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SCOPING REVIEW

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Patient follow-up after discharge from the paediatric intensive care unit: A scoping review

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Abstract

Background: Most children admitted to a paediatric intensive care unit (PICU) now survive because of improvements in care. Many studies have identified the psychological, functional, cognitive and social impact of PICU admission on a child and their family. However, expert recommendations on follow-up are lacking.

Aim: To identify the strategies of clinical follow-up after PICU discharge performed from 2001 to 2021.

Study design: This scoping review was undertaken between January and April 2021 using three databases: PubMed, EMBASE and CINAHL. The search strategy consisted of a combination of keywords, including PICU, post-PICU discharge and follow-up in articles published between 2001 and 2021. The results are reported according to PRISMA-ScR guidelines.

Results: Six-hundred and fifty-two articles were identified and 68 were analysed. Median age was 4.5 years and the two main reasons for PICU admission were cardiorespiratory failure and sepsis. Median length of PICU stay was 8 days. Most follow-up was carried out by research units (88%), while 6% of studies reported follow-up by a multidisciplinary PICU team. The most common follow-up schedule included an assessment at PICU discharge, and then at 3, 6 and 12 months. Follow-up for >1 year was reported in 20% of studies. One third of studies focused on follow-up quality of life and neurological outcomes. Parental emotional impact was assessed in 7% of studies.

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Conclusion: Follow-up after PICU discharge was highly heterogeneous regarding timing, health care professionals involved and assessment methods. There is an urgent need for standardization and coordination of PICU follow-up because of the increasing number of patients impacted by a PICU stay.

Relevance to Clinical Practice: Although most patients admitted to a paediatric intensive care unit (PICU) now survive; they may develop paediatric post-intensive care syndrome (PICS-P). To our knowledge, there are currently no clinical guidelines regarding follow-up after PICU discharge. This review summarizes current approaches to follow-up after PICU discharge, including how it is carried out, who is involved and what the main aims of assessment are.

KEYWORDS

ICU outreach/follow-up, paediatric intensive care, post-intensive care syndrome, psychological issues and support

1 | BACKGROUND

With improvements in care over the last few decades, the mortality of children admitted to paediatric intensive care units (PICUs) has decreased to between 2% and 6% in high-income countries and 12%–16% in low-income countries.[1–4] However, many of the children who are discharged alive from the PICU experience consequences related or not related to the disease responsible for their admission.[5] PICU stay has been described as a traumatic experience not only for the patients themselves but also for their family and the health care professionals involved.[6,7] This can be explained by the PICU environment, including high levels of noise and stress, pain and stress linked to multiple invasive procedures, the use of psychoactive drugs (analgesia, sedation), and the severity of the disease and the clinical frailty, which can be assessed by mortality after discharge.[7–9] In addition, the attitude of health care professionals in the PICU and their care of the patient can be highly variable, depending on an analysis of the situation, which could affect the PICU experience of the patient and their family.[10] Patients hospitalized in PICUs are considered at high risk of developing psychological, functional, cognitive and social morbidities at discharge. These consequences may persist over time and may have repercussions on the patient and their family beyond the PICU stay. Since 2010, these repercussions have been documented by an international panel of experts in intensive care units (ICUs) and are now referred to as post-intensive care syndrome (PICS).[11] A systematic review by Herrup et al. in 2017 classified the morbidities related to PICU stay into three categories: (i) physical and functional, (ii) neurocognitive and (iii) psychological.[8] In this study, more than 50% of the patients had a favourable outcome and were likely to lead an independent life (normal functional status or only mild disability). However, the consequences of paediatric PICS are potentially different because they occur in someone who is developing, and they could also differ depending on the stage of brain development.[12,13] In 2018, Manning et al. conceptualized this syndrome in the literature and added a new dimension to observe in addition to the three described by Herrup et al.,[8] namely the social dimension and the impact on loved ones.[14] The possible repercussions of paediatric post-intensive care syndrome (PICS-P) on the child and their family are important.[14] In adults, the psychological and physiological aspects of post-ICU discharge follow-up are well established. Based on the National Organization of Nurse Practitioner Faculties (NONPF) statement on acute care and primary care nurse practitioner, Dunn et al. highlighted the role that nurses could play in screening the population at risk of PICS.[15,16] However, to our knowledge, there is no consensus or

What is known about the topic

- A stay in a PICU is an important milestone in the life of a child and their family. It can have serious repercussions known as paediatric post-intensive care syndrome (PICS-P), regardless of the causal disease.
- PICS-P is a multidimensional syndrome that can have a significant effect on cognition, emotional, physical and social health of the child and their family.
- Follow-up after PICU discharge is a challenge for medical teams as there are currently no guidelines and organization of care offers many challenges.

What this paper adds

- This review summarizes the existing modalities of post-PICU discharge follow-up, which is highly heterogeneous and poorly formalized.
- Numerous scales and scores are used because of the multidimensionality of PICS-P and no global assessment scale exists.
- The importance of coordinated multidisciplinary follow-up is highlighted by most authors.

recommendations concerning follow-up strategies, that is, modalities, temporality, health care professional involved, objective of the post-PICU follow-up, for children and their families following PICU discharge.[17]

2 | OBJECTIVES OF THE REVIEW

The main objectives of this scoping review were to identify and summarize the different methods of follow-up of children who survive a critical illness and PICU stay, including the assessment times, health care professionals involved and tools used.

3 | DESIGN AND METHODS

3.1 | Type of review

This scoping review of the literature was performed as recommended by the Cochrane Handbook for Systematic Reviews of Interventions,[18] and is reported to conform to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses—Extension for Scoping Reviews) statement.[19] No human subjects were involved in this study. We only searched public databases, and no institutional approval was sought for this study. The review is registered on the Open Science Framework website (OSF review registration: DOI 10.17605/OSF.IO/XUZ6F).

3.2 | Search strategy

Electronic databases were explored for all articles published between 1 January 2001 and 31 December 2021. This period was chosen to explore the evolution of patient follow-up over the 10 years before and 10 years after the first definition of PICS in the literature.[11] Searches were performed using the term "PICU" and "post-PICU discharge follow-up" associated with each other by Boolean operators (AND/OR). The Medical Subject Headings (MeSH) terms used to search the databases were as follows: "Intensive Care Units, Paediatric" (PICU, takes into account articles related to paediatric resuscitation and paediatric intensive care unit) AND "Patient Discharge" (patient at the end of a hospitalization or patient at the end of a hospital stay) OR "Recovery of Function" (consequences from a functional point of view), OR "Quality of Life" (quality of life (QoL) of the patient, impact on the daily life of the patient and their family). The search strategy used in three databases by combining MeSH terms and keywords was as follows: ("Intensive Care Units, Paediatric"[Mesh]) AND ("Patient Discharge"[Mesh] OR "Recovery of Function"[Mesh] OR "Quality of Life"[Mesh]). The steps involved in selecting records are shown in the flow chart (Figure 1).

The systematic search of articles was based on three selected criteria: (i) articles focusing on paediatric populations 1 month to 5 years old; (ii) studies that included paediatric patients who had been admitted to a PICU; and (iii) articles that focused or provided data on the follow-up of patients after discharge from a PICU.

3.3 | Inclusion/exclusion criteria

Filters were used to refine the literature searches on patients 1 month to 5 years old, a period corresponding to early learning and preschool age, and during which cognitive, emotional or psychological damage may affect the child's life. Studies in neonatal ICUs or aimed at neonatal populations were excluded because of specific impairments and complications of prematurity on neurodevelopment. However, during the review, studies that included patients aged 6 years and over were still included in order to collect as much data as possible on follow-up methods. The search was limited to articles in English and French. The scoping review was conducted from January to April 2021 via systematic searches.

3.3.1 | Inclusion criteria

- Studies on PICU patients
- Studies involving PICU patients with PICU follow-up
- Originals studies in English or in French

3.3.2 | Exclusion criteria

- Studies on NICU patients
- Studies on PICU patients not involved in PICU follow-up
- Grey literature, non-scientific studies
- Studies without peer-review

3.4 | Data collection and analysis

3.4.1 | Information sources

Literature searches were conducted using the following databases: PubMed (including MEDLINE, National Library of Medicine and PubMed Central), Embase (including MEDLINE and Elsevier databases), CINAHL (Cumulative Index to Nursing and Allied Health Literature) and The Cochrane Library. This scoping review was undertaken between January and April 2021.

3.4.2 | Selection of sources of evidence

Following the removal of duplicate studies, two authors (DM and SK) independently selected the studies identified using Rayyan web apps (https://rayyan.qcri.org/welcome). The first selection was made by screening the titles and abstracts or full text when in doubt. The same authors then read the full texts of the selected abstracts, and articles

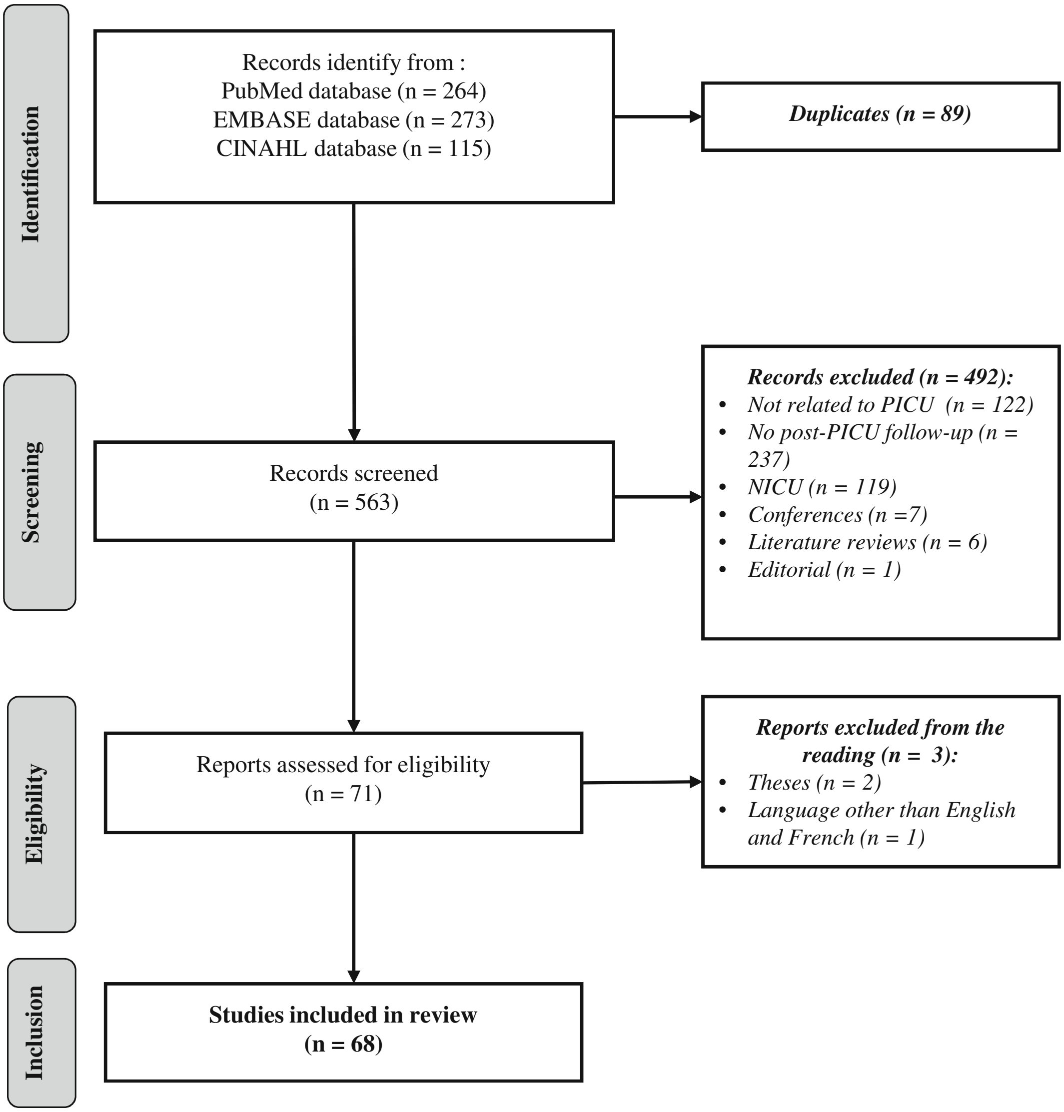

FIGURE 1 Flow chart of the search results and selection procedure.

with a low level of agreement were discussed; if necessary, the abstract was reviewed by a third investigator who made the final decision. The reference lists of original studies were then hand searched and relevant articles were extracted. The first author (DM) read all of the articles and 10% were randomly selected by the second author (SK) to ensure concordance of the extracted data.

3.4.3 | Data charting processing

For data extraction, a table was created by two authors (DM, SK) based on the validated research data, which allowed these two evaluators to extract the data independently. A test run of the data extraction table was carried out on 10 articles, allowing a readjustment by the same authors. A second test was carried out on the next 20 articles before continuing the data collection in the database created by the same authors. The results were then compared, discussed and merged.

3.4.4 | Data items

Data were extracted with two dimensions of analysis: (i) characteristics of the studies included in the scoping review and (ii) characteristics of the patients and follow-up. Details of the articles were collected, including the names of the authors, the country(s) of affiliation, the name and type of journal (intensive care, paediatric, psychology, generalist care) and the year of publication. The rationale for collecting the name of the journal and the type of journal was to identify the specific disciplines affected. The specific characteristics of the patients and post-PICU discharge follow-up were as follows: age, sex, weight, main reason for PICU admission, presence of comorbidity and/or disability, average length of PICU stay, use of sedative treatments, use of mechanical ventilation and the rate of readmissions after commencing follow-up.

The articles reporting the follow-up of paediatric survivors were classified according to the type of study, the study duration (start and end), the number of patients included, the main objective of follow-up (functional, psychological, behaviour and/or social dysfunction), the health care professionals involved in follow-up and the methods used.

3.4.5 | Data analysis

The analysis and synthesis of our findings was based on an inductive approach. Having extracted all the relevant interventions and data during the extraction phase, we analysed them using a statistical analysis, which allowed us to highlight the most common and less common practices and tools. The data for continuous variables are presented as median, interquartile range [IQR: first and third quartiles] and range (min–max), and qualitative variables are presented as frequencies and percentages, with estimations of 95% confidence intervals [95%CIs] when needed. R Statistical Software (version 4.0.3) was used to perform the statistical analyses.

We discussed possible links and other similarities between the interventions. Finally, we classified our findings according to emerging and innovative clinical approaches and practices.

3.5 | Assessment of bias

No assessment of the risk of bias was performed because the objective of the review was to identify the different strategies and modalities of follow-up post-PICU discharge. The effect or impact of these strategies is not reported in this review. The presence or absence of bias has no consequence on the interpretation of the results, which are only on the modalities. Most publications included in the review are peer-reviewed research articles. This suggests that several modalities of post-PICU discharge care may not have been captured by the review, as everyday practice is not described systematically in peer-reviewed journals and papers. Therefore, it is beyond the scope of the exploratory study to assess the risk of bias.

4 | RESULTS

4.1 | Selection of sources of evidence

A total of 652 articles were identified, including 264 in PubMed, 273 in Embase and 115 in CINAHL. Five-hundred and eighty-four articles were excluded, and 68 articles were finally included (Figure 1, Appendix A).

4.2 | Characteristics of sources of evidence

Half of the articles were published in critical care journals ($n = 34$), 18% in paediatric journals ($n = 12$) and 9% in psychology journals ($n = 6$). Fifty-four per cent of the articles were published after 2015 ($n = 37$). Regarding the authors' affiliations, 25% were located in the United States ($n = 17$), 16% in the UK ($n = 11$) and 10% in Canada ($n = 7$). Eighty-two per cent of the studies were retrospective cohorts ($n = 56$). Only one randomized, controlled trial was identified (Appendix B).[20]

4.3 | Synthesis of results

4.3.1 | Characteristics of the patients included in the post-PICU discharge follow-up studies

The main characteristics of the patients included in the studies are shown in Table 1. Median age was 4.5 years [IQR: 2.4; 6.5] and 58%

TABLE 1 Characteristics of the patients included in the selected articles.

Characteristic	All articles ($n = 68$)
Age (years)	4.6 [2.4; 6.5] (0–11)
Sex (male)	58%
Median length of stay (days)	8 [5; 12] (1–54)
Reason for admission	
Cardiorespiratory failure	12 (18%)
Respiratory failure and sepsis	8 (12%)
Trauma (accident)	6 (9%)
Respiratory failure	4 (6%)
Cardiovascular insufficiency	4 (6%)
Respiratory failure and trauma	4 (6%)
Cardiorespiratory arrest	4 (6%)
Sepsis	3 (4%)
Neuro-respiratory failure	3 (4%)
Acute respiratory distress syndrome	3 (4%)
Post-operative care	3 (4%)
Neurology	3 (4%)
Haematology and sepsis	1 (1%)
Other	10 (15%)
Chronic diseases and comorbidities	
Respiratory diseases (asthma, chronic respiratory insufficiency, pulmonary bronchodysplasia)	13 (19%)
Prematurity	6 (9%)
Heart disease	5 (7%)
Onco-haematological disease	4 (6%)
Epilepsy	4 (6%)
Cerebral palsy, neurological failure	3 (4%)
Neuromuscular disease	3 (4%)
Diabetes	2 (3%)
Use of sedative treatments	4 (6%)
Use of mechanical ventilation	32 (47%)
Rate of re-hospitalization in a paediatric care unit or intensive care unit, median in %	22% [11; 35] (2–46)

Note: Data expressed as *n* (%), median [Q1; Q3] and range (min–max).

were male. Median follow-up duration was 3 years [IQR: 1; 4] and median number of patients included was 150 [IQR: 52; 308]. The two main reasons for PICU admission were cardiorespiratory failure and sepsis. Nineteen per cent of the patients had a chronic respiratory disease (*n* = 13), 9% had a history of prematurity (*n* = 6) and 7% had cardiac disease, such as congenital heart disease or heart defects (*n* = 5). Median length of PICU stay was 8 days [IQR: 5; 12] (range: 1–54 days), and median re-hospitalization rate in a PICU or paediatric unit was 22% [IQR: 11; 35] (range: 2%–46%).

4.3.2 | Organization of post-PICU discharge follow-up

The main post-PICU follow-up outcome was QoL for 32% of studies (*n* = 22), followed by mortality assessment after PICU discharge (13%, *n* = 9) (Table 2).

The schedule for post-PICU follow-up was mainly at discharge, and then at 3, 6 and 12 months. Long-term follow-up, defined as >1 year after PICU hospitalization, was performed in only 19% of studies (*n* = 13). This follow-up was carried out in 88% of cases for research purposes and was not in the context of care or formalized clinical follow-up (*n* = 60).

The methods of follow-up differed between the studies. Nearly half (45%) used questionnaires (*n* = 31), 34% used patient medical databases (*n* = 23) and 28% used interviews (*n* = 19).

A clinical visit to a health facility was performed in 15% of studies (*n* = 10) and home visits occurred in 4% (n = 3). Follow-up was provided by a multi-professional PICU team, including clinicians, nurses and/or physiotherapists, in only 6% of cases (*n* = 4). This follow-up was carried out by tele-monitoring, tele-consultation or consultation in a health care facility by a mobile PICU team.

4.3.3 | Assessment scales used in the follow-up of PICU patients

Thirty-two per cent of the studies assessed QoL and 77% used the Pediatric Quality of Life Inventory (PedsQL) scale (*n* = 17) (Table 1). Thirty-one per cent focused on neurological outcome (*n* = 21), 24% on behaviour status (*n* = 16) and 13% on functional status (*n* = 9). From 2012 to 2014, new dimensions were explored, such as post-traumatic stress disorder (PTSD), sleep and emotional disorder. Between 2013 and 2015, some studies focused on parents. Finally, only 7% of the studies assessed the parental emotional impact, such as stress, and the impact on their QoL (*n* = 5).

Figure 2 shows the distribution of the different scores used in the scoping review articles (from 2001 to 2020). QoL, functional status, behaviour and psychomotor status were constantly evaluated over the study period. However, there was an evolution in the scales used over time. The PedsQL scale is now used instead of the Health Utility Index Mark 2 and 3 instruments mark (HUI and HUI 2–3).[21] The Pediatric Cerebral Performance Category (PCPC) and Pediatric Overall

TABLE 2 Characteristics of post-PICU discharge follow-up.

Characteristics of follow-up	All studies (*n* = 68)
Main objective of follow-up[a]	
Quality of life (QoL)	22 (32%)
Mortality after discharge	9 (13%)
Risk factors	6 (9%)
Feasibility	6 (9%)
Neurological	4 (6%)
Morbidity	4 (6%)
Functional	4 (6%)
Global follow-up	4 (6%)
Incidence of events	3 (4%)
Behaviour, psychological	2 (3%)
Effectiveness	2 (3%)
Needs and experiences	2 (3%)
Post-traumatic stress syndrome	1 (1%)
Economic	1 (1%)
Epidemiology	1 (1%)
Timing of follow-up	
Discharge from the PICU	23 (34%)
1 month	13 (19%)
2 months	2 (3%)
3 months	20 (30%)
6 months	27 (40%)
9 months	3 (4%)
12 months	22 (32%)
>12 months	13 (19%)
Individuals responsible for follow-up	
Research team	60 (88%)
PICU clinician	15 (22%)
Clinician from another speciality (paediatrician, PRM, neuropaediatric, neuropsychologist, haematologist, ENT)	10 (1%)
Clinical nurse (resuscitation, asthma)	6 (9%)
Mobile PICU team	4 (6%)
Research nurse	1 (1%)
Other contributors (physiotherapist, psychologist)	4 (6%)
Methods/tools used for follow-up	
Paediatric QoL scales	22 (32%)
Paediatric QoL inventory (PedsQL)	17 (77%)
Health Utility Index mark (HUI 2–3)	5 (23%)
Neurological assessment scales	21 (31%)
PCPC-POPC	15 (71%)
GOSE-Ped (Glasgow Outcome Scale Extended Paediatrics)	6 (29%)
Behaviour scales	16 (24%)
Child Behavior Checklist (CBCL)	8 (50%)

(Continues)

TABLE 2 (Continued)

Characteristics of follow-up	All studies ($n = 68$)
Vineland Adaptive Behavior Scale (VABS-II)	4 (25%)
Adaptive Behavior Assessment System (ABAS-3)	2 (13%)
Behavior Assessment System for Child (BASC 2, BASC 2-SRP)	2 (13%)
Functional scales	9 (13%)
Functional Status Scale (FSS)	6 (67%)
Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT)	3 (33%)
Parametric data (brachial circumference, weight, BMI)	7 (10.3%)
Strengths and Difficulties Questionnaires (SDQ)	5 (7%)
Parenting scales (stress, quality of life, functional)	5 (7%)
Parent's Stressor Scale—PICU (PSS-PICU)	1 (20%)
Parental stress scale	1 (20%)
Pediatric Inventory for Parents (PIP)	1 (20%)
Health Utility Index Short-Form 36 for parent	1 (20%)
Parental Beliefs Scale (PBS)	1 (20%)
Clinical examination	4 (6%)
Bayley scale of infant and toddler development	4 (6%)
Post-traumatic stress disorder (PTSD) assessment scales	3 (4%)
Self-rating inventory for PTSD (SRIP)	1 (33%)
Child PTSD Symptom Scale (CPSS)	1 (33%)
Children Post-Syndrome Inventory (CPTSDI)	1 (33%)
Biomarkers	2 (3%)
Sleep Disturbance Scale for children	2 (3%)
Hospitalization impact assessment scales PICU:	2 (3%)
Parent's Stressor Scale—PICU (PSS-PICU)	1 (50%)
Children's Critical Illness Impact Scale (CCIIS/Y-CCIIS)	1 (50%)
Modalities[b]	
Questionnaires	31 (45%)
Database	23 (34%)
Interview	19 (28%)
Health site visits (medical or paramedical)	10 (15%)
Home visits	3 (4%)
Tele-monitoring	1 (1%)

Note: Data are expressed as *n* (%).

Abbreviations: BMI, body mass index; ENT, ear, nose and throat; PCPC-POPC: paediatric cerebral performance category-paediatric overall performance category; PICU, paediatric intensive care unit; PRM, physical and rehabilitation medicine.

[a] Some studies had more than one main objective of follow-up.

[b] Some studies had more than one modality.

Performance Category (POPC) are two performance scores that are easy to use and quick to obtain a result, even retrospectively, which may explain their constant use over the last 20 years. In terms of behaviour assessment, the Adaptive Behavior Assessment System third edition published in 2015 (ABAS III) has been used more frequently in the 2020s, although the Vineland Adaptive Behavior Scale (VABS and VABS-II), first published in 1985 and second edition in 2005, remained the most widely used scales over the period studied.

5 | DISCUSSION

In this scoping review of 68 articles published over the last two decades, follow-up after PICU discharge was found to be highly heterogeneous and poorly formalized. The majority of follow-ups carried out in paediatric post-PICU discharge were carried out within the framework of clinical studies and not on a clinical basis. Only 6% of studies ($n = 4$) described multidisciplinary follow-up, including a mobile PICU team within a health care institution. Assessment tools were also found to be highly variable. We updated our literature review search in July 2024 to retrieve any sutdies published after 2021, using the scoping review search strategy. This update of literature shows that new articles present similar data to those found in our scoping review. The same results, which are the main interest of researchers in this field, continue to be highlighted in recent literature reviews. Key findings from these reviews point out the need for interventional research to explore and complement research data.[22–25]

Several tools and scores were employed in the different studies, some of which were used constantly while others disappeared or appeared over time (Appendix A). Each of the scores explores one or a few specific dimensions, some of which are self-assessments and others are observational tools. It would be necessary to use at least eight different scales in order to comprehensively assess the health care needs of both the patients and their families. The dimensions to be explored should include assessment of functional, neurological, psychomotor, behaviour, psychological, stress, QoL and post-PICU experience. Using a combination of different scales to correctly screen the patients' needs and impairments can be very complex. Thus, the use of a global score grouping the main domains to be explored more closely appears to be essential in post-PICU discharge follow-up. This global score could allow an initial screening at the end of the PICU stay in order to adapt and individualize the management of patients with potential post-PICU sequelae.[26] The recent review we conducted shows the same facts, that is, the multiplicity of scores in relation to the four dimensions to be studied and that there is no single screening tool in paediatrics. However, some scores are more frequently used such as the POPC/PCPC or the PedsQL.[27–29]

In addition, to completely assess patients using standardized scales, the importance of involving multidisciplinary teams in follow-up has already been highlighted.[30] Many children with chronic diseases are admitted to the PICU, and hospitalization may occur in the context of an exacerbation of this chronic disease. This is particularly the case for chronic respiratory diseases such as asthma or bronchopulmonary dysplasia, heart failure secondary to congenital heart disease and also epilepsy. However, children with chronic diseases may also be admitted to the PICU for an acute problem not directly related

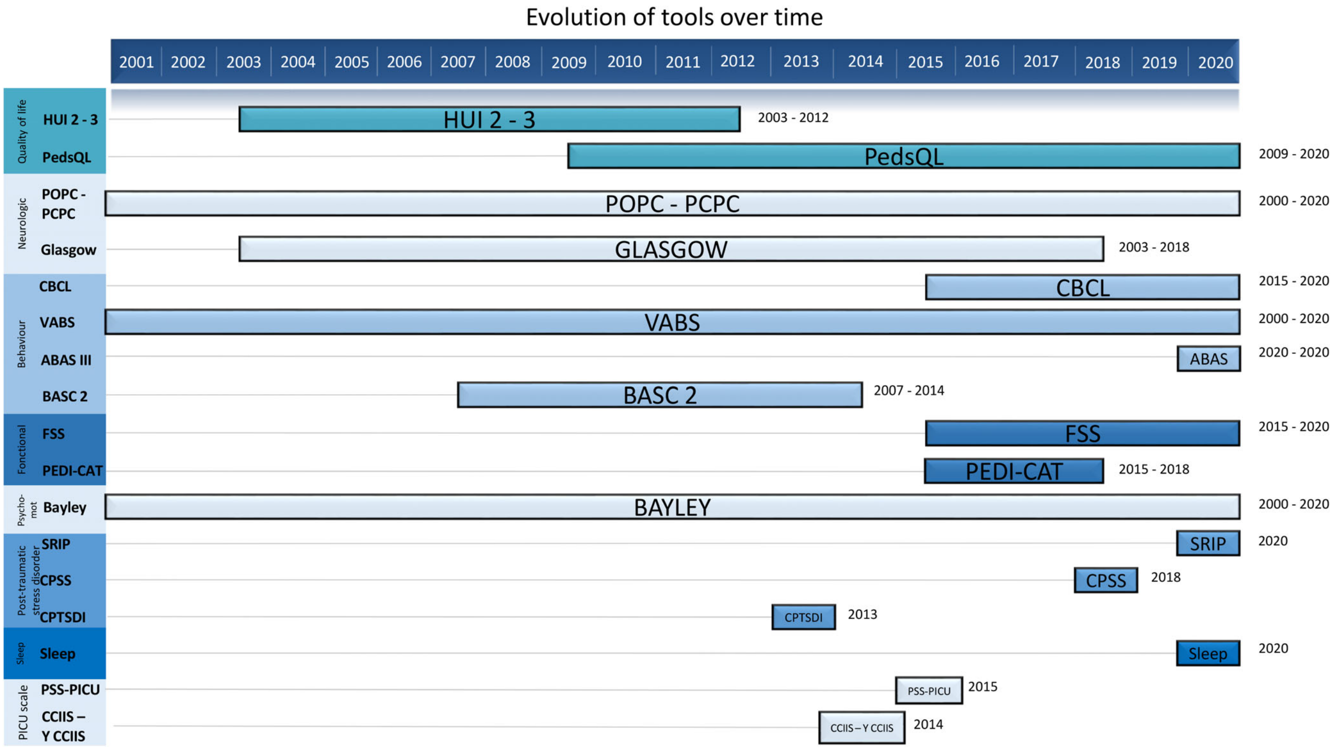

FIGURE 2 Tools used for the follow-up of children after PICU discharge. Pediatric quality of life scales: HUI and HUI 2–3: Health Utility Index and Health Utility Index Mark 2–3; PedsQL: Pediatric Quality of Life inventory. Neurological assessment scales: POPC-PCPC: Pediatric Overall Performance Category–Pediatric Cerebral Performance Category; Glasgow. Behaviour scales: CBCL: Child Behavior Checklist; VABS: Vineland Adaptative Behavior Scale; ABASIII: Adaptive Behavior Assessment System; BASC2: Behavior Assessment System for Child. Functional scales: FSS: Functional Status Scale; PEDI-CAT: Pediatric Evaluation of Disability Inventory Computer Adaptive Test; Bayley: Bayley scale of infant and toddler development. Post-Traumatic Stress Disorder (PTSD) assessment scales: SRIP: Self-Rating Inventory for PTSD; CPSS: Child PTSD Symptom Scale; CPTSDI: Children Post-Syndrome Inventory; Sleep. PICU scales: PSS-PICU: Parent's Stressor Scale-PICU; CCIIS/Y-CCIIS: Children's Critical Illness Impact Scale. Adaptive Behavior Assessment System (ABAS-3); Bayley Scale of Infant Development; Behavior Assessment System for Children & 2 (BASC & BASC-2) BASC-2 Self Report Profile (BASC-2 SRP); Behavioral Pediatrics Feeding Assessment Scale; Caregiver Assistance Scale (CAS); Child Feeding Questionnaire; Children's Behavior Questionnaire—very short version; Child Behavior Checklist (CBC); Children's Critical Illness Impact Scale, written version (CCIIS); Child Impact of Events Scale; Child Health Questionnaires (CHQ); Children's Hope Scale (CHS); Children's PTSD Inventory (CPTSDI); Child PTSD Symptom Scale (CPSS); Children Responses to Trauma Inventory (CRTI); Child Sleep Habits Questionnaire (CSHQ); Children and Youth (PEM-CY); Differential Abilities Scale (DAS-II); Family Assessment Device (FAD); Functional Status Scale (FSS); General Health Questionnaire-28 (GHQ28); Glasgow Coma Scale; Glasgow Outcome Score (GOS); Glasgow Outcome Scale Extended Pediatrics (GOSEP); Harter Scale of Perceived Competence (Harter); Health State Classification (HSC); Health State Utility (HSU) Index; Health State Utility Index Mark 1, 2 and 3 (HUI 1–2-3); Hospital Anxiety and Depression Scale (HADS); Impact of Event scales (IES and IES-8); Infant Behaviour Questionnaire—very short version; Infant Feeding Questionnaire; Infant and Toddler Quality of Life Questionnaire-97 (ITQOL); International Classification of Functioning, Disability and Health – Version for Children and Youth (ICF-CY); Kidscreen-27 questionnaire; Modified Glasgow Outcome Score (MGOS); Mullen Scales of Early Learning (Mullen); Multidimensional Assessment of Caring Activities (YC18); Multi Attribute Health Status Classification (MAHSC); Paediatric Asthma Quality of Life Questionnaire (PAQLQ); Parental Beliefs Scale (PBS); Parental Stress Index (PSI); Parental Stressor Scale: Paediatric Intensive Care Unit (PSS-PICU); Participation and Environment Measure (PEM); Patient Health Questionnaire-4; Peabody Developmental Motor Scale (PDMS-2); Pediatric Depressive Symptoms as a Harmonized Score Metric (PROMIS); Pediatric Evaluation of Disability Inventory (PEDI); Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT); Pediatric Overall Performance Category and Pediatric Cerebral Performance Category Scales (POPC-PCPC); PedsQL Family Impact Module Version 2.0; PedsQL Generic Core Scales Version 4.0; PedsQL Multidimensional Fatigue Scale Version 3.0; PedsQL Pediatric Pain Questionnaire; Pediatric Quality of Life Inventory (PedsQL) Infant Scales Version 4.0; Pediatric Quality of Life Inventory, Version 4.0 (PedsQL 4.0); Positive and Negative Outcomes of Caring (YC20); Post-Hospital Behavior Questionnaire (PBQ); Profile of Mood State (short form); PTSD Checklist—5; Royal Alexandra Hospital for Children (RAHC) Measure of Function; Self-Rating Inventory for PTSD (SRIP); Short-Form 36 questionnaire (SF36); Sleep Disturbance Scale for Children (SDSC); Strengths and Difficulties Questionnaires (SDQ); State–Trait Anxiety Inventory (STAI); TNO-AZL Preschool Children Quality of Life Questionnaire (TAPQOL-PF); TNO-AZL Children's Quality of Life Questionnaire Parent Form (TACQOL-PF); TNO-AZL Children's Quality of Life Questionnaire Child Form (TACQOL-CF); Vineland Adaptive Behavior Scale (VABS–VABS-II); Visual Analogue Scales (VAS); Wechsler preschool and primary scale of intelligence (WASI); Wechsler Preschool and Primary Scale of Intelligence (WPPSI-IV); Young Children's Critical Illness Impact Scale, pictorial version (Y-CCIIS); Young Children's version (YC-PEM); 13-symptom list.

to the underlying pathology, but they may have been weakened by treatments or sequelae related to such a stay. The study by Cremer et al. highlighted the need for additional follow-up complementary to medical follow-up for health problems falling within the scope of other socio-professional categories such as speech therapy or physiotherapy.[30] The rate of multidisciplinary follow-up of 6% found in this scoping review is low considering the fact that it has been shown that this type of organization is useful for the identification of at-risk patients, therapeutic strategy implementation and prompt hospitalization in the case of an emergency.[31–34] Clinical researchers have also been interested in identifying the barriers and levers to implement post-PICU follow-up. These research studies have made possible the publication of practical considerations discussing the monitoring methods: by whom, for whom, why, how and when.[35,36] A key point was also highlighted regarding the need for psychological support for families in order to be able to propose appropriate interventions at an early stage.[37] One study showed that a structured follow-up programme can help to initiate appropriate interventions in a timely manner, including early identification of psychosocial effects.[25] In the study by Manning et al.,[38] post-PICU discharge follow-up was only performed in four out of 28 English and Irish PICUs, and was performed predominantly by PICU doctors, but nurses and specialized nurses were also involved in the follow-up performed within the hospital. Dunn et al. demonstrated and supported a unique role for nurse practitioners in primary care (or advanced practice nurse, APN) in the management, screening and follow-up of patients at risk of PICS at discharge.[16] A scoping review published in 2022 on family outcomes after PICU stay shows that most families were severely affected in a number of ways. There was a decline in mental health, physical health, family cohesion and family finances. Data are also lacking on extended families, such as siblings.[22] Considering these previous points, an APN, in collaboration with a PICU nurse, could be a good candidate to coordinate such follow-up by providing a holistic view and care of the patient and their extended family.[39,40] Gottlieb et al. pointed out the promotion of health by taking into account a person's strengths and not their weaknesses, in relation to a health situation or a traumatic event.[41]

5.1 | Limitations

This scoping review has some limitations. From a methodological point of view, there is no standardization of the studies. Indeed, the studies are quantitative, qualitative, mixed, feasibility or pilot, which results in an important heterogeneity in the analysis of the results. Our research also did not focus on the impact of a PICU stay on family members, even though PICS-P can affect caregivers. We believe that by not including the family dimension in the research strategy, relevant articles have unfortunately not been included in this review. Extending this research to the family circle should be considered in future projects.

5.2 | Implications for practice

The child's post-PICU pathway requires levers and support to facilitate its implementation and sustainability in future practice. This requires strengths within the institution, in particular through collaboration with the different actors involved in the care of these children. It also requires precise targeting of these children to enable them to access this new service. On the professional side, the strengths come from the knowledge and experience of the PICU and the knowledge of the child. From the point of view of the children and their families, presenting this care as a support and a way of sharing their experiences could make it easier for them to adhere to this specific care. Such coordinated care is shown in Appendix C.

6 | CONCLUSION

There is still an important fragmentation of the follow-up health care given to children post-PICU discharge and a lack of coordination is common.

This scoping review not only reveals the interest of researchers and health care professionals in investigating and conducting the follow-up of patients post-PICU discharge but also highlights the urgent need for standardization and coordination. Multiple scores and scales have been used over the last 20 years, but there is currently no validated score to evaluate the sequelae or complications related to PICU stay globally during follow-up. The establishment of a post- PICU discharge consultation needs strong coordination in order to involve an institution's medical and paramedical professionals (including specialists in the various chronic diseases), the PICU team and the child–parent pair. The involvement of an APN in the follow-up of these patients and their families upon discharge from the PICU could be a line of thinking that should be evaluated by comparing the follow-up of young patients post-PICU using standardized tools.

AUTHOR CONTRIBUTIONS

DM and SK conceived the idea. DM wrote the first draft. DM, SK, JN and ML produced the final version. DM collected and reviewed the literature. DM and SK completed the thematic analysis. All the authors have approved the final version of the manuscript.

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest relevant to the article to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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APPENDIX A: STUDIES INCLUDED IN THE SCOPING REVIEW

Authors	Title	Date	Country	Tools used
Biagas and al.	Long-Term Neurobehavioral and Quality of Life Outcomes of Critically Ill Children after Glycemic Control	2020	USA	• CBC • PedsQL 4 • POPC • VABS-II
Boeschoten, S. A and al.	Quality of life and psychosocial outcomes in children with severe acute asthma and their parents	2020	Germany	• CBCL • CRTI • PAQLQ • SRIP
Borges, E.F and al.	Invasive home mechanical ventilation: 10-year experience of a pediatric home care service	2020	Brazil	• None
Hall, T.A and al.	Post-intensive care syndrome in a cohort of infants & young children receiving integrated care via a pediatric critical care & neurotrauma recovery program: A pilot investigation	2020	USA	• ABAS-3 • BSID • DAS-II • FSS • PedsQL 4 • PedsQL F 2 • PROMIS • SDSC • WPPSI-IV
Manning, J.C. and al.	Study protocol for a multicentre longitudinal mixed methods study to explore the Outcomes of ChildrEn and fAmilies in the first year after paediatric Intensive Care: The OCEANIC study	2020	UK	• CIES • CHS • FSS • PedsQL IS 4 • PedsQL 4 • PedsQL MFS 3 • PedsQL Pain • PedsQL FIM 2 • PHQ 4 • POPC – PCPC • PTSD Checklist–5 • SDQ • STAI • YC18 • YC20
Morton, K. and al.	Protocol for a multicentre longitudinal mixed-methods study: Feeding and survivorship outcomes in previously healthy young paediatric Intensive care survivors (the PIES Study)	2020	UK	• BPFAS • CBQ • CFQ • IBQ • IFQ • PSS
Muñoz-Bonet JI and al.	Medical complications in a telemedicine home care programme for paediatric ventilated patients	2020	Spain	• None
Ventura JC and al.	Undernutrition at PICU Admission Is Predictor of 60-Day Mortality and PICU Length of Stay in Critically Ill Children	2020	Brasil	• None
Zimmerman JJ and al.	Trajectory of Mortality and Health-Related Quality of Life Morbidity Following Community-Acquired Pediatric Septic Shock	2020	USA	• FSS • PedsQL • POPC • PCPC
Zimmerman JJ and al.	Critical Illness Factors Associated With Long-Term Mortality and Health-Related Quality of Life Morbidity Following Community-Acquired Pediatric Septic Shock	2020	USA	• FSS • PedsQL
Hassani SA and al.	Cost-effectiveness of home mechanical ventilation in children living in a developing country.	2019	Iran	• None
Pillon, M. and al.	Predictors of mortality after admission to pediatric intensive care unit in oncohematologic patients without history of hematopoietic stem cell transplantation: A single-center experience	2019	Italy	• None
Pulham RA and al.	Pediatric Quality of Life Inventory, Version 4.0 Generic Core Scales (PedsQL)	2019	UK	• PedsQL 4
Watson RS and al.	Risk Factors for Functional Decline and Impaired Quality of Life after Pediatric Respiratory Failure	2019	USA	• ITQOL • PedsQL 4 • POPC-PCPC
Yang, C.-F. and al.	Gross motor developmental dysfunctional outcomes in infantile and toddler pediatric intensive care unit survivors	2019	China	• PDMS-2
Appiah, J. and al.	Characteristics, course and outcomes of children admitted to a paediatric intensive care unit after cardiac arrest	2018	South Africa	• POPC
Choong K and al.	Functional Recovery in Critically Ill Children, the "WeeCover" Multicenter Study	2018	Canada	• ICF-CY • Kidscreen-27 questionnaire • PEDI-CAT • PIP
Feinstein, Y. and al.	Cohort profile of the Biomarkers of Acute	2018	UK	• CBQ • PedsQL 4

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(Continues)

Authors	Title	Date	Country	Tools used
	Serious Illness in Children (BASIC) study: A prospective multicentre cohort study in critically ill children			• POPC-PCPC
Hessey, E. and al.	Long-term mortality after acute kidney injury in the pediatric ICU	2018	Canada	• None
Keim G and al.	New Morbidity and Discharge Disposition of Pediatric Acute Respiratory Distress Syndrome Survivors	2018	USA	• FSS
Khetani MA and al.	Determinants of change in home participation among critically ill children	2018	Canada	• PEDI-CAT • PEM • POPC
Kyösti E and al.	Five-Year Survival and Causes of Death in Children After Intensive Care-A National Registry Study	2018	Finland	• None
Slovis JC and al.	Assessment of Recovery Following Pediatric Traumatic Brain Injury	2018	USA	• GOS • GOSEP
Watson, R.S. and al.	Long-term outcomes after protocolized sedation versus usual care in ventilated pediatric patients	2018	USA	• CPSS • ITQOL • PedsQL 4 • POPC-PCPC
Yu YR and al.	Evaluating quality of life of extracorporeal membrane oxygenation survivors using the pediatric quality of life inventory survey	2018	USA	• BSID • PedsQL 4
Pinto NP and al.	Long-Term Function After Pediatric Critical Illness: Results From the Survivor Outcomes Study	2017	USA	• FSS
Slomine BS and al.	Pediatric cardiac arrest due to drowning and other respiratory etiologies: Neurobehavioral outcomes in initially comatose children	2017	USA	• FAD • Mullen • POPC-PCPC • VABS-II • WASI
Aspesberro F and al.	Construct Validity and Responsiveness of the Pediatric Quality of Life Inventory 4.0 Generic Core Scales and Infant Scales in the PICU	2016	USA	• PedsQL 4
Leite, H.P. and al.	Serum Albumin Is an Independent Predictor of Clinical Outcomes in Critically Ill Children	2016	Brazil	• None
Namachivayam SP and al.	Survival status and functional outcome of children who required prolonged intensive care after cardiac surgery	2016	Australia	• HUI 1 • MGOS
Als LC and al.	A supported psychoeducational intervention to improve family mental health following discharge from paediatric intensive care: feasibility and pilot randomised controlled trial	2015	UK	• CSHQ • HADS • IES • IES-8 • PSS-PICU • SDQ
Chandler HK and al.	Determining comorbidities and quality of life among pediatric survivors of extracorporeal life support	2015	USA	• PedsQL 4
Choong K and al.	Functional recovery following critical illness in children: the “wee-cover” pilot study	2015	Canada	• CAS • FSS • ICF-CY • PEDI • PEM • PEM-CY • POPC-PCPC • PSI • YC-PEM
Del Castillo, J. and al.	Long-term evolution after in-hospital cardiac arrest in children: Prospective multicenter multinational study	2015	Spain	• PCPC
Kirk S and al.	Supporting parents following childhood traumatic brain injury: a qualitative study to examine information and emotional support needs across key care transitions	2015	UK	• None
Lobos AT and al.	Routine Medical Emergency Team Assessments of Patients Discharged From the PICU: Description of a Medical Emergency Team Follow-Up Program	2015	Canada	• None
Van Zellem L and al.	Cardiac Arrest in Children: Long-Term Health Status and Health-Related Quality of Life	2015	Netherlands	• CHQ • HUI2 • HUI3 • PCPC • SF-36
Rennick JE and al.	Children's psychological and behavioral responses following pediatric intensive care unit hospitalization: the	2014	Canada	• BASC-2 • BASC-2 SRP • CCIIS • Harter • PBQ • PSI • SDQ

(Continues)

Authors	Title	Date	Country	Tools used
	caring intensively study			STAI Y-CCIIS
Dow, B.L. and al.	The diagnosis of post-traumatic stress disorder in school-aged children and adolescents following pediatric intensive care unit admission	2013	Australia	CPTSDI
Ebrahim S and al.	Adaptive behavior, functional outcomes, and quality of life outcomes of children requiring urgent ICU admission	2013	Canada	PedsQL 4 POPC-PCPC VABS VAS
Meštrović, J. and al.	Clinical scoring systems in predicting health-related quality of life of children with injuries	2013	Croatia	GCS PedsQL 4
Michel F and al.	Health-related quality of life and its determinants in children with a congenital diaphragmatic hernia	2013	France	13-symptom list Kidscreen-27 questionnaire SDQ SF36
Zeng, J. and al.	The epidemiology and resuscitation effects of cardiopulmonary arrest among hospitalized children and adolescents in Beijing: An observational study	2013	China	PCPC
Atkins E and al.	A 'biopsychosocial' model for recovery: a grounded theory study of families' journeys after a Paediatric Intensive Care Admission	2012	UK	None
Li Y. and al.	Epidemiological features and risk factor analysis of children with acute lung injury	2012	China	None
Namachivayam P and al.	Long-stay children in intensive care: long-term functional outcome and quality of life from a 20-yr institutional study	2012	Australia	GOS HUI 1
Stevens KJ band al.	An assessment of the psychometric performance of the Health Utilities Index 2 and 3 in children following discharge from a UK pediatric intensive care unit	2012	UK	HUI 2 HUI 3
Volakli E.A. and al.	Short-term and long-term mortality following pediatric intensive care	2012	Greece	GCS
Dursun O. and al.	Early and long-term outcome after	2011	Turkey	None
	tracheostomy in children			
Latour J.M. and al.	A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units	2011	Netherlands	None
Moon R.J.	Pituitary function at long-term follow-up of childhood traumatic brain injury	2010	UK	GOS PedsQL 4
Conlon NP and al.	Health-related quality of life after prolonged pediatric intensive care unit stay	2009	Ireland	PedsQL 4
Knoester H and al.	Quality of life in children three and nine months after discharge from a paediatric intensive care unit: a prospective cohort study	2008	Netherlands	TACQOL-CF TACQOL-PF TAPQOL-PF
Knoester H and al.	Surviving pediatric intensive care: physical outcome after 3 months	2008	Netherlands	POPC-PCPC
Lequier L. and al.	Two-year survival, mental, and motor outcomes after cardiac extracorporeal life support at less than five years of age	2008	USA	BSID II WASI
Van Gestel, J.P.J. and al.	Survival in a Recent Cohort of Mechanically Ventilated Pediatric Allogeneic Hematopoietic Stem Cell Transplantation Recipients	2008	Netherlands	None
Ambuehl J and al.	Quality of life of survivors of paediatric intensive care	2007	Switzerland	HSC
Melnyk BM and al.	Testing the theoretical framework of the COPE program for mothers of critically ill children: an integrative model of young children's post-hospital adjustment behaviors	2007	USA	BASC PBS PMS SF STAI VAS
Mestrovic J and al.	Neurodevelopmental disabilities and quality of life after intensive care treatment	2007	Croatia	RAHC Measure of Function
Taylor AK and al.	The long-term outcome of children managed with extracorporeal life support: an institutional experience	2007	Australia	HSU Index POPC

(Continues)

(Continues)

Authors	Title	Date	Country	Tools used
Jones S and al.	Outcome at 6 months after admission for pediatric intensive care: a report of a national study of pediatric intensive care units in the United Kingdom	2006	UK	• HUI 2
Rodríguez-Núñez A, and al.	Effectiveness and long-term outcome of cardiopulmonary resuscitation in paediatric intensive care units in Spain	2006	Spain	• POPC-PCPC
Shears D and al.	Short-term psychiatric adjustment of children and their parents following meningococcal disease	2005	UK	• GHQ28 • IES • SDQ
Jayshree M and al.	Follow up of survival and quality of life in children after intensive care	2003	India	• MAHSC
Taylor A and al.	The functional outcome and quality of life of children after admission to an intensive care unit	2003	Australia	• GOS HUI 1
McPherson ML and al.	Noncompliance with medical follow-up after pediatric intensive care	2002	USA	• None
Morrison AL and al.	Quality of life of survivors of pediatric intensive care	2002	Australia	• RAHC
Fiser DH and al.	Relationship of pediatric overall performance category and pediatric cerebral performance category scores at pediatric intensive care unit discharge with outcome measures collected at hospital discharge and 1- and 6-month follow-up assessments	2000	USA	• BSID • POPC-PCPC • VABS

Legend: list of tools used

- ABAS-3: Adaptive Behavior Assessment System
- BSID: Bayley Scale of Infant Development
- BSID II: Bayley Scale of Infant Development II
- BASC: Behavioural Assessment System for Children
- BASC-2: Behavioural Assessment System for Children-2
- BASC-2 SRP: Behavior Assessment System for Children 2 Self Report Profile
- BPFAS: Behavioral Pediatrics Feeding Assessment Scale
- CAS: Caregiver Assistance Scale
- CFQ: Child Feeding Questionnaire
- CBQ SV: Children's Behavior Questionnaire—very short version
- CBC: Child Behavior Checklist
- CCIIS: Children's Critical Illness Impact Scale, written version
- CIES: Child Impact of Events Scale
- CHQ: Child Health Questionnaires
- CHS: Children's Hope Scale
- CPTSDI: Children's PTSD Inventory
- CPSS: Child PTSD symptom scale
- CRTI: Children Responses to Trauma Inventory
- CSHQ: Child Sleep Habits Questionnaire
- PEM-CY: Children and Youth
- DAS-II: Differential Abilities Scale
- FAD: Family Assessment Device
- FSS: Functional Status Scale
- GHQ28: General Health Questionnaire-28
- GCS: Glasgow Coma Scale
- GOS: Glasgow Outcome Score
- GOSEP: Glasgow Outcome Scale Extended Pediatrics
- Harter: Harter Scale of Perceived Competence
- HSC: Health State Classification
- HSU: Health State Utility Index
- HUI 1: Health State Utility Index Mark 1
- HUI 2: Health State Utility Index Mark 2
- HUI 3: Health State Utility Index Mark 3
- HADS: Hospital Anxiety and Depression Scale
- IES and IES-8: Impact of Event scales
- IBQ: Infant Behavior Questionnaire—very short version
- IFQ: Infant Feeding Questionnaire
- ITQOL: Infant and Toddler Quality of Life Questionnaire-97
- ICF-CY: International Classification of Functioning, Disability and Health – Version for Children and Youth
- Kidscreen-27 questionnaire
- MGOS: Modified Glasgow Outcome Score
- Mullen: Mullen Scales of Early Learning
- MAHSC: Multi Attribute Health Status Classification
- YC18: Multidimensional Assessment of Caring Activities
- PAQLQ: Pediatric Asthma Quality of Life Questionnaire
- PBS: Parental Beliefs Scale
- PSI: Parental Stress Index
- PSS-PICU: Parental Stressor Scale: Paediatric Intensive Care Unit
- PEM: Participation and Environment Measure
- PHQ 4: Patient Health Questionnaire-4
- PDMS-2: Peabody Developmental Motor Scale
- PROMIS: Pediatric Depressive Symptoms as a Harmonized Score Metric
- PEDI: Pediatric Evaluation of Disability Inventory
- PEDI-CAT: Pediatric Evaluation of Disability Inventory Computer Adaptive Test
- POPC: Pediatric Overall Performance Category
- PCPC: Pediatric Cerebral Performance Category Scales
- PedsQL FIM 2: Pediatric Quality of Life Family Impact Module Version 2.0

- PedsQL GCS 4: Pediatric Quality of Life Generic Core Scales Version 4.0
- PedsQL IS 4: Pediatric Quality of Life Inventory & Infant Scales Version 4.0
- PedsQL MFS 3: Pediatric Quality of Life Multidimensional Fatigue Scale Version 3.0
- PedsQL Pain: Pediatric Quality of Life Pain Questionnaire
- PedsQL 4: Pediatric Quality of Life Inventory, Version 4.0
- YC20: Positive and Negative Outcomes of Caring
- PBQ: Post-Hospital Behaviour Questionnaire
- PMS SF: Profile of Mood State (short form)
- PTSD Checklist—5
- RAHC: Royal Alexandra Hospital for Children Measure of Function
- SRIP: Self-Rating Inventory for PTSD
- SF36: Short-Form 36 questionnaire
- SDSC: Sleep Disturbance Scale for Children
- SDQ: Strengths and Difficulties Questionnaires
- STAI: State–Trait Anxiety Inventory
- TAPQOL-PF: TNO-AZL Preschool Children Quality of Life Questionnaire
- TACQOL-PF: TNO-AZL Children's Quality of Life Questionnaire Parent Form
- TACQOL-CF: TNO-AZL Children's Quality of Life Questionnaire Child Form
- VABS–VABS-II: Vineland Adaptive Behavior Scale
- VAS: Visual Analogue Scales
- WASI: Weschler preschool and primary scale of intelligence
- WPPSI-IV: Wechsler Preschool and Primary Scale of Intelligence
- YC-PEM: Young Children's version
- Y-CCIIS: Young Children's Critical Illness Impact Scale, pictorial version
- 13-symptom list

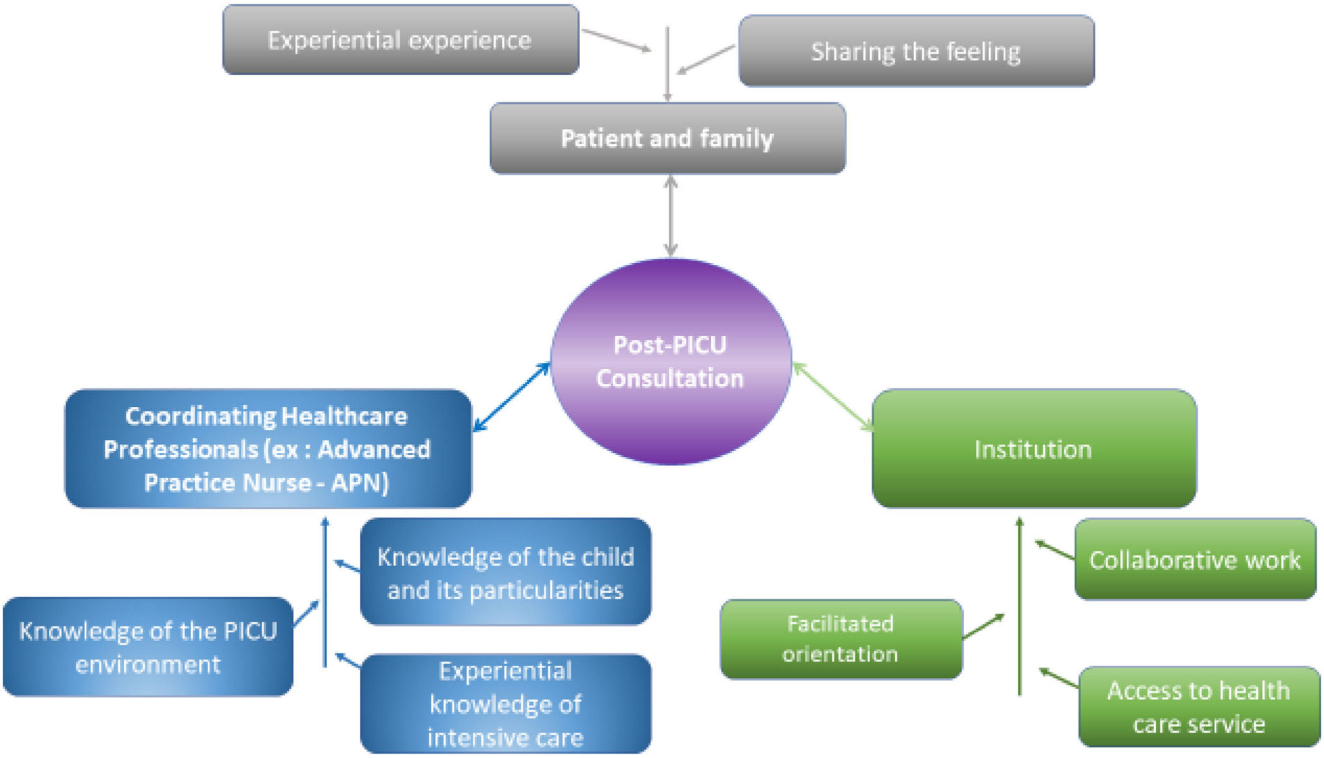
APPENDIX B: DESCRIPTION OF THE ARTICLES

	n = 68
Journal typology	
Intensive care	34 (50%)
Paediatric	12 (17.6%)
Psychology	6 (8.8%)
Others	6 (8.8%)
Generalist	4 (5.9%)
Haematology	4 (5.9%)
Pneumo-thoracic	2 (3%)
Countries	
USA	17 (25%)
England	11 (16%)
Canada	7 (10%)
Australia	6 (8.9%)
Netherlands	5 (7.4%)
Brazil	3 (4.4%)
China	3 (4.4%)
Spain	3 (4.4%)
Croatia	2 (3%)
South Africa	1 (1.5%)
Germany	1 (1.5%)
Finland	1 (1,5%)
France	1 (1.5%)
Greece	1 (1.5%)
India	1 (1.5%)
Iran	1 (1.5%)
Ireland	1 (1.5%)
Italy	1 (1.5%)
Switzerland	1 (1.5%)
Turkey	1 (1.5%)
Year of publication	
2020	10 (14.7%)
2019	5 (7.3%)
2018	10 (14.7%)
2017	2 (3%)
2016	3 (4.4%)
2015	7 (10.2%)
2014	1 (1.5%)
2013	5 (7.3%)
2012	5 (7.3%)
2011	2 (3%)
2010	1 (1.5%)
2009	1 (1.5%)
2008	4 (5.8%)
2007	4 (5.8%)
2006	2 (3%)
2005	1 (1.5%)
2003	2 (3%)
2002	2 (3%)
2000	1 (1.5%)
Study duration (years)	3 [1.4]
Delta graduation and publication date (years)	4 [3; 5]
Type of studies	
Monocentrique cohort	26 (39%)
Multicenter cohort	14 (20%)
Single-center retrospective study	11 (16%)
Retrospective multicenter study	5 (7.2%)
Mixed	3 (4.4%)
Post hoc	3 (4.4%)
Pilot	2 (3%)
Qualitative	2 (3%)
Feasibility	1 (1.5%)
Randomized controlled trial	1 (1.5%)
Median number of patients	150 [52; 308]

(Continues)

Note: Data expressed as headcount, per cent of headcount (%) or median [min; max].

APPENDIX C: STRENGTH OF POST-PAEDIATRIC INTENSIVE CARE UNIT DISCHARGE FOLLOW-UP



According to Gottlieb's theory,[29] strengths-based care should involve every person or group of people involved in the process, not only the patient, but also the advanced practice nurse (APN) and the institution. The presence of post-PICU (paediatric intensive care unit) follow-up in a paediatric hospital, where there are many medical, paramedical and social specialties, is a great advantage for the patient and their family. This should facilitate the patient's journey: easier referral, single point of care and management. Patients and their families, in terms of their experience of paediatric intensive care, are key players in terms of the range of care that such a consultation can provide.