

Family outcomes after the pediatric intensive care unit: A scoping review

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Background: Intensivists are increasingly attuned to the post-discharge outcomes experienced by families because patient recovery and family outcomes are interdependent after childhood critical illness. In this scoping review of international contemporary literature, we describe the evidence of family effects and functioning post-PICU as well as outcome measures used in order to identify strengths and weaknesses in the literature.

Methods: We reviewed all articles published between 1970 and 2017 in PubMed, EMBASE, PsycINFO, Cumulative Index of Nursing and Allied Health Literature (CINAHL), or the Cochrane Controlled Trials Registry. Our search used a combination of terms for the concept of “critical care/illness” combined with additional terms for the pre-specified domains of social, cognitive, emotional, physical, health-related quality of life (HRQL), and family functioning.

Results: We identified 71 articles reporting on the post-PICU experience of more than 2,400 parents and 3,600 families of PICU survivors in 8 countries. These articles used 101 different metrics to assess the various aspects of family outcomes; 34 articles also included open-ended interviews. Overall, most families experienced significant disruption in at least 5 out of 6 of our family outcomes subdomains, with themes of decline in mental health, physical health, family cohesion, and family finances identified. Almost all articles represented relatively small, single-center or disease-specific observational studies. There was disproportionate representation of families of higher socioeconomic status and Caucasian race, and there was much more data about mothers compared to fathers. There was also very limited information regarding outcomes for siblings and extended family members after a child’s PICU stay.

Conclusions: Significant opportunities remain for research exploring family functioning after PICU discharge. We recommend that future work include more diverse populations with respect to the critically ill child as well as family characteristics, include more intervention studies, and enrich existing knowledge about outcomes for siblings and extended family.

Key Words: Pediatrics, critical care, pediatric critical care, outcomes, family, late effects, mental health

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With mortality rates in pediatric intensive care units (PICUs) falling below 10% in many countries,[1-3] intensivists are increasingly attuned to the quality of life and multiple other discharge outcomes experienced by PICU survivors and their families. Pediatric post-intensive care syndrome (PICS-p)[4] collectively describes the psychological, cognitive, and health related quality of life (HRQL) challenges experienced by survivors of childhood critical illness which includes parents, siblings, and extended family members. Much of the related literature has focused on patient-centered outcomes, however, in a systematic review of 33 studies from 2005 to 2019, Abela et al found that many parents of critically ill children reported psychological, physical, and social impacts after their child's hospitalization, sometimes for years after discharge⁶. Importantly, parental health and wellbeing impacts not only the patient, but also his/her siblings. In severe cases, this can create generational dysfunction, as patient recovery and family outcomes are interdependent after childhood critical illness. Therefore, a better understanding of post-discharge family effects is needed to comprehensively understand these phenomena and develop best practice for family support during and after PICU admission.

This study is a subanalysis of a larger scoping review conducted by the POST-PICU Investigators of the Pediatric Acute Lung Injury and Sepsis Investigators (PALISI) in collaboration with the Collaborative Pediatric Critical Care Research Network (CPCCRN). The goal of the primary scoping review was to identify studies of pediatric critical care medicine post-discharge outcomes related to PICS-p. Our aim was to map the evidence of family effects and functioning post-PICU, and outcome measures/instruments used from international contemporary literature.

METHODS

Details describing the methods for the primary scoping review have been published elsewhere.[5] Briefly, articles published between 1970 and 2017 were identified by searching PubMed, EMBASE, PsycINFO, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and the Cochrane Controlled Trials Registry using a combination of keywords and controlled vocabulary for the concept of "critical care/illness" combined with comprehensive terms for the 6 pre-specified domains of social, cognitive, emotional, physical, health-related quality of life (HRQL), and family functioning. Exclusion criteria included: 1) no assessment of

post-discharge outcomes; 2) only survival was assessed; 3) only instrument psychometric properties were assessed; 4) we were unable to determine the relationship between the outcome and ICU care; 5) the majority of the study sample was >18 years old, preterm infants, neonates, or had not been definitively admitted to an ICU; 6) only one subject was included; and 7) if the article was published in a language other than English.

Articles were identified through a stepwise screening process first examining titles and abstracts, followed by full text review. At each step, two people determined appropriateness for inclusion with discrepancies resolved by a third reviewer. To organize our subanalysis, our group (an interdisciplinary panel of experts in critical care outcomes) created an integrated family functioning framework to categorize the family domain articles into six subdomains: 1) family functioning; 2) parent mental health (including grief); 3) parent physical health; 4) family economics/finances (including parent work); 5) siblings; and 6) extended family/other caregivers (Figure 1). We then reviewed each article and extracted details related to the study subjects, assessments, time interval to outcome measurements, and main results.

RESULTS

Out of the 408 articles identified in the larger scoping review, 71 addressed post-discharge outcomes within the family outcomes domain.

Family Functioning

Within the family outcomes domain, nearly a third of articles out of 71 (n=23, 32%) measured family functioning,[6-28] with dominant themes that included changes in family function after the child's illness, interpersonal family relationships, parenting, and family burden (online supplemental Table 1). Most of the articles in this subdomain (n=19/23) assessed family function as one of several outcomes, particularly the intersection of family function with parental mental health and wellbeing. The 23 articles used a total of 41 unique outcome measures, including 13 unique semi-structured interviews, to assess family functioning in 1,066 families and 477 parents after general PICU admission (n=19 articles, including 6 focused on survivors of severe TBI), in mixed NICU/PICU populations (n=1 article, 15 parents), and in a CICU/congenital heart disease population (n=1 article, 29 parents). All articles except one included families whose children had survived their ICU stay. Nearly

two-thirds of the articles (n=13/23) reported on family outcomes beyond 6 months from hospital discharge; the longest interval reported was 11 years post discharge. Two of the articles did not specify the timeframe of their family evaluations in relation to the child's illness.

The impact of a child's PICU admission on general family functioning were mixed, and no consistent risk factors for lower family cohesion were clearly identified. While primary PICU diagnosis and illness severity were associated with greater disruption of family function in some studies,[22, 26] factors most associated with improved family cohesion included lower baseline psychological distress, greater social support, and being in a two-parent family.[24] Interestingly, family adaptability was higher in families with a greater number of children, greater baseline financial concerns, and greater stress about the hospital staff's behavior.[25, 27] Studies also described challenges in the relationship between parents[8, 15, 22] and between siblings[22] after a PICU admission for a child in the family, and several highlighted the difference in emotional responses of mothers compared to fathers.[8] Attitudes towards parenting were also shown to shift after PICU discharge,[6, 9, 18, 21] and the effects of PICU admission on parent-child bonding were reported as being both improved[12] and impaired.[8] Fear of a child incurring a new injury or another illness appears to cause some parents to worry about or limit their child's return to normal activities.[12, 19]

Assessments of family burden quantified how anxiety-provoking a child's post-discharge health and behaviors can be to their parents, the time constraints of these characteristics on parental time, and how the child's health and behavior impacted family interaction, activities, and finances.[22] Increased family burden scores after PICU discharge were associated with worsening child functional status in several studies, and many parents noted that they had to provide more physical and emotional care to a previously independent child.[6] These effects of the child on the family, and the family on the child are interrelated, and it is notable that the family functioning subdomain had significant overlap with all 5 of the other subdomains.

Parent Mental Health

Parental mental health was the focus of 62 manuscripts (86%), representing the largest component of family-centered outcomes within this data set.[6, 7, 12-16, 18, 20, 21, 23, 24, 29-73] These 62 articles used 43 unique validated outcome measures, physical exam, laboratory testing, and 18 qualitative interviews to report on parental

mental health and wellbeing after general PICU admission (n= 45), after specific illnesses/interventions requiring PICU admission (n=11), or CICU admission (n= 7). More than three-quarters of the articles (79%) evaluated multiple parent outcomes by using more than one measure, and the majority of measures were obtained via interview [in person (45%), Mail/email (22%), telephone (0.07%), or a mix (19%)]. All but two of the articles specified timing of measured outcomes, which ranged from 24 hours post event to 16 years post hospital discharge. Nearly half of studies (n=27, 45%) assessed outcome within six months of hospital discharge, and 75% of all the studies specifying a time interval for outcome assessment were completed within a year of hospital discharge.

In the parental mental health subdomain there were 45 quantitative or mixed methods articles that reported having a child admitted to the PICU as a stressful event for parents and evaluated the risk of mental health effects such as post-traumatic stress disorder (PTSD) (n=23), acute stress disorder (n=3), depression (n=20), anxiety (n=22), general psychological dysfunction (n=23) and traumatic growth/coping (n=2). Most of the articles (62%) primarily reported post-discharge outcomes for parents and examined the risk of developing parental mental health issues following PICU admission in the context of pre-admission parental factors and/or in-hospital parental and child/patient factors. Thirteen qualitative articles explored several subthemes, including: feeling disempowered during the child's admission, significant distress during and after PICU admission, unmet information and emotional support needs, and psychological issues such as PTSD and anxiety. Only six of the 58 articles (10%), including one qualitative study addressing parental mental health, were interventional studies. Of these, three protocols implemented in-hospital coping education and expectation setting, one implemented both in-hospital education and a follow-up telephone call, and one implemented the offer of a follow-up visit. The qualitative study identified processes used by parents to make sense of their child's death during bereavement meetings. Only two of the five quantitative articles were adequately powered to evaluate the effect of the intervention; both of these studies showed improvement of parental mental health and a correlation between parental mental health and the child's psychological function.

Grief

Eight articles in the parental mental health subdomain were related to parental grief and need for support surrounding a child's death in the PICU,[56-62, 74-76] and one additional article focused on the parents' views on their other child/children's response to their sibling's death.[28] Most (5/8) reported mental health outcomes within a year of the child's death, but one study contacted families at a mean interval of 3.4 years from their child's death (range 2.3-5.7 years).[58] In addition to open interviews where parents and siblings were asked to share their thoughts and feelings, the eight articles used four standardized measures of grief, and several additional measures of mental health,[75] caregiver burden,[76] and strength of relationships.[76] Studies showed that parents experience high levels of complicated grief symptoms; for some parents, symptoms may decrease within 6-18 months of their child's death, for others complicated grief may persist. Parents reported negative physical and mental health outcomes such as depression, PTSD and anxiety-related hospitalizations. In a few studies, parent grief was associated with the child's cause of death, the chronicity of their child's illness, and parent demographics.

Parental Physical Health

Out of 71 articles, we identified four articles that reported on parental physical health, including three articles that also assessed the surviving child[24, 37, 53] and one that focused on grieving parents of children that did not survive intensive care.[75] The articles included a heterogeneous population of 484 families from three different countries, assessed at a variety of time points ranging from several months to more than a decade post PICU discharge. The articles that assessed parents of PICU survivors included parents of children who had undergone corrective surgery for congenital heart disease (n=113 mothers and 88 fathers),[53] parents of meningococemia patients (n=134 parents),[77] and parents of cardiac arrest survivors (57 families).[24] Ethnicity was specified in only one article.[75] Overall, there was a common theme of impaired physical health among parents at the time of PICU discharge, with improved self-reported health by parents over time. Several explanations for these outcomes were explored, including: "posttraumatic growth" or "response shift" due to changed perspectives or internal standards, finding meaning in their child's illness, and use of available resources and coping strengths.

Family Economics

Family economics or parental work was evaluated in seven of the 71 articles within the family domain, primarily among families of general PICU patients, with multiple articles assessing the families of children who had sustained traumatic brain injury.[10, 11, 22, 24, 36, 75, 78] These outcomes were assessed from six weeks to 16 years following PICU discharge, with the majority of follow-up within the first five years following admission (four articles assessed multiple time points within one year, [11, 22, 36, 75] two were between 2-5 years,[10, 24] and one was between 4-16 years)[78]. Overall themes were that lower socioeconomic status (SES) was associated with less developmental follow-up of former PICU patients, and that higher financial spending and healthcare utilization and work and/or school days missed correlated with severity and length of PICU admission. However, when considering employment and finances, overall parent-reported QOL was more related to the presence of chronic underlying conditions among the children than the acute PICU admission itself. Additionally, parental PTSD was associated with stressful work conditions and unemployment.[36] One additional article commented on a greater predominance of fathers, compared to mothers, to return to work quickly after a child's NICU/PICU death with a range of return to employment between 0-427 days.[75]

Siblings and Extended Family

There is a severe lack of information regarding siblings' outcomes after a child's PICU stay, and even less information about extended family members. Only three out of the 71 studies included in this systematic review evaluated sibling outcomes,[18, 22, 28] and only one of these studies was exclusively focused on siblings.[28] In that 2013 study, 27 parents were interviewed approximately seven months after their child's death, with identification of several themes, including: confusion amongst preschoolers, behavioral changes amongst school-age children and adolescents, and the tendency of siblings to recognize the parent's grief, and attempt to provide comfort to the adult rather than seeking comfort for themselves.[28] In a 2002 study designed to assess outcomes of children with traumatic brain injury after PICU stay, 82 families were assessed at multiple time points the following year. Parents perceived that the relationship between the sibling and patient deteriorated over time, and 21% of siblings were reported to have worsening behavior, and deterioration in relationship with parents. Approximately 40% of families reported that siblings could not stay in their own home and/or missed school due to their sibling's ongoing medical needs.[22] Finally, a small qualitative study in Denmark assessed the effect of

PICU diaries on family recovery at 4-6 months after discharge among three families.[18] The siblings remarked that the diaries provided answers to questions they had about events that had taken place while their sibling was in the PICU. No studies focused on extended family members, including grandparents, stepparents, aunts or uncles.

Outcomes instruments used by the articles in the family domain

In addition to 34 unique unstructured and semi-structured interviews, the articles identified in this scoping review used 101 unique instruments to evaluate mental health (n=50), family functioning (n=5), coping and/or grief (n=8), family economics (n=4), cognition (n=9) and HRQL or general health (n=25). The overwhelming majority of these instruments were commercially or publicly available, and previously validated instruments, with only 6 (4%) representing novel instruments created by study investigators. Specific measures for stress (n=10) and post-traumatic stress symptoms (PTSS) or PTSD (n=6) were the most common themes reported in assessments of child and parent mental health, but there were also a variety of instruments used to assess anxiety (n=5), depression (n=4), coping (n=3), and other mood states (n=3). Only three of the instruments were specific to health care/PICU exposure (Glasgow Meningococcal Septicaemia Prognostic Score, Parent Stressor Scale: PICU, and the Posthospitalization Behavior Questionnaire), while the remaining either adapted scales to measure trauma by defining the PICU admission as the traumatic event under investigation, or used nonspecific measures of mood, economics, or function without reference to the PICU admission specifically. Most of the instruments relied on parent report, including seven of the 12 instruments used to assess child behavior and cognition post-PICU discharge.

Discussion

In a multinational collaboration extending over a several year period, our group conducted a scoping review of the medical literature since 1970 to identify all articles pertaining to family functioning or family member wellbeing after a child's PICU admission. This review identified 71 articles reporting on the late effects of critical illness in childhood on more than 2,400 parents and 3,600 families of PICU survivors in eight countries, and an additional 600 parents and families recovering from the death of their child in the PICU. Articles identified in this review used 101 different metrics to assess the various aspects of family outcomes, and 34 articles additionally

included open-ended interviews that provided a rich narrative of the PICU experience and post-PICU environment from parents' and caregivers' perspectives. Overall, the body of literature identified in this scoping review indicated that most families experienced significant disruption in at least five out of six of our proposed family outcomes subdomains, with strong themes of decline in mental health, physical health, family cohesion, and family finances identified. However, there was also clear demonstration of families' resilience, recovery, and growth after their child's critical illness. Without question, a family's exposure to the PICU environment is often life changing, and we are only beginning to understand the multifaceted and long-term effects of PICU survivorship for children and their families.

Of the 71 articles identified in the family domain, it is notable that 29 (40%) of these were published in the last 10 years. Although it is encouraging that there has been a significant increase in the number of studies that address the effects of a child's critical illness on the entire family over the past 50 years, the fact that only 71 articles were identified in total indicates that there is still much in this area that remains unknown. It is also an encouraging sign that research appears to be moving towards greater inclusion of metrics that assess family function and other aspects of family health and wellbeing, such as family finances, social connections, and the effect of a child's illness on his or her siblings. However, the significant gaps in all three of these content areas, as well as the complete absence of literature that includes more extended family, such as grandparents, is notable. It is also notable that almost all of the identified articles reported the results of relatively small, single-center or disease-specific observational studies, there was disproportionate representation of families of higher socioeconomic status and Caucasian race, and there was much more data about mothers compared to fathers. In addition, the metrics used to measure many functional and financial outcomes were not healthcare specific, and failed to incorporate the different sources of cost to families, including, for example, loss of work productivity and subsequent potential loss of insurance. Focused investigation of the impact of interventions on the overall dynamics of post-PICU family function and economics in a variety of settings is desperately needed.

The results of this scoping review also indicate that the predominance of existing literature on family outcomes has reported on parental mental health; this was overwhelmingly the largest of our six subdomains, with very few articles identified that addressed the physical and mental health outcomes of other family members or the larger societal issues of family finances and social connectivity. However, many of the assessment

instruments used by the articles in this scoping review capture data about other family subdomains which could be used to facilitate broader research in this area without significant increases in cost or duration of follow-up. For example, while the SRS-PTSD is a common instrument for assessing psychological distress, it is possible to analyze the “health problems score” separately, which may give more granular insight into a variety of aspects of family outcomes. The SF-36 and Caregiver Burden Assessment are other examples of “broad spectrum” instruments with subset composite scores that could be used in this way. This approach may be a practical method for defining the scope of family outcomes, as post-discharge PTSD and other stressors are commonly reported by parents, and are associated with a high rate of comorbid medical disorders and social dysfunction.

We acknowledge several limitations inherent to a scoping review, with perhaps the most significant limitation being the time it takes to actually perform such a broad review. By definition, that means there will always be delays between the original search and the ultimate publication of the results; this review included articles published through 2017; given the rapid expansion of research in this area, there are almost certainly newer publications that are not included. A possible approach to this perennial problem with scoping reviews may be to use a similar strategy to Cochrane Reviews, in which updates are published at structured intervals from each other. In addition, no search strategy is perfect. We may have missed articles because of the search terms used, or inappropriately excluded articles during the title and article review. We attempted to mitigate both of these concerns by using well-validated methods for scoping reviews,[5] which include very broad literature searches and dual review by investigators that requires agreement for an article to be eliminated from consideration. Given the exhaustive nature of this review, we are confident that despite these limitations, this report represents the most comprehensive review of this topic to date.

Conclusions

The bulk of post-PICU outcomes research has rightfully focused on the surviving child, however, many factors that influence the quality of that survival fall within a larger family paradigm that is often altered indefinitely by the circumstances of the child’s PICU admission. Family outcomes research has increasingly provided data on parental mental health and family functioning in recent years, but the results of this scoping review demonstrate that much less is known about parental physical health, parental work and family finances,

and the impact of a child's illness on siblings and extended family members. The majority of available work is observational and not interventional, reports on homogenous and limited disease-specific populations, and offers limited causal connections between the child's PICU exposure and ultimate family outcomes. Significant opportunities remain for research exploring family functioning after PICU discharge and possible effective interventions that can be implemented to mitigate decline in family function following PICU discharge.

Declaration of Conflicting Interests

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All other authors declare that there are no additional conflicts of interest.

Table 1. Online supplement: manuscript table

First author	Year	Family domain	Subjects	Study assessments	Time interval	Main results
Als	2015	PMH	31 parents of PICU survivors aged 4–16 years old, randomized to a psychoeducational tool or standard care.	IES, HADS, SDQ, CSHQ, PSS: PICU	3-6 months after hospital discharge	Parents who received the intervention reported lower PTSS in themselves and fewer emotional and behavioural difficulties in their children than standard care parents.
Atkins	2012	FF, PMH	8 Families of children aged 5-16 years with a PICU admission to a large teaching hospital in London.	Semi-structured interviews.	8-18 months after PICU admission.	Families highlighted the importance of physical, psychological and social recovery.
Ballufi	2004	PMH	Parents of 272 children admitted to the PICU for >48 hours (161 parents completed study).	ASDS, PTSD Checklist, semi-structured interviews.	During child's PICU admission, and again 2-11 months after child's discharge.	After discharge, 21% of parents met symptom criteria for PTSD. Risk factors for the development of PTSD included ASD symptoms at first time point. Mothers were more likely than fathers and black parents were more likely than white parents to develop PTSD.
Bloom	1997	PMH	16 children with CHD who had sustained an in-hospital cardiac arrest and a control group of children with CHD.	CBCL, Parenting Stress Inventory, VBAS, and neuropsychological testing.	At least one year after cardiac arrest (mean age 41 months), and age-matched controls.	There were more impairments in cognitive, motor, adaptive behavior functioning, and greater disease severity in children after cardiac arrest.

Board	2002	FF, PMH	Three groups of parents of children ≤ 5 years old (PICU [n=31], general care unit [n=32], and non-hospitalized ill children [n=32]).	PSS:PICU, SCL-90-R, FAM III, FILE.	During the hospitalization/ill visit, 1-2 weeks after discharge, 6-8 weeks after discharge, and 5-6 months after discharge.	Parents are still having stress-related symptoms and difficulties with family functioning > 6 months after a child's illness.
Board	2011	PMH	Families of 8 previously healthy PICU survivors aged 6-12 years from 2 medical centers in New England (USA).	PSS:PICU, STAI, Child Drawing: Hospital; CPTS-RI, salivary cortisol testing.	Within 24 hours of child's PICU admission, and again at 2 weeks and 3 months after hospital discharge. Post-discharge interviews were conducted in family homes.	Mothers' state anxiety significantly increased over time from baseline to 2 weeks, and from baseline to 3 months. Pediatric PTSS decreased from baseline to 2 weeks, and again at the 3-month follow-up. None of the independent variables were predictive of either PTSD symptoms or salivary cortisol levels.
Bronner	2008	PMH	36 Dutch PICU survivors and 355 pediatric survivors of a major fire disaster	CRTI, SRS-PTSD, GHQ-30	3 and 9 months after PICU discharge; 10 months after the fire.	35% of children had subclinical PTSD, while 14% met criteria for PTSD. Maternal PTSD was the strongest predictor for child PTSD. There were no significant differences in PTSS compared to survivors from the fire disaster.
Bronner	2008	PMH	144 Previously healthy Dutch PICU survivors and their parents	SRS-PTSD, medical exam.	3 and 9 months after an unexpected PICU admission.	73% of fathers and 84% of mothers had persistent symptoms of PTSS.
Bronner	2009	PMH	84 Mothers and 65 fathers of previously healthy children, unexpectedly admitted to a PICU in Amsterdam.	SRS-PTSD, HADS, UCL, PDEQ.	At time of child's transfer out of the PICU, and again 3 months after their child's hospital discharge.	Over 10% of parents met criteria for PTSD and almost one quarter for subclinical PTSD. Mothers had more PTSD than fathers. Peritraumatic dissociation was most strongly associated with PTSD, anxiety and depression.
Bronner	2010	PMH	190 Parents of children with an unplanned admission to a PICU.	SRS-PTSD and interviews.	Immediately after child's PICU discharge, and again 3 & 9 months later.	30% of parents met criteria for subclinical PTSD and 13% for clinical PTSD at 3 months. At 9 months, 11% of parents still met criteria for PTSD.

Buyse	2007	PMH, PPH	140 Dutch children with meningococcal septic shock requiring PICU care, and 134 of their parents.	CHQ, SF-36.	median interval of 10 years.	Patients had lower scores on physical domains. Parents had scores closer to the normal range on the majority of HRQL scales, with only physical functioning remaining lower than the adult reference group.
Cantwell-Bartl	2013	FF	29 parents of children with hypoplastic left heart syndrome who survived PICU admission.	Semi-structured interviews, PTSD module of the SCID	Not stated.	All parents reported multiple stresses throughout their infant's time in the PICU. Acute stress disorder or posttraumatic stress disorder was found in 83% of parents.
Choong	2015	PMH	33 Canadian PICU survivors aged 1-17 years and their parents	PEDI, PEM-CY, ICF-CY, McMaster All-Out Progressive Continuous Cycling Test, POPC, PCPC, PSI	During hospitalization, and again 3 & 6 months after discharge.	An outcomes research model that incorporates functional status, health outcomes, and caregiver stress is feasible in a single center. Follow-up rates can be improved by providing families with travel expenses.
Colville	2006	PMH	34 mothers of children who survived a PICU admission (at least 24 hours' duration) in the United Kingdom.	Semi-structured interviews in families' homes and 3 self-report questionnaires: PSS:PICU, GHQ-28, and the IES	8 months (range 79 months) after the child's PICU discharge.	Mothers who talked about their feelings had lower posttraumatic stress scores. Most mothers would have appreciated the offer of a follow-up appointment.
Colville	2009	PMH	50 parents of children admitted to a London PICU for >12 hours	PTGI	at hospital discharge and 4 months later	Post-traumatic growth emerged as a salient concept for this population. It was more strongly associated with moderate levels of post-traumatic stress, than high or low levels.
Colville	2012	PMH	66 child-parent pairs, consisting of children aged 7-17 years old admitted to a PICU, and at least one of their parents.	CRIES-8 and the SPAN.	3 and 12 months post discharge	Nearly half of families had PTSS 12 months after discharge. Distress was predicted by subjective factors and many experienced delayed reactions, indicating need for longer term support.

Colville	2009	PMH	50 parents of UK PICU survivors.	Semi-structured interviews	8 months after PICU admission (range 5.7-12 months)	Parents had intense levels of stress associated with their child's admission and retained vivid memories of their experiences. The PICU experience was hard to process.
Colville	2010	PMH	52 families of London PICU survivors (intervention) and 43 control families.	Demographic and medical variables, Townsend Deprivation Index, PSS:PICU, IES, HADS	Intervention families attended a follow-up appointment 2 months after PICU discharge, and all families completed questionnaires at 4 months post-discharge.	No significant differences were found between groups, but parents in the intervention arm with higher baseline stress reported lower rates of PTSS and depression compared to controls.
Curley	2003	PMH	271 Parents of children supported by extracorporeal membrane oxygenation (ECMO) during a PICU admission.	Questionnaires developed by study team.	4 months after ECMO support.	Most parents were well prepared for and supported during the ECMO course. Fewer parents of non-survivors reported that they would again consent to ECMO.
Dampier	2002	FF	15 families of children who survived PICU admission in the United Kingdom.	Semi-structured interviews.	Between 1-2 months after child's hospital discharge.	Some families had difficulty accessing the healthcare system; most experienced their child's illness as overwhelming; many had no aftercare for their children after hospital discharge.
Diaz-Caneja	2005	PMH	20 parents of children admitted to either a PICU (n=11) or general pediatrics ward (n=9) in a single center in the United Kingdom.	Semi-structured interviews conducted in families' homes by a single investigator.	6 and 12 months after the child's hospital discharge.	In the PICU group, the sources of stress differed according to the stage of their child's illness, transitioning from initial fear to managing the impact of the child's illness on the family. Parents of ward patients reported similar themes but with lower levels of stress.
Erllich	2005	PMH	192 Parents of PICU survivors with meningococemia.	GHQ	3 months-7 years after hospital discharge	Both mothers and fathers experience high levels of psychological distress after discharge.

Franich-Ray	2013	PMH	132 parents of Australian children who underwent cardiac surgery before 3 months of age	Acute Stress Disorder Scale.	1 month after hospital discharge.	One-third of mothers and close to one-fifth of fathers, experienced trauma symptoms consistent with a diagnosis of acute stress disorder.
Garralda	2009	PMH	56 children aged 3-16 years old hospitalized for meningococemia, and their parents.	SDQ, GHQ, IES.	During hospital admission, and again 3 months and 12 months after hospital discharge.	Admission to the hospital with meningococcal disease was followed by psychological symptoms, some of which were persistent and impairing. Psychosocial (pre- and postmorbid) factors predicted problems at 12-mo follow-up.
Guan	2013	PMH	29 school aged Chinese children with CHD who underwent surgery, 35 who underwent transcatheter closure of a VSD, and their parents.	CBCL, GHQ, Wechsler Scale for Children-Second Edition.	2-6 years after surgery/device closure	Behavioural problems were greater for children with CHD than controls. Behavioural problems included depression, somatic complaints, and social withdrawal for boys and thought problems, depression, somatic complaints, and social withdrawal for girls.
Helfricht	2008	PMH	135 mothers and 98 fathers of 139 Swiss children aged 0-16 years with congenital heart disease requiring corrective surgery at a single center in Zurich.	German version of the PDS, SES was estimated by a score that included maternal education and paternal occupation.	Immediately after hospital discharge and again 6 months later.	Acute surgery-related PTSD was found in 16.4% of mothers and in 13.3% of fathers following discharge, which was slightly higher than parental PTSD rates at 6 months. Acute symptoms of PTSD are a major risk factor for the development of chronic PTSD.
Judge	2002	PMH	29 PICU survivors of meningococcal disease aged 2-15 years, from a single center in London, and their mothers.	Semi-structured interviews; BCL; SDQ; IES; GHQ-28	3-12 months after hospital discharge.	Most children experienced stress symptoms following discharge. Nearly one-half of mothers had high levels of psychiatric distress, some disabling.

Kapapa	2010	FF, FW	20 Families of children managed in the intensive care unit for severe TBI.	SF-36, semi structured questionnaire.	Mean interval of 2.1 years after initial TBI.	Children with severe injuries were noted to have cognitive and psychosocial impairments, which greatly impact the family.
Keenan	2006	EF, FF, FW	112 children \leq 2 years old hospitalized in 9 North Carolina PICUs for severe TBI, and 71 of their mothers.	POPC; FSII(R), GHI	One year after the child's injury.	Children with inflicted TBI had worse outcomes and greater resource use than did children with noninflicted TBI. Caregivers did not differ in measures of social capital.
Khanna	2016	PMH	Parents of 11 Australian PICU patients.	Semi-structured interviews guided by unspecified questionnaire.	2 interviews, first at 48 hours after PICU discharge and again < 24 hours later.	One-fifth of parents observed trauma, making it important for PICUs to address. Parents remember traumatic events they have witnessed, and it adds to their overall level of stress.
Kirk	2015	FF, PMH	29 parents/carers of children who were managed in a tertiary medical center in the UK for severe TBI.	Semi-structured interviews	6 months to 7 years post hospital discharge.	Parents experienced fear and uncertainty during the early phases of their child's illness. Many parents felt unprepared and poorly supported for discharge home.
Landolt	2011	PMH, PPH	113 Mothers and 88 fathers of 120 Swiss children aged 0-16 years with congenital heart disease requiring surgical intervention.	Demographic, medical, and SES data, SF-36, German version of the Post-Traumatic Distress Scale, IOS-R.	At hospital discharge after the child's heart surgery and again 6 months later.	Parental mental HRQL is low in the immediate period after their child's surgery, but normalizes after 6 months. Parents in whom the child's disease has a high impact on their family life have low mental HRQL.
Latour	2011	PMH	39 Mothers and 25 fathers of 41 PICU survivors from 7 Dutch PICUs.	semi-structured, in-depth interviews.	Within 1 month after their child's discharge from the PICU.	Interviews identified a range of themes and subthemes providing insight into the complexity of the parental experiences of their child's PICU admission.

Lawson	1985	FF, PMH	20 parents of critically ill children	Unstructured interviews.	Within 3 days of PICU admission; after transfer to the ward; within 3 months after discharge or death.	Parents transitioned from primary concern for child's medical condition, stress and fear to financial concerns, focus on family functioning, and long-term recovery of the child.
Lewis	2014	FF, PMH	52 parents of children who had been supported on ECMO a minimum of 6 months prior, from one center in the UK.	IES-R, FAD, HADS	19-34 months after child's hospital discharge.	21% of parents scored above the cutoff criteria for PTSD. Only 9.6% of the sample reported no post-traumatic stress symptoms.
Lutz	2012	FF, PMH	15 parents of NICU and PICU graduates under age 4 with feeding concern, and 10 professionals who care for this population in the US.	Semi-structured interviews.	Not stated.	Feeding problems greatly impact families. System barriers and financial concerns escalated parents' distress.
Majnemer	2009	PMH	131 infants with congenital heart defects who required open heart surgery.	Medical evaluations, VBAS, WeeFIM, Griffiths Mental Development Scale, WIPSI, CBCL, CHQ, and the PSI.	Evaluations performed prior to surgery, at hospital discharge, 12-18 months later, and at 5 years of age.	Developmental delays were common in children with heart defects, and these deficits persisted to school entry. Many factors were significantly associated with developmental outcomes, suggesting a multifactorial etiology.
Maxton	2008	PMH	14 Parents of critically ill children from one Australian PICU, who had either survived or died following a resuscitation attempt.	Semi-structured interviews.	Survivors: one week after resuscitation, non-survivors: 3 months after child's death.	Parents who did not witness their child's resuscitation were more distressed than those who did.

McCusker	2013	S	31 7-year old children with CHD and 18 of their closest age-matched siblings	CBCL, Teacher Report Form, historical parental mental health, financial stability and family functioning data.	At age 7 years for children with CHD, mean age of 9.6 years for sibling controls.	Problems with attention, thought and social problems, and limitations in activity and school competencies, were found in comparison with siblings.
McGraw	2012	PMH	17 Mothers and 1 father of 18 children who died in the PICU.	Semi-structured telephone interviews.	6 or more months after the child's death.	Parents sought ways to express and assert their parenthood: 1) providing love and care; 2) creating security and privacy; and 3) exercising responsibility for one's child.
Meert	2001	PMH	57 Parents who experienced the death of their child in the PICU	CRI and TRIG questionnaires by mail and over the phone.	Mean of 3.4 years (range 2.3-5.7 years) after child's death.	Parents' physical well-being lessens early grief. Understanding self-worth and the child's illness improves long-term adaptation to loss.
Meert	2008	PMH	33 Parents of 26 children who died in a pediatric intensive care unit.	Semistructured, in-depth, videotaped interviews	2 years after child's death.	The PICU environment affects parents at the time of their child's death and produces vivid and long lasting memories. Positive memories provide comfort during bereavement, negative memories compound the devastating experience.
Meert	2010	PMH	261 Parents whose child died in a pediatric intensive care unit 6 months earlier.	ICG	6 months after the child's death.	Parents experienced a high level of complicated grief symptoms.
Meert	2016	FF, PMH	Caregivers of children who survived at least one year after out-of-hospital-cardiac arrest (n=77).	ITQL, CHQ, VBAS II, POPC, PCPC, caregiver perceptions of function.	During PICU admission, 3 months, and 12 months post-arrest.	Worse POPC and PCPC, lower adaptive behavior, lower global functioning and higher family burden at 3 months post-arrest were associated with higher family burden 12 months post-arrest.

Meert	2011	PMH	136 parents of 106 children who died during admission in 7 U.S. PICUs.	ICG, GAQ, RSQ, CQ, SSQ-SF.	18 months after child's death.	Complicated grief symptoms decrease between 6 and 18 months after their child's death; high symptom levels persist for some.
Meert	2015	PMH	32 Mothers and 21 fathers of 35 children who died during a PICU admission.	Semi-structured group meetings, 1-6 hours long.	2-6 months after the child's death.	4 Meaning-making processes were identified: (1) sense making, (2) benefit finding, (3) continuing bonds, and (4) identity reconstruction.
Melnyk	1997	PMH	30 mothers of 1-6-year old PICU survivors, randomly assigned to receive support education or standard care.	IPS, IPP, STAI, POMS (Short form), PSS:PICU, PBQ, PSI-P, PSI-C, and the PRQ.	1 month after hospital discharge.	Mothers who received the support program: (a) provided more support to their children during procedures; (b) provided more emotional support to their children; (c) reported less negative mood and less parental stress; and (d) reported fewer PTSS.
Melnyk	2004	PMH	163 mothers of PICU patients, 87 who received a coping curriculum and 76 controls.	A-State, POMS, PSS: PICU, PSI-C, PSI-P, IPP, BASC, PBS, VAS-PC, VAS-EC	1, 3, 6, 9, and 12 months after hospital discharge.	Mothers who received the training program experienced improved maternal functional and emotional coping outcomes, which resulted in significantly fewer child adjustment problems.
Melnyk	2007	PMH	Mothers (n=143) and their 2-7-year-old children, unexpectedly hospitalized in 2 PICUs, randomized to a support program or standard care.	Parental beliefs, anxiety, negative mood, and child adjustment. Observers rated maternal support of their children during hospitalization.	During hospitalization and again 3 months later.	Program participation was associated with more maternal support of their children, which was also associated with less internalizing and externalizing behaviors 3 months post discharge.
Mesotten	2012	FF	569 4 year olds who had been admitted to a PICU when they were under 1 year old and 216 healthy control children.	Neurologic examination, WISC, WIPSI-R, DTVM-5, ANT, CMS, CBCL.	3 years after index critical illness.	Children who received tight glucose control during an ICU admission had the same intellect and incidence of poor outcome as children who had received usual care.

Mikkelson	2017	FF, PMH, S	5 children with a PICU stay for more than three days, who had a diary written for them, and their families.	Semi-structured interviews.	4-6 months after PICU discharge.	Diaries were used as a support for both children and families and played a role in making the PICU experience meaningful by providing explanations and coherence.
Moore	2015	FF	15 mothers of children who had an acute hospital stay after TBI	Semi-structured interviews and one small focus group.	Within 5 years of hospital discharge.	Parents valued detailed, frequent communication that set realistic expectations and prepared them for decision-making and outcomes. Areas for improvement included provider cultural humility, parent participation in care and institutional flexibility.
Oxley	2015	PMH	6 parents of PICU survivors from a single PICU in the UK.	Unstructured interviews.	After hospital discharge, but unspecified time interval.	Parents' PICU journey was traumatic, emotional and devastating. They 'cope' while they are in hospital, but, once at home, it takes some time for the reality of what has happened to sink in.
Rees	2004	PMH	PICU survivors aged 5–18 years (n=35), pediatric ward survivors (n=33) and their parents.	CAPS-C, IES, GHQ, HADS, SDQ, Birlson Depression Scale-Revised, Children's Manifest Anxiety Scale, Child Somatization Inventory, BDI.	6-12 months after hospital discharge.	27% of parents of PICU survivors screened positive for PTSD, vs 7% of parents of ward-admitted children.
Rodriguez	2017	PMH	143 parents of Spanish PICU survivors	HADS, PTGI, Davidson Trauma Scale.	6 months after hospital discharge.	There was a moderate, direct association between post traumatic stress disorder, depression and anxiety with post traumatic growth.

Samuel	2015	PMH	209 parents of survivors from a UK PICU, 157 providing full follow-up data, randomized to receive offers of follow-up care or standard care.	Posttraumatic Adjustment Scale, IES, HADS.	Follow-up appointment at 2 months after discharge for intervention group with repeat assessment at 6 months.	High risk parents were significantly more likely to score above the clinical cutoff for psychological outcomes than parents deemed low risk at baseline. At follow-up, there were no differences between the intervention and control groups.
Seddon	1990	PMH	31 Asthmatic children admitted to a PICU for mechanical ventilation on 48 occasions during a 25 year period in a single UK center.	Unspecified neurologic and medical examination.	The median duration of follow up was 11 years (range 1.1-15.6 years).	8/31 children died during their initial hospitalization, and another 4 died subsequently. None of the survivors suffered long term neurological sequelae.
Shears	2005	PMH	60 children aged 3-6 years admitted to the PICU or general ward for meningococcus, plus 60 mothers and 45 fathers.	SDQ-parent and teacher versions, IES, GHQ.	3 months after hospital discharge.	Admission of children to a PICU for meningococcal disease is associated with psychiatric and posttraumatic stress symptoms in children and parents.
Shears	2007	PMH	65 Children ages 3-16 years with meningococcal disease admitted to 3 PICUs and 19 pediatric wards in the London area, and their parents.	Semi-structured interviews; SDQ, CBCL; GMSPS, K-SADS-IV-R, Children`s Global Assessment Scale.	At the time of PICU admission and again 9-12 months after hospital discharge.	Psychiatric disorders are common in the year after meningococcal disease. Predictors of psychiatric disorders were maternal premorbid negative life events and interaction effects between illness variables.
Stowman	2015	PMH	50 PICU survivors aged 9-17 years in a US PICU, and 50 of their parents.	ASDS, BDI-II, MAQ, CBCL, CSDC, PTSD Checklist-Civilian.	4-7 weeks after hospital discharge.	Key mediators of the progression from ASD to PTSD were anxiety, negative affect, and hospital fear. Youth and parent ASD in the PICU predicted parent PTSS at follow-up.

Tomlin	2002	FF, FW, S	Families of 82 children <16 years old who had been managed in UK PICUs for severe TBI.	Outcomes assessment developed by study investigators.	At the time of hospital discharge; 6 weeks, 6 months and 12 months after discharge.	Many families struggle with medical, psychological, social and financial constraints after their child's severe TBI. Poorly organized follow-up and poor parental understanding of the system contributes to suboptimal outcomes.
Tomlinson	1995	FF, PMH	20 children aged 2 days-17 years who survived a PICU hospitalization, and their mothers.	PsySI, MOS, semi-structured interviews.	9 weeks after PICU hospitalization.	Mothers experienced only minor declines in mental health, and generally maintained good overall health.
Tse	1987	PMH	80 Parents of children who survived a <5 day PICU admission in a single center in the midwestern United States.	Development of a model with 30 parents, followed by implementation of the model on another 50 parents.	Interviews were conducted 24-36 hours after the child's discharge from the PICU.	Parents' attitudes towards their child's admission and outcome were influenced by knowledge of similar situations, previous exposure to intensive care units, and previous knowledge of similar illnesses.
van Zelle	2015	PMH, PPH	Families of children who survived cardiac arrest who completed online questionnaires (n=57) or in-person evaluation (n=47).	HUI, CHQ, SF-36.	2-11 years after hospital discharge.	Compared with Dutch norms, parent-reported HRQL for their children was significantly lower than for population norms, while children's self reports were similar to normal peers. Parents' self reported HRQL was better than Dutch norms.
Vermunt	2008	PMH	89 survivors of <i>n. meningitidis</i> infection, aged 6-17 years, admitted to a Dutch PICU.	Semi-structured interview, CBCL, TRF, YSR.	Minimum of 4 years after hospital discharge.	Survivors had more somatic complaints but similar scores on psychological testing compared to reference groups.

Vermunt	2010	PMH	87 Mothers and 77 fathers of children and adolescents who survived meningococcal septic shock.	GHQ, UCL, and semi-structured disease-specific interviews.	4 - 16 years after child's illness.	Most parents reported no current disease-related psychosocial limitations. Somatic and behavioral symptoms were not associated with parental psychiatric symptoms or styles of coping.
Youngblut	1993	FF, PMH	9 two-parent families of children aged 0-5 years old admitted to a Midwestern children's hospital PICU.	PCS, PSI:PICU, FFFS, FACES III, PBQ	24-48 hours after child's admission to the PICU and again 2-4 weeks after child's discharge from the hospital.	Mothers, but not fathers, noted a decline in family functioning. Family adaptability was higher than in population norms. The child's severity of illness was related to some of the family measures.
Youngblut	1995	FF, PMH	Parents of 1-5 year olds who had been admitted to a PICU (n=27) or a general ward (n=25)	FACES III and FFFS	Within 3 years of child's hospital discharge.	No significant difference in family functioning scores between parent groups. Mothers scored differently than fathers.
Youngblut	2006	FF, PMH	97 mothers and 37 fathers of 106 preschool children hospitalized with head injury.	MHI, PSI, FACES II, and a scale of perceived social support.	2 weeks after child's hospital discharge.	Mental health post-discharge was related to social support and baseline mental health. Mothers' distress was related to perceived injury severity and social support.
Youngblut	2013	S, PMH	27 parents of 24 deceased children who had died in a NICU or PICU.	Semi-structured interviews.	7 months after child's death.	Children's responses following a sibling's death vary with the child's sex, parents' race/ethnicity, and the unit where the sibling died. Children recognized their parents' grief and tried to comfort them.
Youngblut	2013	FF, FW, PMH, PPH	176 mothers and 73 fathers of 188 deceased infants/children.	BDI, IES-R, and semi-structured interviews.	1, 3, 6, and 13 months after infant/child death.	Parents, especially minority mothers, have negative physical and mental health outcomes during the first year after their child's NICU/PICU death.

A-State=State Anxiety Inventory; ANT=Amsterdam Neuropsychological Tasks; ASDS=Acute Stress Disorder Scale; BASC=Behavioral Assessment System for Children; BCL=Behavior Checklist; BDI=Beck Depression Inventory; CAPS-C=Clinician Administered PTSD Scale-Child; CBCL=Child Behavior Checklist; CHQ=Child Health Questionnaire; CMS=Children's Memory Scale; CPTS-RI=Child Posttraumatic Stress Reaction Index; CQ=Caregiving Questionnaire; CRI=Coping Resources Inventory; CRIES-8=Child Revised Impact of Events Scale 8; CRTI=Children's Responses to Trauma Inventory; CSHQ=Children's Sleep Habits Questionnaire; DTVM-5=Beery-Buktenica Developmental Test of Visual-Motor Integration, 5th Edition; FACES III= Family Adaptability and Cohesiveness Evaluation Scale, version 3; FAD=Family Assessment Device; FAM III=Family Assessment Measure III; FFFS=Feetham Family Functioning Survey; FILE=Family Inventory of Life Events and Changes; FSII (R)=Stein-Jessup Functional Status II (Revised); GAQ=Grief Avoidance Questionnaire; GHI=Global Health Index; GHQ=General Health Questionnaire; GHQ-30= General Health Questionnaire, version with 30 questions; GMSPS=Glasgow Meningococcal Septicaemia Prognostic Score; HADS=Hospital Anxiety and Depression Scale; HRQL=health-related quality of life; HUI=Health Utilities Index; ICF-CY=International Classification of Functioning, Disability and Health – Version for Children and Youth; ICG=Inventory of Complicated Grief; IES=Impact of Events Scale; IES-R=Impact of Events Scale-Revised; IOS-R=Impact on Family Scale-Revised; IPP=Index of Parent Participation; IPS=Index of Parent Support; ITQL=Infant Toddler Quality of Life; K-SADS-IV-R=Schedule for Affective Disorders and Schizophrenia for School-Age Children-IV-Revised; LOS=length of stay; MAQ=Multidimensional Anxiety Questionnaire; MHI=Mental Health Inventory; MOS=Medical Outcomes Study Short-Form General Health Survey; PBQ=Posthospitalization Behavior Questionnaire; PCS=Parental Concerns Scale; PCPC=Pediatric Cerebral Performance Category; PDEQ=Peritraumatic Dissociative Experiences Questionnaire; PDS=Posttraumatic Diagnostic Scale; PEDI=Pediatric Evaluation of Disability Inventory; PEM-CY=Participation and Environment Measure for Children and Youth; POMS=Profile of Mood States; POPC=Pediatric Overall Performance Category; PICU=pediatric intensive care unit; PRQ=Parenting Role Questionnaire; PSI=Parenting Stress Index; PSI-C=Post-hospital Stress Index-Children; PSI-P=Post-hospital Stress Index-Parent; PSS:PICU=Parental Stressor Scale:PICU; PsySI=Psychological Stability Index; PTGI=Post-Traumatic Growth Inventory; PTSS=Post-traumatic Stress Symptoms; PTSD=Post-traumatic Stress Disorder; RSQ=Relationship Scales Questionnaire; SDQ=Strengths and Difficulties Questionnaire; SCID=Structured Clinical Interview for the DSM-IV Axis Disorders; SCL-90-R=Symptom Checklist-90 Revised; SES= Socioeconomic status; SF-36=Short-Form 36; SPAN=Startle, Physiological arousal, Anger, and Numbing; SRS-PTSD=Self-Rating Scale for PTSD; SSQ-SF=Social Support Questionnaire-Short Form; STAI=State Trait Anxiety Inventory; TBI=Traumatic Brain Injury; TRF=Teacher's Report Form; TRIG=Texas Revised Inventory of Grief; UCL=Utrecht Coping List; VAS-EC=Involvement in Emotional Care; VAS-PC=Involvement in Physical Care; VBAS=Vineland Adaptive Behavior Scale II; WISC=Wechsler Intelligence Quotient Scales; WIPSI=Wechsler Preschool and Primary Scale of Intelligence-Revised; WISC-3=Wechsler Intelligence Scale for Children-3rd Edition; WASC-3=Wechsler Adult Intelligence Scale-3rd Edition; YSR=Youth Self-Report

FF=Family Function, EF=Extended Family, FW=Finance/Economics/Work, PMH=Parental Mental Health, PPH=Parental Physical Health, S=Siblings

1. Hartman ME, Saeed MJ, Bennett T, Typpo K, Matos R, Olsen MA: **Readmission and Late Mortality After Critical Illness in Childhood.** *Pediatr Crit Care Med* 2017, **18**(3):e112-e121.
2. Ghaffari J AA, Nazari Z: **Mortality Rate in Pediatric Intensive Care Unit (PICU): A Local Center Experience.** *international Journal of Pediatrics* 2014, **2**(3.2):81-88.
3. Kalzen H, Larsson B, Eksborg S, Lindberg L, Edberg KE, Frostell C: **Survival after PICU admission: The impact of multiple admissions and complex chronic conditions.** *PLoS One* 2018, **13**(4):e0193294.
4. Manning JC, Pinto NP, Rennick JE, Colville G, Curley MAQ: **Conceptualizing Post Intensive Care Syndrome in Children-The PICS-p Framework.** *Pediatr Crit Care Med* 2018, **19**(4):298-300.
5. Maddux AB, Pinto N, Fink EL, Hartman ME, Nett S, Biagas K, Killien EY, Dervan LA, Christie LM, Lockett PM *et al*: **Postdischarge Outcome Domains in Pediatric Critical Care and the Instruments Used to Evaluate Them: A Scoping Review.** *Crit Care Med* 2020, **48**(12):e1313-e1321.
6. Atkins E, Colville G, John M: **A 'biopsychosocial' model for recovery: a grounded theory study of families' journeys after a Paediatric Intensive Care Admission.** *Intensive Crit Care Nurs* 2012, **28**(3):133-140.
7. Board R, Ryan-Wenger N: **Long-term effects of pediatric intensive care unit hospitalization on families with young children.** *Heart Lung* 2002, **31**(1):53-66.
8. Cantwell-Bartl AM, Tibballs J: **Psychosocial experiences of parents of infants with hypoplastic left heart syndrome in the PICU.** *Pediatr Crit Care Med* 2013, **14**(9):869-875.
9. Dampier S CS, Watson D: **An investigation of the hospital experiences of parents with a child in paediatric intensive care.** *NTresearch* 2002, **7**(3):179-186.
10. Kapapa T, Konig K, Pfister U, Sasse M, Woischneck D, Heissler H, Rickels E: **Head trauma in children, part 2: course and discharge with outcome.** *J Child Neurol* 2010, **25**(3):274-283.
11. Keenan HT, Runyan DK, Nocera M: **Child outcomes and family characteristics 1 year after severe inflicted or noninflicted traumatic brain injury.** *Pediatrics* 2006, **117**(2):317-324.
12. Kirk S, Fallon D, Fraser C, Robinson G, Vassallo G: **Supporting parents following childhood traumatic brain injury: a qualitative study to examine information and emotional support needs across key care transitions.** *Child Care Health Dev* 2015, **41**(2):303-313.
13. Lawson CA, Werner R, Nugent SK: **Parental stress during and after pediatric ICU hospitalization.** *Indiana Med* 1985, **78**(5):372-375.
14. Lewis AR, Wray J, O'Callaghan M, Wroe AL: **Parental symptoms of posttraumatic stress after pediatric extracorporeal membrane oxygenation*.** *Pediatr Crit Care Med* 2014, **15**(2):e80-88.
15. Lutz KF: **Feeding Problems of NICU and PICU Graduates: Perceptions of Parents and Providers.** *Newborn Infant Nurs Rev* 2012, **12**(4):207-213.
16. Meert KL, Slomine BS, Christensen JR, Telford R, Holubkov R, Dean JM, Moler FW, Therapeutic Hypothermia after Pediatric Cardiac Arrest Trial I: **Family Burden After Out-of-Hospital Cardiac Arrest in Children.** *Pediatr Crit Care Med* 2016, **17**(6):498-507.
17. Mesotten D, Gielen M, Sterken C, Claessens K, Hermans G, Vlasselaers D, Lemiere J, Lagae L, Gewillig M, Eyskens B *et al*: **Neurocognitive development of children 4 years after critical illness and treatment with tight glucose control: a randomized controlled trial.** *JAMA* 2012, **308**(16):1641-1650.
18. Mikkelsen G: **The meaning of personal diaries to children and families in the paediatric intensive care unit: A qualitative study.** *Intensive Crit Care Nurs* 2018, **45**:25-30.
19. Moore M, Robinson G, Mink R, Hudson K, Dotolo D, Gooding T, Ramirez A, Zatzick D, Giordano J, Crawley D *et al*: **Developing a Family-Centered Care Model for Critical Care After Pediatric Traumatic Brain Injury.** *Pediatr Crit Care Med* 2015, **16**(8):758-765.
20. Shears D, Nadel S, Gledhill J, Garralda ME: **Short-term psychiatric adjustment of children and their parents following meningococcal disease.** *Pediatr Crit Care Med* 2005, **6**(1):39-43.
21. Shears D, Nadel S, Gledhill J, Gordon F, Garralda ME: **Psychiatric adjustment in the year after meningococcal disease in childhood.** *J Am Acad Child Adolesc Psychiatry* 2007, **46**(1):76-82.
22. Tomlin P, Clarke M, Robinson G, Roach J: **Rehabilitation in severe head injury in children: outcome and provision of care.** *Dev Med Child Neurol* 2002, **44**(12):828-837.
23. Tomlinson PS, Harbaugh BL, Kotchevar J, Swanson L: **Caregiver mental health and family health outcomes following critical hospitalization of a child.** *Issues Ment Health Nurs* 1995, **16**(6):533-545.
24. van Zelle L, Utens EM, Legerstee JS, Cransberg K, Hulst JM, Tibboel D, Buysse C: **Cardiac Arrest in Children: Long-Term Health Status and Health-Related Quality of Life.** *Pediatr Crit Care Med* 2015, **16**(8):693-702.

25. Youngblut JM, Shiao SY: **Child and family reactions during and after pediatric ICU hospitalization: a pilot study.** *Heart Lung* 1993, **22**(1):46-54.
26. Youngblut JM, Lauzon S: **Family functioning following pediatric intensive care unit hospitalization.** *Issues Compr Pediatr Nurs* 1995, **18**(1):11-25.
27. Youngblut JM, Brooten D: **Pediatric head trauma: parent, parent-child, and family functioning 2 weeks after hospital discharge.** *J Pediatr Psychol* 2006, **31**(6):608-618.
28. Youngblut JM, Brooten D: **Parents' report of child's response to sibling's death in a neonatal or pediatric intensive care unit.** *Am J Crit Care* 2013, **22**(6):474-481.
29. Als LC, Nadel S, Cooper M, Vickers B, Garralda ME: **A supported psychoeducational intervention to improve family mental health following discharge from paediatric intensive care: feasibility and pilot randomised controlled trial.** *BMJ Open* 2015, **5**(12):e009581.
30. Balluffi A, Kassam-Adams N, Kazak A, Tucker M, Dominguez T, Helfaer M: **Traumatic stress in parents of children admitted to the pediatric intensive care unit.** *Pediatr Crit Care Med* 2004, **5**(6):547-553.
31. Bloom AA, Wright JA, Morris RD, Campbell RM, Krawiecki NS: **Additive impact of in-hospital cardiac arrest on the functioning of children with heart disease.** *Pediatrics* 1997, **99**(3):390-398.
32. Board R, Dai J: **Effects of five parent-and-child risk factors on salivary cortisol levels and symptoms of posttraumatic stress disorder in school-age, critically ill children: pilot study.** *Heart Lung* 2011, **40**(3):236-246.
33. Bronner MB, Knoester H, Bos AP, Last BF, Grootenhuis MA: **Posttraumatic stress disorder (PTSD) in children after paediatric intensive care treatment compared to children who survived a major fire disaster.** *Child Adolesc Psychiatry Ment Health* 2008, **2**(1):9.
34. Bronner MB, Knoester H, Bos AP, Last BF, Grootenhuis MA: **Follow-up after paediatric intensive care treatment: parental posttraumatic stress.** *Acta Paediatr* 2008, **97**(2):181-186.
35. Bronner MB, Knoester H, Sol JJ, Bos AP, Heymans HS, Grootenhuis MA: **An explorative study on quality of life and psychological and cognitive function in pediatric survivors of septic shock.** *Pediatr Crit Care Med* 2009, **10**(6):636-642.
36. Bronner MB, Peek N, Knoester H, Bos AP, Last BF, Grootenhuis MA: **Course and predictors of posttraumatic stress disorder in parents after pediatric intensive care treatment of their child.** *J Pediatr Psychol* 2010, **35**(9):966-974.
37. Buysse CM, Raat H, Hazelzet JA, Vermunt LC, Utens EM, Hop WC, Joosten KF: **Long-term health-related quality of life in survivors of meningococcal septic shock in childhood and their parents.** *Qual Life Res* 2007, **16**(10):1567-1576.
38. Choong K, Al-Harbi S, Siu K, Wong K, Cheng J, Baird B, Pogorzelski D, Timmons B, Gorter JW, Thabane L *et al*: **Functional recovery following critical illness in children: the "wee-cover" pilot study.** *Pediatr Crit Care Med* 2015, **16**(4):310-318.
39. Colville GA, Gracey D: **Mothers' recollections of the Paediatric Intensive Care Unit: associations with psychopathology and views on follow up.** *Intensive Crit Care Nurs* 2006, **22**(1):49-55.
40. Colville G, Cream P: **Post-traumatic growth in parents after a child's admission to intensive care: maybe Nietzsche was right?** *Intensive Care Med* 2009, **35**(5):919-923.
41. Colville G, Pierce C: **Patterns of post-traumatic stress symptoms in families after paediatric intensive care.** *Intensive Care Med* 2012, **38**(9):1523-1531.
42. Colville G, Darkins J, Hesketh J, Bennett V, Alcock J, Noyes J: **The impact on parents of a child's admission to intensive care: integration of qualitative findings from a cross-sectional study.** *Intensive Crit Care Nurs* 2009, **25**(2):72-79.
43. Colville GA, Cream PR, Kerry SM: **Do parents benefit from the offer of a follow-up appointment after their child's admission to intensive care?: an exploratory randomised controlled trial.** *Intensive Crit Care Nurs* 2010, **26**(3):146-153.
44. Curley MA, Meyer EC: **Parental experience of highly technical therapy: survivors and nonsurvivors of extracorporeal membrane oxygenation support.** *Pediatr Crit Care Med* 2003, **4**(2):214-219.
45. Diaz-Caneja A, Gledhill J, Weaver T, Nadel S, Garralda E: **A child's admission to hospital: a qualitative study examining the experiences of parents.** *Intensive Care Med* 2005, **31**(9):1248-1254.
46. Ehrlich TR, Von Rosenstiel IA, Grootenhuis MA, Gerrits AI, Bos AP: **Long-term psychological distress in parents of child survivors of severe meningococcal disease.** *Pediatr Rehabil* 2005, **8**(3):220-224.

47. Franich-Ray C, Bright MA, Anderson V, Northam E, Cochrane A, Menahem S, Jordan B: **Trauma reactions in mothers and fathers after their infant's cardiac surgery.** *J Pediatr Psychol* 2013, **38**(5):494-505.
48. Garralda ME, Gledhill J, Nadel S, Neasham D, O'Connor M, Shears D: **Longer-term psychiatric adjustment of children and parents after meningococcal disease.** *Pediatr Crit Care Med* 2009, **10**(6):675-680.
49. Guan G, Liu H, Wang Y, Han B, Jin Y: **Behavioural and emotional outcomes in school-aged children after surgery or transcatheter closure treatment for ventricular septal defect.** *Cardiol Young* 2014, **24**(5):910-917.
50. Helfricht S, Latal B, Fischer JE, Tomaske M, Landolt MA: **Surgery-related posttraumatic stress disorder in parents of children undergoing cardiopulmonary bypass surgery: a prospective cohort study.** *Pediatr Crit Care Med* 2008, **9**(2):217-223.
51. Judge D, Nadel S, Vergnaud S, Garralda ME: **Psychiatric adjustment following meningococcal disease treated on a PICU.** *Intensive Care Med* 2002, **28**(5):648-650.
52. Khanna S, Finlay JK, Jatana V, Gouffe AM, Redshaw S: **The Impact of Observed Trauma on Parents in a PICU.** *Pediatr Crit Care Med* 2016, **17**(4):e154-158.
53. Landolt MA, Buechel EV, Latal B: **Predictors of parental quality of life after child open heart surgery: a 6-month prospective study.** *J Pediatr* 2011, **158**(1):37-43.
54. Latour JM, van Goudoever JB, Schuurman BE, Albers MJ, van Dam NA, Dullaart E, van Heerde M, Verlaat CW, van Vught EM, Hazelzet JA: **A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units.** *Intensive Care Med* 2011, **37**(2):319-325.
55. Majnemer A, Limperopoulos C, Shevell MI, Rohlicek C, Rosenblatt B, Tchervenkov C: **A new look at outcomes of infants with congenital heart disease.** *Pediatr Neurol* 2009, **40**(3):197-204.
56. Maxton FJ: **Parental presence during resuscitation in the PICU: the parents' experience. Sharing and surviving the resuscitation: a phenomenological study.** *J Clin Nurs* 2008, **17**(23):3168-3176.
57. McGraw SA, Truog RD, Solomon MZ, Cohen-Bearak A, Sellers DE, Meyer EC: **"I was able to still be her mom"--parenting at end of life in the pediatric intensive care unit.** *Pediatr Crit Care Med* 2012, **13**(6):e350-356.
58. Meert KL, Thurston CS, Thomas R: **Parental coping and bereavement outcome after the death of a child in the pediatric intensive care unit.** *Pediatr Crit Care Med* 2001, **2**(4):324-328.
59. Meert KL, Eggly S, Pollack M, Anand KJ, Zimmerman J, Carcillo J, Newth CJ, Dean JM, Willson DF, Nicholson C *et al*: **Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit.** *Pediatr Crit Care Med* 2008, **9**(1):2-7.
60. Meert KL, Donaldson AE, Newth CJ, Harrison R, Berger J, Zimmerman J, Anand KJ, Carcillo J, Dean JM, Willson DF *et al*: **Complicated grief and associated risk factors among parents following a child's death in the pediatric intensive care unit.** *Arch Pediatr Adolesc Med* 2010, **164**(11):1045-1051.
61. Meert KL, Eggly S: **Follow-up after a child's death in the pediatric intensive care unit: Can it improve family outcomes?** *Pediatr Crit Care Med* 2011, **12**(6):676-677.
62. Meert KL, Eggly S, Kavanaugh K, Berg RA, Wessel DL, Newth CJ, Shanley TP, Harrison R, Dalton H, Dean JM *et al*: **Meaning making during parent-physician bereavement meetings after a child's death.** *Health Psychol* 2015, **34**(4):453-461.
63. Melnyk BM, Alpert-Gillis LJ, Hensel PB, Cable-Beiling RC, Rubenstein JS: **Helping mothers cope with a critically ill child: a pilot test of the COPE intervention.** *Res Nurs Health* 1997, **20**(1):3-14.
64. Melnyk BM, Alpert-Gillis L, Feinstein NF, Crean HF, Johnson J, Fairbanks E, Small L, Rubenstein J, Slota M, Corbo-Richert B: **Creating opportunities for parent empowerment: program effects on the mental health/coping outcomes of critically ill young children and their mothers.** *Pediatrics* 2004, **113**(6):e597-607.
65. Melnyk BM, Crean HF, Feinstein NF, Fairbanks E, Alpert-Gillis LJ: **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.** *J Pediatr Psychol* 2007, **32**(4):463-474.
66. Oxley R: **Parents' experiences of their child's admission to paediatric intensive care.** *Nurs Child Young People* 2015, **27**(4):16-21.
67. Rees G, Gledhill J, Garralda ME, Nadel S: **Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study.** *Intensive Care Med* 2004, **30**(8):1607-1614.
68. Rodriguez-Rey R, Alonso-Tapia J: **Relation between parental psychopathology and posttraumatic growth after a child's admission to intensive care: Two faces of the same coin?** *Intensive Crit Care Nurs* 2017, **43**:156-161.

69. Samuel VM, Colville GA, Goodwin S, Ryninks K, Dean S: **The Value of Screening Parents for Their Risk of Developing Psychological Symptoms After PICU: A Feasibility Study Evaluating a Pediatric Intensive Care Follow-Up Clinic.** *Pediatr Crit Care Med* 2015, **16**(9):808-813.
70. Seddon PC, Heaf DP: **Long term outcome of ventilated asthmatics.** *Arch Dis Child* 1990, **65**(12):1324-1327; discussion 1327-1328.
71. Stowman S, Kearney CA, Daphtary K: **Mediators of Initial Acute and Later Posttraumatic Stress in Youth in a PICU.** *Pediatr Crit Care Med* 2015, **16**(4):e113-118.
72. Tse AM, Perez-Woods RC, Opie ND: **Children's admissions to the intensive care unit: parents' attitudes and expectations of outcome.** *Child Health Care* 1987, **16**(2):68-75.
73. Vermunt LC, Buysse CM, Joosten KF, Hazelzet JA, Verhulst FC, Utens EM: **Behavioural, emotional, and post-traumatic stress problems in children and adolescents, long term after septic shock caused by Neisseria meningitidis.** *Br J Clin Psychol* 2008, **47**(Pt 3):251-263.
74. Meert KL, Briller SH, Schim SM, Thurston CS: **Exploring parents' environmental needs at the time of a child's death in the pediatric intensive care unit.** *Pediatr Crit Care Med* 2008, **9**(6):623-628.
75. Youngblut JM, Brooten D, Cantwell GP, del Moral T, Totapally B: **Parent health and functioning 13 months after infant or child NICU/PICU death.** *Pediatrics* 2013, **132**(5):e1295-1301.
76. Meert KL, Shear K, Newth CJ, Harrison R, Berger J, Zimmerman J, Anand KJ, Carcillo J, Donaldson AE, Dean JM *et al*: **Follow-up study of complicated grief among parents eighteen months after a child's death in the pediatric intensive care unit.** *J Palliat Med* 2011, **14**(2):207-214.
77. Buysse CM, Raat H, Hazelzet JA, Hulst JM, Cransberg K, Hop WC, Vermunt LC, Utens EM, Maliepaard M, Joosten KF: **Long-term health status in childhood survivors of meningococcal septic shock.** *Arch Pediatr Adolesc Med* 2008, **162**(11):1036-1041.
78. Vermunt LC, Buysse CM, Joosten KF, Hazelzet JA, Verhulst FC, Utens EM: **Recovery in parents of children and adolescents who survived septic shock caused by Neisseria meningitidis: a cross-sectional study.** *Intensive Crit Care Nurs* 2010, **26**(3):128-137.