

Ethics in Paediatric Palliative Care

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Introduction: the scope and function of medical ethics

A starting point for medical ethics is that there is potentially an imbalance of power between physician and patient that must be redressed by 'rules of engagement' that set out how a doctor should behave. That conception encompasses the idea that there is a moral obligation for human beings to be fair to one another, and also that one requirement of fairness is that those who are strong should show special consideration to those who are weak. It is particularly relevant to children needing palliative care, who are made multiply vulnerable by their youth, small physical size, illness and usually motor and cognitive impairment.

Ethical codes have elaborated on those basic ideas, starting with the Hippocratic Oath and the principle of *primum non nocere* ("firstly, do no harm") and more recently in the four principles approach of Beauchamp

and Childress (1). The focus of medical ethics was how a doctor should behave towards a patient; the idea that it should also account for a responsibility to society is more recent.

The relationship between physician and child and family largely defines the *scope* of paediatric medical ethics, but not its *function*. From the perspective of the child and family, ethics is a means of empowerment; an attempt to 'level the playing field' in relationship with the clinician. To society, it can be a way of ensuring that doctors are not isolated from contemporary mores of the community in which they live, including notions of how healthcare money should be spent.

From the perspective of the clinician, however, the task of medical ethics is essentially analytical. It is to help resolve moral quandary; to guide decision-making in respect of patient management through an appeal to what is morally right in clinical situations where rationality and medical competence alone do not provide a single clear answer. This chapter sets out current approaches to ethics in paediatric palliative care and suggests that none is completely satisfactory. A coherent and specifically paediatric account of medical ethics is needed that flows from a clear understanding of the moral nature of a child.

1. Ethics in children: paradigms in practice

Two paradigms dominate contemporary ethical dialogue in respect of children: rights-based arguments (2-6), and those based on the 'four principles approach' (1, 7). Rights-based claims that emanate from the UN Convention on the Rights of the Child (8) are child-specific, but are not argued from an ethical premiss. The four principles approach (1) does flow from understandings of ethical theory, but it is not designed for children. Each usefully informs ethical discussions in children, though neither represents a complete account.

1.1 Rights

In the absence of a specifically child-centred ethical understanding, paediatric clinicians often have to fall back on rights-based claims to generate or support ethical arguments. Rights-based dialogue provides a pragmatic and legal, rather than ethical, account of the way in which a clinician should treat a child. This annexing of rights-based understanding to ethical deliberation is justifiable, at least in part, because the idea that children have rights at all is itself a radical, powerful and foundational claim about their moral status.

Modern concepts of children's rights come largely from the United Nations Convention on the Rights of the Child (8), adopted by the United Nations General Assembly in 1989. The Convention is intended to give force to a child-focused legal agenda (4). It does not set out to provide any coherent ethical account of childhood, nor does it attempt any moral argument concerning the nature of rights. The Convention invokes an assertion in the earlier UN Declaration preamble (9) in which rights were held to be self-evident, needing no further justification, to apply to any member of the human race, and to be characteristics of the individual, rather than commodities given to the individual by the state. By applying this definition of rights to children, the United Nations Convention insists there is no distinction between the moral value of the child and that of an adult, irrespective of stage of development or cognitive ability. That is an important assertion. In ethical discussions, children are often considered to be 'works in progress'; to have moral value as potential persons rather than as current members of what the Convention calls 'the human family'. The nature of children is, of course, to develop and to become adults, but a child is arguably no more a potential adult than a 20-year-old is a potential 40-year-old. If a child is considered only a potential person on the basis that they will become something different as they get older, it is logically necessary to claim that the objective of of human potentiality, to which all development is teleologically directed, is represented by the nonagenarian who is close to death.

Despite that emphasis, the UN Convention acknowledges that children are distinct from adults in ways that are morally relevant. According to the Convention, the inherently developmental nature of children imparts special value. The Convention claims that it is the nature of children to be cared for in a family, and that society's responsibility to children should usually be manifest in protecting and supporting the family as they care for the child. These fundamental claims are all located in the preamble of the convention, identifying them as foundational for the whole document.

Properly understood (10, 11), a right imposes a logically entailed duty on whoever the right is held against. If they are truly rights, articulation of any claim by the Convention imposes a moral requirement on state signatories that should override where necessary the legislative process of individual nations. It is that power that concerns many rights sceptics (12, 13). Rights advocate Alderson responds by making a lesser moral claim for rights, describing them as “claims, reasons ... [they are] about solidarity and equality, relationships rather than isolation ... moral relationships between vulnerable, easily harmed persons” (2). Re-defining claims in the Convention as aspirations and statements of moral intent, rather than true rights, allows rights-based arguments more helpfully to inform an account of medical ethics in children.

1.2 Principlism

The four principles approach was formulated by Thomas Beauchamp and James Childress (1). They articulated four medical ethical principles that have come to be the mainstay of most training in clinical medical ethics: beneficence, non-maleficence, respect for autonomy, and justice. These have been elaborated elsewhere in the book. Beneficence is the responsibility of the individual clinician to do what is good for their patient, non-maleficence is the duty to avoid where possible doing harm, respect for a patient's autonomy means allowing freedom to choose (to the extent that they truly possess autonomy), and justice is taken to be the responsibility of individual clinicians to do their part in designing and maintaining a health care system that is fair.

The four principles will sometimes be in conflict, and there is no obvious means of prioritising them to provide an answer to an ethical quandary:

Following an uncomplicated pregnancy, a girl is born prematurely at 25 weeks' gestation. She weighs 695g and is anatomically normal for post-conceptual age. She makes a respiratory gasp but clearly needs intubation and ventilation. Her parents request that “everything” be done, but the neonatal paediatrician is reluctant to ventilate, knowing that majority of children born at this stage will suffer severe long-term cognitive and physical

impairment, and that resuscitation such children is expensive, not only in the immediately aftermath of the resuscitation, but in supporting the child medically and socially for decades afterwards.

Applying the four principles, it is possible to construct:

- An argument from **autonomy** that the child should be resuscitated because her parents request it (either because they want it or because they think she would want it), or
- An argument from **beneficence** that she should be resuscitated because it will do her good
- An argument from **justice** that she should not be resuscitated because to do so would be unjustly consume resources in a world of finite health care funding or
- An argument from **non-maleficence** that she should not be resuscitated because to do so would do her harm.

This is not a shortcoming of the four principles approach, but an illustration of the limitations of its scope. Principlism is not intended to represent a single coherent ethical theory. Rather, it offers a practical heuristic for busy clinicians. Clinical ethics is an application of moral questions and theories that have been debated for thousands of years by moral philosophers and theologians, often in complex, nuanced and sophisticated ways. For clinicians, however, they are a matter of everyday

reality, requiring decisions to be made quickly. The four principles represent a useful practical summary of those philosophical deliberations, suitable for clinicians to use, as it were, 'in the heat of battle'.

An analogy can be drawn between the four principles approach and other practical tools used by clinicians in daily practice, such as local formularies as aids to rational prescribing. Every day, clinicians need to make practical decisions on drugs, dosages and routes. Behind prescribing decisions lie complex principles of pharmacology, physiology and pathology that few clinicians can fully explore in the time available. Clinicians recognise the need for an accessible and well-informed summary, composed by an expert, to which they can turn for reference at short notice. At the same time, it is important that clinicians recognise that there is an extensive theoretical hinterland to that summary, and that they know how to access it in more detail when necessary. Properly used, the four principles approach provides a reference for practical consideration of ethics in the same way that a formulary provides it for practical prescribing. Both offer signposts and practical support to more extensive rational understanding, rather than an alternative to it.

Principlism is not always a reliable paradigm when it comes to quandaries in palliative care, because the theories that underlie it are not designed for children. In Western cultures respect for autonomy is often privileged over the other principles, but it is not clear that any of the ways in which the

term 'autonomy' has traditionally been used can meaningfully be applied to children. Accounts of beneficence and non-maleficence in relation to children do not consistently distinguish between the interests of children and those of their families. Finally, establishing what is fair in treating children is complicated by inconsistent understandings of the nature of children in relation to a society composed mainly of adults.

The result that the status of the child in the four principles approach is often unclear. Children ideally need a coherent ethical approach that is consistent with their nature as moral beings that are both distinct from, and have much in common with, adults.

2. The nature of children: special ethical considerations

2.1 Interests: child vs family

A child with a life-limiting condition often cannot articulate feelings or preferences, and so her interests cannot usually be known with the same confidence as those of adults. They need to be approximated in the course of dialogue between medical team and parents as well as, where possible, the child herself (14). Medical decisions in respect of a child are ideally taken during discussions that occur in the context of a trusting and collegiate relationship in which each of the parties acknowledges the expertise of the others.

When such a relationship breaks down, parents and healthcare team can find themselves entrenched in public opposition to one another¹. Under those circumstances the ethical question appears to be whose voice should carry greater authority; that of the parents or that of the doctors (14). Doctors are generally more knowledgeable about the child's medical condition, but they know less than parents about the disposition and preferences of the individual child and hence, considered properly, do not know enough about her interests to make the decision alone. Doctors might also be influenced by factors that are not relevant to the care of that individual child, such as personal value judgments or concerns about resource restrictions.

On the other hand, parents' knowledge of a child's interests is not enough on its own. There will inevitably be times when the interests of the child will be in tension with those of his or her parents, and an adult's right to autonomy over himself does not extend to making decisions over his child as though she were a possession. Irrespective of their relationship with the child, adults do not have any ethical right to insist on a course of action that will harm her. The authority of parents to influence medical decision-

¹ <https://www.telegraph.co.uk/news/2017/07/28/charlie-gard-tragic-case-short-life/> (accessed June 2018), <https://www.theguardian.com/society/2018/apr/28/alfie-evans-timeline-of-key-events> (accessed June 2018)

making depends on their appreciation of the child's interests, in the same way as the authority of doctors does.

A child will find it hard, however, to express a view of interests that differs from a strongly expressed view on the part of adults. That allows the potential for coercion; that is, the risk that the child's interests are subordinated to those of adults around her such as doctors or parents². The idea of a child's rights safeguards the child's own interests. Some modern sceptics of children's rights contend that any assertion of rights on the part of a child separates the interests of the child and the interests of the family in a way that is spurious (12, 13). That objection risks wrongly implying that the child's interests are always the same as those of her parents.

Underpinning most child welfare legislation is the idea that the 'best interests' of the child are paramount but, taken literally, that idea would be unsustainable in practice (15). There is a level of harm that is so small that it becomes effectively irrelevant. Furthermore, applying the 'best interests test means that nothing other than the best outcome for that individual child can be morally right. Taken to its hypothetical extreme,

² There is an equal and opposite error of assuming that children can only express autonomy by making decisions independently and without considering their family's interests at all. As we have seen, that is a misunderstanding of the term 'autonomy'. Children can and often do manifest autonomy by choosing to let their parents make decisions for them.

that could allow the needs of one child to consume all healthcare resources.

The concept of interests is especially problematic in considering children needing palliative care who are cognitively impaired. There are no objective measures of a good outcome. Survival probability is not appropriate, since death in childhood is the expected outcome. Most other measures are existential (that is, they have no existence other than as the experience of the person experiencing them), so they are subjective and cannot be observed. In short, in order to do good, and to avoid doing harm, we need to understand what the child's interests are, which in turn requires a balancing of the burden of an intervention and its benefits. In the absence of easily measurable outcomes, we need to explore subjective phenomena that relate to the child's experiences of life. In practice, that is often extremely difficult in children with life-limiting conditions, and we are drawn instead to an account of ethics that allows us to regard a child's parents' interests as inseparable from those of the child. That is a problematic assumption, and it is perhaps as a reaction to this that the modern children's rights movement has developed.

2.2 Personal value and rationality

Even in adults, rationality is not a single all-or-nothing phenomenon to be found consistently in an individual. It also seems likely that some non-human animals can reason (16), albeit differently from adult humans. If the criterion for moral agency is simply rationality, it is now not only unclear which humans should be excluded, but which non-human animals should be included.

As a result, the moral status of children as rational beings in ethical theories is often uncertain. Children rationalise in a way that is different from adults. Since forms of rationality associated with adult humans are privileged over other forms, children are systematically undervalued in most accounts. That becomes particularly relevant if children are seen to be competing for limited resources with a group of rational beings that now includes members of species other than humans³. In his book *Practical Ethics*, utilitarian philosopher Peter Singer (17) asserts that infanticide is permissible. The infant, he says, lacks reason and therefore awareness of self over time. Being killed cannot rob the infant of anything she can truly be said to possess. Given modern understandings of neurodevelopment

³ The term 'speciesism' is sometimes misunderstood in this context. Properly used, speciesism refers to a bias towards members of one species – usually humans – over others, that is not justified by a difference in morally relevant characteristics. It does not refer, therefore, to the provision of healthcare to cognitively impaired children, except to the extent that such provision is at the expense of other, non-human, rational beings.

in early childhood (18, 19), Singer's claim is improbable. Infancy is characterised by rapid learning that results from highly effective registration, assimilation and processing of new understanding and knowledge about self and the world. The idea that young children cannot reason is perhaps a contemporary parallel to earlier ideas that they cannot experience pain; a convenient and widely-held belief about children that simplifies decision making for adults, but is ultimately untrue.

Nevertheless, the moral status of children who are genuinely non-rational (such as those with severe cognitive impairment) presents paediatric clinical ethicists with a challenge. If the capacity to be rational is not enough to explain how a child should be treated, then it is important to decide what other characteristics are important in establishing her moral value.

2.3 Dependence and autonomy

Autonomy is often taken to mean freedom, in the sense of having no restrictions on actuating one's will. In practice, a child is multiply restricted in the influence he or she can exert over others, and physical surroundings. Many of these limitations are inherent to the nature of the child; children are physically small, and often lack verbal skills simply by virtue of their age. That is, of course, self-perpetuating. A child who is given less

influence because she is relatively unimportant will inevitably become increasingly unimportant because she cannot exert influence.

In reality, complete absence of restriction is both impossible and undesirable, even for the healthy adult. Properly understood, autonomy does not mean freedom; rather, it describes the ability to decide for oneself which set of restrictions to embrace. That more realistic definition of autonomy does not exclude children quite so clearly. Children often manifest autonomy by choosing to allow their parents to make decisions on their behalf. Furthermore, children do not see themselves as powerless individuals. Empirical evidence (20) suggests that children with cancer often see themselves in a reciprocal and balanced relationship with their family members, and even as morally responsible for the care of others in the family, including adults.

Difficulties defining autonomy in children and young people become relevant in considering the ethics of legislation in respect of euthanasia and physician-assisted suicide that extend into childhood or young adulthood. For neonates and younger children, all euthanasia is involuntary. Moral authority for arguments in support of euthanasia cannot come, as can be argued in adults, from any understanding of individual autonomy. Adolescents are often thought to possess the same autonomy as adults, but they can appear to be more autonomous than they are. A perfectly reasonable adolescent may request euthanasia for reasons that

have little to do with a considered desire to end his or her life. The high frequency of risk-taking behaviour and suicide during adolescence (21) illustrates that an actual desire to die is only one among many influences. Even if it is conceded that people who ask for it should be killed, it is not clear that it is possible, in practice, to distinguish clearly between an adolescent's request for death and (for example) a request for more attention, or a protest against parental restrictions. The assumption that there is always a straightforward relationship between what people say, and what they actually mean, is even less reliable in adolescents than it is in adults.

The concept of autonomy, then, is foundationally problematic in respect of children. Autonomy requires some degree of control over one's own life. For all children, it is more limited than it is for adults, but this is due to a variety of factors, some of which are of no moral relevance. It is clearly not enough to say simply that a child inherently lacks autonomy, and that consideration of the child in ethics therefore need account only for the wishes of parents. At the same time, it is the nature of a child to be part of a relationship with a family. To deny the importance of that relationship, and the authority it gives to parents in practice to speak for their child, would be to deny something central to the ethical questions clinicians need to ask about children.

2.4 Relationality

Several relationships are potentially of ethical relevance in paediatric palliative care. Most of the specific ethical quandaries facing clinicians occur in the context of one or more of these, and relationship critically informs the scope of moral deliberation around them.

It is important to individual families to know that a healthcare system is fair. To that extent, the principle of justice is appropriately considered one of the four medical ethical principles. In other respects, however, it appears out of place. Respect for autonomy, beneficence and non-maleficence all relate primarily to decisions made by an individual doctor about an individual patient. The principle of justice, on the other hand, refers to the development of systems or 'states of affairs' (22) and does not consider the child or physician at all. Typically, an argument from the principle of justice is utilitarian; that the ethically right decision in respect of an individual patient is the one that maximises the amount of happiness available to humanity in the abstract. While the other three principles make the abstract notion of society subordinate to the reality of an individual patient, justice makes individuals subordinate to the needs of society⁴.

⁴ It is often assumed that there is an inevitable and direct connection between the provision of expensive treatment to one individual and the need to withhold effective treatment from others. The parallel is with triage

A three-year old boy with very advanced metabolic degenerative condition was now felt by his paediatrician to be 'almost in a persistent vegetative state'. After a series of chest infections of increasing severity and frequency, his parents brought him to casualty with signs of another pneumonia, insisting that he should be ventilated again. The intensive care paediatrician saw the child in casualty and explained to the boy's parents that ventilation would not be offered, because it would mean their son occupying a bed that another child could use more effectively.

Few clinicians would disagree with the conclusion that the child should not be ventilated. The ethical reasoning given by the intensivist also appears sound in principle. Most people would intuitively feel that it is nevertheless cruel and unreasonable to expect parents to sacrifice their child to the

in war, in which treatment is first offered to those most likely to recover, in order to ensure that a scarce resource is most effectively used. There are problems with the parallel. Any definition of the effectiveness of treatment requires an understanding of its aim. In war, the aim of medical treatment is to maintain the fighting force; as such, its goal is part of the agreed goal of winning the war itself. There is no such agreed goal in treating patients in most other situations. Furthermore, outside a triage situation, the link between denying one patient treatment, and by that fact making treatment available to another, is not as clear as this illustration would suggest.

well-being of others. The Nuffield Council on Bioethics recommends that issues of cost should not be invoked in discussions with parents:

We take the view that it is important to avoid arguments about 'bed-blocking' and instead to focus on the best interests of a baby. This is consistent with our recommendation that resource considerations should not affect decision making between the doctor and the parents of the patient (paragraph 2.43). This is not to deny that decisions in practice are affected by cost ... (23)

These differing ethical conclusions result from, and illustrate, an important limitation of scope of the utilitarian concept of justice. Utilitarian consequentialism assumes that, because all children are of equal importance in the 'eyes of the universe', they should be similarly equal in the eyes of the agent making an ethical decision, in this case the parent or the intensivist. According to utilitarianism, relationship has no moral relevance to ethical deliberation.

That approach is hard to argue convincingly without ignoring the child's nature as a dependant living in the context of a family. If relationship is relevant, then the relationship of physician and child too is of ethical relevance (24-26). In the case above, the child should not be ventilated because ventilation would cause more harm than good. To put it another way, ventilation is not in the interests of the child and so it should not be

inflicted on the child. The impact on hypothetical 'other children' is outside the scope of the decision faced by the clinician in relation to this particular actual child.

That does not mean clinicians should take no interest in resource allocation. Clinicians need to make ethically relevant decisions in two modes simultaneously. They need to make some decisions in the context of their relationship with specific patients, and others in helping develop or maintain fair systems. In the United Kingdom, paediatricians will often participate in the systems that promote fair allocation of resources and so fulfil the obligations of justice. It is in no way inconsistent for them to do this while at the same time advocating in a highly partisan fashion for individual patients. Indeed, it may be ethically necessary for them to do so, given that the context and the scope of the two ethical questions are so different.

Tension between the needs of the individual specific patient and those of hypothetical other patients is quite appropriate in the presence of limited healthcare resources. Dialectic is integral to a consistent ethical system in healthcare, not antithetical to it.

3. Ethics in children: underlying theories

I have suggested that the four principles approach is, in fact, a practical tool that represents and relies on a much wider theoretical framework of ethics. Three of these theories deserve particular exploration. The first of these is deontology, that is, the idea that there are moral rules that are true at all times and in all places. In contrast to that is the second theory, that of consequentialism. Consequentialism refers to an understanding that it is only the practical outcome of an action that gives the action any moral relevance. If an act can be considered to consist of three parts – intention, action and then consequence - then deontology argues that it is intention that defines an action's moral value, while consequentialism insists it is outcome. The third ethical theory is 'eudaimonism', which is distinguished from the first two in that it focuses on the nature of the individual making the ethical decision as well as the person who is being treated.

3.1 Deontology

Deontological arguments flow from an assumption that there is an absolute morality that is equally relevant to all people, in all situations, irrespective of the consequences. In practice, it is rare for any two individuals to agree exactly on what is morally right and wrong, but deontologists might argue that this no more than a practical problem - that they either do not see or do not understand the moral law. There at least

three possible sources for an absolute moral code. One is the authority of God through religious scripture. An obvious response is that the majority of people, at least in the UK, have no formal religious faith. That alone is not an adequate reason to dismiss scripture as a source for an ethical code, because moral principles that emanate from scripture are not by that fact irrational. It would be perverse to dismiss all moral teachings that flow from religion simply on the basis that society as a whole no longer subscribes uncritically to the worldview in which they were articulated, because the teachings themselves are often rationally defensible. A more convincing moral argument for not using religious laws as a basis for ethics is that scripture is often elliptical and/or subject to interpretation. Most scripture was not designed primarily as an exposition of a consistent ethical code, and does not amount to a detailed manual showing how human beings should behave. Ethical accounts derived from a religious understanding are rarely completely agreed, even among those who share that faith.

A second authority for the deontological approach might be that of pure reason. Kant (27) attempted to show that there were certain ethical premises that were beyond debate, simply because for reasonable people they are logically inescapable. Some, he argued, are always true, irrespective of context (categorical imperatives) while others (hypothetical imperative) are contingent on the individual's prior beliefs about context. Applying that idea to children, however, is not straightforward. Kant

expected moral agents to avoid exploiting children, but it is not clear in Kant what exploitation of a child might look like, because he does not obviously consider children to be rational or autonomous.

3.2 Consequentialism

Moral analysis using rules alone, as deontology requires, means that the practical outcome of an ethical decision can be worse by obeying a rule than by breaking it. Consequentialists argue that this is not simply a practical problem with any specific moral code, but an inherent weakness in 'rule-worship' itself, and that the only morally relevant aspect of an action is found in its consequences (22). Consequentialists differ in their view about what outcomes should be measured. Libertarian consequentialists would judge the moral 'rightness' of an action by the extent to which it contributed to freedom. In medical ethics, utilitarianism is the best known form of consequentialism, and the most commonly used outcome measure is its effect on 'the sum total of human happiness'.

There are important ambiguities that restrict the usefulness of utilitarianism in practice. The sum total of happiness could relate to a great deal of happiness on the part of a few people, or moderate happiness on the part of a great many. The nature of happiness itself is not agreed, and may not be measurable. Measuring happiness is particularly problematic in

children needing palliative care, who are often non- or pre-verbal. A close correlation between happiness and observable function or cognitive ability is sometimes assumed (28). That seems intuitively unlikely, and in fact there is little evidence to indicate that life quality is influenced in any readily predictable way by physical condition, or closeness to death. Some proxy report of 'happiness' by a child's family is usually needed, but this is not always easy to disentangle from the needs of the family members themselves. In the Netherlands, neonatal euthanasia is permitted under certain circumstances (29). Its ethical basis is that the best interests of the family and the child cannot be separated meaningfully, since the child cannot express his or her own view. In that claim, two separate ethical arguments are conflated. The first is the relationship and responsibility of parents towards a child. If the child is a possession, there is no need for his or her parents to imagine what the child would want. They need only consider their own interests. If, however, the family's relationship with the child is that of fellow persons, they need to decide what they think the child would express if able to do so; something that is clearly impossible in practice to do with certainty. Verhagen argues that parents are stakeholders in the ethical decision and, since theirs is the only wellbeing that can be assessed, their preferences are the only morally relevant ones. This has recently been taken to a logical, though extreme, conclusion in a suggestion that the ancient Greek practice of allowing infanticide should be revived for newborn babies whose parents do not wish to keep them (30).

As we have already seen, utilitarian consequentialism cannot accommodate any ethical relevance for relationship. Utilitarianism does not concern itself with the happiness of the individual, except insofar as it contributes to the sum total of human happiness. A central principle is that the happiness of each individual person is equally important – or, perhaps more accurately, equally unimportant – to the agent making the ethical decision. A paradox at the heart of utilitarianism is that it cares deeply about the happiness of society, while remaining essentially indifferent to the happiness of all its individual members.

Finally, utilitarian consequentialism does not acknowledge any ethical relevance for intention. This again makes it problematic for most quandaries in medical ethics. A doctor trying to decide on a particular course of clinical action has to decide whether to do a particular act or not to do it. The quandary defines, and is defined by, the agent's intention. Utilitarianism does not provide a mechanism for that decision, because it defines ethical 'rightness' entirely in terms of something entirely isolated from intention; that is, outcome. The physician cannot know the outcome at the time the decision needs to be made. She can only make a judgment on the basis of knowledge and prior experience. That informed judgment is what constitutes intention in the context of medical decision-making. The fact that utilitarianism cannot accommodate intention – still less

complex intentions as in double effect -illustrates an important limitation of its scope.

3.3 Eudaimonism

Eudaimonism is a broadly consequentialist theory in which the object of moral action is to enable the individual to develop towards maximising the quality of their existence. That development is termed 'flourishing', and eudaimonia refers to the hypothetical maximum to which well-being asymptotically tends.

Although deontology and consequentialism might appear to be opposites, they have important things in common. One is that both are absolutist approaches. Each claims unlimited scope; to provide moral values that are always and everywhere right. Another is that both ultimately elevate something abstract over real individual human beings. In the case of deontology, that is a concept of duty. In the case of utilitarian consequentialism, it is a concept of happiness. Since neither duty nor happiness can have any meaning independently of individual human beings, neither deontology nor consequentialism can, on its own, provide an adequate account of medical ethics, which relates primarily to decisions in the context of relationships between such individual beings.

A third thing the two theories have in common is that they are problematic in children. Both privilege moral characteristics that are knowable in adults over those that are demonstrable by children. Utilitarian ethics relies on comparing existential outcomes that are impossible to know in children, or privilege moral characteristics that children do not possess in the same degree as adults. Deontological theories often assert duties in respect of children, but the basis for those duties is not always clear. Most adults intuitively feel the child has inherent value, but that value is hard to explain rationally if we consider the adult to represent the 'finished version' of a human being with full moral status, while characterising the child as a 'work in progress'.

Ancient and mediaeval understanding of the way the universe was constructed was that it was rationally ordered, and that an individual will 'flourish' best (that is, will tend towards the best she can be) when she is cohering with that rational order. The extent to which behaviour promotes the flourishing of both child and moral agent provides the yardstick by which its moral rightness should be measured. So, for example, both the ethical rules by which children should live, and the ethical rules by which parents should care for their children flowed from an understanding of the nature of a child in relation to his or her family. Children participate in human nature, but each child's nature is individual and part of that individuality is that she is a child, dependent on others.

The concept of eudaimonia underpins virtue ethics (31), which has its roots in Aristotle's understanding that an action is right if it is done by a virtuous person for the right reason. Aristotle locates the quality of virtue, not only in the ethical rightness of an act, but in the character of the moral agent whose act it is. Virtuous people, and ethically correct acts, are mutually defining in the same way that force and acceleration are mutually defining in Newton's Second Law of Motion. One cannot argue from virtuous act to virtuous person; it is simply impossible for either to exist independently of the other.

It is an understanding of the virtuous person that emerges from the Hippocratic Oath. The oath describes, in effect, how a 'virtuous doctor' should behave. Similarly, the concept underlies what is becoming known as 'professionalism'; that is, what constitutes good medical practice (32). To be professional is to behave in a certain way that is, as a corollary, the way in which a professional behaves. A virtuous doctor will take moral decisions that are right because they promote the flourishing of her patient, and in doing so her own flourishing will also be promoted.

Eudaimonia is more than just happiness or even well-being. An individual can become stronger through experiences that are deeply unhappy. Since the contribution of a specific action to the flourishing of an individual cannot always be known, eudaimonism does not always provide an obvious 'decision' mechanism for resolving individual ethical quandaries.

Virtue ethics can shape expectations of professional behaviour from doctors, but may not be able to replace an analytical approach to clinical ethics.

Summary

This chapter has outlined some of the theories and paradigms in ethics of care at the end of life, and the special challenges of considering them in relation to children's palliative care. Paediatric palliative care clinicians face all the moral ambiguities of their colleagues working with dying adults, and at the same time have the additional task of considering those quandaries in the absence of a systematic account of ethics in children.

Paediatricians have often had no choice but to turn for ethical guidance to sources that were not intended for that purpose. Of those, the most important currently are the four principles approach, and the UN Convention of the Rights of the Child. The first was developed for adults and is often unsuitable for children, particularly because of its emphasis on autonomy. The second is not an ethical account at all, but simply a series of rights claims, though in those rights are some important fundamental ethical claims about the nature of children. Neither source of ethical support on its own provides the kind of coherent account needed by those working in children's palliative care.

Because it does not accommodate the moral relevance of the relationship of clinician and child, the scope of utilitarian consequentialism in paediatric palliative care is properly limited to development of fair systems, rather than to specific clinical decisions about individual children. Children are particularly vulnerable to misapplication of utilitarian consequentialist principles to clinical decisions, because they are typically unable to express clearly what they want, their removal from the world does little to detract from the sum total of human happiness, and they are often assumed to lack sentience, rationality or self-awareness, particularly in the neonatal period.

Doctors are usually more knowledgeable than parents about what the objective harms and benefits of an intervention might be. But the full extent of harms and benefits cannot be known by the doctor alone, because it must also include assessments of life quality that are subjective. While ultimately those can only be known by the child, parents are in a good position to estimate them; certainly better than most doctors. It is important to establish the place of parents' views in making decisions to withhold or withdraw treatment. Parents are not, however, morally entitled to authorise, still less to instruct, doctors to make decisions that will harm their child. It is essential that doctors engage in dialogue with a child's parents, but it is equally important to recognise that doctors are asking for

parents' help in identifying the child's actual interests. They are not inviting parents to define those interests.

Many of the specific ethical quandaries faced by clinicians working with dying children have their counterparts in the adult specialty. It seems likely that it will become increasingly important to be able to address those quandaries in a way that is specifically paediatric, as it becomes technically possible to resuscitate children at ever earlier extremes of prematurity, and to keep children alive but suffering for ever longer periods of time. To analyse ethical quandaries in children with the same rigour as those in adults, we must do more than extrapolate from existing accounts such as rights or principlism. Paediatricians and bioethicists must work together to develop an account of the nature of children that is consistent, coherent and complete. It should not locate the moral relevance of childhood in the child's capacity to further the interests of adults, or in her capacity to emulate adults now, or even in the probability that she will become an adult later. Medical decisions in a child are right to the extent that they enable the child to flourish as a child.

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