# Reflections of a critical care nurse regarding termination of life-sustaining support

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## SUMMARY

- Prolongation of life is expected nowadays because of advances in technology and medical treatment. This paper presents a case study based discussion around the ethics of withdrawal of life support.
- Death of a child is often regarded as the most painful, stressful, and enduring bereavement experience.
- If life-sustaining support causes more harm than benefit for the patient, then healthcare professionals may be justified in suggesting the withholding or withdrawal of treatment.
- The best ways that healthcare professionals can support a grieving family are by offering a non-judgmental, deep sense of caring and personal involvement.
- In order to provide high-quality care to patients and their families during the transition at the end-of-life, nurses should promote comfort, communicate effectively and compassionately, assess and treat multiple dimensions, and assist patients, and patients' families ability to cope with suffering, grief, loss, and bereavement.

## INTRODUCTION

In Hong Kong, the neonatal unit (NNU) in the hospital where I (SYW) work is divided into a neonatal intensive care unit (NICU) and a special care baby unit (SCBU). NICU, an 18-bed unit, is the unit for ventilated and/or critically ill neonates and SCBU, a 60-bed unit, is the step down unit from the NICU for non-ventilated and relatively stable patients. The admission criteria for NICU and SCBU are based on medical decisions and no objective indicators are used. Nurses are rotated to work in both units, NICU and SCBU, in order to have an equal opportunity to care for critically ill babies. In order to promote the comprehensive experience for caring of the sick neonates, all nurses working in the NNU will receive four weeks' training. The duration of training is based on the administrative decision of the unit, taking into account manpower availability.

Working in the ICU setting, it is not uncommon to care for dying patients and death is not a rare event. However, there was an incident in which I (SYW) was involved, where a baby died following a planned extubation (when the child was not expected to survive), which caused me to examine my role in patient care during this crucial period, at the end of a patient's life.

## Incident

Judy (a pseudonym), a term neonate, was admitted to SCBU at two days old because of repeated vomiting. After Judy's admission, she had faecal vomitus. As a result, she then had a rectal biopsy and soon after the biopsy, which resulted in the diagnosis of Hirschprung's disease, she had several operations during which a large proportion of non-functioning bowel was removed and an ileostomy was formed. Her remaining bowel had poor function, which meant that her feeding needed to be maintained using parenteral nutrition.

Although Judy was born following a well-planned pregnancy and every family member was delighted at her birth, her poor prognosis became a nightmare for her parents; but they always hoped for a miracle. Judy was cared for in NICU for nine months, and during this time the NICU nurses became very attached to Judy. I grew very attached to her; she had such a beautiful smile.

At nine months old, Judy collapsed unexpectedly and suffered a cardiac arrest. After active resuscitation, she was intubated and ventilated. She also required aggressive inotropic support. Because the collapse happened so suddenly, her parents were very shocked. A few days later, Judy's mother began to ask questions about whether it would be appropriate to extubate Judy and remove her ventilatory support, as she and her husband did not want her to suffer. The parents had then consulted two doctors, who had been taking care of Judy, for advice. Unfortunately, the two doctors had differing points of view. One agreed with the parents and suggested that they should decide what would be the best for Judy. The other doctor insisted that the parents had no right to terminate Judy's life. Not surprisingly, these discussions made Judy's parents feel confused, to the point that they had no idea about what would be best to do for the benefit of Judy.

## Supporting the parents

Healthcare providers and family members hold many different points of view about withdrawing life support from a patient (Burns et al., 2001). In Judy's case, at times I felt she was suffering. I felt this because, even though she was sedated using fentanyl and midazolam intravenous infusions, she still appeared to be in pain when we provided care to her. I remember one time when I changed her ileostomy bag, her facial expression told me that she was in great pain, especially when I touched her raw skin. If I was asked to rate Judy's pain on a 1 to 10 numerical pain scale, where 1 refers to no pain and 10 refers to the greatest pain, I would rate her pain level at 10 for that incident and rate her average pain level at 5 to 7. Judy's father yelled at me on that occasion because he thought I had made his daughter suffer.

NICU parents often experience panic, grief, guilt, helplessness, and anger; it is a major life challenge for them to cope when their sick baby is admitted to ICU (Dyer, 2005). Today, nurses promote holistic care, which includes the physical, psychological, social and spiritual well-being of the clients as well as their significant others (Crawford & Hickson, 2002). In fact, healthcare professionals are prepared to share in the grief, loss, and fear experienced by families so as to provide beneficent end-of-life care (Romesberg, 2004).

Although Judy was still hospitalised in NICU, the state of her impending death created great stress and a feeling of loss to her parents. As nurses we felt it was very important to not only provide care for Judy, but to her parents also. Updating them about her condition, allowing them time for questions, answering their questions and concerns, and staying with them whenever possible were the supportive measures offered by NICU nurses. Despite all the support that nurses could offer, Judy's parents sometimes still acted restlessly and agitated during visiting. They were often distant from the healthcare workers and asked questions in an angry tone.

Judy parents' reaction and anger toward healthcare workers was familiar to me as I had experienced similar reactions and anger when my younger brother died from leukaemia. I shared my personal experiences with them and offered emotional support because it was hard for them to go through this critical stage. Nurses cannot make decisions for patients and their families, but nurses can tell families how they feel about a particular end-of-life situation. Without imposing their will, nurses can express their view in a genuine, open manner that provides families some guidance, based on our understanding of their wishes. No one can cure the grief that arises when people lose someone dear to them (Levy, 2001).

Comfort care, including provision of warmth, close physical contact, nutritional support, sedation and pain management should be given to any critically ill child. However, supporting the parents is equally important and their needs may be physical, emotional, social, cultural and spiritual (Stringer et al., 2004). The needs of Judy's parents were basically for physical comfort and psychological support during this critical period. And, it is important for nurses to recognise and accept that families need to feel what they feel regardless of how irrational others may perceive it to be (Romesberg, 2004).

Even though the parents had been informed that Judy's condition would not improve and that no treatment would alter the outcome, they continued to ask questions several times every day regarding her condition and prognosis. They may have been holding on to a hope that continuation of supportive treatment would provide a chance for their daughter to be cured.

With the advancement of technology, people expect to live longer, and prolongation of life is possible these days because of complex diagnostic and curative technologies. I believe that death of an elderly person is far more acceptable to society than the death of a child, which is often regarded as the most painful, stressful, and enduring bereavement experience (Romesberg, 2004). This may explain, to some extent, why many family members find it difficult to accept withdrawing or withholding life-sustaining treatment where children are concerned.

## Ethical issues

Quality of life is at the core of patient care, especially focusing on interventions to limit the patient's suffering. Quality of life has been defined as the quality of total well-being including both physical and psychosocial determinants (Stutts & Schloemann, 2002). If the patient's quality of life cannot be assured, or if the treatment will produce more harm than benefit for the patient, the caregiver may be justified in suggesting the withholding or withdrawal of treatment (Stutts & Schloemann, 2002). This is the ethical principle of beneficence. However, for families, if life-sustaining support is continued, they may still have time to experience a relationship with the patient. It allows time for them to be with their relative and this sustains their hope for a miracle, until they are more able to come to terms with the reality of the prognosis. On the other hand, for an infant as young as Judy, pain and symptom management were the major concerns, from the patient's perspective.

Nurses and other healthcare professionals bear the ethical responsibility to protect the rights and interests of patients. In order to understand the ethics of end-of-life care, the purpose or goal of end-of-life care should be examined. As noted above, due to medical advancements, the public's expectations of achieving a positive health outcome is high. However, if life-sustaining treatment only lengthens a patient's life (with no expectation that the patient is likely to survive) and in addition causes suffering, healthcare professionals should consider discussing withdrawal of treatment with the family, in order to promote a peaceful death.

My personal belief is that everyone has the right to die with dignity regardless of his or her age. Futhermore, patients should be treated with respect and dignity, both during and after the dying process (Truog et al., 2001; Roberts & Boyle, 2005). Life-sustaining support includes pharmacologic, haemodynamic and ventilatory support; the continuing need for which should be evaluated regularly, especially if the patient experiences severe pain, discomfort and suffering. But who has the right to determine withdrawal of treatment from a patient? According to Goh and Mok (cited Crawford & Hickson, 2002), clinically experienced practitioners, basing their predictions on evidence, can and usually do make ethically sound decisions. Of course, although it is not always the case (as illustrated by my example, above), this decision should ideally be agreed with and supported by family members.

Agreement by the family members about the withdrawal of life-sustaining support is usually based on how they perceive the unalterable condition of the patient, and in this regard it is important that medical professionals provide clear and comprehensive and unambiguous information to the family.

## Law and ethics in Honk Kong

Since there is no law or official medical guideline regarding withdrawal of life-sustaining treatment from children in Hong Kong, medical professionals are in a difficult position and ethical dilemmas may arise when the healthcare team and the patient's family have different ideas about which decision is in the child's best interest (Stutts & Schloemann, 2002). Even though parents have the autonomy to make the treatment decision for their infant based on the presumption that they will look for the best interest and well-being of their child (Stutts and Schloemann, 2002), the decision to withdraw life support should never rest with the parents alone, as they might be made to feel directly responsible for bringing about their child's death (Fetus and Newborn Committee & Canadian Paediatric Society, 2001). The burden of decision-making may be reduced, from the parents' perspective, by emphasising that everybody's concerns have the best interests of the baby at heart.

In the UK, the Royal College of Paediatrics and Child Health (RCPCH) published a framework for practice regarding withholding or withdrawing life-sustaining treatment in children. Advising withdrawing or withholding treatment is one of the most difficult areas of clinical practice (RCPCH, 2004). In order to fulfil the medical professional responsibilities in this aspect, this framework provides directions to help all healthcare professionals, children and families to come to the right conclusions.

## DISCUSSION

According to the RCPCH (2004), there are five situations where it may be ethical and legal to consider withholding or withdrawal of life-sustaining medical treatment. The five situations are brain death, permanent vegetative state, no chance to recover from a severe illness, a no purpose situation with severe physical or mental impairment, and an unbearable situation in which progressive and irreversible illness cannot be borne.

It was painful for Judy's parents to have to make a decision about the life of their child but they felt knew what was best for Judy. However, because Judy had such a severe illness that there was no chance that she would recover, and life-sustaining treatment would simply delay her death without significant alleviation of her suffering, the decision that they made was congruent with the framework suggested by the RCPCH (2004).

During Judy's stay in NICU, despite episodes of distance and anger such as that described above, the nurses built up a trusting relationship with her parents. This relationship encouraged a partnership between nurses and the parents during the period of Judy's end-of-life care. This was particularly important at the time when the parents were asked to accept the situation and to make the decision to withdraw treatment. They needed time and space to consider what was best for Judy.

As healthcare providers, we should always try to respect the parents' wishes and give them support, no matter what their decision is. However, this respect and support is not unconditional, and it is the parents' duty to decision-make from the point of view of the child's best interests, as opposed to their own. Families often need to be reassured about the decisions they have reached, and it should be emphasised to them that the responsibility for these decisions is shared between the family and the healthcare team. This can help to dispel lingering doubts and potential feelings of guilt (Truog et al., 2001).

### The parents' decision

During the last few day of Judy's life, her parents struggled with their decision, and they were in deep pain during the whole time. Nurses in the unit counselled them and were able to offer support and comfort even though some nurses were not Judy's case nurses; considerable empathy was demonstrated by the staff.

Finally, Judy's parents came to the decision that her quality of life was unacceptable and that death was inevitable. A planned process of withdrawal of care was discussed. Ideally, when a death is expected and a do-not-resuscitate order is made, planned withdrawal of support can facilitate a more peaceful and less painful death for the patient and the family (Roberts & Boyle, 2005). After extubation, to respect their privacy and confidentiality, Judy and her parents were cared for in a private room until her last moments. The best way a health professional can support a grieving family is by offering a non-judgmental, deep sense of caring and personal involvement. This is what we attempted to provide for Judy and her family.

### Reflections

Although medical advancements can lengthen the life of a terminally ill patient, their quality of life may not be improved. As a nurse, I have a duty to do 'good' to patients. Ethical principles such as beneficence, non-maleficence, truth telling and autonomy can be applied in Judy's case. Beneficence is the ethical principle of doing 'good' for the patient. In this context, the extubation decision was made to reduce Judy's suffering. Non-maleficence means doing no harm. In this respect, adequate analgesia and sedation were provided to Judy to allow her to die without pain.

Parents should be kept updated about their child's condition and the expected changes during the last stage of life. The last principle is autonomy, which in this case is regarded as parental autonomy to make the decision to withdraw life-sustaining support. Compared with other types of bereavement, parental grieving may be particularly intense, complicated and long lasting. They have a difficult transition to make. All parents expect to have a healthy baby during their pregnancy. However, if their baby dies, they often lose hope, and with it their sense of a future (Fetus and Newborn Committee & Canadian Paediatric Society, 2001). Thus, while caring for the needs of critically ill babies, nurses need to meet parents' psychological needs also.

In a situation where an infant dies nurses have a critical role and can promote optimal comfort for the dying baby such as provision of warmth, provision of adequate sedation and pain relief, and minimal prescriptive handling if possible. Additionally, the care provided to the dying child must be family centred (Poor & Poirrier, 2001). Family-centred care is an approach to plan, deliver, and evaluate healthcare that is grounded in mutually beneficial partnerships between healthcare providers, patients, and patients' families. The infant's family may include parents, siblings, and their extended family, all of whom have diverse needs.

In order to provide high-quality care to patients and their families during the transition at the end-of-life, nurses should promote the provision of comfort care to the dying as an active, desirable, and important skill and an integral component of nursing care. Effective communication and compassion are essential when dealing with patients, patients' families, and members of the healthcare team about end-of-life issues. It is also important to assess and treat multiple dimensions, including physical, psychological, social, and spiritual needs to improve quality at the end-of-life, and last but not the least, assist patients, patients' families to cope with suffering, grief, loss, and bereavement in end-of-life care (Roberts & Boyle, 2005). Nurses can encourage parents to spend more time with their baby, participating actively in their care whenever

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they wish. A single room, if available, should be provided in order to allow them to share their last moments together (Truog et al., 2001).

In conclusion, withdrawal of treatment from an infant and the end-of-life care process are complex matters. Whatever the context, the patient's best interests should always be prioritised in order to avoid suffering and to promote a comfortable death.

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