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

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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 Thirteen medical and healthcare databases, unpublished studies and grey literature were searched up to November 5, 2021.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 (
JB	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

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.

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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.

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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.

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Introduction

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

Methods

Review questions

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

Inclusion and Exclusion Criteria

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

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

Data Sources and Search Strategy

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

Data Extraction and Method of Synthesis

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

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

Results

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

Study Designs

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

Distribution of Ethnicity

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

Participants

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

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

Outcome measures and Phenomena of Interest

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

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

Ethnicity and parental emotional health outcomes after PICU discharge

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

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

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

Two studies compared the differences in anxiety and depression in parents (20,21). One study showed non-significant differences in anxiety at both three and six months after PICU discharge (20). The second study found that Latino ethnicity had a protective effect against anxiety at three to five weeks after PICU discharge as compared to White parents (coefficient -4.72 95% confidence interval (CI): -7.8 to -1.63, $p < .001$)(21). Significant difference in depression score (Hospital Anxiety and Depression Scale) was noted at three months (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-Spanish speaking parents, respectively (20). The study by Colville et al. (2009) comparing post-traumatic growth in families among White and other ethnicities showed no significant difference at four months after their child's critical illness (18).

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

Experiences of White parents after PICU discharge

We were unable to extract data related to the impact of ethnicity and parent's experience after their child's critical illness from the included qualitative studies. As such, we synthesized the findings from these studies to reflect the experiences of the most represented ethnic population, White parents. A total of 91 findings from eight qualitative studies were extracted and aggregated to 14 categories. These 14 categories were further synthesized using meta-aggregation (30), which yielded five synthesized findings (Table 3). *Synthesized finding 1: Understanding and making sense of the critical care experiences, changes in child and the parental role.*

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

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

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

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

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

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

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

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

Mixed-Methods Synthesis

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

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

Discussion

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

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

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

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

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

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

Limitations

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

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

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Figure legend

Figure 1: PRISMA flow diagram

Figure 1: PRISMA flow diagram

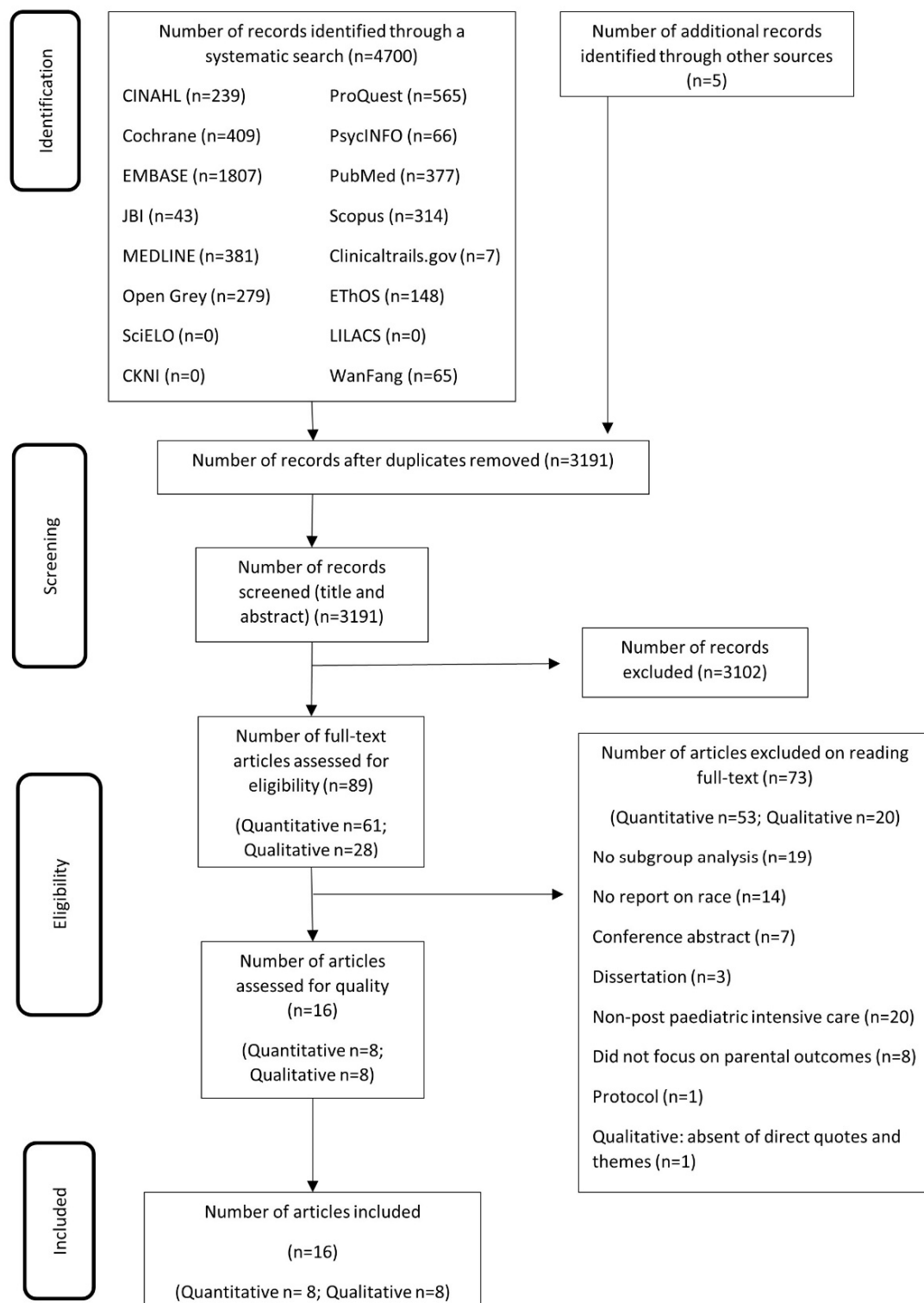


TABLE 1: Characteristics of included quantitative studies (n=8)

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	IES-R PROMIS Depression short form 8a PROMIS Anxiety short form 8a pFS-ICU	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	Davidson Trauma Scale HADS	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	SPAN	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	SRS-PTSD	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	PTG	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	PDS	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	Acute Stress Disorder Scale PTSD Checklist	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	A-State POMS PSI-P	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)

Study	Aim	Participants (sample size)	Equity Diversity & Inclusion	Data collection	Time-points after PICU admission	Setting and location
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
Synthesis one: PICU has long term psychological impact on parents (19 findings)		
Foster et al., 2019a, Australia	Negative psychological impact persists after PICU discharge. Feelings included anxiety, stress, doubt and grief.	Pediatric critical illness create negative experiences and affect the long-term psychological impact of parents. 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.
Foster et al., 2019b, Australia		
Terp et al., 2017, Sweden		
Dampier et al., 2002, United Kingdom		
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		
Synthesis two: Parental coping strategies (14 findings)		
Foster et al., 2019a, Australia	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	Parents uses coping strategies to adjust to life after PICU discharge. 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.
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		
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		

Synthesis three: Caregiving burden of the PICU survivor (25 findings)		
Foster et al., 2019a, Australia	Mental and physical fatigue resulting from caregiving burden has led to delayed self-care in parents.	Lack of preparation and family commitment create negative parental caregiving experiences and affect parental selfcare and employability. 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.
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		
Foster et al., 2019a, Australia	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., 2019b, Australia		
Terp et al., 2017, Sweden		
Roscigno et al., 2011, USA		
Williams et al., 2018, USA		
Synthesis four: Relationship strains and isolation after critical illness (21 findings)		
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.	Pediatric critical illness strengthens relationships within the nuclear family whilst the changing nature of caregiving create feelings of social isolation. 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
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		
Synthesis five: Fragmented aftercare following critical illness (12 findings)		
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.	Fragmented transitions of care to the community after critical illness with limited aftercare and support. 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 that father 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: ethn* 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, Deatrck 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, Stremmer 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, Stremmer 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, Stremmler 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, Stremmler 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

Critical appraisal questions	Rothschild, 2020.	Rodriguez-Rey R, 2018.	Colville G, 2012.	Bronner MB, 2010.	Colville G, 2009.	Helfricht S, 2008.	Balluffi A, 2004.
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	Melnik 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