12th Annual
Quality & Patient Experience
SHARING DAY

Pediatric Compassionate Extubation and Ventilator Discontinuation at Home

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Introduction

- The Pediatric Intensive Care Unit (PICU) at Atrium Health Wake Forest Baptist (AHWFB) provides end-of-life (EOL) care for >20 children annually.
- At AHWFB PICU:
  - 90% of deaths in the past 4 years were anticipated
  - 74% of deaths since 2018 have involved compassionate extubation or discontinuation of ventilator support consistent with EOL care in other PICUs in the U.S.[1]
- Compassionate extubation or discontinuation of mechanical ventilation is an option for children with serious illness in the PICU; prior to 2020, this was offered only in the hospital
- Since 2020, we offered *compassionate extubation or ventilator discontinuation at home (CEVAH)* for 2 children cared for at AFWB PICU.
- Based on our experience, we created **a process, framework**, and checklist for CEVAH for seriously ill children.

Description of Cases

CHILD "Henry" (February 2020)

- 12 year old, "Henry," with Gaucher disease was admitted with refractory seizures and respiratory failure requiring intubation.
- Multiple extubation attempts over a protracted PICU course were unsuccessful.
- **Decision-making**: Henry's mother did not think tracheostomy would improve his quality of life; requested compassionate extubation.
- **Parental wishes**: Because of prior difficult experience with the death of Henry's sibling (also w/ Gaucher) in the hospital, his mother did not want Henry to die in the hospital.
- **CEVAH at home**: The PICU team safely returned Henry to his bed which overlooked his horse pasture on their small farm with extended family present. He was extubated, and was provided with uninterrupted comfort measures through handoff to the hospice team. He died peacefully later that evening.

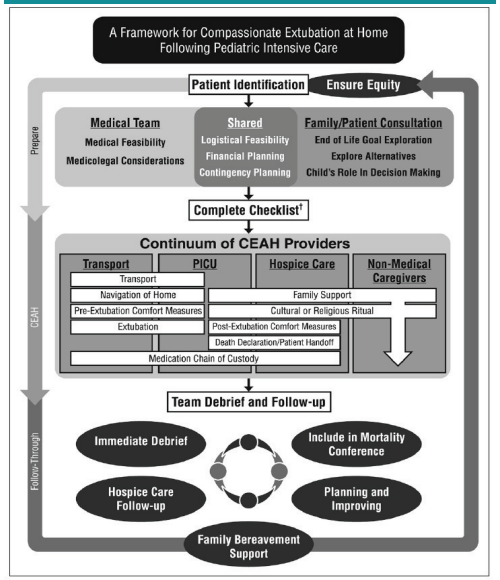
CHILD "Paige" (January 2022)

- "Paige" was a 2 year old girl with holoprosencephaly and tracheostomy was admitted to the PICU with acute respiratory failure due to SARS-COV-2 pneumonia.
- **Decision-making**: When she failed to separate from the ventilator, her family felt that chronic ventilatory support would not provide her with adequate quality of life.
- **Parental wishes**: Her parents wished to take Paige back home with a focus on comfort care.
- **CEVAH at home**: With extended family presence, Paige was removed from the ventilator in her "napping spot," a comfortable beanbag chair under a large family portrait photo featuring "Paige" with a beaming smile. She received uninterrupted comfort measures from the PICU team with subsequent handoff to the hospice team. She died peacefully a few hours later.

Project Goals

- To provide compassionate and family-centered EOL care at home for children with serious illnesses requiring withdrawal of mechanical ventilation.

Framework & Checklist



Checklist for Pediatric Intensive Care Led Compassionate Extubation at Home

Alternatives
- ❑ Organ and Tissue donation considered and ruled out
- ❑ Alternatives discussed with family and ruled out

Clearance
- ❑ Hospital Risk Management
- ❑ ICU Medical Director

Team
- ❑ Consult Case Management
- ❑ Consult Palliative Care and Child Life
- ❑ Meet with hospice agency about home care
- ❑ Arrange hospital or private transport service

Legacy-Making
- ❑ Coordination with pediatric bereavement team
- ❑ Legacy-making activities

Home Durable Equipment
- ❑ Portable Suction
- ❑ Oxygen with calculated supply
- ❑ +/- Feeding pump
- ❑ +/- IV pump(s)
- ❑ +/- Appropriate bed
- ❑ Assure existing home equipment is in working order

Access
- ❑ +/- Subcutaneous or intravenous access needs
- ❑ +/- Enteral tube needs
- ❑ Backup plan and supplies if access lost

Medications
- ❑ Review discharge medication list
- ❑ Adequate concentration, doses, and amount for transport and in home
- ❑ Discuss timing of transfer of responsibility to hospice
- ❑ +/- Home hospice or local pharmacy home delivery

Transportation
- ❑ Ambulance Service
- ❑ Transport ventilator
- ❑ ICU personnel time at bedside discussed with hospice and transport teams
- ❑ Accessibility (e.g. stairs, doorways)
- ❑ Safety considerations (pets, smoking, drugs, social concerns)
- ❑ Bed and patient positioning
- ❑ Resuscitation limitations during transport discussed
- ❑ Finalize maximal ambulance services time at bedside to assure return transport for ICU personnel or alternative return transport.

Personnel
- ❑ Paramedic on transport
- ❑ Hospice providers to meet at home and timing confirmed
- ❑ ICU physician
- ❑ +/- ICU nurse
- ❑ Post-extubation handover planning
- ❑ Non-medical family support/ chaplain

Additional Supplies
- ❑ Gloves
- ❑ 5 mL syringe (for cuffed tubes)
- ❑ Cleaning wipes
- ❑ Absorbent underpads
- ❑ +/- Pulse oximetry
- ❑ +/- Gauze and tape
- ❑ Appropriate Personal Protective Equipment

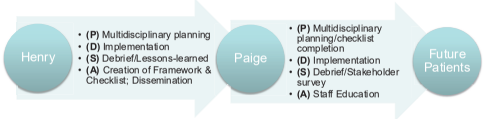
Paperwork
- ❑ Discharge documents
- ❑ Prescriptions
- ❑ +/- Scope of treatment order(s)
- ❑ +/- Do Not Resuscitate orders
- ❑ +/- Approval letter from risk management
- ❑ Responsibility for death verification and certification discussed. +/- Documents available.
- ❑ +/- Post-mortem examination orders

Contingency Planning
- ❑ Discuss conceivable outcomes including prolonged terminal phase or survival
- ❑ Assigned plan for ICU or enhanced care phone follow-up with family and home hospice providers

Plan for follow-up
- ❑ After-action debriefing and support with all providers
- ❑ Plan for ongoing emotional support of patient's family

Figure 1. Following the planning and provision of CEVAH for Henry, this framework (a) and checklist (b) were created to facilitate provision of future CEVAH. These were adapted for provision of CEVAH for Paige. Since a framework for CEVAH was not previously reported, these were also disseminated to the international PICU community through publication in PCCM.[3]

Improvement Process



Process Evaluation

Table 1. Learnings from CEVAH Implementation.

Domain	Lessons Learned
Engagement of teammates	- Engage medical and nursing leadership to navigate organizational issues -Involve all stakeholders who could help with the CEVAH process (i.e. bedside nurses, primary-care and specialist providers) early - Check with Risk Management when delivering care outside of state [C01]
Memory making	- Coordinate with bereavement program early on for memory making - Know that hospice is a resource for families for memory-making
Medications	- Develop a plan for transitioning long-term medications from hospital to home [C01] - Communicate with hospice about IV access and medications used at EOL [C02] - Negotiate with hospice, the plan for medication administration at the EOL - Have a clear process about documentation of medication used at the EOL at home [C02] - Discuss with pharmacy about how to report medication waste [C02]
Preparation of family	- Prepare family about hospice services including ongoing bereavement support - Prepare family for logistic difficulties with CEVAH and delay in implementation - Prepare family about possible trajectories (e.g. child surviving post CEVAH) - Prepare extended family at home about CEVAH and what to expect
Communication with other teammates	- Involve hospice early to build rapport with the family [C02] - Have a systematic nursing hand-off from hospital-based nurses (PICU or palliative care) to hospice nurses - Have a systematic social work hand-off from hospital-based social worker to hospice social worker [C02] - Have hospital pharmacist discuss with hospice team about concentration of medications child was on [C01]
Logistics	- Consider the PICU team visiting the home prior to CEVAH to understand logistic challenges (e.g. narrow hallway etc.), safety concerns, number of people at home - Plan for secondary mode of transport for the physician in order to not depend on the transport team

Participant Feedback

- Solicited feedback using a survey of 24 CEVAH participants
- **Roles**: 13 Physicians or APPs, 9 Nurses, 1 Social Worker, 1 Pharmacist.
- **Location of Practice**: 16 from AHWFB, 7 from Mountain Valley Hospice, 1 Primary-care Pediatrician

Table 2. Perceived Benefits and Concerns of CEVAH

Perceived Benefits (% of respondents selecting)
Helps meet the needs of child and family (96%)
Better quality of care for children (88%)
Avoid end-of-life care in the PICU (75%)
Reduce hospital death rate (46%)
Reduce length of stay (42%)
Perceived Concerns (% of respondents selecting)
Logistic difficulty (50%)
Legal liability (29%)
Lack of resources (29%)
Not getting reimbursed (17%)
Lack of time (17%)
Not being able to control symptoms (17%)
Lack of support (13%)
Lack of expertise (13%)

Qualitative Feedback

Child Centered Care:

"Providing end-of-life care to Henry at home enabled him to spend the last day of his life in the place that he loved the most."

"With this work, we have demonstrated that we are well equipped to keep these children comfortable outside of the ICU"

Family Satisfaction:

"Mom's concerns, fears and questions were appropriately answered."

"The family's desires and goals for the patient were really honored and listened to throughout the planning process".

"Spoke to mother the same morning before CEVAH. She was at peace with plan and grateful about team's involvement."

"Having this little girl come home has meant the world to the family."

Provider Engagement and Satisfaction:

"Overall, very rewarding especially given that the goal was met in a positive manner"

"Because of excellent teamwork, we were able to find solutions and smooth things out"

"Much easier the second time due to previous framework able to be used/adapted and similar providers involved."

"A model process for excellent collaboration both within hospital and with community resources".

Discussion

- We created an innovative model of care delivery for children at the end-of-life that is child- and family-centered and is aligned with Atrium Health's Touchstone goals of **improving the patient and family experience.**
- We have **created tools with which to guide future CEVAH** and to disseminate to outside pediatric and neonatal ICUs who may want to provide this service.[3]
- This work was published in a leading international pediatric critical care journal as a **"Feature Article" and is in the top 5% of all research scored by Altmetrics for views and sharing**.
- Providers perceive CEVAH **as an improvement over the end-of-life care that can be offered in the hospital** for some children.
- Future work will include continuing to improve the systematic processes and additional education for staff and providers.

Resources

1. Burns JP, Sellers DE, Meyer EC, et al.: Epidemiology of death in the PICU at five U.S. teaching hospitals*. Crit Care Med 2014; 42:2101–2108
2. 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 May;11(3):401-3.
3. Woodruff AG, Bingham SB, Jarrah RJ, Bass AL, Nageswaran S. A Framework for Pediatric Intensivists Providing Compassionate Extubation at Home. Pediatr Crit Care Med. 2021 May 1;22(5):454-461.
4. Brierley J. There's No Place Like Home. Pediatr Crit Care Med. 2021 May 1;22(5):504-506.
5. Noje C, Barnier ML, Costablile PM, Klein BL, Kudchadkar SR. Pediatric Critical Care Transport as a Conduit to Terminal Extubation at Home: A Case Series. Pediatr Crit Care Med. 2017 Jan;18(1):e4-e8.

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