CURRENT CONTROVERSY

Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?

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ABSTRACT

Religion is an important element of end-of-life care on the paediatric intensive care unit with religious belief providing support for many families and for some staff. However, religious claims used by families to challenge cessation of aggressive therapies considered futile and burdensome by a wide range of medical and lay people can cause considerable problems and be very difficult to resolve. While it is vital to support families in such difficult times, we are increasingly concerned that deeply held belief in religion can lead to children being potentially subjected to burdensome care in expectation of ‘miraculous’ intervention. We reviewed cases involving end-of-life decisions over a 3-year period. In 186 of 203 cases in which withdrawal or limitation of invasive therapy was recommended, agreement was achieved. However, in the 17 remaining cases extended discussions with medical teams and local support mechanisms did not lead to resolution. Of these cases, 11 (65%) involved explicit religious claims that intensive care should not be stopped due to expectation of divine intervention and complete cure together with conviction that overly pessimistic medical predictions were wrong. The distribution of the religions included Protestant, Muslim, Jewish and Roman Catholic groups. Five of the 11 cases were resolved after meeting religious community leaders; one child had intensive care withdrawn following a High Court order, and in the remaining five, all Christian, no resolution was possible due to expressed expectations that a ‘miracle’ would happen.

INTRODUCTION

Belief in religion is an integral part of humanity and of virtually every culture, although the extent of the belief and the depth of expectation from that belief vary. We describe a number of occasions that religion has featured in disagreements around the care of children on our paediatric intensive care unit (PICU) for whom it was considered further invasive treatment would be futile. We retrospectively reviewed cases in which religion featured heavily in discussions of end-of-life care over a randomly chosen 3-year period.

All cases involved children admitted to PICU with a serious and burdensome medical condition. Staff caring for these children were prompted to consider whether continuing to offer intensive care was in the children’s best interests. However, in every case an impasse was reached between the child’s parents, who insisted on continuing full active medical treatment, and the intensive care and referring teams who were advocating withdrawal or withholding further intensive support. This is not an uncommon situation and completely understandable as parents are defenders of their children’s rights and indeed life. However, what is unique about the cases we describe is that religion was introduced as a non-negotiable aspect of these discussions. We were interested to see if there were any patterns of behaviour or ethical issues common to these cases.

REVIEW OF CLINICAL ETHICS CASES

During the 3-year period of this retrospective review there were 290 deaths on our unit. Recurrently around 70% of deaths on PICU involve agreed limitation or withdrawal of care, around 25% die with full resuscitation ongoing and the remainder have brain death certified.1,2 During the 3-year period 203 children had withdrawal or limitation of invasive care recommended by the medical team and in 186 cases families agreed that this was in the child’s best interests. However, in the remaining 17 cases agreement could not be achieved with the families. We reviewed the case notes and found a predominant theme of expression of strong religious belief influencing the family’s response to the critical illness of their child. Of these 17 initial cases, 6 were resolved by considering the best interest of the child, further time for the families and ongoing multidisciplinary discussions. However, 11 (65%) involved challenging protracted discussions, largely based upon the belief in the sanctity of life as a result of the parents’ religious convictions. A proportion included Christian families from the African subcontinent who seemed to have developed a particular culturally influenced understanding of Christianity; all were interpretive sects within an established religion understanding the basic tenets of the faith through both cultural and individual interpretations. Followers of the Muslim, Jewish and Roman Catholic faiths were also represented in this group.

All cases where withdrawal or withholding of intensive care was considered to be in the child’s best interests are described in the Royal College of Paediatrics and Child Health guidance.3
support the families and discuss the children’s care with the clinical team. The remaining six cases underwent ethical reviews, second opinions from other Trusts and numerous multidisciplinary team meetings between medical staff, the patient advocacy liaison service and the family. In the Christian groups who held fervent or fundamentalist views, the parents did not engage in exploration of their religious beliefs with hospital chaplains and no religious community leaders were available to attend meetings to help discuss or reconcile the differences. The parents had their own views or interpretation of their religion and were not prepared to discuss these tenets. Fundamentalism is defined here as the expectation that specific theological doctrines will be maintained. While this term has been used in the past pejoratively, it is used descriptively here in line with its original use by the Protestant communities of twentieth century America, which indicated an unwavering attachment to a set of irreducible beliefs. Only one case required referral to the High Court, where medical care was ordered to be withdrawn.

In cases in which religion was not a fundamentalist factor all ultimately had successful local resolution. Withdrawal of intensive care occurred in all these children of whom live died and one survived with very limited neurological recovery. Of the total original cohort of 17 children, 14 (82%) died soon after intensive care was withdrawn, one died within a week of withdrawal of intensive care and two children survived with profound residual neurodisability. All three Abrahamic religions were all represented in the groups with whom reconciliation was achieved. Of those in which resolution was not possible, Christian fundamentalist churches with African evangelical origins featured most frequently, though other religions also featured. All these families were explicit in their expectation of a ‘miraculous cure’ for their child, and as such all felt the medical scientific information was of limited use. Although ongoing daily dialogue continued between the family and the teams there was no change in the family’s view that aggressive support must always be continued waiting for God to intervene. These children continued to deteriorate despite continued intensive care, with four eventually dying on leaving PICU, or shortly after, and one surviving with profound neurodisability.

DISCUSSION

It is important to note that while most resistance to medical advice in our series was based on religion, one-third of all refusals to accept advice were not. These were all resolved internally over time. However, this is not to suggest that these families did not have religious beliefs but rather that this was not the reason given for initial or ongoing opposition to advice from the medical teams. However, the most significant recurrent factor in families with whom agreement could not be reached was their expectation of an imminent miracle for their child, which was an expectation of their religious beliefs.

As these 17 cases caused considerable stress, tension and conflict for parents and staff, the need for a different approach became paramount. By beginning to look at the wider issues inherent in these cases we have developed strategies, terms of reference and a transparent method of interaction in which, at the very least, all of the parties have an opportunity to be heard. All the suggestions made here are secondary to the rights and needs of the child.

When death is inevitable and continued treatment is felt to have no purpose or be excessively burdensome, the medical team caring for the child may advocate withdrawal of life-sustaining therapy. Burdensome is described by the Royal College of Paediatrics and Child Health as situations when death is inevitable and treatments cause pain and discomfort, for example, fourth or fifth courses of chemotherapy in disease processes with a 0% chance of survival. At this time parents often resort to their religious beliefs for comfort, support and guidance. Despite overwhelming medical evidence and advice about the eventual outcome, some parents insist on everything being done for their child in a belief that their religion would expect nothing less and would not condone any action or decision that would result in death. There is also a hope or even expectation of a ‘miracle cure’, with time for further prayer and demonstrations of faith necessary for a favourable outcome. For some families in this difficult situation there are additional extraneous pressures from the religious community or church leaders.

While there can be no cultural lack of understanding that death is the natural process that ends life, there may be an expectation that modern artificial interventions preserve life and should restore the body. More interesting is whether the need to have a belief in a religious structure is such a part of the fabric of certain cultures, where creed and culture are so intertwined that to separate out religious from cultural acceptance of death and understanding of futility is impossible.

Our team is accustomed to resolving issues with the more familiar Abrahamic religious groups. However, demographic changes in the UK, especially in London, mean newer groups exist which are not well known or understood and these groups have difficulty accepting end-of-life decision-making processes, especially when this involves withdrawal of artificial life support. Whist this is understandable as it is a parent’s absolute responsibility to preserve the life of their child, we found unorthodox interpretations of religious teaching occurred in a number of cases. However, the use of religious teachings to perpetuate a situation that appears futile and which may result in distress to the child needs to be questioned. One extreme example would be perpetuating full intensive care treatment in a child with anencephaly. Frequently, when the religious leader for the particular faith is consulted, the religious basis of the parental resistance is undermined by the cleric and this can enable parents to accept the imminent death of their child in the context of their faith, almost as if they had been given permission. However, we have experienced sects who are now emerging often with a nominal basis in a mainstream faith, with religious leaders who interpret the rules of their religion in different ways. Increasingly this is coming to the fore in encounters with fundamentalist believers in a variety of religions, including Christianity, Islam and Judaism.

The fervent belief that some parents hold, while often of comfort to themselves, does not always take into consideration the best interests of their child, who may not be old enough to have a religious belief. It is accepted in our society that it is the right of parents to decide upon a child’s religious beliefs and to make decisions for that child based upon this premise. There are interesting echoes here with the Gillick argument7 in terms of age of consent and parents making medical decisions for their children. In many cases, the children about whom the decisions are being made are too young to subscribe to the religious beliefs held by their parents, yet we continue to respect the parents’ beliefs. Children are currently seen as having a religion by virtue of their parents but it could be argued that children have no religious faith until such time as they are deemed mature enough to make decisions around consent. What about children who are
fostered at the age of 6 or 7 or those adopted, for example, from a Chinese or Russian orphanage by a Jewish, Christian or Muslim infertile couple. They are likely to be brought up in the religious beliefs of the adoptive adults irrespective of their ethnic origins. As Dawkins suggests, should we refer to the ‘child of Christian parents’ rather than a ‘Christian child’?8 We suggest it is time to have a default position in that it is presumed that parental religion is not a determining factor in decision-making for the child until the child is ‘Gillick competent’ to choose to consent to be part of the parent’s religion; thereby recognising that religion is important to the parents but should not influence the management of their child.

The most obvious example of a situation when parental beliefs are recognised but put to one side is when parents are Jehovah Witnesses and their child’s life is potentially put at risk if denied a blood transfusion. In these circumstances, the beliefs of parents are respected but the best interests of the child put first.

Yet the less dramatic but equally challenging position of continuing to cause potential pain and suffering by insisting on care that will not improve or cure the child’s condition does not have equal bypass. There is no presumption that the child in a futile condition as perceived by physicians and lay people should have automatic referral to a process that can challenge the parental decision to persist with purposeless, pointless or unbearable treatment based upon their interpretation of their religion.

Article 3 of the Human Rights Act 1998 (Prohibition of torture) is specifically intended to ensure ‘no-one shall be subjected to torture or to 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 or adult has been argued as inhumane.9 Repeated tracheal suctioning and bladder catheterisation are accepted as painful.10

**IMPERIAL ETHICS**

It has been suggested that we are becoming an increasingly ‘secular society’.11 By virtue of the definition of secularism, this would mean that society is not governed by any particular religion. There would nevertheless be the need to know and interpret the guiding principles for decision-making. However, if this were the case then there would be a clear move towards exercising the ‘majority’ secular view and attempts to impose secular ethical values on minority religious beliefs. Numerous healthcare groups in this secular society might feel empowered to criticise any religion that in their view advocated illogical practices, for example, prohibiting the use of condoms in the face of the spread of HIV and AIDS. Yet followers of one of the world’s largest religions within our society, which is accused of being secular, would defend this proclamation from their spiritual leader and expect to have their view accepted and consequently this particular practice is condoned. So in this alleged secular society in the UK, we have a tendency to be more accepting of some religions and their practices more readily without questioning them. Professionals or secularists within the UK or Western world will accept these religious tenets more sympathetically if they come from a faith they recognise, or indeed may once have been part of, more so than other newer religions. This prejudice favouring traditional religions demonstrates a degree of imperial ethics. There is ethical tolerance to values that we are more accustomed to and an overt understanding and acceptance of the validity of religiously founded claims, which emanate from the tenets of older, more established religions. In our readiness to question minority religions we may not be giving them an equal voice and establishing a hierarchy of religions, some of which a secular system is prepared to accept and some to challenge. Sometimes, while not based on established jurisprudence, the perception is that we are prepared to challenge in the courts a newer religion with different belief structures but are prepared to accept the more established religions.

For instance, there are a number of medical procedures which are fundamental to certain religions and ingrained within that culture that have little evidence base, and yet we tolerate them. If a newer Third World religion advocated child injury there would be significant reservations. However, in more established religions male circumcision, carried out 8 days after birth, is essential according to religious law despite this religious-ethnic tradition having a complication rate of up to 16%.12 Male circumcision is also practiced in Islam and Judaism and some Christians in Egypt, and 50% of boys in the USA are circumcised. Female circumcision is practiced in Sudan, Somalia, Egypt and other Arab and Muslim countries.13 Female genital cutting, which can involve removal of the clitoris, may reduce the likelihood of orgasm and cause complications during childbirth. Male circumcision can result in nerve destruction, infection, disfigurement and sometimes death. At the same time the view is taken by some faith communities that this is more than just a scientific surgical process, but based on culture, tradition, society and faith.

Some consider this disfigurement of children without medical reason but for religious purposes as unacceptable, yet it is tolerated. Neither the WHO nor the United Nations oppose male circumcision, and as shown recently in San Francisco, any attempts to legislate against it are strongly resisted.14 However, other communities that value body piercing of the tongue, ear or other parts of their children’s anatomy when aged only 8 days as integral to their religious beliefs may not get as tolerant a reception. Similarly cultures that find the practice of witchcraft or voodoo rituals on their children acceptable might be readily challenged in a secular society.

This hierarchy of religions may revolve around a known, if not totally understood definition of terms. In our context a mutual, imperial-like understanding of terms such as life, hope and fertility is necessary for all parties if they are to have an end-of-life conversation. If families have adopted and adapted their own understandings of their religious teaching then misunderstandings arise. If parents use their personal understanding of their religion to defend their child then shared concepts and conversations become difficult.

If a religion is well established within a society with many millions of followers it may be more challenging to even consider seeking judicial review against a parent of that faith. There may almost be a feeling of challenging the authority of the State or at least the status quo. It is perhaps easier to confront a newer religious sect than the more established Abrahamic religions. The increasing diversity of our multicultural society brings forward different versions of religions with local cultural expectations, which view current limitations of medical science as cultural materialism and believe God will rise above all. In expecting miraculous solutions many of these faiths fail the general principles suggested by Burszyska for assessing the ethical defensibility of a claim made in the name of cultural, spiritual or religious considerations.15 In these cases in which cures are expected on the basis of religious belief, perhaps it is time that a firm legal response to all religions is established. In

this way equal weighting can be expected for all old and emerging religious views.

Recognising the risks of accepting an arbitrary hierarchy of belief systems, a need arises for establishing a transparent provision for weighting. Within the transparency could be a shared decision-making structure. Included in this could be a definition and acceptance of physical and scientific evidence; an articulated faith position from which terms like hope, healing and futility can have their definitions derived; an authority of reference for the faith position, be it in orthodoxy, tradition or personal belief. This would also allow the opportunity for the beliefs to be ‘sited’ within a community, culture or religious hierarchy and as Viens suggested, allow the potential risks and benefits associated with the child’s welfare to involve medical, social and cultural factors. This would also apply to withholding and withdrawing treatment.

In the cases we encountered there were significant differences in interpretation of perceived medical fact as a result of a fervent religious belief. The intensive care staff, the chaplaincy and various mediators attempted dialogue, though in a number of cases with little success. Dialogue by its nature implies shared conversation and if the parties are not sharing the same language then difficulties arise. This becomes particularly troublesome when the ‘religious’ language of families has no relevant grounding in the teachings of their own faith.

We agree that any solution should allow due deference to a family’s beliefs and shared involvement in decision-making and generate possibilities to create mutually agreed solutions.

In developing the argument of religion being legislated against in the best interest of the child, earlier reference was made to the religious views of parents who are Jehovah Witnesses taking second place to giving life-saving blood transfusions to children. This view is accepted by society as a given and the recognition that certain religious beliefs cannot be applied to children who cannot consent to being part of that religion and who will come to harm as a consequence. There is a natural acceptance now in paediatric medicine, indeed it is part of the standard teaching, that if blood is refused for a child by its parent on the grounds of the parent’s religion, protection of the child is paramount. This is to ignore the strongly held belief of the parents on the basis of acting in the child’s best interests.

This type of approach should then perhaps become the standard expectation in cases of withdrawal of futile life-sustaining therapy, which causes pain and discomfort. There has to be a legal presumption that life has to be sustained; but ethically the sanctity of life can be balanced against the futility of inappropriate attempts to prolong it. The current position of ongoing internal and external medical reviews (second opinions) and ethical reviews before seeking a court order can be protracted and arguably damaging to parents, to healthcare workers looking after the child and of course most importantly to the child itself. Such situations should result in rapid intervention, despite clearly conflicting with religious views central to the parents’ life plan. Instead, usually after many weeks or months of protracted unsuccessful discussions, with both sides trying to get the other to see their point of view, a request is made to the courts for a declaration on how to proceed. Many are unused to or unprepared to take this route and leave the child in an unacceptable condition for fear of unfavourable publicity or costs or outcome. We propose that it would be better to have a default position as there is for the Jehovah’s Witness solution. This would not preclude the expectation of providing expert opinion and evidence to support both sides—there would just be an expectation of an accelerated process; it would simply become the default position in religious disagreements on end-of-life management, as it is for refusing consent for transfusion, which could also result in death. The obvious difference being the former is seeking a default position which will result in death whereas the latter is seeking to preserve life. However, we would argue that both are attempting to protect the child’s best interests. The issues revolve around the balance of sanctity and quality of life versus unbearable suffering.

Against our position is the clear legal presumption for the maintenance of life, and an understandable caution within the legal system to making any rapid decisions which may result in death. Many such cases are heard over weeks with considered deliberation of evidence before a decision is made. Furthermore, for some religions it is believed that the suffering we are arguing to avoid is something that brings the truly faithful closer to God. One further argument for such an approach and one we do not shy away from is the resources used in maintaining children in this setting. While we feel the best interests of the child in question are paramount, the interests of society— including the other children who might have used this valuable resource—cannot be ignored, especially when non-medically indicated painful and futile therapies are continued on children due to the expectation of miraculous intervention.

CONCLUSION

On the rare occasions that it occurs, fervent belief in religion and the interpretation of those religious teachings are significant factors in end-of-life conflict between parents and staff on PICUs. For some religious groups with more fundamentalist beliefs, expectation of a miracle cure in which the emphasis is upon temporal recovery as opposed to a more eternal ‘healing’ is commonplace.

Traditional mechanisms for resolution of end-of-life disagreements based upon local cultural, secular or religious values were not infrequently unsuccessful. Protracted dialogue was often unable to resolve these differences, while the child was subject to pain and discomfort from invasive ventilation, suctioning and multiple injections. 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.

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