

FEATURED ORIGINAL RESEARCH ARTICLE

Postsepsis Care Needs in Children and Families: Single-Center, Codesign Qualitative Research From Western Australia

**OBJECTIVES:** Sepsis, for children and their parents, is a life-altering illness with far-reaching psychosocial and physical impacts. We aimed to explore the needs of such patients and their parents after hospital admission for sepsis to inform the development of a Western Australian postsepsis care service.

**DESIGN:** Qualitative study codesigned with four parents of children with personal experience of sepsis, which involved audio recording of interviews and focus groups of parents and healthcare and education professionals.

**SETTING:** Perth Children’s Hospital, Western Australia.

**PATIENTS AND PARTICIPANTS:** Over a 2-month period in 2024, 15 parents of children who had recovered from sepsis were interviewed; four parents participated in a focus group. There were also 23 healthcare or education professionals who participated in two focus groups.

**INTERVENTIONS:** None.

**MEASUREMENTS AND MAIN RESULTS:** The audio-recorded focus groups were transcribed verbatim, anonymized, and analyzed using inductive descriptive thematic analysis. Across both groups of participants, two major themes and six subthemes were identified. The major themes were “the impact of sepsis” and “supportive care after sepsis.” The impact of sepsis varied between individuals with the potential to affect multiple aspects of family life. Parents highlighted the profound psychosocial and physical consequences of sepsis, emphasizing the need for individualized support, communication, and follow-up after discharge. Professionals outlined gaps in current postsepsis care practices and suggested additional support measures for children and their families. Care coordination, described as a holistic, cross-sector healthcare model, was identified as a key need to ensure seamless collaboration across health, education, disability, and community sectors, while providing families with education, information, and resources.

**CONCLUSIONS:** This follow-up study of parents and healthcare or education professionals identified that in postsepsis care there is a need for coordinated, individualized follow-up, with ongoing clinical support for families after discharge.

**KEYWORDS:** education; family-centered care; follow-up; pediatric intensive care; qualitative research; sepsis

Sepsis is a complex, multisystem disease and a leading cause of global childhood morbidity and mortality (1). Beyond the acute phase, survivors and their families often face lasting physical, cognitive, and psychologic effects (2). Over a third of survivors experience long-term physical disabilities, whereas others endure untreated psychologic symptoms and medical traumatic stress (2). In Western Australia, Aboriginal and Torres Strait

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## RESEARCH IN CONTEXT

- Children who survive sepsis and their families often face long-term physical, emotional, cognitive, and psychosocial morbidities.
- At the time of discharge from hospital, transition to home may be a challenging period because of potential complex care needs in the patient and their family.
- We have therefore used a codesign methodology study to better understand the perspectives of parents and professionals about postsepsis care needs.

Islander children are disproportionately affected by sepsis and its aftermath (3). The transition from hospital to home is a challenging period due to ongoing postsepsis care needs. A lack of structured follow-up can lead to missed opportunities to manage significant morbidity and also subtle impacts on a child's development and emotional well-being. At our hospital in Western Australia, follow-up is not standardized and is managed individually by healthcare providers without a coordinated approach. In June 2022, the Australian Commission on Safety and Quality in Health Care released the Sepsis Clinical Care Standard (4), which recommended follow-up care for all sepsis survivors. In response, the Perth Children's Hospital (PCH) in Western Australia launched a sepsis program in July 2022, appointing a medical sepsis lead and clinical nurse consultant, with a key focus on developing and implementing a postsepsis care service.

Our review of the literature in 2024 identified two pediatric postsepsis programs that had reported their practice: the Pediatric Sepsis Survivorship Program at the Children's Hospital of Philadelphia (CHOP) in the United States and the Queensland Pediatric Sepsis Program (QPSP) in Australia. The CHOP program employs a nurse coordinator to provide family education at discharge and conduct 3-month follow-ups (5). The QPSP offers a website, educational videos, a family registry, and a codesigned peer mentor program (6). Both programs emphasize codesign and psychosocial support, but neither has undergone formal evaluation. Therefore, we sought to develop an evidence- and consumer-informed Western

Australian postsepsis care service. In 2024, we carried out a qualitative study to better understand the needs of pediatric patients and their parents after a hospital admission for sepsis. We have used a codesign research method to ensure relevance for clinicians, patients, and end-users (7).

## METHODS

This qualitative study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guideline (8) for comprehensive reporting of interviews and focus groups (**Supplement 1**, <https://links.lww.com/PCC/C630>). Ethics Committee approval was granted by the Child and Adolescent Health Service Human Research Ethics Committee (RGS0000006769) on February 29, 2024. Participants provided written or verbal consent. Researchers followed a four-step triage pathway (9) to manage participant distress, with a clinical psychologist available for follow-up. All research procedures and data handling were performed in accordance with the institution's requirements for human research and the 1975 Declaration of Helsinki.

The research was conducted at PCH, a 298-bed pediatric hospital in Western Australia (population 2.879 million), the sole quaternary hospital in the state caring for children. PCH has about 30,000 admissions and 70,000 emergency visits annually. Approximately, 480 children are affected by sepsis at PCH each year, with 100 having admissions exceeding 7 days.

The codesign was a two-tiered approach: a researcher-consumer partnership and qualitative methods to actively engage participants and capture their experiences (7). The codesign included consumers in every step of the research process, ensuring their diverse perspectives were captured at each stage. Four parents were codesign research team members, each with a child previously treated for sepsis. These parents were recruited through the PCH Sepsis Program Consumer Reference Group and PCH social media. Qualitative data were collected through individual and group interviews with parents of sepsis-affected children and professionals who care for these patients during and after their hospital admission.

## Participants and Recruitment

A purposive sample of parents was recruited via the hospital's sepsis audit database or clinician referrals to

ensure a balanced representation of caregivers across various child developmental stages and age groups. The term “parent participant” refers to an individual responsible for the child’s care. Professionals were identified by the health service clinician group or colleague referrals. Inclusion criteria for parents were that their child: 1) had been admitted to hospital with a diagnosis of sepsis and 2) was 0–19 years old during the admission. Inclusion criteria for professionals were: 1) experience in caring for families and children during their recovery from sepsis in hospital and or in the community and 2) a health or education professional. The professional participants were selected to represent a diverse range of specialties, including nursing, medical, allied health, and education, providing tertiary acute care, primary care, or teaching within the Western Australia community.

A standardized process to recruit parent and professional participants was developed by the codesign research team. An introductory short message service (SMS) was sent to parents, followed by a phone call when the research project was outlined, and the parent invited to participate. A single follow-up SMS and phone call were made if parents had not responded within a week. A SMS template and telephone interview script were followed. The opportunity to participate in a professional focus group was advertised widely through the hospital’s staff newsletters and intranet page, and key professionals were approached via individual emails.

Twenty-seven parents were contacted and invited to be a part of the interviews, with 13 expressing an interest and 11 consenting to be interviewed. Nineteen parents were contacted and invited to participate in family focus groups, with eight expressing an interest and four parents consenting to participate in a focus group and four consenting to be interviewed. Twenty-five professionals expressed an interest to participating in the focus groups and 23 consented to participate in the two focus groups.

## Data Collection

Interviews and focus groups took place between April 2024 and June 2024. Nine open-ended questions were used for family interviews, and four for focus groups (**Supplement 2**, <https://links.lww.com/PCC/C630>). Questions were iteratively refined by the codesign team. Interviews were conducted face-to-face, by

phone, or via Microsoft Teams (Microsoft, Redmond, WA). Focus groups were conducted via Microsoft Teams. Sessions were recorded, transcribed, and reviewed by two researchers. Interviews lasted between 15 and 45 minutes; the family focus group was 1 hour and 45 minutes, and professional groups were 1 hour and 15 minutes each. Field notes documented any factors influencing the sessions, and interviews continued until no new information emerged.

## Data Analysis

Inductive reflexive thematic analysis was conducted following Braun’s and Clarke’s six-phase process (10, 11). Two researchers (K.A., J.W.) independently coded transcripts using NVivo 12 (Lumivero, Denver, CO) software, finalizing a codebook. Themes were reviewed, refined, and discussed in a workshop with the codesign team to reach consensus. Detailed records ensured rigor and dependability (12). For credibility, researchers engaged with participants, and findings were refined by the codesign team (12). Detailed contextual information supported transferability (12), and code saturation was achieved when no new themes were identified (13, 14). Data are summarized as counts and proportions, or median and interquartile range (IQR).

## RESULTS

Two fathers and 17 mothers participated. Six participants identified as culturally and linguistically diverse (CALD), and two participants lived in regional Western Australia (**Table 1**). Group 1 were parents of preschool children from birth to age 5 years; group 2 were parents of primary school age children from 6 to 12 years; and group 3 parents of adolescents from age 13 to 19 years. All parents had lived experience of pediatric sepsis. Their child’s median length of stay in hospital was 13.5 days (IQR, 9.0–26 d), and six of 19 children were admitted to the PICU during their admission for sepsis. Demographics, diagnosis, and additional details about their children’s admission, discharge, and outpatient follow-up were collected from the patient health record and de-identified. Twenty-three professionals participated from a variety of specialties and positions (**Table 2**).

Two overarching themes were identified. First, “the impact of sepsis” describes the impact of hospital

TABLE 1.  
Parent Group Demographics

Child's Age at Sepsis Diagnosis	Group 1: Birth to Preschool (0–5 yr)	Group 2: School Age (6–12 yr)	Group 3: Adolescent (13–18+ yr)
Participant (P) number	P1, P3, P4, P5, P6, P8, P9, P10, P11, P12, P14, P17, P18, P19	P2, P7, P13, P15	P16
Ethnicity			
CALD	4	1	1
Non-CALD	10	3	0
Distance to treating hospital			
Urban (within 100 km)	12	4	1
Rural (> 100 km)	2	0	0
Parent			
Mother	12	4	1
Father	2	0	0
Child represented to multiple healthcare providers during acute illness			
Yes	8	2	0
No	6	2	1
Sepsis recorded on child's discharge summary			
Yes	10	3	1
No	4	1	0
Length of hospital stay for sepsis			
< 7 d	4	0	
≥ 7 d	10	4	1
Severity of illness			
ICU admission	4	1	1
Time from discharge to interview			
< 12 mo	7	1	0
≥ 12 mo	7	3	1

CALD = culturally and linguistically diverse.

admission with sepsis, and the following discharge, on the family. Second, “supportive care after sepsis” captures how parents and professionals perceived insufficient support provided postsepsis, and any requirement for additional supportive and individualized care after sepsis. Participants expressed the view that support could be provided by a health professional but could also be provided by a family member or friend.

Data from parents and professionals were integrated by comparing subthemes emerging from both groups to identify areas of convergence and divergence. Through this process, a strong relationship between the findings from the parents and professionals was

established. The triangulation allowed for a more comprehensive understanding by validating the themes across different perspectives, thereby enhancing the credibility and depth of the results. Key themes and related subthemes are illustrated in **Figure 1**.

Theme 1: The Impact of Sepsis

This theme captures the emotional, psychological, and physical journey patients and parents experienced during their child’s sepsis admission, and after discharge. Both parent and professional participants highlighted the significant physical impact as well as the profound

**TABLE 2.**  
**Professionals Group Demographics**

Speciality	Position	No. of Participants
Child and Adolescent Community Health	Child health nurse	1
Child and Adolescent Health Service	Hospital administrator	1
Child and Adolescent Health Service neonatology	Physician	1
PCH general pediatrics department	Clinical nurse specialist	1
	Physician	1
PCH hospital in the home/postacute services	Clinical nurse specialist	1
PCH infectious diseases department	Physician	1
PCH pharmacy	Pharmacist	2
PCH dietetics department	Dietician	1
PCH oncology department	Physician	2
PCH social work department	Social worker	1
PCH pediatric critical care unit	Physician	1
PCH physiotherapy department	Physiotherapist	1
PCH rehabilitation department	Physician	1
	Physiotherapist	1
	Clinical nurse specialist	1
	Clinical nurse	1
PCH speech therapy department	Speech therapist	2
Primary health	General practitioner	1
Western Australian Department of Education	Teacher	1
Western Australian Country Health Service	Nurse practitioner	1

PCH = Perth Children's Hospital.

emotional and psychosocial toll of the experience on children and families and expressed the need for enhanced follow-up care.

**Subtheme 1.1: Psychosocial Impact.** The parents discussed how the sepsis experience affected both their child's and their own psychological and emotional wellbeing, particularly postdischarge. They also recounted the impact on family relationships. For example, parent participant number 14 said, "So, she's got a real anxiety with night-time and sleep, and she just refuses to be alone." Also, parent participant number 10 said, "...it was definitely a very traumatizing experience...couldn't even look at an ambulance with lights and sirens. I just easily cry. I notice there's triggers for [child's name] as well, so that's why we've gone into therapy."

The professionals described the profound psychosocial toll of sepsis on families. They acknowledged that treating sepsis should extend beyond immediate

healthcare interventions, necessitating a more holistic approach to care delivery. For example, one physician said, "...many of these children and families have many more missed days of work. Lots longer to rehabilitate, even to get back to normal life...often have many missed days of school because they just haven't got the energy to be back." The senior hospital administrator said, "...there's a lot of complexity in our families and their capability to take care of a child post a really severe illness like this."

**Subtheme 1.2: Dealing With the Unknown.** The parent participants expressed fears about what happened during their child's acute illness, the rapid deterioration, and concerns about the future, particularly concerning the possibility of recurrence of sepsis or reinfection. For example, parent participant number 2 said, "I was so worried that what's going to happen next...is he going to get the infection up to that level, which is the sepsis, and what's going to happen? I'm so



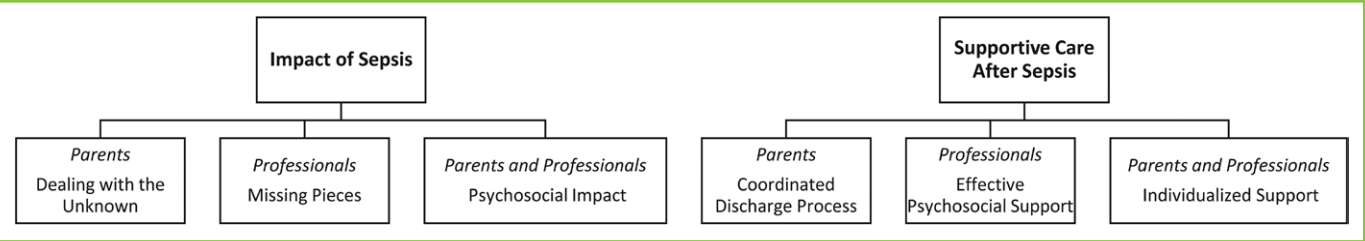


Figure 1. Key themes and related subthemes.

worried.” Parent participant number 4 said, “...life had changed, we were just like more careful with him...because we still don’t know, know how could he get the bug, like *E.coli* [*Escherichia coli*]?”

**Subtheme 1.3: Missing Pieces.** The professionals identified several key gaps in provision of postsepsis care, particularly in supporting families with managing multiple follow-up healthcare appointments, using discharge medications appropriately, and understanding the long-term implications of sepsis for their child and themselves. For example, one pharmacist said, “Going from no medications to a significant number can be quite challenging, and we don’t really have anything in place to support that apart from answering direct questions.” The child health nurse said, “There is a significantly large portion of these families who have zero follow-up and don’t know what they should be accessing...you [can] identify big gaps in the child’s developmental milestones.”

Theme 2: Supportive Care After Sepsis

The second theme reflects the needs and desires expressed by family and professional participants for better, more holistic, and individualized support systems postdischarge, which would ensure that families were not alone when navigating the complex postsepsis recovery journey in their family.

**Subtheme 2.1: Individualized Support.** The parents expressed frustration with the inconsistent advice they had received during their child’s postsepsis care, along with unclear communication about what to expect in the future. They emphasized the need for a unified healthcare team to provide continuous guidance throughout their recovery journey. For example, parent participant number 4 said, “...I wish there could be just one team. Consistency. You know, with his treatment.” Parent participant number 14 said, “There was no real, like, psychosocial stuff. There wasn’t really any. Yeah, it was more just. We’ve

treated you. She’s OK. Go home on these oral antibiotics. Come back if she’s not well.”

The professionals acknowledged the variability in existing discharge processes, and that there was also a need to personalize care tailored to individual needs of each patient and their family. For example, one physician said, “I don’t think there’s a common way of being discharged. Every family requires something different,” and “...our families need...us to all work together [which is] is currently a barrier.”

**Subtheme 2.2: Coordinated Discharge Process.** The parents had experienced varying levels of discharge support during the weeks and months after leaving hospital. Their varied journeys during discharge were influenced by the presence or absence of preexisting medical conditions, their place of residence (urban area or more regional and remote areas), and the severity and complexity of their child’s physical complications postsepsis. For example, parent participant number 11 said, “...we have a visiting pediatrician once a month and you can usually only get in to her every third month...so basically, I am his doctor, nurse, everything up here [in rural North-West Western Australia]. PEG [percutaneous endoscopic gastrostomy] changes. I’ve done all of these PEG changes. I’ve done everything.” Parent participant number 16 said, “...the nurse came from hospital...they came for about a month afterwards [discharge] and would come on a weekly basis.”

**Subtheme 2.3: Effective Psychosocial Support.** The professionals emphasized that a team comprising a physician, nurse, allied health professionals, and comprehensive psychosocial support would be the ideal support format. They also suggested all sepsis patients should have access to a care plan extending beyond hospital discharge. For example, one physician said, “Every patient with confirmed sepsis should have an opt-out care plan for at least the next 12 months.” The general practitioner (GP) said, “...something that I think is really important. Communication with the GP. If we don’t know what’s going on, then we can’t help

## WHAT THIS STUDY MEANS

- This study revealed the varied, individualized impact of sepsis for children and their parents, affecting multiple aspects of their lives.
- Currently, there is not a standardized approach to postsepsis care at our hospital or coordinated follow-up, leaving critical gaps in support for children and their families.
- We believe that a care coordination model that integrates holistic, cross-sector services and provides ongoing family support from clinicians, could bridge this gap, improving postsepsis care for children and their families.

and often we've [been] forgotten about, and the families do come back to us and we don't know anything about what's going on."

## DISCUSSION

Sepsis profoundly impacts children and their families with consequences affecting multiple aspects of life. Our PCH study in 2024 highlights the need for physical and psychosocial care during and after sepsis, with parents and professionals advocating for increased, personalized support. Uncertainty around sepsis causes significant stress and anxiety, underscoring the importance of coordinated discharge planning and individualized follow-up. Gaps in postsepsis care, including inconsistent discharge processes and insufficient follow-up, contribute to ongoing distress. Participants emphasized the need for codesigned, holistic care and better coordination among health professionals to support families during recovery. These findings align with the existing literature on pediatric postsepsis care in the CHOP (5) and QPSP (6) programs.

In adult practice, postsepsis syndrome involves ongoing physical and psychologic challenges for survivors, with many developing long-term health issues (15). Studies have shown that about 25% of pediatric survivors do not return to baseline health within 1 month (16–18), and over a third report new disabilities within 3 months of diagnosis (2). Our study echoed these findings with families reporting ongoing health

issues, such as fatigue, frequent infection, and delayed recovery. Professionals observed that many children frequently missed school days and required prolonged rehabilitation, indicating a failure to regain baseline health even months after discharge.

Our study also supports the existing literature that sepsis can cause psychologic trauma symptoms in both children and their parents, potentially leading to conditions, such as posttraumatic stress disorder if untreated (19–22). In our study, many parents reported ongoing anxiety, fear, and emotional distress long after hospitalization, with heightened concerns about recurrence and distressing memories. Professionals noted that recovery extends beyond physical healing, emphasizing the need for holistic approaches to address emotional and psychosocial well-being. Both families and healthcare providers stressed the importance of early identification and follow-up support to improve mental health outcomes—all aligning with the concept of "family-centered care" in the PICU population (23).

Regarding equity of access to healthcare, our observations are consistent with observations in a 2018–2019 retrospective study at CHOP in which lower follow-up rates occurred among CALD families (5). That is, regional and remote families, as well as those with children who have preexisting conditions, struggle to access consistent postdischarge support. The study also highlights the inadequacy of a one-size-fits-all approach, particularly for Aboriginal and Torres Strait Islander Australian families, who require culturally safe, tailored interventions (4).

The study identified care coordination as a critical gap in the hospital discharge process for many of the families we studied. In our experience at PCH, integrating services across sectors, including health, education, disability, and community resources, for rare disorders can optimize transitions from acute care to community support, enhancing service quality while reducing unplanned readmissions and unnecessary healthcare costs (24). In particular, care coordinators can address the multifaceted needs of sepsis survivors and improve their long-term outcomes (25). In the Australian healthcare system, implementing a pediatric sepsis program requires integrating the Sepsis Clinical Care Standard (4), which includes standardized protocols, resources, and education. In remote and rural areas, to overcome barriers of

accessing services, telehealth can be used for ongoing monitoring and follow-up. In the United States, regional sepsis networks could be used to develop and integrate standardized protocols, resources, and education. Navigating the insurance landscape is also essential to securing reimbursement for pediatric sepsis care, including follow-up and telehealth services.

Our literature review identified two other programs that have published their experience. We do not know the true extent of longitudinal pediatric sepsis care programs, from admission to follow-up, particularly in low- and middle-income countries or underfunded healthcare systems. Further work is needed to standardize guidelines for postsepsis care across fragmented healthcare provision (e.g., primary care, emergency care, and tertiary pediatric care) to overcome gaps in training and awareness, and integrate—for example—follow-up with aftercare in the community, as recently researched in the acute brain injury PICU population (26, 27).

Our study has four important limitations. First, the sample was small, from a single-center, and skewed toward English-speaking families, but it did include representation from Aboriginal and Torres Strait Islanders participants (2/19 participants) and the CALD community (6/19 participants). However, it is possible that population-specific challenges have not been fully identified. Even so, our study methodology reinforces a broader relevance beyond a single institution. Second, the challenges identified in the study may be more pronounced in cases of severe or prolonged sepsis, which were not fully captured in the sample. Only six of 19 participants had children admitted to PICU, whereas 15 had children hospitalized for longer than 7 days. Further research with a more diverse sample, including greater representation of Aboriginal and Torres Strait Islander and CALD families, as well as a focus on long-term outcomes for children with severe or prolonged sepsis, is therefore needed. Third, the study was conducted at a single institution in Western Australia (the largest and most remote state in the Australia), which may not reflect other pediatric hospital settings. However, the work does highlight challenges in integrating follow-up care and addressing acute caregiver stress. As outlined by Butler et al (23), there is growing global recognition of the need for structured,

family-integrated models to improve post-PICU outcomes, reduce caregiver burden, and enhance continuity of care. Also, our work aligns with ideas about “post-intensive care syndrome” in pediatrics with its impact on critical illness survivors and their families and the necessity for mitigations, such as psychologic support and follow-up beyond hospital discharge (28–30). Last, we acknowledge the inherent limitations of thematic analysis and potential subjectivity in data interpretation. For example, our reflexive thematic analysis may not have captured the full complexity of individual experiences, thereby risking an overemphasis on common themes over rarer, yet potentially significant, insights. To limit these risks, we followed Braun’s and Clarke’s six steps of reflexive thematic analysis (10, 11) and the COREQ checklist (8). We sought to purposefully capture a diverse range of perspectives, including less common experiences.

In conclusion, our study explored the needs of pediatric patients and their families after a hospital admission for sepsis to inform development of a Western Australian postsepsis care service. Parents expressed concerns about the uncertainty they faced, often resulting in heightened stress and anxiety impacting both their child and all family members. The two major themes identified by parents and professionals encompassed “the impact of sepsis” and “supportive care after sepsis,” which reemphasizes the varied, profound effects on families and the need for individualized support, improved communication, and enhanced postsepsis care practices. This study also highlights the need for a coordinated and individualized follow-up process involving clinical support after hospital discharge with sepsis.

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Ms. Middleton was involved in conceptualization, methodology, validation, formal analysis, resources, writing the original draft, and reviewing and editing the writing, visualization, project administration, and funding acquisition. Ms. Anastasas and White were involved in conceptualization, methodology, software, validation, formal analysis, investigation, data curation, writing the original draft, and reviewing and editing the writing. Ms. Pienaar and Harvey were involved in conceptualization, validation, investigation, and reviewing and editing the writing. Ms. Bale, Mr. Wakeling, and Dr. McCarthy were involved in conceptualization, validation, and reviewing and editing the writing. Dr. Blyth was involved in conceptualization, methodology, validation, reviewing and editing the writing, supervision, and funding acquisition. Dr. Gill was involved in conceptualization, methodology, software, validation, formal analysis, reviewing and editing the writing, and supervision. The Child and Adolescent Health Service (CAHS) Postsepsis Care Working Group was involved in conceptualization and validation.

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The datasets presented in this article are not readily available because the data are based on sensitive information from parents. Requests to access the datasets should be directed to the corresponding author.

The Child and Adolescent Health Service (CAHS) Postsepsis Care Working Group are listed in the **Appendix** section.

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## APPENDIX

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