

Long-term Sequelae of Pediatric Neurocritical Care: The Parent Perspective

Cyndi N. Williams¹ Carl Eriksson¹ Juan Piantino² Trevor Hall³ Danielle Moyer³ Aileen Kirby¹
Cindy McEvoy⁴

¹Division of Pediatric Critical Care, Department of Pediatrics, Oregon Health and Science University, Portland, Oregon, United States

²Division of Pediatric Neurology, Department of Pediatrics, Oregon Health and Science University, Portland, Oregon, United States

³Division of Pediatric Psychology, Department of Pediatrics, Oregon Health and Science University, Portland, Oregon, United States

⁴Division of Neonatology, Department of Pediatrics, Oregon Health and Science University, Portland, Oregon, United States

Address for correspondence Cydni N. Williams, MD, Division of Pediatric Critical Care, Department of Pediatrics, Oregon Health and Science University, 707 SW Gaines Street, CDRC-P, Portland, OR 97239, United States (e-mail: willicyd@ohsu.edu).

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Abstract

Critical neurologic disease and injury affect thousands of children annually with survivors suffering high rates of chronic morbidities related directly to the illness and to critical care hospitalization. Postintensive care syndrome (PICS) in patients and families encompasses a variety of morbidities including physical, cognitive, emotional, and psychological impairments following critical care. We conducted a focus group study with parents of children surviving pediatric neurocritical care (PNCC) for traumatic brain injury, stroke, meningitis, or encephalitis to determine outcomes important to patients and families, identify barriers to care, and identify potential interventions to improve outcomes. Sixteen parents participated in four groups across Oregon. Three global themes were identified: (1) PNCC is an intense emotional experience for the whole family; (2) PNCC survivorship is a chronic illness; and (3) PNCC has a significant psychological and social impact. Survivors and their families suffer physical, emotional, psychological, cognitive, and social impairments for many years after discharge. Parents in this study highlighted the emotional and psychological distress in survivors and families after PNCC, in contrast to most PNCC research focusing on physical outcomes. Several barriers to care were identified with potential implications on survivor outcomes, including limited pediatric resources in rural settings, perceived lack of awareness of PICS among medical providers, and the substantial financial burden on families. Parents desire improved education surrounding PICS morbidities for families and medical providers, improved communication with primary care providers after discharge, access to educational materials for patients and families, direction to mental health providers, and family support groups to assist them in dealing with morbidities and accessing appropriate resources. Clinicians and researchers should consider the parent perspectives reported here when caring for and evaluating outcomes for children requiring PNCC.

Keywords

- ▶ pediatric
- ▶ critical care
- ▶ patient outcome assessment

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Introduction

Critical neurologic disease and injury, including infectious and inflammatory disease, trauma, and stroke, affect thousands of children annually.¹⁻³ These children suffer high rates of in-hospital death and morbidity, requiring specialized pediatric neurocritical care (PNCC) to minimize the risk of secondary brain injury and maximize recovery.¹⁻⁴ Mortality has decreased significantly over the last several decades, but there has been a rise in morbidities and chronic health conditions among pediatric survivors of critical care, particularly with neurologic diagnoses.⁴⁻¹⁰ Survivors suffer morbidities related to physical and cognitive disability, social impairment, emotional disturbance, and psychologic distress that are interrelated and collectively named postintensive care syndrome (PICS).¹¹⁻¹³ PICS morbidities have also been identified in families of survivors (PICS-F).¹⁴⁻¹⁸ Physical and cognitive disabilities can result from underlying disease, complications of critical care, and muscle weakness that can impair functional abilities in the long term.^{5,7-10,19-33} Emotional, social, and psychological morbidities, such as changes in behavior, depression, and post-traumatic stress disorder (PTSD), have also been identified in survivors and their families.³³⁻³⁹ PICS morbidities lead to impaired quality of life and increased health care costs over time.^{9,23-25,40,41}

Oregon Health and Science University (OHSU) has a PNCC follow-up clinic to assess and treat disease sequelae and PICS morbidities among children with critical neurologic diagnoses. During our initial clinic experience, many different PICS-related morbidities were identified among survivors and their family members, highlighting the difficulties in caring for this population.⁴² Our initial experience with caring for PNCC survivors longitudinally also highlighted gaps in knowledge surrounding therapeutic interventions for many morbidities and the need for further research. We conducted this focus group study to determine outcomes important to our patients and their families and engage these families in identifying barriers to care and potential interventions to improve outcomes. Patient and family-centered outcomes research is increasingly utilized in practice, and we aimed to gain a unique perspective to inform future clinical care and research among these vulnerable children and families.

Methods

We conducted facilitated focus groups of parents of PNCC survivors with a primary diagnosis of traumatic brain injury (TBI), stroke, meningitis, or encephalitis who required a critical care intervention (intubation, central line placement, intracranial pressure monitor placement, arterial line placement, or neurosurgical intervention) and intensive care unit (ICU) admission at the Doernbecher Children's Hospital between 2006 and 2016. This study was approved by the OHSU Institutional Review Board (IRB). Participants were given an information sheet detailing the study and research procedures and verbally consented to participate in the study as approved by the IRB.

PNCC survivors, aged 0 to 19 years at admission, were identified through query of the electronic medical record using diagnosis and procedure codes. We selected for patients with higher severity of illness through requirement of a critical care intervention during admission for acute brain injury. A separate chart review of query results was completed by the study team to identify qualifying patients and ensure accuracy of results. Qualifying patients were used to identify names and contact information for the parent or legal guardian (subsequently referred to as parent). Charts were excluded if the child died in the hospital or after discharge or the parent/guardian no longer had custody of the child. Non-English speaking parents were excluded due to small sample size and limitations of facilitators. Parents and guardians with a qualifying child were mailed an information sheet and a letter detailing the purpose of the study. A follow-up phone call was made by a member of the study team to verify eligibility and offer participation in one of the focus groups scheduled around Oregon with a standard script. Parents who agreed to participate received a reminder phone call, mailer, or email per their preference about the scheduled group.

Focus groups were conducted July-August 2017 by the study team with community liaisons trained in focus group facilitation by the Oregon Clinical and Translational Institute (OCTRI) Community Research Hub in three regions across Oregon. Participants were given a study information sheet prior to participation and filled out an anonymous demographic questionnaire and survey prior to each focus group (see ►**Supplemental Table S1** for survey free text questions [online only]). Results of the questionnaire and survey are reported as percentages of respondents for each question. Likert scale responses are reported as ranges and average with standard deviation (SD). Participants were compensated with a \$50 gift card at the end of each focus group. Groups were anonymous without record of participation and were audio-recorded. Final number of participants was determined based on number of gift cards distributed and transcription. Due to anonymous participation, focus group responses were not linked to clinical characteristics.

Deidentified transcripts were created from each recording and used for thematic network analysis.⁴³ The following codes based on the facilitator script framework (see ►**Supplemental Table S1** [online only]) were used when analyzing transcripts: child sequelae, family sequelae, resources utilized, resources needed, and barriers. Themes were then identified in coded transcripts and used to construct thematic networks identifying the global and organizing themes reported. Exploration and description of thematic networks were used to identify patterns within data for interpretation. Quotations from transcripts and survey free text are included as representative examples of global and organizing themes and to provide further detail.

Results

Parents of 119 qualifying PNCC survivors were identified through chart review. Eighty-eight (70%) parents could not

be contacted in up to three attempts (wrong or nonworking numbers, no messaging system, or no response to messages). Among the 36 contacted parents, 5 (14%) were not interested in participating, 2 (6%) were deemed ineligible after phone interview due to inadequate English communication, and 7 (19%) were interested but not available during scheduled groups. Twenty-two (61%) of the contacted parents were scheduled among four focus groups across Oregon and 16 (44%) parents participated.

Questionnaire responses identified participants as mostly females (89%) ranging in age from 26 to 55 years of age. Most participants identified as white (78%) and others as Asian, African American, or Pacific Islander (11% each). All participants reported at least a high school diploma and 67% reported a college degree. Household annual income was variable with median income between \$30,000 and \$100,000. Participants reported their children received care for TBI (67%), meningitis or encephalitis (22%), or stroke (22%). Child age at admission varied (<1 year [33%], 1 to 4 years [33%], 5 to 8 years [22%], and > 8 years [11%]). Time since hospital discharge ranged from 1 to 8 years. Participants reported ongoing child medical needs in 89%, child psychological or counseling services in 33%, and receipt of school services in 56%. All participants rated the PICU experience 3 (neutral) to 5 (excellent) with an average of 4.4 (SD 0.7). Perceived support after discharge was more variable, rated 1 (poor) to 5 (excellent), with an average of 3.8 (SD 1.3).

Three global themes emerged from the focus groups: (1) PNCC is an intense emotional experience for the whole family; (2) PNCC survivorship is a chronic illness; (3) PNCC has a significant psychological and social impact. There was a recognized need for improved education and access to resources within each of these themes. **Tables 1 to 3** contain participant quotes to illustrate global and organizing themes from thematic networks. While many participants discussed the physical sequelae of illness in their children, the most intense and frequent discussions surrounded the emotional and psychosocial impact the experience had on parents and the family as a whole. Many participants expressed apprehension when discussing their experience, but there was an overwhelming desire to help other families in the future that drove participation in the groups.

PNCC is an intense emotional experience for the whole family: "It was very intensive for me, because I think the whole hospital heard me scream."

Parents discussed a variety of emotions that varied with time from acute hospitalization through years after discharge. Every participant reported overwhelming stress during the acute hospitalization that manifested in a variety of responses. Some reported anger and lashing out in the hospital at providers and other family members, while others reported withdrawal. Many expressed fear of the unknown and loss of control as the predominant sources of acute stress. Parents who reported difficulty dealing with stress often discussed stress in other family members, such

as siblings and grandparents, and reported ongoing sequelae in the child survivor. Other emotions, including grief, guilt, and loneliness, were also prominent during hospitalization. Emotional lability and difficulty dealing with the intensity of emotions were common. Participants expressed desire for increased recognition by medical providers of how stress and emotions affect parents' interactions with the medical team during hospitalization.

Grief and guilt were persistent emotions among parents years after discharge. The emotional toll of the experience was reported to bring some families together, but to result in loss of relationships and family tension in others. Parents often expressed guilt surrounding feeling responsible for the child's illness and for not providing adequate support for siblings of survivors. Parents also expressed gratitude for the medical care their child received, particularly surrounding life-saving therapies and neurologic recoveries, but expressed desire for improved emotional support and awareness from medical providers. Participants desired direction to professional help for parents and families in dealing with overwhelming emotions persisting after discharge.

Sources of emotional support varied for participants. The majority cited family members as the main source of support, though often reported emotional responses in family members that hindered their ability to provide adequate parental support. Others cited community and religious sources of support. During acute hospitalization, social workers, case workers, and nurses were recognized as playing a significant role in providing emotional support. Family friends were another source of support acutely and chronically for which participants expressed gratitude, though discussions of this type of support were also accompanied by expressions of guilt for burdening others and regret over strain placed on these relationships. All participants expressed the desire for parent and/or family support groups to provide emotional support through shared experiences.

PNCC survivorship is a chronic illness: "Even though physically he may look better, here are all of the other things that we're still dealing with."

Child survivors of PNCC have a variety of morbidities after discharge not all directly resultant from the primary neuronal injury. All participants identified at least one ongoing morbidity in their child, even though most described the child as "doing well." Physical sequelae included headaches, weakness or paralysis, scars, seizures, vision or hearing loss, and fatigue. Cognitive sequelae included speech impairments, developmental delay, and memory and attention deficits. Ongoing medical needs, including medications, equipment, and repeated procedures, were also discussed. Some parents reported difficulty with school and social impairments related to these ongoing morbidities.

Intense discussions about the emotional and psychosocial impact on child survivors were common among all groups. Many parents described children as "fearful" and "anxious." Fear of trying new things, of reinjuring themselves, and of complications related to medical equipment such as shunts

Table 1 Participant quotations highlighting the emotional experience of pediatric neurocritical care

Global theme: Pediatric neurocritical care is an intense emotional experience for the whole family	
Acute emotions	<ul style="list-style-type: none"> -Emotionally, it's just been horrendous for the whole family, extended family too, grandparents, aunts, uncles, cousins, we've all been affected -That was another trauma; you have no control over what happens to your child even though you know it's harmful -There were so many times that things had to happen so quickly that was scary as a parent -I can still to this day feel the anger that I felt when I walked into the room and saw that baby in the condition that she was in
Chronic emotions	<ul style="list-style-type: none"> -I see her improved way more than what she was back then...and I'm grateful for it, so I'm hoping for more. You know, maybe I'm being greedy, but I don't know -We didn't know what the outcome of [name]'s situation was going to be, so every little milestone we kind of, we were obviously very excited to see -We live with a lot of guilt of, you know, what if we had done something different that night. You know, that's always been my issue if I had done something different that wouldn't have happened -I think we all go through grieving...mourning the loss of something that was and a new reality of what's going to be -We all go through feeling guilty that part of it is our fault that we didn't notice something sooner. We should have done something different -Just when you think you got to the end of it, something else hits you
Sources of support	<ul style="list-style-type: none"> -My parents hooked up their trailer and drove 3,000 miles from South Carolina and parked their trailer in our driveway for 6 weeks -You don't want to burden your friends who have already done so much for you, and there's only so much want to put on your family. And so, anytime anybody would offer it I'd say, I really don't want to burden -We had a social worker through our insurance company who called and checked in on us on a weekly basis...helped, it was a little overwhelming
Effects of emotional responses	<ul style="list-style-type: none"> -It did put a strain on family relations, so that kind of leaves me feeling like I'm alone -We've been truly lucky and blessed because then I don't know how we could have done it without it...really lucky where the family really rallied behind -My husband and I did intensive grief counseling for 2 years, just to deal with grief and all of a sudden having a kid with special needs -My two kids who were not injured, they've got anger issues and just seem different. As they processed through the medical trauma, what happened to their brother, witnessing the accident and then the separation and then coming back together and everything was different, it's caused them a lot of difficulties -It was a little disturbing for them to see her like that. They cried a lot when they first saw her...Just everything was not her and they were confused. And some of my family members just wouldn't come because they didn't want to see her like that
Barriers	<ul style="list-style-type: none"> -They thought I was crazy that my 8-year old daughter was having a stroke -Medical providers could have been more understanding of our grief and our feelings -It seemed like some of the medical staff was not super aware of how anxiety can affect a person
Interventions	<ul style="list-style-type: none"> -I would really recommend parents get counseling during the time before they blow -I guess the biggest thing is making sure families go into counseling after having something like that go on. Two of us are in counseling, I've been in counseling off and on, but it's a new normal that we live with -It would be nice as a parent to have some sort of support group -They didn't have any good support groups for parents suffering through that grief or to kind of relate with other parents who had children of the same diagnosis...I want to meet other parents that suffer from this same grief I'm going through. Like I want to have a formal support group

were reported. Some reported anger and others internalizing behaviors as manifestations of fear and anxiety. Others reported a negative impact on the child's ability to make friends and socialize in the community. About one quarter of participants reported a diagnosis of PTSD in the survivor requiring interventions. Even without a diagnosis of PTSD or other psychological disorder, participants described counseling interventions as helpful for their child's well-being, but universally reported difficulty accessing these services. Most barriers identified centered on a lack of pediatric trained counselors, psychologists, and psychiatrists as well

as a delayed recognition of the need for professional intervention. Participants desired more education during hospitalization regarding the emotional and psychological impact on child survivors with direction to mental health providers and assistance with accessing these services in under-resourced communities. Parents desired peer support groups and more educational materials, such as children's books, geared toward helping the survivor and family deal with chronic morbidities.

Many child survivors continue to require physical, occupational, and speech therapies years after discharge. Ten

Table 2 Participant quotations highlighting the chronicity of pediatric neurocritical care diagnoses

Global theme: Pediatric neurocritical care survivorship is a chronic illness	
Physical sequelae	<ul style="list-style-type: none"> -He developed some horrific headaches -All the sudden she can't walk, she can't talk, she can't feed herself -With his fatigue, people would have to come and visit us. We couldn't go and visit people or go out and do activities because it was too much -He's constantly running into things, tripping over things, due to lack of sensation
Cognitive sequelae	<ul style="list-style-type: none"> -School is really difficult at best -She'll stop mid-sentence and she'll sometimes forget words here and there
Emotional sequelae	<ul style="list-style-type: none"> -She likes to keep it all up inside of herself and I don't think that's healthy -It's hard for her to keep those fears in an appropriate zone -He's a little hypersensitive to anything that's going on, and he's like, well I don't want to do that because I don't want to hurt myself -It was really difficult for her to go back to school with her head shaven and all her scars kind of showing
Psychological sequelae	<ul style="list-style-type: none"> -We walk on eggshells all the time because he's still dealing with mental health issues. He struggles between what's real and not real and has a real hard time knowing the difference -She's in counseling, she has a lot of anxiety
Ongoing medical needs	<ul style="list-style-type: none"> -She was in a protective helmet for 3 years -Counselor, psychologist, and psychiatrist are what he has now. -He has quite a few problems, so we are continuing to have physical therapy, occupational therapy, and regular therapy
Barriers to care	<ul style="list-style-type: none"> -We went to our regular doctor who freaked out and said go back to OHSU, I don't know how to deal with this -Our town is not a town that really has the facilities for this kind of injury, we've made probably 20 to 25 trips up there in 4 years...We traveled 273 miles each way for surgeries and appointments -Trying to wade through scientific papers and stuff, just to understand what is going on in his body, and what I can do and what is kind of permanent but what can be shifted a little bit, like just all of that. Man, medical papers suck -Not having medical history in layman's terms makes it really difficult to advocate well for the services your child needs...and so trying to navigate those to describe what's going on with your specific child, especially since TBIs are delightfully unique, is incredibly challenging
Interventions	<ul style="list-style-type: none"> -She really needed to be in a setting where she was able to just talk about it with somebody, about what she was going through. There's only so much I can say, I'm not a professional, I'm a mom. -She needs somebody who knows how to talk to kids, who had been through a traumatic experience like this, and have come back from the brink, or are still going through this, so that parents don't have that additional weight and pressure of the emotional well-being of their child -An area of improvement I'd like to see some sort of communication between the doctors here and the doctor the child goes home to because my son's doctors were afraid to touch him -Just even having material for the kids to explain any aspect of what is going on with them, or to read to siblings, just to make it seem like it's not just us

Abbreviation: OHSU, Oregon Health and Science University; TBIs, traumatic brain injuries.

parents specifically discussed these services, and experience with accessing these services varied among participants. Several reported difficulty due to lack of pediatric specialists locally, while others reported lack of flexible evening and weekend scheduling as a barrier. Access to regular medical care was also a frustration for families with many reporting local primary providers' discomfort caring for the complex needs of PNCC survivors. Parents expressed desire for improved communication with primary care providers by critical care and subspecialty physicians.

PNCC has a significant psychological and social impact: "Everything you have to see, it doesn't go away ever. I always have flashbacks."

Psychological disorders among parents and family members were common, including anxiety and PTSD, and often

attributed to the traumatic experiences of witnessing critical care interventions or the appearance of the child during acute hospitalization. Nine participants reported a diagnosis of anxiety, depression, or PTSD following discharge. Even among parents that did not report a diagnosis of PTSD, symptoms of avoidance, nightmares, flashbacks, feeling isolated, trouble sleeping, and hypervigilance were discussed by nearly all participants. Parents reporting a diagnosis of PTSD or anxiety disorder frequently reported similar problems in other family members (grandparents, siblings) and the child survivor. Parents reported a perceived lack of awareness from the medical community about the effects on parents and families following a child's critical illness or trauma. Parents desired more education surrounding the potential for psychological disorders and resources to help themselves and family members suffering from the effects of PNCC-related trauma. Many reported that professional counseling

Table 3 Participant quotations highlighting the psychological and social impact on families

Global theme: Pediatric neurocritical care has a significant psychological and social impact	
Psychological distress	<ul style="list-style-type: none"> -You feel enclosed in, and I needed to breathe. Just like let me breathe. -You kind of feel like you're living in a fog during all of that -It's like things you never thought possible happening every day; it just messes with your brain, so yeah, it's had a huge impact on my life -And I still have like nightmares about it and her screaming
Financial distress	<ul style="list-style-type: none"> -I can't work. I'm on disability -I was on a leave of absence from my job for the rest of the summer -I took 6 months off of work -We ended up spending about \$50,000 that did not go to medical expenses
Social distress	<ul style="list-style-type: none"> -Some of the relationships suffered because we couldn't maintain normal contact with people or go to birthday parties or just maintain some of those friendships -It was difficult to find people who were comfortable taking care of her. -She wasn't able to do things normal little kids could do...so I think that just robbed her of an awful lot of her childhood
Barriers	<ul style="list-style-type: none"> -We could not get out of the hospital until we had a psychiatrist appointment, and we couldn't get a psychiatrist appointment because there are only two pediatric psychiatrists in all of [hometown], who were full and not taking patients -Our whole life would be appointments if we did everything they asked us to do. Honestly if both of us worked, he probably would not get therapy because it would be too much of a burden on our family
Interventions	<ul style="list-style-type: none"> -Maybe somebody could say these people could help you work through these feelings. I think it would have been nice if there had been some awareness on my end, when the initial PTSD symptoms started to show -We need great information about stuff to read as a parent, but then also you could pass off to friends and family who like TBIs don't heal right away...or here are common issues that come up and surprise people

Abbreviations: PTSD, post-traumatic stress disorder; TBIs, traumatic brain injuries.

and intervention was helpful, but symptoms persisted even with intervention.

The social impact of PNCC often overlapped with psychological distress. Many participants reported loss of friends and enjoyable activities as a result. Parents reported restricted activities that also negatively impacted siblings and the family's typical social environment. A majority of participants reported loss of jobs or extended leaves of absence from work resulting in a devastating financial impact that added to stress and strained social relationships. Some parents directly attributed job loss to psychological distress, while others cited difficulty finding adequate care for a child's special needs and need for ongoing medical intervention in the child survivor. The commitment time and money required to meet ongoing medical needs and travel for medical care were a source of stress for parents often compounded by the loss of employment. Parents reported the financial burden for themselves and family members totaled tens of thousands of dollars not including direct medical care costs. Parents cited family members, friends, and community organizations as positive sources of financial support, but reported being under-prepared for the impact and desired additional help accessing resources during and after hospitalization.

Discussion

Survivors of childhood neurologic disease and injury and their families face long-term sequelae related to physical, cognitive, emotional, psychological, and social impacts.

Engagement of PNCC survivors' parents in this study identified several under-evaluated aspects of outcomes research and clinical care gaps with important implications. PNCC survivors are faced with multiple physical sequelae often requiring ongoing medical care; however, parents focused primarily on the emotional and psychological effects when identifying PNCC outcomes during this study. Parents also reported important emotional and psychological impacts on survivors' families. Even years after PNCC, many of these families are still living with the consequences of surviving PNCC. Parents identified significant gaps in care surrounding accessing therapies, education on the long-term sequelae of PNCC on patients and families, direction to mental health providers, emotional support for patients and families, and education of primary care medical providers. Counseling, support groups, and educational materials written in layman's terms were identified as helpful interventions to provide for families in the future.

PICS is increasingly recognized in survivors of critical care, and participants in our study identified a myriad of important outcomes encompassed by PICS in PNCC survivors. To date, research studies on outcomes in this population focus on gross measures of functional ability like Pediatric Cerebral Performance Category or Functional Status Scale.^{7,8,44} Studies have evaluated cognitive function in other PICU patients and select PNCC conditions like stroke and TBI.^{10,19,33,45,46} PTSD in broad populations of PICU survivors has also been reported.^{34,38} This project identified a need to expand outcomes research in PNCC to systematic measures of

emotional, psychological, and social functioning that significantly impact survivors and impair quality of life. Research in PNCC survivors is often limited to short-term measures, but participants in our study identified these as important morbidities many years after discharge. More research is needed to quantify PICS in PNCC and to determine clinical trajectory and risk factors for PICS morbidities.

Our study additionally highlights the long-term effects of PNCC on survivors' families. PICS-F has been described in the critical care literature, but among PNCC survivors the literature is scarce. Parents of the broader PICU population often experience symptoms of anxiety, depression, and PTSD, among other psychological disorders while in the hospital and for months and sometimes years later.^{18,38} PNCC parents in our study similarly suffered significant emotional and psychological distress with long-lasting impacts on their families as a whole. Studies in pediatric TBI outcomes have reported an important association with family environment and patient outcomes including cognitive and psychological outcomes.^{47,48} PICS-F may be an important moderator of patient outcomes, and more research is needed to clarify the bidirectional impact of PICS and PICS-F-related morbidities among survivors and their families. Interventions to improve outcomes for parents could further contribute to improving the long-term health and well-being of survivors.

Parents in our study cited many barriers that have important implications for patient outcomes. Lack of awareness among families and perceived lack of awareness among medical providers about PICS-related morbidities were prevalent in our study. Critical care providers are trained to identify and treat physical deficits, but our study identified a need to improve education surrounding the long-term emotional, psychological, cognitive, and social implications of surviving a significant event such as PNCC. Parents desire more education about potential morbidities and support from medical providers in the hospital and after discharge. One step to providing families with this education is to increase the awareness of PICS among medical providers through continued research highlighting the significance of PICS. The Society of Critical Care Medicine (SCCM) recognizes the gap between critical care providers and other rehabilitation specialists as a barrier to patient awareness of and education on PICS.¹⁷ Interdisciplinary care models that integrate behavioral health and neuropsychological specialists within critical care teams have the potential to increase access to PICS-related resources and improve follow-up assessments and intervention for cognitive and psychological outcomes.⁴² Research is needed to develop and evaluate educational interventions surrounding PICS for survivors and families to determine if increased awareness can impact access to care and outcomes. Potential interventions include direction to existing online resources such as those available through SCCM and at www.afterPICU.com, peer support through connection with other families and survivors, and institutional-specific educational efforts for providers and families. Multidisciplinary clinics geared toward caring for patients after critical care are another potentially valuable educational tool. Providers in critical care follow-up clinics

have unique perspective and need to incorporate dissemination of PICS-related education to families, acute care providers, subspecialty services, and primary care providers into clinic design.

PNCC survivors in our study struggled to access many important outpatient therapies. Pediatric-specific resources are often scarce in rural communities,^{49,50} as highlighted in this study, and families travel hundreds of miles to access services. Adding to this difficulty is the lack of flexible scheduling to accommodate working families and those traveling from other communities. The financial burden of lost wages, cost of travel, and cost of ongoing care also impair survivors' ability to access needed therapies and services in some instances. Our study further highlighted that barriers exist in the transition from inpatient to outpatient care as our families found providers in their local areas hesitant to treat PNCC survivors, similar to prior reports.⁵¹ Education for rural providers surrounding PNCC and PICS morbidities is needed. Facilitated consultation between PNCC teams and rural providers may be one way to improve care, and also may increase the likelihood that families access care if it can be provided close to home.⁴⁹ Medical providers need to be aware of the hardships faced by families and how these issues can affect care and outcomes. Future research should incorporate outcomes such as the financial burden of PNCC and should evaluate interventions to increase access to care for these vulnerable children.

Parents in our study universally identified the need for support groups as an important intervention. The focus groups in this study often included emotionally salient conversation, and having an opportunity to share experiences with surviving PNCC in a supportive and understanding environment appeared to have some therapeutic benefits for many participants. The utility of support groups for survivors and their families has been recognized by the SCCM. In the future, clinicians and institutions should be aware of this need and help facilitate these support groups locally for families. Support groups providing opportunities to participate while hospitalized, soon after discharge, and long-term may serve multiple family needs and may provide a consistent resource to turn to when facing unexpected barriers over the course of rehabilitation and recovery.

While this study highlighted several important outcomes and care gaps, there are limitations to consider. Our focus groups represented only a small percentage of qualifying parents, and sample bias should be considered when interpreting the results. Demographic characteristics of our cohort were representative of a spectrum of PNCC diagnoses, child ages, time from discharge, and socioeconomic characteristics. Despite this heterogeneity, several shared outcomes and experiences were identified as per the goals of our study and similar to PICS literature. Our study showed a high prevalence of PICS morbidities and barriers to care, though sample bias and regional variation should be considered. We utilized trained facilitators with scripted questions designed to minimize bias in participant responses, but this limitation of focus group research should be considered. Despite limitations, parent engagement in our study

identified several themes with implications for future research and clinical care.

Conclusion

PNCC survivors and their families suffer long-term morbidities in the physical, psychological, cognitive, emotional, and social domains encompassed in PICS. While PNCC providers often focus on physical and functional outcomes, parents participating in our focus groups highlighted the emotional and psychological sequelae on the whole family and the substantial impact to family dynamics, financial well-being, and the social environment. The desire for increased awareness, education, and resources related to PICS outcomes for patients, families, and providers was emphasized across groups. Additionally, barriers to care are multifaceted, prevalent, and potentially modifiable in this population. Clinicians and researchers should consider the parent perspectives reported here when caring for and evaluating outcomes for children requiring PNCC.

Conflict of Interest

Dr. Piantino reports grants from the National Heart, Lung and Blood Institute, during the conduct of the study. Dr. Williams reports grants from the Agency for Healthcare Research and Quality, during the conduct of the study.

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