Development of a parent experience measure for paediatric critical care transport teams

Abstract

Aim

Our aim was to describe the development of a new measure of parents' experiences of paediatric critical care transport services (PCCTs), derived from data collected in the DEPICT study.

Background

A third of children admitted to paediatric intensive care units (PICUs) in the United Kingdom (UK) are transported by PCCTs. Parents have described the transfer journey as particularly stressful. Critical care nurses have a key role in mitigating the impact of the journey on parents. Evaluating parents' experiences is important to inform service improvements.

Design

A descriptive cross-sectional survey was used.

Methods

As part of the DEPICT study, a 17-item transport experience questionnaire was developed and given to parents of children transported by PCCTs to 24 UK PICUs during a 12-month period. Analyses included exploratory factor analysis and a validation review by a PCCT stakeholder group.

Results

Families of 1722 children (1798 journeys) completed questionnaires. Five items were excluded from further analysis as correlation coefficients were <0.3. Two factors explained 53% of the variance and all 12 items loaded on one of these factors. Factor 1 (8 items) explained 47% of the variance, had excellent internal reliability and the clustered items were conceptually coherent with a specific relevance to PCCTs; these were offered for consideration, with other items possibly discarded. Twenty-eight PCCT clinicians reviewed the questions. Using a 70% agreement threshold, one additional, previously discarded, item was identified for inclusion, resulting in a 9-item experience measure.

Conclusion

Our brief measure of parents' experience of critical care transport provides a standardised measure that can be used across all PCCTs, enabling national benchmarking of services and potentially increasing the collection and use of parent experience data to improve services.

Relevance to clinical practice

Being able to measure experience provides an opportunity to understand how to make services better to improve experience.

Introduction

Experience as an outcome

The importance of patient experience is increasingly recognised and emphasised as a core outcome together with clinical effectiveness and safety[1, 2]. Feedback collected from patients has traditionally focused on transactions between patients/families and staff. However there is now a greater understanding that what also matters to UK National Health Service (NHS) users is how staff made patients and their families feel, i.e. the 'relational' experience i[1].

Paediatric Critical Care Transport teams (PCCTs) transport nearly 5000 children each year in the UK to paediatric intensive care units (PICUs) , representing one third of all children admitted to PICU. Parents have described the journey to PICU as 'the worst journey of our lives',[3] and PCCT nurses, by virtue of their advanced and constant role in the retrieval journey, are key to mitigating that experience. Parents' emotional well-being is linked to their child's recovery over the longer term,[4, 5] with clear evidence that their emotional well-being can be affected by their distress on arrival to PICU[6] as well as the admission itself. [4,7] However, for parents of children requiring transfer to PICU, their PICU trajectory starts with that journey. Their emotional experience of transfer is likely to be influenced by multiple factors, including the potentially traumatic situation of having a critically ill child,[8] prior parental individual differences[6] as well as staff interactions[9]. In turn, parents' transport experience is likely to contribute to how they feel at the time of the PICU admission,[10] which may influence how they interact with PICU staff and participate in decision making as well as their ability to effectively engage with their child and their care.

A recent national peer review of PCCT services in the UK[12] suggested that most teams (80%) collect experience feedback, usually via paper questionnaires, but the use of individual service-specific measures limits shared insights and there is no opportunity to use this for national benchmarking of services. As part of a wider study (Differences in access to Emergency paediatric intensive care and care during transport – (DEPICT))[13], which included the measurement of parent experiences of their child's transport by a PCCT, a request to develop a national parent experience questionnaire came directly from the PCCT community. Our aim in this manuscript is to describe the development of a new parent experience measure derived from analysis of the transport questions collected as part of the DEPICT study that could be adopted for use by UK PCCTs.

Methods

Context

DEPICT was a national, mixed methods project which included a prospective questionnaire study conducted at 24 PICUs and 9 associated PCCTs in England and Wales in which we collected experience data from parents of transported children. We developed a questionnaire which included questions about the transport experience, the child's medical condition, experience at the referring hospital, experience of arriving at PICU, impact of the child's critical illness on parents' ability to work, family demographics and some general overall evaluation measures (including the NHS Friends and Family Test [FFT][14]). The transport experience questions are the focus of this manuscript.

Participants

Parents whose child was transported as an emergency from a local hospital to one of the 24 participating PICUs in England and Wales during January 2018-January 2019 were eligible to participate in DEPICT. Detailed recruitment processes and eligibility criteria have been reported elsewhere[13]. In summary, eligible parents were approached within 24-48 hours of their child's arrival at PICU and provided with information about the study. If they consented to participate they were asked to complete a questionnaire (on paper or electronically) about their experience of the different stages of their child's transfer to PICU, which included questions about their transport experience.

Ethical approval and confidentiality

Ethical approval for the study was granted by the National Research Ethics Service (ref:17/LO/1267). All participants were assigned a unique study number and no identifiable details were included in the questionnaire. Parents were given a freepost envelope for confidential return of the questionnaire to the research team.

Development of the transport experience questions

Phase 1: Item generation and initial content validity assessment

The transport experience questions were developed by the project chief investigator, who works within a UK PCCT, in collaboration with psychologists with experience in the development and administration of patient experience questionnaires. The items were informed by a review of the various evaluation measures previously used by PCCTs and relevant literature. Existing PCCT questionnaires were amalgamated and similar/duplicate questions removed and further questions added to cover any additional areas considered important.

Parents (n=2) with prior experience of using PCCT services reviewed draft items and provided feedback on the relevance and resonance of the items based on their personal experience. A draft of the experience questionnaire was also reviewed by intensivists and nurses in a national PCCT stakeholder group (Paediatric Intensive Care Society Acute Transport Group – ATG) to assess relevance to staff working within a transport setting. Finally, we piloted the draft with a convenience sample of parents (n=7) whose child was, at the time, an in-patient in one of two London PICUs to assess coherence and appropriateness. Suggested changes to the questionnaire were implemented to improve clarity and readability. Scoring for all transport experience questions was on a Likert scale of 1=strongly disagree to 5=strongly agree, with an option to indicate that a question was not applicable.

Phase 2: Psychometric properties and factor analysis

We used the data collected in the DEPICT study to assess the psychometric properties of the transport experience items. Firstly, we explored whether the generated items believed to measure 'parent experience' were measuring a unitary thing (single factor) or whether parent experience was sub-divided into different dimensions that are to some extent experienced separately and independently (multiple factors). To do this we used exploratory factor analysis to measure which of the variables shared common variance and could therefore be grouped together. This process also enabled us to identify items that did not appear to group together in a meaningful way and highlight for further review of their validity and contribution to an experience scale (see phase 3).

Using previously described methodology,[15] we ran a principal axis factoring analysis using SPSS (version 21). This method of Exploratory Factor Analysis (EFA) was selected as it is recommended when data violates the assumption of multivariate normality as was the case here (all questionnaire items were positively skewed as is usual with experience measures). Items that did not correlate well with each other ($r<0.3$) were excluded and the remaining items were entered into the EFA. Extracted factors were rotated with an oblimin rotation as the identified factors were found to be related. The reliability of items in each factor was examined by Cronbach's alpha.

Phase 3: Validation review

We developed a REDCap[16] survey to elicit views about the proposed transport experience questionnaire and circulated it to all members of the UK PCCT community via the chair of the ATG. Staff were given two weeks to respond. In the survey we presented items from the extracted factor(s) and explained that these were candidate items for a new parent experience measure. We also presented the remaining items from the original 17 and asked respondents to indicate their agreement for inclusion using a scale from 1-10 where a rating of 1-3 indicated disagreement about inclusion, 4-7 meant staff were unsure and 8-10 indicated agreement for inclusion. In addition, we included several other questions from the wider DEPICT questionnaire for review, related to general evaluation of the transfer experience and team and a specific assessment of parents' perception of the quality of care. Staff were also invited to provide free-text comments about any aspect of the questions.

Figure 1 illustrates the process we used to develop and analyse the transport experience measure.

Results

Participants

During the period of data collection, PCCTs undertook 3669 transports in England and Wales and in 2924 cases families were approached for consent to participate in the study. Completed questionnaires were received about 1798 unique journeys (61% of the 2430 consents, representing 1722 individual children; 179 were transported more than once). Questionnaires were completed by mothers (n=1232;72%), fathers (n=329;19%) or both parents together (n=107;6%), with the remainder not specified (n=68;3%) or completed by people other than parents (n=10;1%). The majority of children were under 1 year of age (1033;57%) and were transported because of respiratory illness or infection (n=1020;57%). In 82% of cases this was the first time a child had needed transport to a PICU.

Item generation

Phase 1 resulted in a 17-item measure of transport experience to evaluate parents' perceptions of health professionals' behaviour and interactions, parents' comprehension of the events involved in the transfer and parents' emotional experience of transfer. Minor revisions were made to wording after consultation with parents and the ATG and the piloting with parents whose children had recently been transported to PICU, but no further items were added or removed at this stage (Table 1). These 17 items constituted one section of the broader DEPICT questionnaire which parents completed.

Exploratory Factor Analysis

Five of the 17 items were excluded from further analysis as correlation coefficients were <0.3 (Table 1), leaving 12 items which were entered into the analysis. Missing data for the 12 items ranged from 1.1% to 8.6% and Missing Value Analysis confirmed that missing data were not completely at random (Little's MCAR test result: p<.001) and we therefore ran a MEANSUB analysis. For each variable, missing values were replaced with the variable mean. All Kaiser-Meyer-Olkin values for individual items were above 0.5 (actual minimum was >0.86) and the Kaiser-Meyer-Olkin measure was 0.925, indicating the data were sufficient for exploratory factor analysis. Results of the Bartlett's test of sphericity test were X^2 = 19988.94, df=66, p<0.001 which showed there was a patterned relationship between the items. Using an eigenvalue cut off of 1.0, two factors explained a cumulative variance of 53%. The scree plot confirmed the findings of retaining two factors. Factor loadings after a rotation using a factor criterion cut-off of 0.32[15] showed that all items loaded on one of the two factors. Factor 1 (8 items) explained 47% of the variation in participants' scores and Factor 2 (4 items) explained an additional 6% of the variation in responses (Table 2).

Internal consistency

The Cronbach Alpha scores were 0.9 for Factor 1 (considered to be excellent) and 0.7 for Factor 2 (considered to be good).

Labelling the factors

Naming the factors is an important stage of factor analysis and our aim was to identify the aspects of experience that were conceptually different to offer meaningful sub-scales of parent experience. Factor 1 appeared to relate directly or indirectly to actions from health care professionals, but it was less clear how items in Factor 2 related together under one description. Furthermore, one item in Factor 2 - “confident in the team” -appeared to fit conceptually better in Factor 1.

Validation review by the ATG

As Factor 1 explained the greatest amount of variance, had the higher reliability score and the clustered items were conceptually coherent with a specific relevance to PCCTs, we felt that these eight items should be offered to the ATG for consideration with other items (nine of the original 17) possibly discarded from future use.

Twenty-eight staff participated in the survey, which included at least one member of staff from every PCCT in England and Wales. Using a 70% agreement threshold we identified one additional item from the ‘discarded pool’ that staff felt should be included - “I felt my child was safe during the transfer” (Table 3). Free text comments mainly focused on the inappropriateness of role-specific quality of care assessments, on the basis that it is not always possible for parents to distinguish staff roles and that it is fairer to be judged as a team. Two specific comments highlighted the need for the experience items to capture aspects which are modifiable by the PCCT:

“*I would support items being included that are modifiable in light of feedback, e.g. when I asked questions I received answers I understood, rather than vague ('quality of care') - what to do about that if your services is scoring poorly? - or related to the parent's feelings ('I felt calm') - we can't control other people's feelings*!” Respondent #10

and

"I think the questions are ok but feel as the service lead they don't provide me with anything concrete. I would have to continue to use our current parent satisfaction survey to ensure I could identify more specifically what the families were or weren't happy with". Respondent #26

In addition, the PCCTs agreed that two of the six items relating to overall rating of quality and satisfaction should be included, together with the mandatory FFT items. The final questionnaire proposed is presented in Table 4.

Discussion

Experience of care matters. Health policy documents highlight the importance of 'good experience',[17-19] particularly of the relational rather than the functional aspects of care. Within paediatric services parents are frequently asked to provide feedback on their experiences of the services their children have received, often because children are unable to provide the information themselves. Recent years have seen a rapid growth in the measurement of parents' experiences of paediatric health care but within the UK PICU setting evidence has largely come from qualitative research or the use of centre-specific questionnaires rather than from the routine collection of experience data using validated measures.

Admission to PICU can be a very stressful and difficult time for children and their families[10, 20, 21] and psychological trauma can still be evident many months later. In situations where children require emergency transfer to PICU, parents' experience of the transfer and engagement with the transport team is likely to be an important influencing factor on how the PICU stay is experienced and partnerships developed with the PICU staff. Being able to evaluate that experience using a standardised measure that is relevant, practical and feasible is the first step towards improving services and optimising experiences.

How to measure experience and learn from it

Information collected about patients' and parents' experiences must be easily understood and lead to actionable change[1] and it has been suggested that experience data should be presented alongside clinical effectiveness and safety data to enable explicit links to be made[1]. There are a variety of different ways to measure experiences and ultimately each is a compromise between the richness of the detail of an individual's experience and how generalisable the data collected is to other families[2]. Additionally, each method to collect experience data has a logistical and resource cost attached and this must be considered in the choice of measure, especially as a critically ill child requiring inter-hospital transfer is an acute medical (stressful) situation for parents and staff. However, when making comparisons between services, a quantitative approach to measuring experience is recommended[1].

We have developed a 9-item parent experience measure based on the original 17 items developed as part of DEPICT. This brief measure of experience will, we believe, add to the wealth of data already collected about each individual transport and be a useful measure for adoption by the PCCTs on a national level. The factor analysis of the 12 items that met criteria for inclusion in the analysis resulted in two factors: Factor 1 ("Health Care Professional related") explained 47% of the variance compared with only 6% being explained by Factor 2 ("Parent participation/perceived confidence in the PCCT"). Our decision to offer Factor 1 for consideration to the ATG was supported by the consensus exercise, with the addition of the safety item. The resulting measure reflects aspects of experience related to the PCCT professionals and their interactions with parents rather than to aspects such as parental understanding and perceptions of involvement. Inclusion of items where responses can result in modifications (Factor 1) were preferred by members of the ATG rather than items which were related to parents' feelings (Factor 2). This decision was supported by the greater conceptual coherence of the items, higher reliability score and higher proportion of variance explained by Factor 1 compared with Factor 2.

Limitations

It is important to recognise that as the measure was developed in response to requests from the PCCT community, a somewhat pragmatic approach was adopted to psychometric analyses which precluded us from undertaking everything we may have done had this been the only aim of the wider DEPICT study. For example, we would have undertaken item generation based on qualitative work with parents which may have resulted in a larger pool of items that would then have been subjected to item reduction. Furthermore, although we had small amounts of missing data, they were not missing at random and this precluded us from using the most robust approach to the analysis and inclusion of cases. Some ATG members had concerns that the questions do not provide them with concrete responses that can be actioned. While the additional general experience measures may help to address this, this concern remains a limitation with the 9-item questionnaire. Finally, we have used a 5-point Likert scale for responses with named anchor points (strongly agree, strongly disagree). Although the response categories in a Likert scale have a rank order, there is an assumption that the ‘strength’ of an attitude is linear; furthermore, intervals between values cannot be presumed to be equal.

We have not yet validated the measure with parents who have experience of their child being transferred to PICU but we have reviewed the measure in the context of what factors parents told us during interviews influenced their experience of the transfer as part of DEPICT. There were four key factors: 1) trust and confidence in staff, 2) perceived parental support (i.e. that staff offered material or emotional empathic support directly to them in addition to the child), 3) appraisal of communication, and 4) proximity to the child. The brief 9-item measure includes questions that relate to factors 1, 2 and 3 referred to by parents, supporting the face validity of the selected items, and PICANet (UK national audit)[22] data already includes information on whether parents travel with their child in the ambulance (factor 4).

Adoption by the PCCT community

Consideration now needs to be given to the next step of reaching consensus among the PCCTs about adoption of the new measure – whether it forms a core number of items that sits with others developed by local teams or whether it replaces all other items currently used by the PCCT. As indicated by the free text comments offered by one respondent, there may be differing views on the utility of the proposed measures and therefore there may be reluctance by some to change – but there is also obvious potential value in adopting a standard benchmarking measure for use by all PCCTs.

Implementation considerations

Historically, based on anecdotal feedback, parent engagement with feedback forms from PCCTs has been low (<20%). In contrast the response rate for the DEPICT Parent Questionnaire study which used the 17 items was good (74% response rate). The obvious answer to this discrepancy is that DEPICT had greater resources (dedicated research nurses/clinicians) and more control over the timing of when parents were asked to give feedback. Parents could therefore be approached when it was most convenient for them to engage and they could also be followed up as appropriate. In contrast, PCCT feedback questionnaires are likely to be given by PCCT staff as they are leaving the PICU having transferred the child with or without their parent(s). This is likely to be a challenging time for parents who are having to come to terms with their child's admission to PICU and therefore the questionnaire may quickly lose salience. These differences in approach and the potential impact on engagement and questionnaire return rates require further consideration to be given about how to implement the new measure if the PCCTs decide to adopt it. Possibilities include administration by PICU staff or electronic completion to reduce administration burden.

Conclusion

From a PICU perspective, having parents arrive who have had a positive experience of the emergency transfer of their critically ill child is likely to result in better engagement with PICU staff, parents who are better prepared and informed about their child's condition and a solid foundation for the development of a trusting partnership with PICU nursing staff and other health care professionals during the child's stay in PICU. Being able to measure experience is the first step in understanding how to make services better in order to improve experience. Our brief measure of parents' experience of the transfer was developed through a robust process of item generation, item reduction, exploratory factor analysis and a consensus exercise. It provides PCCTs with an opportunity to introduce a standardised measure that can be used across all transport teams, thus allowing for national benchmarking of services and potentially increasing the collection and use of parent experience data to improve services. Our next steps will include validation of the measure with parents whose children have been transported by a PCCT to PICU and further exploration of its feasibility and acceptability, resource implications and utility.

What is known

Transfer of a critically ill child can be particularly stressful for parents. Critical care nurses have a key role to play in mitigating the impact of the journey on parents through firstly the advanced role that they have in the Paediatric Critical Care Transport teams (PCCTs) and secondly their role in influencing how families perceive the service. Being able to measure parent experience is the first step in understanding how to make services better to improve experience.

What this paper contributes

A 9-item parent-completed transport experience measure has been developed through a robust process of item generation, item reduction, exploratory factor analysis and a consensus exercise, providing PCCTs with an opportunity to introduce a standardised measure that can be used across all transport teams, thus allowing for national benchmarking of services and potentially increasing the collection and use of parent experience data to improve services.

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Table 1: Initial 17-item parent experience measure

1	I was confident in the transport team
2	I understood what was going on overall
3	My child being transported to this PICU was difficult to cope with emotionally
4	I felt involved in my child’s care
5	The time it took to get to this PICU was bearable
6	I felt calm during the time my child was looked after by the transport team
7	I was confused about what was happening while my child was being transported to this PICU
8	I felt my child was safe during the transfer
9	The transfer to this PICU was chaotic
10	The transport team listened to me
11	I trusted the transport team
12	My child’s transfer to this PICU went well
13	The transport team were caring and understanding
14	I was satisfied with the care my child received from the transport team
15	The transport team treated my family and me with respect
16	When I asked questions, during the transfer, I received answers I understood
17	I felt reassured by the transport team

Shaded items were those that were removed prior to the exploratory factor analysis because correlation coefficients were <0.3

Table 2: Factor loadings for the two extracted factors

	Factor 1 “Health Care Professional related”	Factor 2 “Parent participation/perceived confidence in the PCCT”
The transport team treated my family and me with respect	0.868	
The transport team were caring and understanding	0.900	
I was satisfied with the care my child received from the transport team	0.774	
I felt reassured by the transport team	0.830	
I trusted the transport team	0.617	
When I asked questions, during the transfer, I received answers I understood	0.626	
My child’s transfer to this PICU went well	0.541	
The transport team listened to me	0.491	
I felt my child was safe during the transfer		0.331
I understood what was going on overall		0.850
I was confident in the transport team		0.721
I felt involved in my child’s care		0.481
Variance explained	*47%*	*6%*
Cronbach’s Alpha	*0.903*	*0.693*

Table 3: Responses from the consensus exercise with the ATG (n=28): percentage agreement for inclusion of each item

Item	N	%
I felt my child was safe during the transfer	**22**	**78.6**
I felt calm during the time my child was looked after by the transport team	4	14.3
I felt involved in my child's care	11	39.3
I understood what was going on overall	16	57.1
I was confident in the transport team	17	60.1
The time it took to get to this PICU was bearable	2	7.1
My child being transported to this PICU was difficult to cope with emotionally	4	14.3
I was confused about what was happening while my child was being transported to this PICU	8	28.6
The transfer to this PICU was chaotic	6	21.4
Other items also included in the consensus survey which featured in the research questionnaire		
How would you rate the quality of care of the whole team	**20**	**71.4**
How would you rate the quality of care of the nurse	5	17.9
How would you rate the quality of care of the nurse practitioner	4	14.3
How would you rate the quality of care of the doctor	5	17.3
How would you rate the quality of care of the ambulance driver	4	14.3
Overall satisfaction with the transport service	**23**	**82.1**
How would you rate the quality of care of the whole team	**20**	**71.4**

Shaded items met criteria (>70% agreement) for inclusion in the final measure

Table 4: Final proposed measure

1. The transport team treated my family and me with respect
2. The transport team were caring and understanding
3. I was satisfied with the care my child received from the transport team
4. I felt reassured by the transport team
5. I trusted the transport team
6. When I asked questions, during the transfer, I received answers I understood
7. My child’s transfer to this PICU went well
8. The transport team listened to me
9. I felt my child was safe during the transfer

Additional general experience measures to be included along with the newly revised Friends and Family Test*

10. How would you rate the quality of care of the whole team
11. Overall satisfaction with the transport service
12. Thinking about your child’s recent transfer to PICU [or other setting e.g NICU/ HDU]: overall, how was your experience of our service?*
13. Please can you tell us why you gave your answer?*
14. Please tell us about anything that we could have done better?*

Figure 1: Process of development and analysis of the transport experience measure.