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Limiting and rationing treatment in paediatric and neonatal intensive care

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In this chapter I consider the ethical decisions surrounding the provision and limitation of treatment offered to children requiring intensive care. I focus on the processes surrounding end of life decision making and consider how the concepts of futility, burden and uncertainty should impact upon these decisions. I also examine resource allocation to children's critical care services.

The discussion does not provide a structure that will solve any given situation. It does take a practical approach to the issues faced by considering why we should engage in life limiting discussions; When they should occur; Who should be involved; How they should be carried out; and where and by what means withholding or withdrawal should occur.

I have drawn the discussions closer to clinical practice with the intention of making them more useful, for those engaged in direct patient care, than those focused around philosophical principles.

Key words: PICU; children; futility; unbearable; ethics; end-of-life; rationing.

INTRODUCTION

Decisions regarding the appropriate care that should be administered to infants and children may be both complex and controversial, especially when they encompass life and death.[1–3] On initial consideration it might seem reasonable that decisions about the very young should be similar to those involving incompetent adults. By similar argument those approaching maturity might be the same as competent adults. It is immediately clear that those children that fall between these epochs present a different challenge. If one probes a little deeper it becomes clear that even at the two extremes there are factors at play that mark a significant difference between the adult and

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paediatric scenarios. Not the least of these is the role of the child's guardians in the decision making process and the influence of the wider family. These individuals usually occupy a position that may be the best to judge what is in the child's best interests. However it must not be forgotten that the presence of a strongly protective emotional overlay and complex personal and family agendas may hinder objective consideration. In addition, when the scenario requires a timely decision, a further pressure is added that may preclude a full and comprehensive analysis by those involved.[4]

From a more distant perspective the effects on, and consequences to, our society of pursuing extraordinary measures to sustain the lives of young people with ongoing complex needs should be examined. It is highly emotive and in many people's eyes quite wrong to value one life over another because of the physical or mental imperfections that may be present in one individual. It is an inescapable fact that the healthcare budget is not infinite and the consequences of providing advanced support to a young child or a premature baby cannot be ignored. In some areas of practice, such as neonatal care at the extremes of viability, there is a significant likelihood that survivors will need to draw on resources from health, social and educational services, for many years, over and above their contemporaries. As a society we must recognise the impact this will have on our finite pool of resources. Many will feel that we should embrace life purely for its own sake, whatever its perceived quality. In practical terms, a choice must be made between offering lifesaving care to a few, where both the acute and chronic resource implications are high, or a greater number of people with conditions that are likely to be cured or successfully managed or palliated by appropriate care.

In this chapter I will explore the above issues as encountered in the delivery of paediatric and neonatal intensive care. In particular I will examine the concept of futility and the practice around end of life decision making for, or with, young people. I will discuss the conundrums of delivering potentially futile treatment to all young children and the complex interplay between the best interests of the child, the family's vision of these interests and those of the clinical team. Finally I will examine the allocation of resources to paediatric services, consider the options, and their implications in terms of healthcare provision for the future.

WITHHOLDING, WITHDRAWING AND FUTILITY

There are probably no other areas of medical decision making that are more difficult to consistently, compassionately and justly navigate than those where one course will inevitably lead to the demise of a patient. Arguably this is at its most challenging when a child's life resides at the centre of the debate. This is not because there is any fundamental difference to the ethical considerations at play. The interaction between objective consideration of the options and the natural emotions of adults to protect the young, combined with the absence or limited availability of a true and accurate knowledge of what the child might want for themselves, results in very grey decision boundaries. Add to this the ever present factor that the predicted outcomes occur in a stochastic fashion, framed by probability rather than certainty and it is not hard to see why individuals can struggle to reach a conclusion. Each of the parties that takes part in the decision making process has to wrestle with these unknowns and sometimes may reach opposite conclusions even when they share similar philosophies on life. The diversity of cultural beliefs encountered in contemporary society can be a compounding factor. There can be little surprise that reaching a consensus is often very difficult.

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