

"The worst journey of our lives": parents' experiences of a specialised paediatric retrieval service

Gillian Colville, Fiona Orr and David Gracey

In this retrospective study, a sample of 233 parents were surveyed, by means of a postal questionnaire, about their experience of a specialised paediatric retrieval service (median time interval after child's retrieval = 10 months). Although all parents were routinely provided with written information about the retrieval service, only 46% remember receiving it. Also, although generally high, satisfaction ratings relating to the period of the child's transit were significantly lower ($P < 0.005$) than those relating to the other stages of the transfer. Two main reasons were given by parents for their dissatisfaction: distress at being separated from their critically ill child and logistic problems locating and parking at the new hospital. Implications for future service provision are considered.

© 2003 Elsevier Science Ltd. All rights reserved.

Gillian Colville

BSc, MPhil,
Consultant Clinical
Psychologist, St.
George's Hospital
Medical School,
London SW17
ORE, UK. E-mail:
g.colville@sghms.ac.uk

Fiona Orr

BA, RN, RGN,
Regional Retrieval
Coordinator, Guy's
Hospital, London
SE1 9RT, UK

David Gracey

BSc, PhD, Trainee
Clinical
Psychologist,
Institute of
Psychiatry, London
SE5 8AF, UK
(Requests for
offprints to GC)

Manuscript
accepted: 20/02/03

Introduction

The [British Paediatric Association \(1993\)](#) identified the need for specialist paediatric retrieval teams to be involved in the transportation of critically ill children almost 10 years ago. Their recommendations were based on a growing body of evidence from the USA, Canada and Australia, that children transferred in the care of specialised teams arrived in better condition and suffered fewer adverse incidents in transit, as compared with those transferred by less experienced staff. [Britto et al. \(1995\)](#), in their prospective study of 51 cases, stressed the importance of the team's skills in stabilising the child at the referring hospital, arguing that reduced morbidity levels depend to a significant extent on the retrieval service being a 'mobile intensive care' service brought to the patient's bedside as opposed to a 'swoop and scoop' service. Subsequently, a

set of minimum standards for this form of emergency transportation was drawn up by the [Paediatric Intensive Care Society \(1996\)](#) (recently revised in 2001).

In terms of the experiences or roles of parents during retrieval, [Hill \(1999\)](#) has observed that very little has been written, other than the recommendation that parents should not routinely travel with the sick child in the ambulance ([Department of Health 1997](#)). The main emphasis in the research literature on retrieval is on the rates of morbidity and mortality and their relation to level of expertise of staff accompanying transfer. However, one study on the impact on parents of inter-facility paediatric transport in Vancouver, reported higher levels of problems in families who were not allowed to travel in the ambulance ([Macnab 1992](#)).

In this retrospective postal questionnaire study, quantitative and qualitative data were

obtained on a sizeable sample of parents whose child had been retrieved by the South Thames Regional Retrieval Service in London (Doyle & Orr 2002), over a period of 1 year. The implications of the responses received for this, and similar paediatric retrieval services, are considered.

Method

Methodology

In order to maximise sample size, it was decided to elicit parents' views by means of a mail survey. The advantages of survey research are well documented (Fox et al. 1988). Although face to face interviews might have yielded more detailed information on individual families' experience, these would not have been practical on a sufficiently large scale, given the distances families lived from the base hospital and the resources available. Ethical approval for the study was obtained from all three participating hospitals.

Sample

In total 578 children were retrieved by the service during the study period. A hospital database search was carried out before the questionnaires were mailed to check current address and to establish whether the child was still alive. Cases were excluded from the survey if the child had died ($n = 59$); if current address was unknown ($n = 9$); if the parents were recorded as non-English speaking ($n = 6$) or if there were suspicions of non-accidental injury ($n = 4$). The sample mailed, therefore, consisted of 500 families.

Questionnaire

In the two-page questionnaire (see Appendix A) parents were asked whether they had received a leaflet about the service and whether they were satisfied with the explanations given about the need for their child to be transferred to another hospital. They were also asked to rate their satisfaction with the care at different points throughout the retrieval process, on a 5-point Likert scale. Lastly, space was provided for any freehand comments parents had about their experiences.

Analysis

The results are presented below, mainly in the form of frequencies. Pairwise comparisons were employed to examine differences between parental satisfaction ratings for the different stages of the child's transfer. (Non-parametric statistics were used as the ratings were not normally distributed.) In addition, examples of parents' freehand comments are provided, by way of an illustration of the main themes that emerged.

Results

Response rate

A total of 233/500 questionnaires were returned. This represents a 47% response rate. The median whole number of months since admission to PICU was 10 months (range 5–17) and 201/233 (86%) parents were prepared to supply a contact telephone number.

Reaction to leaflet

Despite the fact that the information leaflet was given to parents as a matter of routine by the retrieval team during this period, only 112 families (46%) remember receiving it. Some parents reported that they had simply been too anxious at the time to read it. One mother described it as helpful but then went on to admit "I didn't really read it until my son was discharged".

Of those that did remember receiving the leaflet, the vast majority found it helpful ($n = 106/112$, 95%) and only a small proportion would have liked more information at that time ($n = 12/112$, 11%).

Satisfaction ratings

In general satisfaction ratings were high throughout the retrieval experience, but as can be seen from Fig. 1, they were lowest relatively for the period of time when the child was in transit. Repeated pairwise comparisons were carried out on all complete sets of ratings ($n = 202$), using Wilcoxon's Signed rank test. Apart from the two exceptions of 'contact with team' versus 'PICU handover' and 'PICU handover' versus 'PICU stay', all comparisons

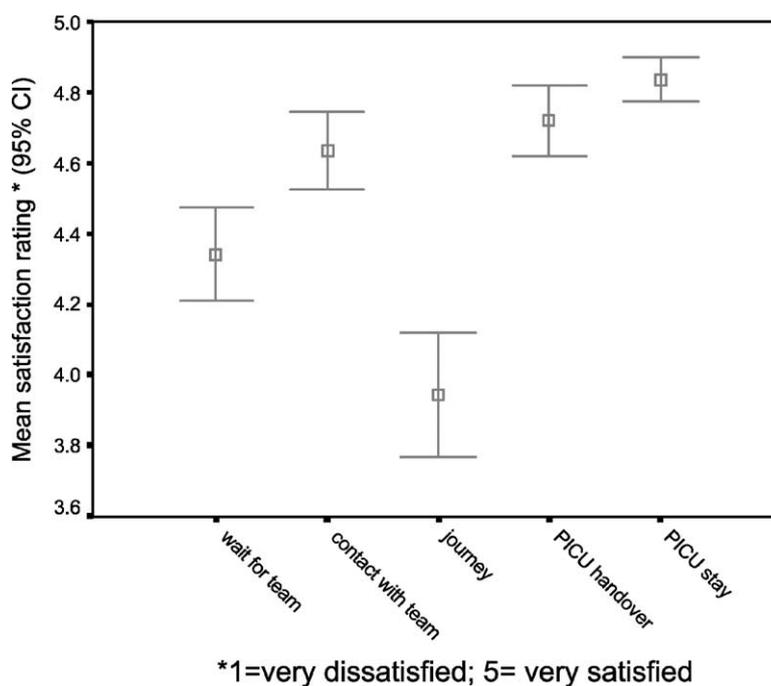


Fig. 1 Mean satisfaction rating by stage of transfer ($n=202$).

were significantly different at the $P < 0.005$ level.

Waiting for the retrieval team

The majority of parents were satisfied with the explanation given for the need for retrieval (221/233, 95%), although this was clearly a stressful time for them. Comments on this section mainly concern the strain inherent in waiting for the team to arrive, with parents acknowledging "It seemed like ages but it wasn't".

Contact with retrieval team

Although some families had relatively little contact with the team, the quality of parents' contact with the retrieval team was rated highly. Particular value was placed on clarity of information provided. One family explained how reassured they were that "Every step of the way was explained in great detail".

Journey between hospitals

Over 70% of respondents (170/233) made a comment about the journey from the local hospital to the intensive care unit. This was

clearly, for many, the hardest part of the whole experience and was described in terms that were both dramatic, as "the worst journey of our lives", and poignant: "The worst part was seeing the ambulance disappearing in the distance".

Parents' comments related to their distress at being separated from their critically ill child, at a time when they felt a strong instinctive need to be present, to protect and comfort. They were also quite explicit about their worst fear: "For all I knew she was dying and I wasn't allowed to be with her".

In contrast, those parents who mentioned that they had been allowed to travel with their child in the ambulance ($n = 13$) were extremely grateful. No information was available on how this decision had been arrived at, but there was a suggestion from parents' comments that they were more likely to be allowed in the ambulance if the child was conscious.

Another theme that emerged was that of the difficulties parents encountered finding the hospital to which their child had been taken. Sometimes the problem was that they did not have an adequate map, or the car park was not clearly signposted, but more often it was quite simply that they found it difficult to

concentrate on driving. One couple explained "We were so knocked sideways by the experience that we got lost".

Arrival on PICU

Although satisfaction with care during this stage of their experience was generally high, some parents felt they had to wait too long before they were allowed to see their child. Also a number mentioned their distress on finding that they had arrived before the child: "Waiting for his arrival and not knowing how he was, was unbearable". This made them once again fear the worst, namely that their child had died en route. Parents reported that they needed to hear confirmation that the child was still alive and appreciated it when staff took them to their child as soon as possible after they arrived on the unit since this meant "no waiting around getting more worried".

PICU admission

Parental ratings of the quality of care during their child's admission were overwhelmingly positive. Parents wrote that staff "made a very traumatic time bearable" and were grateful that "they never gave up hope". In comments such as "We just can't thank them all enough" many articulated the feeling that they would always feel a profound sense of indebtedness to the people that had played a part in saving their child's life.

Other comments

There were a number of comments about the contrast between the quality of care on general wards and that on PICU. Parents complained about inadequate facilities, lack of cleanliness, less individual attention and, occasionally, poor communication between medical teams. Several even went as far as to state that their distress was highest at this stage: "The biggest stress came from the transfer from PICU to the ward".

However, the majority of further comments reiterated the parents' gratitude for the care they and their child had received. Many were in no doubt that they owed their child's life to the work of the PICU team, and were very keen that this message of thanks should be relayed to staff.

Discussion

On the basis of this survey it appears that parents are generally very satisfied with the retrieval service. They do, however, report intense levels of distress during particular stages of their child's transfer. The realisation that a child is critically ill will inevitably produce extremely high levels of anxiety, but the freehand comments of parents attest to the particularly intense pain associated with separation from their child during transit and, in some cases, on arrival at the destination hospital.

Hill (1999) has outlined the main reasons why it is not normal practice for a parent to travel in the ambulance with the child. These relate to concerns about insurance cover and space (Melville & Print 1996), and anxieties about staff time being taken up with the need to provide explanations and support (Valentine 1998). In a similar debate over whether relatives should be allowed to witness resuscitation attempts in hospital, the Resuscitation Council (1996) has recommended that the option to remain in the room be provided to relatives, as long as a member of the medical team is available to support them through the process. This report found that many relatives would prefer to be present if given the choice, and emphasised the value of relatives seeing that everything possible had been done. However, a number of physicians have voiced reservations about adopting these recommendations, taking the view that "Doctors' primary duty is to patients, not to relatives" (Stewart & Bowker 1997), and clearly in the situation of an emergency paediatric retrieval, the ideal of involving parents cannot override the priority of stabilising the child's condition. The need for the utmost concentration in the cramped and noisy working conditions of a moving vehicle, may preclude the possibility of providing appropriate support for an accompanying parent, even if a dedicated member of staff could be made available for this purpose.

Although it may be impractical to have parents travel with their children in the ambulance in most cases, there may be other ways to reduce their anxiety before, during and after transfer. There may be value in spending more time addressing the fear that

the child might die in transit (a relatively small risk, particularly with the current emphasis on stabilising the child's condition before removal). Another possibility would be to maintain contact with parents by mobile phone during the journey. Lastly there is the issue of the importance of keeping the length of separation as short as possible once child and parents have arrived safely on PICU, by facilitating a swift reunion.

There is a large body of research evidence that anxiety reduces people's ability to take in information in medical settings (Ley 1988). The finding that half this sample have no recollection of ever receiving the information leaflet, suggests that repeated verbal reassurance and information may be necessary, in addition to written material, for this highly anxious group.

There is also the issue of the parents' ability to drive safely in such a state of anxiety. In the most recent set of standards published by the Paediatric Intensive Care Society (2001), referring hospitals are stated as being "obligated to provide transport to the Lead Centre for parents", but if the experiences of the parents in this survey are typical, it is clear that this standard is not currently being met. Given the variability in the availability of resources at referring hospitals it could be argued that an additional car, funded centrally by the Lead Centre, as part of the retrieval service, might enable this standard to be achieved routinely.

Interpretation of these findings, however, is inevitably limited by a number of factors.

Although the sample size is high, the response rate, whilst typical of postal surveys in medical settings (Asch et al. 1997), is relatively low, which has implications for the generalisability of these results. In particular the responses may not be typical of parents whose first language is not English or those with literacy problems, since by definition both these groups are likely to be under represented, as a direct result of the methodology chosen. The fact that this study is retrospective is another acknowledged weakness, as is its cross-sectional nature and corresponding wide variation in length of follow up.

Nevertheless, in the context of the government's emphasis on both (a) the importance of parental involvement in the care of sick children (Audit Commission 1993), and (b) the need to attend to the experience of intensive care patients and their carers (Department of Health 2000), the information obtained in this survey is useful in that it suggests a number of ideas for potential interventions aimed at reducing parents' distress. A parent's mental state is likely to have a direct impact on their ability to meet their sick child's needs, both during admission and subsequently. It is, therefore, in the interests of children that we continue to explore and evaluate ways to facilitate parental coping in the difficult situation that is emergency retrieval.

Appendix A

Evaluation questionnaire

1. Which local hospital was your child admitted to?
2. Which Children's Intensive Care Unit was your child taken to?
3. Did you receive a Parents' Information Leaflet about the South Thames Regional Retrieval Service, prior to your child being transferred? Y/N
4. Was this leaflet helpful? Y/N
Comments
5. Would further information have been useful? Y/N
Comments
6. Were you satisfied with the explanations as to why your child needed to be transferred from your local hospital to a children's ICU? Y/N
Comments

Do you have any comments on your experiences with regards to the following:

7. Whilst at your local hospital awaiting the arrival of the retrieval team?
 Comments
 very satisfied 5 4 3 2 1 very dissatisfied
8. Your journey to the children's intensive care unit?
 Comments
 very satisfied 5 4 3 2 1 very dissatisfied
9. Your arrival on the children's intensive care unit and the transfer of your child to the staff in the intensive care unit?
 Comments
 very satisfied 5 4 3 2 1 very dissatisfied
10. The contact you had with the retrieval team?
 Comments
 very satisfied 5 4 3 2 1 very dissatisfied
11. Your child's stay on the children's intensive unit?
 Comments
 very satisfied 5 4 3 2 1 very dissatisfied
12. Are there any other aspects of your child's retrieval or care that you would like to comment on?

References

Audit Commission 1993 *Children First: A Study of Hospital Services*. The Stationery Office, London

Asch DA, Jedrzejewski MK, Christakis NA 1997 Response rates to mail surveys published in medical journals. *Journal of Clinical Epidemiology* 50(10): 1129–1136

British Paediatric Association 1993 *The Care of Critically Ill Children*. British Paediatric Association, London

Britto J, Nadel S, Maconochie I, Levin M, Habibi P 1995 Morbidity and severity of illness during interhospital transfer: impact of a specialised paediatric retrieval team. *British Medical Journal* 311: 836–839

Department of Health 1997 *A Framework for the Future: Report from the National Co-ordinating Group on Paediatric Intensive Care to the Chief Executive of the NHS Executive*. The Stationery Office, London

Department of Health 2000 *Comprehensive Critical Care. A Review of Adult Critical Care Services*. The Stationery Office, London

Doyle YG, Orr FE 2002 Interhospital transport to paediatric intensive care by specialised staff: experience of the South Thames combined transport service, 1998–2000. *Archives of Disease in Childhood* 87: 245–247

Fox RJ, Crask MR, Kim J 1988 Mail survey response rate: a meta-analysis of selected techniques for inducing response. *Public Opinion Quarterly* 52: 467–491

Hill Y 1999 Is there a place for parents in the retrieval of critically sick children? *Nursing in Critical Care* 4(3): 121–127

Ley P 1988 *Communication with Patients*. Croom Helm, London

Macnab AJ 1992 Paediatric inter-facility transport: the parents' perspective. *Social Work Health Care* 17(3): 21–29

Melville M, Print M 1996 Legal issues surrounding neonatal emergency transport: minimising the risk. *Journal of Neonatal Nursing* 2: 18–22

Paediatric Intensive Care Society 1996 and 2001 *Standards for Paediatric Intensive Care*. Saldatore Ltd., Hertfordshire

Resuscitation Council 1996 *Should Relatives be Allowed to Watch Resuscitation? Report from a Project Team of the Resuscitation Council (UK)*. Resuscitation Council, London

Stewart K, Bowker L 1997 Resuscitation witnessed by relatives. *British Medical Journal* 314: 144–145

Valentine F 1998 Empowerment: family-centred care. *Paediatric Nursing* 10: 24–27