

More information on ethics and end-of-life decision-making

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The basic ethical principles

In clinical ethics there are a number of basic principles, which identify key ethical values. In the most general terms, these principles are

- **Beneficence** – the principle of producing benefit or doing good to the patient
- **Non-maleficence** – the principle of not causing harm, or allowing harm to occur to the patient
- **Autonomy** – the principle of respecting the patients' right to make their own choices about their own lives. Put into practice via the processes of informed consent and shared decision-making.
 - **Confidentiality and privacy**
Also grounds the ethical value of confidentiality and privacy, because control of who knows or sees things about oneself is an important aspect of making choices about one's own life.
- **Justice** – fairness or distributive justice in the allocation of resources, and of benefits and burdens of health care. Includes non-discrimination.

(Reference: TL Beauchamp and JF Childress. *Principles of Biomedical Ethics*)

These principles provide a broad framework of ethical analysis and decision-making in the paediatric context, but need some adaptation and further specification. This is needed for a number of reasons, in particular because

- The child patient in most cases has no capacity for autonomous decision-making, and so parents will be making decisions for their children. This complicates the principle of respect for autonomy.
- Older children begin to develop cognitive capacities and life skills, and hence begin to develop their own capacity for autonomy. This also has to be considered, and again complicates the principle of respect for autonomy.
- The well-being of a child actually depends to a significant extent on the child's parents and their capacity to provide care and support, especially in the context of serious long-term condition, chronic illness or disability. So what will benefit a child, or promote his or her well-being, is actually partly determined by the parents – their attitudes, beliefs, skills and abilities, resilience and determination, family circumstances (such as other children), and many others. However, whilst there is this entanglement and inter-dependency of interests, it should be remembered that the child is also a separate individual. The child's well-being is not the same as the parents' or the family's well-being. This complicates the principles of beneficence and non-maleficence.

- Children may have no sense of privacy (either about their bodies or their information) but their privacy is still important. It is also possible, especially for older children, that they may want some degree of privacy from their parents, even though their parents are their medical decision-makers.

Ethical principles in paediatrics

Taking into account the ethical complexities of the situation described above, the following would be a more specific refinement of the ethical principles for paediatrics

- Promote the well-being of child (beneficence and non-maleficence)
 - Act in way that will benefit the child – physically, psychologically, emotionally, socially
 - Protect the child from harm
 - Protect future-related interests (things that will matter to them in the future, but do not matter to them now – eg fertility)
- Promote well-being of family (beneficence and non-maleficence)
- Respect parents as decision-makers for the child (autonomy)
- Respect child's (developing) autonomy
- Respect privacy of child
- Respect the privacy of the parents and family
- Allocate resources at your disposal fairly

In the paediatric context, there are some particular complexities in using these principles. The most obvious of these relates to the principle of respect for autonomy. In adult medicine, this means respect for the autonomy of the competent adult patient. In paediatrics, it means both respecting the right of parents to be the decision-makers for their children, and also respecting the child's developing capacity for decision-making, and hence their evolving right to be involved in decision-making about their treatment. However, the parents' right to be decision-maker for their child is not absolute in the same way as a competent adult's right to make decisions about him or herself. It is clear in both law and ethics that parents' decisions about their children can be overridden, if the decision puts the child at significant risk of harm. This because the principle of non-harm to the child is ultimately considered to carry more ethical weight than the principle of respect of parental autonomy. The precise circumstances under which this should occur is contested and difficult to specify (see below on parental rights and autonomy), but the basic principle is very clear: parents' decisions are not necessarily final, and there are clear avenues for making legal challenges to them.

For an adolescent with developing maturity and decision-making capacities, there are also complexities. The accepted theoretical position in ethics is that the growing

decision-making capacity of adolescents should be respected, and that they should be involved more and more in making decisions about their own treatment, as that capacity increases. Finally, they will attain full capacity to make their own decisions, perhaps in many cases before they reach 18, the legal age of adulthood, at which capacity is presumed to exist. In legal terms, these are the so-called mature minors, who are regarded as having the capacity to consent to treatment independently of their parents, and whose decisions ought to be respected. This is a clear idea in theory, but hard to put into practice. Before the stage of full capacity or competence, there is a grey area, where it is not clear what weight to give to a young person's wishes or preferences, especially where these are contrary to their parents' wishes. (see under "**When children disagree with parents over medical treatment**")

Parental rights and respect for parental autonomy

What is the ethically correct thing to do when parents' wishes appear to be contrary to a child's best interests? This could occur either when parents decide against treatment which could save the child's life, or when parents want to continue active treatment when doctors believe that this is simply prolonging the child's suffering, and death is inevitable. Parents' decisions can sometimes be overridden – there are legal mechanisms to permit and facilitate this, and there are ethical reasons why in particular situations, the decision should be overridden. Even if legal steps are not taken, more subtle sorts of pressure can be exerted on parents to change their minds. However, there is not full agreement in ethics about what these situations are in which it is ethically acceptable, or even required, to intervene and go against or change parental views.

There are two different ways of understanding these situations, based on two different views of the ethical basis for the parents' role as decision-maker: the *parent as proxy* view, and the *parental autonomy* view. They differ in the degree of latitude that they would allow parents, before it becomes ethically necessary to intervene and go against parents' wishes. On the parent as proxy view, the parents have less latitude – if their decision is contrary to the child's best interests (ie fails to do the best for the child), then their decision should be overridden. On the parental autonomy view, parents have more latitude, and their wishes should only be overridden if the child will be done significant harm by their decision (in contrast to the child not being given the absolute best).

Deciding to initiate legal action, or to take informal steps to persuade parents, is a significant decision in itself. Doctors frequently prevail in these sorts of situations and so it is important to have thought through the ethics before taking such steps.

View 1: Parent as proxy - threshold for intervention is a decision that is not in the child's best interests

The more traditional way, in both law and ethics, is to view the parents as proxy decision-makers for their child, whose obligation is to make decisions which are in their child's best interests. Broadly, this would mean decisions which best promote that child's health and well-being. The implication of this is that whenever parents' decisions do not

promote the child's best interests, then in theory, it would be ethically appropriate to intervene and override the parents.

In practice, the decision to intervene is more complex. For a start, any intervention would only be justified if it had a good chance of succeeding in improving the child's situation. If, for example, getting a court order to treat a child against the parents' wishes would most likely result in the parents absconding with the child, then this would not succeed in promoting the child's best interest, since the child would end up with no treatment at all. Also, an intervention would not be reasonable if it would be likely to do more harm than good in the long term. For example, if the parents would be alienated and not provide the child with emotional support during difficult treatment, or not provide appropriate follow-up care at home, going against their wishes may make things even worse in the long run.

View 2: Parental autonomy – threshold for intervention is a decision that will cause significant harm to the child

The less traditional view, but one which is gaining wider and wider acceptance, is that parents' job is to make a "good enough" decision for their child. As parents, they have an obligation to consider the needs of any other children they have, and the family as whole. They also have a right to consider their own, at least to some extent, and to act on their own values and understandings of how best to raise and care for their children.

The best interests of a child

The term "interests" is a technical term in moral philosophy and ethics. It refers to those things which are needed to have a good life, and which a person therefore has a significant ethical claim to. It encompasses the ideas of beneficence and non-maleficence. Interests include physical matters, such as not suffering or being in pain, having capacity to move etc – that is, things which a person would experience as good, and the loss of which they would experience as bad. Interests also include social and emotional factors, such as having interactions with other people, feeling safe etc. Future interests are particularly relevant to children – these are things that will matter significantly to their lives in the future, even though they do not matter to the child at the moment, such as capacity to have children or form intimate relations. Another way to think about interests is in terms of well-being, in broad terms.

To act in a child's "best interests" is to do whatever will best promote all the child's interests. It is a maximizing concept – doing the best for the child overall. However, since a child has a range of different but important interests, it is not always possible to fulfil all interests all of the time. For example, a child has an interest in being pain-free and in living longer, but it may not be possible to have both. So acting in a child's best interests can be a matter of working out the best compromise, or deciding between competing considerations. Acting in a child's best interests should not necessarily be equated with prolonging the child's life for as long as possible. In both law and ethics, it is recognised that it is not always better for a child live longer, nor is a child necessarily harmed by dying sooner than might have been possible with the full application of medical technology.

This makes judgements of best interests not a straightforward factual matter. Reasonable people working on the same evidence can disagree, either because they have different views about probabilities of possible outcome, or more likely because they have different values. That is, they place greater weight on one sort of interest (eg living longer) than on another sort (eg not being in pain).

Is parental consent always required for withdrawal or withholding of life-sustaining medical treatment?

Whilst it is in general much preferable to have mutual agreement between clinical staff and parents about withdrawing or withholding life-sustaining treatment, it is not absolutely necessary for parents to agree to this course of action before it can go ahead. There are some circumstances under which it could be ethically appropriate and legally permissible for doctors not provide some form of medical treatment, even if parents want the treatment and make an informed decision in favour of it. The basic reason for this is that neither doctors nor the hospital have a legal or ethical obligation to provide treatment which they believe is either

- (a) clearly contrary to the child's best interests, or causes the child unjustified suffering – for example, treatment that would cause suffering and would only prolong life for a very short time before inevitable death.
- (b) Not within the hospital's resources to provide

The limits to parent autonomy discussed above (under **“Parental rights and respect for parental autonomy”**) apply as much to parents' decision to pursue further active treatment as they do to parents' decisions to refuse treatment for their child. The parents' decision is overrideable.

‘Waiting for the parents to come around’

As well as having ethical obligations to the child patient, clinicians do have obligations to care for the family. So it is entirely ethically appropriate, in general terms, to allow parents time to adjust to their child's situation, come to terms with it, and reach their own decision that it would be better for their child if treatment were withdrawn or not commenced. This would be best practice, in theory. However, difficulties can arise. If the child is experiencing physical pain, or suffering in other ways, whilst time is being given for the parents to come around, then two ethical values are in conflict. If this can be resolved by increasing pain relief medication or level of sedation, even if there is some added risk of death for the child, then this would be the appropriate way to resolve it. If suffering cannot be effectively reduced, however, there is a stark ethical choice, and the standard position is that the interests of the child patient should be put first.

Somewhat different questions arise if the time waiting for parents to come to agree with the recommendation to withdraw or withhold treatment starts to stretch out. Even if the child is apparently not suffering (eg because unconscious or deeply sedated) in the weeks or months that are passing by, it may still be felt to be ethically problematic to continue to treat the child, when this is primarily being done for the sake of the parents. In particular, it may be seen as contrary to respect for the child's dignity, when the treatment can bring

no improvement in the child's condition, or offer the child any sort of positive or happy experience of life. It could be regarded as using the child as a mere means to help the parents, without having due regards to the child as a person in his or her own right. However, the ethical case for stopping treatment against the parents' wishes is not nearly as strong as it would be if the child were suffering whilst treatment continued.

The other issue to consider in this matter is whether the parents are actually willing or able to be the decision-makers in end-of-life situations. Whilst many parents will want to be actively involved in all medical decisions regarding their child, others may find this too confronting, distressing and burdensome, especially when the decision they are being asked to make will result in the death of their child. Respecting parental autonomy includes offering parents the option not to be the final decision-makers, and respecting their right to hand over decision-making to someone else. For example, parents may understand their role as being the protector of their child in a way that would never allow them to agree to limitation of treatment. For the sake of their own conscience and mental well-being in the future, they may need to take the role of arguing for continued treatment right up to the end, so that they can feel they have everything possible to save their child. If this is happening, it may be appropriate for doctors to play the role of the one putting in limits on treatment, which the parents may accept when done by doctors, but could never do themselves. In situations like this, it makes no sense to "wait for the parents to come around", since that is never going to happen.

What does it mean to respect the child's "developing capacity for autonomy"?

Some aspects of respecting a child's developing capacities, whilst not treating them as having full ethical authority to make decisions for themselves, are quite clear. Such respect would certainly include providing children with information about their condition and treatment or management planned, giving explanations in a way which is understandable to them, giving the opportunity to ask questions, and providing truthful answers to these. It would also include eliciting and listening to children's concerns, and taking these seriously. In some cases, it might be possible to allow children with developing capacity to make some choices about some aspects of their treatment (eg time or place where an intervention is done, site where an IV is inserted etc), without this affecting the overall plan of management.

But beyond that, if a child who is not yet fully competent (ie does not count as a mature minor) does not want to have the treatment that his or her parents have decided on, this is an ethically complex situation to manage. See under "**When children disagree with parents over medical treatment**". When a mature minor does not want treatment that the parents are in favour of, this is arguably clearer, especially in ethical terms. A mature minor is ethically on the same footing as an adult – which means having the right to decide what treatment to have, and what treatment not to have, even if these decisions are thought foolish by clinicians. In practice, however, it would be a very difficult thing to treat a mature minor when the parents do not want treatment, or not to treat when the mature minor refuses treatment but that the parents are in favour. In these sorts of circumstances are

on the horizon, clinicians are advised to contact the Clinical Ethics Service and the RCH Legal Counsel (Margaret Kingston) for case-specific discussion.

When children disagree with parents over medical treatment

When younger children resist treatment which their parents have decided on or consent to, it is ethically appropriate to treat the child's resistance (verbal or physical), as a behavioural matter, rather than as a refusal of treatment. The planned treatment is presumably aimed at the child's best interests in the long run, and so the challenge is find a way to do the treatment without unduly compromising the child's short term interests in not being in pain, and in not feeling ignored, distressed or compelled. So it would be appropriate to attempt various strategies to negotiate and compromise, to try to reduce the child's resistance and distress as much as possible. But in the end the long-term benefits of treatment would presumably outweigh the short terms harms caused to by forcing treatment on an unwilling child.

When an older child does not want to have treatment, especially life-sustaining treatment, which the parents do want, things become a bit more complex.. The first steps would always be further discussion with the child or young person, both with and without the parents present, to try to identify reasons for the young person's view, clarify any misunderstanding, provide any information that is lacking, and lend a sympathetic ear for the young person to air their feelings. The aim would be to assist the young person and their parents to come to a decision which they were all comfortable with, which respected the need, concerns and developing autonomy of the young person, as well as the parents autonomy and views about what is best for their son or daughter. Again, negotiation and compromise would be appropriate. However, this will not always work to produce agreement.

The accepted theoretical position in ethics is that the growing decision-making capacity of adolescents should be respected, and that they should be involved more and more in making decisions about their own treatment, as that capacity increases. Finally, they will attain full capacity to make their own decisions, perhaps in many cases before the they reach 18, the legal age of adulthood, at which capacity is presumed to exist. So if an older child or adolescent were judged to be competent, and made an informed decision to refuse treatment, it would seem that this be respected, even if the parents disagree. However, not all ethicists accept this view. Some argue that even if the young person is competent in the sense that he or she understand the implications of their decision and has meaningful reasons for it, the parents' decision should still be final. There are reasons for this. The first is that the young person, even though technically competent, still lacks maturity and experience of life, and is not as well placed as the parents to protect his or her own long-term interests. The second, related to this, is that parents of a competent adolescent still have a parental obligation to protect their child's interests, and hence a right to do so in the way they judge best, as part of the exercise of parental autonomy.

These considerations are important, but are not necessarily compelling in every instance. It is hard to imagine, for example, forcing chemotherapy on a 16 year old who had many

years of treatment, remission and relapse, when the parents believe that the 10% chance of another remission is worth the burdens of treatment, but the 16 year old does not. The 16 year old has plenty of life experience of both cancer treatment and living with cancer on which to base a decision, and probably has about the same level of cognitive skills needed for decision-making as the parents do. However, going against the parents wishes in the situation would also not be easy. In addition, the law tends to look differently at decisions for and against treatment made by mature minors, being much more likely to support the young person's decision to have treatment without parental consent, than to grant the young person a legal right to refuse treatment, when parents wishes are contrary. If such a situation seems to be developing, clinicians are advised to contact both the Clinical Ethics Service and the RCH Legal Counsel.

Quality of life

Quality of life is a term often used, but unfortunately it can often be open to interpretation, or ambiguous. There are some main points to note:

- Quality of life is a subjective concept. Quality of life refers to the way life is experienced by the patient – what life is like for them, from their own perspective. This makes assessing the quality of life of a child quite difficult, especially if the child is too young to be able to describe his or her own experiences to others, or if a older child, due to illness or injury, is unable to communicate their thoughts and experiences. It is not about primarily about what activities the child can perform, or what abilities they have – it is about what their life is like to them, having those particular capacities and experiences.
- Avoid projecting your own views about life onto the child. It is vital to remember when trying to assess a child's quality of life that you are trying to see the world through that child's eyes, not your own. The key question is “how does life feel for this child?”, and not “How would I feel if I were this child?” This is because the way we experience life, as happy or sad, good or bad, depends on our thoughts, feelings, desires, expectations and interests, as much as on our physical condition. This is particularly important when considering a child with a disability. There is an important difference between the experience of a child who has always had a disability, such a quadriplegia, and a child who was previously well and is now experiencing the loss of abilities that he or she once had. Parents are usually the best source of understanding what a child's life is like for that child, since they are so familiar with their child. But they are not infallible – parents may see what they want to see, fail to see what is unpleasant, or misinterpret signs of distress, all without realizing it. Nevertheless, parents' views should always be sought and be accorded due weight.
- Negative vs zero quality of life: Unpleasant experiences vs *no* experiences In the end-of-life context in particular, it is not uncommon to describe a child as having “no quality of life” or “low quality of life”. Unfortunately, these sorts of terms are ambiguous between two very different concepts. One is “negative” or “bad” quality of life, where a child has only bad experiences, such a physical suffering and fear, or has a lot of bad experiences and few good ones, so that there are not enough good experiences (pleasure, happiness) to outweigh the bad ones. The

other is “zero quality of life”, which strictly speaking means no quality of life at all – that is no experiences at all, either good or bad (for example, a child in a coma, or with massive brain damage). This distinction is vitally important. Prolonging the life of a child who has negative quality of life is causing harm to that child, because the child is suffering. But prolonging the life of a child with zero quality of life is not causing harm to the child, because the child is not capable of experiencing suffering. (There may be other good ethical reasons not to prolong the life of a child with zero quality of life, but avoiding doing harm to child is not one of them).

Is treatment futile?

Futility is a relative concept. Whether or not something is futile can only be judged with reference to its goal. So when questions arise about whether medical treatment is futile, the key issue to consider is the goal of treatment. Doctors and parents may have different views about what the goals are, and so different views about whether or not a particular treatment is futile. (Of course, the same differences can exist between clinicians) For example, parents may see the goal as keeping their child alive for as long a possible, even if the child has severe and irreversible brain damage and permanent loss of consciousness. Doctors treating this child may see the goal as improving the child’s quality of life, and producing some improvement in their condition. In this situation, parents would see continued ventilation as an effective treatment, because it would succeed in keeping the child alive. Doctors would see continued ventilation as futile, because it would not be able to achieve the goal of improving the child’s medical condition or quality of life.

The real disagreement is not about whether ventilation is futile, but rather about what goal is appropriate, or, put differently what outcome is worth aiming for. This is a difference in values, not a difference in facts, and is not easily resolvable. Nevertheless, progress cannot be made until the goals of the relevant parties have been identified

