

**Journal**

European Journal of Pediatrics

Manuscript accepted: 16-08-2022

**Title Page****Impact of ethnicity on parental health outcomes and experiences after paediatric intensive care unit discharge: A mixed-methods systematic review**

Pei-Fen Poh, RN, MSc<sup>a,b</sup>, Matthew C. Carey, RN, PhD<sup>a,c</sup>, Jan Hau Lee, MBBS, MRCPCH, MCI<sup>b,d</sup>, Joseph C. Manning, RN, PhD<sup>e,f</sup> and Jos M Latour, RN, PhD<sup>a,c,g,h</sup>

**Affiliations**

<sup>a</sup>School of Nursing and Midwifery, Faculty of Health, University of Plymouth, Plymouth, United Kingdom;

<sup>b</sup>Children's Intensive Care Unit, KK Women's and Children's Hospital, Singapore;

<sup>c</sup>The University of Plymouth Centre for Innovations in Health and Social Care: a Joanna Briggs Institute Centre of Excellence, Faculty of Health, University of Plymouth, Plymouth, United Kingdom

<sup>d</sup>Duke-NUS Medical School, Singapore;

<sup>e</sup>Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust, UK;

<sup>f</sup>Centre for Children and Young People Health Research, School of Health Sciences, University of Nottingham, Nottingham, United Kingdom.

<sup>g</sup>School of Nursing, Midwifery and Paramedicine, Faculty of Health Sciences, Curtin University, Perth, Australia.

<sup>h</sup>Department of Nursing, Hunan Children's Hospital, Changsha, China.

**Email address**

Pei-Fen Poh : [peifenpoh@gmail.com](mailto:peifenpoh@gmail.com)  
Matthew C. Carey : [matthew.carey@plymouth.ac.uk](mailto:matthew.carey@plymouth.ac.uk)  
Jan Hau Lee : [gmsljh@nus.edu.sg](mailto:gmsljh@nus.edu.sg)  
Joseph C. Manning : [Joseph.Manning@nottingham.ac.uk](mailto:Joseph.Manning@nottingham.ac.uk)  
Jos M Latour : [jos.latour@plymouth.ac.uk](mailto:jos.latour@plymouth.ac.uk)

**ORCID**

Pei-Fen Poh : 0000-0002-9078-6929  
Matthew C. Carey : 0000-0003-3411-0657  
Jan Hau Lee : 0000-0002-8430-4217  
Joseph C. Manning : 0000-0002-6077-4169  
Jos M Latour : 0000-0002-8087-6461

## **Abstract**

The impact of ethnicity on parental health outcome after paediatric intensive care unit (PICU) discharge remains unclear. Thirteen medical and healthcare databases, unpublished studies and grey literature were searched up to November 5, 2021. We performed a mixed-method systematic review to understand the impact of ethnicity on parental outcomes after PICU discharge, including eight quantitative and eight qualitative studies. Among 1529 parents included, 1064 (72%) were White. Higher prevalence of post-traumatic stress disorder was seen in Black parents (17% White vs 36% Black,  $p=.03$ ). Latino ethnicity was found to have protective effect against anxiety as compared to White parents (coefficient -4.27,  $p<.001$ ). A total of 91 findings were aggregated into 14 categories and five synthesized themes from the eight qualitative studies were: long-term psychological impact after PICU, use of coping strategies, challenges of re-integration, changes in relationships and the utilisation of formal support services and resources. Mixed-method synthesis found that parents of ethnic minority group were underrepresented (18%) and had higher attrition rates in a longitudinal study as compared to White non-Hispanic parents following childhood critical illness.

*Conclusion:* There are significant gaps in evidence related to the impact of ethnicity on long-term parental health outcomes after PICU discharge. Ethnic diversity and inclusiveness in long-term PICU research may aid understanding of the parental experiences and outcomes to close the gap in health disparity.

**Keywords:** Ethnicity; paediatric intensive care; parental outcomes; race

## List of Abbreviations

ASD	Acute stress disorder
CINAHL	Cumulated Index to Nursing and Allied Health Literature
CKNI	China National Knowledge Infrastructure
COPE	Creating opportunities for parent empowerment
EBP	Evidenced Based Practice
EDI	Equity, diversity and inclusion
EMBASE	the Cochrane Library, Excerpta Medica dataBASE
EThOS	E-These Online Service (
JBI	Joanne Briggs Institute Literatura Latino-Americana em Ciências da Saúde – Latin American and Caribbean Health
LILACS	Sciences Literature
MEDLINE	Medical Literature Analysis and Retrieval System Online
PICU	paediatric intensive care unit
PISC-p	Post-Intensive Care Syndrome-pediatrics
PTS	Post-traumatic stress
PTSD	Post-traumatic stress disorder
PubMed	ProQuest, Public/Publisher MEDLINE
SciELO	Scientific Electronic Library Online
T	Time-point
TBI	Traumatic brain injury

## What is Known

- Survival rates of paediatric critical illness has improved
- Families of paediatric intensive care unit survivors continue to experience mental-health issues, with 30% experiencing symptoms of post-traumatic stress six months after discharge.

## What is New

- Parents from different ethnic backgrounds are underrepresented in paediatric critical care research
- Minorities experiences worse short-term outcomes after intensive care discharge.
- Current available studies are limited in the description of experiences of parents from different ethnicities.

## Corresponding Author:

Pei-Fen Poh, Children's Intensive Care Unit, KK Women's and Children's Hospital, 100 Bukit Timah Road, Singapore 229899, [poh.pei.fen@kkh.com.sg](mailto:poh.pei.fen@kkh.com.sg) , 65-6394 1778

## **Statements and Declarations**

**Funding:** This research is supported through the KK Women's and Children's Hospital (KKH) Academic Medicine Start-up Fund (Ref: KRDUK20AR100, October 2020) and SingHealth FY2019 Talent Development Fund (TDF) Award-Research (December 2018).

**Conflicts of interest/Competing interests:** Pei-Fen Poh received funding from the KK Women's and Children's Hospital. Dr Jan Hau Lee received funding from the National Medical Research Council, Singapore. Dr Joseph Manning is currently funded through NIHR HEE ICA Clinical Lectureship and therefore the views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care, UK.

**Authors' contributions:** PFP, MCC, JHL, JCM and JML conceptualized and designed the systematic review. PFP and MC performed the data collection. PFP, MCC, JCM and JML conducted the data synthesis. PFP drafted the first manuscript and MCC, JHL, JCM and JML critically reviewed the manuscript drafts. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

**Availability of data and material:** Yes

**Code availability:** Not applicable

**Ethics approval:** Not applicable

**Consent to participate:** Not applicable

**Consent for publication:** Not applicable

# **Impact of ethnicity on parental health outcomes and experiences after paediatric intensive care unit discharge: A mixed-methods systematic review**

Pei-Fen Poh, RN, MSc<sup>a,b</sup>, Matthew C. Carey, RN, PhD<sup>a,c</sup>, Jan Hau Lee, MBBS, MRCPCH, MCI<sup>b,d</sup>, Joseph C. Manning, RN, PhD<sup>e,f</sup> and Jos M Latour, RN, PhD<sup>a,c,g,h</sup>

## **Affiliations**

<sup>a</sup>School of Nursing and Midwifery, Faculty of Health, University of Plymouth, Plymouth, United Kingdom;

<sup>b</sup>Children's Intensive Care Unit, KK Women's and Children's Hospital, Singapore;

<sup>c</sup>The University of Plymouth Centre for Innovations in Health and Social Care: a Joanna Briggs Institute Centre of Excellence, Faculty of Health, University of Plymouth, Plymouth, United Kingdom

<sup>d</sup>Duke-NUS Medical School, Singapore;

<sup>e</sup>Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust, UK;

<sup>f</sup>Centre for Children and Young People Health Research, School of Health Sciences, University of Nottingham, Nottingham, United Kingdom.

<sup>g</sup>School of Nursing, Midwifery and Paramedicine, Faculty of Health Sciences, Curtin University, Perth, Australia.

<sup>h</sup>Department of Nursing, Hunan Children's Hospital, Changsha, China.

## **Corresponding Author:**

Pei-Fen Poh: [peifenpoh@gmail.com](mailto:peifenpoh@gmail.com)

## **Abstract**

The impact of ethnicity on parental health outcome after paediatric intensive care unit (PICU) discharge remains unclear. Thirteen medical and healthcare databases, unpublished studies and grey literature were searched up to November 5, 2021. We performed a mixed-method systematic review to understand the impact of ethnicity on parental outcomes after PICU discharge, including eight quantitative and eight qualitative studies. Among 1529 parents included, 1064 (72%) were White. Higher prevalence of post-traumatic stress disorder was seen in Black parents (17% White vs 36% Black,  $p=.03$ ). Latino ethnicity was found to have protective effect against anxiety as compared to White parents (coefficient -4.27,  $p<.001$ ). A total of 91 findings were aggregated into 14 categories and five synthesized themes from the eight qualitative studies were: long-term psychological impact after PICU, use of coping strategies, challenges of re-integration, changes in relationships and the utilisation of formal support services and resources. Mixed-method synthesis found that parents of ethnic minority group were underrepresented (18%) and had higher attrition rates in a longitudinal study as compared to White parents following childhood critical illness.

*Conclusion:* There are significant gaps in evidence related to the impact of ethnicity on long-term parental health outcomes after PICU discharge. Ethnic diversity and inclusiveness in long-term PICU research may aid understanding of the parental experiences and outcomes to close the gap in health disparity.

**Keywords:** Ethnicity; paediatric intensive care; parental outcomes; race

**List of Abbreviations**

ASD	Acute stress disorder
CINAHL	Cumulated Index to Nursing and Allied Health Literature
CKNI	China National Knowledge Infrastructure
COPE	Creating opportunities for parent empowerment
EBP	Evidenced Based Practice
EDI	Equity, diversity and inclusion
EMBASE	the Cochrane Library, Excerpta Medica dataBASE
EThOS	E-These Online Service
JBI	Joanne Briggs Institute
LILACS	Literatura Latino-Americana em Ciências da Saúde – Latin American and Caribbean Health Sciences Literature
MEDLINE	Medical Literature Analysis and Retrieval System Online
PICU	Paediatric intensive care unit
PISC-p	Post-Intensive Care Syndrome-pediatrics
PTS	Post-traumatic stress
PTSD	Post-traumatic stress disorder
PubMed	ProQuest, Public/Publisher MEDLINE
SciELO	Scientific Electronic Library Online
T	Time-point
TBI	Traumatic brain injury

1 **Introduction**

2 Survival rates of critically ill children **have** improved over time (1). Given this improvement, the broader focus  
3 on survivors and their parents' health outcome is increasingly important and has been propelled by the  
4 conceptualization of the Post-Intensive Care Syndrome-pediatrics (PICS-p) framework (2). This framework  
5 recognizes that parents of these survivors often experience impairments in their emotional and social health  
6 following paediatric intensive care unit (PICU) discharge. Although there is a significant body of work on  
7 parental outcomes after PICU discharge, there **are** a limited number of studies that are conducted to compare  
8 ethnic differences in health outcomes among parents or caregivers of these young survivors (3). **Ethnicity is**  
9 **described as the multi-faceted quality referring the group, to which people particularly shares cultural**  
10 **traditions and language (4). Although ethnicities are surrogates for socioeconomic, cultural and genetics,**  
11 **information relating to socioeconomic and genetics are often unavailable (5). For these reasons, health**  
12 **researchers have used ethnicity as surrogates to examine its relationships with health outcomes.** Racial  
13 disparity in access and quality of mental health services are well documented, the minority groups suffer greater  
14 in their overall health (6). **A study conducted in the UK showed that children from minority ethnic groups**  
15 **were at higher risk of death after congenital heart surgery (7).** Race and ethnicity may also shape different  
16 patterns of coping styles and thereby explain differing mental health outcomes among family caregivers  
17 (8). **Understanding** the potential influence of ethnicity in parental health outcomes is **important to help us**  
18 **provide targeted support to families following PICU discharge (9,10).** There remains a lack of collective  
19 evidence **about** this important aspect of post-PICU care. To address this gap, we undertook a systematic review  
20 to evaluate the association between ethnicity and family health outcomes and experiences after PICU discharge.

21  
22 **Methods**

23 **Review questions**

- 24 (1) What differences have been reported on ethnicity impacting parental outcomes after PICU discharge? and  
25 (2) What are the experiences of parents from different ethnic backgrounds after PICU discharge?

26  
27 **Inclusion and Exclusion Criteria**

28 We included all studies on parents and caregivers (including grandparents etc.) of infants and children aged 0 to  
29 18 years who have been discharged from a PICU. The quantitative component of the review included studies  
30 that examined the effects of ethnicity on parental outcomes after PICU discharge. The qualitative component of



31 this review considered **the impact of ethnicity and parent’s experience after PICU discharge**. Studies that  
32 included bereaved **families, families receiving end-of-life care, or were conducted within the** neonatal and  
33 adult intensive care were excluded.

34

### 35 **Data Sources and Search Strategy**

36 **Thirteen** databases were searched CINAHL, EMBASE, JBIEBP, MEDLINE, PubMed, Scopus, PsychINFO,  
37 SciELO, LILACS, CKNI and Wanfang database. For unpublished studies and **grey** literature, we searched  
38 Clinicaltrials.gov, EThOS, Google Grey, Open Grey and Proquest Dissertations and Theses Global. All  
39 databases were searched until November 5, 2021, using search terms organized around the following key  
40 concepts: “paediatric intensive care units”, “parental outcomes” and “racial or ethnic disparities”. The search  
41 terms used included: “Parent”, “paediatric intensive care”, “outcomes”, “race” and “ethnicity”, were used to  
42 develop a full search strategy for MEDLINE (Online Resource 1). The initial search returned with no results  
43 after including all keywords and hence the terms “race” and “ethnicity” were removed from the full search  
44 strategy. The reference list of the articles selected for critical appraisal were searched for additional studies. Our  
45 search strategy conformed to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses  
46 (PRISMA) guidelines for systematic reviews (11).

47

### 48 **Data Extraction and Method of Synthesis**

49 The JBI standardized critical appraisal instruments for randomized controlled trials, cohort studies and  
50 qualitative studies were used for quality assessment (12-14). Information extracted focused on ethnic differences  
51 in health outcomes such as stress, anxiety, depression, experiences, and attrition rates. Any disagreements that  
52 arose between the reviewers (PFP and MCC) at each stage of the study selection, appraisal and data extraction  
53 process were resolved through discussion, or with a third reviewer (JML).

54

55 This review followed a convergent segregated approach (15). In the event that we **found** high heterogeneity  
56 among the included studies, we *a priori* planned not to proceed with a meta-analysis. In such instance, we  
57 instead planned to provide a narrative synthesis, and conduct a meta-synthesis of parental experience based on  
58 the most represented ethnic group. The review protocol was registered on PROSPERO (protocol number:  
59 CRD42020172648).

60

## 61 **Results**

62 **Sixteen** studies were deemed suitable for inclusion (Figure 1): eight quantitative and qualitative studies,  
63 respectively (reasons for excluded studies are reported in Online Resource 2). All included studies were  
64 assessed to be of moderate to good quality (Online Resource 3).

65

## 66 **Study Designs**

67 Among the eight included quantitative studies, one was a randomized controlled trial (16) and seven were cohort  
68 studies (9,10,17-21). Of the eight included qualitative studies, five described the specific philosophy which were  
69 grounded theory (22), phenomenology (23-25), and interpretive theory (26), and three studies described only  
70 qualitative data collection and analysis methods (27-29).

71

## 72 **Distribution of Ethnicity**

73 The number of study participants in the 16 included studies ranged from nine to 272 with a total of 1529  
74 participants. **Studies were conducted in mainly developed countries such as: Australia (2), Denmark (1),**  
75 **Netherlands (1), Spain (1), Sweden (1), Switzerland (1), UK (4) and USA (5).** Of the 1361 parent  
76 participants in the quantitative studies, 950 (73%) were White, 118 (9%) were Black, 136 (10%) were Hispanic,  
77 and 12 (0.9%) were Asian (Table 1)(9,10,16-21). Two studies included parents who were able to speak and  
78 understand the national languages (10,20), one study included parents who spoke English or Spanish (21), one  
79 study excluded participants who could not speak English (29). There was sparse information on the ethnicity  
80 background of participants in the qualitative studies (29). Of the 168 parents that participated in the qualitative  
81 studies, 111 (66%) were White, 1 (1%) were Black, 4 (2%) were Hispanic, 2 (1%) were Asians and 4 (2%) were  
82 others. **Two studies from Australia reported parental characteristics as “born locally” and residency**  
83 **(26,27) (Table 2).**

84

## 85 **Participants**

86 Mothers, fathers, and parent-couples were involved in both quantitative and qualitative studies. Median parental  
87 age was 37.4 years (interquartile range [IQR]: 34.5–40.3 years). Ethnicities were reflected as race  
88 (9,16,18,19,22-24,28,29), country of birth (10,17), language spoken (10), current country of residency (26,27),  
89 and both as race and ethnicity (21).

90 Five studies reported parents' education levels: 65/564 (12%) primary, 199/564 (35%) secondary, 227/564  
91 (40%) college, and 73/564 (13%) post graduate education (16,17,20,26,29). Child's demographic and medical  
92 data were reported in 13 studies (n=1259 patients)(9,10,16,19-22,24-29). Median age of patients was 4.2 (IQR:  
93 3 – 8.6) years and 521 (56%) were male. Thirteen studies reported child's diagnosis: 299 (24%) circulatory, 256  
94 (20%) neurologic, 263 (21%) respiratory and 22 (2%) oncology critical illness and 57 (5%) critical injury  
95 (9,10,16,19-22,24-29). Overall median PICU length of stay was 6.1 (IQR: 4 – 11.2) days (9,10,16-21).

96

### 97 **Outcome measures and Phenomena of Interest**

98 Outcomes measured in the quantitative studies were post-traumatic stress disorder (PTSD) (9,10,17-21), stress  
99 (9,16,18-20), anxiety (16,18-21), depression (16,18-21), post-traumatic growth (18), negative mood (18,20),  
100 resilience (21), parental satisfaction (21), healthcare utilization (10), parental involvement (16), parental belief  
101 (16) and coping (20). Among these 11 outcomes, only six outcomes had subgroup analysis performed by  
102 ethnicity: parental stress (9,16,20,21), anxiety (16,18-21), depression (16,18-21), post-traumatic stress disorder  
103 (9,10,17,19-21), post-traumatic growth (18), and parents satisfaction (21). **The instruments used in these**  
104 **studies reported high internal consistency** (9,10,16-21).

105

106 Phenomena of interest addressed by the qualitative studies were as follows. Four studies described the recovery  
107 experiences of parents after critical illness (22-24,27). Experiences and psychosocial support needs after critical  
108 injury (25,26), long-term effect of PICU on parents (28) and important outcomes and barriers experienced by  
109 families after critical illness were explored by individual studies (29).

110

### 111 **Ethnicity and parental emotional health outcomes after PICU discharge**

112 Findings from the eight quantitative studies demonstrated mixed emotional health outcomes from various ethnic  
113 groups. Due to the heterogeneity in the use of outcome measures, a meta-analysis was not possible and hence, a  
114 narrative synthesis of parental health outcomes after PICU discharge is presented.

115

116 Three studies demonstrated worse short-term psychological health outcomes in ethnic minority groups and no  
117 differences beyond three months after discharge as compared to the mainstream population (e.g., White  
118 )(9,10,17). Of the eight quantitative studies, seven studies compared the prevalence of PTSD between various  
119 ethnic groups (9,10,17-20). Of these, three studies showed that minority groups such as Black (9) (17% White

120 vs 36% Black,  $p=.03$ ), migrant(10) (Correlation  $r=.16$ ,  $p <.01$ ) and participants who did not speak the local  
121 language e(17) (OR 5.79, 95% CI [1.43 – 23.45],  $p=.015$ ) reported higher prevalence of PTSD at three weeks  
122 post discharge to 2 months after their child's critical illness as compared to mainstream ethnic group. Four  
123 studies reported no significant difference at discharge to six months after discharge (18-21).

124

125 Two studies compared the differences in anxiety and depression in parents (20,21). One study showed non-  
126 significant differences in anxiety at both three and six months after PICU discharge (20). The second study  
127 found that Latino ethnicity had a protective effect against anxiety at three to five weeks after PICU discharge as  
128 compared to White parents (coefficient -4.72 95% confidence interval (CI): -7.8 to -1.63,  $p <.001$ )(21).

129 Significant difference in depression score (Hospital Anxiety and Depression Scale) was noted at three months  
130 (mean (SD): 4.29 (3.47) vs 7.00 (5.87),  $p <.05$ ) and not at six months after PICU discharge in Spanish and non-  
131 Spanish speaking parents, respectively (20). The study by Colville et al. (2009) comparing post-traumatic  
132 growth in families among White and other ethnicities showed no significant difference at four months after their  
133 child's critical illness (18).

134

135 No difference was found in parental satisfaction between White and parents of minority ethnicity (21). Helfricht  
136 et al. (2008) found that non-Swiss nationality received more social services after PICU discharge (10). Colville  
137 et al. (2012) reported no significant difference in research participations amongst parents from various ethnic  
138 group (19). Five studies reported that parents of minority ethnicity (9,16), non-native speakers (10) and migrants  
139 (17,20) were significantly more likely to drop out from a long-term study with multiple time-points of data  
140 collection ranging from three to 12 months after PICU discharge.

141

#### 142 **Experiences of White parents after PICU discharge**

143 We were unable to extract data related to the impact of ethnicity and parent's experience after their child's  
144 critical illness from the included qualitative studies. As such, we synthesized the findings from these studies to  
145 reflect the experiences of the most represented ethnic population, White parents. A total of 91 findings from  
146 eight qualitative studies were extracted and aggregated to 14 categories. These 14 categories were further  
147 synthesized using meta-aggregation (30), which yielded five synthesized findings (Table 3). *Synthesized finding*

148 *1: Understanding and making sense of the critical care experiences, changes in child and the parental role.*

149 Overall, parents reported the overall PICU experience as overwhelming, stressful, and volatile. Long-term

150 psychological impact was present up to two years after discharge (26-28). Parents continued to experience  
151 anxiety and stress while they attempt to make sense of their experiences (23,26). Functional morbidities and  
152 child's behavioural changes further impeded re-integration to home (26). The change of parental role,  
153 heightened alertness and guilt stemming from various sources such as the child's critical illness attributed to the  
154 feelings of overwhelmed (22,26-29). Success of re-integration after critical illness was determined by the ability  
155 to achieve normalcy (26). Parenting challenges included changes in child's tantrums (27) and disturbed parental  
156 attachment for younger children (28). The caregiving commitments following discharge has resulted in neglect  
157 of other children and further reinforce the feelings of parental guilt.

158

159 *Synthesized finding 2: Coping strategies and emotional well-being facilitators.* Coping strategies included self-  
160 care, belief in a higher order or purpose (24,26), practicing gratitude (26,27), taking control of the situation (24),  
161 appreciation for survivorship (24), understanding the PICU experiences through diaries and progress made by  
162 child (21). Poor coping strategies strained spousal relationships (22). Consequently, parents judge their ability to  
163 cope based on the child's well-being (26).

164

165 *Synthesized finding 3: Challenges faced by parents of PICU survivors in caregiving.* Caregiving burden arising  
166 from sources, such as care of the PICU survivor and the numerous medical-follow up appointments, can impede  
167 reintegration. Competing needs from family life and other children resulted in delayed parental self-care (26),  
168 worsened mental health and the loss of employment. Self-care may be delayed up to 12 months due to  
169 caregiving commitments (26). Caregiving burden has also resulted in sleep deprivation and impaired coping and  
170 ability to care (27). Parents frequently experienced and were not prepared for the cultural insensitivity from  
171 healthcare professionals and the community towards their child's disabilities following critical illness (24,26).  
172 The loss of employment is often the result of prolong caregiving commitment leading to financial difficulties  
173 (26,28) and worsened parental stress (29).

174

175 *Synthesized finding 4: Relationships between parents and child, friends, and family.*

176 Support from friends and families were seen as important but was not long lasting (24). Parents described  
177 feelings of isolation as they distanced from friends and found it difficult to relate to trivial matters (24,28).  
178 Couples previously separated, reported that the child's critical illness further strained relationships (26).  
179 Difficulties in relating to trivial matters (28), inability to participate in social events due to the child's new

180 disabilities, difficulties in sharing the critical care experiences (22), and long-term emotional impact (29) were  
181 identified as reasons for feelings of isolation and impaired social recovery. Family support varies in usefulness  
182 with some support presenting as hindrance to parental caregiving (29). Lack of enduring support and readiness  
183 to give up on child were identified as challenges in dependence of informal support (24). Parents wished for  
184 support groups with similar experiences of paediatric critical illness (29).

185

186 *Synthesized finding 5: Parents experiences of formal support services and material resources.* Fragmented  
187 aftercare arising from poor communication and accessibility to paediatric specialist care were reported. They  
188 had no contact with the tertiary hospital after discharge (26), impaired transition to primary care due to  
189 communication breakdowns (23,29). In addition, paediatric specific rehabilitation were limited for families  
190 living away from the city (26,27,29). It was also highlighted that parents received limited support on follow-up  
191 psychosocial services for their child and themselves (26).

192

### 193 **Mixed-Methods Synthesis**

194 We summarized the participation of ethnic minorities and extracted participant retention data to synthesize  
195 thematic representations for minority ethnic families of critically ill children.

196

197 Collectively, only 18% and 7% participants from ethnic minority groups were represented in the quantitative  
198 and qualitative studies, respectively. Ethnic minorities such as Blacks, Asian, migrant and others were more  
199 likely to drop out from a longitudinal study (9,10,16,17,20). The reasons for the higher attrition rates were not  
200 described in the studies. Mixed results were seen in the participation of minority ethnic groups. One study  
201 reported no differences seen in participation rates (19), while one noted that non-respondents were more likely  
202 to be migrants (10). Four quantitative studies described diversities in the sampling methods or discussion  
203 section (22,24,26,27). These studies were from the United Kingdom (UK) (22), Australia (26,27) and the United  
204 States of America (USA) (24). Two studies described sampling of participants from a large number of families  
205 from ethnic minority backgrounds (28,29) and three recommended further research to include a wider group of  
206 parents from varying cultural backgrounds (24,26,27). Due to language limitation, families who did not speak  
207 the national official languages were excluded in two qualitative studies (28,29).

208

209

210 **Discussion**

211 Sixteen studies were identified to examine the impact of ethnicity on parental emotional health outcomes,  
212 support needs and experiences after their child's critical illness. **The available literature does not allow the**  
213 **research questions relating to the relationship between ethnicity and parental health outcomes and**  
214 **experiences to be answered reliably. In addition, the diversity aspect in the studying of health outcomes**  
215 **of PICU admission on parents has been understudied. With the available data** we found that ethnic  
216 minority groups were underrepresented and had higher attrition during a longitudinal study. The minority groups  
217 in the included studies had **the** worst short-term emotional health outcomes and utilized more healthcare service  
218 after PICU discharge. The experiences of ethnic minorities were not extractable from the qualitative studies.

219  
220 Despite awareness of the importance of cultural diversity, participants were excluded from studies where data  
221 collection were conducted in their respective national languages (10,20,25,28,29). Amongst these studies, there  
222 were at least 25% of the population with migration backgrounds across the national census (31). In terms of  
223 recruitment efforts, studies that attempted to sample from a large pool of ethnic diverse groups were not  
224 successful in gaining enrolment of ethnic minorities (22,24). None of the included studies to date have  
225 effectively recruited ethnic minority groups that were proportionate to its national norms. Consequently, studies  
226 included in this review explored the views of mainly White and parents.

227  
228 The lack of resources required for interpretation services may have resulted in the lack of inclusivity in this area  
229 of research. Researchers may consider working with peer researchers who are fluent in the languages of ethnic  
230 minority groups to expand inclusivity (32). Barriers to minority participations includes mistrust, fear of family  
231 member's opinion, time and resource constraints and the lack of health research awareness (33). The inclusion  
232 of ethnic minority or bilingual members in the study team and the involvement of the public and patients during  
233 the study design may overcome communication barriers, understand participants preference on the use of  
234 culturally sensitive languages and methods for recruitment and retention (34).

235  
236 Participants of ethnic minority groups that have participated were also more likely to drop out, especially if  
237 follow-up period was long (9,16,20). The underrepresentation of ethnic minorities in health researches in this  
238 review were consistent with other prior reports (33). Socio-economic disparity is evident among ethnicity  
239 minorities and migrant groups (3,35). To support continuity of participation, researchers should consider

240 offering meaningful compensation and reimbursing child care and transportation expenses to reduce  
241 socioeconomic barriers to long-term follow-up (36).

242

243 The lack of diversity in health research is not unique to post PICU research (33). Despite policy statements on  
244 ethical conduct for equity, diversity, and inclusion (EDI), there remains a gap in methodological guidance and  
245 regulation for research with participants of ethnic minorities (37). For example, in this review, the included  
246 qualitative studies scored high in the critical appraisal despite inadequate EDI in their sampling methods. This  
247 calls into question the appropriateness of the quality appraisal tools in contemporary times to reflect the  
248 importance of EDI in health research. No included studies in this review defined or included a definition of  
249 ethnic minority. Minority ethnic populations were generally conceptualized in the following ways 1): by race  
250 [e.g., White, White (UK), Black, Hispanic, Asian](9,16,18,19,22-24,29) 2) by language(e.g., Swedish speaking)  
251 (28), 3) country of origin (10,17,20), 4) country of residence (26,27). Lack of diversity in clinical research may  
252 cause study results to be skewed to the majority and hence not generalizable (33). Collaborative efforts among  
253 government institutions, publisher, funders and researchers in the development of methodological guidance can  
254 promote ethnic inclusiveness in health research to break the vicious cycle of invisibility of the experiences of  
255 minority groups(36).

256

### 257 **Limitations**

258 We identified research gaps in relation to the experiences and health outcomes of ethnic minorities after a PICU  
259 discharge. However, there are several limitations to this review. **We were unable to extract data related to**  
260 **ethnic differences in parental experiences within the qualitative studies. Although, data from the**  
261 **quantitative data reflected worst outcomes in parents of ethnic minority groups, we were unable to verify**  
262 **if the instruments used were validated in multi-ethnic populations.** For all the included studies,  
263 participants were recruited through conventional instead of homogenous convenience sampling which may limit  
264 the generalizability of the results to the ethnic minorities(38). In addition, all studies were conducted in high-  
265 income countries (e.g., USA Australia and UK) and may limit the applicability of results to ethnic diverse low-  
266 middle income countries (38).

267

268

269



270 **Conclusion**

271 We showed that parents of ethnic minority groups experienced worse short-term health outcomes after their  
272 PICU discharge. Due to the lack of ethnic diversity from the included studies, we were unable to explain the  
273 worse short-term health outcomes. Moving forward, we recommend that investigators improve recruitment  
274 strategies to be inclusive of diverse groups of parents in post paediatric critical care research. This might provide  
275 a better understanding of the differences observed between ethnicity groups and the impact of ethnicity on  
276 health outcomes in critically ill children and their families.

277 **Conflict of Interest Disclosures:**

278 Pei-Fen Poh and Dr Jan Hau Lee are related to KK Women's and Children's Hospital by employment. Dr

279 Joseph Manning, Dr Matthew Carey and Professor Jos Latour do not have any financial relationship with KK

280 Women's and Children's Hospital, Singapore

## References

1. Pollack MM, Holubkov R, Funai T, et al: Pediatric intensive care outcomes: development of new morbidities during pediatric critical care. *Pediatr Crit Care Med* 2014; 15:821-827
2. Manning JC, Pinto NP, Rennick JE, et al: Conceptualizing Post Intensive Care Syndrome in Children-The PICS-p Framework. *Pediatr Crit Care Med* 2018; 19:298-300
3. Mitchell HK, Reddy A, Perry MA, et al: Racial, ethnic, and socioeconomic disparities in paediatric critical care in the USA. *Lancet Child Adolesc Health* 2021; 5:739-750
4. Senior PA, Bhopal R: Ethnicity as a variable in epidemiological research. *BMJ* 1994; 309:327-330
5. Paulus JK, Kent DM: Race and Ethnicity: A Part of the Equation for Personalized Clinical Decision Making? *Circ Cardiovasc Qual Outcomes* 2017; 10
6. Cook BL, Liu Z, Lessios AS, et al: The costs and benefits of reducing racial-ethnic disparities in mental health care. *Psychiatr Serv* 2015; 66:389-396
7. Knowles RL, Ridout D, Crowe S, et al: Ethnic-specific mortality of infants undergoing congenital heart surgery in England and Wales. *Arch Dis Child* 2019; 104:844-850
8. Weiss NH, Johnson CD, Contractor A, et al: Racial/ethnic differences moderate associations of coping strategies and posttraumatic stress disorder symptom clusters among women experiencing partner violence: a multigroup path analysis. *Anxiety Stress Coping* 2017; 30:347-363
9. Balluffi A, Kassam-Adams N, Kazak A, et al: Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatr Crit Care Med* 2004; 5:547-553
10. Helfricht S, Latal B, Fischer JE, et al: Surgery-related posttraumatic stress disorder in parents of children undergoing cardiopulmonary bypass surgery: a prospective cohort study. *Pediatr Crit Care Med* 2008; 9:217-223
11. Moher D, Liberati A, Tetzlaff J, et al: Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *J Clin Epidemiol* 2009; 62:1006-1012
12. Moola S, Munn Z, Tufanaru C, et al: Systematic reviews of etiology and risk In: JBI Manual for Evidence Synthesis JBI, 2020 Aromataris E, Z M (Ed).
13. Lockwood C, Munn Z, K P: Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc* 2015; 13:8
14. Tufanaru C, Munn Z, Aromataris E, et al: Systematic reviews of effectiveness. In: JBI Manual for Evidence Synthesis Aromataris E, Z M (Ed).
15. Lizarondo L, Stern C, Carrier J, et al: Chapter 8: Mixed methods systematic reviews. In: Joanna Briggs Institute Reviewer's Manual [Internet] Aromataris E, Munn Z (Ed).
16. Melnyk BM, Alpert-Gillis L, Feinstein NF, et al: Creating opportunities for parent empowerment: program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics* 2004; 113:e597-607
17. Bronner MB, Peek N, Knoester H, et al: Course and predictors of posttraumatic stress disorder in parents after pediatric intensive care treatment of their child. *J Pediatr Psychol* 2010; 35:966-974
18. 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; 35:919-923
19. Colville G, Pierce C: Patterns of post-traumatic stress symptoms in families after paediatric intensive care. *Intensive Care Med* 2012; 38:1523-1531
20. Rodriguez-Rey R, Alonso-Tapia J: Predicting Posttraumatic Growth in Mothers and Fathers of Critically Ill Children: A Longitudinal Study. *J Clin Psychol Med Settings* 2019; 26:372-381
21. Rothschild CB, Rychlik KL, Goodman DM, et al: Association Between Resilience and Psychological Morbidity in Parents of Critically Ill Children. *Pediatr Crit Care Med* 2020; 21:e177-e185

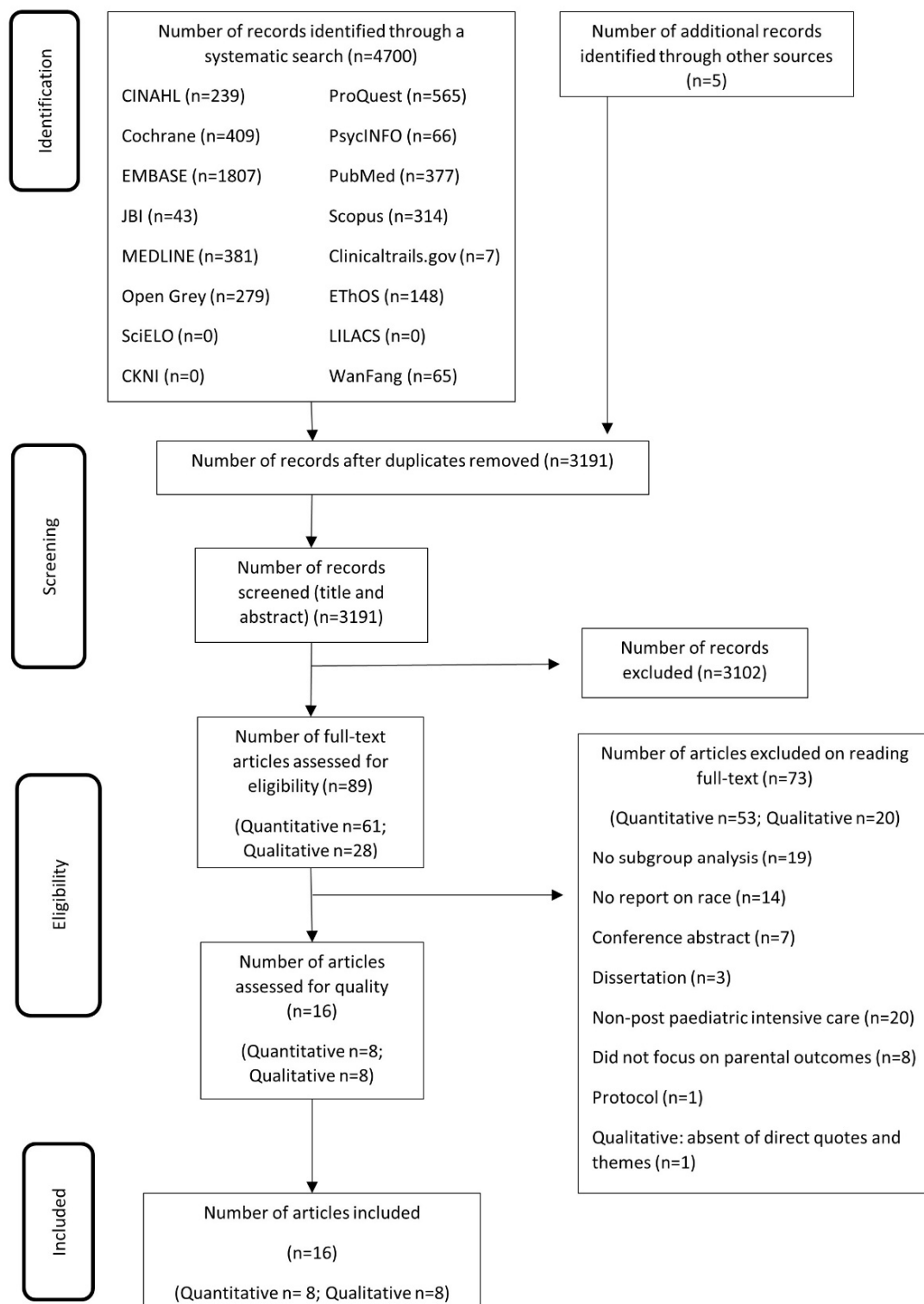
22. Atkins E, Colville G, John M: A 'biopsychosocial' model for recovery: a grounded theory study of families' journeys after a Paediatric Intensive Care Admission. *Intensive Crit Care Nurs* 2012; 28:133-140
23. Dampier S, Campbell S, Watson D: An investigation of the hospital experiences of parents with a child in paediatric intensive care. *NT research* 2002; 7:7
24. Roscigno CI, Swanson KM: Parents' experiences following children's moderate to severe traumatic brain injury: a clash of cultures. *Qual Health Res* 2011; 21:1413-1426
25. Jakobsen L, Kristensen KK, Laerkner E: Parents' experiences during and after their child's stay in the paediatric intensive care unit - A qualitative interview study. *Intensive Crit Care Nurs* 2021; 67:103089
26. Foster K, Mitchell R, Young A, et al: Parent experiences and psychosocial support needs 6 months following paediatric critical injury: A qualitative study. *Injury* 2019; 50:1082-1088
27. Foster K, Mitchell R, Van C, et al: Resilient, recovering, distressed: A longitudinal qualitative study of parent psychosocial trajectories following child critical injury. *Injury* 2019; 50:1605-1611
28. Terp K, Sjostrom-Strand A: Parents' experiences and the effect on the family two years after their child was admitted to a PICU-An interview study. *Intensive Crit Care Nurs* 2017; 43:143-148
29. Williams CN, Eriksson C, Piantino J, et al: Long-term Sequelae of Pediatric Neurocritical Care: The Parent Perspective. *J Pediatr Intensive Care* 2018; 7:173-181
30. Lockwood C, Munn Z, Porritt K: Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc* 2015; 13:179-187
31. United Nations Department of Economic and Social Affairs PD: International Migration 2020 Highlights. 2020, p^pp
32. Casado BL, Negi NJ, Hong M: Culturally competent social work research: methodological considerations for research with language minorities. *Soc Work* 2012; 57:1-10
33. Clark LT, Watkins L, Pina IL, et al: Increasing Diversity in Clinical Trials: Overcoming Critical Barriers. *Curr Probl Cardiol* 2019; 44:148-172
34. Hughson JA, Woodward-Kron R, Parker A, et al: A review of approaches to improve participation of culturally and linguistically diverse populations in clinical trials. *Trials* 2016; 17:263
35. Chauhan A, Walton M, Manias E, et al: The safety of health care for ethnic minority patients: a systematic review. *Int J Equity Health* 2020; 19:118
36. Premji S, Kosny A, Yanar B, et al: Tool for the Meaningful Consideration of Language Barriers in Qualitative Health Research. *Qual Health Res* 2020; 30:167-181
37. Glickman SW, Ndubuizu A, Weinfurt KP, et al: Perspective: The case for research justice: inclusion of patients with limited English proficiency in clinical research. *Acad Med* 2011; 86:389-393
38. Jager J, Putnick DL, Bornstein MH: More Than Just Convenient: The Scientific Merits of Homogeneous Convenience Samples. *Monogr Soc Res Child Dev* 2017; 82:13-30

**Figure legend**

Figure 1: PRISMA flow diagram



Figure 1: PRISMA flow diagram



**TABLE 1: Characteristics of included quantitative studies (n=8)**

Study	Study Aims	Participants (sample size)	Equity Diversity & Inclusion	Design	Time-points after PICU admission	Setting	Instruments	Outcomes measures examined by ethnicity
Rothschild, 2020, USA	Association between resilience and PTS	Total: 232 White:190 Black: 42 Others: 20	Included English and Spanish speaking  pFS-ICU- medical translator to Spanish	Prospective cohort	T1: consent T2: 3 weeks – 2 months	PICU	<b>IES-R</b>  <b>PROMIS Depression short form 8a</b>  <b>PROMIS Anxiety short form 8a</b>  <b>pFS-ICU</b>	Post-traumatic stress IES-R (USA tool) Depression Anxiety Family satisfaction
Rodriguez, 2018 Spain	Examine predictors for PTSD after PICU	Total: 143 Hispanic: 134 Others: 9	Excluded non-Spanish speaking  Spanish version adequate internal consistency	Prospective cohort	T1: consent T2: 48 hours T3: 3 months T4: 6 months	PICU	<b>Davidson Trauma Scale</b>  <b>HADS</b>	Post-traumatic stress- Anxiety and Depression – Participant Attrition
Colville, 2012 UK	Determine associations of PTSD with outcomes	Total: 62 White: 40 Others: 22	Not mentioned	Prospective cohort	T1: 3 months T2: 12 months	PICU	<b>SPAN</b>	Post-traumatic stress Minority participation
Bronner, 2010 Netherlands	Identify risk factors for PTSD	Total: 201 Born locally: 190	Not mentioned High internal consistency	Prospective cohort	T1: 3 months T2: 9 months	PICU	<b>SRS-PTSD</b>	Post-traumatic stress Minority participation
Colville, 2009 UK	Examine post-traumatic growth	Total: 50 White: 30 Others: 20	Not mentioned	Prospective cohort	4 months	PICU	<b>PTG</b>	Post traumatic growth Minority participation
Helfricht, 2008 Switzerland	Evaluate risk factors for PTSD	Total: 238 White: 233 Others: 5	Excluded non-German speaking  German version demonstrated	Prospective cohort	T1: hospital discharge T2: 6 months	Tertiary pediatric medical centre	<b>PDS</b>	Post-traumatic stress Healthcare utilisation Minority participation



			high internal consistency					
Balluffi, 2004 USA	Examine relationship of ASD and PTSD	Total: 272 White:195 Black:57 Others: 20	Not mentioned	Prospective cohort	T1: consent T2: 2 months	PICU	<b>Acute Stress Disorder Scale</b>  <b>PTSD Checklist</b>	Acute stress disorder Post-traumatic stress Participant attrition
Melynk, 2004 USA	Evaluate effectiveness of the COPE program	Total: 163 White: 116 Black: 2 Hispanic: 33 Asian: 3 Others: 9	Parents had to speak and understand English	RCT	T1: 1 month T2: 3 months T3: 6 months T4: 12 months	PICU	<b>A-State</b>  <b>POMS</b>  <b>PSI-P</b>	Effect of treatment Attrition

ASD: Acute stress disorder, A-state: State Anxiety Inventory, COPE: Creating Opportunities for Parent Empowerment, HADS: Hospital Anxiety and Depression Scale, IES-R: Impact of Event Scale- Revised, PDS: Posttraumatic Diagnostic Scale, pFS-ICU: Pediatric Family Satisfaction-ICU, PICU: pediatric intensive care unit, POMS: Profile of Mood States, PSI-P: Post Hospitalization Stress Index for Parent, PTG: Posttraumatic Growth Inventory, PTSD: post-traumatic stress disorder, RCT: Randomized controlled trial, SPAN: 'Startle', 'Physiological Arousal', 'Anger' and 'Numbness', SRS-PTSD: Self-Rating Scale for PTSD, T: Time-point, UK: United Kingdom, USA: United States of America

**TABLE 2: Characteristics of included qualitative studies (n=8)**

<b>Study</b>	<b>Aim</b>	<b>Participants (sample size)</b>	<b>Equity Diversity &amp; Inclusion</b>	<b>Data collection</b>	<b>Time-points after PICU admission</b>	<b>Setting and location</b>
Jakobsen, 2021, Denmark	To explore parents' experiences during and after their child's hospitalization in the PICU.	Total: 12 White: 12	Danish speaking parents only	Semi-structured interview	6 to 14 weeks after discharge	PICU
Foster, 2019a Australia	To explore parent experiences and psychosocial support needs in the 6 months following child critical injury.	Total: 22 Born locally: 19 Others: 3	Not mentioned	Semi-structured interview	6 months	Hospital
Foster, 2019b Australia	Explore parent experiences and psychosocial support needs and identify parent psychosocial trajectories in the 12 months following child critical injury.	Total:27 Residence: 27	Not mentioned	Semi-structured interview	T1: Admission T2: 6 months T3: 12 months	Hospital
Williams, 2018 USA	To determine outcomes important to our patients and their families and engage these families in identifying barriers to care and potential interventions to improve outcomes	Total:16 White:13 Black: 1 Asian: 1 Others: 1	Non-English-speaking parents were excluded	Focus group	1 to 8 years	PICU
Terp, 2017 Sweden	Describe parents' experiences and the effect on the family two years after this child was admitted to a PICU	Total:10 White: 10	Parents had to speak and understand Swedish	Semi-structured interview	2 years	PICU
Roscigno, 2011 USA	Describe the common experiences of a sample of English-speaking parents from across the USA following their respective child's moderate to severe traumatic brain injury	Total: 42 White: 38 Hispanic: 4	Several targeted attempt to achieve ethnic diversity	Semi-structured interview	T1: 4 months to 3 years after TBI T2: 12 to 15 months after T1	National
Atkins, 2011 UK	Investigate how families came to understand their recovery following their child's admission to PICU	Total: 9 White: 8 Asian: 1	Considered ethnic minority in sampling	Semi-structured interview	8 to 18 months	PICU
Dampier, 2002 UK	Understanding the pathways that comprise the journey followed by a child who is critically ill and his/her family.	Total: 30 White: 30	No mention	Semi-structured interview	1 to 2 months	PICU

PICU: pediatric intensive care unit, T: Time-point, TBI: traumatic brain injury, UK: United Kingdom, USA: United States of America

**TABLE 3: Results of Meta-synthesis**

Studies, Country	Categories	Synthesised finding	
<b>Synthesis one: PICU has long term psychological impact on parents (19 findings)</b>			
Foster et al., 2019a, Australia Foster et al., 2019b, Australia Terp et al., 2017, Sweden Dampier et al., 2002, United Kingdom	Negative psychological impact persists after PICU discharge. Feelings included anxiety, stress, doubt and grief.	<p data-bbox="1283 229 2134 304"><b>Pediatric critical illness create negative experiences and affect the long-term psychological impact of parents.</b></p> <p data-bbox="1283 341 2134 676">Pediatric critical illness has long term psychological impact on parent. Following discharge, parents continue to experience symptoms of stress and anxiety while they make sense of their experiences. The change in parental role, heightened alert and guilt stemming from various sources such as failure to protect child, making correct timely decision and neglect of other children further attribute to the feeling of being overwhelmed. Success of re-integration after critical illness was determined by the ability to achieve normalcy.</p>	
Foster et al., 2019a, Australia	Parents adapt to child's needs and behavioural changes in working towards a new normal.		
Foster et al., 2019a, Australia	Guilt arising from various sources (work demands, prevention of illness/injuries, reduced visitation due to fear, neglect of other children) which continues to exist after the critical illness		
Foster et al., 2019b, Australia			
Terp et al., 2017, Sweden			
Atkins et al., 2012, United Kingdom			
Williams et al., 2018, USA			
<b>Synthesis two: Parental coping strategies (14 findings)</b>			
Foster et al., 2019a, Australia Jakobsen 2021, Denmark Foster et al., 2019b, Australia Atkins et al., 2012, United Kingdom Dampier et al., 2002, United Kingdom Roscigno et al., 2011, USA	Parent relied on positive and negative coping strategies to navigate the care of their child after a critical illness and to adjust to the interactions between their child and the environment		<p data-bbox="1283 858 2134 933"><b>Parents uses coping strategies to adjust to life after PICU discharge.</b></p> <p data-bbox="1283 970 2134 1225">Coping strategies effective for enhancing parental resilience after their child's critical illness included self-care, a higher order belief or purpose, practising gratitude, taking control of situation and appreciation for survivorship and progress made by the child. The use of poor coping strategies strained relationships between spouse and children while parents judge their ability to adapt based on the child's well-being.</p>
Foster et al., 2019a, Australia	Feelings of gratitude, hope, growth, acceptance, and sense of duty were helpful on parental coping in reintegration back to family life.		
Foster et al., 2019b, Australia			
Roscigno et al., 2011, USA			

<b>Synthesis three: Caregiving burden of the PICU survivor (25 findings)</b>		
Foster et al., 2019a, Australia	Mental and physical fatigue resulting from caregiving burden has led to delayed self-care in parents.	<p><b>Lack of preparation and family commitment create negative parental caregiving experiences and affect parental selfcare and employability.</b></p> <p>Caregiving burden arising from caring for the PICU survivor and the medical appointments was worsened by the lack of preparation on the child's emotional health and insensitivity towards child's morbidity in the community. Caregiving commitment and competing needs have resulted in the delay of self-care, worsened parental mental health, neglect of other children and the loss of employment.</p>
Foster et al., 2019b, Australia		
Roscigno et al., 2011, USA		
Foster et al., 2019a, Australia	Importance of psychological impact of the critical illness of child is under-recognised and parents felt ill-prepared and needed more information to deal with the psychological impact after discharge.	
Foster et al., 2019b, Australia		
Atkins et al., 2012, United Kingdom		
Williams et al., 2018, USA	Insensitivity arising from healthcare providers and the community had negative impact in families.	
Foster et al., 2019a, Australia		
Roscigno et al., 2011, USA	Caregiving commitments has resulted in negative financial impact from the lack or loss of employment. Understanding employer and flexible work arrangement may facilitate caregiving needs of parents.	
Foster et al., 2019a, Australia		
Foster et al., 2019b, Australia		
Terp et al., 2017, Sweden		
Roscigno et al., 2011, USA		
Williams et al., 2018, USA		
<b>Synthesis four: Relationship strains and isolation after critical illness (21 findings)</b>		
Foster et al., 2019a, Australia	Support from friends and families were seen as important and the experience of critical illness may strengthen relationships between spouses and the PICU survivor.	<p><b>Pediatric critical illness strengthens relationships within the nuclear family whilst the changing nature of caregiving create feelings of social isolation.</b></p> <p>Nuclear family focused as a result of the critical illness and caregiving of the PICU survivor has led to stronger relationships between spouses and the child for most families. Relationship strains were reported in spouses who felt neglected or who was previously separated. Social isolation was a result from the inability to participate in social functions, reduced capacity to care for others, lack of tangible and sustainable support from the</p>
Foster et al., 2019b, Australia		
Terp et al., 2017, Sweden		
Atkins et al., 2012, United Kingdom		
Williams et al., 2018, USA)		
Terp et al., 2017, Sweden	Isolating nature of caregiving had negative impact on families' social recovery.	
Jakobsen 2021, Denmark		
Atkins et al., 2012, United Kingdom		
Williams et al., 2018, USA		
Foster et al., 2019b, Australia		
Roscigno et al., 2011, USA		

Williams et al., 2018, USA	Lack of enduring formal and informal support were seen as challenging following pediatric critical illness.	social circles and the fear of burdening friends and family. Parents desire for support groups with similar experiences.
Williams et al., 2018, USA		
<b>Synthesis five: Fragmented aftercare following critical illness (12 findings)</b>		
Foster et al., 2019a, Australia	Poor aftercare experiences from the lack of contact, difficulty in navigating services, ineffective communication and limited knowledge on local health services.	<b>Fragmented transitions of care to the community after critical illness with limited aftercare and support.</b>  Parents experienced lapse in communication between tertiary and primary healthcare providers, lack of knowledge in services available, difficulty in accessing medical and rehabilitation services and the lack of pediatric specialities in the local area. Parents sought professional help to improve emotional well-being, mothers were more likely than fathers to seek help.
Dampier et al., 2002, United Kingdom		
Williams et al., 2018, USA		
Foster et al., 2019a, Australia	Professional help with parental psychological issues were preferred over emotional support from friends and family to avoid being burdensome	
Foster et al., 2019b, Australia		
Williams et al., 2018, USA		

USA: United States of America

## **Online Resource 1: Search strategy**

Search conducted for MEDLINE on EBSCOhost

S1: Parent\* OR father\* OR mother\* OR family OR families OR caregiver [ti,ab]

S2: intensive care OR pediatric intensive care OR pediatric intensive care OR PICU OR critical care OR pediatric critical care OR pediatric critical care OR ICU [ti,ab]

S3: child\* OR infant\* OR pediatric\* OR pediatric\* OR adolescen\* [ti,ab]

S4: outcome OR psycholog\* OR anxiet\* OR depression OR stress OR social

S5: ethni\* OR race\*

S6: S1 AND S2 AND S3 AND S4 AND S5

## **Online Resource 2: Reasons for exclusion**

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).

**Reason for exclusion: Reported on race/Ethnicity as White, UK with no subgroup analysis**

Als LC, Vickers B, Nadel S, Cooper M, Garralda ME. A brief intervention to improve parent post-traumatic stress symptoms following paediatric critical illness: A pilot randomised controlled trial. *Archives of Disease in Childhood*. 2014;99:A159–60.

**Reason for exclusion: Conference abstract**

Atkins E, Colville G, John M. Finding the way to a “new normal”: Families’ recovery in the year after a paediatric intensive care admission. *Pediatric Critical Care Medicine*. 2011;12(3):A3–4.

**Reason for exclusion: Dissertation results reported in Atkins, 2012**

Bent KN, Keeling A, Routson J. Home from the PICU: are parents ready? *QUALI*. *Mcn*. 1996;The American journal of maternal child nursing. 21(2):80–4.

**Reason for exclusion: Focused on parental outcomes post abrupt PICU discharge**

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 and Lung: Journal of Acute and Critical Care*. 2011;40(3):236–46.

**Reason for exclusion: Reported on race/Ethnicity as Caucasian, African American and Hispanic American with no subgroup analysis**

Board R, Ryan-Wenger N. Stressors and stress symptoms of mothers with children in the PICU. *Journal of Pediatric Nursing*. 2003;18(3):195–202.

**Reason for exclusion: Reported on race/Ethnicity as Caucasian, African American and Hispanic American with no subgroup analysis**

Board RM. Long-term effects of PICU hospitalization on families with young children. 1999. p. 111 p-111 p.

**Reason for exclusion: Reported on race/Ethnicity as Caucasian, African American and Hispanic American with no subgroup analysis**

Boyden JY, Hill DL, Carroll KW, Morrison WE, Miller VA, Feudtner C. The Association of Perceived Social Support with Anxiety over Time in Parents of Children with Serious Illnesses. *Journal of palliative medicine*. 2019;7.

**Reason for exclusion: Reason excluded: Reported on race and Ethnicity as White, African American. Ethnicity as Hispanic/Non-Hispanic with no subgroup analysis**

Bright MA, Franich-Ray C, Anderson V, Northam E, Cochrane A, Menahem S, et al. Infant cardiac surgery and the father-infant relationship: Feelings of strength, strain, and caution-MixedMethods. *Early Human Development*. 2013;89(8):593–9.

**Reason for exclusion: Non-PICU**

Bronner MB, Kayser A-M, Knoester H, Bos AP, Last BF, Grootenhuis MA. A pilot study on peritraumatic dissociation and coping styles as risk factors for posttraumatic stress, anxiety and depression in parents after their child’s unexpected admission to a Pediatric Intensive Care

Unit. Child And Adolescent Psychiatry And Mental Health. 2009;3(1):33–33.

**Reason for exclusion: No report on race/Ethnicity**

Bronner MB, Knoester H, Bos AP, Last BF, Grootenhuis MA. Follow-up after paediatric intensive care treatment: Parental posttraumatic stress. *Acta Paediatrica, International Journal of Paediatrics*. 2008;97(2):181–6.

**Reason for exclusion: Reported on race with no subgroup analysis**

Buyse CM, Raat H, Hazelzet JA, Hop WC, Maliepaard M, Joosten KF. Surviving meningococcal septic shock: health consequences and quality of life in children and their parents up to 2 years after pediatric intensive care unit discharge. *Critical Care Medicine*. 2008;36(2):596–602.

**Reason for exclusion: No report on race/Ethnicity**

Buyse CMR. Long-term health-related quality of life in survivors of meningococcal septic shock in childhood and their parents. *Qual Life Res*. 2007;

**Reason for exclusion: No report on race/Ethnicity**

Callans KM, Bleiler C, Flanagan J, Carroll D. The Transitional Experience of Family Caring for Their Child With a Tracheostomy. *Journal of Pediatric Nursing*. 2016;31(4):397.

**Reason for exclusion: Non-PICU**

Carney NA, Petroni GJ, Lujan SB, Ballarini NM, Faguaga GA, Du Coudray HEM, et al. Postdischarge care of pediatric traumatic brain injury in Argentina: A multicenter randomized controlled trial. *Pediatric Critical Care Medicine*. 2016;17(7):658–66.

**Reason for exclusion: No report on race/Ethnicity**

Chan YHL. The Health and Well-Being of Caregivers of Technologically Dependent Children. 2019;6.

**Reason for exclusion: Non-PICU**

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):146–53.

**Reason for exclusion: Reported on race/Ethnicity as White, UK with no subgroup analysis**

Colville GA, Gracey D. Mothers' recollections of the Paediatric Intensive Care Unit: associations with psychopathology and views on follow up-QUALI. *Intensive Crit Care Nurs*. 2006;22(1):49–55.

**Reason for exclusion: Not related to parental social or emotional outcomes**

Crowe L, Simpson E, Reinhardt Z, Rankin J. Parental responsibility for pediatric ventricular assist devices: Views of families on the acceptability of hospital discharge. *Pediatric Transplantation*. 2020;24(1).

**Reason for exclusion: Not related to parental social or emotional outcomes**

Ehrlich TR, Von Rosenstiel IA, Grootenhuis MA, Gerrits AI, Bos AP. Long-term psychological distress in parents of child survivors of severe meningococcal disease. *Pediatric Rehabilitation*. 2005;8(3):220–4.

**Reason for exclusion: No report on race/Ethnicity**



Garralda ME, Gledhill J, Nadel S, Neasham D, O'Connor M, Shears D. Longer-term psychiatric adjustment of children and parents after meningococcal disease. *Pediatric Critical Care Medicine*. 2009;10(6):675–80.

**Reason for exclusion: Reported on race/Ethnicity as White, UK with no subgroup analysis**

Geldhill J, Tareen A, Cooper M, Nadel S, Garralda ME. Joint paediatric and psychiatric follow-up for families following paediatric intensive care unit admission: An exploratory study. *Advances in Critical Care*. 2014;5.

**Reason for exclusion: No report on race/Ethnicity**

Golfenshtein N, Hanlon AL, Deatrack JA, Medoff-Cooper B. Parenting stress trajectories during infancy in infants with congenital heart disease: Comparison of single-ventricle and biventricular heart physiology. *Congenital Heart Disease*. 2019;14(6):1113–22.

**Reason for exclusion: Reported on race and ethnicity as White, Black, others; Hispanic, non-Hispanic with no subgroup analysis**

Gonzalez R, Bustinza A, Fernandez SN, Garcia M, Rodriguez S, Garcia-Teresa MA, et al. Quality of life in home-ventilated children and their families-Mixed Methods. *European Journal of Pediatrics*. 2017;176(10):1307–17.

**Reason for exclusion: Non-PICU**

Hawley CA, Ward AB, Magnay AR, Long J. Parental stress and burden following traumatic brain injury amongst children and adolescents-Mixed. *Brain Injury*. 2003;17(1):1–23.

**Reason for exclusion: Reported on race and ethnicity as White no subgroup analysis**

Hill C, Knafl KA, Docherty S, Sheila Judge S. Parent perceptions of the impact of the Paediatric Intensive Care environment on delivery of family-centred care. *Intensive & Critical Care Nursing*. 2019;50:88–94.

**Reason for exclusion: Not post PICU discharge**

Hordijk J, Verbruggen S, Vanhorebeek I, Van den Berghe G, Utens E, Joosten K, et al. Health-related quality of life of children and their parents 6 months after children's critical illness. *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care And Rehabilitation*. 2020;29(1):179–89.

**Reason for exclusion: No report on race/Ethnicity**

Iwata M, Han SJ, Hays R, Doorenbos AZ. Predictors of depression and anxiety in family members 3 months after child's admission to a pediatric ICU. *American Journal of Hospice & Palliative Medicine*. 2019;36(10):10.

**Reason for exclusion: Reported on race and ethnicity as White; Hispanic with no subgroup analysis, not added as confounders**

Judge D, Nadel S, Vergnaud S, Garralda ME. Psychiatric adjustment following meningococcal disease treated on a PICU. *Intensive Care Medicine*. 2002;28(5):648–50.

**Reason for exclusion: Reported on race and ethnicity as White European with no subgroup analysis**

Keenan HT, Runyan DK, Nocera M. Longitudinal follow-up of families and young children with traumatic brain injury. *Pediatrics*. 2006;117(4):1291–7.

**Reason for exclusion: Not related to parental social or emotional outcomes**

Mikkelsen G. The meaning of personal diaries to children and families in the paediatric intensive care unit: A qualitative study. *Intensive & Critical Care Nursing*. 2018;45:25–30.

**Reason for exclusion: Not post PICU discharge**

Mitchell MJ. Prospective study of family adjustment and adaptation following pediatric hospitalization. (intensive care unit, resiliency model). *Dissertation Abstracts International: Section B: The Sciences and Engineering*. 1999;60(6-B):2953.

**Reason for exclusion: Reported on race and ethnicity as Caucasian, African American, minority with no subgroup analysis**

Moore M, Robinson G, Mink R, Hudson K, Dotolo D, Gooding T, et al. Developing a family-centered care model for critical care after pediatric traumatic brain injury. *Pediatric Critical Care Medicine*. 2015;16(8):758–65.

**Reason for exclusion: Not post PICU discharge**

Morgan GJ, Craig B, Grant B, Sands A, Doherty N, Casey F. Home videoconferencing for patients with severe congenital heart disease following discharge. *Congenital Heart Disease*. 2008;3(5):317-324.

**Reason for exclusion: Not post PICU discharge**

Mortensen J, Simonsen BO, Eriksen SB, Skovby P, Dall R, Elklit A. Family-centred care and traumatic symptoms in parents of children admitted to PICU. *Scandinavian Journal of Caring Sciences*. 2015;29(3):495–500.

**Reason for exclusion: No report on race/Ethnicity**

Mu P-F. Parental perception of family stress in pediatric health crisis: A phenomenological study. 1993. p. 159.

**Reason for exclusion: Not post PICU discharge-Interviewed during early hospitalization**

Muscara F, McCarthy MC, Hearps SJC, Nicholson JM, Burke K, Dimovski A, et al. Featured Article: Trajectories of Posttraumatic Stress Symptoms in Parents of Children With a Serious Childhood Illness or Injury. *Journal of Pediatric Psychology*. 2018;43(10):1072–82.

**Reason for exclusion: Non-PICU**

Nct. Does a Follow-up Appointment Help Parents of Children on PICU?-Await author reply-Bristol. <https://clinicaltrials.gov/show/NCT01628263>. 2012;

**Reason for exclusion: Dissertation published as Samuel,2015**

Nelson LP, Lachman SE, Li SW, Gold JI. The Effects of Family Functioning on the Development of Posttraumatic Stress in Children and Their Parents Following Admission to the PICU. *Pediatric Critical Care Medicine: A Journal Of The Society Of Critical Care Medicine And The World Federation Of Pediatric Intensive And Critical Care Societies*. 2019;20(4):e208–15.

**Reason for exclusion: Reported on race and ethnicity as White, Black, others; Hispanic, non-Hispanic with no subgroup analysis**

Notario PM, Gentile E, Amidon M, Angst D, Lefaiver C, Webster K. Home-Based Telemedicine for Children with Medical Complexity. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association*. 2019;25(11):1123–32.

**Reason for exclusion: Not related to parental social or emotional outcomes**

October TW, Jones AH, Greenlick Michals H, Hebert LM, Jiang J, Wang J. Parental Conflict, Regret, and Short-term Impact on Quality of Life in Tracheostomy Decision-Making. *Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*. 2020;21(2):136–42.

**Reason for exclusion: Non-PICU**

Pulham RA, Wray J, Feinstein Y, Brown K, Pierce C, Nadel S, et al. Feasibility and Acceptability of Methods to Collect Follow-Up Information From Parents 12 Months After Their Child's Emergency Admission to Pediatric Intensive Care. *Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*. 2019;20(4):e199–207.

**Reason for exclusion: No report on race/Ethnicity**

Rees G, Gledhill J, Garralda ME, Nadel S. Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study. *Intensive Care Medicine*. 2004;30(8):1607–14.

**Reason for exclusion: Reported on race and ethnicity as White, Black, others with no subgroup analysis-UK**

Rennick JE, Dougherty G, Chambers C, Stremler R, Childerhose JE, Stack DM, et al. Children's psychological and behavioral responses following pediatric intensive care unit hospitalization: The caring intensively study. *BMC Pediatrics*. 2014;14(1):1–11.

**Reason for exclusion: Study Protocol**

Rennick JE, Dryden-Palmer K, Stremler R, Chambers C, Campbell-Yeo M, Xun Z, et al. The Caring Intensively Study: Children's Psychological and Behavioural Responses Following Pediatric Intensive Care Unit (PICU) Hospitalization. *Canadian Journal of Critical Care Nursing*. 2017;28(2):45–6.

**Reason for exclusion: Conference abstract**

Rodriguez-Rey R, Alonso-Tapia J. Predicting Posttraumatic Growth in Mothers and Fathers of Critically Ill Children: A Longitudinal Study. *Journal Of Clinical Psychology In Medical Settings*. 2019;26(3):372–81.

**Reason for exclusion: No report on race/Ethnicity**

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 & Critical Care Nursing*. 2017;43:156–61.

**Reason for exclusion: No report on race/Ethnicity**

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. *Pediatric Critical Care Medicine*. 2015;16(9):808–13.

**Reason for exclusion: No report on race/Ethnicity**

Shears D, Nadel S, Gledhill J, Garralda ME. Short-term psychiatric adjustment of children and their parents following meningococcal disease. *Pediatric Critical Care Medicine*. 2005;6(1):39–43.

**Reason for exclusion: Reported on race and ethnicity as White, English with no subgroup analysis**

Sjostrom-Strand A, Terp K. Parents' Experiences of Having a Baby With a Congenital Heart Defect and the Child's Heart Surgery. *Comprehensive Child And Adolescent Nursing*. 2019;42(1):10–23.

**Reason for exclusion: Not post-PICU**

Small L, Melnyk BM. Early predictors of post-hospital adjustment problems in critically ill young children. *Research in Nursing and Health*. 2006;29(6):622–35.

**Reason for exclusion: No report on race/Ethnicity: secondary data analysis from Melnyk COPE study**

Sood E, Karpyn A, Demianczyk AC, Ryan J, Delaplane EA, Neely T, et al. Mothers and fathers experience stress of congenital heart disease differently: Recommendations for pediatric critical care. *Pediatric Critical Care Medicine*. 2018;19(7):626–34.

**Reason for exclusion: Non-PICU**

Stowman SA. Posttraumatic stress disorder and other consequences of a PICU admission. *Dissertation Abstracts International: Section B: The Sciences and Engineering*. 2009;71(3–B):2062.

**Reason for exclusion: Reported on race and ethnicity as Caucasian; Hispanic; African American; Hispanic, non-Hispanic with no subgroup analysis**

Tearl DK, Hertzog JH. Home discharge of technology-dependent children: Evaluation of a respiratory-therapist driven family education program. *Respiratory Care*. 2007;52(2):171–6.

**Reason for exclusion: Not related to parental social or emotional outcomes**

Tregay J, Brown K, Crowe S, Bull C, Knowles R, Wray J. “I was so worried about every drop of milk” - feeding problems at home are a significant concern for parents after major heart surgery in infancy. *Maternal and Child Nutrition*. 2017;13(2).

**Reason for exclusion: Focuses on discharge process**

Tregay JW. Going home after infant cardiac surgery: a UK qualitative study. 2016 Jan 31;101(4):5.

**Reason for exclusion: Focuses on discharge process**

Van Gestel JPJ, Drossaert CHC, Van Klink M, Taal E, Kampelmacher MJ, Van Vught AJ. Experiences of children and their parents with home mechanical ventilation. [Dutch]. *Tijdschrift voor Kindergeneeskunde*. 2009;77(3):131–6.

**Reason for exclusion: Non-PICU**

Vermunt LCAC, Buysse CMP, Joosten KFM, Hazelzet JA, Verhulst FC, Utens EMWJ. Recovery in parents of children and adolescents who survived septic shock caused by *Neisseria meningitidis*: A cross-sectional study. *Intensive and Critical Care Nursing*. 2010;26(3):128–37.

**Reason for exclusion: Qualitative reporting: descriptive and did not offer direct quotes and themes**

Wray J, Brown K, Tregay J, Crowe S, Knowles R, Bull K, et al. Parents' Experiences of Caring for Their Child at the Time of Discharge After Cardiac Surgery and During the Postdischarge Period: Qualitative Study Using an Online Forum. *Journal Of Medical Internet Research*. 2018;20(5):e155.

**Reason for exclusion: Non-PICU**

Wray J, Tregay J, Bull C, Knowles RL, Crowe S, Brown K. Issues facing families of infants discharged after cardiac surgery: the perceptions of charity helpline staff. *Acta Paediatrica, International Journal of Paediatrics*. 2018;107(8):1418–26.

**Reason for exclusion: Non-PICU**

Yeates KOT. Race as a moderator of parent and family outcomes following pediatric traumatic brain injury. 2002;

**Reason for exclusion: Non-PICU**

Youngblut JM, Brooten D. Pediatric head trauma: Parent, parent-child, and family functioning 2 weeks after hospital discharge. *Journal of Pediatric Psychology*. 2006;31(6):608–18.

**Reason for exclusion: Non-PICU**

Youngblut JM, Shiao SYP. Child and family reactions during and after pediatric ICU hospitalization: A pilot study. *Heart and Lung: Journal of Critical Care*. 1993;22(1):46–54.

**Reason for exclusion: No report on race/Ethnicity**

Zoet GJ, Calff MM, Garssen BJ, Bijmer RP, Schildwacht T. Parents' experiences in a pediatric intensive care unit. [Dutch]. *Tijdschrift voor Kindergeneeskunde*. 1992;60(6):199–205.

**Reason for exclusion: Not post-PICU discharge**

Burnside Georgiana M, Canty H, Sanders L. Family characteristics associated with acute stress in children and caregivers after PICU admission. *Critical care medicine*. 2021;49(1 SUPPL 1):400.

**Reason for exclusion: Conference abstract**

Minogue J, Hamblin S, Long D, Dow B, Schults J, Stocker C. Child and parent distress following paediatric critical illness and its impacts on family functioning: A retrospective study. *Pediatric Critical Care Medicine*. 2021;22(SUPPL 1):26.

**Reason for exclusion: Conference abstract**

Rennick Janet E, Knox Alyssa M, Treherne Stephanie C, Dryden-Palmer K, Stremler R, Chambers Christine T, et al. Family Members' Perceptions of Their Psychological Responses One Year Following Pediatric Intensive Care Unit (PICU) Hospitalization: Qualitative Findings From the Caring Intensively Study. *Frontiers in pediatrics*. 2021;9:724155.

**Reason for exclusion: Conference abstract**

Treherne S, Knox A, Rennick J, Dryden-Palmer K, Stremler R, Chambers C, et al. The caring intensively study: Family members' perceptions of psychological outcomes one year following pediatric intensive care unit hospitalization. *Pediatric Critical Care Medicine*. 2021;22(SUPPL 1):247-8.

**Reason for exclusion: Conference abstract**

Ducharme-Crevier L, La K-A, Francois T, Gerardis G, Beauchamp M, Harrington K, et al. PICU Follow-Up Clinic: Patient and Family Outcomes 2 Months After Discharge. *Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*. 2021.

**Reason for exclusion: Reported on race with no subgroup analysis**

Hordijk J, Verbruggen S, Vanhorebeek I, Van den Berghe G, Utens E, Joosten K, et al. Health-related quality of life of children and their parents 6 months after children's critical illness. *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care And Rehabilitation*. 2020;29(1):179-89.

**Reason for exclusion: Reported on race with no subgroup analysis**

Graj E, Muscara F, Anderson V, Hearps S, McCarthy M. Quality of life in parents of seriously ill/injured children: a prospective longitudinal study. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 2021;30(1):193-202.

**Reason for exclusion: Non-PICU**

Leonard S, Holding E, Turner E, Bradbury Kathryn R, Williams C, Luther M, et al. Emotional Aspects of Pediatric Post-Intensive Care Syndrome Following Traumatic Brain Injury. *Journal of Child and Adolescent Trauma*. 2021;14(2):177-87.

**Reason for exclusion: Non-PICU**

Woodruff Alan G, Choong K. Long-Term Outcomes and the Post-Intensive Care Syndrome in Critically Ill Children: A North American Perspective. *Children (Basel, Switzerland)*. 2021;8(4).

**Reason for exclusion: Non-PICU**

Edwards Jeffrey D, Salant Jennifer A, Gangopadhyay M, Jia H, Wocial Lucia D. Distress and the Long-Stay Pediatric Intensive Care Unit Admission: A Longitudinal Study of Parents and the Medical Team. *Journal of Pediatric Intensive Care*. 2021.

**Reason for exclusion: Not post PICU discharge**

### Online Resource 3: Methodological quality of included articles

#### Cohort Studies

	Rothschild, 2020.	Rodriguez-Rey R, 2018.	Colville G, 2012.	Bronner MB, 2010.	Colville G, 2009.	Helfricht S, 2008.	Balluffi A, 2004.
Critical appraisal questions							
1. Were the two groups similar and recruited from the same population?	N/A	N/A	N/A	N/A	N/A	N/A	N/A
2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	N/A	N/A	N/A	N/A	N/A	N/A	N/A
3. Was the exposure measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y	Y
4. Were confounding factors identified?	Y	N	N	N	N	N	Y
5. Were strategies to deal with confounding factors stated?	Y	N	N	N	N	N	Y
6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	N	N	N	N	N	N	N
7. Were the outcomes measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y	Y
8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	Y	Y	Y	Y	Y	Y	Y
9. Was follow-up complete, and if not, were the reasons to loss to follow-up described and explored?	Y	Y	N	U	U	N	Y
10. Were strategies to address incomplete follow-up utilized?	N	Y	Y	Y	N	N	Y
11. Was appropriate statistical analysis used?	Y	Y	Y	Y	Y	Y	Y

N: no, NA: not applicable, Y: Yes

## Qualitative Studies

Critical appraisal questions	Jakobsen, 2021	Foster K, 2019a.	Foster K, 2019b.	Williams CN, 2018.	Terp K., 2017.	Atkins E, 2012.	Roscigno CL, 2011.	Dampier S, 2002.
1. Is there congruity between the stated philosophical perspective and the research methodology?	Y	Y	Y	U	U	Y	Y	Y
2. Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y	Y	Y	Y	Y	Y
3. Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y	Y	Y
4. Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	Y	Y	Y	Y	Y	Y
5. Is there congruity between the research methodology and the interpretation of results?	Y	Y	Y	Y	Y	Y	Y	Y
6. Is there a statement locating the researcher culturally or theoretically?	Y	N	N	Y	Y	N	U	Y
7. Is the influence of the researcher on the research, and vice-versa, addressed?	U	U	U	Y	Y	U	U	U
8. Are participants, and their voices, adequately represented?	Y	Y	Y	Y	Y	Y	Y	Y
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Y	Y	Y	Y	Y	Y	Y	Y
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y

N: no, NA: not applicable, U: unclear Y: yes



## Randomized Controlled Trial

Critical appraisal questions	Melnyk BM., 2004.
1. Was true randomization used for assignment of participants to treatment groups?	U
2. Was allocation to treatment groups concealed?	Y
3. Were treatment groups similar at the baseline?	Y
4. Were participants blind to treatment assignment?	Y
5. Were those delivering treatment blind to treatment assignment?	Y
6. Were outcomes assessors blind to treatment assignment?	U
7. Were treatments groups treated identically other than the intervention of interest?	U
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Y
9. Were participants analysed in the groups to which they were randomized?	Y
10. Were outcomes measured in the same way for treatment groups?	Y
11. Were outcomes measured in a reliable way?	Y
12. Was appropriate statistical analysis used?	Y
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	U

U: unclear, Y: yes