

Home Extubation in a Neonate

Prakash Loganathan, MD,^{a,b} Judith Simpson, MD, MRCPCH,^a Paul Boutcher, MB, ChB, Dip Pall Med,^c Andrew Cooper, MRCPCH,^a Allan Jackson, MRCPCH,^{a,d} Rebecca J. Benson, MD, PhD^e

End-of-life care for many infants involves the withdrawal of mechanical ventilation. Usually this takes place in the hospital environment, but sometimes parents request that their infant dies at home. Facilitating this has significant practical and resource implications and raises both logistical and ethical questions. In this article, we report a neonatal case involving home extubation, explaining the processes involved as well as providing an ethical context.

abstract

Some infants are born with a life-limiting condition. In such cases, doctors usually offer palliative care as an option, and many parents choose to forego life-prolonging interventions. Sometimes, this decision is made prenatally or at birth. In other cases, life-prolonging interventions are offered until the diagnosis and prognosis become clear. At that point, the goals of care can shift toward palliation and symptom management. This shift in goals may necessitate compassionate extubation of the infant. Compassionate extubation is now common in NICUs and PICUs. It is less common for such extubation to occur at home, despite the fact that there are guidelines to assist health professionals and parents who choose to remove mechanical ventilation at home.¹ Sometimes, doctors or parents are uncomfortable with home extubation. In other cases, logistical problems make it difficult to provide compassionate extubation in the home setting. We present a case in which, at the parent's request, extubation occurred in the family home, allowing their infant to die in the environment of their choice.

THE CASE

Infant C.P. was born at term with a diagnosis of trisomy 13 complicated by gastroschisis, intestinal atresia, and

bowel perforation. The neonatal and surgical teams met with the family to explain the life-limiting nature of this condition. After these discussions, his parents were adamant that they wished to pursue active management rather than palliative care. Although C.P.'s life would be significantly foreshortened, the hope of taking him home for even a short time was important to them.

C.P. underwent a laparotomy with primary closure of gastroschisis, excision of atresia, and oversewing of an intestinal perforation on day 1 of life. It was not possible to restore bowel continuity during his surgery. This was achieved after a second planned laparotomy 6 weeks later. Unfortunately, he deteriorated after this procedure, and extensive perforated necrotizing enterocolitis was identified at a third laparotomy.

Once his parents understood that further surgery would be futile, they expressed a desire for his end-of-life care to take place at home. The relationship between the parents and clinical team had been challenging at times, but there was a consensus that facilitating the parents' wishes would aid their grieving process. Having not previously discharged a ventilated infant from the hospital for end-of-life care at home, there were concerns raised about not only the logistical

^aNational Health Service Greater Glasgow and Clyde, NICU, Royal Hospital for Children, Glasgow, Scotland; ^bNICU, University Hospital of North Tees, Stockton-on-Tees, United Kingdom; ^cChildren's Hospice Association of Scotland, Edinburgh, Scotland; ^dNeonatal Transport Service, Glasgow, Scotland; and ^eDivision of General Pediatrics and Adolescent Medicine, Stead Family Department of Pediatrics, University of Iowa, Iowa City, Iowa

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Address correspondence to Prakash Loganathan, MD, University Hospital of North Tees, Hardwick Rd, Hardwick, Stockton-On-Tees TS19 8PE, UK. E-mail: prakash.kannanloganathan@nth.nhs.uk

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and resource implications but also the legal and ethical complexities involved in achieving this.

ETHICS QUESTION

In infants with life-limiting conditions whose parents have expressed a strong desire for end-of-life management at home, is it ethical, feasible, and an appropriate use of resources to facilitate home extubation?

DRS LOGANATHAN, SIMPSON, BOUTCHER, COOPER, AND JACKSON COMMENT

Even with the best family-centered ethos, the neonatal unit is often not an ideal place in which to provide end-of-life care. Nevertheless, more than 98% of neonatal deaths occur in the hospital setting.² Palliative care in the home may provide positive memories to the bereaved parents and aid their subsequent grieving process. Nelson et al³ reported that parents who choose this option find that the experience brings both comfort and fulfillment. Inwald⁴ showed that providing choice about the place of end-of-life care provided parents with a degree of control over events at the end of the child's life and that this opportunity could make grieving easier.

Many parents make choices similar to those of the parents in this case. Janvier et al⁵ reported that, among parents of infants with trisomy 13 and 18, there is marked heterogeneity in decisions regarding life-sustaining treatment. The majority of the parents opted for comfort care, but 30% of parents opted for full intervention. Even when parents were told that the infant had a poor prognosis, 97% reported that they could communicate and understand the needs of their child. The parents also reported that the experience of caring for a critically ill infant

enriched their experience as a family, irrespective of the length of the infant's life. When the child died, parents considered the child's short life as valuable. As a result of such parental preferences, more doctors and hospitals offer life-sustaining interventions for infants with trisomy 13 and 18.⁶

There are pros and cons to various location options for neonatal end-of-life care.^{7,8} Some units have endeavored to create protocols and checklists to assist clinicians in providing the best possible care in transferring a child to home or hospice for compassionate extubation.^{9,10} There are also guidelines available that outline options through a framework to plan the care of home extubation.^{11,12} The Royal College of Paediatrics and Child Health has provided guidance to clarify situations involving removal of life-sustaining therapy and recognizes the importance of offering choice in place of the end-of-life care.¹³

Any discussion of transfer to home or hospice for compassionate extubation must acknowledge the fair and equitable use of the finite resources in neonatal or pediatric intensive care. If home hospice services are unavailable, then they cannot be offered, raising the question of resources allocation. It is difficult to know whether resources should be taken from intensive care budgets to ensure that we can provide high-quality palliative care. When services are available, offering a choice of place for the end-of-life care is not only about the best interest of the infant but also about supporting the family and/or parental preference.

Although there may be substantial financial and administrative obstacles to providing compassionate home extubation, a lack of ethical foundation is not one of them. It is always ethically appropriate to choose treatments that reduce

suffering for both the infant and the family.

A 2011 UK survey of neonatal palliative care showed that most units had infants discharged from the hospital and taken home for end-of-life care. The study did not say whether the infants were on ventilators at the time of discharge.¹⁴ There is often an assumption by neonatal staff that withdrawal of intensive care must happen in the hospital unit, and parents are not given the option of going home. The argument for in-hospital palliation includes ease of access to appropriate resources and continued family support from staff that they are familiar with. Not all parents would choose to take their infant home for extubation. For some, there are anxieties around the impact on siblings and fear that they will not be able to care for their infant. There is limited evidence for the withdrawal of ventilator support at home. A 10-year retrospective review of this practice in London identified only 5 children in whom it had been successfully achieved. This included both neonatal and pediatric cases, and the time from removal of ventilator support until death ranged from "immediate" to 5 days. There were no reported unanticipated complications.⁷

As neonatologists strive to improve survival with advances in intensive care, it is equally important to reflect on our palliative and/or end-of-life care. Cases like this should prompt us to explore all options for end-of-life care.

DR REBECCA BENSON COMMENTS

Whose welfare is improved by transporting an infant home so that the family can experience their child's death in familiar surroundings? Parents are asked to make decisions in the best interest of their child and also in accordance with their own values and

preferences. For many families, being able to bring their child home and have the family together, even if for a short period of time, is incredibly meaningful.

Time at home is meaningful for adults with a serious illness as well. Many adults with a serious illness say that they would prefer to die at home. It is unclear to what extent children and young people share that goal. There is little information available describing the preferred place of death for children and adolescents with a serious illness, especially in the form of self-report. Most of the data available are retrospectively reported by parents, and the data do suggest a preference for home in most studies.¹⁵ Most infants in the NICU have never been home, or have been home only for a short time. They cannot express their own preferences. The actual transport could be stressful for an infant, and death could occur en route. Ideally the same comfort medications and strategies could be administered in either setting.

Death for seriously ill infants in the NICU frequently occurs after withdrawing life-sustaining treatment and redirecting care to a comfort focus, either because the infant is clinically deteriorating despite treatment or because there is an anticipated poor outcome caused by a lack of treatment options or perceived quality of life.^{16–18}

In situations in which it is feasible to transport an infant on medical support and provide redirection of care in an out-of-hospital setting, the possibility of providing options for home end of life exists. Neonatal and pediatric palliative transport for end-of-life care has been reported, but is not standardized and may not be available in many settings.^{3,9} It can be costly and complex to transport an infant who is ventilated or dependent on other life-sustaining treatment. The transport vehicle, equipment, and personnel are highly specialized

and may be relatively scarce resources. If the transport team is engaged in a palliative transfer, the transport of other infants might be delayed. If the resources can be made available, the cost of a palliative transfer may not be covered by insurance. Some families may be able to pay for the transport themselves, but, if this option is deemed desirable, then health care systems should devise an equitable way to provide the opportunity to patients on the basis of medical qualification rather than the ability to pay.

The availability of a hospice to receive the patient and provide neonatal comfort care is another essential resource that must be considered. In some areas, there might not be access to a hospice that would be able to take on the care of a pediatric patient in a home setting or hospice house.

Considering all these factors, doctors may conclude that transporting an infant home for removal of life-sustaining treatment may feel like the right thing to do, but in a world of finite resources, the challenges of making it an accessible, effective, and equitable service may be too daunting.

The length of time an infant would be at home and the amount of awareness he or she would have of the environment is difficult to assess. In several studies, the time between the extubation and death of infants in a NICU setting was most often minutes to hours, although it could be variable, lasting up to days.^{16,17}

Traditional end-of-life care for infants may include holding, rocking, soft talking, and music, all of which the parents may find easier and more natural to do in the home setting. Although the welfare of the infant should take priority for the infant's care team, the well-being of the parents is also important. In situations in which the options for the infant are relatively neutral,

such as having comfort care in the hospital versus the home setting, a plan that allows parents to act on their preferences and values should be supported. There is evidence that parents whose child with cancer died in the hospital are more likely to meet criteria for complicated grief several years later than parents whose child died at home.¹⁹

If a health care professional truly feels that an infant might be harmed or have suboptimal care because of their condition and the options for care during transport and at home, they should make their concerns known to the family and team. However, overall, the goal of increasing the available resources to help families receive care in their preferred location at the end of life is one that we can ethically support when it helps provide the right care in the right place to the right patient at the right time. Systematic development and sharing of policies and protocols for palliative transport has begun and will help overcome barriers and allow more families to have the option of meaningful time at home at the end of life.¹⁹

OUTCOME OF THE CASE

We liaised with neonatal transport team, children's hospice service, community nursing team, and general practitioner (GP). We also conducted a risk assessment to ensure that the home environment was accessible and safe for the family and staff. We assessed the risk of fire if oxygen cylinders were present.

Before discharge, we circulated a clear and comprehensive clinical summary to all involved in the ongoing care of the child. A "Children and young people acute deterioration management" form was completed that outlined the care that would be provided in the event of an acute clinical deterioration in transit. A detailed plan was made for management at home, which included

procedures for symptom control, administration of medications, memory-making, the timing of extubation, and management after removal of ventilator support, including plans if death did not ensue quickly. Parents were engaged in all of these discussions. We discussed the need for postmortem, Procurator Fiscal referral, and notification to emergency services. We clarified who would be responsible for verifying death out of hours (eg, the GP, hospice staff, or out of hours service).

The neonatal transport team made specific arrangements for a dedicated team to be put together that would not have other clinical commitments on the day. The funding for the neonatal transport and their staff were provided by the Neonatal Transport Service (Scottish Transport Applications and Research).

The family was introduced to the hospice team before discharge and/or transfer. In the event of delayed death, hospice nursing staff would be able to manage symptoms by administering medications nasally or buccally (anticipatory prescribing) and also to verify death.

The transfer to home went smoothly. The infant was extubated in the mother's arms. After extubation, hand ventilation with oxygen was continued for a short period to facilitate family time, photographs, and memory making. Then, the team withdrew, allowing time and privacy for the family with their infant. The infant survived for a short time and then died peacefully with family nearby.

Finger, hand, and footprints were obtained for the family, and information was provided regarding bereavement support services. Chaplaincy services were involved to honor the family's religious traditions.

The GP and all relevant services were informed. Paperwork was completed,

including clinical notes and the death certificate. A staff debriefing was arranged by our clinical psychologist (within 1–2 weeks). At 6 weeks, we met with the family for bereavement counseling. At this meeting, the family expressed their gratitude for having had the opportunity to spend time with their infant at home; they greatly appreciated the team's support in facilitating this.

JOHN D. LANTOS, MD, COMMENTS

Some families who have chosen to withdraw life support for their infant prefer to have palliative extubation at home. It is feasible to do this, but it requires careful planning and close collaboration among many different services and professionals. When it can be successfully achieved, parents are generally grateful. If we only consider the needs of the patient and the family, such an approach is clearly ethically preferable to death in the hospital. The only ethical objection to such an approach to end-of-life care is concern about resource allocation. Much time and energy and many scarce resources must be deployed to make palliative extubation at home happen. Nevertheless, if the will is there and the resources are available, there is every reason to try to implement home extubation for families who choose that option. It illustrates an admirable commitment to family-centered care.

All of the cases in Ethics Rounds are based on real events. Some incorporate elements of a number of different cases in order to better highlight a specific ethical dilemma.

ABBREVIATION

GP: general practitioner

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