

Legal aspects of caring for dying newborn infants

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Series Editor

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Does the law unduly prolong the dying period of critically ill newborn infants? Should they be given palliative care for their parents' and carers' benefit as well as their own?

Parents' perceptions of the dying process

Three Scottish health practitioners have recently challenged the medical community (and the law) to think of new ways to deal with the dying of critically ill newborn infants from whom intensive care is withheld or withdrawn after deciding that death is inevitable. Their multicentre study investigated parents' perceptions of the dying process from the time that it was agreed to withhold or withdraw intensive care until the child's death. Of the 61 babies in the study, 61% died within the first week of life but 10% lived for more than three months, and one child lived for almost nine months.¹ The researchers found that 'overall, the parents conveyed a strong message both soon after the event and a year later, that, even though it was traumatic, they valued the experience of being with their child at this time'. In most cases, both parents were present during the death.

The study also showed, however, that more than one-fifth of the parents were distressed by the time it took for their child to die. This is illustrated by the experience of one family, as follows.¹

'After treatment withdrawal, the parents of one severely asphyxiated baby had her in a quiet room with them for 36 hours before she died. Again and again they said their goodbyes.

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Utterly exhausted, during the nights they drifted into sleep themselves expecting the child would be dead when they awoke. But she survived two whole nights. As time went on, they began seriously to question the decision to let her die. On the third morning ... she did eventually die.'

In addition to questioning whether death was really inevitable, parents were distressed by babies apparently struggling to breathe, 'coughing, spluttering, gasping', and changing colour during the process of dying.

The researchers concluded from their study that parents should continue to be involved in the dying process and should be informed as fully and openly as possible about what to expect (including the uncertainty of the process in each case). The doctors also questioned whether the dying process should sometimes be shortened to minimise distress for parents and hospital staff.

What is lawful?

Common medical practice

It is lawful to withhold or withdraw treatment if it is 'futile' to initiate or continue it; or if the burden imposed by the treatment exceeds the likely benefit and so is not in the person's best interest. But it is not lawful to take any active steps to cause or hasten a person's death (euthanasia), even if the person is terminally ill, in great pain and there is general agreement that an early death

would be in the person's best interests. This is a real challenge for the law.

A doctor who deliberately causes or hastens a child's death, whether by withdrawing or withholding treatment or by excessive doses of pain-killing drugs, is liable to criminal prosecution for homicide. It makes no difference that the child's condition is incompatible with life and that he or she will die shortly. If the parents participate in the decision, it is conceivable they could also be prosecuted, although this is very unlikely to happen in practice.

There will be cases where the law's sharp distinction between unlawful acts (lethal injections and oversedation) and lawful omissions (withholding or withdrawing treatment) must be questioned.

This means that the law supports the common medical practice of withholding or withdrawing futile intensive care and allowing critically ill newborn infants to die. Indeed, a two-year study of infant deaths at the Royal Children's Hospital in Melbourne found that, of the 132 babies who died, 76.5% of the deaths occurred following withdrawal of life supporting treatment.² Extremely premature infants with severe respiratory failure unresponsive to mechanical ventilation, infants with severe bronchopulmonary dysplasia unresponsive to steroid treatment and mature infants with severe asphyxia are all examples of critically ill neonates who should probably be allowed to die. The underlying principle in these cases, as in *Airedale National Health Service v. Bland* (1993), is that 'if the treatment is futile ... it is no longer in the best interests of the patient to continue it'.^{3,4}

But the law will not permit doctors to hasten the child's death even when it is imminent and inevitable.

The concept of 'double effect'

The one avenue legally available to doctors seeking to minimise the distress of parents and staff when the dying process is protracted is the ill-defined concept of 'double effect'. It is lawful for doctors to give extra drugs if necessary to alleviate pain and distress, even if that hastens death. Even if the doctors know that the drug may accelerate death, that is not the primary intention of giving the drug. The primary intention is to alleviate the infant's pain or distress (that is, palliation), and that should be supported by documentation in the records.

However, there are difficulties with this option in the ward. First, the infant must be in pain or distress. The situation

described by some parents in the Scottish doctors' study seems to meet this requirement, such as babies struggling to breathe and gasping for breath. If appropriate sedation is given and the baby dies more quickly, the doctor will not be criminally liable. Drug dosages are, however, much harder to calculate for children than adults and a relatively small dose for pain or distress may kill a child more readily than an adult. If this is regarded as oversedation, a coroner or court may not believe a doctor who says the intention was to relieve pain or distress.

Wait for nature to take its course

Some dying infants will not be suffering pain or distress but will still be taking longer than anticipated to die. Here, doctors cannot lawfully intervene. They must wait for nature to take its course.

This waiting may raise problems. Often better facilities and support systems are needed for parents. Given resources, bedrooms could be provided close to a dying child so that the parents can rest and sleep while still being close at hand. That will do little for parents of infants who take weeks or months to die but some will regard the extended dying period as a time to adjust, to spend time with the child and come to terms with the death.

Unlawful acts versus lawful omissions

Ultimately, however, there will be cases where the law's sharp distinction between unlawful acts (lethal injections and oversedation) and lawful omissions (withholding or withdrawing treatment) must be questioned. Should this distinction remain? Doctors have duties in caring for traumatised parents as well as critically ill infants.

Series Editor's comment

Most of the energy consumed in the euthanasia debate in recent times has been expended in heat, not light. The 'Right to Lifers' grab as many headlines as the 'Right to Deathers', and most of the debate has nothing to do with medicine but everything to do with personal religious and ethical views.

At least two pertinent claims spring immediately to mind. In these, the Medical Indemnity Protection Society defended the doctor involved and the plaintiff, albeit willing, was a pawn being used by others to push a claim into court and to judgment, to establish a precedent that might have given legal force to what was primarily a moral view. Whether that view was a religious prejudice to be imposed on others, or a morally justified crusade to protect the innocent, is a matter of personal perspective.

Professor Skene says that doctors do not have a duty at law, and I say not ethically either, to administer 'futile' treatment. I would go further and say that a doctor has a duty not to persist with futile treatment. Sometimes, that duty is obvious to

everyone but the doctor(s) immediately involved. I remember being the coronary care resident involved in resuscitating a patient whom I knew well. I tried everything in our armamentarium of drugs, and then tried it all again. I was determined not to give up, to bring the patient back from the grave. After well over an hour, during which the anaesthetic registrar kept patiently pumping the bag and inflating the patient, the registrar gently asked me, 'How old was this patient?' Everyone around the bed except me knew that further attempts at resuscitation were futile.

We sometimes see this with oncologists who forget that palliative care and managing an easeful death is part of their brief. Some seem to think that if the patient is still coming to see them, then he or she wants them to do something – and so they keep pumping in more and more magic bullets. Thankfully, the vast majority of oncologists are not in that camp, but will say to patients, 'I've done my best but there is no further prospect of cure or remission. We need to move from helping you live with cancer, to helping you in the phase of dying with cancer.'

We all have seen some doctors, without grandstanding, quietly break the law and, while being prepared to plead 'double effect' as described by Professor Skene, deliberately give a dose of narcotic large enough to depress the respiratory centre in the brain and hence cause death. I think most of us are very uncomfortable with that thought, or perhaps not as courageous. Others doctors may order or administer enough, say, narcotic analgesic to ease the patient's suffering, even if they know that it will also hasten death. The difference is in the primary intent – the latter doctor's primary intent is palliation while the former doctor's primary intent is to hasten death; the effect of the treatment is to cause both, hence the term 'double effect', albeit single intent.

Newborn infants cannot tell us of their distress and plead for relief. But the same principles as enunciated above apply.

I hesitate before introducing another issue in this discussion. A recent article in the *British Journal of Psychiatry* reported that at least 20% of women who have a stillbirth suffer post-traumatic stress disorder (PTSD) in their subsequent pregnancy.⁵ Although what might have been anticipated factors (such as lack of social, family and partner support) were confirmed as increasing the risk of PTSD, the researchers also, perhaps surprisingly, found that PTSD was more common among women who had seen or held their stillborn baby than among those who had not. The researchers concluded that: '...the findings suggest that the current practice of encouraging women to see and hold the dead infant may increase the risk of PTSD' (my emphasis).

This is very much at odds with current practice where mothers are encouraged to spend many hours, even days, with their dead baby, to say goodbye and effect closure as a first step

in the grieving process. If confirmed by other studies, these findings would suggest that parents are harmed if forced to experience a child's attenuated and distressing process of dying. Does the doctor have a duty to the living as well as the dying?

Personal views and professional duties

I have a view on this, a very personal view, as do most doctors. I don't intend to share it. That's not a cop-out, I just don't think I have a right to impose my moral views on others. I no longer have to make these decisions as I no longer have direct patient contact. My conscience is comfortable with what I did and did not do when faced with end of life decisions.

My discussions with doctors lead me to believe that most doctors do not want these issues determined in court, nor in parliament, and certainly not in the media. They want them determined at the bedside by doctors who have one and only one commitment – the best interests of the patient. Of course we must honour, respect and abide by the laws and ethical mores of our community. But our duty is more than that. I know it sounds paternalistic, but sometimes doctors face an awesome burden of responsibility, a responsibility that, if shirked, is an abrogation of our professional duty. MT

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