintain communication with the PICU patient when possible can foster maintenance of the sibling connection through the experience of PICU hospitalization.

Conclusions and Implications

Based on the results of this study, the following conclusions were reached:

- Participants described memories, interaction, and emotions linked to their experiences of their sibling’s PICU hospitalization.
- Having a sibling in the PICU disrupts family functioning and sibling interactions.
- Siblings have expressed needs for information about and contact with the PICU patient.
- Being recognized and addressed by members of the healthcare team helped siblings process their experience.
- Other adults are essential in supporting siblings of PICU patients during parents’ absence.
- Siblings viewed their families as changed after PICU hospitalization.

The following implications for nursing are derived from the findings of this study:

- Nurses, as the professionals with the most family contact, are key to recognizing and supporting siblings of PICU patients.
- Information to parent during PICU hospitalization should include the impact on siblings.
- Support for siblings in the PICU setting is needed and should include consultation with services such as child life and clinical psychology.
- Nurses at the bedside can support siblings through age-appropriate engagement and conversation.
- Support for families who experience PICU hospitalization needs to include the transition to post-hospital life and the expected family and sibling relationship changes.

Recommendations for Future Studies

Based on this study, the following recommendations for further research were identified:

- Additional studies with siblings of PICU patients from other locations that explore their experiences and perceptions.
- Studies that explore nurses' experiences and perceptions of siblings interactions in the PICU setting.
- Interventional studies with siblings to test strategies for reducing stress and anxiety and improving support during and after PICU hospitalization.

- Further research on the impact of education to nurses and other healthcare professionals on sibling experiences and effective support strategies.
- Further research into effective methodology for conducting videoconference interviews with school aged and adolescent children.
- Research on the perception of the sibling relationship from the perspective of the PICU patient.

Study Limitations

This study had some limitations, including:

- Small sample size, although saturation of themes was achieved with the enrolled participants.
- Each participant was interviewed only once; repeat interviews might have strengthened findings.
- Participants are all from one hospital; broader recruitment might provide greater insight into the phenomenon.
- Limited diversity in participant families, particularly socioeconomic and education levels of families.
- Interviews rely on child's memories of events; interviews during PICU hospitalization might reveal variation in perceptions as events unfold.

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APPENDIX A

Invitation to Participate Letter

[Date]

Dear [parent],

I am inviting children ages 6 years to 17 years old whose brother or sister was hospitalized in the pediatric intensive care unit (PICU) at Dell Children's Medical Center within the past two years to participate in a study about their experiences. Our records indicate that your child may be eligible to participate.

The purpose of this study is to better understand what it's like to have a brother or sister in the PICU and how the well sibling views their relationship with their brother or sister after they come home from the hospital. Being in the study is a choice and no one has to participate. If you and your child agree that they can be in the study:

- You will receive a phone call to set up a time for the researcher to meet you and your child
- I will ask permission to review the medical record of your child who was in the PICU to get information on why they were there, how long they stayed in the PICU and in the hospital, and how long it's been since they went home
- Your child will participate in an interview that lasts about an hour and includes questions about what it was like when their brother or sister was in the PICU, what was helpful to them, and how things have been since their brother or sister came home from the hospital
- When your child finishes the interview, he or she will be given a gift card to either Target or Walmart as a thank you for being in the study
- You will receive a gift card to your choice of Target, Walmart, or HEB as compensation for your time

Being in this study has a few risks. It might be upsetting to your child to remember and talk about when their brother or sister was sick or injured. They may feel tired from talking about their experiences. If this happens, they can take a short break during the interview. There is a risk that private information may be seen by someone outside the study, a breach of confidentiality. There are several protections in place to keep these things from happening.

If you have questions about the study or think that you and your child want them to be in the study, please call me at 512-324-0000, extension 86529 or email christie@ascension.org. I hope that you and your child will join me in this important work.

Sincerely,

LeeAnn Christie, MSN, RN
Research Scientist, Dell Children's Medical Center
Doctoral Student, Texas Woman's University

APPENDIX B

Telephone Script

[After confirming that person answering phone is the parent or guardian of the PICU patient and sibling(s)]

[introduce self: state name and “I am calling from Dell Children’s Medical Center about a research study with brothers and sisters of PICU patients”]

If family has been sent recruitment letter:

A letter was sent to the address we have in your child’s medical record. Do you remember getting that letter?

[if yes]: Did you have a chance to read through the information in the letter? It talked about what the study is about, why it’s being done, and what happens if you’re in the study.

[if yes]: Do you have any questions about any of the information that I can answer for you?

[yes]: answer questions; ask if family is interested in participating, then set appointment for consent and interview

[no]: ask if family is interested in participating

[yes]: set appointment for consent and interview

[no]: Thank you for talking to me. If you change your mind, you can reach me at the phone number or email that is at the bottom of the letter.

[if no]: Is it okay if I tell you a little bit about the study and see if it’s something you are interested in letting your child be part of?

[yes]: Okay. Stop me at any time if you have a question.

The purpose of this study is to better understand what it’s like to have a brother or sister in the PICU and how the sibling views their relationship with their brother or sister after they come home from the hospital. Being in the study is a choice and no one has to participate.

I want to let you know that there are a few risks to being in the study. It might be upsetting to your child to remember and talk about when their brother or sister was sick or hurt. They may get tired when talking about their experiences. If that happens, we will take a break until they feel better. There is a risk that some private information may be seen by someone outside the study, but we do everything we can to keep that from happening.

If you and your child agree to be in the study, your child will receive a \$10 gift card to either Target or Walmart (their choice) and your family will receive a gift card for \$15 to Target, Walmart, or HEB for your time.

If you and your child agree that they can be in the study, we will set an appointment while we are on the phone for a time and place that we can meet to

go through more details, get permission from you and your child for them to be in the study, and do the interview with your child.

Do you have any questions so far?

Would you like to set a time and place that we can meet?

[no]: Thank you for talking to me. If you change your mind, you can reach me at the phone number or email that is at the bottom of the letter

If family is being called from word-of-mouth recruitment:

I was given your name by [contact person] as a family who might be interested. Is it okay if I tell you more about the study?

[yes]: Okay. Stop me at any time if you have a question.

The purpose of this study is to better understand what it's like to have a brother or sister in the PICU and how the sibling views their relationship with their brother or sister after they come home from the hospital. Being in the study is a choice and no one has to participate.

I need to let you know that there are a few risks to being in the study. It might be upsetting to your child to remember and talk about when their brother or sister was sick or hurt. They may get tired when talking about their experiences. If that happens, we will take a break until they feel better. There is a risk that some private information may be seen by someone outside the study, but we do everything we can to keep that from happening.

If you and your child agree to be in the study, your child will receive a \$10 gift card to either Target or Walmart (their choice) and your family will receive a gift card for \$15 to Target, Walmart, or HEB for your time.

If you and your child agree that they can be in the study, we will set an appointment while we are on the phone for a time and place that we can meet to go through more details, get permission from you and your child for them to be in the study, and do the interview with your child.

Do you have any questions so far?

Would you like to set a time and place that we can meet?

[no]: Thank you for talking to me. If you change your mind, you can reach me at the phone number or email that is at the bottom of the letter

APPENDIX C

Demographic Information

Study ID _____

Age of participant _____

Gender of participant _____

Race and Ethnicity of Participant _____

Number of siblings in household _____

Age of sibling (PICU patient) _____

Gender of sibling _____

Race and Ethnicity of Participant _____

Diagnosis category for sibling admission

- ___Respiratory
- ___Trauma
- ___Medical
- ___Cardiac

Length of PICU hospitalization _____

Length of total hospitalization _____

Time since PICU discharge _____

Time since hospital discharge _____

APPENDIX D

Interview Schedule

Interview Questions Mapped to Research Questions

Research Question	Pertinent Interview Questions
What is the lived experience of having a sibling hospitalized in the PICU?	• What was it like for you when your brother/sister was in the PICU? • What was helpful to you when he/she was there? • What were your days like while your brother/sister was in the PICU?
What is the perception of the sibling relationship following hospital discharge for the brother or sister of a PICU patient?	• How have things been since your brother/sister came home from the hospital? • What kind of things do you do together now that he/she is home?

Sample Interview Script:

I'd like to first talk about what it was like when your [brother/sister] was in the hospital, when [he/she] was in the [intensive care unit/PICU]. I want to talk to you about what that was like for you, what your feelings were, and what kinds of things were and were not helpful to you.

Think about when your [brother/sister] was in the [intensive care unit/PICU].

What was it like for you when [he/she] was there?

What was helped you when your [brother/sister] was in the [intensive care unit/PICU]?

What made that helpful?

What kind of things did the nurses and other people taking care of your [brother/sister] do when you went to visit [him/her]? Can you give me an example?

What were your days like?

What kinds of things did you do during the day?

Who took care of you/helped you when your Mom or Dad was at the hospital with your brother/sister?

I'd like to talk now about how things have been since your [brother/sister] came home from the hospital, and what kinds of things you do with your [brother/sister] since then.

How have things been since your [brother/sister] came home from the hospital?

Do you do the same kinds of things together that you did before the hospital?

Is anything else the same or different?

Is there anything else you think we should talk about or that you want to tell me?