A Team Approach to Compassionate Extubation in the Home

MAYO CLINIC

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Abstract

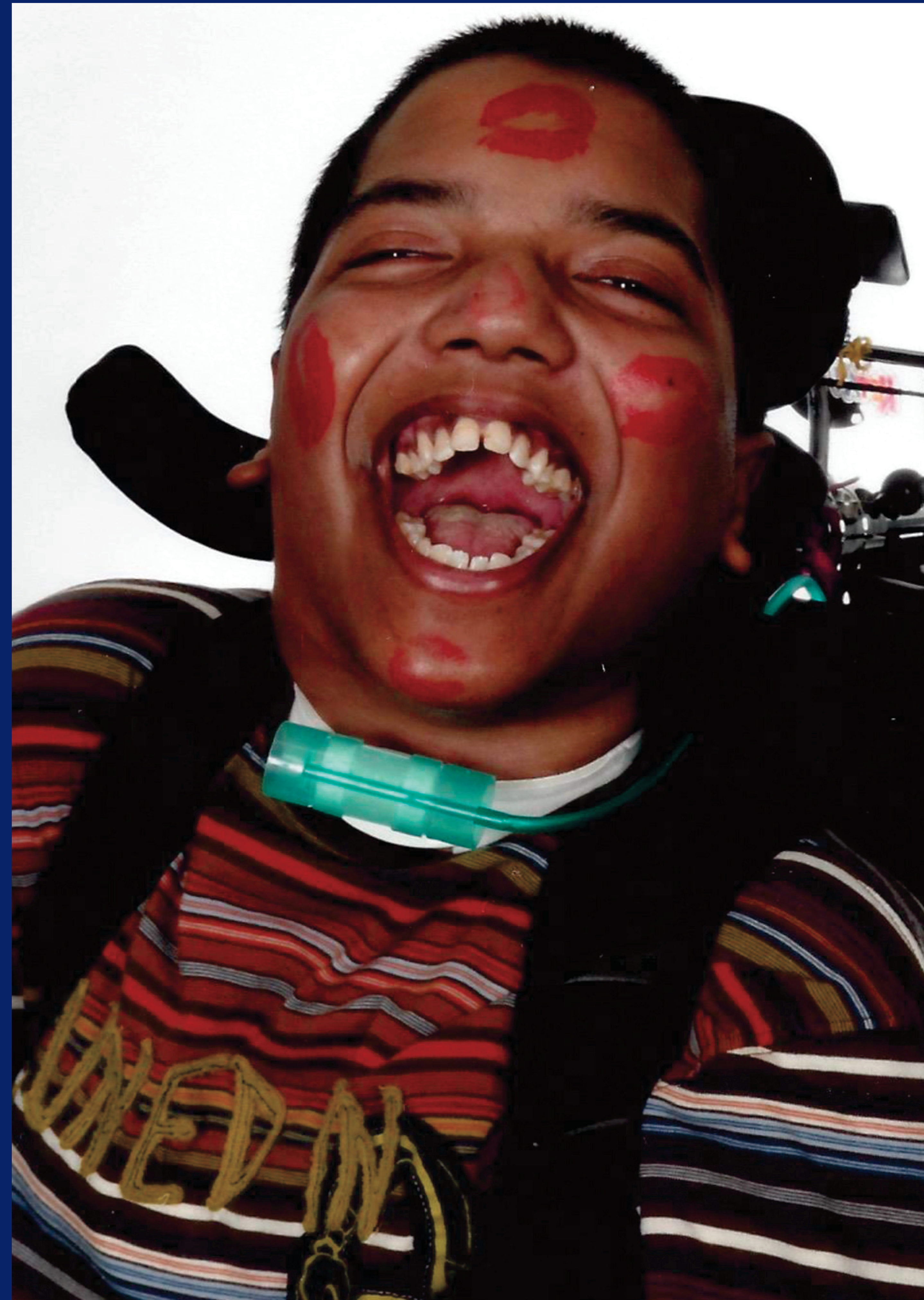
The integration of palliative care into the home, which would otherwise be performed in the hospital, empowers patients and families by allowing for more choices when facing difficult end of life decisions. Compassionate extubation, also known as palliative extubation, is the withdrawal of mechanical ventilation. This is performed to alleviate suffering while avoiding the prolongation of death. Compassionate extubation in a non-ICU setting requires seamless collaboration amongst the interdisciplinary team. The logistics of such a process generally requires an inpatient setting. In the case of a 28 year old patient with cerebral palsy, multiple medical complications resulted in ventilator dependence and a subsequent decline in quality of life, ultimately prompting hospice enrollment. Discussion surrounding end-of-life issues, particularly involving the withdrawal of mechanical ventilation, can be especially difficult if the patient's family are in unfamiliar surroundings. In an effort to meet his mother's goal for compassionate extubation at home, the Mayo Clinic Hospice team formulated a new procedural guideline to facilitate the process. Through collaboration of the interdisciplinary team, the patient was removed from mechanical ventilation and died peacefully at home surrounded by his family. This outcome resulted in an high level of satisfaction for the patient's family and helped bring them peace as they began their journey through grieving the loss of their loved one.

The Patient

- Adopted from an orphanage in India as an infant
- Past history: tetraplegic cerebral palsy with multiple ongoing medical complications
- Non-verbal, but led an active, joyful life thanks to his family
- Enjoyed outings, holiday gatherings and watching movies.
- Repeated hospitalizations and eventual ventilator dependence led to diminished quality of life
- Hospitalization was distressing for him and led to increased agitation
- Mother opted to shift goals of care to focus on comfort at home and enrolled him in hospice

Literature Review

- When compared to families of terminally ill children that die in the hospital, families of children who die at home have an improved grieving process before, during and after the death of their child and these families have more positive adjustment patterns, improved social reorientation and reduced feelings of guilt (Zwerdling, 2006).
- Privacy, adequate space and the opportunity to freely access and care for their child are of paramount importance during end of life care. The ability for parents to care for themselves is also paramount and this can be better achieved in the home setting (Meert et al., 2008).



"I prayed for probably over a year that when his time came, he could die at home in his own bed and wouldn't be alone and I'd be by his side. My prayer was answered with all of the hard work and dedication of all of the staff on the hospice team."

-Mother

Collaboration and Planning

- Met with mother to discuss expectations, benefits and feasibility of compassionate extubation at home
- Continued support and education for family regarding end of life symptoms and when would be the "right" time to withdraw support
- Agreement in place with ICU in case of emergency that could not be managed at home
- Met with team and mother the week prior to the planned extubation to discuss roles
- Necessary medications, supplies and equipment delivered to the home
- Team members in home at time of withdrawal
- 24/7 care from hospice staff for the first 48 hours after the extubation, daily visits thereafter
- Died peacefully surrounded by his family 5 days after the ventilator was withdrawn
- Hospice bereavement staff will follow family for 13 months

Procedural Guideline

- Procedure never before completed by the Mayo Clinic Hospice team
- Procedural guideline created with input from the interdisciplinary team to guide practice
- Detailed plans for symptom management created in preparation for the procedure using the procedural guideline as an initial guide

Conclusions

- Family reports high satisfaction with completion of the extubation in the home because the patient was able to remain in a peaceful, familiar environment.
- Family feels that remaining at home has been very beneficial for the grieving process for the entire family.
- Team debriefing completed to refine processes and provide support for the team members.

References

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2. Meert, K.L., Donaldson, A.E., Newth, C.J, et al. (2010). Complications of grief and associated risk factors among parents following a child's death in the pediatric intensive care unit. Archives of Pediatric and Adolescent Medicine, 164(11), 1045-51.

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