

How parents discuss dying with their child with a life-limiting illness who requires long-term ventilation.

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Introduction

Children with life-limiting illnesses who require long-term ventilation are living longer and are living more active lives than ever before. However, the trajectory of uncertainty surrounding their illness or condition creates situations not typically found in the pediatric setting. Parents must consider when and if to discuss dying with their child, a topic that is extremely distressful to all involved.

Discussions are often left up to physicians, because families do not want to be viewed as having given up on their child. In many cases though, the children are already aware of the nature of the illness and choose not to ask questions of the parents to avoid upsetting them. Parents also have a fear of upsetting the child, so opportunities for crucial conversations are lost.

Ensuring that children with a life limiting illness who require long-term ventilation have an understanding about what is happening to them is something that should be discussed with any child who is able to understand, but there is a paucity in the literature regarding how and when to discuss dying with the child and family.



Objectives

1. Describe the ethical issues surrounding palliative care in children with life-limiting illness requiring long-term ventilation and their families.
2. Explain the importance of discussing dying with children with a life-limiting illness requiring long-term ventilation.

Ethical Considerations

Palliative care in children with a life-limiting illness who require long-term ventilation is focused on providing quality time for the child for as long as possible. Some of the ethical issues surrounding these children include: the use of analgesia, professional boundaries, and how best to manage the child who is dying (Feudtner, & Nathanson, 2014; Jankowski, 2013; Weidner & Plantz, 2014).

Deciding when enough is enough. How and when is the decision to remove ventilator support made? Long-term ventilation itself is an ethical issues. Making the decision to place a child on home ventilation is a difficult decision, but it is often a quality of life issue. Many considerations go into this decision such as who will care for the child at home, what kinds of support systems are in place to assist the family, who will assume medical care of the child in the home, and how long will the child be able to live at home (Dybwik, Nielsen, & Brinchmann, 2012). Discussions about future resuscitation efforts can be difficult for the child and family. However, this is a difficult decision to make on the spur of the moment. Discussing plans ahead of time helps ensure that the input of the child and family are considered and that procedures will be carried out per their specifications.

In their 2012 study exploring how best to discuss advanced care planning with this population, Edwards, Kun, Graham, & Keene reported that none of the children had ventilator support withdrawn as part of their end-of-life care; however, 21 children with a poor chance of survival had received orders to waive or limit extraordinary measures such as cardiopulmonary resuscitation or other life-saving measures. In three of the cases, families had elected to withdraw inotropic medications after the child suffered a severe near-death event.

For parents with a child with a life-limiting illness who requires long-term ventilation, there are many hard questions. End-of-life issues are no different. Parents need the assistance of trained healthcare providers, such as a palliative care team, to help them in facing these issues and discussing them with the child.

Critical Points of Discussion

When do these discussions typically occur?

- When there is a change in the child's condition
- The child survives a near death event
- The child starts asking questions

Who initiates the conversation?

- Physician
- Parents
- Child

What types of things are discussed?

- The child's wishes
- Does the child want to leave a legacy?
- What is it like to die?
- What happens when we die?

Advanced Care Planning

As families begin to think about the future life of their child with life-limiting illness who requires long term ventilation, discussions for advance care planning need to begin. Very often such discussions are precipitated by a change in status, leaving families little time to make big decisions (Edwards, Kun, Graham, & Keene, 2012). Advanced care planning for children with a life-limiting illness who require long term mechanical ventilation includes involving the child in the decision-making processes about end-of-life care in spite of the use of chronic ventilation (Edwards, Kun, Graham, & Keens,). Most children who require long-term ventilation have at least a few unexpected hospitalizations, intensive care stays, or cardiopulmonary arrests during the course of their illness.

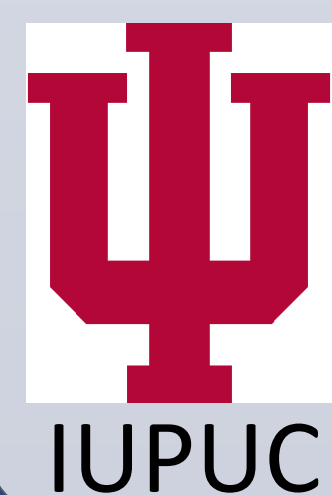
There are very few articles that explore how parents discuss dying with their child with a life-threatening illness. One 2004 article (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck) explored whether or not parents should talk about death with their child with a terminal malignancy. A total of 44 of an eligible 561 parents participated in the study. Of those, 146 parents discussed death with their child and none had regrets about doing so. Of the 258 parents who chose not to discuss death with their child, 69 (27%) regretted never having talked with their child about dying. There was no discussion about how and when to broach the subject of dying with the child or arguments provided for not speaking with the child, the study did open the door for future research in this area.

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Disclosure

I am the parent of a child with a life-limiting illness who requires long-term ventilation. This is a situation that we have faced and have discussed at length. As research often comes out of necessity, I am currently conducting research about why parents choose or choose not to talk with their child about dying.



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