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Transferring critically ill babies and children home to die from intensive care.

KE Morton

A Richardson

MA Coombs

AS Darlington

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Morton, KE

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3. Authors:

Kathryn Elizabeth Morton

Alison Richardson

Maureen A Coombs

Anne-Sophie E Darlington

Transferring critically ill babies and children home to die from intensive care

Structured abstract

Background

A significant proportion of hospital deaths occur in intensive care units and often follow a decision to limit or withdraw life-sustaining treatment. Facilitating the preferred choice in place of death for babies/children is increasingly being advocated, although the literature on a home death is often limited to case reports.

Aims

To examine (1) healthcare professionals' (HCPs) views and experience of transferring babies/children home to die from intensive care, (2) patient clinical characteristics that HCPs would consider transferring home and (3) barriers in transferring home.

Design

A cross-sectional descriptive web-based survey.

Methods

900 HCPs from Paediatric and Neonatal Intensive Care Units across the United Kingdom were invited to participate.

Results

191 (22%) respondents completed the survey. 135 (70.7%) reported being involved in transferring home to die. However, most (58.4%) had just transferred one or two patients in the last three years. Overall, respondents held positive views towards transfer, although there was some evidence of divided opinion. Patients identified as unsuitable for transfer included unstable patients (57.6%) and those in need of cardiovascular support (56%). There was statistically significant difference in views between those with and without experience, with those having experience had more positive views. The most significant barrier was the lack of access to care in the community.

Conclusions

HCPs view the concept of transferring critically ill babies/children home to die positively but have infrequent experience. Views held about transfers are influenced by previous experience. The clinical instability of patients and access to community care are central to decision-making.

Relevance to clinical practice

A home death for critically ill babies/children is occurring in the UK but infrequently. Experience of a transfer home positively influences views and increases confidence. Improved multi-organisational collaboration between intensive care units and community care teams would assist decision-making and facilitation for a transfer home.

Main Body

1. Introduction

Children admitted to intensive care units (ICU) undergo aggressive and invasive treatments aimed at cure or stabilisation (Sturman and Cassidy, 2006). Advancements in medical knowledge and technology have led to a considerable reduction in infant and childhood mortality over the past few decades. With the exception of deaths resulting from chronic complex conditions, acute illness or injury; death in childhood is uncommon (Ramnarayan *et al.*, 2007). Nevertheless, over 5000 children aged from birth to 18 years, die each year in the United Kingdom (UK) (Department of Health [DoH], 2005), with the majority of deaths occurring within a hospital ICU. Mortality rates amongst general and cardiac Paediatric Intensive Care Units (PICUs) within the UK and Republic of Ireland, reported 692 paediatric deaths in 2016, with European data showing approximately 70% of these deaths occurring after limiting or withdrawing life-sustaining treatments (Sprung *et al.*, 2003, PICANet, 2017). Once a decision has been made to limit or withdraw life-sustaining treatment, the transition from curative management to end-of-life care and subsequent death, has traditionally occurred within the ICU environment (Moore *et al.*, 2008). The delivery of end-of-life care in ICU is often

influenced by the aggressive treatments and clinical characteristics of the critically ill baby or child. The resultant physiological instability leads to an unpredictable period of time between withdrawal of treatment and death (Garros *et al.*, 2003; Oberender and Tibballs, 2011). However, for some babies or children who are stable enough, a home or hospice death can be planned, raising issues surrounding patient choice and preferred place of death (DoH, 2007; Siden *et al.*, 2008).

2. Background and Study Aims

Research indicates that children and families prefer palliative care to occur at home (DoH, 2007) and that the death of a child in a hospital setting can have an adverse psychological effect on parental grief (Goodenough *et al.*, 2004). The ICU environment makes it difficult to facilitate privacy, quietness, familiar surroundings and a family-orientated atmosphere that a death at home may enable (Simpson and Penrose, 2011). Facilitating the preferred choice in place of death for babies and children is increasingly being advocated (Meert and Sarnaik, 2010). A small number of papers have described centres transferring critically ill babies and/or children home to die and argue that health care professionals consider this to be a viable and meaningful option to offer families in ICUs (Hawdon *et al.*, 1994; Zwerdling *et al.*, 2006; Needle, 2010; Simpson and Penrose, 2011; Laddie *et al.*, 2014). However, this evidence is limited to case reports and the experience of very few paediatric or neonatal ICUs.

In this paper, we report on a study that describes experiences and views of health care professionals (HCPs) working in all specialities (general, cardiac, surgical, mixed) of UK Paediatric ICUs (PICU) and Neonatal ICUs (NICU), in transferring critically ill patients home to die. An additional aim of this study was to identify specific patient characteristics that influenced decision-making towards a transfer home and to identify the most important barriers to transfer, in order to understand the practical challenges in transferring babies/children home at end of life.

3. Design and methods:

Design

A cross sectional descriptive survey was sent to a UK national sample of PICU and NICU HCPs. The web-based survey was administered by iSurvey, a software platform developed by the Department of Psychology at the University of Southampton, UK. By using a web-based survey design, the survey was sent to HCPs professionals working across all UK PICUs and NICUs covering the wide variety of specialities, including general, medical, cardiac, surgical and mixed units.

Survey Development

The survey tool was developed from previous work exploring the practice of transferring critically ill adults' home at end of life (Darlington *et al.*, 2015) and adapted for the paediatric and neonatal population. In order to establish face and content validity, the survey was pre-tested. The survey was given to: two palliative care research experts from the Faculty of Health Sciences at the University of Southampton, UK; four clinical consultants working in NICU and PICU; two senior PICU nurses; and two clinical research nurses. All gave verbal and written feedback. Following the pre-test work, several changes were made to the survey content. These included reducing the number of views about transfer home by removing statements of a similar nature and to encourage full questionnaire completion. The outcome of these changes resulted in a more succinct questionnaire taking no more than 15 minutes to complete. The survey was designed to focus on: transferring babies/children home at end of life; experience of transfer home; views about transfer home; characteristics of patients suitable for transfer and barriers to transfer. See **Table 1** for a brief description of survey contents and **Appendix One** outlining the views, patient characteristics and barriers.

Sample and Recruitment

Identification of HCPs working in UK NICUs was achieved through the British Association of Perinatal Medicine, and identification of HCPs working in UK PICUs was enabled through the

Paediatric Intensive Care Society. Once ethical approval for the study was obtained from the University of Southampton Ethics Committee (Submission ID: 8105), emails were sent to 900 HCPs inviting them to participate in the study with links to the web-based survey. A paper version of the survey was distributed to HCPs at Paediatric Intensive Care Society and Paediatric Intensive Care Audit Network meetings held in the UK over a 6 month period. An additional 80 HCPs were approached in this way.

For the web-based survey, a tick box was placed at the beginning of the survey to indicate that the respondent consented to taking part in the study. Written informed consent was obtained at times when a paper version of the questionnaire was used.

Data Analysis

Data analysis was carried out using IBM SPSS (Statistical Product and Service Solutions) Version 21. Descriptive statistics were used in the analysis of the survey, including using raw scores, percentages, means and standard deviation. Non-parametric testing, Mann Whitney U and Chi-Square, was used to compare views held within and across groups.

4. Ethical and research approvals

Ethical approval for the study was obtained from the University of Southampton Ethics Committee (Submission ID: 8105).

5. Results

Respondent Characteristics

From the 900 invitation emails and promotion at UK annual meetings, 191 HCPs completed the questionnaire, giving a response rate of 22%. Of these 191, 18 questionnaires were completed using the paper version and 173 were completed online. 178 HCPs fully completed the questionnaire and 13 returned a questionnaire with only the respondent information, experience

and patient characteristics completed. There was an equal split of doctor and nurse respondents (48% and 49% respectively), and a majority of respondents working in a PICU (58%). Due to the way in which the sample was identified, less than 20% of those invited to take part worked within a NICU, resulting in an invited sample dominated by PICU HCPs, which could explain the PICU majority.

Of those 20 respondents who reported their roles as 'Other', additional information for 19 respondents was given. These were: Advanced Nurse Practitioner (n=7); Clinical/Practice Educator (n=1); Associate Specialist (n=3); Lecturer/Practitioner (n=1); PICU physiotherapist (n=1); Clinical Coordinator (n=1); Clinical Nurse Manager (n=1); Retrieval Co-ordinator (n=1); Pharmacist (n=1); Family Liaison Sister (n=1); Specialist Nurse Organ Donation (n=1).

Experience of Transferring Critically ill Babies/children Home to Die

A total of 70.7% (n=135) of respondents reported they had transferred a critically ill baby/child home to die in the last three years. Of those who had transferred a patient home to die, 30.4% (n=41) had transferred one patient and 28% (n= 38) had transferred two patients. A total of 74.9% (n= 143) reported that they had been involved in discussions about transferring home to die that did not lead to a transfer. Of these, most (62.5%, n=75) reported being involved in one to three discussions in the last three years.

Views towards Transferring Critically ill Babies/children Home to Die

Results of the survey indicated that respondents held largely positive views about transferring critically ill babies/children home to die. For example, 51.3% (n = 98) of respondents strongly agreed and 30.4% (n= 58) agreed with the statement 'Critically ill babies/children should be transferred home to die if this is the wishes of the child and/or family'. Furthermore, respondents tended to agree with positively phrased statements as seen in the above statement, and disagree with negatively phrased statements. For instance, 48.7% (n= 93) of respondents strongly disagreed

and 36.1% (n= 69) disagreed with the statement 'Taking critically ill babies/children home to die is a waste of health care resources'.

Some responses resulted in an overall neutral viewpoint towards some of the views. This occurred when the mean score was close to 3 on the five-point Likert scale (in which 1 = strongly disagree, 3 = neutral and 5 = strongly agree). For example, the statement 'It is unethical to prolong a baby/child's life so that they can be transferred home to die' had a mean score of 2.84, suggesting an overall neutral viewpoint. However, despite the mean score of 2.84, the raw scores indicate a substantial group of respondents who actually disagreed (35.1%, n= 67) to the statement, demonstrating a more divided opinion. See **Appendix Two** for full responses.

Subgroup analysis

Difference in Views between Those with Experience and Those without Experience of Transfer Home

There was a statistically significant difference in views between respondents with experience of transfer than those with no experience. Those with experience of a transfer home had a statistically significant higher mean score (4.26) compared to those with no experience (3.58) towards the statement 'We would be able to organise the transfer home to enable a baby/child to die at home', demonstrating a stronger agreement in being able to organise a transfer home (U= 1921.500, p= 0.00). For the negatively phrased statement 'NICU/PICU staff have more pressing clinical priorities than organising home transfers for dying babies/children', there was a statistically significant lower mean score for those with experience (1.73) compared to those with no experience (2.06) (U= 2480.500, p= 0.025) demonstrating a stronger disagreement with the statement .

Transferring critically ill Babies/children Home to Die: Patient Characteristics

Respondents were asked to indicate whether they would consider transferring a patient home with a specific clinical characteristic. **Table 2** shows the number and percentages for each characteristic, where 'yes' or 'no' were the only response options. Six respondents did not answer this section and so data is missing for these respondents. The majority of respondents answered 'yes' to most patient characteristics with up to 95.3% (n=182) of respondents willing to transfer a stable patient home to die. For characteristics described as 'unstable' and those in 'need of cardiovascular support i.e. inotropes', notably less said 'yes' to considering transferring these patients home with just 57.6% (n=110) and 56% (n=107) respectively.

Barriers to Transferring Critically ill Babies/children Home to Die

Respondents were asked to rank their top five barriers in transferring critically ill babies/children home to die, from a list of predetermined options. The first three choices for all respondents were calculated to identify which barriers featured most often in respondents top three. The most important barrier to the sample population, was reported as the 'Lack of access to care in the community' (46.1%, n= 88), followed by 'Unpredictability of time to death after withdrawal of treatment' (30.9%, n= 59) and 'Patient's relatives unlikely to be able to cope with transfer and death at home' (29.3%, n= 56), closely followed by 'Staff confidence' (28.3%, n= 54).

The barriers considered the least important to the sample population included 'Unclear responsibility for care of child before or after transfer' (3.6%, n=7), 'Lack of back up staff or ambulance' (3%, n=6), 'Unclear legal issues' (1%, n=2), and 'Parental religious beliefs' (1%, n= 2).

6. Discussion

This study is the first to explore the experiences and views of NICU and PICU HCPs about transferring critically ill babies/children home to die. While this practice has been described within the critical care literature as an uncommon event (Hawdon *et al.*, 1994; Zwerdling *et al.*, 2006; Craig

and Mancini, 2012; Laddie *et al.*, 2014), the results of this study show that nearly three-quarters of the HCPs who completed the survey had some experience of transferring critically ill babies/children home to die in the last three years. This evidence implies that the choice in place of death for critically ill babies/children can go beyond the intensive care environment and that a home death is feasible (Longden and Mayer, 2007).

However, of those who had transferred a patient home to die, most had transferred just one or two patients in the last three years, suggesting that experience is limited to a small number of babies/ children. Furthermore, three-quarters of respondents reported being involved in discussions about transferring critically ill babies/children home to die. Although this survey did not ask for the reasons as to why these discussions did not result in a transfer taking place, they could reflect the complex nature of the practicalities needed to transfer a critically ill baby/child home for end-of-life care and the difficulties in supporting the needs of dying children and their families (Longden and Mayer, 2007). Future studies should investigate these practical challenges further in order to help inform clinical practice.

Part of the survey explored HCPs views towards transferring critically ill babies/children home to die. Overall, respondents held positive views about transferring home to die. Positive views towards home transfers are echoed in current literature and describe HCPs reporting satisfaction in achieving end-of-life care in a place of the family's choosing (Simpson and Penrose, 2011). Negative views are rarely reported in the literature, although reference is made to the emotional difficulty for HCPs to withdraw life-sustaining treatment in the family home compared to the familiar surroundings of the intensive care environment (Simpson and Penrose, 2011). Results of this study indicate that there can be divided opinions and that not all HCPs working in ICUs agree that transferring a critically ill baby/child home to die is always a positive and ethical concept.

Subgroup analysis showed that views of HCPs were influenced by experience, both positively and negatively. It could be that experience and views mutually influence each other, with positive experiences shaping views which then lead to greater engagement in transfer possibilities, and negative experiences lead to more negative views thus reducing the instigation of transfers (Darlington *et al.*, 2015). This can be seen in the results of this survey where an experience of a transfer home resulted in increased HCP confidence in organising a transfer, and yet on the other hand, 'staff confidence' was identified as one of the top barriers to transfer. Future work is needed to explore what can be done to increase HCPs confidence in organising a transfer home and how others can support those with little or no experience. Suggestions of how to influence practice within adult ICUs revolve around better guidelines and local simulations to guide inexperienced ICU HCPs through the transfer process (Coombs *et al.*, 2015). The paediatric literature recommends ICUs adopting formal guidelines and providing end-of-life care training in order to increase HCPs involvement and confidence in end-of-life processes (Lisle-Porter and Podruchny, 2009). Although there are many guidelines and care pathways offering guidance to reduce indecisions during the withdrawal of care outside of the NICU or PICU environment (Longden and Mayer, 2007; Simpson and Penrose, 2011; Association for Children's Palliative Care, 2011), it appears that there remains local influences, varying clinical judgements and a wide divergent use and acceptance of standardised guidelines (Truog *et al.*, 2006). Therefore, a local approach in the first instance might be of benefit.

The results of this study show that the clinical characteristics and subsequent instability of a patient affects whether HCPs would consider a transfer home, with a clear change in opinion about transferring patients who are unstable and/or in need of cardiovascular support. Clinical instability has also been described within the adult international literature as being a key limiting factor to a transfer home (Lusardi *et al.*, 2007). A survey of HCPs working in adult ICUs were more disapproving of transferring unstable patients, those ventilated via an endotracheal tube and in need of

cardiovascular support, with over 68.5% of HCPs not willing to transfer such a patient (Darlington *et al.*, 2015). Transferring a critically unstable baby/child home to die, especially those who require cardiovascular support necessitates technical skills, equipment and drugs, and potentially taking these resources away from the ICU (McPherson *et al.*, 2007). Nevertheless, there has been a substantial growth in specialised UK neonatal and paediatric retrieval teams who transfer critically ill babies/children who are intubated, ventilated, requiring invasive haemodynamic monitoring and vasoactive drugs, from local hospitals to regional NICUs/PICUs (Ramnarayan *et al.*, 2010). As a result, many centres have highly trained staff skilled in transferring critically ill babies/children, subsequently being able to offer a transfer home.

Within the literature, reference is often made to the considerable amount of collaboration needed between different multidisciplinary healthcare teams in order to facilitate a transfer home (Laddie *et al.*, 2014). This is also reflected within the results of this survey where the top most important ranked barrier to transfer for the sample population was reported as being the lack of access to care in the community. Community resources for paediatric palliative care are viewed as inadequate and usually only available for children with cancer, despite the increasing use of hospices and palliative care teams (IMPACT, 2007; Craig and Mancini, 2012). In order to ensure the clinical safety and emotional needs of the baby/child and family are met, there needs to be considerable amount of multi-organisational collaboration in preparing for the transfer, the transfer itself, care post withdrawal of life-sustaining treatment, and post death (Laddie *et al.*, 2014). Future work is needed to determine whether HCP working in NICUS/PICUs, the community and within palliative care teams can work together to reduce these barriers and offer a seamless approach to end-of-life care for critically ill patients outside of the ICU.

7. Limitations

A response rate of 22% is considered low, even for online surveys (Nulty, 2008). Therefore the results of this survey are at risk of non-response bias. Furthermore, it is possible that this survey was subject to self-selection bias in which HCPs with an interest in end-of-life care completed the survey, and those with little interest did not respond to the invite. This bias could have contributed to the overwhelmingly positive views towards transferring critically ill babies/children home to die, despite minimal experience.

8. Conclusion

This study is the first to explore the experiences and views of UK NICU and PICU HCPs towards transferring critically ill babies/children home to die. As such, it makes significant contribution to the literature currently dominated by case reports. The findings of this research suggest that HCPs working in UK NICUs and PICUs, view the concept of transferring critically ill babies/children home to die positively but have infrequent experience of this practice. Furthermore, the clinical instability of patients' and subsequent need for aggressive treatments, are considered significant factors in decision-making. Respondents within this survey identified the key barrier to transfer as the lack of access to care in the community. However, results suggest that having experience of a transfer positively influences views and increases HCP confidence in being able to facilitate a transfer home.

Future work should focus on supporting HCPs to gain experience in transferring critically ill children/babies home to die through working alongside those with experience, via practice simulations involving ICUs and community teams, in addition to local guideline development. This could help support HCPs who are less confident and enable learning from simulations. Future research is needed to explore the impact of place of death on the bereavement of parents of critically ill babies/children and the resource implications in transferring a critically ill baby/child home to die for the ICUs and community teams.

TABLE 1: Survey Description

Survey section	Description
1: Demographics & background information	<ul style="list-style-type: none">• Respondent information.• NICU/PICU details (size, speciality).• End-of-life care policies.
2: Experience of transferring critically ill babies/children home to die	<ul style="list-style-type: none">• Experience of transferring critically ill babies/children home to die (yes/no/how many).• Discussions about transfers that did not result in a transfer home (yes/no/how many).
3: Views	<ul style="list-style-type: none">• 15 views towards transferring critically ill babies/children home to die. Respondents were asked to indicate to what extent they agreed or disagreed with the statements on a five-point Likert scale (1 = strongly disagree to 5 = strongly agree).
4: Patient Characteristics	<ul style="list-style-type: none">• 11 patient characteristics i.e. Intubated and ventilated.• Respondents were asked to indicate whether they would consider transferring a patient home to die.• Respondents were forced to make a choice between 'yes' and 'no'.
5: Barrier to transfer	<ul style="list-style-type: none">• 16 predetermined barriers listed.• Respondents were asked to rank barriers to transferring patients home to die, from 1 (most important) to 5.

TABLE 2: Responses to Questions about Patient Characteristics that Respondents Would Consider (or not consider) Transferring Home to Die, Expressed as Raw Scores and Percentages

Patient Characteristic	Yes	No
Is unconscious	166 (86.9%)	19 (9.9%)
Is conscious	179 (93.7%)	6 (3.1%)
Is unstable	110 (57.6%)	75 (39.3%)
Is stable	182 (95.3%)	3 (1.6%)
Is intubated and ventilated via an endotracheal tube	151 (79.1%)	34 (17.8%)
Is ventilated via a tracheostomy	167 (87.4%)	18 (9.4%)
Is receiving non-invasive ventilation	169 (88.5%)	16 (8.4%)
Is self-ventilating	180 (94.2%)	5 (2.6%)
Needs cardiovascular support i.e. inotropes	107 (56%)	78 (40.8%)
Relatives have a high level of emotional needs	143 (74.9%)	42 (22%)
Lives outside of local catchment area	149 (78%)	36 (18.8%)

References

Association for Children's Palliative Care. (2011) A Care Pathway to Support Extubation within a Children's Palliative Care Framework. 1st Edition. Bristol: ACT in England. ISBN 1 898447 14 4

Craig F, Mancini A. (2012) Can we truly offer a choice of place of death in neonatal palliative care? Seminars in Fetal and Neonatal Medicine.

<http://dx.doi.org/10.1016/j.siny.2012.10.008>

Coombs MA, Darlington A-SE, Long-Sutehall T, Richardson A. (2015) Transferring critically ill patients home to die: developing a clinical guidance document. Nursing in Critical Care. 20 (5): 264-270

Darlington A-SE, Long-Sutehall T, Richardson A, Coombs MA. (2015) A national survey exploring views and experience of health professionals about transferring patients from critical care home to die. Palliat Med. 29 (4): 363-370

Department of Health. (2005) Commissioning Children's and Young People's Palliative Care Services: A Practical Guide for Primary Care Trusts and Practiced-Based Commissioners. London: Department of Health.

Department of Health. (2007) Palliative Care Services for Children and Young People in England. London: Department of Health.

Garros D, Rosychuk RJ, Cox PN. (2003) Circumstances surrounding end of life in a pediatric intensive care unit. Pediatrics. 112 (5): 371-379

Goodenough B, Drew D, Higgins S et al. (2004) Bereavement outcomes for parents who lose a child to cancer: are place of death and sex of parent associated with differences in psychological functioning? *Psychooncology*. 13: 779-791

Hawdon JM, Williams S, Weindling AM. (1994) Withdrawal of neonatal intensive care in the home. *Arch Dis Child*. 71: 142-144

IMPACT. (2007) IMPACT: Standards for paediatric palliative care in Europe. *European Journal of Palliative Care*. 14 (3): 109-114

Laddie J, Craig F, Brierley J, Kelly P, Bluebond-Langner M. (2014) Withdrawal of ventilator support outside the intensive care unit: guidance for practice. *Arch Dis Child*. 99: 812-816

Lisle-Porter M, Podruchny AM. (2009) The dying neonate: Family-centred end-of-life care. *Neonatal Network*. 28 (2): 75- 83

Longden JV, Mayer A-P T. (2007) Family involvement in end-of-life care in a paediatric intensive care unit. *Nursing in Critical Care*. 12 (4): 181-187

Lusardi P, Jodka P, Stambovsky M, et al. (2011) The going home initiative: getting critical care patients home with hospice. *Crit Care Nurs*. 31: 46–57

McPherson ML, Jefferson LS, O'Brian Smith E, Sitler, GC, Graf JM. (2007) Reverse Transport of Children from a Tertiary Pediatric Hospital. *Air Medical Journal* (July-August); 183-187

Meert K, Sarnaik A. (2010) Choosing between death at home or in the hospital: Respecting the principle of autonomy. *Pediatr Crit Care Med.* 11: 438-439

Moore P, Kerridge I, Gillis J, Jacobs S, Isaacs J. (2008) Withdrawal and limitation of life-sustaining treatments in a paediatric intensive care unit and review of the literature. *Journal of Paediatrics and Child Health.* 44: 404-408

Needle JS. (2010) Home extubation by a pediatric critical care team: Providing a compassionate death outside the pediatric intensive care unit. *Pediatr Crit Care Med.* 11 (3): 402- 403

Nulty DD. (2008) The adequacy of response rates to online and paper surveys: what can be done? *Assessment & Evaluation in Higher Education.* 33 (3): 301-314

Oberender F, Tibballs J. (2011) Withdrawal of life-support in paediatric intensive care- a study of time intervals between discussion and death. *Pediatrics.* 11 (39)

PICANet. (2017) Annual Report. Paediatric Intensive Care Audit Network: University of Leeds

Ramnarayan P, Craig F, Petros A, Piec. (2007) Characteristics of deaths occurring in hospitalised children: changing trends. *J Med Ethics.* 33 (5): 255-260

Ramnarayan P, Thiru K, Parslow RC, Harrison DA, Draper ES, Rowan KM. (2010) Effect of specialist retrieval teams on outcomes in children admitted to paediatric intensive care units in England and Wales: a retrospective cohort study. *Lancet.* 376: 698-704

Siden H, Miller M, Straatman L, Omesi L, Tucker T, Collins JJ. (2008) A report on the location of death in paediatric palliative care between home, hospice and hospital. *Palliat Med.* 22: 831-834

Simpson EC, Penrose CV. (2011) Compassionate extubation in children at hospice and home. *International Journal of Palliative Nursing.* 17 (4): 164-169

Sprung CL, Cohen SL, Sjøkvist P et al. (2003) End-of-life practices in European intensive care units. The ETHICUS Study. *JAMA.* 290 : 790 – 7

Sturman J, Cassidy JV. (2006) End-of-life care in a paediatric critical care setting. *Current Anaesthesia and Critical Care.* 17: 271-275

Truog RD, Meyer EC, Burns J. (2006) Toward interventions to improve end-of-life care in the pediatric intensive care. *Crit Care Med.* 34 (11): S373-379

Zwerdling T, Hamann KC, Kon AA. (2006) Home pediatric compassionate extubation: bridging intensive care and palliative care. *American Journal of Hospital and Palliative Care.* 23 (3): 224-228

Supplemental Digital Content: Appendix One

Views

Respondents were asked to indicate to what extent they agreed or disagreed with the statements on a five-point Likert scale (1 = strongly disagree to 5 = strongly agree).

Statements:

- Transferring critically ill babies/children home to die is a good idea
- It is better for critically ill babies/children to die in NICU/PICU
- We would be able to organise the transfer home to enable a baby/child to die at home.
- It is important to offer good end of life care on the NICU/PICU rather than transfer babies/children home to die.
- NICU/PICU staff have more pressing clinical priorities than organising home transfers for dying babies/children.
- Taking critically ill babies/children home to die is a waste of health care resources.
- It is hard for NICU/PICU staff to handover the care of a dying baby/child to community services, who may not know the child.
- It would be better to transfer a baby/child to a hospice than to transfer them home to die.
- Parents and relatives have enough privacy to say goodbye in the NICU/PICU environment.
- It would be too distressing for the baby/child and family, to take them out of the familiar NICU/PICU environment.
- Patients will still receive the best possible care if they are transferred home to die.
- Critically ill babies/children should be transferred home to die if this is the wishes of the child and/or family
- It is unethical to prolong a baby/child's life so that they can be transferred home to die.
- Transferring critically ill babies/children home to die is not worth the risk of possibly dying in the ambulance on the way.
- Transferring critically ill babies/children home to die is not worth the risk of having a bad death at home.

Patient Characteristics

Respondents were asked to indicate whether they would consider transferring a patient home to die with the following characteristics. Respondents were forced to make a choice between 'yes' and 'no'.

Characteristics:

- Is unconscious
- Is conscious
- Is unstable
- Is stable
- Who is intubated and ventilated via an endotracheal tube
- Who is ventilated via a tracheostomy
- Who is receiving non-invasive ventilation
- Who is self-ventilating
- Who needs cardiovascular support i.e. inotropes
- Who relatives have a high level of emotional needs
- Who lives outside of local catchment area

Barriers

Section 5 asked respondents to rank barriers to transferring patients home to die, from 1 (most important) to 5, from a list of sixteen predetermined options:

- Lack of access to care in the community
- Lack of contact with patient's GP
- Unpredictability of time to death after withdrawal of treatment
- Lack of information about home environment, to ensure transfer can be achieved
- Lack of backup of staff in NICU/PICU
- Staff confidence
- Lack of backup ambulances to carry out the transfer

- Lack of time to organise the transfer home
- Patient's relatives unlikely to cope with the transfer and death at home
- Unrealistic expectations of relatives about death at home
- Unclear responsibility for care of the child during the transfer
- Unclear responsibility for care of the child after transfer
- Legal issues with transfer home are unclear
- Lack of guidelines on transferring patients from NICU/PICU to home
- Parental religious beliefs
- Ability to get a DNR signed

Supplemental Digital Content: Appendix Two

Responses to the Views about Transferring Critically ill Babies/Children Home to die, in Raw Numbers, Percentages, Means and SD

	1 Strongly disagree	2 Disagree	3 Neutral	4 Agree	5 Strongly agree	Mean	SD
Transferring critically ill babies/children home to die is a good idea	1 (0.5%)	0 (0%)	36 (18.8%)	79 (41.4%)	61 (31.9%)	4.12	0.77
It is better for critically ill babies/children to die in NICU/PICU.	28 (14.7%)	60 (31.4%)	82 (42.9%)	7 (3.7%)	0 (0%)	2.38	0.80
We would be able to organise the transfer home to enable a baby/child to die at home.	2 (1%)	10 (5.2%)	11 (5.8%)	103 (53.9%)	50 (26.2%)	4.07	0.82
It is important to offer good end of life care on the NICU/PICU rather	13 (6.8%)	64 (33.5%)	74 (38.7%)	19 (9.9%)	5 (2.6%)	2.65	0.88

than transfer babies/children home to die.							
NICU/PICU staff have more pressing clinical priorities than organising home transfers for dying babies/children.	64 (33.5%)	90 (47.1%)	15 (7.9%)	7 (3.7%)	1 (0.5%)	1.82	0.80
Taking critically ill babies/children home to die is a waste of health care resources.	93 (48.7%)	69 (36.1%)	12 (6.3%)	1 (0.5%)	2 (1%)	1.59	0.74
It is hard for NICU/PICU staff to handover the care of a dying baby/child to community services, who may not know the child.	16 (8.4%)	60 (31.4%)	16 (8.4%)	78 (40.8%)	7 (3.7%)	3.00	1.14
It would be better to transfer a	6 (3.1%)	60 (31.4%)	86 (45%)	20 (10.5%)	5 (2.6%)	2.76	0.80

baby/child to a hospice than to transfer them home to die.							
Parents and relatives have enough privacy to say goodbye in the NICU/PICU environment.	19 (9.9%)	64 (33.5%)	51 (26.7%)	41 (21.5%)	2 (1%)	2.68	0.98
It would be too distressing for the baby/child and family, to take them out of the familiar NICU/PICU environment.	27 (14.1%)	111 (58.1%)	37 (19.4%)	2 (1%)	0 (0%)	2.08	0.63
Patients will still receive the best possible care if they are transferred home to die.	3 (1.6%)	10 (5.2%)	62 (32.5%)	76 (39.8%)	26 (13.6%)	3.63	0.86
Critically ill babies/children	5 (2.6%)	6 (3.1%)	10 (5.3%)	58 (30.4%)	98 (51.3%)	4.34	0.94

<p>should be transferred home to die if this is the wishes of the child and/or family.</p>							
<p>It is unethical to prolong a baby/child's life so that they can be transferred home to die.</p>	<p>9 (4.7%)</p>	<p>67 (35.1%)</p>	<p>55 (28.8%)</p>	<p>36 (18.8%)</p>	<p>10 (5.2%)</p>	<p>2.84</p>	<p>0.99</p>
<p>Transferring critically ill babies/children home to die is not worth the risk of possibly dying in the ambulance on the way.</p>	<p>21 (11%)</p>	<p>109 (57.1%)</p>	<p>34 (17.8%)</p>	<p>13 (6.8%)</p>	<p>0 (%)</p>	<p>2.22</p>	<p>0.75</p>
<p>Transferring critically ill babies/children home to die is not worth the risk of</p>	<p>14 (7.3%)</p>	<p>100 (52.4%)</p>	<p>46 (24.1%)</p>	<p>17 (8.9%)</p>	<p>0 (%)</p>	<p>2.37</p>	<p>0.77</p>

having a bad death

at home.

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