

**Title:** Emergency inter-hospital transfer of children to PICUs in the United Kingdom: qualitative exploration of parents' experiences of retrieval teams

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Keywords: inter-hospital transfer, paediatric retrieval, qualitative, parents, experiences

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## **Abstract**

**Background:** Each year, in the United Kingdom, there are around 5000 inter-hospital transfers of critically ill children into Paediatric Intensive Care Units (PICUs). There are few published descriptions of what this experience is like for parents.

**Objectives:** To describe parents' experiences of the inter-hospital transfer of their critically ill child to a PICU.

**Design:** Qualitative in-depth interviews.

**Setting:** 24 PICUs in England and Wales.

**Participants:** Parent interview participants (n=30) were purposively sampled from a larger pool of parent questionnaire respondents to create a sample diverse in child's age, presenting medical illness, retrieval team and whether a parent travelled in the ambulance.

**Measurement:** Open-ended semi-structured interviews using topic guides to encourage parents to describe their experiences of transfer. Interviews were audio recorded, transcribed verbatim and thematically analysed using Framework Analysis.

**Main results:** Parents' perceptions of transport staff as confident and competent through observation of clinical care, and positive communication experiences during the transfer process, were related to feelings of trust and being supported, as well as relief from distress. Parents varied in their needs for conversation and support. Parents who did not travel in the ambulance had fewer opportunities to interact with the transport team and experienced different challenges in the period prior to their child's admission to the PICU.

**Conclusion:** Retrieval teams can influence how parents experience their child's emergency transfer to the PICU, offering parents' proximity to knowledgeable staff. Satisfaction may be related to matching parents' needs. Understanding parents' needs and optimising opportunities for effective communication between parents and staff is beneficial to parents.

Article tweet: Communication with retrieval teams can influence how parents feel during their child's transfer to PICU.

Keywords: Paediatric Intensive Care, Paediatric Critical Care Transport, Parent Experiences

## **Introduction**

Paediatric Intensive Care is organised regionally in the UK. Each year approximately 5000 children are transferred from local hospitals to Paediatric Intensive Care Units (PICUs), 80% of whom are retrieved by specialist Paediatric Critical Care Transport teams (PCCTs) with the remainder transported by other specialist and non-specialist services(1). Inter-hospital transfer to a PICU is recognised as potentially stressful for families(2) with influencing factors including: perceptions of threat arising from being told of the need to transfer to a PICU, anxiety of waiting for the retrieval team to arrive, and separation anxiety if parents cannot travel with their child. Parents have described the journey to the PICU without their child as the “worst” journey of their lives(3) and parents who did not travel in the ambulance reported higher levels of anxiety compared to those who did travel with their child(4). Admission to intensive care (including admission of a family member) has been identified as a potentially traumatic event(5) and in a recent review reports of parental psychological morbidity in the months after a PICU admission included symptoms of post-traumatic stress disorder in 18-84%(6), anxiety in 15-50% and depression in 15-30%(6, 7). Increasingly, the value of delivering care to children in a PICU and their families through a trauma-informed lens is being recognised(8).

Predictors of longer-term parental psychological morbidity include distress on admission to a PICU(9); speaking about feelings at the time of admission is associated with reduced distress(10). Describing parents’ experiences of the inter-hospital transfer process may help to understand what impact this aspect of the PICU admission plays in influencing the wider - longer term - experience of having a critically ill child who is cared for in a PICU, with the goal of identifying ways to support parents and to possibly mitigate some of the distress experienced. As part of a national study exploring variations in paediatric critical care transport service provision, we aimed to describe the experience of parents whose critically ill child experienced an inter-hospital transfer to a PICU.

## **Methods**

Ethical approval for the study was granted by the National Research Ethics Service Committee Riverside -London (reference: 17/LO/1267).

### *Setting and sample*

Parents of critically ill children and young people (aged 0-16 years) transferred to one of 24 PICUs (tertiary care) in England or Wales from another hospital, by either one of nine specialist PCCTTs, or other specialist or non-specialist services, were approached for consent (typically within 24-48 hours of a PICU admission) to participate in a parent experience study, over a 12-month period from January 2018 to January 2019. Parents initially completed a questionnaire about their transfer experiences and indicated their consent to participate in an interview at a later date. Further details of recruitment are published elsewhere(11). Purposive sampling was used to create diversity within the sample of parents invited to participate to ensure there was a range of child's age, diagnosis, whether a parent travelled in the ambulance, and PCCT. These characteristics were identified based on responses parents gave in the demographic section of the questionnaire or from documentation completed by the PCCT. Families were approached for interview by email, 2-8 months after the PICU admission. Parents who responded were then sent, via email or post, a participant information booklet and consent form and were contacted again to organise the interview. The approach to eligible parents was made in English as we did not have resources to approach parents in alternative languages. Approximately 90 families were contacted, and 30 interviews completed. Please see S1 supplementary material for a flow diagram of participants.

### Data collection

Interviews were either face to face (n=27) or completed by telephone (n=3), where and how the interview was completed being determined by parents. Interviews were completed with either one or both parents present and lasted 35-65 minutes. Parents were asked for consent to audio-record the interview and all agreed. The interviews, facilitated by authors VB and RE, were semi-structured using topic guides (developed with input from clinicians and parents with prior experience of retrieval, see S2 supplementary material). Parents were asked questions to prompt a description of their child's transfer to the PICU in the sequence in which events happened starting from the hospital from which they were transferred through to arrival at the PICU. Within each stage parents were encouraged to evaluate their experiences, with questions prompting them to explore if and how they would have liked things to have been different. The interviewers positioned themselves as being separate from the retrieval teams and

confidentiality and anonymity were assured, all with the intention of encouraging participants to feel comfortable to share their experiences openly.

#### Data analysis

The Framework approach(12) was used to enable an inductive thematic analysis of parents' described experiences. Interviews were transcribed verbatim and entered into NVivo 12(13) which facilitated some of the 5 stages of the Framework approach: familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation. The thematic codebook and mapping of themes to codes are provided in supplementary material S3 and S4. Verbatim quotes are presented in Tables 2 and 3 to illustrate key themes and sub-themes. Themes are linked to the temporal sequence of the transfer. Please refer to supplementary material S5 for a reflexivity statement outlining the ontological and epistemological stance and a more detailed description of the steps to enable the reader to make an assessment of the trustworthiness of the findings.

The COREQ checklist was used for reporting the study.

## Results

### *Demographics*

Demographic characteristics of parents and their transported child are shown in Table 1.

### *Qualitative Findings*

A summary of parent experiences is described chronologically starting at the local hospital before travel through to arrival at the PICU (Figure 1).

#### 1. The context of transfer

At the local hospital, prior to transfer, parents described being distressed and wanting reassurance about their child's condition, some were sleep deprived, some reported having difficulties processing information. The decision to transfer from the local hospital was perceived by parents as a sign of the seriousness of their child's medical condition and some expressed relief, perceiving the PICU to be where their child would receive specialist care.

Anxieties were described about the safety of the transfer journey and about relocating to an unfamiliar hospital, some parents reported being upset at how their child looked when prepared for travel. Waiting for the retrieval team was stressful especially if there was uncertainty, perceived delay or if parents perceived their child's condition was deteriorating.

## 2. With the retrieval team

Parents' perceptions of retrieval staff as confident and competent through observations of caring for their child, as well as positive communication experiences, appeared related to trust in the team, reports of 'relief from distress', as well as descriptions of 'parental support'. Parents who did not travel in the ambulance spent time with the PCCT staff but there were potentially fewer opportunities to observe and interact compared to parents who travelled in the ambulance to the PICU.

Parents described relief from distress when distracted by talking with staff about what their child was usually like, or conversely unrelated 'small talk'; reassurance was gained directly from things staff said - about what was happening in the moment and what to expect at the PICU - as well as through positive appraisal of staff actions, and calm was 'borrowed' from the emotional demeanour of the retrieval team.

Parents described different aspects of support. Feeling cared for by the retrieval team appeared to be derived through empathetic, sometimes light-hearted, general conversation in addition to receiving care packs (containing food and toiletries) and self-care advice e.g. to eat or rest during the journey. Parents were impressed by the capacity of staff to offer them support while caring for their critically ill child. Not every parent felt supported, some felt alone during the transfer and self-care advice around eating was interpreted by one parent as being 'guilt-tripped'. Some parents discussed the lack of support for themselves alongside recognising that despite this, their priority was that the PCCT cared for their child.

Parents varied in their preference for communication, and negative appraisal may have been related to a mismatch between preferences/expectations and what happened - jovial small talk



perceived to be superficial or inappropriate, conversation perceived as lacking empathy or simply not enough conversation.

### 3. Arrival on the PICU

On arrival some parents described being encouraged to wait in the “family room” either straight away or after being shown the bed space where their child would be cared for. There was variation in how long parents waited before contact with the PICU staff from five minutes to longer.

Despite travelling with their child in the ambulance, separation at this point was still difficult for some families for a variety of reasons: a longer than expected wait led to worries that their child had deteriorated and being denied the opportunity to observe and potentially contribute to the handover. Some parents described being prepared for this stage by staff in the ambulance which helped with the wait, others reported that they had wished that this had happened for them.

### 4. Parents’ independent travel to the PICU

Before the child was transferred, retrieval teams confirmed whether parents could accompany their child in the ambulance. Parents we interviewed described being upset when no opportunity to travel was offered, especially if this was contrary to expectation. Some parents chose not to travel and this could be for practical (e.g. picking up clothes from home) or emotional reasons.

Independent of whether they travelled with their child, parents expressed that they would have liked to, or described benefits of having a parent accompany their child; for some this was contingent on travelling as a couple. Acceptance of travelling separately was associated with parent trust in the capabilities of the medical team, parents’ evaluation of their ability to cope emotionally in the ambulance and/or their perceptions of their ability to help their child, as well as the state of consciousness of the child.

Parents’ descriptions of their journeys to the PICU included challenges: making the journey alone, sleep deprivation, distance, unfamiliarity of the PICU location, time of day, traffic and weather conditions, along with emotional distress about their child’s condition, being separated from their child and not knowing what was happening in the ambulance. Finding the PICU and

gaining access was not always easy especially if the journey was made 'out of hours', and finding out the health status of the child on arrival was emotionally difficult.

Parents who travelled together were able to share the burden of navigation, and one parent who was initially disappointed not to be able to travel with their child reported in hindsight it was a valued opportunity to express emotion and process together with their partner what had happened up to that point.

Some retrieval teams take a parent's phone number and/or give a number to parents with agreement that calls will happen if the child deteriorates during transfer - parents and staff reported this offered reassurance but it could also offer false reassurance.

#### *Summary of influencing factors on parents' experience of the journey to the PICU*

Factors that seemed influential in families' experience of transfer to the PICU are multiple and varied and supplementary material S6 represents a summary of those identified in this study with the additional aim of identifying those that may be modifiable through future intervention.

#### **Discussion**

In this study parents described ways in which the retrieval team influenced their experience of their child's transfer to the PICU beyond the clinical care given to their child. Retrieval teams were described as offering direct and indirect emotional support as well as practical support, both when parents travelled in the ambulance and when parents had to make the journey independently. Parents differed in their need for communication and we can infer whether these needs were met from parents' descriptions of the communication between themselves and the retrieval staff.

Understanding parental experience during the emergency transfer to the PICU matters because there is evidence that suggests parents' mental well-being is important in a child's ultimate recovery trajectory from critical illness(14, 15). Objectively the situation where a child becomes so ill that PICU care is needed - especially if this is on an emergency basis - is inevitably distressing for parents at the time and, while transient for most, the experience of an admission to a PICU is associated with chronic poor mental health for a significant minority(9, 16). Higher

levels of parental distress (perceived stress and negative emotions) around the time of a PICU admission are associated with later parent psychopathology(9) and it has been suggested that traumatic events at the DGH and enroute to the PICU should be considered as part of the PICU experience narrative(17); understanding what happens before arrival to the PICU could help to identify ways to mitigate some of the 'peri-trauma' distress reported at the PICU arrival.

There may be utility in understanding the communication process between parents and retrieval teams in terms of the framework of trauma-informed care which uses a 'DEF' approach where Distress is acknowledged, Emotional support given and Families are involved(18, 19). The positive impact for some of travelling in the ambulance could be explained via the concept of Psychological First Aid(20), central to trauma informed care; this approach aims to increase coping in a traumatic situation; the close proximity to PCCT staff is an opportunity for families to understand and normalise their distress, make sense of what has happened and prepare (mobilise coping) for what happens next, to feel comforted and connected to those caring for their child. This appears to happen in the ambulance for some, with the support of staff who have the experience and skills to offer families information, guidance and a framework to understand the critical care experience and potentially (subject to the medical stability of the child) in a calm environment which may contrast with earlier busier experiences at the referring hospital.

### **Limitations**

In our sample the patient in all interviews survived their transfer and time in the PICU, albeit some with subsequent life-changing diagnoses. We did not interview anyone whose child died either during transfer or afterwards and their experiences may differ from those described here. In addition, no parents described an experience where there was an acute medical emergency in the ambulance e.g. cardiac arrest, which does happen, and this may have influenced their experiences. All interviews were conducted in English with English-speaking families so we were unable to describe the experience of transfer with families where English is not spoken. Parents were interviewed several months or more after their experiences and while Colville and Gracey(10) have previously commented on the vividness of recall, and we would concur, it is possible that parents' recall may be biased or limited in some aspects of their experience.

### **Implications for practice and future research**

Interventions evaluated to date - based on the PICU or at a later follow-up clinic - aimed at reducing the longer term emotional impact on parents of a PICU stay have had limited effectiveness(21) but could earlier intervention have a greater impact? Research has begun to explore staff understanding, knowledge and confidence in trauma-informed care in related services, such as pre-hospital ambulance services. While staff feel psycho-social care is a part of their role, confidence is influenced by paediatric care experience and training, and there is an expressed wish for more training(22). However, there are some key messages from our findings that we believe will be helpful for members of the PCCT (Figure 2).

Parent experiences during transfer contribute to the bigger question of the cost and benefit of regionalised care rather than local provision. It would be helpful to explore the psychological trajectory of this significant sub-population of PICU families (circa 25% of all PICU admissions) and see whether there are differences in their emotional recovery as a family compared to PICU admissions that are internal transfers. This evidence would help to answer the question about whether the transfer to the PICU represents a further stressor in a difficult situation, increasing the risk of adverse psychological outcomes for this group, or whether it represents a unique opportunity for grounding, normalising distress, preparation and an opportunity to engage parents' coping resources and is therefore potentially protective.

### **Conclusion**

This study describes parents' experiences with the retrieval team and outlines ways in which the retrieval team influences parents' experiences beyond the clinical care of their child. Communication was central to this experience and further work to understand what factors/ conditions give rise to effective rapport may be helpful to identify training opportunities for clinicians at every step of the transfer journey.

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Figure legends:

Figure 1: Map of themes related to the journey to the PICU starting at the district general hospital

Figure 2: Seven key messages for members of a Pediatric Critical Care Retrieval Team

### **Research in context**

- Each year thousands of children are transferred from local hospitals to a paediatric intensive care unit (PICU) but we know little about what this experience is like for parents.
- Distress on admission to a PICU is a predictor of longer-term parental psychological morbidity. Greater understanding of the impact of the transfer may enable ways of supporting parents to be identified, with the aim of mitigating some of their distress.
- As part of a national study involving all paediatric critical care teams and PICUs in England, 39 parents, some of whom did not accompany their child, were interviewed about their experiences of their child's inter-hospital transfer to a PICU.

### **At the bedside**

- The retrieval team influences parents' experiences beyond the clinical care of their child. Communication is a key element and positive communication experiences during the transfer process were related to feelings of trust and being supported.
- Parents who did not travel in the ambulance had fewer opportunities to interact with the transport team and experienced different challenges in the period prior to their child's admission to PICU.
- Inter-hospital transfer could provide a unique opportunity for normalising parental distress, preparing parents for what will happen in PICU and engaging parents' coping resources but retrieval teams need training and support to enable them to effectively and confidently implement this.