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Review paper

# Emerging elements of paediatric post-sepsis care programs: A scoping review

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ABSTRACT

*Background:* Sepsis is a significant cause of mortality for children in Australia, particularly affecting young children, those with pre-existing health conditions and Aboriginal and Torres Strait Islander populations. The transition from hospital to home can be challenging for survivors, often leaving long-term impacts unaddressed.
*Objectives:* The objective of this study was to identify and describe existing post-sepsis care interventions and models of care for paediatric survivors, with the aim of informing the development of a post-sepsis care pathway.
*Methods:* The JBI Scoping Review Framework guided the identification and selection of relevant literature, Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines ensured transparent reporting, and the Patterns Advances Gaps Evidence for practice and Research and recommendations framework supported analysis and synthesis. Peer-reviewed literature was sourced from databases, the Cochrane Collaboration, reference lists, and expert consultations. Grey literature was identified through targeted searches of healthcare and paediatric organisation websites.
*Results:* Of 1843 records screened, eight met inclusion criteria: two peer-reviewed articles and six grey literature resources. Two emerging models of care were described: the Children's Hospital of Philadelphia Pediatric Sepsis Survivorship Program and the Queensland Paediatric Sepsis Program. The Children's Hospital of Philadelphia introduced a nurse coordinator role for discharge education and follow-up at 3 months utilising a survivor-needs questionnaire. The Queensland Paediatric Sepsis Program developed a webpage, videos, a family registry, and a peer mentor program codesigned with families. Both emphasised psychosocial support and care coordination, though neither had formal evaluations or measurable outcomes. Grey literature described general service approaches without defined interventions.
*Conclusion:* There is an evidence gap in structured, evaluated post-sepsis care for children. Only two emerging models of care were identified, neither formally assessed. Findings support the need for a comprehensive, culturally sensitive, family-centred care model and have informed the development of a pilot post-sepsis care pathway.


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## 1. Introduction

Sepsis is defined as a life-threatening organ dysfunction caused by a dysregulated host response to an infection[1] and is a leading cause of paediatric morbidity and mortality worldwide.[2,3] In Australia, young children, those with pre-existing health conditions, and Aboriginal and Torres Strait Islander populations are disproportionately affected by sepsis.[3,4] Although mortality has declined, growing recognition of long-term impacts has highlighted the need to optimise outcomes for survivors.[2]

Some sepsis survivors experience what is referred to as post-sepsis syndrome, characterised by persistent or new physical, cognitive, or psychological impairments following sepsis.[5] In a 2015 study across 26 countries, 30% of children developed new or worsening impairments after sepsis.[3] Other studies report lasting effects across physical, emotional, and cognitive domains up to 9 to 12 months post illness.[6] Sepsis can also have profound emotional impacts on survivors and families, especially where children have significant post-sepsis disability[6] and parental mental health diagnoses nearly double following paediatric intensive care unit (PICU) admission,[7] which includes but is not limited to children treated for sepsis.

Despite these findings, the frequency, severity, and trajectory of paediatric post-sepsis syndrome remains poorly defined and how it differs from the adult experience is not well understood. The age and developmental stage of the child affected likely influence the nature of post-sepsis syndrome, but evidence to guide optimal screening timepoints, methods, or interventions is limited.

In recognising the global burden of disease of paediatric sepsis, the World Health Organization 2017 resolution on sepsis[8] appealed to members to recognise the burden of long-term morbidity after sepsis and address survivors' needs.[9] In 2018, the International Sepsis Forum met to discuss longer-term sepsis recovery to enhance sepsis survivorship.[5] In 2022, the Australian Commission on Safety and Quality in Health Care released the Sepsis Clinical Care Standard,[10] recommending follow-up care for all sepsis survivors. However, despite these calls to action, there is currently no consensus on post-sepsis care clinical guidelines for children.[11]

While there have been post-sepsis care pathways developed for the adults, they primarily focus on return to work and management of chronic comorbidities.[12–14] These models do not account for children's unique developmental needs, educational needs, and family dynamics, highlighting the need for paediatric-specific approaches. Although care coordination models of care exist in other paediatric specialties such as oncology, trauma, and post PICU,[15–17] much of the paediatric work has focused on quality-of-life outcomes and recovery trajectories after sepsis[18–20] rather than structured post-sepsis interventions. The transition from hospital to home is a vulnerable period for children recovering from critical illness and has been identified by consumers and clinicians as a key opportunity to improve outcomes.[21]

To support the development of post-sepsis care interventions and models of care for children, a clearer understanding of the current evidence is required. The aim of this scoping review was to identify and describe existing post-sepsis care interventions and models of care for paediatric sepsis survivors and their families following hospital discharge. The term *intervention* is used broadly to encompass clinical follow-up, psychosocial or education support, and health service resources designed to support children and families after sepsis. Scoping reviews enable the exploration of broad research questions and synthesis of evidence from diverse sources,[22] and this review seeks to inform the development of a post-sepsis care pathway.

## 2. Method

### 2.1. Aim

The aim of this scoping review was to identify and describe existing post-sepsis care interventions and models of care for paediatric sepsis survivors and their families following hospital discharge, with the goal of informing the development of a post-sepsis care pathway.

### 2.2. Method

This research was undertaken in partnership with a post-sepsis care working group, established within a tertiary paediatric health service, which functioned as a researcher–consumer partnership.[23] The group included four parent research partners, each with a child previously treated for sepsis. Recruited through an existing consumer reference group and the health service's social media channels, the parents provided strategic input into the project, including shaping the review question and refining search terms. They were not involved in literature screening or review, data analysis, or manuscript drafting. Their contributions are acknowledged as members of the working group.

The review followed the JBI Scoping Review Framework[24] to guide the methodological process and was reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) Extension for Scoping Reviews checklist.[25] The JBI framework's five-step process includes (i) identifying the research question; (ii) identifying relevant studies; (iii) study selection; (iv) data charting; and (v) collating, summarising, and reporting the results.[26] This structured process supported the systematic identification and organisation of relevant literature. The Patterns Advances Gaps Evidence for practice and Research and recommendations (PAGER) framework[26] was subsequently applied to analyse the findings, enabling identification of key patterns, advances in knowledge, gaps requiring further research, implications for clinical practice, and targeted research recommendations to address those gaps.

Peer-reviewed literature was sourced from online databases (MEDLINE and CINAHL) and the Cochrane Collaboration. The rationale to utilise MEDLINE and CINAHL for this scoping literature review was based on the strong focus of databases on health care, nursing, and biomedical research, aligning most closely with the objective of this scoping literature review. These databases were deemed sufficient to provide comprehensive coverage of the relevant literature within the review's scope. ProQuest was not included due to its broader, multidisciplinary coverage, which could introduce significant overlap with the selected databases and yield less focused results, potentially increasing resource demands without adding substantial value to the review.

Additional search strategies included reference lists of eligible articles, global health care, and paediatric organisations, as well as targeted Google© searches. Furthermore, the authors conducted online meetings via Microsoft Teams© with subject matter experts in Australia and the United States of America (USA), including program leads and clinicians with firsthand experience in post-sepsis care programs, to gather relevant unpublished data. This approach sought to identify gaps in existing research and uncover programs not documented in academic literature.

The review protocol was pre-registered with Open Science Framework DOI 10.17605/OSF.IO/B9EA6 on May 23rd, 2024.

### 2.3. Inclusion and exclusion criteria

The research question and objectives were defined using the Population, Concept, and Context framework, specifying the population of interest, concept under investigation, and context in which the research is conducted (Table 1).[24] The population of interest was children under 18 years of age who were treated for sepsis and received follow-up care post discharge as part of a post-sepsis intervention. For the purposes of this review, *intervention* was defined as clinical follow-up, psychosocial or educational support, and health service resources for children and families post sepsis. Both peer-reviewed and grey literature studies in English were considered to ensure comprehensive and relevant data.

The inclusion criteria for peer-reviewed literature were:

- Participants aged <18 years (neonates were excluded due to distinct clinical and developmental considerations)
- A diagnosis of sepsis or septic shock
- Postdischarge follow-up or care provided as part of an intervention
- Models of care related to recovery after sepsis or septic shock

Exclusion criteria included:

- Studies involving only in-hospital interventions or acute sepsis management
- Research focussed solely on sepsis risk factors, aetiology, prevention, or pathophysiology
- Economic analyses, health service utilisation, or epidemiological studies without a postdischarge care component
- Studies focused exclusively on bereaved families were considered outside the current scope and will be addressed in future work

Grey literature was included to capture emerging and unpublished interventions. Documents were considered relevant if they described or proposed post-sepsis support educational resources and or services, particularly within paediatric contexts, or included adaptable models developed for adult and paediatric populations.

### 2.4. Identifying relevant studies

Peer-reviewed databases (CINAHL and MEDLINE), the Cochrane Collaboration, Google, relevant healthcare and paediatric organisation websites, and interviews with subject matter experts were conducted in May/June 2024. For grey literature, websites of healthcare and paediatric organisations were purposively selected based on their recognised involvement in sepsis care, policy development, or advocacy. Selection was informed by the research team's expertise and existing national and international networks. These included the Sepsis Alliance, Queensland, Victorian and New South Wales Clinical Excellence Commissions, United Kingdom Sepsis Trust, Canadian Sepsis Foundation, Sepsis Australia, Australian Commission of Safety and Quality in Health Care, Children's Hospital Association, and World Health Organization.

Search terms were combined using Boolean operators (e.g., “AND”, “OR”) to link key concepts and refine results. The primary search was (*sepsis OR sepsis*) AND (survivor*) AND (post-sepsis syndrome OR intervention OR follow-up). Searches were restricted to paediatric populations using database filter “all child”. The term “survivor*” was selected to reflect international discourse on sepsis survivorship and post-sepsis care. While alternative terms such as “recovery” and “post-discharge” were tested in preliminary searches, “survivor*”, “post-sepsis syndrome”, “intervention”, and “follow-up” returned the most relevant and comprehensive results aligned with the aim of this review.

The study selection process comprised two phases:

- Title screening: Two independent reviewers (CP and JH) screened titles to determine eligibility based on the inclusion criteria. Discrepancies were resolved through discussion and mutual agreement or a third reviewer (NM).
- Abstract/full-text screening: Abstracts and full-text articles were reviewed, and eligibility was confirmed by two independent reviewers (CP and JH). Discrepancies were resolved through discussion and mutual agreement or a third reviewer (NM).

EndNote© (version 21; Clarivate, Philadelphia, PA, USA) and Excel© software were used to manage citations, track decisions, and organise the selected sources. Studies selected for inclusion underwent data extraction and further analysis. Example search of MEDLINE was conducted as per Supplement 1.

### 2.5. Data charting, collection, and extraction

Data extraction was completed using a standardised data extraction template (Table 2), designed by the research team to capture key information relevant to post-sepsis interventions. For the selected articles, data were systematically extracted to capture the following elements: (i) article/resource title; (ii) author(s); (iii) type/publisher; (iv) date of publication; (v) populations/participants; (vi) context; (vii) description; and (viii) outcomes. Two reviewers (CP and JH) pretested the data extraction form for consistency.[22] No discrepancies required resolution through discussion or adjustments as the data were clear and reliable.

## 3. Results

The initial search yielded 1843 records. After removal of duplicates (n = 49) and the initial title review (n = 1740), 54 records remained. Of these, 45 were identified through database and register searches and proceeded to abstract screening, while nine records identified through other sources (e.g., organisational websites) were retrieved directly for full-text review. Following this, 46 records were excluded for the following reasons: not paediatric population (n = 11), not a postdischarge intervention (n = 27), acute sepsis management (n = 6), cost of sepsis for an at-risk population (n = 1), and nurse-led postdischarge intervention for paediatric trauma

**Table 1**
PCC framework.

| | Description |
|---|---|
| Population | Children aged under 18 years who were treated for sepsis and received follow-up care post discharge as part of a post-sepsis intervention. |
| Concept | Follow-up care and outcomes related to post-sepsis interventions. |
| Context | Studies published in English, including both peer-reviewed and grey literature, ensuring comprehensive and relevant data. |

PCC: Population, Concept, and Context.

**Table 2**
Data extraction table.

| | Article/resource title | Author(s) | Type/publisher | Date of p ublication | Populations/ participants | Context | Description | Outcomes |
|---|---|---|---|---|---|---|---|---|
| 1. | Information for Parents, carers, and Families of Children with Sepsis[30] | Australian commission on safety and Quality in Health Care (ACSQHC) | Information brochure | 2022 | Paediatric (Australia) | Consumer information fact sheet | Ancillary materials attached to the Sepsis Clinical Care standard to guide parents, carers, and families, covering hospitalisation, discharge, and post-sepsis complications. | Aims to provide families with knowledge to improve care transitions and support long-term recovery for children with sepsis. |
| 2. | Queensland Paediatric Sepsis Project 5-Year roadmap[33] | Children's Health Queensland | Webpage | April 2022 | Paediatric (Australia) | Graphic report and news piece | Describes the Australian paediatric-focused sepsis program with a holistic approach. Includes acute care, post-sepsis support, an integrated care model, and sustainability-focussed pathways. | The roadmap includes development of education and awareness platforms, integrated inpatient and post-sepsis support, family support, and peer mentorship programs that are tailored for CALD families and promotes health equity for aboriginal and torres strait islander families.<br>Aims to improve sepsis management, family experiences, and health service efficiency. |
| 3. | Sepsis Family Support[32] | Children's Health Queensland | Webpage | September 2023 | Paediatric (Australia) | Informational and educational resource | Information for families about sepsis with information sheets translated into 11 languages, bereavement resources, the family support network and peer mentor program. | Provides access to a range of resources relating to acute sepsis and post-sepsis support. |
| 4. | Sepsis Family Experiences—8-Part Video series[34] | Children's Health Queensland | Video series | November 2023 | Paediatric (Australia) | Informational and educational resource | Online video series covering each stage of a child's sepsis journey, from diagnosis to rehabilitation and postdischarge support. | Provides understanding of the sepsis journey for families through visual education. |
| 5. | Pediatric Sepsis Program[31] | Children's Hospital of Philadelphia | Information brochure | July 2018 | Paediatric (USA) | Consumer information fact sheet | Sepsis program resource. | Brief outline of survivorship program and contact information for further support. |
| 6. | Implementation of a Follow-Up System for Pediatric Sepsis survivors[28] | Julie C. Fitzgerald et al. | Frontiers in Pediatrics vol 9 | June 2021 | Paediatric (USA) | Retrospective case series | Nurse-coordinated survivorship program for sepsis survivors, leveraging outpatient resources, providing education, and offering follow-up care. | Twenty of 80 patients referred for services, with 13 receiving subspecialty follow-ups. Program continues to evolve to meet needs. |
| 7. | Designing Support Structures Post-Sepsis in Children: Perspectives of the Queensland Paediatric Sepsis Program[27] | Sainath Raman et al. | Frontiers in Pediatrics vol 9 | 2021 | Paediatric (Australia) | Descriptive study | Developed in response to a review identifying sepsis as a critical issue. Includes a family support structure with consumer and multidisciplinary team input. Features a registry, webpage, educational video series, and peer mentor program. | Program is in early implementation stages, with plans for evaluation to assess impact on families and outcomes. |

| | | | | | | |
|---|---|---|---|---|---|---|
| 8. Sepsis Survivors[29] | Sepsis alliance | Webpage | Updated 2024 | Paediatric/generic (USA) | Informational and educational resource | Online library including fact sheets, videos, and guidance tailored to paediatric and adult survivors, families, and clinicians, with multilingual availability videos, fact sheets, and advocacy opportunities. Addresses the physical, emotional, and psychological challenges often faced after surviving sepsis, including post-sepsis syndrome. Covers mental health sequelae like PTSD and depression. | The resources provide information about the multifaceted challenges faced by sepsis survivors and their families |

PTSD: post-traumatic stress disorder.

population (n = 1). Eight unique titles were included (see Fig. 1 PRISMA flow chart; Table 2). Two articles identified were academic, peer-reviewed papers,[27,28] and six were grey literature resources including a webpage and information brochure providing general information about paediatric post-sepsis interventions[29,30] or supplement resources, webpages, an information brochure, and video series, for the programs described in the peer-reviewed articles.[31–34]

The two peer-reviewed articles reported on the Pediatric Sepsis Survivorship Program at the Children's Hospital of Philadelphia (CHOP), USA,[28] and the Queensland Paediatric Sepsis Program (QPSP), Australia.[27] The key components of these two models of care are described in Table 3. Both report of the use of codesign, incorporating family members and prioritising psychosocial support. As formal evaluations have not yet been published, their impact on patient outcomes and the specific measures of success remain undefined.

The CHOP model of care, established in 2018, employed a nurse coordinator to provide family education at discharge and conduct a telehealth clinical review 3 months following discharge[28] using a screening tool developed with neuropsychology input. Children with identified concerns were referred to primary or subspecialty care for medical or allied health follow-up, and those with psychosocial or cognitive issues were fast-tracked for neuropsychological evaluation. An educational letter was also prepared for schools and coaches to support reintegration. Eighty patients were identified in the first 12 months as eligible for follow-up, 85% met the 2005 consensus criteria for paediatric septic shock,[35] and 80% had pre-existing comorbidities.[28] After excluding those with existing follow-up arrangements or complex needs, 20 were referred to the nurse coordinator. Of these, nine completed the follow-up, all reporting new difficulties impacting quality of life and over half had not returned to baseline function or resumed all preillness activities.

The QPSP model of care, launched in 2018, focused on family-centred psychosocial support. Reported components included a dedicated webpage for families, educational videos, a family registry, and a codesigned peer mentor program[27] led by Advanced Social Workers. The peer mentor program enabled families impacted by sepsis to connect with one other, with mentors providing support during the acute phase or after. Length of participation was open ended.

The grey literature review identified educational resources (an intervention centred on education) targeting families and caregivers of paediatric sepsis survivors, designed to raise awareness of sepsis, support care transitions, and facilitate initial recovery. While resources such as those from the Sepsis Alliance[29] address broader challenges like post-sepsis syndrome and mental health, they remain generalised rather than specifically tailored to paediatric populations. Overall, these materials describe education and awareness but lack detailed, actionable frameworks for sustained recovery, integrated support, and holistic care tailored to the unique needs of survivors and their families.

The PAGER framework[19] (Table 4) identified patterns with the literature and articles including a consistent emphasis on survivorship, the need for increased resources and collaboration, the importance of holistic follow-up, psychosocial support, care coordination, and the role of multidisciplinary teams. While not all of these represent interventions, they reflect common thematic priorities in the limited available literature without providing structured models or evaluative data. Gaps were both identified in the literature and extrapolated by the research team based on the absence of key components. These included (i) a lack of evaluation; (ii) inadequate attention to the mental health needs like post-sepsis depression and post-traumatic stress disorder in either child or parent; and (iii) variability in accessibility and effectiveness of care.

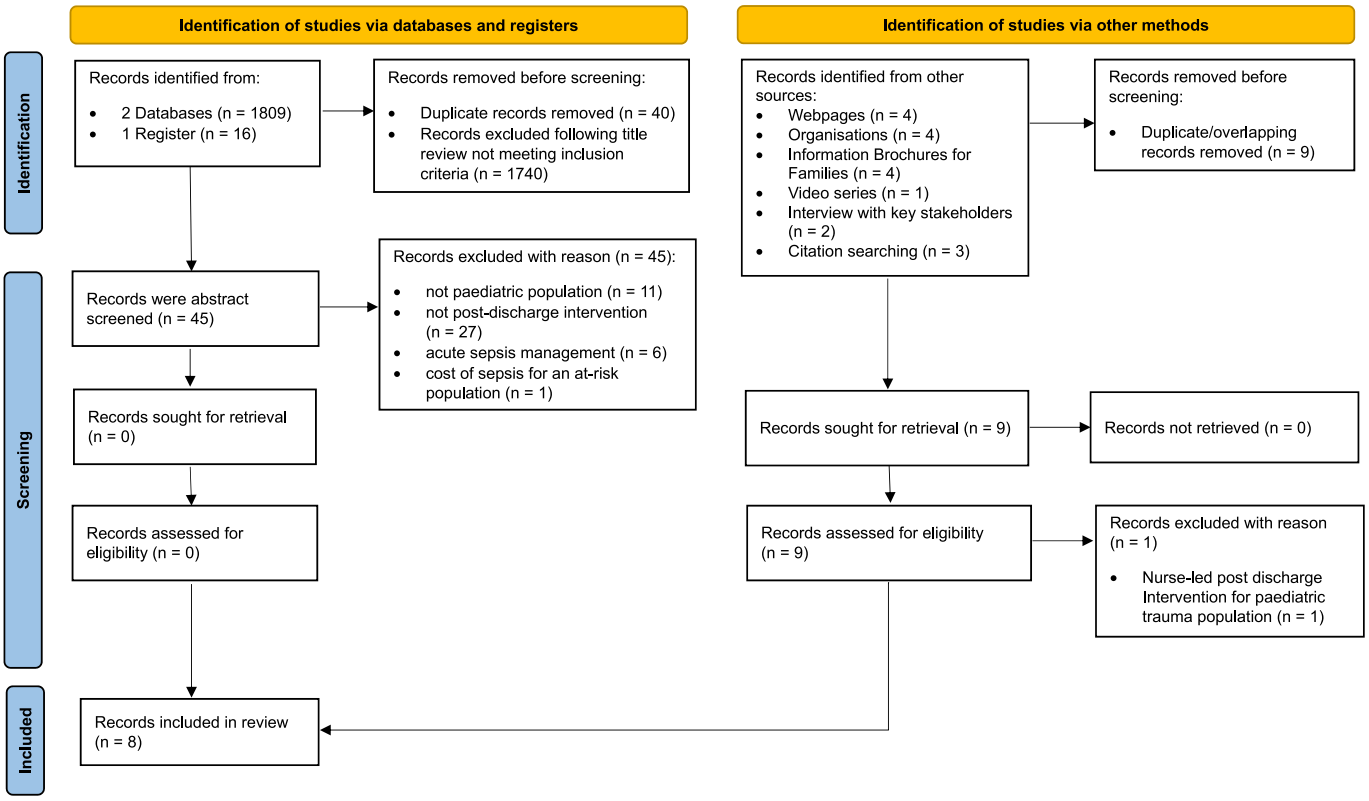


**Fig. 1.** PRISMA flow chart. PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses.

The CHOP reported the use of individualised assessment, leveraging existing services and addressing new concerns through structured referral pathways, while QPSP described cultural inclusivity and psychosocial support yet lacked formal care pathways for ongoing medical follow-up.

In line with the literature themes and research team insights, a future post-sepsis care pathway should include follow-up assessments up to 12 months following discharge to quantify long-term impacts. Enhancing accessibility and expanding resources to include dedicated mental health support and culturally sensitive materials are critical steps towards delivering comprehensive, equitable care for paediatric sepsis survivors and their families.

## 4. Discussion

The paucity of reported paediatric post-sepsis approaches highlights a gap in the evidence needed to guide service development. Although neither the CHOP nor the QPSP model encompasses every

**Table 3**
Similarities and differences between the CHOP Pediatric Sepsis Survivorship Program and the QPSP.

| Feature | CHOP Pediatric Sepsis Survivorship Program | Queensland Paediatric Sepsis Program |
|---|---|---|
| Year established | 2018 | 2018 |
| Focus area | Post-sepsis follow-up and referral to medical care | Psychosocial support and family engagement |
| Intervention leader | Nurse coordinator with intensive care experience | Advanced social workers and multidisciplinary team |
| Follow-up | Discharge review and telehealth follow-up 3 months post discharge | No specific follow-up timeframe |
| Assessment tools | REDCap-administered questionnaire developed with neuropsychologist input | No structured medical assessment tool |
| Referral pathways | Referrals to specialists (neurological, psychosocial, and complex care teams) | No formal medical or complex care referral pathways |
| Educational resources | Teacher/coach letter, family education at discharge, and brochure about the program with contact details | Webpage with links to brochures and video series |
| Family support | Addressed through individual follow-up, referrals, and education | Codesigned peer mentorship program, family registry |
| Cultural inclusivity | Not specified | Includes pamphlets translated into 11 languages and support for CALD families and aboriginal and torres strait islander families |
| Consumer input | Incorporated in program design and follow-up processes | Incorporated in design and implementation (e.g., peer mentor program) |
| Program scope | Focus on post-sepsis recovery and addressing quality-of-life challenges | Support for families during acute sepsis, post-sepsis, and bereavement stages |
| Evaluation | No program evaluation reported | No program evaluation reported |
| Key outcomes reported | Identified quality-of-life impacts and deficits in motor skills; over 50% not returned to baseline activities | Not reported |

CHOP: Children's Hospital of Philadelphia; QPSP: Queensland Paediatric Sepsis Program; RED-Cap: Research Electronic Data Capture.

**Table 4**
PAGER framework.

| Pattern | Advances | Gaps | Evidence for practice | Research recommendations |
|---|---|---|---|---|
| Focus on paediatric survivorship. | Identification of a need for holistic follow-up care for child and family after sepsis, integrating acute care, post-sepsis support, and cultural inclusivity for CALD families. Assessing the child for new physical or psychosocial morbidity and referring to specialists if new concerns identified. | The existing interventions have not been evaluated. Duration of the existing programs varies, assessing for new morbidities did not continue beyond 3 months post discharge after sepsis. | Data from pilot studies (e.g., QPSP) and retrospective case series (e.g., CHOP sepsis survivors) describe early implementation success but lack formal evaluation. | Conduct systematic evaluations of existing programs to quantify benefits and identify areas for improvement. Follow-up for a 12-month duration to provide robust evidence of longer-term intervention outcomes. |
| Resources for paediatric post-sepsis follow-up. | A range of targeted tools including fact sheets, videos, clinical guidance, and peer mentorship programs developed for post-sepsis care survivors and families. | Resources provide useful information but are generalised and not tailored for individual needs. They do not constitute a care pathway. Resources catering for mental health needs of the family post sepsis are sparse. | Broader resources like the Sepsis alliance library provide educational materials, though impact of resources has not been evaluated. | More comprehensive resources focusing on mental health of families are needed. Resources should be expanded to include culturally sensitive information that is widely accessible. |
| Collaboration between multidisciplinary teams and consumers. | Programs are consumer driven, include multidisciplinary team input. Survivorship programs are collaborative and leverage on existing services. | Variability in program availability and accessibility, particularly in underserved or international contexts. | Consumers with lived experience are coresearchers building programs to cater for needs of child and families affected by sepsis. | Continue to drive collaboration between consumer and health care providers around paediatric post-sepsis care innovation. |

CHOP: Children's Hospital of Philadelphia; PAGER: Patterns Advances Gaps Evidence for practice and Research and recommendations; QPSP: Queensland Paediatric Sepsis Program.

element, the components they describe include family education, psychosocial support, discharge planning, ongoing follow-up (e.g., via telehealth), and culturally sensitive care systems. These models illustrate the potential value of tailored, family-centred interventions developed through codesign which respond to needs after discharge, including medical, access to follow-up, and psychosocial impacts. However, the lack of formal evaluations limits the understanding of the described practices, their scalability, and their impact. Feedback from families and robust evaluation, including process and outcome measures such as child health outcomes and equity of access, is essential. Moreover, extending evaluations beyond 3 months for the CHOP program may offer a more comprehensive assessment of outcomes.

While dedicated post-sepsis care remains nascent in paediatrics, established follow-up models from oncology, trauma, and post PICU offer valuable insights.[15–17] These often involve long-term follow-up (most commonly at 3, 6, and 12 months for the PICU), shared care between tertiary and primary providers, nurse-led coordination, and integrated psychosocial and family support. Such elements may be transferable to post-sepsis care. However, the evidence base for paediatric post-sepsis syndrome is limited. Its prevalence, duration, and specific manifestations across physical, cognitive, psychological, and social domains are not yet well defined.[6,11,36,37] These knowledge gaps should be considered when adapting interventions from other specialties.

Although strong empirical evidence remains limited, the models of care identified in this review, along with established follow-up approaches, will inform the development of a local post-sepsis pathway. The literature highlights the diverse and often unpredictable recovery trajectories of paediatric sepsis survivors, reinforcing the need for a flexible, individualised care pathway. The pathway must accommodate variations in comorbidities, illness severity, and access to care. This review identified significant barriers to access, particularly among culturally and linguistically diverse (CALD) and marginalised families, underscoring the importance of a culturally sensitive model that promotes equitable engagement and support. Integrating telehealth may improve accessibility, and a structured program commencing at discharge and continuing through a 12-month period would help address the extended nature of recovery. The pathway should be age-specific accommodating the changing developmental and health needs across childhood. Delivery through nurse-led clinics, supported by an integrated multidisciplinary team, offers a cost-effective and sustainable model of care. As the evidence base expands, the model should remain adaptable and responsive to the complex and potentially long-term needs of survivors and their families.

Strengths of this review include the involvement of a codesign team to ensure inclusivity and grounding in real-world experiences, and the application of the PAGER framework to enhance rigour in evidence synthesis. However, notable limitations include the lack of focus on Aboriginal and Torres Strait Islander survivors and other underserved populations including those living in rural and remote areas and children with pre-existing complex medical needs or disabilities. Future research should address these gaps by incorporating methodologies reflecting Indigenous ways of knowing, being, and doing, as outlined by Brodie et al. (2023).[38] Such approaches would address structural barriers to access, better account for diverse care needs, and enrich the review's cultural sensitivity and alignment with the needs of these communities. Additionally, while the search strategy was internally developed and tested with multiple terms, it did not undergo formal press review, which could have enhanced methodological quality. The term “intervention” was ultimately most effective in identifying relevant literature as “follow-up” often yielded studies focussed on quality of life rather than intervention specifics.

## 5. Conclusion

This scoping review found limited evidence of post-sepsis care interventions for paediatric survivors and their families. The provide insights into two emerging models of care that have published their experience, identifying gaps and opportunities for further research and program development. The findings do highlight the need for a culturally sensitive, family-centred framework that addresses the

unmet needs of children and families recovering from sepsis. While limited, this evidence has contributed to a deeper understanding of the post-sepsis journey and will inform the development of a post-sepsis care pathway. This pathway will integrate best practices and incorporate mechanisms for ongoing evaluation to measure the long-term outcomes.

## CRediT authorship contribution statement

**Natalie J. Middleton:** Conceptualisation, Methodology, Validation, Formal analysis, Resources, Data Curation, Writing – Original Draft, Writing – Review & Editing, Project administration, Funding acquisition; **Catherine Pienaar:** Conceptualisation, Methodology, Validation, Formal analysis, Resources, Data Curation Data Curation, Writing – Original Draft, Writing – Review & Editing, Visualisation; **Joanne Harvey:** Conceptualisation, Validation, Formal analysis; **Emily Rice:** Conceptualisation, Formal analysis**; Bernard McCarthy:** Conceptualisation, Formal analysis, Writing – Review & Editing, Visualisation, Funding acquisition; **Fenella J. Gill:** Conceptualisation, Methodology, Formal analysis, Resources, Writing – Review & Editing, Visualisation, Supervision, Funding acquisition; **Christopher. C Blyth:** Conceptualisation, Methodology, Formal analysis, Resources, Writing – Review & Editing, Visualisation, Supervision, Project administration, Funding acquisition.

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## Data availability statement

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.

## Declaration of competing interests

The authors declare no conflict of interest.

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