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Ethical Issues in Paediatric Practice - Part II: Issues relating to disability

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Abstract

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 judgement 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. This article will explore the ethical principles which help to guide the medical management of such difficult cases.

MeSH: Ethics

Introduction

The area of disability raises its own special ethical problems, particularly in paediatric management where the total or near-total reliance on third parties, with their own personal bias and agenda, may not always be in the child's best interests. Dilemmas are common, especially in situations of initiation or discontinuation of therapy, particularly if this involves intensive or extraordinary measures.

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 and the dependent disabled, and this great responsibility is usually taken over by parents/guardians who must be supported by detailed, informed discussion(s) with the caring professionals. Although the vast majority of parents act in accordance with their child'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. Differences of opinion stem from several differing fundamental values including cultural and religious beliefs which, although strictly not essential to the ethico-legal principles of medicine should, if at all possible, be considered and respected in all cases.

Quality of life

Ultimately, therapy whether curative or palliative, strives toward achieving ‘quality of life’. However, quality of life is highly subjective and what is acceptable to one individual may be abhorrent to another. Although it is ethically wrong to withhold therapy simply on the basis of ‘disability’, it is often very difficult to predict the degree of disability and, as a rule, the benefit of the doubt is generally given to patient. 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. The latter allows for a trial period during which time the patients’ response, severity and irreversibility of their disease can be established beyond doubt. Indeed, both under or over treatment of disabled children 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 prexisting 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. However, it may lead to negative discrimination against those with disabilities who may be considered to be ‘less deserving’. 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.

Euthanasia and the disabled

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 countries. It is difficult to accept from third parties and, therefore, is not applicable to children and the dependent disabled. 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 the disabled

A significant proportion of the benefits resulting from biomedical research will help future patients rather than those directly involved in the research. Given that patients should never be used as a means to an end, and difficulties with informed consent in the non-competent disabled, it is hard to reconcile the participation of disabled patients in research. However, a total ban on such research activity will restrict contemporary and future disabled patients from benefiting from any potential advances.

Conclusion

In many ways, the ethics which govern the management of children with a disability are no different to those which apply for other children. The respect for autonomy and confidentiality, avoidance of conflict and paternalism whilst aiming for beneficence and 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, as physicians, it is important that we accept that others including relatives, may have far wider limits to this definition and should strive to respect their divergent views, provided it is ultimately in the patient's interest. Finally, an effort to respect the disabled as individuals with an equal right to healthcare, will facilitate acceptance of their disability and ensure fairness in their management.