law and ethics

Just because we can, should we? A discussion of treatment withdrawal

Abstract
Children's nurses are vocationally committed to promoting the health of children, relieving their suffering, enhancing their development, helping them to achieve a sense of worth and a confidence in their future. Supporting parents and medical colleagues while the decision is made to withdraw or withhold life-sustaining treatment is one of the most difficult aspects of children's nursing practice. Current guidelines support the withholding or withdrawing of life-sustaining treatment from children in brain death, permanent vegetative state, and no chance, no purpose or unbearable situations. Societal and professional attitudes to euthanasia and assisted suicide may be changing and this could lead to changes in legislation and guidelines. However, nurses must be clear about the differences: currently any measure, practice or treatment administered with the primary intention to cause death is not allowed. This is not the same as any measure, practice or treatment administered with the intent to relieve suffering and promote comfort, that can cause or hasten death.

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The discontinuation of aggressive medical management of infants and children is a highly emotive subject and one that has, in one way or another, probably touched all children's nurses in a professional capacity. It may also have affected them in their personal lives. The attitudes to this subject of nurses, other healthcare professionals and members of the public will vary greatly, and so will their interpretation of guidelines on the withdrawal of life-sustaining technology.

The value and use of life-sustaining technology was debated at a fringe event during the RCN congress in 2008 – hosted by the RCN Paediatric and Neonatal Intensive Care Forum – and in the main congress session.

Following on from those debates, this article reviews attitudes and practices related to guidelines for discontinuing aggressive medical management, in a bid to stimulate further discussion among those mostly closely involved – nurses caring for infants, children and young people. The views expressed here are not those held by the RCN or the Nursing and Midwifery Council (NMC).

Law and bioethics
Arguably, medical technology and sociological norms and values have evolved faster than medical ethics and legislation. Bioethics refers to the ethical and moral issues raised by new biological discoveries and biomedical advances. Although there have been some valuable and potentially practical publications on some aspects of bioethics (Nuffield Council of Bioethics 2006), there has been little change in legalisation governing what it is acceptable to do for those at the end or on the borderline of life.

Lord Joffe (2004) attempted to take a euthanasia bill through parliament in 2006 and there was a high profile and controversial debate on abortion and viability in 2008.

This resulted in the upholding of the status quo with regard to the 24-weeks gestation limit to termination for so-called ‘social’ reasons.

There is a considerable difference between viability and vitality, and a few signs of life at the birth of a borderline gestation infant are no indicator of outcome; this can also apply to infants born at later gestations. To complicate matters further, the debate as to what constitutes a live birth is largely a professional one; signs of life following an extremely premature birth can be subtle and liable to subjective interpretation.

These matters are of great interest to the public and several pressure groups have stimulated debate and pushed for changes in the legalisation on assisted suicide.

Although most of this action is concerned with adult end-of-life issues, the public debate and the outcomes may alter attitudes to terminally ill
It is important that children’s nurses monitor legal developments in this area and understand the implications of such legislation.

**Ethos of children’s nursing**

Children’s nurses are vocationally committed to promoting the health of children, relieving their suffering, enhancing their development, helping them to achieve a sense of worth and a confidence in their future. Sadly, there are times when these goals are not possible. In these cases, the humane response could be inaction, or a series of strategic actions designed more to relieve suffering and promote comfort than to prolong life. Such decisions occur most frequently in the paediatric intensive care and neonatal units, although they may also be required in other areas, such as emergency departments and oncology wards.

It is vital that the child does not become a hostage to technology. Supporting the parents and medical colleagues while the decision is made to withdraw or withhold life-sustaining treatment is one of the most difficult aspects of children’s nursing practice.

Being part of the team involved in the care process and management of these cases stretches professionalism to the full. Knowing that all that can be done for the child is not going to be done can create a sense of disquiet. The process demands the most delicate balance between the desire to do the best thing, being an advocate and acting paternalistically. However, it is professionally reassuring to know that any decision is made in the best interests of the child and family.

**Current guidelines**

The guidelines which support the practice of withholding or withdrawing life-sustaining treatment from children are published by the Royal College of Paediatrics and Child Health (2004) and are framed against the Children Act (1989) and the Human Rights Act (1998), to which the UK is a signatory.

There are five situations where it is deemed ethical and lawful to withdraw or withhold life-sustaining management; these are:

- **Brain death** Aggressive and extreme therapy can be withdrawn when the child is brain dead, although this criterion currently excludes neonates on the basis that it is more difficult to elicit cranial nerve responses in the premature and the immature. Diagnosis of brain death can be made through a series of cranial nerve tests which indicate that independent survival is no
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longer possible and that further intervention or continued support is futile. These criteria are adopted to assess beating heart donors who, under current legalisation, are on the donor register or who have expressed a wish to donate tissue and the parents have no objection.

- **Persistent vegetative state**: Persistent vegetative state refers to a child who deteriorates to or develops a condition resulting in the need for complex support. The child is unaware of the world and unable to sustain any sort of reciprocal relationship with their family and loved ones. The vital centres are intact and the cardiac sinus rhythm is maintained. But, although the child may survive, and growth may be possible (provided that management is sufficiently supportive and sustained), there will be no developmental progress. These children require continuous intervention to prevent a range of complications and deformities which will occur as a direct result of their condition, such as pneumonia, postural and orthopaedic abnormalities.

- **No chance**: The no-chance situation refers to a child who has suffered such severe trauma or has such extensive disease that life-sustaining management merely delays death and prolongs suffering. These cases are clear-cut and, although there could be religious and philosophical debate as to the rights of the child and parents and the responsibility of the professionals and society, the consensus of opinion (were opinion to be sought from the public and professionals) is likely to support the decision to withhold or withdraw treatment. Situations that are not so clear-cut fit into the ‘no purpose’ or ‘unbearable’ criteria below.

- **No purpose**: In this category, where survival may be in doubt, what is in question may be the quality of the child’s life. This criterion can be applied to cases where mental and/or physical impairment is so great that it would be unreasonable to expect the child to tolerate such a life, or the family or the healthcare professions to impose it. Examples include the asphyxiated infant who, after suffering a catastrophic lack of oxygen, is successfully resuscitated and maintained by technology.

- **Unbearable**: The illness is progressive and irreversible and further treatment is more than can reasonably be borne. The family and sometimes the child may wish to refuse further treatment or have it withdrawn, as in for example, a severe case of spinal-muscular atrophy, where it may be decided to withdraw conventional ventilation or not to intubate and ventilate.

The decision to withdraw life-sustaining treatment does not mean that a decision to remove all form of treatment has been taken. Palliative, holistic and comforting medical and nursing care continues. Whatever can be provided for the child and family should be provided until no longer required.

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**Current practice**

Except in the most unexpected and critical emergency resuscitation procedure, making a decision to withhold treatment is possibly easier than making one to withdraw. A decision, made in advance, not to make further interventions could be seen as letting nature take its course.

Withdrawing life-sustaining treatment often involves taking actions with the knowledge that the likely outcome is the child’s demise.

Having time for negotiation and reflection on agreed care strategies with the child and the family may make the decision harder for some but easier for others.

There are no predetermined scripts to be followed and it would be foolish to imagine that a protocol could ever be developed for the range of scenarios that might occur.

Unexpected events arise more frequently in the emergency department where cases of suspected Sudden Infant Death Syndrome (SIDS), sudden collapse or multiple traumas following road traffic incidents are seen. Although guidelines can be developed to support decision-making, and some staff may develop more expertise than others, no one is ever likely to regard themselves as comfortable in these circumstances.

In the labour ward, staff must manage births of extremely pre-term infants, babies of any gestation with gross congenital abnormalities, fresh stillbirths and the obviously hypoxic infant. The decision not to start resuscitation should be made by the most senior person available.

If there is doubt, resuscitation and life-supporting management should be started and decisions deferred. This was the essence of the view expressed in the NMC (2007) circular regarding the decision on whether to resuscitate at birth or not. The NMC advises that the situation should be reviewed by senior colleagues when more information and evidence are available. However, in practice, this means that in some cases there will be periods of intense suffering and prolongation of a technologically-dependent life.

In every circumstance, all possible measures must be taken to prevent suffering and to provide tactful, truthful communication for the parents, so that they do not build up false hopes.

**Euthanasia**

None of the circumstances considered here relate to euthanasia, defined as a practice in which the intended result of an intervention or management is to bring about a person’s death. Some healthcare professionals may hold the view that euthanasia is acceptable and their views are to be respected. But the current laws are clear, and, for the occasions when life-sustaining management is withdrawn and the life does not end, there must be no direct action to expedite the demise.

It is in circumstances like these that the flexibility in paediatric services becomes apparent.
Management and care continues but at a different level; the child receives palliative care and the family supportive attention.

**Time for change?**
The children’s nursing ethos of making the most of the situation and supporting the child and family through this difficult time in their lives is unlikely to change, even in the event of a euthanasia bill succeeding or of relaxation of the laws related to assisted suicide.

It is highly unlikely that such statutes would be applied directly to children, although it could be anticipated that children might be affected by them.

For example, if a parent decided to take advantage of assistance to shorten his or her own life, provision would have to be made for the future care and wellbeing of his or her dependent children.

To protect vulnerable groups in society, any future euthanasia bill could impose restrictions on the patients who qualify for assisted suicide and this might affect the latter two paediatric criteria used to withhold or withdraw life-sustaining treatment.

Furthermore, although the operation of a legalised euthanasia process would depend on the pharmacology and technology available at the time, related restrictions could be imposed on the use of some therapeutic agents; for example, the use of muscle relaxants, sedation and high morphine doses at the end-of-life could come under scrutiny. If these medications were to be more regulated this could affect end-of-life care for children.

**Stay informed**
Children’s nurses have a legal duty of care which must include being informed, and understanding the distinction between causing death and withholding or withdrawing treatment. Currently, any measure, practice or treatment administered with the primary intention to cause death is not allowed.

This is not the same as any measure, practice or treatment administered with the intent to relieve suffering and promote comfort, but which causes or hastens death.

There is a clear need for the guidelines to be reviewed and kept under scrutiny, particularly as law and bioethics evolve to match societal concerns.

**References**

**When a child refuses treatment**

Patric Devitt comments on the case of Hannah Jones (below), aged 13, who refused to accept a heart transplant

From time to time, certain segments of the popular press work themselves into a state of hysteria about young people seeking medical intervention without the consent or even, in many cases, the knowledge of their parents. This is generally coupled with an appeal to save the moral soul of the nation as the intervention concerned is often about access to contraception, emergency or otherwise, or the termination of an unplanned pregnancy. The real issues are usually hidden behind the moral outrage.

The recent case of Hannah Jones has brought the issues into stark relief (http://news.bbc.co.uk/1/hi/england/hereford/worcs/7721231.stm). Hannah has suffered cardiac damage as a result of her (to date) successful treatment for leukaemia, and her only chance of long-term survival is a heart transplant. This intervention carries with it a significant chance of side effects, including death. Even a successful transplant would require extended and repeated hospital stays, without the assurance that her original disease would not reoccur. In the light of this, Hannah has refused the option of a transplant.

This decision has led to the questioning of her ability, or indeed any 13-year-old’s ability, to make such a decision. Anyone who has heard her discuss the reasons behind her decision (or her Radio 5 live interview last year) cannot fail to be impressed by her mature attitude. She is able to articulate the facts and opinions about her options. Without doubt, she is ‘Gillick competent’ and it would be a brave person who argued that her opinion should be set aside.

This case does, however, reveal important lessons for children’s nurses. It is the first high profile case in England to suggest that young people like Hannah can dissent from treatment. In the past it has been about seeking rather than refusing treatment, and it has even been suggested that refusal shows a lack of understanding. The NHS Trust backed down from legal action so Hannah’s case has not set a legal precedent, but it will have reverberations within the NHS. It is an acceptance that an informed, mature young person can make real decisions about their own health care. At last the issue is consent, not merely assent.

Every children’s nurse has to act on what has happened. Every child and young person has a right to be involved in the decisions that affect their lives. To enable this they must be provided with the fullest, age-appropriate information available, and it is the nurse’s role to give, or at least ensure this is given. The education of children’s nurses should ensure that they are able to support young people and their families to come to the correct decisions. While Hannah’s death is sadly unavoidable, it may well be that she leaves a legacy: a real regard for young people and respect for their ability to make meaningful decisions about themselves.

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