What about Ventilators and "Pulling the Plug"?

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When I first became a registered nurse in 1969, ICUs (intensive care units) were still new. The first one I worked was set up in the former visitors' lounge and we learned how to read EKGs (heart tracings) by using a book.

By the early 1970s, I worked in a surgical/trauma ICU where we used sophisticated ventilators like the MA-1. We were able to get almost all our patients off ventilators by weaning, the process of gradually lowering ventilator support until the patient can breathe on his or her own.

But in 1976, I was shocked by the Karen Quinlan case that changed everything.

Karen was a 21 year old woman who suffered brain damage after apparently taking drugs at a party. She was hospitalized and placed on a ventilator. When she was thought to be in a "persistent vegetative state", her adoptive parents asked that her ventilator be removed. The doctors disagreed and they case eventually went to the New Jersey Supreme court that allowed the removal of the ventilator on the grounds of an individual's right to privacy. Shortly afterward, California passed the first "living will" to refuse "life support" if or when the signer is incapacitated.

Ironically, Karen lived 10 more years because, as some ethicists criticized, she was weaned off the ventilator instead of just abruptly stopping the ventilator.

My experience with ventilators became personal in 1983 when my baby daughter Karen died on a ventilator before she could get open-heart surgery. Unfortunately, one young doctor earlier offered to take her off the ventilator to "get this over with". I reported him to the chief of cardiology who was furious with the young doctor.

In the 1990s, I returned to working in an ICU and was shocked by the development of the "terminal wean" for some patients on ventilators. Often the families were told that there was no hope of a "meaningful" life. The terminal wean involved abruptly disconnecting the ventilator and "allowing" the patient to die. I brought up at least trying regular, gradual weaning and oxygen as we did for the other patients on ventilators but I was ignored.

After I retired from bedside nursing, I was asked to be with an elderly man on a ventilator who had had a massive stroke and the family was told that he would never have any quality of life and would die soon anyway. I tried to bring up weaning but some members of the family were adamant.

When the ventilator was stopped. I held the man's hand and prayed while he gasped for air and turned blue. I asked the nurse to at least giving him oxygen for comfort but she ignored me. Instead, she gave frequent doses of morphine intravenously until the man's heart finally stopped after 20 minutes.

I still haunted by this man's death.

INFORMED CONSENT?

The medical definition of informed consent requires understanding "the purpose, benefits, and potential risks of a medical or surgical intervention…".

But most people seem to have a vague understanding of ventilators when they sign a "living will" or other advance directives and thus have very little information about this often life-saving medical intervention.

As a nurse, I found that most people-especially the elderly-tend to automatically check off ventilators without understanding that a sudden problem with breathing can come from a number of treatable conditions that don't require long-term use of a ventilator such as asthma, drug overdoses, pneumonia and some brain injuries.

In some circumstances such as certain spinal cord injuries and late-stage neurodegenerative diseases like amyotrophic lateral sclerosis, the ventilator is necessary long-term to live. But even then, people like Christopher Reeve and Stephen Hawking have used portable ventilators to continue with their lives. Some people with disabilities use small ventilators only at night.

It is important to know that ventilators move air in and out of the lungs but do not cause respiration-the exchange of oxygen and carbon dioxide that occurs in lungs and body tissues. Respiration can occur only when the body's respiratory and circulatory systems are otherwise intact. A ventilator cannot keep a corpse alive.

It's also important to know that not all machines that assist breathing require the insertion of a tube into the windpipe. Non-invasive positive-pressure ventilation like the BiPap successfully used for my elderly friend Melissa allowed her to use a face mask to assist her breathing until antibiotics cured her pneumonia.

WEANING FROM A VENTILATOR

Many patients are easy to wean from a ventilator but some patients are more difficult.

Years ago, I cared for an elderly woman with Alzheimer's who needed a ventilator when she developed pneumonia. She had made her son and daughter her medical decision makers in her advance directive.

However, the doctors found it very difficult to try to wean the ventilator after the woman improved. They spoke to the family about removing the ventilator and letting her die. The daughter agreed but the son was adamantly against this.

The woman was totally awake after the sedation to keep her comfortable on the ventilator was stopped. She was cooperative and made no effort to pull out the tube in her windpipe. She just smiled when asked if she wanted the ventilator stopped.

Having known of some great respiratory therapists in the past who were able to successfully wean difficult patients from ventilators, I suggested that she be transferred. She was transferred and a week later we were told that she was successfully weaned from her ventilator.

About a year later, I encountered the woman again when she was recuperating after a routine surgery. Although her Alzheimer's disease was unchanged, she was doing well in an assisted living residence.

CONCLUSION

As a student nurse, I was as initially intimidated by ventilators as anyone else. But as I learned how to use them and saw the constant improvements not only in the technology but also in our care of patients on ventilators, I came to see ventilators as a great blessing when needed.

And while we are never required to accept treatment that is medically futile or excessively burdensome to us, sometimes this can be hard to determine in a crisis situation. Most of my patients on ventilators recovered but some could not be saved. We were surprised and humbled when some patients with a poor prognosis recovered while others who seemed to have a better chance died unexpectedly. There are no guarantees in life or death.

That is why my husband and I wrote our advance directives that designate each other as our decision maker with the right to have all current options, risk and benefits of treatment fully explained.

We don't want an advance directive that could be hazardous to our health!