Parental stress in the Pediatric Intensive Care Unit

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Abstract

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Purpose: The purpose of this dissertation is to address parental experiences and responses to their child hospitalization in the Pediatric Intensive Care Unit (PICU). There are three papers in this dissertation, all of which include a sample 15 parents of children admitted to a tertiary PICU in the USA. *Paper 1* describes the parent's experience in the modern PICU during acute hospitalization of their child and elaborates, in the parent's own words, the potential types and sources of parental stress. *Paper 2* elaborates, in parents' own words, their reported challenges beyond the PICU that concurrently occurred during their child's PICU hospitalization. *Paper 3* examines the content validity of the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU) scale by comparing the items on the existing measure with data obtained in the elicitation interviews. Paper 3 also proposes initial refinements of the PSS: PICU scale based on interviews and questionnaire analysis

Methods: Paper one and two in this dissertation were based on single occasion interviews were conducted with 15 parents (*n* = 13 mothers, and *n* = 2 fathers) of children with complex medical conditions admitted for 48 or more hours to a tertiary PICU. Interviews were inductively coded using methods adapted from Grounded Theory. For paper one and two, only data from the interviews were used. Paper three was is based mixed methods study using single occasion interviews and quantitative measure that included PSS: PICU and to identify items that needed refinement then make recommendation for refinement in the scale. There are four components of research method: (1) The interviews were inductively coded using content analysis method to identify areas of stress to the parents; (2) Using descriptive statistics to identify items associated with high stress to parents and decide where improvement need to be made; (3) Compare interview coded data with existing questionnaire items; and (4) Use decision rule across those methods to make recommendation for improvement.

Results: *Paper 1* Riding a Roller Coaster was the core construct that explained parents' experiences. Four domains were identified: Being in a New Stressful World, My Brain Is Burning All the Time, Going through a Hurricane of Emotions, and Being in a Safe Place with Great People. *Paper 2* Fraying at the Seams while Balancing between Two Worlds, Home and Hospital was the core construct that captured parents' challenges. Parents' lives were brought to a halt and as a result their whole lives were thrown off. The day-to-day lives of parents were shattered by being pulled apart between the hospital, home, and work. Even though parents were physically and emotionally present with their ill child in the PICU, they felt frayed and did not know how to help their ill child even as they concurrently struggled with their physical detachment and distance from other children at home. This strain of living in two worlds caused feelings of inadequacy and incompetence to fulfill the parental role. Paper 3 Three limitations were found in the existing PSS: PICU scale, including construct underrepresentation, construct-irrelevant variance, and item redundancy.

Conclusion: This dissertation adds new knowledge about parents' experiences and challenges to their child's hospitalization in the modern PICU. Findings also showed that despite outstanding medical services, parents were traumatized by seeing their child in a life-threatening situation and were buffeted by a tidal wave of emotions. Parents lived in a constant state of uncertainty, helplessness and fear, not knowing if their child would survive or have devastating outcomes or permanent disabilities. It could be helpful for parents to listen to their concerns and life challenges even if the nurses are not able to alter those extra life challenges. Listening to parents' journeys and attending to their stories could mitigate the intensity of their stress. Findings from the elicitation interviews and parents' responses on the scale items raised a question about the PSS: PICU scale's relevance and utility in the current PICU. Examining the content validity of the PSS: PICU scale revealed that the scale can be missing content that is important to the current PICU. Researchers need to be aware of the relevance and limitation of the scale when applying it in the current PICU.

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CHAPTER ONE

A qualitative study of parents' experiences in the pediatric intensive care unit: Riding a roller coaster

Abstract

Purpose: Post-traumatic stress disorder rates in parents following PICU admission have increased from 12.2% to 42% in the recent three years. Despite the numbers affected and the magnitude of parents' distress, little is known about parents' experience in the PICU that could be a source of their stress. This study sought to describe parents' experience of the PICU during their child's stay, including their perceived stressors.

Methods: Single occasion interviews were conducted with 15 parents of children with complex medical conditions admitted for 48 or more hours to a tertiary PICU in the USA. Interviews were inductively coded using methods adapted from Grounded Theory.

Results: Riding a Roller Coaster was the core construct that explained parents' experiences. Analyses revealed four domains: Being in a New Stressful World, My Brain Is Burning All the Time, Going through a Hurricane of Emotions, and Being in a Safe Place with Great People.

Conclusion: Despite outstanding medical services, parents were traumatized by seeing their child in a life-threatening situation and were buffeted by a tidal wave of emotions. Parents lived in a constant state of uncertainty, helplessness and fear, not knowing if their child would survive or have devastating outcomes or permanent disabilities.

Practice Implications: Supporting parents during their emotional roller coaster ride requires targeted services throughout the child's illness trajectory, including ways to interpret what is happening in the PICU, helping parents self-regulate their stress, and offering services around parents' fears, concerns, and strategies to manage their uncertainty and feelings of helplessness.

Keywords: PICU; parent; stress; experience

Introduction

An estimated 230,000 or more children are admitted to the Pediatric intensive Care Unit (PICU) annually in the United States (Watson & Hartman, 2014). Within three years, posttraumatic stress disorder (PTSD) in parents after PICU discharge has increased from 12.2 to 42%, with PTSD subclinical symptoms rate up to 84% (Nelson & Gold, 2012). Despite the numbers affected and the magnitude of parents' distress, very little is known about how and what parents experience in the PICU that could be a source of their stress or long-term trauma. This hinders providers and scientists from developing evidence-based programs to minimize or assist parents in managing the impact of the PICU on the parent. A close examination of the parental experience in the PICU could help establish a deeper and more comprehensive understanding of potential sources of parental stress and fear.

What it is known about the parent's experience with the modern PICU is limited to two studies, one led by Dahav and Sjostrom-Strand (2018) and one led by Hagstrom (2017). Dahav and Sjostrom-Strand (2018) interviewed twelve parents (seven mothers, two fathers and three couples) one to four weeks after their child’s discharge from the PICU using a semi-structured interview. Parents viewed the PICU as a chaotic and unfamiliar environment, experienced feelings of unreality and felt they were "in another world” (Dahav & Sjostrom-Strand, 2018, p. 365). The authors also reported that parents felt uncertain about their child surviving and felt powerless because of not being able to take care of their child in the overwhelming environment.

Hagstrom (2017) conducted a mixed methods study whose goal was to explore sources of parents' stress and to describe family experiences with their child's admission to the PICU. Nine parents (eight mothers and one father) from eight families were interviewed during their PICU stay ranging from five days to two weeks. Parents identified three main sources of stress that included separation from other children at home, their child’s illness, and not knowing about the child's course of recovery and outcomes. Parents in the study described the ups and downs in the PICU and the trajectory of their child’s condition as a roller coaster.

What is still needed is a study that focuses on parents' experiences in the PICU during the acute period of hospitalization of their child that is not confounded by recall error or bias. A study that enables the parents to elaborate their experiences in their own words in real time as the parent is going through them is also needed. The timing of the report of experiences matters because it is linked with the timing and duration of stress development (Gee & Casey, 2015). This study was designed to fill these gaps. The current study has two aims: (1) To describe the parent’s experience in the modern PICU during acute hospitalization of their child and (2) To elaborate, in the parent's own words, the potential types and sources of parental stress.

Conceptual Framework

The Transactional Theory of Stress and Coping guided this study (Carter & Miles, 1989; Carter, Miles, Buford, & Hassanein, 1985; Lazarus, 1966, 1991; Lazarus & Folkman, 1984; Lazarus & Launier, 1978; McGrath, 1982; Miles, Carter, Hennessey, Eberly, & Riddle, 1989). From the perspective of that theory, parents' psychological stress response in the PICU is a result of a complex transaction between the individual parent's characteristics along with their situational and environmental factors. Individual factors include the parent's age, level of education, gender, parental role, and other life stresses. Situational factors include the type of admission (planned vs. unplanned), the severity of the child's illness, and the child's diagnosis. Environmental factors include physical aspects of the PICU environment such as alarms, monitors, and machines.

Lazarus (1991) posited that stress was a relational concept and not defined as a specific kind of external stimulus nor a specific pattern of physiological, behavioral, or subjective reactions. Instead, “Psychological stress refers to a relationship with the environment that the person appraises as significant for his or her well-being and in which the demands tax or exceed available coping resources” (Lazarus & Folkman, 1986, p. 63).

Methods

Study Design

The study was a single occasion interview study with parents of children admitted to the PICU.

Participants and Setting

Parents of consecutively admitted children in the PICU were recruited when they met eligibility criteria and were approved for recruitment by a site intermediary, most typically the primary or charge nurse. A total of 15 parents were enrolled from a 32-bed PICU at a comprehensive medical center providing tertiary care to critically ill children in the Pacific Northwest United States. Parents were eligible if their child had been admitted for more than 48 hours to the PICU. A parent was defined as a person who served in a primary caregiving role and provided constant and sustained care to the child during the child's stay in the PICU. This included biological parents, foster parents, grandparents, or guardians. It did not include family members or friends providing respite care when the parent was absent.

Exclusion criteria were readmission of the child within the month, receiving end-of life treatment, insufficient English to complete questionnaires, and identified by the clinical team as inappropriate to enroll. The latter might occur for many reasons, including knowledge about the child that only the clinical team knew.

Recruitment Strategy

Study participants were recruited after review and approval from the institutional review board (IRB). An IRB-approved brief recruitment script was used that included a description of the study. Parents were offered signed informed consent if they agreed to participate in the study. Enrolled parents were asked to complete a demographic questionnaire. Demographic information of the 15 children was obtained from the electronic medical record

Study Interview

Semi-structured face-to-face interviews were conducted in the PICU at the ill child's bedside or in the “quiet rooms” located in the PICU, depending on parent preference. Data analysis for this paper focused on seven broad-band open-ended questions; see Table 1. During each interview the investigator encouraged full elaboration of the parent's response to each question.

Table 1

Interview questions.

Interview Questions
1) Describe what the PICU environment is like for you?
2) How do you feel physically when you are in the PICU?
3) How do you feel emotionally when you are in the PICU?
4) How has your child’s admission to the PICU affected your life right now?
5) What concerns you about your child being in the PICU?
6) What is the top most concern you have right now?
7) What fears, if any, do you have while your child in the PICU?

Analysis

Interviews were digitally audio-recorded and converted to mp3 audio-files for transcription and analysis. Transcriptions were verified for 100% accuracy by two different transcriptionists.

Interviews were inductively coded using methods adapted from Grounded Theory (Shands, Lewis, & Zahlis, 2000; Thomas, 2006; Zahlis & Lewis, 2010). Initially, transcribed data were unitized into units. The unit of analysis that was coded was the complete idea, not the complete sentence. Units were next sorted into initial categories. Initially each question was coded separately and categories were labeled using parents' words, not labels imposed from the study authors. Initial categories were increasingly refined and defined. As coding proceeded and was continually refined, categories were aggregated across questions, enabling us to achieve greater parsimony in summarizing parents' experiences. Refined categories were organized into higher order domains that shared common properties.

Constant comparative analysis was carried out to verify the unique fit of each unit with each category and the fit of each category with each domain (Zahlis & Lewis, 2010). After all domains were identified, the final step in the analysis involved identifying the core construct, the central explanatory process that explained the parents' experiences in the PICU (Zahlis & Lewis, 2010).

Credibility was protected by peer debriefing on the units, categories, domains, and core construct. The first and second authors conducted face-to-face regular meetings to discuss the coding process, categories and domains, resolve any discrepancies, and discuss study findings throughout data collection and analysis.

Dependability was ensured through transparently describing the research steps and recording the research path taken from the start of the research project to the development and reporting of the findings, including maintaining an audit trail (Polit & Beck, 2012). Conformability of the data and results was ensured through verbatim transcription of the audio recordings and using parents' words to describe categories and domains (Polit & Beck, 2012).

Transferability “refers to the potential for extrapolation, that is, the extent to which findings can be transferred to have applicability to other setting or groups” (Polit & Beck, 2012, p. 585). Parents in this study provided robust description of their experiences in a naturalistic setting.

Study Results

Fifteen parents completed the elicitation interviews: two fathers and 13 mothers. Fourteen interviews were conducted at the child's bedside and one was conducted in the quiet room. Interviews were digitally audio recorded and lasted 10.18 to 80 minutes, median 22 minutes.

Parents were 20 to 60 years old, averaging 34.40 (*SD* = 11.79) with a median age of 34. The median length of PICU stay was 4 days (range: 2 to 171 days). Fifty-three percent of the parents had no prior experience with a PICU admission; see Table 2. The study sample was comparable to admitted cases into the PICU at the referring hospital for the same populations. Children in the larger population admitted to the PICU between January and December 2018 averaged 7.6 (median 5.25 years), and their average length of stay was 5.27 days (range: 0.02-220). The total admission was 1941, and 265 patients (17.5%) had a previous admission to the PICU during their current hospitalization.

Table 2

Demographic Characteristics for the Interviewed Parents (*n*=15).

Characteristic	***n***	**%**
Parent Gender		
Male	2	13.3
Female	13	86.7
Marital status		
Married	10	66.7
Single	2	13.3
Divorced	3	20
Education		
< High school	1	6.7
High school	3	20
Some college or technical training	4	26.7
College graduate	7	46.7
Employment		
Full-time	3	20
Not working	11	73.3
Retired	1	6.7
Ethnicity		
White	13	86.6
Hispanic	1	6.7
Other	1	6.7
Previous PICU admission		
Yes	7	46.7
No	8	53.3

The majority of the parent's children admitted to PICU were male (67%). The type of PICU admission was almost evenly split between an unplanned admissions *n* = 7 (47%) and planned admission *n* = 8 (53%). See Table 3. Some children were admitted to PICU due to unexpected life-threatening conditions and some were admitted after planned or elective surgery because they needed special medical support and services after an operation.

Table 3

Demographic Characteristics of the Children (*n*=15).

ID.	Child age	Gender	Diagnoses	Planned	LOS in days	Previous PICU
102	13 months	Male	Bone marrow transplant, acute respiratory failure	Yes	60	Yes
103	2 months	Male	Acute bronchiolitis, E-coli UTI	No	4	No
106	8 years	Female	Acute respiratory failure	No	4	Yes
108	8 years	Female	Respiratory distress, developmental disorder	No	3	No
110	11 months	Male	Alagille syndrome, Liver transplant	Yes	11	No
113	39 months	Male	Acute respiratory failure	No	81	No
114	4 months	Female	Chronic GERD	Yes	9	No
117	9 months	Male	Acute respiratory failure, chronic illness	No	4	Yes
119	35 months	Male	Wilms tumor	No	4	Yes
122	16 years	Male	Kidney transplant	Yes	4	No
124	6 months	Male	Chronic respiratory failure, chronic illness	Yes	171	Yes
127	1 month	Female	Respiratory distress, chronic illness	No	2	No
129	13 months	Male	Tracheomalacia, chronic illness	Yes	8	Yes
130	5 years	Male	Brain tumor	Yes	2	No
131	17 years	Female	Brain tumor	No	14	No

Core Construct

The core construct that explained parents' experience in the PICU was Riding a Roller Coaster on which there were sharp peaks and plunges, bad moments and better ones, unfamiliar noises, fast moving staff, and loud sounds and noises. Parents felt the ride was “crazy,” unpredictable, and perplexing. They anticipated good and bad things that could happen at any time. As the roller coaster reached a peak, parents reported heightened stress. This stress subsided when the ride slowed down. Parents reported a whirlwind of feelings during this ride, which varied for each parent, depending on their prior experience with their ill child and the length of hospitalization in the PICU.

During the roller coaster ride, parents tried not to scream, attempted to contain themselves, and worked hard to hold onto every ounce of positivity they could. During the ride, parents worked to change their mindset so they could stay away from negativity. They knew how to speak positively even during the darkest points and plunges of the ride. They hoped that the ride would safely and peacefully stop and they would be able to get off the ride one day. For some parents the PICU environment was “constantly like rapid-fire,” “crazy” and “just wild." Analyses of interview data yielded four domains of parents’ experiences, each of which is summarized below (Table 4).

Table 4

Domains and categories

Domain	Categories
Being in a Stressful New World	Suffocating with reality Being sketchier a couple of days ago Being stressful Not being super comfortable Never having quiet
My Brain Is Burning All the Time	Feeling I am losing my mind Fearing my child will die Overthinking impossible things
Going through a Hurricane of Emotions	Going through a tidal wave of feelings Not having a hopeful outlook Feeling helpless
Being in a Safe Place with Great People	Feeling safe and peaceful being here Everyone is helping heal and comfort my child

Domain 1: Being in a Stressful New World

Parents described how frightening, hostile and perplexing the physical PICU environment appeared to them. They also reported some uncomfortable aspects of the environment that contributed to their stress. Most parents reported that physical aspects of the PICU caused sleep disruption due to limited privacy, their beds, noise, light, and beeping monitors. Some parents reported that they expected uncomfortable environmental factors as a hallmark of the PICU. Other parents reported that they got used to the uncomfortable environment. This domain consisted of five categories.

Suffocating with what is unreal. At the beginning of PICU admission, parents were shocked when they realized their child was in a life-threatening situation. One mother explained, “you feel like you’re suffocating.” They explained that their child’s illness and admission to the PICU happened so fast, felt “unreal” and everything looked “very surreal.” A mother explained, “it’s just kind of been like a lot of adrenaline, because it was so unexpected.”

Being sketchier a couple of days ago. The actual admission to the PICU was viewed as a low point by some of the parents. They described their initial feelings when their child was admitted to the PICU and claimed that admission was a “hurdle” or “bittersweet." Some parents said that it was “harder,” or “rougher” when they first arrived to the PICU. One father said, “I’m talking about it from the perspective of the last couple days when the couple days before that were sketchier like really being worried about is, you know, is he gonna keep getting worse?” Some parents felt they were “stuck here at the PICU.”

Being stressful. Many parents reported that the PICU environment was “a stressful world”, even if they were expecting it. One mother said, “it’s probably the most stressful place I think that you could ever be, only because it’s your child.” The stressful environment impacted parents’ lives; this mother said, “it’s definitely been a stressful impact on our lives, but it is to be expected.”

Some parents claimed that the PICU was not the source of their stress but rather it was their child’s condition that affected their stress. This mother explained**,** “I think it’s stressful, just because our child is here sick.”

Not being super comfortable. Some parents felt they were “living in an unfamiliar environment.” They explained that it was not “super comfortable living in front of people” and “beds are uncomfortable aspects of being here.” One father said, “from a like day-to-day life perspective, it’s a little tough, actually like basically living here, and like that’s a little tougher just because it’s—you don’t normally live in front of everyone, right? You know, even though it’s kind of our space, it’s still somewhat public with people coming in and out.” Parents tried to adjust to living in the PICU, “it’s kind of how you have to get used to that cadence of bringing changes of clothes and going home to shower and things like that to.”

Parents explained that beds were hard to sleep on or not at a comfortable length. One father said, “I’m somewhat tall, so these things *[beds]* aren’t nearly long enough, tall enough for me, so my feet hang off the end.” However, some parents made some effort to make their beds comfortable and brought their favorite sheets or blanket, “I’ve made my bed quite comfortable for myself over there, so sometimes I sleep there.”

Some parents talked about the difficulty of needing to be in isolation precautions which severely limited their activities and social life. Isolation precaution was a measure implemented to minimize pathogen transmission and mitigate against the risk of hospital-acquired infection. However, some parents felt that this restriction was “just a whole mess by its own.” Being in isolation restricted parents from going to the main cooking area and family lounge and created inconveniences.

Some children were on Extracorporeal Membrane Oxygenation (ECMO) that was overwhelming for parents to see; it also overly congested the physical space of the room. “He was on a lot of machines. And then just coming in here when he was on life support, there was no room in here at all.”

Never having quiet. Because of the constant noise and interruptions, the PICU was “not a restful environment.” Parents explained that they were constantly surrounded by lots of machines, bright lights, and something beeping. Many parents reported, “there is no quiet,” “there is always something going on,” and “a lot of hurry up.” Parents described some of the constant challenging environmental factors: in-room-interruptions (e.g. nurses checking on the child, “doctors rush in,” “there’s always tests,” “and people to round back on you.” Another mother said, “it is draining just being here in a hospital and constantly, you know, there’s something going on. There’s something beeping. They’re (nurses) having to check on my child.”

Parents had different responses to the challenging environment. Parents’ responses included: acceptance, stress trigger, and exhaustion. Some parents claimed that the noise of the monitors was expected, “just the way it is,” and was reassuring, “it’s just like kind of the level of care that he needs right now.” One father said, “you’re always gettin’ messed with just the way it is. So they come like whenever he needs it or whenever they have to do labs or do diaper.”

For other parents, the beeping monitors triggered their stress. One mother said “you’d think, oh no, what’s wrong, every time something beeps.” Some parents claimed that noises from the monitor interfered with their ability to sleep in the PICU, “it’s hard to sleep with monitors are goin’ off, and everything like that.” One mother explained that not sleeping and eating well would make her body more tired of everything. Parents shared some reasons for not being able to sleep that included their child needing to undergo long surgery, their child was not sleeping, or having someone constantly around the child. However, sleeping was not an important matter for some parents, because their primary focus was on their child. Many parents felt that they were “exhausted,” “completely drained,” “extremely tired,” and “worn out” from being in the PICU. For some parents, the monitors were initially “overwhelming” and “used to scare” them. Upon the PICU admission, parents felt “overwhelmed” because “there were so many faces, so many doctors, nurses. It’s just a lot of people at a lot of times.”

Domain 2: My Brain Is Burning All the Time

Parents described ways in which the PICU experience and admission affected them mentally. They felt their brains were on fire. They were “mentally burning” from the flame of “what is happening,” “what could happen tomorrow,” “is my baby going to die?” and “is this treatment going to work”? Parents had several wondering questions that occupied their minds about their child’s current condition and future health outcomes. Others kept feeling they were going to “lose their minds.” One father said, “mentally, I’m kinda—cuz your brain’s burnin’ all the time.” Three categories comprised this domain.

Feeling I am losing my mind. For parents, the “mental exhaustion” and “confusion” of being in the PICU were more burdensome than the physical impact of the environment. Parents explained that their minds were constantly asking, “what is happening,” “what can happen” and “is my baby going to die?” One father said, “you just lose your mind in here.” The father explained that his mental exhaustion was due to feeling helpless, “you’re just watching from afar cause you can’t really help.” Two mothers said that trying to make sense of how and why everything had happened would “drive you crazy.”

Overthinking impossible things. Parents were “overthinking” about “what will happen to my child” when they were not around, which led them to “think about the impossible things.” For example, some parents felt “nervous” to leave the PICU room even for a short time and that their child might “pass out” or something could happen to their child. One mother expressed her fears whenever she leaves her child for a short time to grab coffee or have a walk, “when you walk back up is your door gonna be open, and is there gonna be 50 doctors in here? And all you did was go change a load of laundry or go get something to eat, and you come back."

Fearing my child will die. Parents were lost in a maze of emotions, their thoughts wandering far and wide, especially when they lived in uncertainty of not knowing if their child would survive or not. Parents harbored initial fears, worries and concerns that they would lose their child when the child was in a "life threatening" situation. "The one fear I have, that she's not gonna make it, that she might die. That's the biggest fear I have." Another mother said, "my biggest concern was: Is my baby going to die?" Thinking of death was "terrifying" and "real tough" for the parents. They lived in uncertainty of not knowing whether their child would survive and if they would have to deal with death. A mother described her fear, "I feel like the way I kind of emotionally process things, I feel like I'm just like numb, almost. It's weird. Cause it was so unexpected. So, and then sometimes I just feel like I can't handle it, or like sometimes I feel like I'm having a panic attack. Um, it's just I think it's gonna take a while for it all to sink in, because it happened so fast."

Domain 3: Going through a Hurricane of Emotions

This domain represented the emotional toll on parents from the constant highs and lows of being in the PICU. Parents went through "a hurricane of emotions." This domain involved three categories.

Going through a tidal wave of feelings. Parents' emotions involved "ups and downs" like "tidal waves." One mother described it this way, "it's not a slow wave coming in, and it smacks you, and you're still going, what's going on?" Parents' "tidal wave of feelings" occurred at two junctures in their child's illness: when their child showed signs of improvement or signs of deterioration. A mother said, "my emotion varied hour by hour or even minute-to-minute depends on like how he’s doing because, one minute, we think he’s doing good, and the next minute, well, he’s not.” Other parents “felt every single emotion all at the same time.” One mother explained, “my emotions run the gamut every day. I go all the way from so sad to so happy, at least once a day.” Furthermore, parents felt as they were “going downhill” and it was “nerve-wracking” when their child was “rolling downhill” in response to deterioration in their child’s condition. Other parents carried two opposite emotions at the same time, “being hopeful and optimistic even when I am sad.” One mother said, “it’s like you got these two (being hopeful and sad) kinda going on at the same time.”

Parents experienced positive emotions when their child showed steady improvement or had "a really good prognosis, and felt “comfortable,” “pretty good,” hopeful and “optimistic.” One mother said, “If I get like good news about how he’s recovering, I squeeze every little ounce of like positivity I can out of that and continue to be happy.” One father said, “emotionally, it’s closely tied to how well he’s doing and when we see him getting better or even staying the same, then emotionally I’m pretty-pretty comfortable.”

Parents reported they felt panic, anxious, nervous or worried about their child's uncertain treatment and outcomes. One parent said, “that nervousness of not knowing if this treatment’s gonna work right or if this treatment’s gonna work right kind of, you know, going against the grain on some of it.” Parents often experienced uncertainty characterized by the unpredictability of their child’s condition and what could happen in the next hour; they had no idea what the future held. One mother elaborated, “down here, this is, like, anything can happen at any minute.” Another mother said, “one hour, things can be crazy, and the next, nothing’s really going on.”

Feeling helpless. Parents reached a state of mental exhaustion from feeling helpless. There were four explicit triggers that caused parents to feel "helpless" and "sad": Seeing other "sick children," "struggling parents," "hearing the code calls," and "seeing your child in pain." Some parents felt helpless seeing other suffering children and parents and were not able to reduce others' suffering. One mother said, "it's very sad to see children being sick and being ill." They also felt "sad" and "sympathetic to all mothers that have to go through this." Parents said it was "hard" for them to see "crying parents", who were "struggling" and "clearly suffering." They wished they "could do something to make that (suffering) go away." Some parents said they were "extremely depressed," because it was hard for them to see their child going through hard time and "suffer this much." They felt helpless when their child suffered from pain, "if he is feeling pain, I cannot do anything. So that's, that makes me sometimes stressed." "Seeing your child in pain is the worst thing in the world" as they described. Another mother said, "it's kind of a helpless situation because it's your kid."

Not having a hopeful outlook. Parents felt hopeless when the treatment plan did not work or their child continually deteriorated, "I don't have a hopeful outlook because of the decline." Another mother said, "I guess at first, like, for a while, you feel that, like, nothing is gonna happen, like, nothing good is gonna happen. There's no progress."

Domain 4: Being in a Safe Place with Great People

Despite the stressful environment and intensity of parents' emotional response to the PICU environment, parents felt "pretty good" and "safe" being in the PICU. Parents positively appraised the PICU as the "best possible place," "a great place", and that the PICU staff were "great" and "extraordinary." Staff included nurses, physicians, social workers, mental health professionals, and sitters. One mother said having a great team helped her when she was experiencing an emotional breakdown, “there's a lot of great people that make me—even when I am—you know, when I'm emotionally crashing, there's a lot of great people that help me here.” This domain involved two categories.

Feeling safe and peaceful here. Parents felt “a lot safer,” “pretty comfortable,” and more “peaceful” being in the PICU with their child than anywhere else. One father explained, “I’d use the word comfort because we just know it’s the best place for him to be in terms of getting care.” Another mother said, “And I actually feel really comfortable with how well everybody takes care of my son.”

One mother added, “I don’t feel comfortable bringing him home.” Although parents were unhappy to be in the PICU and see their child being in close monitoring, they believed this was the type of care their child needed, which gave them “a little bit of peace of mind.” Parents felt “reassured” when surrounded by a multidisciplinary team during daily rounds to discuss the child’s case and plan of care. One mother said, “it’s really great to see, like I said, a team of 30 people, every morning, come together and talk about a little, tiny 11-month-old baby who’s fought so hard for his life in the last year.” Another mother said, “they all might be, like, 15 different opinions, but they’re all here to figure out what’s going on.”

Healing and comforting my child. Parents said that they were “in a new world with a good team,” who did “their best” to “heal” “cure” and “comfort” their child. A mother said, “that’s the biggest thing I’ve learned is just everyone’s here to help him and to cure him or fix him and make him comfortable.” Parents also shared their positive experience on how doctors approached them, “doctors are very good and careful how they approach me as a mother.”

Discussion

The four domains and their categories characterized parents' experiences when their child was admitted into the PICU (Table 4). These results deepen our understanding of parents' experiences in the modern PICU and complement and further elaborate selected findings from prior studies by Hagstrom (2017) and Dahav and Sjostrom-Strand (2018).

Parents in this study labeled their experience in the PICU as a wild roller coaster ride marked by many ups and downs. Similar to results from the Hagstrom's (2017) study, these ups and downs were characterized by uncertainty, helplessness, unpredictability, and occasional hopelessness. The current study elaborates Hagstrom's (2017) study findings by offering a more in-depth description of parents' emotional and mental states. Parents were in a constant state of emotional arousal and activation. There was no "down" or "quiet" time. There was no safe emotional space for them. Parents felt they were "deer in the headlights" and hung onto any and everything positive they could, even in the throes of uncertainty and unpredictability. Uncertainty occurred even in the presence of what they appraised as outstanding medical care and nursing services. Notably, the focus of those services was on their child, not on the parent's response to what was happening in the PICU. Parents experienced mixed feelings – feeling reassured that their child was receiving good care, yet feeling worried about their child and feeling uncomfortable and unsure in the new situation.

Being in another world and feeling an "unreality" are consistent with findings by Dahav and Sjostrom-Strand in Sweden (p.365). In their study, parents felt they were in another chaotic world where everything was "surreal" by the sight of their children in the middle of chaos under flashing lights and alarms (Dahav & Sjostrom-Strand, 2018). The current study expands on Dahav and Sjostrom-Strand's findings through deep description of the chaotic PICU experience, which included exposure to multiple uncomfortable environmental factors such as missing privacy, uncomfortable beds, noise, light, and beeping monitors that caused sleep disruption. Although parents acknowledged that the beeping monitors and being interrupted by nurses frequently checking their child was physically uncomfortable, some thought it was somehow mentally comforting and reassuring that their child is receiving an appropriate needed care. For some parents, who had a PICU experience, they anticipated room interruptions and noises as PICU norm.

Parents viewed their child at a constant risk for “going downhill.” Having their child in the PICU often challenged parents' beliefs about their child's survival. Parents' "tidal wave" of emotions depended on the child's condition and what they understood at the time. Fluctuations in their child’s condition created tremendous stress that "burned" their mind from the inside out. For some parents “a hurricane of emotions” grew inside them and swirled around constantly and forcefully. Parents found their emotions swinging quickly "hour by hour,” flipping them from sad and hopeless to happy and optimistic, to depressed, to sad all over again. Parents were in an adrenergic arousal phase because everything “happened so fast.” They were helpless that elicited their fear, worries, stress and sadness. We argue that mental health depends on emotional clarity (Wang, Weiss, Pachankis, & Link, 2016) that the constant emotional arousal did not allow time for processing, and reflection. Parents said that they did not let their “emotions to sink in” because everything looked “surreal.”

We began this study aware of the high rates of PTSD in parents of children admitted to the PICU, hoping to better understand factors in the PICU that could be plausible explanations of these high rates. Four categories of data in our results suggest three plausible sources: a) exposure to a constant threat (never having quiet, and feeling I am losing my mind); b) uncontrollable and unpredictable stimuli (going through a tidal wave of feelings), and c) intense emotions (going through a tidal wave of feeling), all of which are summarized in Figure 1. We speculate that living in a constant state of threat (Lancaster, Teeters, Gros, & Back, 2016) with no predictability (Foa & Kozak, 1991) has the potential to trigger development of PTSD symptoms. Additionally, study results revealed that parents manifested three categories of PTSD symptoms during PICU hospitalization: emotional avoidance, numbing (feeling I am losing my mind fearing my child will die), and dissociative symptoms (i.e. derealization and depersonalization) (suffocating with what is unreal) (*Diagnostic and Statistical Manual of Mental Disorders (DSM-5®)*, 2013).

Study limitations should be noted. Study results are limited to English speaking parents who were a convenience sample of parents willing to participate. We excluded children who were admitted within the month, received end-of life treatment, and were identified by the clinical team as inappropriate to enroll. Single occasion data are limited in their ability to capture parents' total experiences over time in the PICU. Most parents were college educated, married, and White. Results may not generalize to other less well-educated, non-White single parents. Further, a single hospital may not represent the experience in all PICUs; most of the participants were mothers.

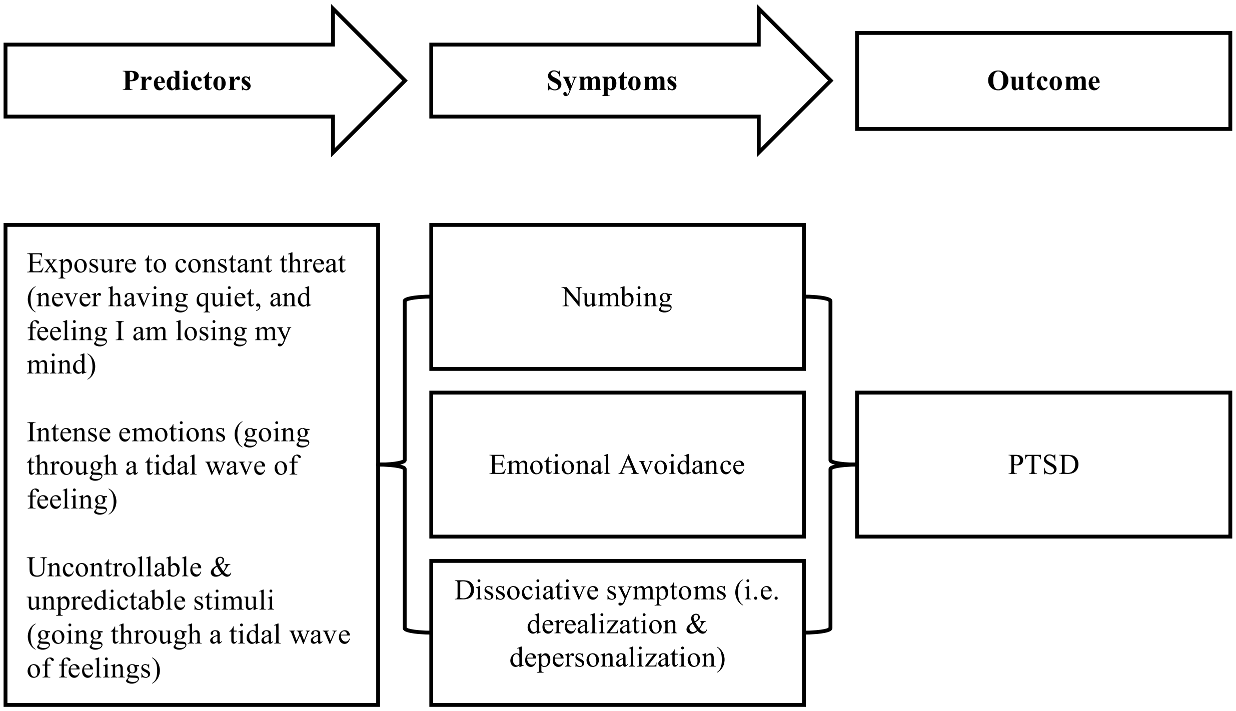

Figure 1.

Proposed explanation of PTSD development in parents of children admitted to the PICU

Practice implications

Both clinicians and scientists need to develop multidisciplinary targeted services throughout the child's illness trajectory to support parents during their emotional roller coaster ride. These services need to consist of nurses, physicians, social workers and mental health professionals. Services need to focus on helping parents find ways to interpret what is happening in the PICU, gain ways to self-regulate their emotions, better manage their fears and concerns, and help them add strategies to better manage their uncertainty and feelings of helplessness. Even in a busy PICU, it would be wise to train PICU professionals on techniques to help parents express and label their feelings. Labeling emotions helps mitigate the intensity of their stress (Frattaroli, 2006; Kircanski, Lieberman, & Craske, 2012). Putting words to feelings may be one of the most important aspects of the affect-language-cognition interaction (Frattaroli, 2006;

Kircanski et al., 2012). Evidence from prior studies by others shows that verbalizing feelings leads to tension-regulation, self-soothing, and self-reflection (Frattaroli, 2006; Kircanski et al., 2012). By definition, PTSD occurs three months after a traumatic event, not during the event. Even if nurses invited parental disclosure, naming, and labeling their emotions, this may not be sufficient to minimize or prevent PTSD. Instead, post-discharge support services are likely needed as a component in preventing PTSD following the PICU traumatic event.

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CHAPTER TWO

Parents’ Challenges outside the Pediatric Intensive Care Unit: Fraying at the Seams while Balancing between Two Worlds, Home and Hospital

Abstract

Purpose: To elaborate parents' reported challenges with which they must concurrently deal when their child is hospitalized in the Pediatric Intensive Care (PICU).

Design and Method: Single occasion, semi-structured interviews were carried out with 15 parents of children admitted for 48 or more hours to a tertiary PICU. Interviews were inductively coded using content analysis methods adapted from Grounded Theory.

Findings: Fraying at the Seams while Balancing between Two Worlds, Home and Hospital was the core construct that captured parents' challenges. Parents' lives were brought to a halt and as a result their whole lives were thrown off. The day-to-day lives of parents were shattered by being pulled apart between the hospital, home, and work. Even though parents were physically and emotionally present with their ill child in the PICU, they felt frayed and did not know how to help their ill child even as they concurrently struggled with their physical detachment and distance from other children at home. This strain of living in two worlds caused feelings of inadequacy and incompetence to fulfill the parental role.

Conclusions: Nurses are naïve if they think parents of children in the PICU are focused only on the hospitalized child. Evidence is that they are focused on both that child and the challenges beyond the confines of the hospital.

Clinical Relevance: Listening to parents' challenges and journey in and beyond the PICU may help parents to express their feelings which ultimately can contribute to self-soothing, self-reflection and tension regulation, even if the nurse is unable to change or alter those extra-PICU challenges. PICU nurses are in a key place to encourage parents to take time for themselves away from the turmoil of the PICU. Scheduling times with parents where they can go home may optimize their parental presence at home, reduce the physical and emotional separateness from other children and family, reduce parents' emotional and physical tension. **Key words:** PICU; Parent*;* challenges; parenting; role; qualitative research

Introduction

PICU admissions have increased since the 1980s in the United States and currently more than 230,000 children are admitted annually to the PICU (Watson & Hartman, 2014). The consequences of PICU admission on parents are alarming, including physiological stress, and posttraumatic stress disorder (Balluffi et al., 2004; Colville & Pierce, 2012; Samuel, Colville, Goodwin, Ryninks, & Dean, 2015). To date, studies of parental stress in the PICU have predominately focused on identifying sources of parental stress in the PICU while leaving parents' broader life beyond the PICU understudied. Despite over 30 years of published research on parental stress in the PICU, little is known about parents' challenges beyond the PICU including parents' normal daily routines, family and personal daily life, family roles, and responsibilities. Qualitative studies have instead been limited to exploring parents stress and reactions within the PICU, not beyond it. Despite an extensive review of the literature, only eight qualitative studies examined parents' report of the stressful experience of having a child in the PICU; see Table 1, all published between 2004 and 2018. These studies examined parental reactions and stressors in the PICU. The most commonly reported stressors across the studies were: the overwhelming physical environment, child's appearance, uncertainty about the child's survivorship and outcomes, relationship with staff, and alteration in the parental role. The impact of PICU admission on family dynamics was reported in two studies (Cantwell-Bartl & Tibballs, 2013; Hagstrom, 2017). Cantwell-Bartl and Tibballs (2013) found that family separation and fathers' strains in commuting long distances to the hospital were some of the parental stressors. The expenses of commuting and financial constraints were also reported in the study by Diaz-Caneja, Gledhill, Weaver, Nadel, and Garralda (2005). Parents in the study by Hagstrom (2017) were stressed from being separated from their homes and torn between their homes and hospital.

Although results from these eight studies add to our understanding about parental stress in the PICU. However, they do not help us understand parents' daily life challenges beyond the PICU. In the systematic review of 13 studies that examined parental stressors and their impacts, Shudy et al. (2006), recommend that further studies are needed to identify family disruption, marital cohesion, and financial effects when a child is admitted to the PICU. Recognizing and understanding the many nuances underpinning parents' challenges during this stressful period are essential to provide quality interventions to assist parents in managing the impact of the PICU experience on themselves and their families. Identifying parents' unique challenges when their child is admitted to the PICU is a necessary first step to develop effective interventions in the future. The aim of this study was to elaborate, in parents' own words, their reported challenges beyond the PICU that concurrently occurred during their child's PICU hospitalization.

Table 1.

Qualitative studies of sources of parental stress in the PICU

Author (year)	**Sample**	**Stressors Findings**
Dahav and Sjostrom-Strand (2018)	12 parents*	• The unfamiliar environment of the PICU alarms and flashing lights • Parental role alteration; unable to be close to their child and could not be involved in their care • Uncertainty if the child would survive or not • Change in child's appearance
Hagstrom (2017)	9 parents (8 mothers and 1 father)	• Separation from their children at home • Conflicting feelings about leaving the hospital despite knowing that their child in good care • Not knowing about the child's trajectory and outcomes • Being prepared for changes in the child's hospital course
Oxley (2015)	6 parents*	• Experiencing post-traumatic stress symptoms with heightened anxiety, nightmares, and flashbacks, • Anxiety from a lack of communication with the staff • Child's appurtenance (being connected with tubes) • Fear to leave their child in the PICU • Pressure from transferring the child from the PICU to ward and changing responsibilities
Cantwell-Bartl and Tibballs (2013)	29 parents (16 mothers and 13 fathers) of children with Hypoplastic	• Diagnosis of HLHS • PICU environment • Infant's health and recovery;

	Left Heart Syndrome (HLHS) in the PICU	• Infant’s appearance after surgery • Relationships with staff • Family separation • Strains from commuting long distances to the hospital •
Latour et al. (2011)	39 mothers and 25 fathers of 41 children	• Attitude of the professionals • Coordination of care • Emotional intensity • Information management • Environmental factors • Parent participation
Colville et al. (2009)	50 parents (32 mothers and 18 fathers)	• Vivid memories of PICU • Communication with staff • Anxiety pre-admission and distress following transfer to the ward
Diaz-Caneja et al. (2005)	11 parents*	• PICU environment • Sudden onset of the child’s illness and admission to the PICU • Limited information received from the medical team • Physical and emotional separation from the child due to machines connected to the child • Financial constraints and expenses of commuting, • Worries related to child’s outcomes and illness reoccurrence after discharge
Stratton (2004)	6 parents*	• Feeling helpless • Unanticipated care for the child • Uncertainty

* No data provided about number of fathers and mothers

Theoretical Framework

This study derives from theory of cognitive adaptation to threatening events (Taylor, 1983). Taylor (1983) theorized that adjusting to life-threatening events usually entails three processes. The first component is a search for meaning that involves two forms: a causal attribution at understanding why the event happened, and the implications of the event on one’s life at the present time. One of the ways in which meaning is addressed is through causal attributions. It is assumed that not all parents will be able to accurately attribute the medical causes but they always have the potential to generate their own attributional model (Lewis & Daltroy, 1990). The implication of the crisis can be positive on one’s life through which the experience of a child’s admission to the PICU can bring a new attitude, self-knowledge, self-change on parents and reordering their priorities. However, not all parents can draw positive meaning from the experience. The second component of the theory is gaining a sense of mastery. This involves personal beliefs that a person can control the event or keep it from reoccurring. Parents can attempt to control the causes or reasons for their child's admission to the PICU. A sense of mastery can also be fulfilled by other than direct efforts such as believing that physicians or treatments can control the child's illness, or acquiring information about the illness of their child. However, parents may not achieve this sense of mastery if those conditions cannot be fulfilled when there is uncertainty about the diagnosis and treatment. The final component of the theory involves restoring self-esteem. Restoration entails efforts to enhance a positive sense of the self, despite the occurrence of the threatening event.

Methods

Design

The study was a single occasion descriptive study whose data was obtained from semi-structured face-to-face elicitation interviews of parents of children admitted to the PICU. Inductive content analysis was used to analyze transcribed and verified parent interviews. Constant comparative analysis and peer debriefing were carried out at all stages of data coding: unitizing, inductive coding for categories and domains, and identification of core construct.

Participants

Participants were parents of 15 consecutively admitted children in the PICU with complex medical conditions at a tertiary medical center for children in the Pacific Northwest. Parents were eligible for inclusion if their child had been admitted for more than 48 hours to the PICU. A parent was defined as a person who served in a primary caregiving role and provided sustained care to the child during the child's stay in the PICU. This included biological parents, foster parents, grandparents, or guardians. It did not include family members or friends providing respite care when the parent was gone. Exclusion criteria were children who were readmitted within the last month, received end-of-life treatment, deemed by the clinical team as inappropriate to enroll, and parents with insufficient English to complete questionnaires.

Study procedure

Study approval from the institutional review board of the study center was obtained prior to data collection. Recruitment occurred in four steps: (a) identifying potential eligible parents through reviewing the electronic medical record of all children admitted to the PICU; (b) confirming parent's eligibility and obtaining a verbal agreement from the primary or charge nurse prior to approaching each parent; (c) inviting the parent to enroll; and (d) obtaining signed informed consent from the parents who agreed to participate in the study.

Semi-structured face-to-face interviews were conducted in the PICU at the child's bedside or in the “quiet rooms” located in the PICU by the principal author. See Table 2 for study interview questions. Interviews were digitally audio-recorded and lasted between 10 and 80 minutes, with a median of 22 minutes. Parents were asked five questions related to their current PICU challanges: what are the biggest challenges you are facing right now? What challenges, if any, are you not able to manage right now? How are you dealing with the biggest challenges? What else is going on in your life while your child is in the PICU? And how is your child’s admission to the PICU affecting your life right now? After the interviews, the parents were asked to complete a demographic questionnaire.

Data Analysis

Recorded interviews were transcribed verbatim and verified 100% for accuracy against the audio-recordings. The transcribed interviews were inductively coded using content analysis methods that derived from grounded theory by following the analysis steps described by Glaser and Strauss (1967) and Shands, Lewis, and Zahlis (2000). Prior to coding, the first two authors read the transcripts multiple times to gain an in-depth understanding of the content. Coding began with unitizing the transcribed data into codable units. A unit was defined as the complete idea, not a complete sentence. Units that possessed a common characteristic or property were then grouped together to form initial categories. Categories were labeled using participants' words, not words imposed from the authors. Categories were continually examined for similarity and refined to ensure they were mutually exclusive and to reach parsimony in summarizing study data. Categories were then organized into higher order conceptual groups, called domains. Categories within a domain shared common properties. As with categories, each domain was labeled using parents' words. Domain labels were chosen to best capture the manifest meaning of the categories and each domain was implicitly defined. Constant comparative analysis was carried out to verify the unique fit of the categories in the domains. After generating the final set of domains, categories and definitions, the core construct was identified. The core construct is the explanatory process that captured parents' reported broader life beyond the PICU.

Four strategies protected the trustworthiness of study results: credibility, dependability, conformability, and transferability (Polit & Beck, 2012). Credibility was protected by conducting face-to-face regular meetings between the first and second authors to peer debrief the units, categories and domains, core construct and resolve any discrepancies. They verified the transcribed interviews for 100% accuracy. The second author listened to 50% of the recorded interviews and checked the verbatim transcriptions. Dependability was ensured by maintaining an audit trial and formal peer debriefing the data and coding process to confirm the accuracy of the findings and ensure that the findings are supported by the interview data. Interpretation of the data was examined against the interview data to determine the accuracy of the interpretations. Conformability was also ensured by examining the distinction between categories for their uniqueness and non-overlapping characteristics, and requiring 100% consensus between the peer debriefer (2nd author) and the primary coder (1st author), and using parents' words in describing the categories and domains. Parents in this study provided a robust description of their challenges and how they handled them in a naturalistic setting that the phenomenon occurred (i.e. PICU), which reflected the transferability of the data and results.

Results

Study Sample

A total of 13 mothers and 2 fathers (n = 15) completed study interviews. Eighty-seven percent of the parents were White and ranged in age from 20 to 60 years (mean 34.40; SD = 11.79) with a median age of 34. Most parents were married (67%) and 47% had a college degree. The median length of PICU stay was 4 days, ranging from 2 to 171 days. Fifty-three percent of the parents had no prior experience with a PICU admission. The vast majority of interviewed parents were not working (73%) at the time of the study. Most parents had additional children at home (73%) whose ages ranged from 5 months to 19 years old.

The PICU-admitted critically ill children (n = 15) were mostly male (67%), with a mean age of 40 months (Supplemental Table 2). PICU admissions were was almost evenly split between unplanned (n = 8; 53%) and planned (n = 7; 47%). Some children were admitted to PICU due to unexpected life-threatening conditions and some were admitted after a planned or elective surgery; they needed intensive medical support and services after the surgery.

Core Construct

The core construct, Fraying at the Seams while Balancing between Two Worlds, Home and Hospital, summarized parents' reported challenges. Family and personal daily life were "thrown off" as the parent's entire existence focused completely on their hospitalized child's health and survival. Parents reported their family roles and responsibilities often had to be changed, and normal daily activities and routines had “fallen by the wayside.” Two domains were identified, each of which is summarized in Table 3.

Table 3

Domains and categories

Domain	**Categories**
Bringing My Life to a Halt	Putting everything on the back burner Being pulled back and forth between here and home Strained by finances and separation
Throwing Our Whole Life Off	Being disruptive to our lives Being less of a family

Domain 1: Bringing My Life to a Halt

While parents focused on their sick child, they “put everything else on hold,” as “it is hard to have your son here at the hospital and also deal with your house.” Their sick child “took up all of our time and energy and got our attention.” A mother said, “it’s definitely brought like our—my life to a halt. And it’s just a new world, is the only way I could think of. It’s a new world with no sleep and high stress levels, and a good team, but I don’t see my husband as much because he’s working again. Um, during the weekdays, he doesn’t come very long just because he’s gotta go to work, and it can be tired. So that’s difficult, and, we haven’t really seen any friends or family or anything.” Three categories comprised this domain.

Putting everything on the back burner. “She’s my full-time job” was a frequent response from mothers. Some mothers explained, “I technically can work, but I’ve chosen not to work so I can be here with him.” Other mothers needed to quit their jobs: “we’ve made the decision for me to leave work and be staying with the boys instead.” Many parents said that their child was their “biggest focus” or “priority over anything else at the house,” so everything was “put at the back burner.” Two parents prioritized their children over themselves. One mother said, “at least I’ve been really hyper-focused on him, and not really thinking about myself," Another mother said, "I'm here for her and putting her before me." Parents also felt that the child got their "full attention" and they were always at the PICU "making sure that my child is taken care of" and "making sure everything is okay." One father said, "being here put everything on hold. Um, work, our other two kids. You know, we don't get to see them, except on Facetime or, you know, we put everything on hold to focus on getting her better, which we had never been able to do before. It's always been one or the other, so. Um, it's kinda nice, actually, that we can." Many parents talked about the challenge of temporarily leaving the child in the PICU such as "leaving to the store", because they were scared to briefly leave their child even for a short time. Mothers "did not want," "did not like," or "felt bad getting out or being away from my baby." Some mothers felt "nervous." A mother said, "I am very leery of leaving my child up in the PICU." Many mothers felt that they "have to be here" for their child.

Being pulled back and forth between here and home. Parents reported the challenge of being "pulled back and forth" between the PICU and house, and "balancing" their lives. One father said, "it's busy, it's a lotta pull back and forth between what's going at my house and what's going here." Two fathers tried to "make sure everybody's cared for" or they "tried to take care of everybody else's." One father said, "when you multitask you do good at everything, but not great at one." Many mothers talked about the challenge of "trying to juggle being here and being home, a mom, a mother to my other child, a wife, a homemaker." They described their houses being in "shambles" and "a lot going on at home" when they were at the PICU.

Strained by finances and separation. Some mothers had financial problems or pressure where money caused extreme stress, "financially, things are extremely stressful," and "having difficulty with money." Mothers that talked about their financial difficulties were not working. A mother said, "Now we can't afford paying the rent. So we actually are losing our apartment, and me and the baby [other child, five months old] will be staying here. Um, his dad lost his job while we were here.” Another mother struggled with transportation and commuting because she was not “living close to the hospital.” Other financial challenges included, debt, bills, gas, “not having a car to use”, food and daycare cost for the other child was “extremely stressful.” A mother explained, “financially, things are extremely stressful, so we have a lot of bills to pay, and it’s very, very hard when your husband loses his job. We have a lot of debt.” She had to quit her job because of what’s happening.” She was renting a “very, very small house” and was stressed how to “make structural changes to accommodate” her child when he would be discharged home. For her, “eating healthy and affordably” was “hard because “food is expensive in the cafeteria. It’s expensive at the nearest grocery store.” Two mothers had husbands who lost their jobs while their child was in the PICU. One mother shared her story, “his dad is technically out of the picture right now. He’s—doesn’t know how to stay out of trouble, now we can’t afford paying the rent. So we actually are losing our apartment, and me and the baby will be staying here. Um, his dad lost his job while we were here.”

Some fathers of the children were not involved in the PICU admission or supportive of the mothers. Five mothers shared their challenges of “not having that other parent as a support person” and “dad is out of the picture.” Some mothers said that their child’s father “couldn’t be here” in the PICU, because the father was “in the military,” or lived in a different State, or they were “going through a divorce.” One mother explained, “his dad’s also military, so it’s kinda hard to—it just puts a strain on that relationship, because he can’t be here.”

Domain 2: Throwing Our Whole Life Off

Admission to the PICU disrupted and scrambled parents' lives, schedules, physical activities, and family dynamics because of the constant pull back and forth between the PICU and home. Parents reported that “being in the PICU threw our lives off.” Many parents reported that they had stopped “making plans” such as “trips and vacations,” “had to drop off classes,” and “missed going to a conference or work.” Two categories comprised this domain.

Being disruptive to our lives. Parents reported that PICU was “definitely disruptive to our lives” including their self-care and physical health. Parents faced a challenge of being “physically active” as they used to be and “get much exercises” as they would like. One father described the challenge, “that Monday, which was supposed to be our first kind of calm day, he was admitted again, so it’s just been so busy and that we’re still working. We felt under more stress than we have, you know, through a lot of this and we could feel ourselves fraying a little bit at the seams.” One mother “had to stop breastfeeding” while she was in the PICU. Parents wanted to take care of themselves, maintain their “hygiene” and “shower” and eat well because it was “hard to eat well” and eat food that “isn’t junk.” Parents also wanted to maintain their “sanity.” One mother believed that she was doing okay but when the PICU situation would be over, she would need therapy, “I always, I’ve been telling my friends, I’m okay right now but when this is all said and done, I’m gonna need some major therapy.” A father said:

> “Disruptive. Being in the hospital, not just being in the ICU. ICU is more disruptive, but they’re both disruptive to kind of our lives and schedules and that kinda stuff, obviously. And I can’t get a—you know, just being here means I can’t be getting like as much exercise as I’d like. We’re spending a whole lot less time at home, obviously. But we’re taking turns, so we at least get some time home. We’re getting—I mean we’re getting less time with our other son, who is at home with the other parent, so that he’s only getting one parent at any one time. Yeah less time at home and less time at

> home as a family is the biggest challenge. Even going home by myself, like it's just—it's still quiet and kinda sad at home."

Being less of a family. Parents reported that being in the PICU affected their family role and changed their lives at home as a family. They were not able to see their partners, family, and friends. A mother said, "I see my husband and the three-year-old kid probably one, maybe two, days a week." As parents were continually present and "spending more time" with the sick child in the PICU, they "spent a whole lot less time at home with other kids" and "did not get to see other children except on FaceTime and Skype" It was a "big challenge" for them not being able to "bring other children to the PICU." One mother explained that her son at home was "only getting one parent at any one time," because she was not continuously able to stay at home with her other son. She explained that spending less time with other children and being home "started to wear on everyone at the beginning, everybody kind of rallies, and it's like, okay, we'll get through this. But then as it continues to trudge on, people start to get more tired." Having only one parent at home affected other children at home. In addition, having one parent at home confused other kids; a mother said, "so he's [other child] confused why his mom's not around so much." They also missed seeing their sick child at home playing with his or her siblings. One father viewed his home as "kinda sad and very quiet." Because parents were mostly at the hospital, they tried to "balance" their lives at home and the hospital. A mother said, "I have another child at home. She's three. So, you know, balance between child and husband and home and here." Another mother said, "I'm just trying to balance the home life and taking care of here." They "spent lots of time with the kiddo while being at home." Some mothers described, "making sure both kids get equal time, which is not really happening and hard to deal with."

PICU admission led them feel miss "chunk" of other children's' lives, and feel "isolated and apart from family." One mother said about her five months old daughter, "the biggest way that it’s affecting my life, and then, um, at first, I wasn’t spending as much time with my other child, so I missed a pretty big chunk of her life. She’s still young, and I’m thankful for that, but she’s also like at the age where she’s like—she’s starting to sit up and roll over and all of that stuff, and so I’ve missed a good portion of her life. I had to stop breastfeeding while I was here.” Another mother explained, “I’m working on forgiving myself for being a position where I can’t be a full-time mom, I feel like, to both of my boys, and feel kind of like a part-time mom to two boys, so half my time here and half my time there. So trying to forgive myself for that.”

In addition, parents felt “isolated” from their families and “missed” their homes and hometowns. They felt “homesickness” and described being in the PICU as “a world away” from home. Many parents reported that they did not “have anyone here” and they have been by themselves because their family was living far away from the hospital. One mother said, “my biggest challenge is being away from the rest of my family. So, being far away from our family is very hard.” For two mothers they felt that they did not “have a lot of families to fall back on” so they did not “have anyone to help.” Another mother experienced loneliness, “cause it can be lonely even though there’s so many people in and out, they’re not your friends.”

Discussion

Parents faced a cascade of challenges that went far beyond stresses they experienced in the PICU. Their child's hospitalization impacted parents' family and home life, putting parents’ lives into turmoil. As parents were constantly present in the PICU, they were physically and emotionally distant from their other children at home, partners, friends, and family members. Consistent with findings described by Hagstrom (2017), parents felt that they were “being split” and “torn between being home and being at the hospital.” “The constant pull” between wanting to be home with other children and in the PICU with the ill child was the most stressful thing for parents (Hagstrom, 2017, p. 36). Parents talked about feeling reluctant to leave the hospital despite knowing that their child was receiving a great care. Parents in the current study were “frayed at the seams” despite their attempts to balance their PICU life with the other children, family, and work. Parents could look like they were handling the PICU admission well, but if we just looked a little closer we would see that damage was being done that threatened the fabric of their life. Parents did not talk about finding the balance of their own physical and emotional needs, or even try to find some down time for themselves. Study data suggest that parents led lives that included two parts: living in the PICU with their child and living at their home with their partner and other children. “Being pulled back and forth between the PICU and home” created two worlds in which parents were forced to live. For the most part, parents tried to find strategies to compensate gaps and restore their lives such as trying to spend equal or more time at home and using virtual communication with other children at home.

Although the study was initially derived framed by Taylor's Theory of Cognitive Adaptation to Threatening Events, content within the interviews surfaced an additional theory: at a broad conceptual level the content and consequences of parents’ reported challenges can be further understood by Role Theory, including three concepts: role distancing, role conflict, and role competence (Biddle, 1986). According to Role Theory, individuals are members of social positions, and their behaviors are guided by expectations held by the individuals themselves and other people (Biddle, 1986). The normative expectation associated with mothers, in particular, is to place the care of her child above all other concerns. The role expectation of parents is also to take care of all of their children. However, parents in the current study were distant from children at home, reflecting what Goffman called role detachment and role distance, that is, separateness between them and their putative role with their other children (Goffman, 1975). Role competence, or success in carrying out a role, can vary depending on social contexts and resources (Belsky, Robins, & Gamble, 1984). As parents were pulled to carry out multiple roles, they felt pressured to conform successfully to every single role. When they were pulled between the hospital, home and work, they felt the gap between role expectations and their performance. One mother claimed that “my number one challenge is my child being sick, but number two is trying to juggle being here and being home, a mom, a mother to my other child, a wife, a homemaker, everything.” We speculate that the unresolved role challenges in being pulled back and forth between hospital and home heightened parents’ stress. Results from a previous study showed that PICU caused mental and physical exhaustion (Alzawad, Lewis, & Kantrowitz-Gordon, 2019). The additional life challenges beyond the PICU shattered parents' lives, threatening to crush or break them.

Study results should be interpreted with caution. Non-English parents were excluded, limiting generalizability. Non-English speaking parents may report different challenges than those in the current study. The sample of parents was almost exclusively mothers; experiences of fathers may be different than those of mothers. Third, single occasion data are limited in their ability to capture parents’ challenges over time in the PICU.

Clinical Implications

Nurses in the PICU are informed if are aware of the pressures and challenges parents of hospitalized children carry, even as they seek to support the parent's acutely ill child. Even if unable to change these pressures and challenges, PICU nurses can invite parents to talk about their challenges outside the PICU. Evidence from a prior study by others showed that listening to mothers of preterm infants significantly reduced their depressive and anxiety symptoms (Segre, Chuffo-Siewert, Brock, & O'Hara, 2013). Attending to parents’ stories may help parents express their feelings which may ultimately contribute to self-soothing, self-reflection and tension regulation (Frattaroli, 2006; Kircanski, Lieberman, & Craske, 2012). PICU nurses are also in a key place to encourage parents to take time for themselves away from the turmoil of the PICU, including reinforcing the value of scheduling times where and when they can rest, go for a walk, exercise, do their favorite activities or even return to their homes to see their families and other children. Our recently completed prior study showed that continuously staying in the PICU can be emotionally and physically draining for parents (Alzawad et al., 2019). Therefore, we speculate that scheduling rest periods or break times has the potential to positively impact parents' physical and emotional well-being. Brief, planned visitation has the potential to reduce parents' emotional and physical tension, and enable the parent to better support both children at home and their child admitted to the PICU.

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CHAPTER THREE

Assessing the content validity of the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU) Measure

Abstract

Despite that over 230,000 children are admitted annually to the pediatric intensive care units in United States, the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU) is the only available scale that measures parental stressors in the Pediatric Intensive Care Unit. Because the scale was developed over 30 years ago, it is unfortunate given the substantial changes that have occurred in the modern PICU since the measure's initial development and the importance of having a valid measure for assessment and research.

Methods: This mixed methods study examined the content validity of the PSC in order to propose refinements. Semi-structured elicitation interviews were conducted with 15 parents of children admitted to a tertiary pediatric intensive care unit, followed by administration of the PSS: PICU scale. Interviews were inductively coded using content analytic methods adapted from the Grounded Theory; quantitative data were examined for descriptive statistics and reliability.

Results: Data from both the elicitation interviews and standardized questionnaires were compared to PSS: PICU items to identify items that disconfirmed, corroborated, or were under-represented in the existing scale items. Three limitations were found in the existing PSS: PICU scale, including construct underrepresentation, construct-irrelevant variance, and item redundancy.

Keywords PICU, parental stressor, instrument revision, content validity, interview

Introduction

Parents in the Pediatric Intensive Care Units (PICU) are subjective to many stressors (Aamir, Mittal, Kaushik, Kashyap, & Kaur, 2014; Jee et al., 2012; Nizam & Norzila, 2001). Over 230,000 of children are admitted annually for intensive care in the United States (Watson & Hartman, 2014). Despite the large numbers affected, the only standardized measure of parental perceived stress in the PICU was developed 30 years ago, severely limiting our ability to develop programs and services for the affected parents. Carter, Miles, and coauthors developed the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU) scale, which was designed to measure the potential sources of stress parents experience when the child is admitted to the PICU (Carter & Miles, 1989; Carter, Miles, Buford, & Hassanein, 1985; Miles & Carter, 1982; Miles, Carter, Hennessey, Eberly, & Riddle, 1989; Miles, Carter, Riddle, Hennessey, & Eberly, 1989; Miles, Carter, Spicher, & Hassanein, 1984). Carter and Miles (1989) refined the scale to 39 items with seven subscales.

The validity of the PSS: PICU in measuring parents' stress in the PICU environment is in doubt because the stressors and parents' reaction may have changed in the 30 years since the scale was developed. It is possible that the complexity of illness and the prevalence of chronic illness have increased since the scale's development that can influence parents' perceptions and reactions to stressors. Additionally, nursing care and parents' involvement in patient care have changed dramatically with the implementation of family-centered care in the PICU. The scale is limited in that it measures only PICU-related types of stressors, not the broader range of potential stressors to which parents may be exposed. As such, it may not adequately depict all the aspects of parental stress that occur when a child is admitted to the PICU. As the only available instrument to assess sources of parental stress in the PICU, it is worthwhile to reevaluate the PSS: PICU scale for validity to assess if the scale capture all PICU sources of stressors that parents may currently experience in the modern PICU. It is unfortunate given the substantial changes that have occurred in the modern PICU since the measure's initial development and the importance of having a valid measure for assessment and research. Understanding the unique stressors experienced by parents during such an illness crisis is crucial in planning evidence-based and effective interventions for testing in future research.

Purpose

The purpose of this study was to: (1) examine the content validity of the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU) scale by comparing the items on the existing measure with data obtained in the elicitation interviews, and (2) propose initial refinements of the PSS: PICU scale based on interviews and questionnaire analysis.

Methods

Design

Mixed methods study using semi-structured elicitation interviews and quantitative measures to identify items that needed refinement then make recommendation for refinement in the scale. There are four components of research method: (1) The interviews were inductively coded using content analysis method to identify areas of stress to the parents; (2) Using descriptive statistics to identify items associated with high stress to parents and decide where improvement need to be made; (3) Compare interview coded data with existing questionnaire items; and (4) Use decision rule across those methods to make recommendation for improvement.

Participants and Setting

Fifteen parents of consecutively admitted children admitted for 48 hours of more in the PICU were recruited from a comprehensive medical center for children in the Pacific Northwest United States with a total of 32 beds. The PICU provides tertiary care to critically ill children with complex conditions up to 21 years old. The single patient rooms are equipped with the most advanced Technology. Parents were eligible for inclusion if their child had been admitted for more than 48 hours to the PICU. A parent was defined as a person who served in a primary caregiving role and provided sustained care to the child during the child's stay in the PICU. This included biological parents, foster parents, grandparents, or guardians. It did not include family members or friends providing respite care when the parent was gone. Parents were excluded if their child was readmitted within the month, received end-of-life treatment, and identified by the clinical team as inappropriate to enroll, or when parents insufficiently speak English to complete questionnaires.

Measure

Elicitation interviews. Parents were asked seven questions related to their experience and responses to their child's hospitalization in the PICU. The questions included: Describe what the PICU environment is like for you. How do you feel physically when you are in the PICU? How do you feel emotionally when you are in the PICU? How has your child's admission to the PICU affected your life right now? What concerns you about your child being in the PICU? What is the top most concern you have right now? And what fears, if any, do you have while your child in the PICU?

PSS: PICU. The scale is 39-item designed to measure the overall stress response of parents to the potential sources of stress when their child is hospitalized in a PICU. It consists of seven subscales which are: child's appearance (three items), sights and sounds (four items), procedures (seven items), professional staff communication (five items), child's behavioral and emotional responses (ten items), behavior of staff (four items), and parental roles (six items). The coefficient for all of the eight dimensions was above 0.73, except for the sight and sound (Carter & Miles, 1989).

Procedure and Analysis Plan

The Institutional Research Board (IRB) approval was obtained prior to starting the study. A full explanation of the purpose of the study to the parents and written informed consent was obtained. Parents were asked to do the interviews then complete the PSS: PICU scale. The sequence of administration of the interviews before administration of the PSS: PICU was purposeful with an attempt to minimize bias and contamination by the PSS: PICU. Study procedure and data analysis were conducted in three steps included:

Elicitation interviews. Face-to-face semi-structured elicitation interviews were conducted in the PICU at the ill child's bedside or in the "quiet rooms" located in the PICU. During each interview, the first author encouraged the full elaboration of the parent's response to each question by applying two techniques: think aloud and verbal probing (Dillman, Smyth, & Christian, 2014) to identify parents' stress responses experienced when their child was in the PICU. The word "stress" was not used in the interview questions to avoid concept biases and enhance concept elicitation. Concept elicitation guide was used for eliciting spontaneous reports of experiences along with probing to further explore and confirm concepts. Concept elicitation helps to generate items that can inform the scale (Cheng & Clark, 2017).

Interviews were digitally audio-recorded and transcribed verbatim. The interviews were inductively coded using content analytic methods adapted from Grounded Theory (Glaser & Strauss, 1967; Shands, Lewis, & Zahlis, 2000), to identify areas of concern to the parents and to compare areas of stress with existing questionnaire items. The coding process included: unitizing interview data, sorting units into categories, and organizing categories into domains. Participants' words were used to label the categories and domains. Constant comparative analysis was carried out to verify the unique fit of the categories in the domains. Debriefings were regularly organized between the first and second author to discuss and refine categories and domains to reach a consensus about coding and definitions. After identifying all domains and categories, the frequency and percentage of the expressed stressors from the interviews were calculated from the number of units reported and organized under each category.

Standardized questionnaires. Following the elicitation interview, parents were asked to complete a demographic questionnaire and PSS: PICU scale. Descriptive statistics (means and standard deviations) were used to examine responses distributions in order to identify items associated with high stress to parents. Internal consistency reliability coefficients for both total scale and seven subscales were calculated on original version of scale. For the 6-point scale, the items were scored from 0 to 5 (0 = not experienced; 1 = not stressful; 2 = minimally stressful; 3 = moderately stressful; 4 = very stressful; 5 = extremely stressful). The decided cutoff score was 2.00 in order to flag items for which the stress level perceived by the parents was minimally stressful or lower. The decision of choosing 2.00 as a cut-off score was: (1) Subscale's means ranged from 0.53 to 3.20 therefore a score of 2 is referred to “minimally stressful”; (2) Researchers and healthcare providers would be interested to know items that are more than minimally stressful in order to plan an intervention; and (3) To identify all items for which the stress level perceived by the parents was minimally stressful or lower to delete those items

PSS: PICU scale evaluation and proposed refinement. Data from the elicitation interviews were compared to parents’ responses on the PSS: PICU items to identify construct underrepresentation, construct-irrelevant variance, and item redundancy of the PSS: PICU scale. Construct underrepresentation occurs when a scale does not adequately measure all aspects of the construct of interest (Frey, 2018). Caution should be taken to avoid construct underrepresentation, which is when a scale does not capture important aspects of a construct because its focus is too narrow (MacKenzie, Podsakoff, & Podsakoff, 2011; Messick, 1995).

Construct underrepresentation can reduce the scale validity (Messick, 1995). Construct-irrelevant variance is the degree to which test scores are influenced by processes that have little to do with the intended construct and is increased by inclusion of unrelated items. Having irrelevant items in the subscale would adversely affect the meaningfulness and accuracy of the assessment outcomes and reduce the validity of the scale items (Messick, 1995). Item redundancy occurs when the same item is repeated in a different guise or exactly the same. Cronbach's alpha can be artificially inflated when a measure contains redundant items. A high value of alpha > 0.90 may suggest redundancies. In our study, the total scale's internal consistency reliability was 0.959, which is consistent with redundant items (Tavakol & Dennick, 2011). Item redundancy in a questionnaire or interview may increase respondent burden (Tavakol & Dennick, 2011).

Three proposed decisions were made: to add, revise and consider deleting. The decisions were made based on: (1) examining the mean responses of the subscales' items against the cutoff score 2.00 (minimally stressful); and (2) comparing parents' reported stressors from the interview with the existing scale's items (i.e., evaluating item-by-item against parents' experience in the PICU and their reported type of stressors). We suggested to add new items based on the interview data when parents reported new sources of stress. We also suggested some revision and deletion of certain items on the scale when they were redundant, ambiguously worded, or not applicable based on interviews, or when the cutoff score was less than 2.00.

Results

Participants

A total of 15 parents (*n* = 2 fathers; *n* = 13 mothers) completed the interview and the standardized questionnaires. Interviews lasted 10 to 80 minutes, with a median of 22 minutes. Parents were 20 to 60 years old (mean 34.40, *SD* = 11.79) with a median age of 34. Most parents (67%) were married and had a college degree (47%). The median length of PICU stay was 4 days (range 2 to 171 days). Eighty-seven percent of the parents were White, and majority were not employed (73%).

Elicitation Interviews

Four domains were identified from the coded interview data that captured parents' type of stressors. Table 1 summarizes the most commonly reported sources of stress supported by quotations from the parents. Of note, the fourth domain "Being in a Safe Place with Great People," parents (*n* = 10; 67%) positively appraised PICU staff attitude and behavior. Parents' interaction and communication with the PICU staff possibly helped them to reduce their stress.

Table 1

Parents' description of sources of stressors (N = 15)

Stressors	***n* (%)**	**Quotations**
Domain 1: Being in a Stressful New World		
Environmental factors: beds, noise, light, and beeping monitors	12 (80)	"Those beds are a little hard, "there's always bright lights," "there is constantly something going on and something beeping," "there's no quiet"
Sleep deprivation/disruption	11 (73.33)	"I'm sleep deprived," "it's not like the most comfortable place to sleep," "the challenge that I can't resolve is the sleep because there's constantly something going on"
Child's condition	10 (66.66)	"I think it's stressful just because our child is here sick," "I feel pretty good does depend on what kind of a day my baby is having. So, if he's having a good day, then I have a good day, and if he's having a hard day, then usually I also have a hard day"
Seeing other sick children	7 (46.66)	"I can also be affected by other children, other rooms, because it's sad"
Unexpected/hard when arrived at the PICU	5 (33.33)	"I'm talking about it from the perspective of the last couple days when the couple days before that were sketchier like really being worried about is, you know, is he gonna keep getting worse?" "because

		sometimes I feel like I'm just like numb, almost. Cuz it was so unexpected"
Seeing suffering parents	5 (33.33)	"I'm seeing a lot of parents that are really, clearly suffering. It's sad," "it's hard seeing other parents crying"
Seeing my child in pain	4 (26.66)	"If he is feeling pain, I cannot do anything. So that makes me stressed."
Limited privacy	4 (26.66)	"That's a little tougher just because you don't normally live in front of everyone, right? Even though it's kind of our space, it's still somewhat public with people coming in and out"
Domain 2: My Brain Is Burning All the Time		
Uncertainty, not knowing, unpredictability about child's treatment and outcomes	9 (60)	"That nervousness of not knowing if this treatment's gonna work right or if this treatment's gonna work right kind of, you know, going against the grain on some of it."
Fearing my child will die	7 (46.66)	"The one fear I have, that she's not gonna make it, that she might die"
Feeling helpless	6 (40)	"Mentally I'm burning, I'm kinda—cuz your brain's burnin' all the time. You're just watching from afar cuz you can't really help"
Overthinking about "what is happening"	4 (26.66)	"Mentally, I'm kinda—cuz your brain's burnin' all the time," "even though your poor brain is always constantly going through what can happen and what's happening"
Fear to leave my child even for short time	4 (26.66)	"When you walk back up is your door gonna be open, and is there gonna be 50 doctors in here? And all you did was go change a load of laundry or go get something to eat, and you come back"
Domain 3: Confusing Communication between Doctors		
Specialists do not talk to each other, conflicting information	5 (33.33)	"Specialists won't talk to each other" "If one doctor will say one thing and then another doctor will say. I wish they'd all stay on the same page. So I think it's confusing"
Domain 4: Being in a Safe Place with Great People		
PICU staff were "great" & "extraordinary" people, "heal," "cure," and "comfort" children	10 (66.66)	"When I'm emotionally crashing, there's a lot of great people that help me here"

Original PSS: PICU Scale Analysis

Table 2 contains the mean and standard deviation of each item in relation to the cutoff score 2.00. Based on item statistics, 20 items had mean responses above the cutoff score indicating that 51% of the items were perceived more than minimally stressful by the study participants: Q2 color changes in my child; Q5 the sound of monitors and equipment; Q7 the sudden sounds of monitors alarms; Q9 tubes in my child; Q10 suctioning; Q11 putting needles in my child for fluids, procedures or tests; Q13 having a machine (respirator) breathe for my child; Q17 doctors tell conflicting information to parents; Q18 doctors do not tell what is definitely wrong with my child; Q19 not talking to me enough; Q20 confusion; Q22 my child is crying or whining; Q24 my child acting or looking as if in pain; Q26 inability to talk or cry; Q27 my child myself; Q38 not being able to hold my child; and Q39 not knowing how to help my child during this crisis. However, item Q19 and Q31 were redundant.

Internal consistency reliability coefficients for both total scale and seven subscales reached or exceeded 0.70, except for the sight and sound subscale. The total scale's internal consistency reliability for the 39 items was 0.959. The seven subscales' Cronbach's alphas were: appearance 0.704; sights and sounds 0.684; procedures 0.844; staff communication 0.946; child's behavior and emotions 0.901; staff behaviors 0.885, and parental role 0.910. The internal consistency reliability coefficient for the 19 items after removing one redundant Q31 was 0.938.

Table 2

Item Descriptive Statistics for the 39 items (N= 15).

Subscale	Items	Minimum	Maximum	Mean	SD
Subscale 1	Q1	0	4	1.93	1.58
	Q2	0	5	2.13	1.96
	Q3	0	4	1.93	1.33
Subscale 2	Q4	0	5	2.00	1.46
	Q5	0	5	2.13	1.55
	Q6	0	5	0.87	1.69
	Q7	0	5	2.47	1.64
Subscale 3	Q8	0	5	1.53	1.69
	Q9	1	5	3.00	1.56
	Q10	0	5	2.40	1.35
	Q11	0	4	2.27	1.49
	Q12	0	4	1.80	1.42
	Q13	0	5	2.47	1.92
	Q14	0	5	1.93	1.67
Subscale 4	Q15	0	4	1.40	1.64
	Q16	0	4	1.47	1.55
	Q17	0	5	2.60	2.13
	Q18	0	5	2.80	2.04
	Q19	0	5	2.27	2.19
Subscale 5	Q20	0	5	2.07	2.09
	Q21	0	4	0.73	1.22
	Q22	0	5	2.93	1.94
	Q23	0	3	0.53	0.99
	Q24	0	5	3.20	2.04
	Q25	0	5	1.93	1.58
	Q26	0	4	2.20	1.57
	Q27	0	5	2.07	2.05
	Q28	0	5	1.53	1.77
	Q29	0	5	2.53	2.03
Subscale 6	Q30	0	4	1.13	1.13
	Q31	0	5	2.33	2.19
	Q32	0	4	1.33	1.35
	Q33	0	5	1.13	1.55
Subscale 7	Q34	0	4	2.20	1.27
	Q35	0	5	1.53	2.00
	Q36	0	5	1.80	2.40
	Q37	0	5	1.73	2.22
	Q38	0	5	3.13	2.03
	Q39	0	5	3.00	2.17

PSS: PICU Scale Evaluation and Proposed Refinement

Table 3 contains a summary of the recommended refinements. The following is an evaluation of each subscale.

Subscale 1 "Child's Appearance." In Table 2, only Q2 was stressful to parents as the mean score was above 2.00. Item Q3 "child appearing cold" had unclear meaning, whether looking cold or feeling cold. We considered deleting two items Q1 and Q3, because parents in the interview did not identify child appearance as a source of stress and both items had low cutoff scores. Instead, the child's condition and intensity of illness were stressful factors that parents mentioned. The recommendations for this subscale are to consider deleting Q1 and Q 3, retaining Q2 and adding four related to child's condition can be added in this subscale can be added based on the interview data as shown in Table 3. This subscale could be renamed to be child's condition.

Subscale 2 "Sight and Sounds." Examining the scale items in Table 2, two mean responses were stressful: Q5 and Q7. These two items appeared relatively similar and could confuse the parents which are: item Q5 "the sounds of monitors and equipment" and item Q7 "the sudden sounds of monitor alarms" as both items reflect the audio type of alert. There is a potential redundancy in this subscale. Item Q6 "other sick children in the room" was the least stressful factor (0.87; *SD* = 1.66) because there was only one child per room. We suggest to consider deleting Q4, Q5, and Q6, retaining item Q7, and adding seven items that were generated from the interview data (Table 3).

Subscale 3 "Procedures." Examining the responses on the measures, four items were stressful as the mean responses were above 2.00: Q9 "tubes in your child", Q10 "suctioning," Q11 "putting needles in my child for fluids, procedures, or tests," and Q 13 "having a machine (respirator) breathe for my child" (Table 2). During the interview, parents did not talk about procedures as a stressful factor. The recommendations for this subscale are to consider deleting Q8, retain items Q9, Q10, Q11 and Q13, and revise Q12 and Q14.

Subscale 4 "Communication with Professional Staff." On the scale responses (Table 2), three items were more than minimally stressful: Q17 "telling me different (conflicting) things about my child's condition," "Q18 "not telling me what is definitely wrong with my child," and Q19 "not talking to me enough" as the mean responses scores was above 2.00. However, Q19 "not talking to me enough" could have an ambiguous meaning as to whether the staff were not talking to the parents in general, or not talking about the child's outcomes and treatment. Also, this item Q19 is redundant to item Q31 in Behavior of Professional Staff subscale "not talking to me enough." Parents positively appraised staff communication and keeping the "informed." Parents explained further stress factors that can be added in this subscale (See Table 3). We consider deleing Q15 and Q16, retaining Q17 and Q18, and revising Q19, and adding two items (Table 3).

Subscale 5 "Child's Behavior and Emotional Responses." Six items were identified as more than minimally stressful with mean responses above 2.00: Q20 "confusion," Q22 "crying or whining," Q24 "acting or looking as if in pain", Q26 "inability to talk or cry," Q27 "fright," and Q29 "sadness or depression" (Table 2). Parents said they were "extremely depressed," because it was hard for them to see their child go through a hard time and "suffer this much." The recommendations for this subscale are to consider deleting Q21, Q23 and Q28, retaining Q20, Q22, Q24 and Q29, revising Q26 and Q27.

Subscale 6 "Behavior of Professional Staff." Mean scores were all below the cutoff score except for item Q31. Item Q31 "not talking to me enough" is redundant to item Q19 "not talking to me enough." Parents (67%) reported that staff behavior and attitude relieved their stress. Parents reported that staff interruptions coming in and out disturbed their sleep. Based on the interview data, it is suggested to consider deleting this subscale.

Subscale 7 "Parental Role." In Table 2, three items in this subscale had mean responses above 2.00: Q34 "not taking care of my child myself," Q38 "not being able to hold my child" and Q39 "not knowing how best to help my child during this crisis." Other items with low mean scores were not applicable to the current PICU guidelines that promote parental presence with their child in the PICU. Parents (60%) reported they were anxious, nervous or worried about their child's uncertain treatment and outcomes. They also reported that they did not know how to help their child. It is recommended to consider deleting Q35, Q36 and Q37, retaining Q38 and Q39, revising Q34, and adding two items (Table 3).

Reliability of the Retaining items

The suggested recommendations for the scale items were to consider deleting 19, revising 6, retaining 15, and adding 14 items. To internal consistency coefficient fir the retained n=15 items was 0.913.

Table 3

Item decision based on cognitive interview findings.

Item	Decision	Suggestion
Subscale 1: Child's appearance		
Q1. Puffiness of my child	Delete/Add	Add one item: "we are unexpectedly admitted to the PICU"
Q2. Color changes in my child (pale, blue or yellow)	Retain	–
Q3. Child appearing cold	Delete/Add	Add three items: "I cannot see improvement in my child's condition," "my child looks extremely ill," "my child's condition is declining"
Subscale 2: Sight and Sounds		
Q4. Seeing the heart beat on the monitors	Delete/Add	Add five items: "Bright light," "uncomfortable beds," "not being able to sleep," "limited privacy," "staff interruptions coming in and out the room"
Q5. The sound of monitors and equipment	Delete/Add	Item Q5 is relatively similar to item Q7 Add one item: "seeing other suffering parents"

Q6. The other sick children in the room	Delete/Add	Add one item: “seeing other sick children”
Q7. The sudden sounds of monitor alarms	Retain	Add five items: “Bright light,” “uncomfortable beds,” “not being able to sleep,” “limited privacy,” “staff interruptions coming in and out the room”
Subscale 3: Procedures		
Q8. Injections/shots	Delete	–
Q9. Tubes in your child	Retain	–
Q10. Suctioning	Retain	–
Q11. Putting needles in my child for fluids, procedures, or tests	Retain	–
Q12. Making my child cough and deep breath/pounding and clapping on my child's chest	Revise	Contains multiple stressors. To separate them
Q13. Having a machine (respirator) breathe for my child	Retain	–
Q14. Bruises, cuts, incisions on my child	Revise	Contains multiple stressors. To separate them
Subscale 4: Professional staff communication		
Q15. Explaining things too fast	Delete/Add	Add one item: “I feel doctors do not talk to each other enough.”
Q16. Using words I don't understand	Delete/Add	Add one item: “not talking to me enough about my child’s outcomes”
Q17. Telling me different (conflicting) things about my child's condition	Retain	–
Q18. Not telling me what is definitely wrong with my child	Retain	–
Q19. Not talking to me enough	Revise	“Not talking to me enough about my child’s treatment”
Subscale 5: Child’s Behavior and Emotional responses		
Q20. Confusion	Retain	–
Q21. Rebellious or uncooperative behavior	Delete	–
Q22. Crying or whining	Retain	–
Q23. Demanding	Delete	–
Q24. Acting or looking as if in pain	Retain	–
Q25. Restlessness	Retain	–
Q26. Inability to talk or cry	Revise	Contains multiple stressors. To separate them
Q27. Fright	Revise	To “scared”
Q28. Anger	Delete	–
Q29. Sadness or depression	Retain	–
Subscale 6: Behavior of Professional Staff		
Q30. Joking, laughing, or talking loudly	Delete	–
Q31. Not talking to me enough	Delete	Redundant to item Q19
Q32. Too many different people (doctors, nurses, staff) talking to me	Delete	–
Q33. Not telling me their names or who they are	Delete	–
Subscale 7: Parental Role		
Q34. Not taking care of my child myself	Revise	Revise wording “Not being able to take care of my child”

Q35. Not being able to visit my child when I wanted	Delete	Add one item: “not wanting to leave my child for a short time”
Q36. Not being able to see my child when I wanted	Delete	–
Q37. Not being able to be with my crying child	Delete	–
Q38. Not being able to hold my child	Retain	–
Q39. Not knowing how best to help my child during this crisis	Retain	–

Discussion

Results from interviews confirmed that parents in the current PICU had additional types of stressors when compared with scale items in the original questionnaire, which reflected construct underrepresentation. Parents were less likely to be stressed by their child’s appearance, seeing their child’s heart beat on monitors, and procedures because they understood the acuity of their child’s illness and the importance of close monitoring. Instead, they were stressed about their child’s condition, illness, treatment, outcomes, and future. While the scale should capture the most important aspects of parental stressors, the scale has a relatively limited scope. Items in scale likely did not compressively capture parents’ stress described in the study domains. An important new domain was generated from the coded interview “My Brain Is Burning All the Time.” In this domain, parents described the mental impact of the PICU admission that was associated with “overthinking impossible things,” and “fearing my child will die,” and “fearing to leave my child even for short time.” For parents, the mental impact of being in the PICU was more burdensome than the physical environment. They were in a vulnerable state of mind. These important stress responses are not overlooked in the PSS: PICU in the modern PICU. Therefore, there is a possibility that this scale does not capture the multidimensionality of the construct.

About construct-irrelevant variance, several items in the following subscales possibly were not relevant to the current PICU context and guidelines: Child Appearance, Sights and Sounds, Staff Communication, Behavior of Professional Staff, and Paternal Role.

Item redundancy evident the scale. Item Q19 and Q31 were exactly similar “not talking to me enough.” Another two items were Q5 “the sounds of monitors and equipment,” and Q7 “the sudden sounds of monitors and alarms” as both indicate the audio type of alert that parents might not find them distinguishable.

Overall, our findings from the elicitation interviews and parents’ responses on the scale items raised a question about the scale’s relevance and utility in the current PICU. Examining the content validity of the PSS: PICU scale revealed that the scale can be missing content that is important to the current PICU. Researchers need to be aware of the relevance and limitation of the scale when applying it in the current PICU.

It is important to understand the limitations to be addressed in future research and considered when selecting an assessment strategy for parental stress in the PICU. Certain study limitations that could affect the generalizability of the results need to be addressed. The study was conducted in a single tertiary referral center and magnet accredited hospital. Children who were admitted into this tertiary setting likely presented more complex problems and the unit may be better resourced and staffed than other units. It is assumed that parents’ responses, particularly to staff communication and behavior, could be different in other PICUs. A further possible limitation is that the sampling strategy was based on convenience sampling and willingness to participate, and the sample size was small. Therefore, there is a possibility that our sample did not achieve range and diversity in terms of education level, ethnicity, marital status, employment, and most importantly stress level. The results are not necessarily representative of the larger population parents of children admitted to the PICU. Future research can build upon the approach used in the current study in a heterogeneous larger sample size to guide the generation of new items. More importantly, future studies need to test the proposed revised scale on the same and different PICUs. It is also worthwhile to consider using a purposive sampling technique in future research to ensure that different level of parental stress were included.

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