**Abstract**

**Aim:** To review research on interventions to support the psychological well-being of parents after their child’s discharge from Paediatric Intensive Care.

**Background:** Having a child admitted to a Paediatric Intensive Care Unit (PICU) is a highly stressful experience and post-traumatic stress among parents is well documented. How best to support these parents is currently unclear.

**Review Methods:** Searches were conducted using Medline, PsycINFO, PubMed, CINAHL and The Cochrane library in January 2017. Study selection was carried out using pre-specified criteria. Following appraisal of methodological quality and risk of bias, data were extracted and analysed using a narrative synthesis.

**Findings:** Six quantitative studies met the inclusion criteria. Intervention types included follow-up appointments, telephone calls, educational information and post admission interviews. Insufficient evidence was found to fully support any intervention in isolation but findings support a clear trend that some form of follow-up is beneficial.

**Conclusions and recommendations:** Testing costly interventions is challenging and takes time. In the meantime, a low-cost intervention (such as an information leaflet) to raise awareness of potential problems to staff and to provide a support resource for parents is recommended.

**Relevance to clinical practice**

Parents and carers of children admitted to PICU can develop post-traumatic stress symptoms after their child’s discharge from PICU. This paper addresses how best to support these parents to improve their psychological well-being.

**INTRODUCTION**

**Background**

Having a child admitted to a Paediatric Intensive Care Unit (PICU) is a highly stressful experience for parents (Rodriquez-Rey and Alonso-Tapia 2016) and one, which can impact negatively on their psychological well-being. Between 18% and 45% of parents whose children are admitted to PICU report clinically significant rates of post-traumatic stress symptoms (PTSS) regardless of the severity of their child’s illness or length of stay (Bronner *et al.* 2008, Bulluffi *et al.* 2004, Colville and Gracey 2006, Shudy *et al.* 2006). In their review, Nelson and Gold (2012) identified subclinical symptoms of PTSS among parents to be a very concerning 84%. These symptoms can persist long after discharge (Colville and Pierce 2012).

A PICU admission involves the risk of death, serious injury, or threat to the child’s short or long-term health (Woolf *et al.* 2016). The PICU environment itself with its rapid pace, noises, sleep deprivation and medical interventions present further challenges for parents who are already stressed (Rodriguez-Rey and Alonso-Tapia 2016). Observed trauma has also been identified as a source of stress (Khanna *et al.* 2016). In addition, PTSS in parents has been associated with poorer psychological recovery in the child (Landolt *et al.* 2012) and can affect parents’ relationships with their child (Colville *et al.* 2009). Whilst for most parents the acute traumatic stress reaction is transient, long-term, significant PTSS will develop in a subset of individuals (Bronner *et al.* 2010). Early detection of those at risk allows early intervention to prevent later mental health problems (Bryant *et al.* 2012).

Previous reviews support the significant prevalence of PTSS in children and their parents post PICU discharge (Nelson *et al,* 2012, Shudy *et al.* 2006) and have investigated the early traumatic stress response in parents of children diagnosed with a serious illness or injury (Woolf *et al.,* 2016). The findings of this review contribute to the current understanding of how psychological well-being in parents after discharge from PICU might be improved through the implementation of preventative parent focused interventions.

**Aims**

To review the impact of interventions on the psychological well-being of parents after their child’s discharge from PICU.

**Design** **and methods**

This review follows best practice guidance for reporting a systematic review (Moher *et al.* 2009). All papers reporting primary research (qualitative and/or quantitative), published after the release of Comprehensive Critical Care (DH 2000), exploring or assessing the effectiveness of any intervention designed to improve parents’ psychological well-being after their child’s discharge from PICU were considered eligible for inclusion. Population: parents of children admitted to PICU (parent/carer/mother/father); Intervention: follow up/discharge/clinic/phone call/education/ support group; Comparison: usual care if appropriate; Outcomes: parents’ psychological well-being. Studies, which focused on the experiences of the child/adolescent; those reporting data from bereaved parents; those with children with chronic conditions and those related to neonates were excluded.

**Search Strategy**

The final search was carried out on CINAHL for Kings, OVID Medline (R) 2000 to January 2017 and PsycINFO via EBSCO and PubMed on 23/01/2017. Search terms covered each main facet of the research question. Exploded MeSh (medical subject) headings, such as ‘Critical Care’, ‘Intensive Care Units, Pediatric were used where available. A scoping search including the outcomes well-being, stress disorder and post-traumatic stress yielded many results, none of which fulfilled the inclusion criteria. Thus, both the comparison and outcome element of PICO were omitted for the final search.

 The \* facility (e.g. parent\*) was applied where possible to identify all potential endings of the search terms. Results within each facet were combined using the principles of Boolean logic, with the Boolean operator OR (Aveyard 2008). The Boolean operator AND was then used to combine the results making them as specific as possible to the research question. Forward and backwards citation searching ensured no relevant studies were missed.

**Search results**

The online database search yielded 1,262 results, with 104 potentially relevant citations (see Figure 1). After duplicates were removed 57 citations remained. Application of inclusion criteria resulted in a further 44 studies being excluded. Where abstracts were relevant or where review was not possible from the abstract alone, full text articles were retrieved (*n*=13). Six of the studies (Aldridge 2005, Atkins *et al.* 2012, Dampier *et al.* 2002, Haines and Childs 2005, Rodriguez-Rey and Alonson-Tapia 2016, Youngblunt and Brooten 2008) did not specifically look at an intervention to improve parents psychological stress (see supplementary information for more detail on reasons for exclusion) and two studies (Melnyk *et al.* 2006, Nadal and Als 2015) reported findings from studies already included. A reference list search yielded one additional study, resulting in a final six included studies. A synopsis of included studies is illustrated in Table I.

**Data extraction**

Data extraction included author, year of publication, study design and setting, hypothesis, theoretical underpinning, population, sample size and inclusion/exclusion criteria, interventions, outcome measurements, relevant results and attrition.

**Study designs**

Studies varied in design but all reported quantitative data (Table 1). They included one full scale randomised controlled trial (RCT) (Melnyk *et al.* 2004), an exploratory RCT (Colville *et al.* 2010), a feasibility and pilot RCT (Als *et al.* 2015) and a feasibility study using a RCT design (Samuel *et al.* 2015). The remaining two studies used a non-randomised design. Colville and Gracey (2006) carried out a retrospective cohort study and Gledhill *et al.* (2014) a non-randomised feasibility study. The Cochrane Collaboration’s tool for assessing risk of bias in RCTS (Higgins *et al.* 2011) and the Risk of Bias in Non-Randomised Studies – of Interventions (ROBINS-I) tool (Sterne *et al.* 2016) were used to assess methodological quality. Considering the range of evidence yielded and the nature of the outcomes being assessed, an acceptable, consistent, and expected risk of bias was found across all studies. Due to the nature of the interventions, none of the RCTs included participant blinding leading to potential performance bias (Higgins et al. 2011). There was also a high risk of attrition bias in all RCTs with a low uptake of the intervention proportional to sample size. In the non-randomised studies, a moderate risk of bias due to missing data between baseline and the collection of outcome measures was reported.

**Data analysis**

Due to the high degree of heterogeneity between studies, a narrative summary was deemed the most appropriate method by which to analyse data (The Joanna Briggs Institute 2015). This narrative synthesis includes investigation of the similarities and the differences between the findings of different studies as well as an exploration of patterns in the data (Ryan 2013).

**Results**

***Interventions***

Apart from Colville and Gracey (2006), who explored the views of participants about support needs, all studies focused on a specific intervention designed to support parents’ psychological well-being after PICU discharge. These interventions were, however, provided at different time points, ranging from PICU admission (Melnyk *et al.* 2004) to within seven days of discharge (Als *et al.* 2014); six weeks after discharge (Gledhill *et al.* 2014) up to two months after discharge (Colville *et al.* 2010, Samuel *et al.* 2015) (Table I).

Three studies (Als *et al.* 2014, Gledhill *et al.* 2014, Melnyk *et al.* 2004) used some form of information although none used it in isolation. In the feasibility study by Gledhill et al. (2014), a follow-up appointment offered six weeks after discharge was combined with a leaflet titled ‘Readjusting to Family Life after PICU Admission’. The leaflet included suggestions on how to cope with the potential psychological stress of PICU, how to support the child and how to get further help if required.

Melnyk *et al.* (2004) combined targeted information with the COPE program, a multiple phased intervention, involving an educational behavioural intervention programme, written information, activity work books and a telephone call 2-3 days post discharge. This was the only study to deliver the intervention throughout the whole PICU period from admission to post discharge. Als *et al.* (2015) used an information intervention, similar to that described by Gledhill *et al.* (2014) and Melnyk *et al.* (2004), given to parents within seven days of their child’s discharge from PICU. In this case the information was supplemented with a telephone call within 14 days of receiving the intervention.

In contrast to the studies above, Colville *et al.* (2010) evaluated the provision of a follow-up clinic provided two months after discharge. Finally, Samuel *et al.* (2015) explored whether prospective screening of parents for psychological vulnerability enabled better targeting of a follow-up clinic two months after PICU discharge for high-risk parents.

**Outcome assessment**

Different follow-up times and outcome assessments were evident (Table 1). Gledhill *et al*. (2014) assessed outcomes three months post discharge, a similar timescale to Als *et al*. (2015), Colville *et al*. (2010) and Samuel *et al*. (2015) who assessed parental outcomes five-six months post hospital discharge. In contrast, Melnyk *et al.* (2004) assessed their outcomes at various time points throughout the intervention delivery period.

Most studies used the Impact of Events Scale (IES) (*n*=4), often supplemented by use of the Hospital Anxiety and Depression Score (HADS) and non-validated questionnaires to measure the impact of an intervention on the PICU experience (Table 1). The study by Colville and Gracey (2006) was the only one to use semi-structured interviews to collect participants’ views about a potential intervention.

***Outcome differences***

Colville *et al.* (2010) and Samuel *et al.* (2015) reported some data in favour of the intervention (see supplementary information Table B).However, no statistically significant differences were found (*p*-values 0.239-0.738). Colville *et al.* (2010) also reported that attendance at the clinic was positively associated with distance between home and hospital (*p*=0.042), length of stay (*p*=0.001) and baseline stress (*p*=0.040) i.e. ‘high stress’ parents were significantly more likely to attend the appointment. Als *et al.* (2015) and Melnyk *et al.* (2004) also report results, which support improved psychological wellbeing in the intervention group. Effect sizes range from 0.1-0.4 for all outcomes measured in the study by Als *et al* (2015) and Melnyk *et al.* (2004) report positive effect sizes for the intervention (COPE programme) at three of the four post discharge time points, although most of the statistically significant differences occurred at later data collection points (6-12months) (see supplementary information Table C). The non-significant findings and wide confidence intervals could be related to insufficient sample sizes (Grove *et al.* 2015) and the variation in the thresholds used to determine risk.

***Participants’ views and experiences***

In the study by Als *et al.* (2015), despite the high rate of attrition due to the low uptake of the intervention, 13 out of 17 (77%) parents who received the intervention stated that the information they received made them feel less anxious or concerned and 14 of the 17 (82%) parents reported the telephone call as useful. Results from Gledhill *et al.* (2014) are limited since it focused on the feasibility of setting up and evaluating the take up of a follow-up service. One family did, however, comment that the meeting and advice was useful and recommended that an appointment be offered to everyone. Colville and Gracey (2006) and Gledhill *et al.* (2014) also reported very positive views about the provision of a follow-up appointment. In Colville and Gracey’s (2006) study, 25/34 (74%) of mothers stated that they would have appreciated the offer of a follow up appointment with the PICU team post discharge, feeling that it would have had some psychological benefit. Those who reported higher levels of stress were also found to be more likely to state that they would have liked a follow up appointment (Colville *et al.* 2010). However, the study by Samuel *et al.* (2015) targeting parents with higher levels of stress found no statistically significant differences despite a reported desire for follow up.

**Discussion**

Despite the adverse effects of a PICU admission on parents’ mental health (Bronner *et al.* 2010, Colville *et al.* 2009) and repeated recommendations in scholarly reviews (Nelson *et al.* 2012, Shundy *et al.* 2006), this review highlights that there are surprisingly few published studies reporting the development and evaluation of interventions to improve the psychological well-being of parents of critically ill children. The lack of attention given to parents’ psychosocial needs is also noted in the Neonatal Intensive Care (NICU) population by Purdy *et al.* (2015) and Hall *et al.* (2016). This area of research will always suffer from the inherent problem of engaging potentially traumatised populations who, by definition, often avoid experiences that remind them of the traumatic event (Weisaeth 1989). Colville *et al.* (2010) acknowledge that despite this, it is only by testing out interventions systematically that a better understanding of their effectiveness and feasibility in the clinical setting can be obtained.

Data from this review and from other research literature (Nelson *et al.* 2012, Lasiter *et al.* 2016, Woolf *et al.* 2016) serve as a reminder that more research on psychological interventions with parents is required urgently. In the meantime, findings support a clear trend showing that some form of follow-up is beneficial, whether it be an appointment, the provision of targeted information or a telephone call. Current evidence does not, however, support any intervention used in isolation. Findings further support that parents with higher levels of stress at hospital discharge are more likely to want psychological follow-up suggesting that these interventions are addressing an unmet need.

A scoping review by Lasiter *et al*. (2016) found that follow up clinics for adult intensive care unit (ICU) survivors have existed for decades. However, their specific nature, cost and impact remains unknown. Connolley *et al*. (2014) highlight that ICU survivors require a team with appropriate ICU expertise to recognise and treat the characteristic group of symptoms that may present. This is also likely applicable to families of the NICU/PICU patient. Studies suggest, however, that few nurses have the requisite family intervention skills to provide family members with adequate support during crisis and interventions (Tomlinson *et al*. 2011).

In line with data from the adult population (Bench *et al*. 2013), a key finding was the need for appropriate information to raise awareness of the prevalence of symptoms and to signpost appropriate support resources (Gledhill *et al*. 2014). The provision of personalised discharge information has been shown to be feasible and valued by adult ICU survivors, family members and health care staff (Bench *et al*. 2014, Bench *et al.* 2015), although its impact on health outcomes remains unknown (Bench *et al*. 2015). Similar information resources could also help support the family members of PICU patients.

In such a resource-constrained environment, it is important to target interventions appropriately. National UK guidance (NICE 2005) recommends providing interventions that are directed only at those most likely to benefit. Future interventions focused on identifying families at high risk of mental health sequelae could help target might services more appropriately. Screening parents could also help to predict the risk of parental PTSS following child hospitalisation (Rodriguez-Rey & Alonso-Tapia 2016). Although further research is needed, Frank *et al*. (2015) have also shown the potential value of screening to ensure those at high risk are provided with relevant support. This need for screening and psychological support and referral (where necessary) is also recognised as a priority in the NICU setting (Hynan *et al*. 2013, Purdy *et al*. 2015 and following accidental child injury (Meijel *et al*. 2011). However, there remains insufficient evidence to support its widespread use and a number of potential challenges, such as finding one simple screening measure, which can be used and tested across a variety of PICUs. Parents not deemed at high risk on or during the admission might also develop psychological symptoms after discharge. An intervention that is given out to all parents circumvents this risk.

No data were reported about the cost of a follow-up clinic despite cost-effective approaches needing to be considered. In the studies by Als *et al.* (2015) and Gledhill *et al.* (2014), the follow-up intervention was delivered as part of a package. Analysis of this method is particularly challenging as there is little similarity in the methods of these studies and very few results reported from which to make comparisons.

Primary care services have ongoing responsibility for continuing the management of health following discharge from hospital (McGovern *et al.* 2011). The provision of comprehensive, individualised, realistic, and ideally flexible discharge plans with parents is needed just like in the NICU setting (Purdy e*t al.* 2015) to ensure a healthy transition. Discharge summaries with sufficient information to support primary care staff in managing the post PICU care of patients and their families would help ensure staff are more aware of the events that occurred in hospital and make them better equipped to deal with any future problems (Bench *et al.* 2016). This has also been identified as a goal for NICU follow-up care where Purdy *et al.* (2015) refers to building bridges from NICU to the community by working together across health care teams to ensure appropriate mental health and psychosocial services are put in place before NICU discharge.

Such findings are also relevant to the support of parents of the children admitted to PICU and their introduction would fulfil the recommendations from the Department of Health (2016) for a more balanced emphasis on managing both physical and mental health and National Institute for Health and Care Excellence (NICE 2009) recommendations that critical care rehabilitation requires follow-up from secondary and primary care staff. One practice recommendation would be to include family support services in a discharge check-list including resources for helping parents. Hall *et al.* (2015) found that staff education in the provision of such support leads to feelings of empowerment and reward and the improvement of family well-being.

**Limitations of the review**

The limited evidence available is a significant limitation of the review. In addition, the search, assessment of methodological quality, data extraction and synthesis was carried out by one independent, novice researcher with resource constraints. The impact of this is unmeasurable but is a source of personal bias (Aveyard 2007). Strategies, however, were put in place to minimise potential effects and a supervisor with extensive experience was available to ensure the review followed protocol.

Studies varied in quality, types of interventions and outcomes. Although the risk of bias was considered acceptable many studies suffered significant attrition. Avoidance is recognised as a core symptom of PTSS and people with high levels of avoidance may be less likely to take part in research (Weisaeth 1989).

**Implications and recommendations for practice and future research**

In the light of the challenges to future research in this area, it could be argued that what is needed is an efficient, easily administered, and reproducible intervention for parents of critically ill children, which can be routinely provided. Due to the high levels of anxiety on admission, a phased approach, starting at the time of admission and continuing throughout might prove to be beneficial. However, not all PICU admissions allow time to do this and the most stressful events may occur before information can be given. The huge variation in types of admissions and sources of stress add to the challenge of developing one intervention that suits all parents.

Future research needs to be on a much larger scale to achieve any statistical significance when testing interventions. This review has demonstrated that attrition rates in research in this area will likely be a challenge so sample sizes need to be increased sufficiently to account for this. Complex, long-term research designs are needed to study coping over time, across diverse sources of stress in sufficient numbers to address both its process and trait aspects with an appreciation of the whole person (Lazarus 1993). There is also a need to conduct more research on specific theory based interventions.

This review showed a trend towards a range of different interventions being of potential benefit. Making people aware of the prevalence of symptoms and advising them how to get help would be a very achievable first step for most units. This could be done by providing information leaflets to parents, which include contact details for parent support organisations and primary care providers (Bench *et al.* 2013, Purdy *et al.* 2015). Such leaflets, detailing the increased risk of developing psychological symptoms, and advice on what to do should they experience symptoms could be handed out to all families on discharge from PICU. This might also raise awareness of the problem to the nursing staff.

**Conclusion**

The aim of this review was to identify how we can support the psychological well-being of parents following PICU Discharge. Using information to raise awareness of the problem with staff and families may be of benefit, however, current evidence does not support any intervention used in isolation. Further research is required to establish the value of different assessment tools and interventions.

**Impacts**

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| **What is known about the subject*** + - * There is a significant risk that parents and carers of children admitted to PICU will develop psychological symptoms after hospital discharge.

**What this paper contributes*** This paper highlights the absence of any conclusive evidence for any particular follow-up intervention to support the psychological wellbeing of parents
* Findings of this review support the recommendation of a low-cost intervention, such an information leaflet, while more conclusive robust evidence supporting follow-up interventions is carried out.
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