'Slippery slope' fears for legal euthanasia of very sick newborns unfounded

May 1 2013

Fears that legalising euthanasia for very sick newborns would prompt the start of a "slippery slope" and lead to abuse of the option have proved groundless, says the architect of a dedicated protocol used by doctors in The Netherlands, in a special issue of the *Journal of Medical Ethics*.

The Groningen Protocol, which was devised to help doctors curb the suffering of very sick newborns and identify the situations in which euthanasia might be appropriate, was introduced in 2005 in The Netherlands.

Its development was triggered by the case of a baby girl with excruciatingly painful and progressive skin disease whose parents asked doctors to end her suffering. The request was refused on the grounds that the doctors concerned could be prosecuted for murder. The little girl died three months later.

But protocol author, Dr Eduard Verhagen, says that evidence from two national surveys of end of life care in 1995 and 2001 indicates that doctors were taking decisions to end a child's life for humanitarian reasons before 2005, but were not being open about it.

In 1% of deaths among children under the age of 12 months during this period, drugs were given with the explicit intention of hastening death, leading the author to conclude that between 15 and 20 children every year had their lives ended in this way in The Netherlands. Yet only three such cases were officially reported.

The protocol stipulates that five criteria must be met before euthanasia can even be considered: diagnosis and prognosis beyond doubt; presence of hopeless and unbearable suffering; a second independent medical opinion to confirm the first; the consent of both parents; and compliance with strict medical standards.

But the protocol's publication provoked a storm of controversy, including that it would open the floodgates for euthanasia of newborns, or, conversely, that it would make doctors more accountable and increase transparency.

So the author reviewed all reported cases of infant euthanasia between 2001 and 2010.

In 95% of cases, treatment was withheld or withdrawn. In 60% of cases this was because the child had an incurable condition from which they were soon going to die. In the remainder, it was the child's quality of life that prompted the decision.

But in the five years following the introduction of the protocol, the proportion of euthanasia cases dropped to two - both babies with lethal epidermolysis bullosa, a condition that causes extensive internal and external blistering of the skin.

The author says that the introduction of screening and a subsequent rise in terminations for inborn abnormalities after 2007 might help explain these figures. Or it might be that there is still no consensus among doctors on what constitutes euthanasia - a situation that might be clarified when the Dutch Medical Association publishes its report on the issue, later this year.

But he suggests that some parents may prefer the option of euthanasia for very sick babies to termination of pregnancy, because the level of

certainty around diagnosis and prognosis is much clearer after birth, and they can discuss all the treatment options available, including palliative care.

"If all the stakeholders conclude that the prognosis is very grim, the baby's condition is judged as one with sustained and intolerable suffering, and the parents request euthanasia, why should that not be permissible as an alternative to second trimester termination?" argues Dr Verhagen.

In this way, parents can be involved and organise their child's death in the way they want, he adds.

And he questions what the moral difference is between withholding food/water and treatment and euthanasia, a question that has become even more relevant now that the American Academy of Pediatrics Committee on Bioethics has concluded that there are certain circumstances where withholding/withdrawing treatment and food/water is permissible.

"The practice of withholding feeding and hydration is another example of an approach in palliative care that might need rethinking," he writes.

"I'd like to argue that for some patients and/or parents, neonatal euthanasia might be preferable… especially in situations where every hour, every day of life imposes an intolerable burden on the baby and the parents," he concludes.

In an accompanying editorial for the special issue, *Journal of Medical Ethics* Editor, Professor Julian Savulescu, points out that withholding treatment with the intention of hastening death is "not uncommon" in neonatal intensive care.

"The active withdrawal of life-prolonging medical care (an intentional act that kills, even if not necessarily with the intention to kill) is a standard part of medical practice in relation to people who experience severe disability and suffering, including newborns," he writes.

"Discussions of infanticide [allowing the newborn to die] should be contextualised in those practices that end life, which society already accepts, even if they are euphemistically re-described," he writes.

"Infanticide is an important issue and worthy of scholarly attention because it touches on an area of concern that few societies have had the courage to tackle openly and honestly: euthanasia," he adds.

More information: The Groningen Protocol for newborn euthanasia; which way did the slippery slope tilt? J Med Ethics 2013; doi 10.1136/medethics-2013-10140

Provided by British Medical Journal