Title:

Parents' and carers' experiences of transition and aftercare following a child's discharge from a Pediatric Intensive Care Unit to an in-patient ward setting: A qualitative systematic review

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Conflict of Interest

The authors have no conflicts of interest to declare.

Abstract

Objectives

To explore parents' experiences of transition and aftercare following their child's discharge from a pediatric intensive care unit to an inpatient ward.

Methods

A qualitative systematic review was conducted. Electronic databases CINAHL, MEDLINE, EMBASE, Psych INFO, and ASSIA were searched for qualitative studies with no date limits imposed. Methodological quality was assessed using the JBI QARI standardised critical appraisal instrument. Data were extracted into a standardised data extraction tool. Findings were pooled using a meta-aggregative approach.

Results

Four studies were included in the final review that included a total of 95 participants. Forty-nine findings were extracted and through an iterative process resulting in four synthesised findings being developed. These included: (1) Dynamic emotional response pre, peri and post-transfer; (2) Involvement in care absent but fundamental to functioning; (3) Changes in care delivery and environment provoking adverse emotions; and (4) Transition as a physical, emotional and social balancing act.

Conclusion

Transitioning from the pediatric intensive care unit to an in-patient ward can be a challenging time for parents, exposing them to a turbulent emotional and social status, and depleting their personal resources. Parents are aware of differences in the organisation and delivery of care between clinical areas which can compound the adversity experienced. Health professionals need to provide targeted support in order to mitigate these negative emotional, physical and social effects experienced.

Keywords

Parents; children; pediatric intensive care; transition; meta-synthesis; Qualitative research; aftercare; discharge; inpatient ward

Implications for clinical practice

- Health professionals working in the PICU and inpatient ward settings must be aware that transitioning out of the PICU can provoke a range of emotional responses in parents.
- Transitioning from the PICU can be a stressful and exhausting experience for parents, hindering their abilities to perform normal tasks.
- Parents often identify that preparation and information by health professionals about the transition process are inadequate, exacerbating negative feelings and impaired confidence.
- Effective communication and the provision of timely and appropriate information prior, during and post-transfer from the PICU to the ward setting may enhance the parental experience and their emotional outcome.

Introduction

Due to advances in pediatric critical care medicine and technology, survival rates from childhood critical illness have soared (Pollack et al. , 2014). However, having a child who is critically ill or injured and who warrants admission to PICU is recognised as a distressing and uncertain time for parents (Nelson and Gold, 2012). The negative emotional impact of being a parent of a child who is critically ill has been reported widely within the literature, particularly with stress, low mood, and anxiety symptoms being identified (Manning et al. , 2018, Nadel et al. , 2015, Nelson and Gold, 2012, Watson et al. , 2018, Woolf et al. , 2016). A recent study by Stremler et al. (2017) investigated the prevalence of, and factors associated with, anxiety, depressive symptoms, and decisional conflict of 118 parents with children on the PICU. Data were collected using validated instruments, actigraphy and sleep diaries. Results showed that 24% of parents experienced severe anxiety, 51% had severe depression, and 26% had significant decisional conflict (Stremler et al., 2017). Furthermore, family dynamics and functioning can be negatively affected (Doucette and Pinelli, 2004). This adverse impact on parents has been attributed to the uncertainties surrounding the child's illness trajectory which can fluctuate between deterioration and recovery (Fuhrman and Zimmerman, 2011). Moreover, 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 can provoke negative emotions in parents (Shudy et al. , 2006).

The transition or transfer from the PICU to an inpatient ward has been recognised as a potentially challenging experience for patients and families (Berube et al. , 2014). Fear, stress, and anxiety have been reported to be experienced by family members due to: not knowing what to expect from a different environment; the decreased supervision of nursing observations and treatments; and the differences in the nurse-patient ratio (Ridling et al. , 2011). Subsequently, these may result in family members having to adjust to changes in routine and roles which can impact on their own health and wellbeing (Knapp et al. , 2010).

In order to provide appropriate and effective support to parents transitioning from the PICU, it is important to have a comprehensive and in-depth understanding of their experiences and needs during this time. It is evident from a preliminary scope of the literature (MEDLINE, CINAHL, ASSIA, and JBI Database) that no qualitative systematic review has been undertaken that appraises, reviews and synthesizes the existing evidence base to provide a comprehensive overview of the phenomena. Therefore, this review aimed to systematically review and explore parents' experiences of transitions and aftercare following their child's discharge from the PICU to an in-patient ward setting.

Methods

The systematic review was conducted in line with the published protocol (Suleman et al. , 2016).

Search strategy

Six electronic databases (CINAHL, MEDLINE (OVID), EMBASE, PsychINFO, ASSIA, Open Grey) were searched. Search terms are listed in *Supplementary File 1*. No date limits were imposed on the database searches. Searches were conducted between October 2015 – January 2016 and updated in May 2018.

Study selection and inclusion criteria

All citations were exported into EndNote™. Duplicates were removed and ZS and JCM assessed titles and abstracts against the eligibility criteria (shown in Table 1). Only studies published in the English language were considered for inclusion. Full papers were obtained for the studies deemed 'included' or 'uncertain' and again, these papers were screened against the inclusion criteria.

****Insert Table 1****

Assessment of methodological quality

Methodological quality was assessed by two independent reviewers (ZS and JCM). The JBI QARI critical appraisal instrument was used, after which, the reviewers met to discuss the results of the appraisal. Any disagreements that arose between the reviewers were resolved through discussion.

Data extraction

Data were extracted using a standardised data extraction tool. Data included: details about the phenomenon of interest, populations, study methods and outcomes of significance to the review question and specific objectives. ZS and JCM read each paper several times to obtain an overall understanding of the study's key themes, findings and clinical implications and extracted the data. Each extracted finding was supported by a verbatim data excerpt from the studies' research participants to demonstrate its meaning. Where this was not possible, the author's narrative was extracted. Findings were reviewed and assigned levels of credibility: Unequivocal (U), findings were accompanied by illustrations that were beyond reasonable doubt and therefore were not open to challenge; Credible (C), findings were accompanied by illustrations that lack a clear association and were therefore open to challenge; Unsupported (US), findings were not supported by data (Joanna Briggs Institute, 2011). The assigned levels of credibility are reported with the synthesised findings in Tables 5-8.

Data synthesis

Data were pooled using JBI QARI. This involved the aggregation of data to generate a set of statements and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings (Joanna Briggs Institute, 2011).   Data synthesis was conducted by ZS and JCM through an iterative process. This synthesis was then reviewed by the third reviewer (CE) and through discussion was revised until an agreement was reached.

Results

A summary of study selection is presented in Figure 1. The literature search yielded 542 citations. Fifty duplicates were removed. From the 492 citations, 12 studies appeared to be eligible for inclusion. Full-text versions of the 12 included papers were examined and resulted in nine papers being deemed ineligible. Excluded papers and their reasons for exclusion were listed (see *Supplementary file 2*). From the three papers that were included, reference lists identified an additional study that was eligible for inclusion. In total, four papers were eligible for critical appraisal.

****Insert Figure 1 ****

Description of studies

Table 2 presents a summary of the characteristics of the four included papers (Berube et al., 2014, Colville et al. , 2009, Keogh, 2001, Kirk et al. , 2015). Three studies were conducted in the UK (Colville et al., 2009, Keogh, 2001, Kirk et al., 2015) and one in Canada (Berube et al., 2014). All studies were conducted in the PICU setting and included a total of 95 participants, composed of 59 mothers, 30 fathers, two grandparents, and two couples (n=4) with unspecified gender. Studies used a range of methodological approaches including mixed methods (Colville et al., 2009) and hermeneutic/interpretive phenomenology (Berube et al., 2014, Keogh, 2001). One study did not state a specific methodology (Kirk et al., 2015) instead it reported using a broad qualitative approach. Interviews were used in all studies and ranged from structured (Colville et al., 2009), semi-structured (Kirk et al., 2015) and unstructured (Berube et al., 2014, Keogh, 2001). The location and time-point of interviews ranged across the studies. Two studies interviewed parents in the hospital following their child’s transfer to the ward (Berube et al., 2014, Keogh, 2001), whereas the other studies conducted interviews in the family home at eight months (Colville et al., 2009) to 72-months (Kirk et al., 2015) after PICU discharge.

****Insert Table 2 ****

Methodological quality

A summary of quality appraisal of included studies is presented in Table 3. Overall, the studies were considered to be methodologically rigorous with congruity between research methodology, study objectives, methods used to collect data, and the interpretation of results.

****Insert Table 3 ****

Results of meta-synthesis of qualitative research findings

A total of forty-seven findings with supporting illustrations were extracted. The study source, findings, and illustration are presented in *Supplementary File 3*. These were aggregated, according to the similarity of meaning, into nine categories which were then analysed further into four synthesised findings (shown in Table 4).

****Insert Table 4 ****

Synthesised finding one: Dynamic emotional response pre, peri and post transfer

Findings suggest that transitioning between PICU and the ward triggered a dynamic emotional response amongst parents (summarised in Table 5). Both positive and negative feelings were reported prior to, during, and following transfer of their child from the PICU to the ward.

****Insert Table 5 ***

Parents experienced positive feelings upon hearing the news of the transfer, perceiving this as an indication of improvement and progress in their child’s condition. However, the need to adapt to new staff, a different environment, and different approaches to care were associated with negative feelings. Parents were reported to experience high levels of anxiety, tension, insecurity, and isolation due to concerns pertaining to the prospect of the impending transfer (Keogh, 2001).

Synthesised finding two: Involvement in care absent but fundamental to functioning

All studies highlighted the importance of parents being involved in their child's care as it was perceived as fundamental to support their own daily functioning (summarised in Table 6). However, in both the PICU and ward settings, parents identified deficits in information and involvement pertaining to their child's care. This was associated with various emotional responses that appeared to negatively affect parental functioning (Berube et al., 2014, Colville et al., 2009). In particular, Colville et al. (2009) reported that the main source of stress for parents immediately before and after PICU admission was their fear for the child's immediate safety. Anxieties were reported in dramatic terms such as feeling bewildered due to the abandonment on transfer to the general ward (Colville et al., 2009).

****Insert Table 6****

The findings also highlighted the inconsistencies in information and communication from health professionals across the PICU and ward settings. Parents reported that timely and relevant information was associated with transparency and honesty and helped them to gain mental and emotional comfort whilst on PICU (Berube et al., 2014). However, once on the ward the level of information regarding their child's care was perceived to decrease. This was concurrent with an increased expectation of parents providing greater levels of input and care for their child and resulted in parents feeling anxious and uninformed.

Synthesised finding three: Changes in care delivery and environment provoking adverse emotions

All studies indicated that parents' experiences of transition were affected by changes in how care was delivered in the PICU and ward settings (summarised in Table 7).

****Insert Table 7****

Findings revealed that parents felt reassured by the intensive observation, intervention and monitoring that occurred in PICU. However, stress and anxiety in parents were attributed to the 'stepping down' in care from the PICU to the ward setting. Parents felt that the PICU was a controlled and supportive environment; in contrast, the ward appeared to be noisy and chaotic. Parents were receptive to the differences in the organisation and delivery of nursing care between PICU and the ward and it provoked them to feel less in control and unsupported by ward staff (Berube et al., 2014, Keogh, 2001). Subsequently, parents reported experiencing heightened levels of stress and anxiety once reaching the ward and they identified that there was a lack of preparation in supporting them to undertake this transition.

Synthesised finding four: Transition as a physical, emotional and social balancing act

All studies suggested that transition was perceived and experienced by parents as a physical, emotional and social balancing act with exhaustion affecting parental readiness (for the transfer) and functioning (summarised in Table 8).

****Insert Table 8****

The findings showed that parents felt physically and mentally exhausted from being involved in parenting an ill child. This impacted upon all other aspects of their ability to function as a parent and hindered their ability to cope with facing a new situation. For example, they became very distracted and were not able to remember directions or vital information (Berube et al., 2014). Attempts by parents to balance the multiple demands between home, work, and caring for an unwell child affected their readiness for transition. Parents reported that they felt the strains of wanting to be with their child whilst also still trying to fulfil normal roles and responsibilities (Berube et al., 2014). However, parents appeared to overcome this period of physical and emotional exhaustion through the support of family and friends (Kirk et al., 2015).

Whilst some parents associated positive reports with support from their healthcare teams (such as support in doing laundry and grocery shopping) (Berube et al., 2014), this was a minority. The majority of reports from across the studies identified that parents felt unsupported due to the absence of information and lack of continuity of nursing care (Colville et al., 2009, Kirk et al., 2015). This appeared to hinder the relationships between health professionals, patients and families. Parents reported that they had little information from professionals, and the information that they did receive was inconsistent and lacked clarity (Kirk et al., 2015). Furthermore, some parents also reported that a clear understanding of their child's health status was inhibited by health professionals lack of time and unapproachable manner (Berube et al., 2014).

Discussion

The results of this systematic review show that parents can experience a mixture of emotions, ranging from elation and relief to heightened stress and anxiety. Concurrently, parents can face physical and social adversities prior to and following the transfer of their child from the PICU to the ward. Much of the previously published literature has attributed parents' negative experiences to the environment of the PICU, and the uncertainties and emotional turmoil of having a critically ill and physiologically vulnerable child (Ames et al. , 2011, Dahav and Sjöström-Strand, 2018, Nelson and Gold, 2012, Terp and Sjöström-Strand, 2017). However, this review indicates that many other individual, relational, and organisational factors can affect parental experiences, and that these vary at different stages of the transfer process. Furthermore, results show that parents are aware and receptive to the differences in approaches, coordination and delivery of care between the PICU and the ward. Negative emotions were attributed to the transition from a controlled and supportive environment to the less regulated ward setting, with the concomitant loss of one to one nursing care. Similar findings have been reported in the adult ICU literature with studies identifying both patients and their families feeling vulnerable and abandoned immediately prior to and following transfer to the ward (Chaboyer et al. , 2005, Cullinane and Plowright, 2013, Forsberg et al. , 2011, McKinney and Deeny, 2002). Health professionals need to be aware of these potential adversities and target parental support in order to address and minimise the negative impact. The results from this review demonstrate that parents have a requirement for timely information and communication from health professionals pertaining to what to expect and what is expected of them prior to and post discharge from the PICU. However, their ability to process and utilise this information may be impaired due their emotional status and level of fatigue. This finding appears congruent with the study by Latour et al. (2011) which qualitatively explored the experiences of 64 parents with children admitted to seven Dutch PICUs. The analysis of the interview data identified that parents had a requirement for information on discharge and in the post-PICU period, and being provided this information was perceived to have facilitated their ability to cope (Latour et al., 2011). The results from this review enhance understanding of parental experiences in transitioning from the PICU to the ward and therefore provides a platform for the focused development and testing of interventions to support their needs during the transition process.

Strengths and limitations

The results of this review provide novel and contemporary insights into the experiences and perspectives of parents that have a child being transferred from the PICU to the ward. As such it enhances professionals understanding of the potential emotional, physical and social adversities that may be faced by parents during this time. However, a number of limitations exist that must be acknowledged. Firstly, from a total of 95 participants included, 64 of those were mothers. It is therefore not clear how well the results represent the experiences and views of fathers who may perceive and experience the phenomena differently to mothers. Secondly, two studies (Berube et al., 2014, Colville et al., 2009) excluded families of children who had been readmitted to the PICU. Children who are chronically critically ill and require multiple admissions to the PICU make up an increasing proportion of the PICU populous. Therefore it must be recognised that the potentially unique needs, experiences and perspectives of these families may not have been fully comprehended by this review. Thirdly, from the papers included in this review, there was a lack of information pertaining to the cultural context in which parents experienced transitioning from the PICU to the ward, thus limiting understanding of the phenomenon through different cultural lenses. Fourthly, this review only considered studies reported in the English language, which may have limited insights into the phenomenon of interest pertaining to non-English speaking groups.

Conclusion

In conclusion, the results from this systematic review provide novel insights into the complex experiences that transitioning out of the PICU to an inpatient ward exposes parents to. It is evident from the synthesised results that for some parents this aspect of their child's care pathway can expose them to a turbulent emotional and social status, depleting their personal resources. Furthermore it identifies that parents are aware of differences in the organisation and delivery of care between the PICU and ward clinical areas and that this can compound the adversity experienced. It is therefore important that health professionals at each juncture of the child's care pathway offer parents targeted support in order to mitigate or reduce any negative emotional, physical and social effects experienced. By developing a clearer understanding of the experiences and potential needs of parents during this transitionary phase, health professionals will be better placed to offer support prior- and post-PICU discharge.

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Table 1. Eligibility criteria for included studies

Criteria
1. **Population:** Parents (defined as having parental responsibility that could include mother, father, or grandparent) of an infant, child or adolescent, aged 0-18 years who have had an admission to PICU for treatment of critical illness or injury
2. **Phenomena of interest:** the experiences and perceptions of parents during the transition and aftercare of their infant, child or adolescent from PICU to an inpatient ward
3. **Setting:** PICU and/or inpatient ward setting in any country
4. **Types of studies:** Qualitative data including, but not limited to designs such as; phenomenology, grounded theory, ethnography, action research and feminist research
5. Studies published in English.

Table 2 – A summary of characteristics of included studies

Study	**Methodology**	**Phenomena of interest**	**Cultural context/ geographical setting**	**Participants**	**Inclusion/ exclusion criteria**	**Data analysis**	**Authors conclusions**
Berube, et al (2014)	• Phenomenological method • Unstructured interviews	Lived experience for parents when their child was transferred from the PICU to the hospital ward.	*Cultural context:* not stated *Geographical:* Hospital in Canada	The study recruited 10 participants in total n = 8 mothers n = 2 fathers	*Inclusion:* • Parents over 18 years of age • English speaking parents • Biological parents or legal guardians of a child being transferred from the PICU to the ward. • Transfer occurring less than 48 hours prior to interview. *Exclusion:* • Parent of a child readmitted to the PICU	Thematic analysis, Van Manen (1990)	The study provided new understanding of the experiences of parents in transition from a pediatric intensive care unit to the hospital ward. Parents were searching for comfort throughout all of the transitions. The child's critical illness, the physical environment of the hospital, and being from out of town were reported to impede comfort. The need for

					• Involvement with child and family services case		further education and implementation of Family Centred Care is required.
Colville, et al (2009)	• Cross-sectional mixed methods cohort study • Interviews (open ended questions)	Establish rates of psychological distress in parents, 8 months after discharge from PICU and other variables	*Cultural context:* not stated *Geographical:* 8 bedded PICU in a London hospital	The study recruited 50 participants in total n = 32 mothers n = 18 fathers	*Inclusion:* • Parents with a child admitted to PICU for over 24 hours, *Exclusion:* • Death of a child • Readmission to PICU	Thematic analysis, Framework Approach. Data Software Package NVivo2	Removal of all stress is an unattainable aim. Nevertheless, health professionals should acquire better understanding of parent's experiences and provide better evidence based decisions about care.
Keogh. (2001)	• Phenomenological method • Unstructured interviews	Explore and illuminate parent's experiences of the transfer of their child from the PICU to the ward.	*Cultural context:* not stated *Geographical:* 16 bedded general and cardiothoracic pediatric ICU in	The study recruited 6 participants in total. n = 2 couples n = 2 mothers	*Inclusion:* • Parents over the age of 18 • Could express feelings • Had a child in PICU for at three days	Thematic Analysis, Van Manen (1984).	The findings revealed a mixed response, but overall the parents found the transfer experience stressful. Critical care nurses are in a

			a central London teaching hospital		*Exclusion:* none stated		unique position to prepare and facilitate a smoother transition to the ward as they are a constant attendance to the child and family prior transfer.
Kirk, et al. (2015)	• Qualitative approach • Semi-structured interviews	Examine parent's experiences and support needs following a childhood TBI from the time to the accident to their child's discharge home.	*Cultural context:* not stated *Geographical:* children's hospital in the North of England	The study recruited 29 participants in total n = 18 mothers n = 9 fathers/stepfathers n = 2 grandmother	*Inclusion:* • Families of children with a severe TBI who had been discharged from one specialist children's hospital in the North of England between January 2007 and July 2012. *Exclusion:* • Discharge within the previous 6 months	Framework Approach.	The study contributes knowledge by examining the changing experiences and support needs of parents across the care trajectory. A holistic approach enables key care transitions within hospital and community settings to be explored and the services

					• Parent who was also seriously injured • Injuries suspected as non-accidental		implications identified.

Table 3 - Quality appraisal of included studies using JBI-QARI

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Keogh, S 2001[15]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Kirk, S Fallon, D Fraser, C et al, 2015[16]	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8
Berube, KM et al, 2014[2]	Y	Y	Y	Y	Y	U	U	Y	Y	U	7
Colville, G Darkins, J Hesketh, J et al, 2009 [14]	Y	Y	Y	Y	Y	U	U	Y	Y	U	7
Criteria (Y=yes, N =no, U=unclear, NA=not applicable)											

Table 4 – Categories and synthesised findings

Synthesised finding	Categories
1. Dynamic emotional response pre, peri and post transfer.	1. Positive response to transfer 2. Fears of the unknown pre, peri and post transfer
2. Involvement in care absent but fundamental to functioning.	3. Being involved and informed is fundamental to satisfaction but lacking in both the PICU and ward settings 4. Lack of information provoked parents to rationalise child's status to justify transfer
3. Changes in care delivery and environment provoking adverse emotions	5. Finding comfort through observation, intervention and monitoring. 6. Provoking stress through stepping down care. 7. Transitioning from a controlled and supportive environment to chaos and uncertainty.
4. Transition as a physical, emotional and social balancing act	8. Physical and emotional exhaustion affecting parental readiness and functioning. 9. Balancing home and work life with an unwell child.

Table 5 - Findings and categories for synthesised finding one

Finding	**Category**	**Synthesised finding**
Positive feelings: All the parents initially responded positively to the news of the transfer of their child from the ICU. They linked this with progress and an improvement in their child's condition[15] - (U)	Positive response to transfer	**Synthesised finding one:** Dynamic emotional response pre, peri and post transfer
On a positive note, parents expressed their appreciation of the aesthetics of nursing care. That is, the caring, creative and imaginative side as opposed to technical knowledge[15] - (U)		
Emotional support from health care teams was expressed in more general terms [2] - (U)		
Making the move examined the physical move from the PICU to the inpatient ward. The actual process of the physical move was relatively smooth and uneventful for parents [2] - (C)		
Parents recognised that the fact that their child was well enough to be transferred out of PICU was a positive development [14]- (U)		
Negative feelings: The negative feelings of anxiety, tension, insecurity and isolation were largely attributed to the parent's fear of the unknown and the need for them to adapt to new staff, a different environment and different approaches to care [15] - (U)	Fears of the unknown pre, peri and post transfer	
They [parents] found this change very stressful and were emotionally unprepared, particularly for the reduction in staffing ratios [14]- (U)		
Parents also searched for a plan of care and found it very uncomfortable and exhausting not knowing what would or could be done for their child, what their progress would look like, and what the future would involve [2] - (U)		
Most parents were given little information, and what they did get was not consistent [2] - (U)		
Other parents were told information that made the ward sound less than desirable and that they needed to be concerned [2] - (U)		
Transitions: Although the focus of the interview was intended to be the PICU experience, it was noteworthy how often parents raised the subject of their child's care outside the unit, preceding the admission and afterwards[14] - (U)		
Parents frequently described a powerful sense that there was something seriously wrong prior to the child's intensive care		

Table 5 - Findings and categories for synthesised finding one

admission and that it was difficult to have these fears taken seriously by health professionals[14] - (U)		
The anxiety parents felt on the journey to the local hospital to PICU was also recounted geographically [14] - (U)		
The main source of stress for parents immediately before and after PICU admission was their fear for the child's immediate safety, but their anxiety was compounded by the bewilderment of abandonment on transfer to the general ward, which they described in dramatic terms and seemed to be related to the loss of intense relationships forged with staff on PICU [14] - (U)		
Moving to the ward: Parents felt unprepared for the transfer of their child from ICU to the ward. Decisions appeared to be made suddenly without any discussion with parents who perceived their children as being seriously ill and in need of intensive care. Consequently they found it difficult adjusting to the contrast between ICU and the ward which led to concerns over their child's safety [16] - (U)		

Each extracted finding was supported by a verbatim data excerpt from the studies' research participants to demonstrate its meaning. **Key:** (U) = Unequivocal. Findings were accompanied by illustrations that were beyond reasonable doubt and therefore were not open to challenge; (C) = Credible. Findings were accompanied by illustrations that lack a clear association and were therefore open to challenge; (US) = Unsupported. Findings were not supported by data.

Table 6 - Findings and categories for synthesised finding two

Finding	**Category**	**Synthesised finding**
Although diagnosis is for the patients I feel can be usefully applied to parents to aid in identifying nursing actions and intervention that could increase their satisfaction with the new environment [15] - (U)	Being involved and informed is fundamental to satisfaction but lacking in both the PICU and ward settings	**Synthesised finding two:** Involvement in care absent but fundamental to functioning
All the parents in the study expressed the desire for and potential benefit of meeting one of the ward nurses and/or visiting the ward prior to transfer [15] - (U)		
Being kept in the know: The second theme was a way for parents to be involved in their child's care, and this information helped parents to gain mental comfort [2] - (U)		
Receiving information was seen as the information provided by health care professionals without them being asked. This receipt of information helped parents to feel as though the health care team was being transparent and upfront with them, which was emotionally comforting [2]- (U)		
Parents sought information by participating in rounds or asking questions to clarify or confirmation information they had heard or of which they were unsure [2]- (U)		
Some parents talked about not being able to get information as easily on the ward, which left them feeling uncomfortable or as though something was being hidden from them, thus they had to more actively seek information on the ward [2]- (C)		
Being transferred: In the sub category 'your child is ready' most parents were told their child was ready to leave the PICU because they were doing better. Two parents shared that they were told the reason for their child's transfer was that their child's PICU bed was needed for another patient which may have made them feel uncomfortable with the transfer. Generally, a few details about the transfer were given to the parents [2] - (U)	Lack of information provoked parents to rationalise child's status to justify transfer	
In the sub-category 'is my child ready?' parents assessed for themselves if their child was ready for transfer based on more practical cues, such as how the child was breathing, what the child looked like, and if he/she was eating [2] - (U)		

4 out of 10 parents thought it was too early for their child's readiness to leave the PICU [2]- (U)		
Children had a lot less attention [on the ward] [2] - (U)		
Finally, regarding information and communication post-transfer, parents commented on the lack of inclusion in conversations on the ward compared to PICU [2] - (U)		
Parents found that the communication between PICU and the ward was lacking [2] - (U)		
Parental responsibility for their child's care increased on the ward; however, parents were unsure of staff expectations about the nature of their involvement as well as how to care for their child. During this time, their child's difficulties began to emerge, such as seizures, behaviour problems, mood swings and personality changes. That lack of continuity of nursing care meant parents did not develop the relationship that would enable them to discuss their concerns and feelings which was compounded by a perception that staff lacked time for emotional support [16] - (U)		
Parents felt that they needed greater emotional support during this time in terms of someone to talk to in order to help them understand their 'new' child [16] - (U)		

Each extracted finding was supported by a verbatim data excerpt from the studies' research participants to demonstrate its meaning. **Key:** U = Unequivocal. Findings were accompanied by illustrations that were beyond reasonable doubt and therefore were not open to challenge; C = Credible. Findings were accompanied by illustrations that lack a clear association and were therefore open to challenge; US = Unsupported. Findings were not supported by data.

Table 7 - Findings and categories for synthesised finding three

Finding	Category	Synthesised finding
Dependency: … found that patients equated the nurse's competency and level of caring with the degree of monitoring (by personnel and technology). The abrupt cessation of the patient/nurse relationship and intense monitoring would initiate a stress response [15] - (US)	Finding comforts through observation, intervention and monitoring	**Synthesised finding three:** Changes in care delivery and environment provoking adverse emotions
Parents watched over their child to search for comfort [2] - (U)		
Parents described monitoring as nursing presence[2] - (U)		
Care management: The loss of one to one care was a significant source of stress for all patients in the study as well as in related studies[15] - (U)	Provoking stress through 'stepping down' care	
Parents seemed to note a decreased nursing presence (i.e. what parents called monitoring) and less availability of the nurses for them or their child which made them uncomfortable [2] - (U)		
Although parents recognised that the fact that their child was well enough to be transferred out of PICU was a positive development, they found this change very stressful and were emotionally unprepared, particularly for the reduction in staffing ratios[14] - (U)		
The loss of one to one nursing care and the perception that nurses were busy and unapproachable led to parents feeling that there were no opportunities for information provision other than the daily ward round which could be a difficult context for asking questions [16] - (U)		
Parents made comparisons between the PICU and the ward in the sub category 'it's different here'. The way it was different was the physical space, the level of care, and the information and communication [2] - (US)	Transitioning from a controlled and supportive environment to chaos and uncertainty	
Parents found the ward less physically comfortable than the PICU [2] - (U)		
Parents also found things more chaotic on the ward as compared to the PICU [2] - (U)		
The chaos was described as noise, alarms, phones ringing, and/or babies crying, and made parents feel uncomfortable [2] - (US)		

The other major transition parents mentioned, was the child's discharge to the general ward [14] - (US)		

Each extracted finding was supported by a verbatim data excerpt from the studies' research participants to demonstrate its meaning. **Key:** (U) = Unequivocal. Findings were accompanied by illustrations that were beyond reasonable doubt and therefore were not open to challenge; (C) = Credible. Findings were accompanied by illustrations that lack a clear association and were therefore open to challenge; (US) = Unsupported. Findings were not supported by data.

Table 8 - Findings and categories for synthesised finding four

Finding	**Category**	**Synthesised finding**
Being a parent of a critically ill child is exhausting: The first theme reflected that all parents were mentally and physically exhausted from the tasks involved in parenting an ill child [2]- (U)	Physical and emotional exhaustion affecting parental readiness and functioning	**Synthesised finding four:** Transition as a physical, emotional and social balancing act
Parents also talked about their exhaustion in terms of not being able to remember directions, information, and being very distracted ….[2] - (C)		
One mother suggested that her exhaustion was the cause of a car accident that happened just blocks from the hospital when she was returning home after caring for their child in the PICU [2]- (US)		
Under the category organising home and work, parents felt a lot of strain wanting to both be with their ill child while still fulfilling normal roles and responsibilities [2] - (U)	Balancing home and work life with an unwell child	
Feeling supported by others: The two categories in this theme were 'support from health care teams' and 'support from family and friends'. Feeling supported increased parents mental and physical comfort. It helped them to have a comfortable place to stay and sleep, be able to talk to someone about their worries, know someone cared about them and their child, and was willing to help them at home and in the hospital [2]- (U)		
Practical support from family and friends included watching over the other children, offering rides, and help in general [2]- (C)		
The emotional support from family and friends was exhibited in them being around to listen to parents concerns and being available [2] - (C)		
The practical support received from the health care team was mainly provided by the social workers and included "things that we weren't thinking of that were fairly important, ah, like housing,…she pointed out where we could do laundry, she pointed out how close quick shopping was" (participant 10). For another parent, the		

social worker helped with “just getting everything organized. Making sure we had places to stay, and making sure we had the money” (participant 5).[2] – (U)		

Each extracted finding was supported by a verbatim data excerpt from the studies’ research participants to demonstrate its meaning. **Key:** (U) = Unequivocal. Findings were accompanied by illustrations that were beyond reasonable doubt and therefore were not open to challenge; (C) = Credible. Findings were accompanied by illustrations that lack a clear association and were therefore open to challenge; (US) = Unsupported. Findings were not supported by data.

Supplementary file 2: Study finding, illustration and source

Source	**Findings**	**Illustration from publication (page No.)**
Keogh, (2001)	Positive feelings: All the parents initially responded positively to the news of the transfer of their child from the ICU. They linked this with progress and an improvement in their child's condition.	One participant said "… (The move) is good in one way because he is making progress" while another said "we are on our way." (P. 11 – Para 2)
Keogh, (2001)	Negative feelings: The negative feelings of anxiety, tension, insecurity and isolation were largely attributed to the parent's fear of the unknown and the need for them to adapt to new staff, a different environment and different approaches to care.	One participant stated "I liked watching it all (the monitoring). It was reassuring" (P. 11 – Para 3)
Keogh, (2001)	Although diagnosis is for the patients I feel can be usefully applied to parents to aid in identifying nursing actions and intervention that could increase their satisfaction with the new environment.	Participants discussed the effect the move had on them in the following statements "I felt a bit confused and isolated when I came to the ward: it was very different" and "if I had known where I was going and knew a familiar face" (P. 11 – Para 4)
Keogh, (2001)	Dependency: … found that patients equated the nurse's competency and level of caring with the degree of monitoring (by personnel and technology). The abrupt cessation of the patient/nurse relationship and intense monitoring would initiate a stress response.	This scenario appears to be similar for the relatives of the PICU patient and this is echoed in the parent's descriptions in this study. (P. 11 – Para 7)

Keogh, (2001)	Care management: The loss of one to one care was a significant source of stress for all patients in the study as well as in related studies.	One participant said "… they don't have one-to-one nursing. X was the centre of attention before and now she's just one of many" (P. 11 – Para 11)
Keogh, (2001)	All the parents in the study expressed the desire for and potential benefit of meeting one of the ward nurses and/or visiting the ward prior to transfer.	For example one participant said "… if we had visited the ward then it might have been less of a shock" and another said "…at least we'd have known a familiar face" (P. 12 – Para 2)
Keogh, (2001)	Intermediate facility: All the parents in the study raised the possibility for an intermediate facility for the child and family.	For example one participant said "…it would have been nice (for us) if there had been somewhere in between" (P. 12 – Para 4)
Keogh, (2001)	On a positive note, parents expressed their appreciation of the aesthetics of nursing care. That is, the caring, creative and imaginative side as opposed to technical knowledge.	One participant recalled a PICU nurse explaining a procedure to her child "The ICU nurse had gone to great lengths to talk to her teddy bear and get X to do this and gone through the whole process, and it was wonderful, it was really working" (P. 12 – Para 4)
Berube, K. (2014)	Being a parent of a critically ill child is exhausting: The first theme reflected that all parents were mentally and physically exhausted from the tasks involved in parenting an ill child.	Parents described the experience as being the "worry of wondering" (Participant 6) where they did not know what would come next. (P. 589 – Para 3)
Berube, K. (2014)	Parents also talked about their exhaustion in terms of not being able to remember directions, information, and being very distracted ….	"it's been a real fog" (Participant 10) (P. 589 – Para 3)

Berube, K. (2014)	Parents watched over their child to search for comfort.	In particular parents referred to the fact that there was “always somebody in the room” (Participant 10), either themselves or a nurse, so that their child was being watched. (P. 589 – Para 4)
Berube, K. (2014)	Parents described monitoring as nursing presence.	Participant 3 explained that it was “just kind of keeping, I guess, watch over him more closely. I guess you know, watching his vitals more.” (P. 589 – Para 4)
Berube, K. (2014)	Parents also searched for a plan of care and found it very uncomfortable and exhausting not knowing what would or could be done for their child, what their progress would look like, and what the future would involve.	For one parent (Participant 6), there were several attempts to get their child diagnosed, and once diagnosed, it was recognized as an emergency necessitating transfer to the current study’s institution: “I’m thankful that they caught it enough to send us here and … I believe that a lot of doctors…do not really look over a patient, or whatever…I think they bypass a lot of things” (p. 589 – Para 5)
Berube, K. (2014)	Under the category organizing home and work, parents felt a lot of strain wanting to both be with their ill child while still fulfilling normal roles and responsibilities.	Parent’s ways to make this work often involved going back and forth to the hospital, where one parent was at the hospital during the day and one stayed overnight while the other was home with the other children: “I’d rather be home. But, yeah, for us, it works. We switch off at around… starting between 7:30 and 9 at night... My son continues his routine” (Participant 1). (P. 589 – Para 6).
Berube, K. (2014)	One mother suggested that her exhaustion was the cause of a car accident that happened just blocks from the hospital when she was returning home after caring for their child in the PICU.	

Berube, K. (2014)	Being kept in the know: The second theme was a way for parents to be involved in their child's care, and this information helped parents to gain mental comfort.	"information is the absolute key to my comfort level" (P. 589 – Para 7).
Berube, K. (2014)	Receiving information was seen as the information provided by health care professionals without them being asked. This receipt of information helped parents to feel as though the health care team was being transparent and upfront with them, which was emotionally comforting.	A parent described how a physician kept him informed: "this one fellow... has gone out of his way many times to hunt us down to say, you know, 'here's what we're doing with (patient)'… 'Look at this x-ray, here's what I'm doing'. He's really proactive, and ah, that's again, you know, that's very appreciated, it is, because it takes away that wonder" (Participant 10). (P. 589 – Para 8).
Berube, K. (2014)	Parents sought information by participating in rounds or asking questions to clarify or conformation information they had heard or of which they were unsure.	Parents appreciated "to be given that opportunity to hear, and know, and… that's where I get all my information… first hand, right?" (Participant 1). (P. 590 – Para 1).
Berube, K. (2014)	Some parents talked about not being able to get information as easily on the ward, which left them feeling uncomfortable or as though something was being hidden from them, thus they had to more actively seek information on the ward.	

Berube, K. (2014)	Feeling supported by others: The two categories in this theme were ‘support from health care teams’ and ‘support from family and friends’. Feeling supported increased parents mental and physical comfort. It helped them to have a comfortable place to stay and sleep, be able to talk to someone about their worries, know someone cared about them and their child, and was willing to help them at home and in the hospital.	The practical support received from the health care team was mainly provided by the social workers and included “things that we weren’t thinking of that were fairly important, ah, like housing… she pointed out where we could do the laundry, she pointed out how close quick shopping was” (participant 10). For another parent, the social worker helped with “just getting everything organized. Making sure we had places to stay, and making sure we had money” (Participant 5). (P. 590 – Para 3).
Berube, K. (2014)	Emotional support from health care teams was expressed in more general terms.	For example “the nurses are really supportive, you know? They really kinda…reach out, you know?” (Participant 3). (P. 590 – Para 4).
Berube, K. (2014)	Only one parent mentioned being asked how she was doing, and this inquiry was by a social worker.	“She’s the one that approached me… she asked how I was feeling and how’s things going and everything…” (Participant 6). (P. 590 – Para 4).
Berube, K. (2014)	Practical support from family and friends included watching over the other children, offering rides, and help in general.	“People just kinds like, step up you know, like. Whatever you need, we’re good.” (Participant 1). (P. 590 – Para 4).
Berube, K. (2014)	The emotional support from family and friends was exhibited in them being around to listen to parents concerns and being available.	“Well, they say talking is good… But, they’re there for me. I could call my older sister… anytime day or night and she’ll be here. If I need anything, she’ll bring it and that” (Participant 6). (P. 590 – Para 4).

Berube, K. (2014)	Being transferred: In the sub category ‘your child is ready’ most parents were told their child was ready to leave the PICU because they were doing better. Two parents shared that they were told the reason for their child’s transfer was that their child’s PICU bed was needed for another patient which may have made them feel uncomfortable with the transfer. Generally, a few details about the transfer were given to the parents.	The following quotation was fairly typical of the way parents were told their child was the PICU “she was doing really well in the PICU and they just told us she’s ready to be moved out if we have a bed and if we have a nurse, then she can go to the floor” (Participant 2). (P. 590 – Para 6).
Berube, K. (2014)	In the sub-category ‘is my child ready?’ parents assessed for themselves if their child was ready for transfer based on more practical cues, such as how the child was breathing, what the child looked like, and if he/she was eating.	“She was really perking up, and I guess, looking a lot healthier than she had been in the previous 48 hours” (Participant 1). (P. 590 – Para 7).
Berube, K. (2014)	4 out of 10 parents thought it was too early for their child’s readiness to leave the PICU.	“I think, you know what, when you move from…ICU anyways, you always worry because they’ve been so sick, and you know… it’s hard. Because you worry that they’re not quite ready, or that they’ve been ok because they’re being watched so closely…” (Participant 3). (P. 590 – Para 7).
Berube, K. (2014)	Most parents were given little information, and what they did get was not consistent.	Some parents recalled being told about the Critical Care Outreach Team: “they told us that the team would be available…and so that if there’s any time we had concerns… we could always ask for (them) to come in.. there was this interim follow up kind of process” (Participant 7). (P. 590 – Para 8).
Berube, K. (2014)	Other parents were told information that made the ward sound less than desirable and that they needed to be concerned.	“Well I think the nurse kind of cracked a joke, like, you should enjoy this now, because everything is going to change when you go upstairs... It’ll be really loud and noisy. It is more crowded, for sure. But, ah, yeah, that’s about what was said” (Participant 8). This made parents feel uncomfortable around the time of the transfer. (P. 590 – Para 8).

Berube, K. (2014)	Making the move examined the physical move from the PICU to the inpatient ward. The actual process of the physical move was relatively smooth and uneventful for parents.	“It was just a nice smooth transition” (Participant 4). (P. 591 – Para 1).
Berube, K. (2014)	Parents made comparisons between the PICU and the ward in the sub category ‘it’s different here’. The way it was different was the physical space, the level of care, and the information and communication.	
Berube, K. (2014)	Parents found the ward less physically comfortable than the PICU.	“Well, where parents sleep isn’t really comfortable. And the rooms are very, very tight. But, no everything’s…been ok” (Participant 9) (P. 591 – Para 2)
Berube, K. (2014)	Parents also found things more chaotic on the ward as compared to the PICU.	“It was really noisy here too.. the nursing station, its quiet now, but a lot of the times, it’s really noisy” (Participant 4) (P. 591 – Para 2)
Berube, K. (2014)	The chaos was described as noise, alarms, phones ringing, and/or babies crying, and made parents feel uncomfortable.	
Berube, K. (2014)	The level of care on the ward was described by parents as…	“a whole different level of care” (Participant 1) (P. 591 – Para 3)

Berube, K. (2014)	Children had a lot less attention	“You have all that attention… its almost too extreme. Like, you go from all kinds of attention to virtually none.. You know, much less right?” and not seeing people right there all the time” (Participant 8). (P. 591 – Para 3).
Berube, K. (2014)	Parents seemed to note a decreased nursing presence (i.e. what parents called monitoring) and less availability of the nurses for them or their child which made them uncomfortable.	
Berube, K. (2014)	Finally, regarding information and communication post-transfer, parents commented on the lack of inclusion in conversations on the ward compared to PICU.	“I did feel more involved. And I think the average parent would definitely feel more involved In PICU” (Participant 1). (P. 591 – Para 4)
Berube, K. (2014)	Other parents found that the communication between PICU and the ward was lacking.	“I don’t think the communication was great, like between the ICU and here. Cause they didn’t really know what his medications were... it was after a while, so… and then they figured that out… there is always that kind of gap” (Participant 3). (P. 591 –Para 4)
Colville, G. (2009)	Transitions: Although the focus of the interview was intended to be the PICU experience, it was noteworthy how often parents raised the subject of their child’s care outside the unit, preceding the admission and afterwards.	In particular parent’s responses to the question asking what they considered to be the worst point often clustered around these two important stages of the child’s journey. As one father put “the difficulties were… before and after. PICU itself was fine” (021F) (P 75 – Para 9)

Colville, G. (2009)	Parents frequently described a powerful sense that there was something seriously wrong prior to the child's intensive care admission and that it was difficult to have these fears taken seriously by health professionals.	One mother described herself as having a "hysterical fit" (021M) when trying to gain the concern of a doctor at the local hospital. Another father said he "nearly had to punch the doctor to get them to listen" (028F) (P 75 – Para 10)
Colville, G. (2009)	The anxiety parents felt on the journey to the local hospital to PICU was also recounted geographically.	One mother recalled: "I thought she was dying in the back of the car with me… the journey to the hospital was probably the worst 12 minutes of my life" (095M). (P75 – Para 12).
Colville, G. (2009)	The other major transition parents mentioned, was the child's discharge to the general ward.	
Colville, G. (2009)	Although parents recognized that the fact that their child was well enough to be transferred out of PICU was a positive development, they found this change very stressful and were emotionally unprepared, particularly for the reduction in staffing ratios.	The following narrative by a mother is a representative of the concerns experienced by many parents in the sample. "there was no 24 hours nurse, which was the biggest thing which upset me… the poor nurse who received us had to deal with more than (my child)… it was awful, it was like a refugee camp" (104M) another described the wards as "planets apart from PICU" (021M) (P. 75 – Para 13)

Colville, G. (2009)	The main source of stress for parents immediately before and after PICU admission was their fear for the child’s immediate safety, but their anxiety was compounded by the bewilderment of abandonment on transfer to the general ward, which they described in dramatic terms and seemed to be related to the loss of intense relationships forged with staff on PICU	Parents described being “spat out” (109M) and “shunted upstairs” (083F). One father explained “you interact with them very intensely over a short period and then you never see them again” (008F). (P. 76 – Para 14)
Kirk, S. (2015)	Moving to the ward: Parents felt unprepared for the transfer of their child from ICU to the ward. Decisions appeared to be made suddenly without any discussion with parents who perceived their children as being seriously ill and in need of intensive care. Consequently they found it difficult adjusting to the contrast between ICU and the ward which lead to concerns over their child’s safety.	“Massive leap yeah with the ratio then. Going from one to one to, gosh I don’t know, probably four or eight patients to one member of staff, the problems that he really suffered with are when he went onto that ward. We felt safe in there (ICU). On the ward we did not feel, it was not out safety it was his (17). (P. 308 – Para 2)
Kirk, S. (2015)	The loss of one to one nursing care and the perception that nurses were busy and unapproachable lead to parents feeling that there were no opportunities for information provision other than the daily ward round which could be a difficult context for asking questions.	“in intensive care you know, you didn’t really have to ask much, they let you know every step of the way, you know, what they were doing, but when they went to the ward, I mean, you saw a doctor in the morning… you had to ask the doctor when you saw him there and then, you see, because later on, the staff would just say to you, well its best if you ask the doctor tomorrow.. we was always, sort of, like, waiting and then when they did come, they were only in there about five minutes” (7) (P. 308 – Para 3)

Kirk, S. (2015)	Parental responsibility for their child's care increased on the ward; however, parents were unsure of staff expectations about the nature of their involvement as well as how to care for their child. During this time, their child's difficulties began to emerge, such as seizures, behaviour problems, mood swings and personality changes. That lack of continuity of nursing care meant parents did not develop the relationship that would enable them to discuss their concerns and feelings which was compounded by a perception that staff lacked time for emotional support.	"there isn't anywhere to go to just talk to, or just for that reassurance… you don't feel like you can talk to them really because you're putting them, you're keeping them back from their job basically aren't you, and that's not a good feeling to be sat there thinking you know you cant. I don't want to put on them because they've got so much to do (19). (P. 308 – Para 6)
Kirk, S. (2015)	Parents felt that they needed greater emotional support during this time in terms of someone to talk to in order to help them understand their 'new' child.	