

Deeply held religious beliefs prompting sick kids to be given 'futile' treatment

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Parental hopes of a "miraculous intervention," prompted by deeply held religious beliefs, are leading to very sick children being subjected to futile care and needless suffering, suggests a small study in the *Journal of Medical Ethics*.

The authors, who comprise children's <u>intensive care</u> doctors and a hospital chaplain, emphasise that <u>religious beliefs</u> provide vital support to many parents whose children are seriously ill, as well as to the staff who care for them.

But they have become concerned that deeply held beliefs are increasingly leading parents to insist on the continuation of <u>aggressive</u> <u>treatment</u> that ultimately is not in the best interests of the sick child.

It is time to review the current ethics and legality of these cases, they say.

They base their conclusions on a review of 203 cases which involved <u>end</u> <u>of life decisions</u> over a three year period.

In 186 of these cases, agreement was reached between the parents and healthcare professionals about withdrawing aggressive, but ultimately futile, treatment.

But in the remaining 17 cases, extended discussions with the medical team and local support had failed to resolve differences of opinion with



the parents over the best way to continue to care for the very sick child in question.

The parents had insisted on continuing full active medical treatment, while doctors had advocated withdrawing or withholding further intensive care on the basis of the overwhelming medical evidence.

The cases in which withdrawal or withholding of intensive care was considered to be in the child's best interests were consistent with the Royal College of Paediatrics and Child Health guidance.

Eleven of these cases (65%) involved directly expressed religious claims that intensive care should not be stopped because of the expectation of <u>divine intervention</u> and a complete cure, together with the conviction that the opinion of the medical team was overly pessimistic and wrong.

Various different faiths were represented among the parents, including Christian fundamentalism, Islam, Judaism, and Roman Catholicism.

Five of the 11 cases were resolved after meeting with the relevant religious leaders outside the hospital, and intensive care was withdrawn in a further case after a High Court order.

But five cases were not resolved, so intensive care was continued. Four of these children eventually died; one survived with profound neurological disability.

Six of the 17 cases in which religious belief was not a cited factor, were all resolved without further recourse to legal, ethical, or socio-religious support. Intensive care was withdrawn in all these children, five of whom died and one of whom survived, but with profound neurological disability.



The authors emphasise that parental reluctance to allow treatment to be withdrawn is "completely understandable as [they] are defenders of their children's rights, and indeed life."

But they argue that when children are too young to be able to actively subscribe to their parents' religious beliefs, a default position in which parental religion is not the determining factor might be more appropriate.

They cite Article 3 of the Human Rights Act, which aims to ensure that no one is subjected to torture or inhumane or degrading treatment or punishment.

"Spending a lifetime attached to a mechanical ventilator, having every bodily function supervised and sanitised by a carer or relative, leaving no dignity or privacy to the child and then adult, has been argued as inhumane," they argue.

And they conclude: "We suggest it is time to reconsider current ethical and legal structures and facilitate rapid default access to courts in such situations when the best interests of the child are compromised in expectation of the miraculous."

In an accompanying commentary, the journal's editor, Professor Julian Savulescu, advocates: "Treatment limitation decisions are best made, not in the alleged interests of patients, but on distributive justice grounds."

In a publicly funded system with limited resources, these should be given to those whose lives could be saved rather than to those who are very unlikely to survive, he argues.

"Faced with the choice between providing an intensive care bed to a [severely brain damaged] child and one who has been at school and was



hit by a cricket ball and will return to normal life, we should provide the bed to the child hit by the cricket ball," he writes.

In further commentaries, Dr Steve Clarke of the Institute for Science and Ethics maintains that doctors should engage with devout parents on their own terms.

"Devout parents, who are hoping for a miracle, may be able to be persuaded, by the lights of their own personal...religious beliefs, that waiting indefinite periods of time for a miracle to occur while a child is suffering, and while scarce medical equipment is being denied to other children, is not the right thing to do," he writes.

Leading ethicist, Dr Mark Sheehan, argues that these ethical dilemmas are not confined to fervent religious belief, and to polarise the issue as medicine versus religion is unproductive, and something of a "red herring."

Referring to the title of the paper, Charles Foster, of the University of Oxford, suggests that the authors have asked the wrong question. "The legal and ethical orthodoxy is that no beliefs, religious or secular, should be allowed to stonewall the best interests of the child," he writes.

More information: Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children? Online First doi 10.1136/medethics-2011-100104

Commentaries:

Just dying: the futility of futility Online First doi 10.1136/medethics-2012-100683
When they believe in miracles Online First doi 10.1136/medethics-2012-100677



Religious red herrings Online First doi 10.1136/medethics-2012-100676 If you ask the wrong question, you'll get the wrong answer Online First doi 10.1136/medethics-2012-100682

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