

# Ethical principles in paediatric practice

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## INTRODUCTION

Clinical problems with significant ethical implications pose an ever increasing dilemma in everyday medical practice in the 21st century and rarely present a simple solution. This is particularly the case with ethical issues involving children and those unable to take their own decisions. Whilst the patients' interests should come first and all personal, cultural and religious bias eliminated, the impact of costly treatment for the individual patient on the available healthcare resources must also be taken into account. Hence, it is essential to establish an ethically acceptable code of practice which will allow doctors to provide an objective approach to management that is rational and consistent, both for the patient as well as society at large regardless of creed or culture. An equally important code of practice is required for medical research, whether this involves clinical trials on children, laboratory and animal studies. Although the same general principles are applied to guide all medical ethical problems, these may be adjusted to different research scenarios. Particularly difficult issues relate to research involving subjects who are unable to fully comprehend the ethical issues at stake, especially the embryo, children and those with a disability, as well as issues relating to the initiation of intensive care or 'extraordinary' measures and, finally, issues relating to the discontinuation of care and the dying process.

## A. GENERAL ETHICAL PRINCIPLES

The ideal code of ethically-acceptable practice may be approached, if not fully achieved, by applying the following accepted principles in the decision-making process.

### 1. Respect of the individual's autonomy

*Autonomy* implies that all are free to take an active and totally independent role in the decision-making process. For this to occur, patients and study participants must be fully informed and understand the implications of their medical condition or involvement in research, any treatment, complications and outcome (De Lourdes, et al., 2003). In practice, however, many including young

children do not have the ability to be truly informed, and may rely on others for guidance. *Informed consent* is not necessary simply to satisfy medico-legal requirements, but is indeed a pivotal issue with regard to patients' 'free choice' and active participation in their own management. It is fraught with problems in the competent adult, and is doubly more difficult to achieve in minors. *Truly informed consent* can only exist when patients are sufficiently informed to weigh up all the pros and cons of treatment, and their consent is given *freely* without coercion, vested interest or bias from physicians, researchers or third parties. If anything, the situation relating to children heightens the doctors' and/or researchers' responsibility to ensure true *informed consent*, albeit through third parties (Parekh, 2007; Smith-Tyler, 2007).

### 2. Respect of the individual's competence

*Competence* implies the patient's level of understanding that allows him or her to weigh up the ethical issues posed by a clinical situation, assimilate these and reach a rational decision (Parekh, 2007; Larcher and Hutchinson, 2010). This degree of comprehension is often a problem with young children and those with developmental disabilities, thereby increasing the responsibility of parents and the medical team to assume the role of competent advocates on their behalf (Cherry, 2010).

### 3. Respect beneficence

*Beneficence* defines the medical principle of 'do no harm', a hallmark of the Hippocratic oath, and should apply in all cases. Medical practice frequently entails a compromise between benefit and harm, especially with regard to interventional procedures and drug therapy, but should always be biased toward 'benefit'. Hence, in practice, it may be perfectly acceptable to embark on high-risk therapy in a fully informed individual (or his/her advocate), provided there is a *realistic* chance of *reasonable* benefit.

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#### 4. Respect of the truth

There is never a case for wilfully lying to patients. Similarly, there is rarely any justification in withholding or omitting information from patients, unless this is deemed to be against their best interests, and this option only adopted after considerable in-depth reflection and broad consultation. For those whose ability to comprehend the nuances of complex medical issues is limited by their tender age, then this responsibility is passed on to third parties.

#### 5. Respect of patient confidentiality

All patients have a right to confidentiality. However, disclosure of confidential information without consent may be justified in situations where failure to report may lead to greater disadvantage to the patient, e.g. in some cases of child abuse.

#### 6. Avoidance of paternalism and bias

Practitioners should strive to remain truly objective and avoid all personal, racial, cultural, religious or other bias when counselling or treating patients. Personal prejudice and preconceived ideas must never influence the provision or withholding of medical care to children, regardless of whether they are disadvantaged, have a pre-existing disability or otherwise. The wishes of parents and guardians must also be respected, again regardless of any personal bias.

#### 7. Avoidance of all conflicts of interest

The child must always come first, before any vested interest of any third party including physicians, parents, guardians, extended family and society (Cherry, 2010; Chen and Fan, 2010). Numerous conflicts of interest may be associated with research activities (e.g. recruitment in clinical trials, treatment arms, outcomes, pharmaceutical support), and cannot be allowed to influence any decisions whatsoever. It is 'good practice' and, indeed, should now be mandatory for all 'interests' to be declared by all co-workers and co-authors involved in any given research project. Special attention is required in the formulation of letters of instructions and consent forms dealing with research studies, such that these are specially designed to be 'child-friendly' and also account for the ultimate responsibility being taken by third parties.

#### 8. Respect the limitations of medical care

Medical care should strive to support the patient, and should be tailored to the needs of the individual. It is ethically appropriate to appreciate realistic goals which medical care can achieve, and wrong to aim toward exaggerated or impossible expectations. Hence, it is equally unacceptable to 'treat at all costs', as it is to 'play god'.

#### Ethics in the decision-making process

Given the above accepted guidelines, ethically acceptable decisions can only be based on:

- *omniscience* - knowledge of all the facts
- *omnipercipience* - consideration for all the points of view
- *disinterest* - absence of any vested interest in the various parties
- *dispassion* - avoidance of any emotional bias
- *consistency* - management that is reproducible for all similar cases

In practice, many of the above ideals may not fully apply to a particular case. For example, it is often difficult to completely separate disinterest and dispassion from children with whom an attending paediatrician has built a close, professional relationship. For these reasons, it is not just desirable but essential to establish **independent ethics committees** to oversee particularly difficult decisions (both with regard to clinical medicine and research). These should be composed of medical, nursing, paramedical and legal experts, laypersons and representatives of various support groups.

#### Conclusion

Medicine is never a pure science and contentious issues in management abound. Although 'best interest' should be taken as the standard for decision-making (Spence, 2000), in practice a single, simple solution to a given ethical problem in medicine is extremely unlikely, particularly in those patients who are either too young or incapable of grasping the nuances of treatment. These patients rely on third parties for their decision making, and this adds a further dimension to an already complex situation. It is only by careful attention to a strict code of ethics based upon respect and tolerance of other persons, whether 'competent' or not, that decisions can be taken which are truly in the best interest of patients and society at large.

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## **B. ETHICAL ISSUES RELATING TO CHILDREN AND THE DISABLED**

### **Introduction**

Ethical issues in child care are often complicated by the child's inability to take responsibility in their own management decisions and, therefore, their reliance on third parties. This situation is further complicated in those children who have an underlying disability which may influence judgment decisions of the child's surrogate guardians, both toward over or under treatment. This is particularly the case with regard to decisions relating to life support, ongoing and quality of life, appropriate use of limited healthcare resources, and medical research (Smith-Tyler, 2007; Luce, 2003).

The area of disability raises its own special ethical problems, particularly where there is total or near-total reliance on third parties, with their own personal bias and agenda that may not always be in the patient's best interests. Dilemmas are common, especially in situations of initiation or discontinuation of therapy, particularly if this involves intensive or extraordinary measures and where 'best interest' is not always easy to define (Armstrong, et al., 2011; Bellieni and Buonocore, 2009).

### **Life support and critical intervention**

A competent person has an almost unquestionable right to decide what to do with his/her own body, even when this may entail the refusal of curative or life-saving care (e.g. blood products and competent, consenting Jehovah witnesses). This 'choice' cannot apply to children, the dependent disabled and those who are unconscious, and this great responsibility is usually taken over by parents/guardians/relatives who may have widely differing views (Michelson, et al., 2009) and who must be supported by detailed, informed discussion(s) with the caring professionals (Bellieni and Buonocore, 2009). Although the vast majority of parents act in accordance with their relative's best interests this is, at times, not perceived to be the case by the professional team and the issue may need to be resolved through legal procedures (Cherry, 2010). Differences of opinion stem from several differing fundamental values including cultural and religious beliefs that, although not strictly essential to the ethico-legal principles of medicine should, if at all possible, be considered and respected in all cases. Finally, good practice would entail the clear documentation in the child's case file of all critical decisions taken by those

interested parties (e.g. paediatrician, parents/guardians, nursing staff, etc), and any subsequent changes to the plan of management again documented accordingly.

### **Quality of life**

Ultimately, therapy whether curative or palliative, strives toward achieving 'quality of life' (QOL). Although quality of life is highly subjective, it is consistently cited as a major priority by parents in, for example, situations where withdrawal of therapy is being contemplated (Meyer, et al., 2002). What is acceptable QOL to one individual or a particular society may be abhorrent to another (Lam, et al., 2009). Although it is ethically wrong to withhold therapy simply on the basis of 'a perceived disadvantage' (e.g. a disability), it is often very difficult to predict the degree of disadvantage and, as a rule, the benefit of the doubt should be given to the patient (Kluge 2009). In the critical care setting, although it may be acceptable to withhold therapy at the outset, it may be easier to initiate and withdraw treatment at a later date (Hussain and Rosenkrantz 2003). The latter allows for a trial period during which time the child's response, severity and irreversibility of their disease can be established beyond doubt. Indeed, both under- or over-treatment is wrong and a modus operandi which balances the two should apply in all cases.

### **Healthcare and resource constraints**

In an ideal world, all treatments should be available to all patients at all times, regardless of age, gender, race, creed, social status and pre-existing disease or disability (co-morbidity). Modern medical care, and especially intensive and high dependency therapy, is extremely expensive and in limited supply, even in developed countries. In practice, this inevitably leads to an overt or covert system of health care rationing which, in the context of society at large, is ethically reasonable (Sabik and Lie, 2008). However, it may lead to negative discrimination against those who, for whatever reason be it medical, social, cultural or otherwise, may be considered to be 'less deserving' (Zlotnik Shaul and Vitale, 2009; Antommara, Sweney and Poss, 2010). Hence great care is required to ensure that any rationing is reasonable and that any inclusion/exclusion criteria for these patients are fair and ethically acceptable (Kluge, 2009; Antommara, Sweney and Poss, 2010; Miljeteig, et al., 2010).

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## Euthanasia

*Passive euthanasia* allows patients to die naturally of their underlying disease and is generally acceptable in those with irreversible disease. Although this does not include active intervention, passive euthanasia ensures supportive and palliative care at all times. Furthermore, it does not justify a decision not to treat on the basis of an underlying disability. *Active euthanasia*, by positively helping a patient to expedite his/her demise, is considered unlawful in most but not all countries (Kon, 2009). Indeed, although prosecuted, individuals have been found not guilty to the charge of assisted murder after they have admitted to help a loved one take their own life, even in countries where this provision is not empowered by law. The Dutch protocol goes further in that it lays down criteria for legitimately euthanizing neonates whose medical condition falls within three defined categories and is incompatible with sustained life (Kon, 2009). Although gaining wider support and acceptance, such active euthanasia is generally difficult to accept by third parties. It remains, therefore, more difficult to apply to neonates, children and dependent individuals who are unable to make an informed request for this to be carried out. Furthermore, it allows no room for error and further obscures the cut-off limits of what is and what is not ethically acceptable practice.

## Medical research and children

A significant proportion of the benefits resulting from biomedical research will help future patients rather than those directly involved in the research (Matutina, 2009). Given that patients should never be used as a means to an end, and difficulties with informed consent in the non-competent child or disabled person (Parekh, 2007; Larcher and Hutchinson, 2010), it is hard to reconcile the participation of these groups in active research. However, a total ban on such research activity will restrict other children and disabled patients from benefiting from any potential advances. 'Good practice' research involves randomisation, use of placebos, and similar concepts that may be very difficult if not impossible for many, but especially for children, to comprehend (Matutina, 2009). Research trials must be unbiased, and avoid any discrimination whilst protecting all participants (Diekema, 2008). 'Negative' findings may be equally if not more important than 'positive' results in research that aims to add to dependable, evidence-based medical practice (Henschel, Rothenberger and Boos, 2010). To this end, therefore, clear ethical, legal and methodological

guidelines are essential in the design and conduct of clinical trials involving all subjects, but especially children (Henschel, Rothenberger and Boos, 2010; Burns, 2003; Coleman, 2007).

## Conclusion

In many ways, the ethics which govern the management of those with a disability are no different to those which apply for children. The respect for autonomy and confidentiality, avoidance of conflict and paternalism whilst aiming for acting in the child's interests with honesty should apply for all. However, the disabled subgroup with its inherent potential for negative discrimination when it comes to healthcare support does need greater attention particularly in the areas of critical care where the issue of realistic goals is paramount. The problem of defining quality of life is highlighted in this subgroup, and it is important that physicians accept that others including relatives, may have widely differing views on this definition and should strive to respect their divergent views, provided it is ultimately in the patient's interest. Finally, an effort to respect children and the disabled as individuals with an equal right to healthcare, will facilitate acceptance of their position and/or disability and ensure fairness in their management.

## C. ETHICAL ISSUES RELATING TO THE DYING PROCESS IN CHILDREN

### Introduction

Despite the application of robust ethical principles, complex issues in patient care commonly result in ethical dilemmas with no clear answers. This is especially so in those 'life and death' decisions relating to continuing curative therapy or opting for palliative care (Spence, 2000; Lam, et al., 2009). As with many situations in medicine, and probably more so in paediatrics, these decisions are complicated by difficulties in establishing clear prognostic outcomes both in terms of disease progression and timescales, patient's reliance on third parties, and appropriate use of resources (Kluge, 2009; Sabik and Lie, 2008; Brook and Hain, 2008). Great efforts are required to ensure family members are fully informed of the evolving clinical situation relating to their loved one, and helping them to accept the inevitability of death. Whenever possible, they should be encouraged to plan for their relative or child's death in a manner that is most appropriate for them as an individual family. This section will explore the ethical principles which offer guidance in these situations, and strives toward: i) establishing

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the acceptance of death by the patient and family, ii) ensuring 'quality time' for both family and their dying relative or child and, iii) safeguarding every person's right to die with dignity.

### **The dying process in children**

Fortunately, most childhood illness is curable and, indeed, death in childhood is an unlikely event in 2011. Often death is not a totally unexpected event but can usually be anticipated after a short or long term illness (Brook and Hain, 2008). For these children, a point is reached when cure is no longer possible and is replaced by palliative care. Not uncommonly, this transition can be complicated by ethical dilemmas. Many of the decisions relating to the dying child are complex, and invariably have a significant impact on the child as an individual, his/her family and friends, as well as society at large. If this transition is to be appropriate and acceptable, a code of practice based on sound ethical values is essential.

### **When to opt for care and not cure?**

This difficult milestone requires a multidisciplinary decision involving the patient, whenever possible, the family, relatives, friends and the entire team of carers (Hechler, 2008; Brien, Duffy and Shea, 2010). Stopping curative therapy will depend on medical considerations such as patient viability, futility of further aggressive therapy, and the exhaustion of all reasonable, potentially curative options. The patient must be 'ready' for the transition (with appropriate, sensitive discussion in competent adults and the older child). The importance of family acceptance of palliation versus cure cannot be stressed enough and requires frank discussion, often over several hours (Hechler, 2008). Finally, but equally important, the acceptance of carers must never be overlooked and the personal view of each individual should be actively explored (Duffy and Shea, 2010; Floriani, 2010). Ultimately, a unified team decision is required to avoid conflict that will only add to the distress of the patient and his/her family.

### **Medical ethics that apply to palliative care**

The transition to palliation in critically ill children does not involve a special set of medical ethics. Indeed, the appropriate application of basic principles provides the platform on which difficult issues can be discussed and ethically acceptable decisions taken. Hence, carers

should strive toward the patient's best interests whilst respecting the patient's autonomy within the confines of his/her competence. They should respect confidentiality, avoid being paternalistic, anticipate and avoid conflict (Masri, 2000). All issues should be aired realistically, honestly and sympathetically, with due consideration for the patient's/family's views, beliefs and wishes. As with other ethical dilemmas, for medical decisions to be ethically acceptable, they should be based on *all the facts* and *points of view*, free of *bias* and *emotional overtones*, and consistent from one patient to another.

Despite this ideal, the decision making process is rarely straightforward in practice. Often an accurate prediction of outcome (and time-scales) may be difficult in the critically ill, and especially children. Prolongation of life through palliative care raises the issue of quality of life (Michelson, et al., 2009; Meyer, et al., 2002), an extremely subjective issue dependent on personality, inherent expectations (realistic or otherwise), cultural background, religious beliefs and pressure from third parties. Nevertheless, the caring team have a primary duty to maintain the quality of life at all times of, firstly, the child and, secondly, that of the family. In addition, they must present an honest assessment of the medical condition with realistic goals and argue toward the reasonableness, or otherwise, of continuing support. In practice, this cannot be done without taking account of available resources, although healthcare 'rationing' in the terminally ill child can pose a great challenge.

Moreover, these problems are made doubly difficult in patients and children who are unable to grasp the complex issues involved and, therefore, cannot participate in the decision process and depend on third parties, usually their immediate family members (Moro, et al., 2006). In the vast majority of cases, the latter correctly decides what is right for their loved one and for them as a family, and the role of the caring team is essentially to support and facilitate their decisions. Rarely family members may, knowingly or unwittingly, hold strong views that may be biased by their own fears/beliefs and may not be in their relative or child's interest. At this point the caring professionals may be required to gently redress any misguided views to ensure that the dying person is not put through any unnecessary suffering. Once a decision for palliative and not curative care is taken, the unified focus should be toward support, quality and not quantity of life.

## The final stages

Toward the later stages of palliative care respect must be shown for the wishes of the patient, the family and carers in the light of their background, culture and creed. Throughout the dying process, great attention must be paid to the child and his family's needs, both physical and emotional (Moro, et al., 2006). Whenever possible, decisions relating to *Where to die?*, *With whom?* and *How?* should be planned with the family (Floriani, 2010). What may be the ideal for one family may be abhorrent for another. Every effort should be made to enroll all support services (e.g. Hospice movement, social workers, friends, etc) in order to fulfill the patient's and the family's wishes. Certainly in the majority of expected deaths (e.g. cancer relapse) this is eminently feasible, but it is extremely difficult with sudden, unexpected deaths (e.g. post-accidental).

The fact that each child will die only once and that this is invariably a major event for loved ones should form the basis for a modus operandi that strives to ensure that death is as 'acceptable' as possible. A concerted drive to respect the patient's and family's wishes, to ensure 'quality time', and 'humanize' the dying process can help enormously in allowing loved ones to 'let go with resigned acceptance'. In this regard, the spiritual needs of the family must be taken into consideration (Feudtner, Haney and Dimmers, 2003; Fleischman, et al., 1994), and a conscious effort made to ask the family if they would like the appropriate religious counsellor to attend. Equally, it is important to respect the wishes of those who do not hold any particular religious beliefs and it is wrong to attempt to introduce this, in whatever guise, during the final moments. It is entirely appropriate to decide,

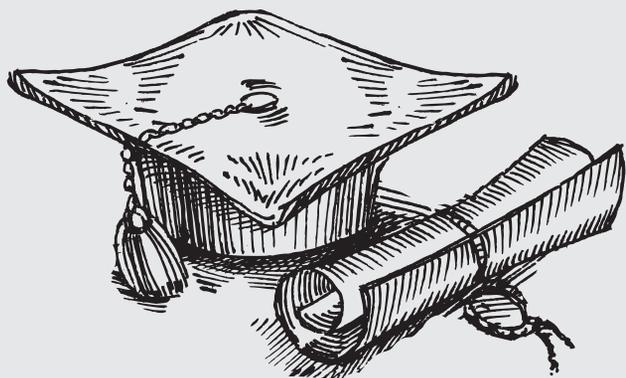
together with the family, against active resuscitation and the initiation of further extraordinary (but futile) measures. Indeed, there is little to compare death after a frantic resuscitative attempt often in the absence of family or friends, with the peaceful death of a child in his/her mother's arms or an adult in tranquil surroundings offering sufficient privacy, quietly surrounded by loved ones. Finally, the needs of the surviving family members must not be underestimated and addressed appropriately (Meert, et al., 2007).

## Conclusion

For critically ill patients, cure should not be pursued at all costs and there may come a time when cure is impossible and palliative care is in the patient's best interest. Certainly, appropriate supportive care should continue at all times and must include the patient's family and friends. Acceptance of death is very important, particularly for the family, and can only be achieved after sympathetic, often prolonged and repeated discussion with loved ones. Palliation should provide 'quality time' for both family and their dying relative and, ultimately, strive for one overriding goal: namely, to safeguard the patient's right to die with dignity.

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