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Physician Authority, Family Choice, and the Best Interest of the Child

Alister Browne

Department of Philosophy, Langara College, Vancouver, British Columbia V6M 2J2, Canada
Corresponding author. Email: davidalisterbrowne@gmail.com

Abstract

Two of the most poignant decisions in pediatrics concern disagreements between physicians and families over imperiled newborns. When can the family demand more life-sustaining treatment (LST) than physicians want to provide? When can it properly ask for less? The author looks at these questions from the point of view of decision theory, and first argues that insofar as the family acts in the child's best interest, its choices cannot be constrained, and that the maximax and minimax strategies are equally in the child's best interest. He then proposes a guideline according to which the family can demand LST if it is physiologically possible to preserve a life the child can be expected to welcome, and refuse such treatment if it causes suffering that is "more than can be borne" even if an uncompromised life is expected to emerge.

Keywords: life-sustaining treatment; decision theory; pediatrics; physician authority; family choice; best interest of child

Two worrisome and common questions in pediatrics are "When can physicians say 'No' to family requests for more life-sustaining treatment?" and "When can physicians refuse family requests to withhold, withdraw, or limit such treatment?" It is generally agreed that physicians and families must always act in the child's best interest, but there is no agreement on how to determine what that is. The two leading strategies in decision theory designed to promote the best outcome for the individual are the maximax and minimax strategies. These, however, give widely divergent advice on where the child's best interest lies, and I will argue that it is impossible to say which is better. The upshot is that, since families are the presumptive decisionmakers and cannot be displaced unless they act contrary to the best interest of the child, they must be free to follow either strategy. This means that the range of choice the family legitimately has is considerably wider than commonly accorded it, and I propose a guideline to allow for that.

Maximax and Minimax Strategies

The view that decisionmakers must always act in the child's best interest is generally accepted as the basis of all pediatric decisionmaking. This enables decisionmakers to decide what to do by determining what is in the best interest of the child, and the Canadian Paediatric Society (CPS) defines the best interest of the child as "the balance of potential benefits over potential harm or distress resulting from the pursuit of a given line of treatment."¹ To arrive at a best interest judgment, decisionmakers take into account the potential positive results of treatment such as the benefits or pleasures (physical and emotional) continued life might bring, and weigh those against the potential negative ones such as any distress of intensive care, and the ongoing pain (physical and emotional) that continued living might bring to the child, including that of living with severe disability. Whether treatment is in the child's best interest is

determined by whether the positive effects are expected to outweigh the negative to a greater extent than any alternative available.²

But to arrive at a determination of what is in the child's best interest, it is not enough to enumerate benefits and burdens. In addition, these factors need to be weighted. In particular, we need an account of the relative value of life and disvalue of suffering, and the valuation we assign to those things will determine when (if ever) it is permissible for physicians to withhold or withdraw or limit life-sustaining treatment (WLST). Given the great good that life can be, the initial presumption must be to preserve life, and hence that any child born alive should receive maximal life-sustaining treatment (LST). But that presumption comes into question as the expected outcome becomes problematic. When there is doubt about whether the child will survive at all, or will only survive in a compromised state, or maximal LST will cause the child great suffering, it is appropriate to rethink the presumption. What to do in such a circumstance depends on whether we accept the maximax or minimax strategy.

According to the maximax strategy, decisionmakers should always aim at the best possible outcome attainable. In pediatric cases, this is to provide the child with whatever treatment is necessary for a worthwhile life to emerge. I use the phrase "worthwhile life" in this context to mean not just biological life, but a life the child can be expected to welcome, and understand that to be a life that has the potential to have a preponderance of positive over negative experiences in its lifetime. While everyone making decisions for a child must begin by aiming to produce such a life, what is distinctive about the maximax strategy is that maximum LST should be continued as long as it is possible for a worthwhile life to emerge. Many clinicians are aghast at such a recommendation because of the burdens it may impose on children with scant prospects of a positive outcome, but the right of the family to insist on that level of LST is backed by sober argument, and was endorsed by the Judicial Council of the American Medical Association in 1982 when it wrote: "In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents."³ This is an old view, to be sure, but it has never been refuted, and mere age is not a ground for superannuation.

By contrast, the minimax strategy holds that life is not such a great good that it should be pursued whatever the risk. On this view, if at some point the probability of a good outcome becomes very low, or that of serious suffering very high, it is better to switch from pursuing the best outcome to avoiding the worst. Many will find this a more congenial strategy and most pediatric societies accept it. The CPS, for example, endorses it when it writes that physicians may WLST when there is a "high degree of probability that: (1) there is irreversible progression to imminent death; (2) treatment is clearly ineffective or harmful; (3) life will be severely shortened regardless of treatment, and the limitation or withdrawal of interventions will allow greater palliative and comfort care; or (4) lives will be filled with intolerable distress and suffering that cannot be prevented or alleviated."⁴

Since the maximax and minimax strategies are designed to promote the best interest of the individual, which strategy should be adopted depends on which will better do that. But it does not seem possible to identify one strategy as the uniquely prudentially rational one. The maximax strategy holds out for the possibility of the best outcome, but also poses the greatest risks. The minimax minimizes risks, but provides no chance of the best outcome. Individuals may differ on which strategy they prefer, and choose different ones in different situations, but there does not seem to be any objective answer to the question of which is better in the case of life and death decisions in pediatrics. To the minimax strategist's challenge, "How can anyone expose a child to such serious and likely risks?"; the maximax strategist can reply "How can anyone forego the possibility of a worthwhile life when it is still attainable?" And there, after a recitation of devastating tragedies and miraculous outcomes, the matter would seem to rest. But if it is as prudentially rational to gamble in such a circumstance as to play it safe, each strategy must be as good as the other in pediatric settings. If, however, the strategies are equally good, and the only constraint on decisionmaking is to act in the child's best interest, families should be free to choose either one. I now turn to provide a guideline that allows for this.

A Third Way

This guideline begins with the view that decisions to WLST should be made jointly by physicians and the family, and then delineates those roles. Because the family is the unit that is typically most concerned and impacted by decisions to WLST, it is plausible (and generally agreed) it should be the presumptive decisionmaker. But it is also plausible (and again generally agreed) that this authority should not be unlimited, and hence that physicians can sometimes say “No” to family requests. They can do this both to family requests for more treatment and to family requests to forego or discontinue or limit treatment. However, since the maximax and minimax strategies are equally prudentially rational, those limits must allow the family a wide range of options, and setting them raises hard questions.

I begin with the question of how much treatment families can demand in the light of diminishing expectations. Given the viability of the maximax strategy, physicians cannot refuse LST as long as it is possible for a worthwhile life to emerge. The question now is what is meant by “possible,” and the sense I propose as relevant here is *physiological* possibility. On this account, to say that it is not possible for a worthwhile life to emerge is not merely to say that the chance of it happening is vanishingly small or unprecedented, but that it is incompatible with what is known about physiology. This sets the bar of saying “No” to LST very high, but that is required by the high value that families must be allowed to put on a worthwhile life for their child.

The great problem with the maximax strategy is the fear that following it may result in a child who is not living a worthwhile life, will not improve, but is not dependent on LST that can be removed to end the life. The maximax strategy is thus most plausible when it is accompanied with an understanding that a child in this condition can have death provided by expedients such as terminal sedation or euthanasia as allowed in the Netherland’s Groningen Protocol.⁵ Trials of treatment were never given a fair run for their money until it became permissible for physicians to withdraw as well as withhold LST. Similarly, and paradoxically, permitting euthanasia in newborns may result in an increase in worthwhile life by encouraging the fullest possible attempt to bring it about.

Whether families should be able to request and receive LST beyond the point at which what I have described as a worthwhile life is physiologically possible is a nice question, and a practically important one. Families sometimes request (or demand) LST when their child has suffered brain-stem death, or been diagnosed in a permanent vegetative state or some other state in which he or she will never be aware of themselves or their surroundings. But I set aside this question here since a key element in it concerns the allocation of resources, and thus cannot be settled solely by physicians at the bedside.

I now turn to the question of when physicians can say “No” to family requests to WLST. Given that physicians must always act in the child’s best interest, physicians must say “No” to such requests as long the child is benefitting from the treatment. Both maximax and minimax strategists agree on this, and only disagree on when that time occurs. A maximax strategist holds that the child is benefitting from LST as long as it is physiologically possible for a worthwhile life to emerge. A minimax strategist holds that the shift from seeking the best outcome to avoiding the worst should occur earlier, for example, when (as the CPS has it) there is a high degree of probability that a good outcome will not occur or that continued treatment is harmful. The question now is how much LST can a minimax theorist allow families to reject or withdraw.

The Royal College of Paediatrics and Child Health in its 2004 guideline identifies three circumstances in which it is permissible to WLST.⁶ The first two are what it describes as “The ‘No Chance’ Situation” where treatment will only delay death and not alleviate suffering, and “The ‘No Purpose’ Situation” where the child will survive with unacceptable impairments. The third it calls “The ‘Unbearable’ Situation” and gives two statements of this. In its “Summary” at the beginning of the guideline, the College formulates it as a situation where “the child and/or family feel that *in the face of progressive and irreversible illness* (my italics) further treatment is more than can be borne” and says that they may request to have “a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion that it may be of some benefit.” In the body of the text, however, the italicized qualification is omitted, and the College simply says that it is permissible to WLST when the child

and/or family feel that further treatment is more than can be borne irrespective of the medical opinion that it may be of some benefit.⁷

These statements are significantly different. If the College only meant that the family can refuse treatment when the benefit is something like delaying death or preserving life but life with unacceptable impairments, no one could take exception to the claim. But then the “Unbearable” situation is indistinguishable from the “No Chance” and “No Purpose” situations. “The Unbearable Situation” is worth picking out for special mention only if the College meant that it is sometimes permissible to WLST from a child on the request of the family or child when refusing that treatment would save the child significant suffering even when there is the possibility of a significant good such as a worthwhile life emerging.

In 2015, the College rewrote its guideline. In that edition, the five situations in which limitation on treatment might be considered are replaced by a more formal classification based on quantity or quality of life,⁸ but the College gives no indication that it has changed the substance of its view. Unfortunately, the ambiguity in question also persists. When the College writes in the 2015 edition that “If a child’s life can only be maintained at the cost of significant pain and distress it may not be in their best interests to receive such treatments...” this suggests that extreme suffering, even with the possibility of a good outcome, can be sufficient for physicians to WLST if the family or child request that. However, when the College gives, as an example of when it is permissible to WLST, “the use of invasive ventilation in severe irreversible neuromuscular disease,”⁹ this suggests that it is permissible to WLST in cases of extreme suffering only when that condition is irreversible.

But what view the College actually holds is not as important as which position is better, and there is good reason to suppose that the more radical one is preferable. The possibility of a worthwhile life emerging is a hefty counterweight to a decision to WLST because of suffering. But, as the maximax–minimax strategy standoff showed, a systematic preference for life over the reduction of suffering cannot be demonstrated to be in the best interest of the individual. Thus, capable adults can argue that it is in their best interest (and not merely their right) to refuse chemotherapy when there is a good chance of a good outcome but the treatment will be very burdensome. Similarly, the best interest standard must also allow mature minors to sometimes do the same for themselves, and a family to WLST from a child in great distress but whose condition is not hopeless.

If the physiological impossibility of a worthwhile life and unbearable suffering mark the boundaries of what LST families can demand and refuse is correct, families should be able to request and refuse more LST than they commonly can. The grounds on which physicians can say “No” to such requests/refusals is also narrowed. They cannot say “No” because they have an ideological, personal, or professional preference between the maximax and minimax strategies, as there is no prudentially rational reason to prefer one to the other. Physicians must therefore be strictly impartial between them, and only oppose family requests for LST on the ground of physiological impossibility, or family requests to WLST on the ground that there is no medical reason to think the suffering is sufficiently grievous to justify that. Physicians can thus still say “No” to family requests, and this is an important safeguard of the best interest of the child. But they also do not have the last word. Families that are dissatisfied with the decision must have access to second or third or even more independent opinions, with the courts being available as a last resort.

The right of the family to be the presumptive decisionmaker, the limitations on that right, and the latitude of judgment allowed to the family by it, all flow directly from three simple principles:

- 1) Physicians and families must always act in the child’s best interest.
- 2) Insofar as the family acts in the child’s best interest, its choices cannot be constrained.
- 3) The maximax and minimax strategies are equally in the child’s best interest.

The guideline thus bids fair to be not merely an alternative account of when it is appropriate to say “No” to family requests for more or less treatment to those more commonly in use (such as that of the CPS and Royal College), but the only account that is fully compatible with giving primacy to the interests of the child and the family its legitimate decisionmaking authority.

Best Interest Judgments and Ethics

There can be no question that decisions about whether to say “No” to family requests for more or less treatment are ethical decisions. Yet, it is a striking fact that insofar as those decisions are made by arriving at a judgment of what is in the best interest of the child, the decisionmakers do not engage in any ethical reasoning. Ethics is concerned with what is right or wrong, dutiful, or forbidden; the business of ethics is to tell us what our duties are. By contrast, best interest judgments are solely concerned with whether benefits outweigh burdens; their business is to tell us what is (or is expected to be) on balance beneficial or harmful. We arrive at a conclusion about what we ethically ought to do only when we combine a judgment of what is in the best interest of the child with the principle that we ought to always act in the best interest of the child. This last is the only ethical view in the whole chain of reasoning concerning decisions about saying “No.” Once it is accepted—and it is usually taken for granted—decisions about whether to say “No” follow directly from best interest judgments. The real and hard work in those decisions is thus done by arriving at best interest judgments, and ethical judgments only emerge when that work is done.

The principle that decisionmakers must always act in the best interest of the child is accepted by the CPS and widely throughout pediatrics.¹⁰ But it is not uncontroversial. On this view, the interests of the family cannot impinge the interests of the child, and this can have devastating effects on the family. It may mean the end of a marriage, changing professional or personal goals, and depriving other children of attention or social and educational opportunities. In light of this, John Hardwig argues that the interest of the child should not receive the primacy typically given it.¹¹ Rather, since morality requires weighing everyone’s interests equally, the “patient’s best interest” standard should be exchanged for a “family’s best interest” standard according to which other (and perhaps more numerous) interests may outweigh those of the child.

There is undeniable force in this, but the problem is to give the view practical effect. Hardwig suggests that decisions be made in a family conference where all those impacted may make their case, but this decision procedure threatens to be both computationally intractable and potentially unfair. My view, which does not allow for elaboration here, is that the child’s best interest standard is sound. This is not because the interest of the child is more important than the interests of others. It is because giving anyone the authority to take the interests of others into account, and balance them against the interests of the child, will open the door to overwhelming abuses and discrimination, and make decisions to WLST impossibly complex and undesirably contentious.

Notes

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2. Mercurio MR. Parental authority, patient’s best interest and refusal of resuscitation at borderline gestational age. *Journal of Perinatology* 2008;26:452–7.
3. Selections from Opinions of the Judicial Council of the American Medical Association, Dr. John H. Burkhardt, Chairman, American Medical Association, Chicago (1982) at 9–10. Cited in President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment*, March 1983: Appendix C, at 299.
4. Bioethics Committee, Canadian Paediatric Society. Treatment decisions regarding infants, children and adolescents. *Paediatric Child Health* 2004, reaffirmed 2016;9(2):99–103.
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6. Royal College of Paediatrics and Child Health. *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice*. 2nd ed. London: Royal College of Paediatrics and Child Health; 2004:328–9, at Sec. 3.1.
7. See note 6, Royal College of Paediatrics and Child Health 2004, at 329, Sec. 3.1.

8. Royal College of Paediatrics and Child Health. *Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: A Framework for Practice*. London: Royal College of Paediatrics and Child Health; 2015:S13–14, at Sec. 3.1. Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J; Royal College of Paediatrics and Child Health. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A framework for practice. *Archives of Disease in Childhood* 2015;**100**(Suppl 2):s1–s26. doi:10.1136/archdischild-2014-306666.
9. See note 8, Royal College of Paediatrics and Child Health 2015, at S14A.
10. For example, by the Canadian Paediatric Society (see note 1), the Royal College of Paediatrics and Child Health (see notes 6 and 8), and the American Academy of Pediatrics, Guidelines on forgoing life-sustaining medical treatment. *Pediatrics* 1994;**93**:532.
11. Hardwig J. What about the family? *Hastings Center Report* 1990;**20**(2):5–10.