

7. When Care does not Cure Ethical issues in Neonatology & Paediatrics

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Introduction

Fortunately, most childhood illness is curable without any lasting sequelae. Indeed, death in childhood is an unlikely event in 2001. Although approximately 10% of all newborns in Malta and Gozo require intensive care, less than 10% of these will succumb. About 8% of these early deaths are due to extreme prematurity (i.e. before 28 completed weeks of gestation), with a smaller percentage due to congenital anomalies and infection. Less than 1% of older children do not survive and most of these deaths are due to childhood cancer and accidental injury. In children, death is usually not a totally unexpected event but can be anticipated after a short or long term illness. For these, a point is reached when cure is no longer possible and cure is replaced by palliative care.

The transition from cure to care can be difficult and ethical dilemmas are not uncommon at this stage. Indeed, many of the decisions that need to be addressed are complex, and many issues relating to the dying child rarely provide a simple answer. These 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 does care not cure?

Palliative care replaces curative care in children with different underlying conditions. In the newborn period, these often include infants where viability is not an option e.g. extreme prematurity (below 24 weeks gestation), and those with severe genetic or congenital anomalies. In older children, cure may not be possible due to the severity of their illness (e.g. overwhelming sepsis), in those where there has been a failure to respond to potentially curative therapy (e.g. relapsed cancer), and in situations where no effective therapy is yet available (e.g. certain inborn errors of metabolism). Hopefully, as medical and surgical intervention improves, many of these conditions will become 'salvageable' in the future but, until such time, every effort should be made to provide comprehensive care and effective on-going support for these children.

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 preparedness and, especially, 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 by all involved will avoid painful conflict which can only add to the distress of the child and his/her family.

Medical ethics which apply to palliative care in children

The transition to care but not cure 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 'do good', or in this context, 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 avert conflict. All issues should be aired realistically, honestly and sympathetically, with due consideration for the patient's/family's views, beliefs and wishes. If medical decisions are to be ethically acceptable, they should be based on the following simple criteria:

- omniscience - *decisions based on all the facts*
- omnipercipience - *decisions based on all points of view*
- disinterest - *decisions taken without any bias*
- dispassion - *decisions with no emotional overtones*
- consistency - *decisions reproducible from one patient to another*

Other considerations

Although the foregoing ethical guidelines would constitute the ideal, in practice, the decision making process is rarely straightforward. Often an accurate prediction of outcome (and time-scales) may be difficult in critically ill children, especially in the light of unexpected 'cures', albeit anecdotal. Prolongation of life through palliative care raises the issue of quality of life, invariably an extremely subjective issue dependent on a plethora of factors including personality, inherent expectations (realistic or otherwise), cultural background, religious beliefs and pressure from third parties.

The caring team have a primary duty to maintain the quality of life of, firstly, the child and, secondly, that of his/her family. In addition, they must portray an honest assessment of the medical condition with realistic goals and argue toward the reasonableness, or otherwise, of continuing support. In the real world with monetary/resource constraints, this cannot be done without taking account of healthcare resources. Clearly the concept of healthcare 'rationing', although ethically acceptable, is a very difficult issue in the context of the terminally ill child.

Indeed, all these decisions are made doubly difficult in children, most of whom are too young to grasp the complex issues involved. Many cannot participate in the decision process and depend on third parties, usually their immediate family members. In the vast majority of cases, the family correctly decides what is right for their child and for them as a family. At this stage the role of the caring team is essentially to support and facilitate their decisions. Rarely family members may, knowingly or unwittingly, hold strong views which 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 and, ultimately, the child's right to die with dignity.

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 discussed and planned with the family. What may be the ideal for one child/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 death (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* which 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 'humanise' 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, whatever their creed, and a conscious effort made to ask the family if they would like the appropriate religious counsellor 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 ensure death with dignity.