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in
PAEDIATRIC
CARDIOLOGY

Images Paediatr Cardiol. 2002 Apr-Jun; 4(2): 32–34.

PMCID: PMC3232517

Ethical Issues in Paediatric Practice - Part III: Issues relating to the dying process

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Abstract

Despite the application of robust ethical principles, complex issues in child 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. As with many situations in paediatrics, these decisions are complicated by difficulties in establishing clear prognostic outcomes both in terms of disease progression and timescales, the child's reliance on third parties, and appropriate use of resources. Great efforts are required to ensure family members are fully informed of the evolving clinical situation relating to their child, and helping them to accept the inevitability of death. Whenever possible, they should be encouraged to plan for their child's death in a manner that is most appropriate for them as an individual family. This article will explore the ethical principles which offer guidance in these situations, and strives toward: i) establishing the acceptance of death by the child and family, ii) ensuring 'quality time' for both family and their dying child and, iii) safeguarding the child's right to die with dignity.

MeSH: Ethics

Fortunately, most childhood illness is curable and, indeed, death in childhood is an unlikely event in 2002. Often death is not a totally unexpected event but can usually be anticipated after a short or long term illness. 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. 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 the older child). The importance of family acceptance of palliation versus cure cannot be stressed enough and requires frank discussion, often over several hours. Finally, but equally important, the acceptance of carers must never be overlooked and the personal view of each individual should be actively explored. Ultimately, a unified team decision is required to avoid conflict that will only add to the distress of the child and his/her family.

Medical ethics that apply to palliative care in children

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 beneficence (essentially, in this context, do what is in the patient's best interest) whilst respecting the patient's autonomy within the confines of his/her competence. They should respect confidentiality, avoid being paternalistic, anticipate and avoid conflict. All issues should be aired realistically, honestly and sympathetically, with due consideration for the patient's/family's views, beliefs and wishes. As highlighted in Part I of this series, 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 critically ill children, especially. Prolongation of life through palliative care raises the issue of quality of life, 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 be very difficult.

Moreover, these problems are made doubly difficult in children 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. In the vast majority of cases, the latter correctly decides what is right for their child 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 child's interest. At this point the caring professionals may be required to gently redress any misguided views to ensure that the child 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.

Children and dying

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. Whenever possible, decisions relating to Where to die?, With whom? and How? should be planned with the family. 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 child'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, and a conscious effort made to ask the family if they would like the appropriate religious counselor to attend. Finally, 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 without family or friends, with the peaceful death of a child in his/her mother's arms quietly surrounded by loved ones.

Conclusion

For critically ill children, cure should not be pursued at all costs and there may come a time when cure is impossible and palliative care is in the child's best interest. Certainly, appropriate supportive care should continue at all times and must include the child's family and friends. Acceptance of death is very important, particularly for the child's 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 child and, ultimately, strive for one overriding goal: namely, to safeguard the child's right to die with dignity.

