Parents’ and carers’ experiences of transitions and aftercare following a child’s discharge from a pediatric intensive care unit to an inpatient ward setting: a qualitative systematic review protocol

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Review question/objective
The primary objective of this review is to identify and describe parents’ and carers’ experiences of undergoing transitions and aftercare following a child’s discharge from pediatric intensive care Unit (PICU) to an inpatient ward environment for the treatment of an acute, life threatening critical illness or injury.

Background
In the UK and US, each year PICUs provide medical care to approximately 250,000 infants, children and young people for the treatment of acute life-threatening illnesses and injuries, or exacerbations of pre-existing long term medical conditions.¹ ² The majority of PICU activity involves the provision of intensive therapies to support and treat children with acute, life threatening conditions, such as traumas, organ failure and acute disease.³ Invasive treatments can include endotracheal intubation and ventilation, infusions of inotropic medications, and renal replacement therapies, with the purpose of assisting the child’s body to function through a life threatening illness or injury.² Such experiences for parents and families can be daunting to witness and result in detrimental physical and psychological effects.⁴

Following a child’s admission to intensive care, family dynamics and functioning can be negatively affected.⁵ This has been attributed to the uncertainties surrounding the child’s illness trajectory which can fluctuate between deterioration and recovery.⁶ Having a child in PICU can result in family members compromising own health and wellbeing and needing to cope with changes in routines and
roles. This situation can provoke feelings of uncertainty, fear, stress and depression, with such factors reported to lead to long lasting effects on both the patient and family. The stress experienced by family members can be due to various factors such as: alterations in the child’s appearance (with the use of needles and tubes), alarming monitors, changes in parental role, and communication difficulties with staff members. When the patient is discharged from an intensive care environment to another healthcare setting, parents may additionally encounter other types of anxiety and uncertainties.

The transition from intensive care to a ward based setting has been recognized as a challenging experience for both patients and families. There are multiple reasons for this for example, although specialist care continues for the patient, the intensity of certain treatments decrease, making the transition a potentially challenging experience. In addition, fear and anxieties experienced by family members are reportedly linked to various factors, such as not knowing what to expect from a different environment, decreased supervision from nursing observations and treatments, and the difference in nurse patient ratio. Such factors are seen to not only impact the patient but also the family. The nursing profession is required to take into account the fact that the transition from pediatric intensive care to the ward environment can be a stressful encounter for children and their families. It is therefore apparent that multitude factors influence the emotional, psychological and social status and functioning of parents and carers following the child’s transition from the PICU and during aftercare. In order to provide appropriate and effective support and care, it is important to explore and understand parental experiences and perceptions in more depth. It is therefore timely and necessary to produce a systematic review to identify and summarize existing literature exploring parents’ and carers’ experiences of transition and aftercare following a child’s discharge from PICU.

A preliminary search of databases (CINAHL, Medline and Prospero) and the JBI Database of Systematic Reviews and Implementation Reports has been undertaken and no current or similar systematic reviews or protocols have been identified on this or a similar topic.

**Keywords**

Intensive care; critical care; PICU; parent; family member; loved one; carer; coping; experiences; perceptions; transition; relocation; aftercare; need; coping; satisfaction; support

**Inclusion criteria**

**Types of participants**

This review will consider studies that include parents or carers (defined as having parental responsibility) of a child or adolescent, aged 0-18 years that have had an unplanned admission to a PICU for treatment of a critical illness or injury.

**Phenomena of interest**

This review will consider as the phenomena of interest the experiences and perceptions of parents and/or carers of: (1) the transition of the child from the PICU to an acute inpatient setting, and (2) the child receiving aftercare within an inpatient setting.
**Context**

The review will include a hospital based PICU and an inpatient care in any country. The review will include participants from any culture or group. Studies that exclusively report on parental experiences and perceptions within the community setting will be excluded.

**Types of studies**

This review will only consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

**Search strategy**

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies.

The databases to be searched include:
- CINAHL – Cumulative Index of Nursing and Allied Health Literature
- Medline (Ovid)
- EMBASE – Excerpta Medica Database
- PsycINFO
- ASSIA – Applied Social Sciences Index and Abstracts

The search for unpublished studies, including grey literature, will include:
- Open Grey – research reports, conference papers and doctoral dissertations

Initial keywords to be used:

Paediatric Intensive care OR pediatric critical care OR critical care OR PICU OR PCCU, Parent OR carer OR family OR loved one; Transition OR relocation OR aftercare; Inpatient OR hospital OR ward Qualitative research, patient experience, interviews, phenomenology, grounded theory, ethnography.

Appendix I shows a more detailed search strategy in CINAHL.

No date limits will be placed on databases searches. Due to the linguistic abilities of the reviewers, only studies published in English will be included. These will not be excluded following the database searches to enable the number of studies not reported in English to be identified.

**Assessment of methodological quality**

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using a standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-
QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

**Data extraction**

Qualitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives. Data extraction will primarily be carried out by one researcher (ZS); however the whole team will meet regularly to discuss emerging issues and to ensure all relevant procedures are being correctly followed.

**Data synthesis**

Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation through assembling the findings (Level 1 findings) rates according to their quality, and categorizing these findings on the basis of similarity in meaning (Level 2 findings). Using a collaborative team based approach, these categories will then be subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where contextual pooling is not possible the findings will be presented in narrative form.

**Conflicts of interest**

The authors declare that there are no conflicts of interest.
References


Appendix I - Detailed search strategy example on CINAHL

Identifiers I (Subject headings that relate to the term ‘transition’ combined with ‘OR’):
- Transfer discharge
- Transfer intrahospital
- Relocation
- Aftercare
- Health transition
- Transitional programs

‘AND’

Identifiers II (Subject headings that relate to the term ‘PICU’ combined with ‘OR’):
- Intensive care units, pediatric
- Intensive care units
- P*ediatric units
- P*ediatric critical care nursing
- Critical care
- Critical care nursing
- Child care providers

‘AND’

Identifiers III (Subject headings that relate to the term ‘Child’ combined with ‘OR’):
- Child
- Infant

‘AND’

Phenomenon I (Subject headings that relate to the term ‘parental experience’ combined with ‘OR’):
- Parents
- Parents of disabled children
- Single parent
- Foster parent
- Adolescent parent
- Adoptive parents
- Biological parents
- Life experiences
- Parental attitudes
- Emotions
- Feeling

‘OR’

Phenomenon II (Keywords that relate to the term ‘experience’ combined with ‘OR’):
- Meaningfulness
- Journey
‘AND’

Design (Subject headings that relate to ‘qualitative research’ combined with ‘OR’):

- Qualitative studies
- Ethnographic research
- Phenomenology
- Semi-structured interviews
- Surveys
- Open ended questionnaires
- Survey research
- Questionnaires
Appendix II: QARI appraisal instrument

**JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research**

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<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not Applicable</th>
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<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</td>
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<td>3. Is there congruity between the research methodology and the methods used to collect data?</td>
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<td>5. Is there congruity between the research methodology and the interpretation of results?</td>
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<td>6. Is there a statement locating the researcher culturally or theoretically?</td>
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<td>7. Is the influence of the researcher on the research, and vice-versa, addressed?</td>
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<td>8. Are participants, and their voices, adequately represented?</td>
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<td>9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?</td>
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<td>10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
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Overall appraisal: Include □ Exclude □ Seek further info. □

Comments (including reason for exclusion)

______________________________________________________________________________________
Appendix III: QARI data extraction instrument

**JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewers  ............................................. Date  .............................................

Author  ................................................ Year  ................................................

Journal  ................................................ Record Number  ............................

**Study Description**

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete  Yes [ ]  No [ ]
<table>
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<tr>
<th>Findings</th>
<th>Illustration from Publication (page number)</th>
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Extraction of findings complete  

Yes ☐  No ☐