The implication of end-of-life transfers on a transport service

This article describes the role of a transport team in organising and carrying out transfers for end-of-life care. This involvement is increasing and needs to be recognised, not only for the development of the transport service but also because of the implications to the staff.

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Key points

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1. Transport services are becoming involved in end-of-life care.
2. Requests for this type of transfer are increasing.
3. There are implications for service development and delivery.
4. Support for all staff involved in these transfers must be provided.

Embrace, Yorkshire And Humber Infant And Children's Transport Service (**FIGURE 1**), began in December 2009. The service had a phased implementation with paediatric transfers starting in December 2009, followed by neonatal transfers in April 2010. It is the first combined neonatal and paediatric transport service in the UK and during design and development of the service, it was estimated to carry out approximately 2,000 transfers per year. Embrace is a stand-alone service with dedicated staff based at a non-hospital site. There are 65 members of staff including administrative staff, drivers, nursing and medical staff[1].

Since starting the service, reconfiguration of neonatal care within networks and centralisation of both paediatric and neonatal specialist care has led to an increase in transfer requests (**TABLE 1**). Anecdotally it seemed there was a steady increase in the number of babies and children referred, who could not be transferred due to a serious deterioration in their condition.

When a patient is referred, a call handler (administrative staff) takes demographic details. The call is then transferred to a consultant who takes the clinical details while the call handler continues to listen to the phone call. This enables them to involve tertiary specialists/intensivists for specialist advice. A transport team is then mobilised.

On arrival, an initial assessment of the patient is carried out followed by a phone call to base with a clinical update. This again, is a conference-call, so that the base team is aware of the situation. If the patient's condition deteriorates and a decision is made that the baby/child cannot be transferred or if care is reoriented to palliative care, the base team are involved.

The administrative staff are from a non-medical background and have not previously been exposed to working with critically sick infants or children. The authors were concerned about the impact these situations might have on staff, especially administrative staff and those new to this arena. Due to the small number of staff working in the service, it seemed likely that most team members would have been involved in a transfer where the outcome was poor. Previously there was no structure in place for formal debriefing after these incidents and the authors were keen to develop a debriefing pathway and to promote coping strategies in all staff groups.

As the number of transfer referrals increased, there seemed to be an increasing number of patients referred for transfer to either a hospice or home for palliative care. It was thought important to investigate this situation in detail.

This article describes the incidence of referrals where transfer did not occur due to a deterioration in the patient's condition, how the service has dealt with this type of situation to date and the national picture with regard to transfers for palliative care.

Period	Neonatal transfers	Paediatric transfers	Total
April 2010-March 2011	1598	504	2102
April 2011-March 2012	1730	506	2236

TABLE 1 Number of transfers carried out by Embrace, April 2010 to March 2012.

The aims of the project were threefold:

1. To determine how many people had been involved in transfers that were abandoned due to the patient's clinical deterioration.
2. To establish whether a formal debrief had occurred following the event.
3. To determine how the the debrief was carried out and whether it was a useful experience.

Methods

A short questionnaire was devised and distributed to all Embrace staff, including administrative staff, drivers, nursing and medical staff. A total of 65 questionnaires were sent out.

The Embrace database was used to identify all cases where a transfer did not happen due to deterioration in the patient's condition, or the patient died, after referral between April 2010 and March 2012. The data were split into neonatal and paediatric age groups, and whether the patient died before or after the arrival of the transport team. The decision making regarding reorientation of care was investigated to identify who had taken responsibility – referring consultant, transport consultant or a combination of both.

Data were also collated on transfers to a hospice or home for palliative care in the same time period. Data were grouped into neonatal or paediatric categories, where the patient was transferred to and whether the patient required any ventilatory support. Composition of the transport team was analysed as well as determining whether a parent accompanied the baby/child (it is routine practice for a parent to be invited to accompany their baby/child during a transfer by Embrace).

Fourteen other transport services throughout the UK were contacted to ascertain regional pathways for moving infants or children with palliative care needs and how many palliative care transfers they had carried out.

Results

Staff questionnaire

The questionnaire had a good response (86%) with mixed opinions but with representation from all staff groups. All staff who replied had been involved in a difficult or traumatic transfer. Of the 56 responses, only 38% had been offered debriefing. Of those who did attend a debriefing session the feedback was varied, but the majority (95%) felt it was a useful experience. Of the staff who had not been offered or did not attend a debrief session, 80% said they would have attended if offered and felt it would be of benefit, however, should not be made mandatory. No staff group in particular felt they would benefit more from counselling. The remaining 20% of this group did not express an opinion.

FIGURE 1 Members of the Embrace team.

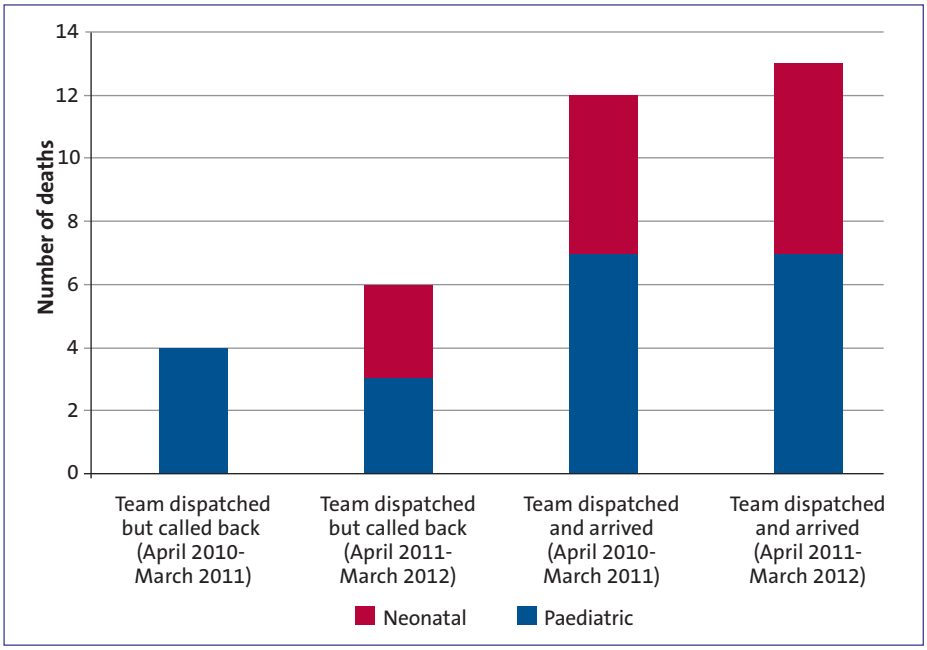

FIGURE 2 Outcome of referral, April 2010 to March 2012.

Data

Between April 2010 and March 2011 there were 16 deaths (**FIGURE 2**); five neonatal (up to four weeks' old) and 11 paediatric patients. In four cases (all paediatric) the transport team set off from base to the referring hospital, but was called back due to further deterioration of the child's condition. In the other 12 cases (five neonatal, seven paediatric) the transport team was dispatched and arrived at the referring hospital, where the patient died in the presence of the team.

There were a further 11 referrals (seven neonatal, four paediatric) where the patient was not suitable for transfer due to their clinical condition and ultimately no transport team was dispatched. These cases did however involve the call handlers and transport consultants during the referral call and thus team members were exposed to potentially stressful and emotional situations.

Between April 2011 and March 2012 there were 19 deaths (**FIGURE 2**); nine neonatal and 10 paediatric. In six cases (three neonatal, three paediatric) the transport team set off from base but was

called back due to further deterioration of the patient's condition.

The other 13 cases (six neonatal, seven paediatric) involved the team arriving at the referring hospital, where the patient died in the presence of the team.

The 12 cases in 2010/11 where the transport team had arrived at the referring hospital and care was reoriented were further examined. **FIGURE 3** shows the involvement of the transport service in the end-of-life decision process. By 2011/12 Embrace were involved in all cases where reorientation of care was felt appropriate, with shared discussions between referring clinicians, Embrace and receiving intensivists.

Palliative care transfers

From April 2010 to March 2011, Embrace carried out eight transfers for palliative care; six to a hospice and two to the baby's/child's home. Four patients were ventilated, one required continuous positive airways pressure (CPAP) and three required no respiratory support. Five transfers had one or both parents present during the transfer. Five transfers had a member of the referring team (either a nurse or doctor) with the patient for continuity of care and support for the parents and baby/child.

In the following year from April 2011 to March 2012 there were 11 palliative and respite care transfers undertaken by Embrace; 10 to a hospice (one neonatal, nine paediatric) and one (neonatal) to the home. In this time period there were eight other palliative care referrals that Embrace could not transfer due to high activity on those days. Of the 11 transfers, eight patients were ventilated, two babies were on CPAP and one did not require respiratory support. Only two cases in 2011/12 had a parent with the team for transfer. Eight cases had a member of the referring team during transfer.

From a national transport service overview, 14 teams were contacted and all responded. This comprised 10 neonatal teams, and four paediatric teams. Three teams had moved a patient to their home for end-of-life care, six teams had carried out a transfer to a hospice (two of which would move ventilated patients to the hospice if asked) and five teams had never been asked to carry out this type of transfer. Only one team had carried out more than one transfer for end-of-life care (two); all the other teams had undertaken one.

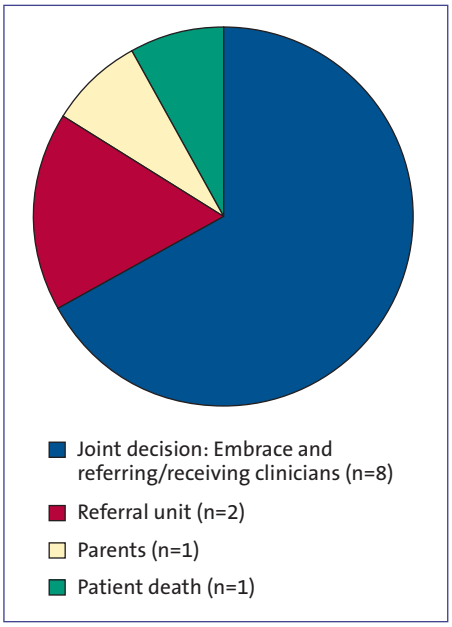

FIGURE 3 Involvement in the end-of-life decision process.

No transport team surveyed had a palliative care guideline although three teams used an end-of-life care pathway and were aiming to develop a guideline. One team was working with a hospice to develop their service.

Discussion

This project demonstrates that transport teams are becoming more involved in end-of-life care. The nature of transport services leads to teams being referred, and attending to, critically sick patients with the aim to move them to specialised, centralised units for intensive care. The numbers are increasing; in 2010/11 there were 16 referrals where the transport team was dispatched, with 19 referrals the following year.

Transfers for palliative care are also increasing from eight (2010) to 11 (2011), with eight additional referrals in 2011 that Embrace could not transfer due to other activity.

Since December 2009 when the service started, the database has been evolving and it is likely the figures underestimate the numbers of transfers. Much of the data in the time period have been collated by reviewing the clinical transfer notes. In future, these data will be more accurate and readily available from the database.

As a non-hospital-based, stand-alone transport service with a core group of staff, there was concern about the impact of end-of-life cases on team members. In a team as small as Embrace, most team members have been involved in this type of transfer, especially the smaller groups such as the call handlers and ambulance drivers. Although not directly involved in the care of the sick baby or child, administrative staff find themselves in the difficult position of listening to phone calls describing critically sick babies and children. Likewise the drivers are rarely involved in direct care but are often present at the bedside. These two staff groups may not have been previously exposed to cases such as these, compared with nursing and medical staff, and may be less likely to have developed or been taught a coping strategy to deal with end-of-life situations. The authors were concerned in particular about these staff groups, but the staff questionnaire suggested that they are supported through these difficult cases and do take up debriefing opportunities.

Research has shown that such events have a cumulative negative impact on the staff involved[2] and although teams can appear resilient, provision of support for the emotional health of staff should be available.

The findings have supported the development of a palliative care team at Embrace who have had training into the possible effects on staff of such difficult cases and consequently the benefit of debriefing. There is also access to trained counsellors if further help is needed. The Samaritans have offered training to all members of staff to develop emotional resilience in the workplace and help with taking difficult calls. Two members of the palliative care team have attended this course with positive feedback about its transferability to the transport setting. The course content included: identifying individuals at risk of stress, how to support these individuals and how to develop a framework in the service to aid personal coping strategies. The Samaritans have offered a specifically tailored course for the service to promote individual and team coping mechanisms to enhance the effectiveness of the team.

Following unexpected deaths or particularly traumatic transfers, an operational debriefing pro forma has been developed. This should be completed as soon as possible following the event. This can be difficult if the case occurs at the end of a shift or if the team involved return to base and all other teams are out. In this situation the team members are contacted the next day to provide acknowledgement of the difficult situation they were in and to offer debriefing and support if needed.

Due to shift patterns, the same team will rarely work together again so ideally debriefing should occur immediately after the event. A 'buddy' system has been devised to provide support for staff if debriefing cannot occur. Every member of the team (all staff groups) has a buddy they are comfortable with and who they can contact following a traumatic event. Often staff just need recognition for having been on a difficult transfer, requiring a simple phone call to make sure they are all right. This can be done by their buddy or by a senior member of the team the following day during the review of the previous day's transports.

Difficult cases such as these are also formally reviewed in clinical governance meetings, which team members are encouraged to attend. These meeting focus on clinical aspects of the case and suggest learning points if appropriate. Debriefing meetings are kept separate from these clinical reviews but staff often find these helpful to attend.

Transport services occasionally describe themselves being likened to the 'cavalry' on arrival at referring units and how the referring team may leave further management decisions to the transport staff. Reassuringly the findings indicated that the decision for end-of-life care was in the majority of cases (eight out of 12) shared between referring clinician, intensivist and Embrace clinician (**FIGURE 3**).

With established paediatric hospices in many regions and palliative care clinicians, there have been recent developments on end-of-life care[3,4] with the aim to move some babies/children to home or a hospice. Paediatric transport services are increasingly being asked to be involved in these transfers. Embrace has developed a guideline to assist with the organisation of palliative care transfers. When transferring a baby/child home, the logistics of such a move can heighten anxiety for staff and family. Issues such as equipment needed at home, access to the house, and medications need to be planned. A pro forma has been designed to address these issues in advance to enable a smooth and efficient transfer. The aim is to take a member of the referring team (nurse or doctor) with the transport team, to provide ongoing continuity of care and support for families at this difficult time. A Limitation Of Treatment Agreement (LOTA) (or equivalent) must be in place prior to the transport team moving the baby/child to cover all eventualities on the transfer. The LOTA is to be completed by the referring clinician who knows the child and family and their needs and wishes.

Conclusion

Transport services are becoming more frequently involved in end-of-life care. This has implications for service development and delivery. Most importantly, there is a need to ensure ongoing support for all staff involved in these challenging and emotional transfers.

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