



HHS Public Access

Author manuscript

Pediatr Crit Care Med. Author manuscript; available in PMC 2018 January 01.

Published in final edited form as:

Pediatr Crit Care Med. 2017 January ; 18(1): e4–e8. doi:10.1097/PCC.0000000000000997.

Pediatric Critical Care Transport as a Conduit to Terminal Extubation at Home: A Case Series

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Abstract

Objective—To present our single-center’s experience with three palliative critical care transports home from the pediatric intensive care unit (PICU) for terminal extubation.

Design, Setting, Patients—All cases were identified from our institutional Pediatric Transport database. Patients in the case series were terminally ill children unable to separate from mechanical ventilation in the PICU, who were transported home between January 1, 2012 and December 31, 2014 for terminal extubation and end-of-life care according to their families’ wishes.

Interventions, Measurements, Main Results—The rate of palliative care transports home for terminal extubation during the study period was 2.6 per 100 deaths. The patients were 7 months, 6 years, and 18 years old and had complex chronic conditions. The transfer process was protocolized. The families were approached by the PICU staff during multidisciplinary goals-of-care meetings. Parental expectations were clarified and home hospice care was arranged pre-transfer. All transports were performed by our pediatric critical care transport team, and all terminal extubations were performed by physicians. All patients had unstable medical conditions and urgent needs for transport to comply with the families’ wishes for withdrawal of life-support and death at home. As such, all three cases presented similar logistical challenges, including establishing do-not-resuscitate status pre-transport, having limited time to organize the transport, and coordinating home palliative care services with available community resources.

Conclusions—Though a relatively infrequent practice in pediatric critical care, transport home for terminal extubation represents a feasible alternative for families seeking out-of-hospital end-of-life care for their critically ill technology-dependent children. Our single-center experience supports the need for development of formal programs for end-of-life critical care transports to

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Conflicts of Interest

For the remaining authors, none were declared.

include patient screening tools, palliative care home discharge algorithms, transport protocols, and resource utilization and cost analyses.

Keywords

critical care transport; palliative care; pediatric end-of-life; pediatric terminal extubation; death at home

INTRODUCTION

Despite an overall declining temporal trend in both pediatric mortality rates and in-hospital deaths, over 40,000 children aged 0 to 19 years die each year in the United States (1). Most die in a hospital intensive care unit (ICU) via withdrawal or limitation of life-support (2, 3). Twenty percent of all pediatric deaths involve children with complex chronic conditions, and these children commonly require prolonged hospitalizations with ICU level care and mechanical ventilation (4, 5). Death after terminal extubation outside of the hospital environment could represent a compassionate alternative for terminally and critically ill, technology-dependent ICU patients. However, pediatric palliative critical care transports from the ICU to home or hospice are an uncommonly described practice in the United States and, perhaps, an underutilized or underreported conduit to palliative care worldwide.

Our objectives were to 1) present a case series describing our single-center's experience with three palliative critical care transports home from the pediatric ICU (PICU) for terminal extubation and 2) review the existing literature regarding pediatric palliative critical care transports from the ICU for in-home terminal extubation.

METHODS

A chart review of cases from the Johns Hopkins Hospital Pediatric Transport database between January 1, 2012 and December 31, 2014 was conducted to identify terminally ill children and adolescents unable to separate from mechanical ventilation in the PICU, who were transported home by our pediatric critical care transport team for terminal extubation and end-of-life care according to their families' wishes. Johns Hopkins Pediatric Transport receives approximately 3,000 requests for transport yearly. Most transports are inbound calls. Less than 5% are reverse transports to rehabilitation centers, long-term care facilities, other acute care institutions, or home.

Demographic and clinical data were abstracted from the patients' individual medical records and included age, diagnoses, past medical history, plans of care following multidisciplinary meetings, details surrounding transport pre-planning, as well as clinical status, resuscitation limitations, and interventions performed the day of transport. Transport logistics were abstracted from the patients' transport documentation and included mode of transportation, team composition, interventions performed during transport, adverse events, details surrounding arrival at home, terminal extubation, transition of care to hospice, symptom control post-extubation and patient outcomes. Transport staff perspectives were elicited from interviews with the fellows who participated in the transports. Statistics pertaining to our annual PICU census and PICU mortality, as well as our annual pediatric transport call

volume, including total requests for transport and number of reverse transports, were obtained from the respective departmental databases.

RESULTS

The rate of palliative care transports home for terminal extubation was 2.6 per 100 deaths in our tertiary care PICU between January 1, 2012 and December 31, 2014. The three cases described in this series represented 0.03% of the requests for transport received by Pediatric Transport, and 0.7% of the number of reverse transports performed by the team during the study period. The patients were 7 months to 18 years old children with complex chronic conditions, who underwent a protocolized transfer home for terminal extubation.

Case Series

Patient 1—An 18-year-old male with relapsed T-cell acute lymphocytic leukemia after bone marrow transplant had been hospitalized in the PICU for several months. He was terminally ill with respiratory failure complicated by pulmonary hypertension, septic shock, gastrointestinal bleeding, renal failure, and hemolytic anemia. As curative interventions and therapies proved unsuccessful and death was imminent, the care team initiated end-of-life conversations with the family during multidisciplinary goals-of-care meetings. The family declined withdrawal of life support until the potential option of death at home was presented. Stating that dying at home would have been his wish, the family elected to pursue transport from ICU to home for terminal extubation.

After establishing do-not-resuscitate (DNR) status and securing home hospice care (with hospice staff to be on site at the patient's house upon his arrival home), the transport team coordinated a same-day transport due to concerns of impending cardiopulmonary arrest. Less than ten hours elapsed from the family's request to team dispatch. The patient was transported by ground by our pediatric critical care transport team, which included an emergency medical technician (EMT), paramedic, respiratory therapist (RT), two transport nurses, and a PICU fellow. Family followed behind the ambulance in a private vehicle, with one parent accompanying the team in the ambulance. The patient was maintained on sedative and analgesic infusions for comfort, mechanical ventilation with inhaled nitric oxide, and two high-dose vasoactive infusions during transport. Despite an initial period of hemodynamic instability, he was safely transported the 80 kilometers in 90 minutes.

Hundreds of family and friends lined the street outside the family's home to greet the ambulance and welcome the patient home. After a smooth transition into the first-floor living room, the transport team discontinued the transport monitor and vasoactive infusions. After extubation by the PICU fellow to nasal cannula, patient care was transferred to the hospice team, who ensured comfort via a narcotic infusion. The patient died peacefully 15 minutes later surrounded by his family.

Patient 2—A six-year-old male was hospitalized in the PICU with a history of prostatic rhabdomyosarcoma and acute myelogenous leukemia after bone marrow transplant. He had devastating neurologic injury following cardiac arrest and a brief period of extracorporeal

membrane oxygenator support. His family elected to pursue transport from PICU to home for withdrawal of life support.

Similar to Patient 1, DNR status was established pre-transport, as was coordination with home hospice. A same-day ground transport was performed by our pediatric critical care transport team, which included an EMT, paramedic, RT, transport nurse, and PICU fellow. The patient was maintained on sedative and analgesic infusions to optimize comfort en-route, and mechanically ventilated for the 50 kilometer transport, which was completed uneventfully in 75 minutes. Upon the patient's arrival home, the hospice nurse was on-site at the family's house. The transport team carried the child to his bed, where the transport monitor was discontinued. After the PICU fellow extubated him to room air, care was transitioned to the hospice nurse. He died later that day surrounded by family.

Patient 3—A seven-month-old female with spinal muscular atrophy type 1, shunted hydrocephalus, and chronic respiratory failure was admitted to the PICU after cardiopulmonary arrest at home. Owing to severe neurologic injury and previous home hospice care, her family elected to pursue transport from the PICU to home for terminal extubation and death.

Having met the prerequisites of DNR status and prearranged home hospice care, the patient was transported that same day by ground by our pediatric critical care transport team. Comfort en-route was achieved with sedative and analgesic infusions. She was maintained on mechanical ventilation during the 22 kilometer transport, which was completed in 90 minutes. The hospice team (including the pediatric hospice physician with whom the family had a long-standing relationship with) was on-site upon the patient's arrival home. Following an uneventful transition into the house, patient care was transferred to the hospice team, and the hospice physician extubated the infant. She died 15 minutes later in her mother's arms.

Perspectives from the Transport Team

The senior PICU fellows who were part of the transporting teams were invited to share their perspectives via open-ended interviews. Two of the three fellows responded, and they described initial apprehension towards the transport and sadness for the task at hand, but stated that they were able to find meaning in knowing they were helping fulfill the patients' and/or families' wishes at the end of life. They appreciated partnering with hospice professionals, as it allowed for a seamless transition of care in the patients' homes. Both fellows found the experiences to be positive and stated they would participate again.

“I had never met this family before, nor directly cared for their son. However, I was relieved after early introductions to hear his sister proclaim how excited [he] would be to finally “go home” and “be at home with his family.” ...Turning on to his home street was a sight unexpected; through social media [his] homecoming was announced as we left the hospital. Lining his home street were his scouting group, high school marching band playing the school's fight song, schoolmates, church members, and hundreds of others spilling onto the street and neighbors' yards. It was a true, joyous celebration. After parking in his driveway, the mood outside

turned calm and quiet, with a moment of silence as we carried [him] into his home. ...As we left the main house to allow the immediate family some time, [he] opened his eyes and was able to interact with his family. When his family mentioned they were ready, I returned with the transport nurse to perform the extubation, we said our condolences, and excused ourselves.” (Fellow for Patient 1)

“The experience was profoundly moving personally and professionally and was eased by knowing the patient had previously stated his wishes to die at home. The outpouring of support from his local community for his family solidified in my mind that this was the “right thing” to do for this family since we had that opportunity and ability to do so.” (Fellow for Patient 1)

DISCUSSION

All three pediatric palliative care transports from our PICU shared similar logistical challenges due to the patients’ unstable medical conditions and urgent needs for transport to comply with the families’ wishes for withdrawal of life-support and death at home. These logistics included clarifying resuscitation status pre-transport, organizing the transport expeditiously due to imminent death, and coordinating with available community resources for home palliative care.

When death was imminent, our medical team coordinated multidisciplinary goals-of-care meetings with the families to present the options of 1) compassionate withdrawal of life-sustaining therapies in the PICU itself or 2) going home from the PICU for terminal extubation and end-of-life care. Only one patient had preexistent involvement with hospice. Mode of transportation and team configuration were similar for all patients: each was transported by ground by our pediatric critical care team who maintained ICU-level cardiopulmonary support, pain control, and sedation for the duration of transport. Fellow participation in transport was consistent with internal guidelines, given patient acuity and anticipated need for critical care interventions or procedures. We considered it imperative that DNR status be confirmed, in advance, for the duration of the transport. Families were aware that there was a high risk of death during transport. However, in all cases they stated their strong preference that death at home was a priority, and if death were to occur during transport, that the transport would continue to the home. The safety of the family and transport team was of utmost importance, and it was agreed upon that the ambulance would not stop mid-transport if the patient’s condition worsened or death occurred en-route. Terminal extubation in the home was performed by the PICU fellow or the home hospice physician. Appropriate symptom management peri- and post-extubation was of paramount importance, as the main goal was to ensure patient comfort. All three patients died peacefully shortly after extubation, surrounded by their families. These palliative critical care transports from our PICU to home provided a compassionate and sensitive end-of-life care alternative for these terminally ill children and their families.

The pediatric literature on palliative critical care transports home consists of six reports. Of the 34 neonates and children with complex chronic conditions included, 21 were transported from ICU home for end-of-life care, 16 of whom died after terminal extubation outside of

the ICU setting (6–11) (Table 1). These neonatal and pediatric critical care transports were performed by either ground or air, generally with ‘clinical stability’ and home palliative care services or hospice referral as prerequisites for transfer. When reported, extubation was performed by the ICU physician or staff.

Laddie et al (7) reported the largest cohort of 15 children (11 from PICU, 4 from NICU) who died after terminal extubation outside of the ICU. They identified the importance of pre-planning, effective communication with families and team members, and early palliative care involvement. Institutional practice guidelines were developed to address the five phases of extubation outside of an ICU: introduction of withdrawal, preparation pre-transfer, extubation, care post-extubation, and care after death. Longden and Mayer (8) reported four children who were mechanically ventilated and transported by ground with a physician and nurse team. Two were transported home, one to hospice, and one to an adult hospital (for terminal extubation close to his parents, who were recovering from a motor vehicle accident). All died soon after extubation, and the PICU developed a booklet with relevant information for parents. Nelson et al (10) reported ten children who underwent palliative transports from the ICU over a nine year period, five of them for terminal extubation. A case series focusing on neonates described the air transport process from the NICU, with patient stability as a prerequisite for transport home (6). In the two included case reports, a 250 mile transport for terminal extubation was reported (9), as well as a transport where a 24 hour waiting time was necessary before transfer to home could be arranged (11).

The patients in our series underwent a protocolized transfer process home for terminal extubation and end-of-life care: families were approached by the PICU staff during multidisciplinary goals-of-care meetings; parental expectations were clarified and home hospice care was arranged pre-transfer; all transports were performed the same day by our pediatric critical care transport team; and all terminal extubations were performed by physicians.

A same-day transport becomes fundamentally important when the patient’s medical condition is unstable (thus, time is of the essence) and when the family has a strong emotional or cultural investment in the concept of “death at home.” Ideally, such decisions should never be rushed, and the multidisciplinary and palliative care meetings will succeed in gently guiding the family’s end-of-life decision-making process, so as to avoid time-sensitive transitions from PICU to home. However, our experience was that families only acknowledged their children’s dire medical conditions when death was imminent, and this sudden realization perhaps triggered their wish for death at home as the “only way” or the “right way” out of the ICU. From a practical standpoint, same-day pediatric critical care transports home for terminal extubation are often difficult to orchestrate, mainly due to the need to coordinate both transport resources and home hospice availability; as such, some palliative care programs mandate clinical stability (6), and a 24 hour waiting time as prerequisites for transfer (11).

There are reports in the literature describing unit-based critical care transport teams performing palliative critical care transports home, including performing the in-home terminal extubation, declaring death, and then spending some time with the family after the

patient's demise. A physician in England reported during a focus group interview that "we've washed the child, stayed for a cup of tea, stayed for lunch" (12). While this practice may help enhance family comfort, it may also lead to a protracted overall transport time, impacting the balance between the potential benefit to the patient and family versus the utilization of critical care resources and the cost of the transport. In contrast, our transport team's mission was to safely transport the patients home, transition them to the house, discontinue life-sustaining therapies (including performing the terminal extubation), and thereafter transition further care (including analgesia and sedation) to the home hospice staff who would then be responsible for ensuring patient comfort post-extubation and ultimately declaring death. Our palliative critical care transports home were therefore contingent upon securing home hospice care for the remainder of the patients' lives at home, with the predetermined plan that the hospice providers would be waiting for the patients to arrive home, so that hand-off from the transport team could occur in a timely fashion, and terminal extubation not be delayed.

Our case series and review of the pediatric literature demonstrate that palliative critical care transports for in-home terminal extubation are feasible and have positive value for the family and, in some cases, the child (particularly if transport home honors a dying wish). Although withdrawing or limiting life support can be emotionally and sometimes ethically challenging, clinicians have a duty to help provide an appropriate environment for death, support the parents in choosing a place of death for their child, and advocate for the patient's wishes. It is unknown how many ICUs offer parents the choice of place of death for their critically ill children, and the opportunity to withdraw life support outside the hospital environment. A study of 31 pediatric intensive care units in Great Britain concluded that children admitted to PICUs have a very low rate of discharge to palliative care (0.7%) (13). However, anecdotal and unpublished observations have suggested that home and hospice terminal extubations may not be uncommon in healthcare communities with strong palliative care services commitment and hospice involvement (12). Although performed in a protocolized fashion, home terminal extubations are currently a relatively infrequent practice in our PICU, hence the identified benefit of future formal program building in collaboration with the hospital palliative care team.

There are important limitations to our patient series. Whereas we obtained perspectives from two of the PICU fellows who participated in the transports, we did not formally solicit the perspectives of the rest of the PICU and transport staff or the parents regarding these palliative critical care transports home. However, the pediatric literature reports favorable critical care provider and familial views and experiences (10, 12).

Furthermore, we did not evaluate the cost-effectiveness of the three palliative critical care transports, or their impact on hospital and transport resource utilization. The families in our series were not billed for the cost of the transports, but we are unaware of any potential hospice charges they incurred. Given the current very low rate of palliative critical care transports relative to both the number of PICU deaths as well as the number of reverse transports, the impact on hospital or transport resource utilization is low. Nevertheless, in a case-control study comparing 25 children undergoing reverse transports with matched controls, McPherson et al (14) suggest an opportunity for third party payer reimbursement,

as well as a potential benefit by increasing intermediate care bed availability during times of high occupancy.

CONCLUSIONS

Palliative critical care transports for terminal extubation and end-of-life care at home pose a unique set of challenges in the pediatric population. Though a relatively infrequent practice reported in pediatric critical care, transport home for terminal extubation represents a feasible alternative for families seeking out-of-hospital end-of-life care for their critically ill technology-dependent children. Our single-center experience supports the need for development of formal programs for end-of-life critical care transports to include patient screening tools, palliative care home discharge algorithms, transport protocols, and resource utilization and cost analyses.

Acknowledgments

Sources of Funding: Dr. Kudchadkar was supported by the Johns Hopkins CTSA Award Number 5KL2RR025006 from the National Center for Advancing Translational Sciences of the National Institutes of Health.

We wish to thank Blair Anton for search strategy assistance and Claire Levine for editing the manuscript.

References

1. Child health. [Accessed November 6, 2015] 2013. <http://www.cdc.gov/nchs/fastats/child-health.htm>
2. NHPCO Facts and Figures. Pediatric Palliative and Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization; Sep. 2014
3. Meert KL, Keele L, Morrison W, et al. End-of-life practices among tertiary care PICUs in the United States: A multicenter study. *Pediatr Crit Care Med*. 2015; 16:e231–e238. [PubMed: 26335128]
4. Feudtner C, Christakis DA, Zimmerman FJ, et al. Characteristics of deaths occurring in children's hospitals: Implications for supportive care services. *Pediatrics*. 2002; 109:887–893. [PubMed: 11986451]
5. Feudtner C, Feinstein JA, Satchell M, et al. Shifting place of death among children with complex chronic conditions in the United States, 1989–2003. *JAMA*. 2007; 297:2725–2732. [PubMed: 17595273]
6. Hawdon JM, Williams S, Weindling AM. Withdrawal of neonatal intensive care in the home. *Arch Dis Child*. 1994; 71:F142–144. [PubMed: 7979471]
7. Laddie J, Craig F, Brierley J, et al. Withdrawal of ventilatory support outside the intensive care unit: Guidance for practice. *Arch Dis Child*. 2014; 99:812–816. [PubMed: 24951460]
8. Longden JV, Mayer AP. Family involvement in end-of-life care in a paediatric intensive care unit. *Nurs Crit Care*. 2007; 12:181–187. [PubMed: 17883599]
9. Needle JS. Home extubation by a pediatric critical care team: Providing a compassionate death outside the pediatric intensive care unit. *Pediatr Crit Care Med*. 2010; 11:401–403. [PubMed: 19838140]
10. Nelson H, Mott S, Kleinman ME, et al. Parents' experiences of pediatric palliative transports: A qualitative case series. *J Pain Symptom Manage*. 2015; 50:375–380. [PubMed: 25891665]
11. Zwerdling T, Hamann KC, Kon AA. Home pediatric compassionate extubation: Bridging intensive and palliative care. *Am J Hosp Palliat Care*. 2006; 23:224–228. [PubMed: 17060283]
12. Simpson CE, Penrose CV. Compassionate extubation in children at hospice and home. *Int J Palliat Nurs*. 2011; 17:164–169. [PubMed: 21537317]
13. Fraser LK, Fleming T, Miller M, et al. Palliative care discharge from paediatric intensive care units in Great Britain. *Palliat Med*. 2010; 24:608–615. [PubMed: 20233896]

14. McPherson ML, Jefferson LS, Smith EO, et al. Reverse transport of children from a tertiary pediatric hospital. *Air Med J.* 2007; 26:183–187. [PubMed: 17603946]

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TABLE 1
Literature Review: Pediatric Palliative Critical Care Transports from Intensive Care Unit to Home for Terminal Extubation

Authors, Year of Publication	Study Design	Study Population	Transport Logistics	Mechanical Ventilation During Transport	Hemodynamic Support During Transport	Transfer Destination	Outcome	Comments
Hawdon et al, 1994 (6)	Case series	3 neonates, NICU, Great Britain	Air transports; staff nurse +/- physician	Yes (2 of 3)	No	Home	2 of 3 died after terminal extubation	Stability as transfer prerequisite
Laddie et al, 2014 (7)	Retrospective cohort	15 children, PICU (11), NICU (4), Great Britain (2003–2012)	Ground transports; 2 ICU staff members (physician + nurse, or 2 nurses)	Yes	Yes (some)	Home (5) Hospice (8) Other (2)	All died after terminal extubation within 5 days	Practice guidelines: 5 phases of extubation outside the ICU setting
Longden and Mayer, 2007 (8)	Case series	4 children, PICU, Great Britain (12 months)	Ground transports; 2 ICU staff members (physician + nurse)	Yes	Yes (2 of 4)	Home (2) Hospice (1) Adult hospital (1)	All died soon after terminal extubation	PICU booklet with relevant information for parents
Needle, 2010 (9)	Case report	1 infant, PICU, US	250 mile medical transport; RT and physician	Yes	No	Home	Died after terminal extubation	Home extubation by PICU staff
Nelson et al, 2015 (10)	Case series	10 children, PICU, US (2005–2013)	Ground transports	Yes (5 of 10)	Unknown	Home (9) Hospice (1)	6 (60%) died soon after transfer, 4 (40%) survived for 4–40 days	All parents recommended palliative transports during open-ended interviews
Zwerdling et al, 2006 (11)	Case report	1 infant, PICU, US	Pediatric critical care ground transport	Yes	No	Home	Died after terminal extubation	24 hour waiting time before home discharge

Abbreviations: ICU, intensive care unit; NICU, neonatal intensive care unit; PICU, pediatric intensive care unit; RT, respiratory therapist