2.4 Other Dimensions of Limits to Treatment

In the previous sections, some key elements of decisions to limit treatment have been described. However, numerous other morally relevant dimensions may be present in actual situations in which you face these choices. Table 4-1 contains a list of many considerations commonly cited in connection with such decisions.

The boundaries between some of these items are not sharp and well defined (e.g., items 15 and 16), and others are subject to differences of interpretation (e.g., item 43). Furthermore, actual cases almost always contain complexes of these elements intermingled. The first step in analyzing a case, then, is to identify the elements within it. Then the valence and weight of each element can be determined, and each can be weighed against the others to reach a final judgment.

Three valences are possible. A certain consideration may suggest a given treatment is either:

a. obligatory or morally required
b. optional or morally permissible (i.e., either the choice to treat or the choice not to treat would be justified)

Three valences are possible. A certain consideration may suggest a given treatment is either:

a. obligatory or morally required
b. optional or morally permissible (i.e., either the choice to treat or the choice not to treat would be justified)
c. prohibited or morally wrong.

For example, that the patient explicitly requests a certain treatment (Table 4-1, item 1) creates a *prima facie obligation* (a) to provide it. That the procedure is without significant risk (cf. item 8) counts toward classifying it as *morally optional* (b). That the procedure itself involves doing harm (cf. item 39) makes it *prima facie morally wrong* (c).

If (as often happens) the same proposed treatment has all these features, conflicting factors must be weighed against each other to determine on which side the resultant moral force is found. Consider the following two situations, both of which have the valences described:

**Patient A asks the doctor to lance a painful boil, even though it has been explained that the procedure itself will cause some discomfort.** Here the harm done (discomfort) seems justified by the patient's acceptance of it and by the fact that it may prevent greater discomfort in the future. Thus, considered on the whole, the act is morally permissible. We can see that it is not morally obligatory because it would be permissible to forego this treatment if the patient has a change of mind at the last minute and decides she prefers some other treatment approach.

**Patient B asks the doctor to cut a hole in the side of his nose through which he can hang jewelry in the "punk rock" style. He says he is aware that the procedure will cause some discomfort, and that it will leave a permanent scar.** Here the harm done (discomfort, scar) does not seem justified, even though the patient accepts it, since no therapeutic benefit results. Thus, on the whole, it is morally wrong for a physician to perform this procedure.

Let us consider how this sort of analysis works in a concrete case situation.

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9. Throughout Sections 2 and 3 of this chapter, any citation of "item" with a number refers to the list on Table 4-1.
Table 4-1 Terminating Treatment: Grounds For and Against

A. Consent Elements
1. Patient's informed consent/refusal of treatment/demand for treatment/demand to die
2. Substituted judgment: decision made by another, but based upon an attempt to determine what the patient himself/herself would choose if competent.
3. Proxy consent/refusal/demand: decision made on behalf of the patient by a designated agent, ideally based upon the agent's judgment as to what is in the patient's best interests.
4. Family's or friends' wishes in the matter; decision based upon the best interests, values, etc. of the family and/or friends themselves.
5. Consensus judgment: of any or all of the following: patient, family, friends, healthcare professionals, hospital ethics committee.

B. Quality of Life Judgments
7. Evaluation of the patient's quality of life from the perspective of an observer: e.g., "I don't know what that state of life feels like from the inside, but I consider it unacceptable."
9. To prevent the patient from "losing hope."

C. Medical Judgments
11. Determination that death has already occurred
12. Efficacy of treatment: "Treatment wouldn't do any good anyway."
13. Reversibility of illness
14. Imminence of death: "She doesn't have long to live no matter how much we do."
15. Standard-medical-care policy: assumes that a given procedure is obligatory if its use is "standard medical care" in cases of this clinical type.
16. Medical-indications policy (Ramsey 1978): assumes that a given procedure is obligatory as long as there exist "medical indications" or "biological indices" for its use.
17. Implications of the patient/professional relationship: "Patients expect their physicians to . . . ."
18. Principles of professional ethics
19. Goals of medicine: e.g., to extend life, to relieve suffering, to restore health, etc.
20. Educational values: "To attempt to extend this patient's life for a short period could teach me how to save lives of future patients."
21. Research values: "Medical science could learn something from this patient which would save lives of future patients."

D. Other—Regarding Judgments
22. Patient's obligations to others: "The patient owes it to his children to allow them some time to adjust to the prospect of his death," or "The patient owes it to his family to spare them the agony of a prolonged death watch."
23. Family's obligations to patient: "The family owes it to the patient to spare her this suffering," or "The family owes it to the patient to see that everything is done that can possibly be done."
24. Family's obligations to its members and others: "The family members owe it to themselves not to prolong their agony in a protracted death-watch," or "They owe it to his friends to allow them time to adjust to the prospect of his death."
25. Societal obligations to patient: e.g., to provide treatment resources, to spare the patient from pain and indignity
26. Societal needs: e.g., for the resources required to sustain this patient, for the moral example the patient could provide.
27. Public health issues
28. Allocation of resources issues: e.g., effects of denying resources to others, issues of equity, social worth of patient, expenses of treatment.
29. Effects on health services personnel who must work with the patient.
E. Conceptual Elements

30. Ordinary/extraordinary measures distinction
31. Natural/artificial support distinction
32. Killing/allowing-to-die distinction
33. Active/passive measures distinction
34. An "act of mercy"
35. Providing "a good death"
36. To avoid "playing God"
37. To avoid acting "contrary to Nature"
38. To avoid "prolonging dying"
39. To satisfy the precept "do no harm"
40. Deontological religious standards: accordance with God's will, the Ten Commandments, other biblical dictates, etc.
41. To satisfy requirements of law

F. Moral Principles

42. The Golden Rule: "because this is what I would want done if I were in the patient's shoes (or bed)"
43. Principle of sanctity of life
44. Principle of right to life
45. Principle of value of life
46. Slippery slope objections: even though this act may not be wrong in itself, undertaking it may incline us in the future to perform acts that are clearly objectionable.
47. Appeal to the "symbolic meaning" of treatment (or nontreatment)
48. Appeal to the long-term consequences of this decision: e.g., disabilities become intolerable; the infirm may feel social pressure to refuse treatment.

G. Factual Appeals

49. "A miracle cure might come along."
50. Appeal to uncertainty of diagnosis, prognosis: "We cannot know for certain that death is near."

2.4.1 Case: A Physician in an Overseas Hospital: Part 1  The following case has been adapted from Symmers (1968, 442).

A physician, aged 68 years, was admitted to an overseas hospital after a barium meal had shown a large carcinoma of the stomach. He had retired from practice five years earlier, after a severe myocardial infarction had left his exercise tolerance considerably reduced.

The early symptoms of the carcinoma were mistakenly attributed to myocardial ischemia. By the time the possibility of carcinoma was first considered, the disease was already far advanced. Laparotomy showed extensive metastatic involvement of the abdominal lymph nodes and liver.

Palliative gastrectomy was performed with the object of preventing perforation of the primary tumor into the peritoneal cavity, which appeared to the surgeon to be imminent. Histological examination showed the growth to be an anaplastic primary adenocarcinoma. There was clinical and radiological evidence of secondary deposits in the lower thoracic and lumbar vertebrae.

The patient was told of the findings and fully understood their import. He was not asked for, nor did he offer, any expressions of his wishes with regard to resuscitation or aggressive life support measures. His primary physician had indicated nothing about such decisions in the medical record.

In spite of increasingly large doses of pethidine, and of morphine at night, the patient suffered constantly with severe abdominal pain and pain resulting from compression of spinal nerves by tumor deposits.
On the tenth day after the gastrectomy, the patient collapsed with classic manifestations of massive pulmonary embolism and suffered cardiac arrest. A staff physician happened to be on the unit when the arrest occurred. His first impulse was to order full resuscitation measures and to undertake an emergency pulmonary embolectomy. But he hesitated a moment, wondering whether this was the right thing to do with this particular patient.

Consider the following questions:

1. If you faced this decision, what would you do? Why?

2. Do you see this decision as a dilemma (i.e., an option with strong moral considerations weighing both for and against each alternative)? List the moral considerations involved in the choice.

3. What measures (if any) could have been taken in advance to prevent this choice becoming a dilemma for the staff physician?

The chief difficulty in making a decision in this situation is the absence of information about consent elements (items 1–5). One can question why this information was not obtained from the patient earlier, but the fact remains that at this point it is too late to gather any information about the patient's wishes, nor is there time to discuss the matter with the staff of the unit to reach a consensus judgment.

Judgments about the patient’s quality of life are obviously an important factor in the decision. But notice that, absent a discussion with the patient, quality of life must be judged from the standpoint of an observer (item 7) rather than from the patient's own assessment (item 6). A reliable judgment on this basis would require a much closer relationship with the patient than the staff of this unit had experienced in the brief time they had cared for him. Furthermore, the state of life of this patient immediately prior to the arrest was not obviously below the threshold of a worthwhile quality of life. He was conscious, alert, and capable of communicating with those around him. He appeared to have been reasonably mobile. Although his pain was considerable, it was not so severe as to cloud his consciousness or to prevent meaningful mental activity.

Determinations of the efficacy of treatment (item 12) and the reversibility of illness (item 13) will vary depending upon the basis on which the judgment is made. Resuscitation and embolectomy offer a fairly good prospect of reversing the cardiac arrest. However, even if they are successful in achieving this limited objective, the patient's underlying cancer and heart disease will not be reversed. Thus, from a perspective of the overall condition of the patient, the proposed treatments must be ruled ineffective and the conditions irreversible.

A standard-medical-care policy (item 15) or a medical-indications policy (item 16) faces similar difficulties. Determinations of "standard" care or medical
"indications" are often made from the limited perspective of efficacy regarding the immediate medical crisis, with little attention to the overall life prospects of the patient. Overcoming the immediate problem benefits the patient little if the life situation to which he is restored is painful, hopeless, and/or unwelcome.

In this situation little is known of the patient's family or other social relationships, so the other-regarding elements (items 22–24) cannot be ascertained sufficiently to make them a major factor in the decision.

None of the conceptual elements (items 30–40) appears to offer a decisive basis for choice in this situation either. One might argue that refraining from resuscitating this patient would be an "act of mercy" (item 34) that would provide a "good death" (item 35) and avoid prolonging the dying process (item 38). However, without any indication from the patient that he finds his condition intolerable, to make such a judgment would be an extremely presumptuous exercise of paternalism.

The application of the distinctions in items 30–33 does not entail one conclusion rather than the other. Resuscitation might be classified as an ordinary measure (and thus perhaps as morally obligatory), but a case might be made for considering the emergency embolectomy as an extraordinary measure. If resuscitation is foregone, the patient would have been allowed to die rather than killed (item 32), and his death would have resulted from passive rather than active death-dealing measures (item 33). These factors might indicate that foregoing resuscitation would be morally permissible, but they do not provide a decisive reason for or against this choice.

Most of the moral principles listed (with the possible exception, in this case, of item 42) dictate sustaining life, but they would be challenged by many people in precisely this sort of situation. The factual appeals (items 49–50) seem clearly misguided if applied to this situation: the diagnosis has been thoroughly confirmed, and the patient's medical problems are so overwhelming that the possibility of a cure is virtually nonexistent.

The law (item 41) leaves decisions in such situations to the discretion of the physician present (wisely, in our judgment), but this means that it cannot be looked to as a basis for decision.

On what basis, then, is a decision to be made in this situation? Without decisive indications of the patient's wishes or other consent elements and decisive negative quality of life judgments, the most reasonable basis for choice is to invoke what the President's Commission describes as a "presumption in favor of sustaining life" [see Appendix II, Section 2, recommendation 2] This presumption, in turn, is rooted in the principle of the value of life (item 45).

Thus, we conclude that resuscitation is morally obligatory in this situation. And that, indeed, is the decision that was made in the actual case, as you shall now see.
2.4.2 Case: Part II

The staff physician decided to proceed with resuscitation and emergency pulmonary embolectomy. The patient was successfully resuscitated and stabilized.

When the patient had recovered sufficiently, he expressed his appreciation of the good intentions and skill of his young colleague. At the same time, he asked that if he had a further cardiovascular collapse no steps should be taken to prolong his life, for the pain of the cancer was now more than he would needlessly continue to endure. He himself wrote a note to this effect in his case records, and the staff of the hospital were made aware of his feelings.

Two weeks after the embolectomy, the patient collapsed again—this time with acute myocardial infarction and cardiac arrest. (adapted from Symmers 1968, 442)

Consider the following questions:

1. Should the patient be resuscitated this time? Why or why not?

2. Do you see this decision as a dilemma? List the moral considerations involved in the choice.

3. What further measures (if any) could have been taken in advance to prevent this choice becoming a dilemma for the staff?

What elements are relevant to the choice in this new situation? Clearly it is of great importance that the patient has emphatically expressed his own wishes in the matter. At this point the staff is provided with the strongest sort of consent element: an informed judgment to refuse treatment made by the patient himself (item 1). This consideration heavily favors the judgment that further resuscitation would be morally wrong. In legal terms resuscitation would constitute a battery, and the moral assessment here would concur with the law.

Furthermore, the patient has supplied a clear and emphatic personal assessment of his quality of life (item 6). An observer might not agree with this assessment (item 7), but there is little (if any) basis for preferring an external assessment to the patient’s own in this case. A quality-of-life judgment is made up of at least two elements: 1) a prediction about what future life events are in prospect for the patient, and 2) an evaluation of these life events based on the patient’s fundamental values. In some cases an observer might be in a better position than the patient himself to make judgments of the first type—e.g., a physician making a technical prognosis based on her past professional experience with similar cases. There might even be some situations in which an observer can ascertain the patient’s fundamental values better than the person himself—e.g., a friend who knows that the person is likely to get over his broken heart and find a new romantic interest in time, whereas the lovestruck one insists, “There will never be anyone else for me.” However, neither of these sorts of situations apply in the present case. This patient is likely to know his central values, and he understands the prospects for satisfaction of those values. Thus his own quality-of-life judgment must prevail.
What (if anything) would favor a decision to resuscitate under these conditions? There is the consideration that the immediate condition is probably reversible (item 13), although the fact remains that the underlying conditions are not. A strong sanctity-of-life principle (item 43) would emphatically favor resuscitation. There is enough ambiguity in the law on these matters (item 41) to make one nervous about any decision reached, but one is more likely to encounter civil suits and/or criminal prosecution as a result of nontreatment than from an error in the opposite direction.

However, disturbing as this legal situation might be, protecting oneself from suit is not as weighty a factor in moral terms as the consent and quality-of-life elements. Thus, the weight of moral considerations in these circumstances would make nonresuscitation not only *morally permissible*, but even *morally obligatory*.

The "time to heal" is past, Instead, it is now "a time to embrace," "a time to love," and otherwise a time to comfort and sustain this patient as he faces the inevitable "time to die." It is now time to acknowledge the statement of the ACP Ethics Manual that "the physician has a responsibility to ensure that his hopelessly ill patient dies with dignity and with as little of suffering as possible" [ACP 1984a (Manual), 26; 1984b (Annals), 265].

Read on to see what was actually done in this case.

2.4.3 Case: Part III

His wish notwithstanding, the patient was again revived by the hospital's emergency resuscitation team. His heart stopped on four further occasions during that night, and each time was restarted artificially.

The body then recovered sufficiently to linger for three more weeks, but in a decerebrate state, punctuated by episodes of projectile vomiting accompanied by generalized convulsions.

Intravenous nourishment was carefully combined with blood transfusions and measures necessary to maintain electrolyte and fluid balance. In addition, antibacterial and antifungal antibiotics were given as prophylaxis against infection, particularly pneumonia complicating the tracheotomy that had been performed to ensure a clear airway.

On the last day of his illness, preparations were being made for the work of the failing respiratory center to be given over to an artificial ventilator, but the heart finally stopped before this endeavor could be realized. (adapted from Symmers 1968, 442)

Consider the following questions:

1. Analyze the considerations for and against each of the measures that were taken in this case:
   a. the initial resuscitation
   b. the four additional resuscitations required that same night
   c. intravenous nourishment
   d. blood transfusions
e. measures necessary to maintain electrolyte and fluid balance
g. mechanical ventilator

2. Do you see these choices as dilemmas?

3. What measures (if any) could have been taken in advance to prevent these choices becoming a dilemma for the staff?

These actions go beyond any reasonable presumption in favor of life. Instead, they appear to involve a blind inertia to "keep trying" or perhaps an unthinking sanctity-of-life principle. As indicated earlier, we contend that the patient's explicit request and his own quality-of-life assessment were sufficient to show that the first resuscitation attempt in this series was morally prohibited. However, even if this had not been so, surely once that effort was completed and the patient's resulting mental status was assessed, it should have been obvious that the patient's quality of life was so low as to make further life-sustaining efforts morally optional at best or even morally wrong.

Each step taken moved further in the direction of heroic or extraordinary measures (item 30). The introduction of intravenous nourishment and substances to maintain electrolyte balance was clearly an artificial means of sustaining this life (item 31) and, as such, morally optional or questionable in this context. Even if these were introduced before the patient's mental status could be determined, to withdraw them once the patient's quality of life became clear would not be an act of killing (item 32). The quality of life is so low here as to be below the threshold that creates an obligation to sustain life.

All in all, the reaction at this stage seems to be undeniably a case of misuse of medical techniques and technology, serving no valid purpose. Lest you take comfort from supposing that this could only happen in an "overseas" hospital and not in our society, you should notice that this case is taken from a British medical journal. The "overseas" hospital may have been in the United States.

2.4.4 Conclusions

1. No one of these considerations is decisive by itself.

The strongest individual factor is the personal consent element (item 1). However, even this does not establish conclusively an obligation on its own. If a patient with a critical but fully reversible illness such as bacterial meningitis emphatically refuses treatment, many physicians would find it unconscionable to honor this request. [For extended discussion of such a case, see Jonsen et al. (1982, 78–80).]

10. The conceptual elements in Table 4-1 (items 30–33) are addressed in many of the works listed in the "Further Reading" section, so they will not be treated in detail here. For an especially thorough and balanced discussion, see Deciding to Forego Life-Sustaining Treatment (President's Commission 1983, 60–90; see also recommendation 5 in Appendix II, Section 2).
Absent a quality-of-life judgment, a judgment about the irreversibility of the condition, or a prognosis of the imminence of death that makes sense of this refusal, it does not carry sufficient weight to make honoring it obligatory. At the very least, a physician would be justified in refusing to carry out the patient’s request on grounds of conscience. (However, there would be questions about the conscience of any other professional who allowed the patient to carry out this request.)

The Golden Rule (item 42) is often cited as a sufficient standard by itself. Upon analysis, however, the Golden Rule has a limited usefulness. It can point out certain fairly obvious moral wrongs in a context of shared values. ("Stop biting people. How would you like it if people bit you?") This is, of course, even more effective if accompanied by a demonstration.) But this principle by no means provides the basis for the whole of morality.

The Golden Rule is especially troublesome in circumstances in which value pluralism reigns, because it invites us to impose our own personal values on other people. If my personal distaste for eating snails is so strong that I would not want anyone even to offer me snails, for example, the Golden Rule might lead me to propose outlawing the eating of snails altogether.

More to the point here, one might have personal values at present that strongly oppose any measure to limit treatment—for example, a desire to exhibit courage and endurance in the face of suffering, which might lead her to judge that requests by others to avoid prolonging suffering ought to be ignored. At the extreme, she might even decide now not to have granted a future request of her own to cease treatment, since she can only assume that she would have lapsed into irrationality before making such a request. There might be justification for her adopting such a policy in her own case (through specification on an advance directive document). The objectionable move is for her to employ the Golden Rule argument to impose the same policy on others.

Similarly, a unilateral quality-of-life judgment (items 6 and 7) is not generally a reliable guide to decision. Since quality-of-life judgments are composed of both a "subjective" or personal element as well as an "objective" or predictive element, it is ethically problematic for any person to make such assessments alone. The physician may be able to predict with precision the level of comfort and functioning in store for the patient, but only the patient can decide whether this state is worthwhile. A long-term knowledge of the patient can give strong clues here, but even this cannot provide a solid base for judgment, since the patient’s assessment may change when conditions of illness are actually encountered. In the last analysis, then, it is hazardous for anyone other than the patient him- or herself to make these judgments. And the patient may not be able to understand fully the predictive element in such judgments. (For a useful catalog of subjective factors that might affect unilateral quality-of-life judgments, see Appendix III for the excerpt from the ACP Ethics Manual entitled "Quality of Life.")
Quality-of-life judgments, then, are inherently problematic. They may have a role in treatment/nontreatment decisions, but they must be employed with extreme caution.

Judgments of medical indications (item 16) are problematic in the same way. The probability that the immediate medical crisis can be reversed might be quite high. However, if this leaves an irreversible underlying condition, then the value of successfully achieving this limited objective can be assessed only by determining its contribution to the patient's quality of life.

2. No one of these considerations is irrelevant to a decision.

Some of them may turn out to carry very little weight in the final assessment of an action, but none can be discounted entirely. And in certain circumstances the relatively small weight of one factor may "tip the scales" in one direction.

Many commentators eschew reference to financial considerations in connection with these decisions. It is tragic, for example, when a patient feels it necessary to reject further treatment on the grounds that its cost would ruin his family financially (item 22). However, this sense of tragedy may be due largely to a belief that society owes it to the patient and family (item 25) not to allow them to be driven to a choice such as this; this belief overlooks the harsh fact that parallel choices must be made at a societal level (items 26 and 28). Although these are usually addressed in abstract rather than personalized terms, a specific case could arise in which the costs of life-sustaining measures were so exorbitant that we could not permit allocation of this proportion of societal resources to this one patient. Thus, the question is how much weight to give this factor, not whether to weigh it in at all.

Similarly, educational values (item 20) and research values (item 21), although they should not be elevated in importance above the best interests of the patient, may be factored into the decision. Occasionally they may be decisive in the choice between two treatments that are closely balanced in the extent to which they serve the patient's best interests.

3. A priorities list for urgent situations can be constructed.

When a decision about a life-sustaining treatment must be made immediately, the following order of considerations is appropriate:

1. Consent elements, especially item 1
   a. If a clear directive has been offered by the patient (as it should have been in most cases if the advance work of the DPA has been carried out), it should be honored.
   b. If there is no clear directive that covers the case at hand, proceed to the next item.
2. Imminence of death without treatment
   a. If death is imminent and the need for action is urgent, the presumption in favor of sustaining life may dictate initiating action immediately, without further consideration.
   b. If time allows further reflection, then proceed to the next item.
3. Efficacy of treatment from a limited perspective
   a. If the odds are high that the treatment will be ineffective in overcoming the immediate crisis, there is little point in initiating it.
   b. If there is a reasonable chance that the immediate crisis can be combated successfully, proceed to the next item.
4. Disvalues of treatment
   a. If the disvalues of treatment are so great that they vastly outweigh the benefit of overcoming the immediate threat, it would be a net harm to the patient to initiate it.
   b. If the disvalues are within reasonable limits, proceed to the next item.
5. Imminence of death with treatment
   a. If reversing this condition restores the patient to an overall life situation with little prospect of long-term survival, it seems pointless to undertake it.
   b. If the patient’s overall life prospects are more hopeful, proceed to the next item.
6. Quality of life
   a. If your evaluation of the patient’s net quality of life is overwhelmingly negative and well grounded, there seems no moral justification to act to sustain this life.
   b. If your evaluation is affirmative, proceed to the next item.
7. Financial burden
   a. If the treatment imposes no financial burden, there is every reason to undertake it.
   b. If the treatment imposes a severe financial burden, weigh this negative factor against the benefits to be derived from treatment.

3 Seriously Ill Newborns

3.1 Issues

Decisions about treatment for seriously ill newborns are parallel in many (but not all) crucial respects to decisions for an incompetent adult patient. Among the chief differences are:

1. The infant has had no opportunity to develop personal values and plans of her own to form a basis for a substituted judgment (item 2); thus the best interests
standard (item 3) is the only patient-oriented basis for judgments. (This trait is shared by some adult patients, i.e., those who have been significantly mentally retarded from birth. See, for example, the court case of Joseph Saikewicz in "Further Readings.")

2. A prognosis of irreversibility is even more uncertain here than with adult patients, due to both the remarkable healing potential of the infant metabolism and the dramatic and rapid developments in neonatology. (There may be near-parallels to this in certain volatile adult conditions.)

3. The role of parents is unusually forceful with regard to infants and children. This stems largely from the child-rearing responsibility that society has entrusted to the parents.

The key question is how far the authority of parents extends. In general, parents are given wide latitude in carrying out their responsibilities, bounded by certain social policies. Parents are free to choose among a variety of forms of schooling for their children, but they are not free to avoid education for them altogether. Child abuse and neglect are prohibited by the state acting in its role as parent of last resort (i.e., parens patriae). However, many of these limits to parental responsibility have been recognized only relatively recently, and in some jurisdictions some restrictions are still only weakly enforced. (See Marsh 1981, especially Chapter 2: "The Historical Perspective of Children's Rights.")

The Judicial Council of the AMA endorses giving parents a dominant role in these decisions (see the second paragraph from the opinion on "Quality of Life," quoted in Section 2.1).

In contrast, the Federal Government has in recent years proposed a series of regulations dealing with these decisions that does not acknowledge any discretionary authority on the part of the parents. These rules, which have come to be called "Baby Doe regulations," if enacted would employ the mechanisms of civil rights enforcement to police decisions regarding limits to treatment for seriously ill newborns. Several versions of such regulations have been struck down by the courts (wisely, in our judgment). The latest version, passed by the US Congress in October 1984 after lengthy negotiations between several interested parties, moves away from this civil-rights model. Instead, it requires state child protective services agencies to establish definitions of and responses to forms of child neglect and abuse involving medical treatment. This brings these decisions more into line with the bounded domain of authority characteristic of parental responsibilities.

The legislation defines "withholding medically indicated treatment" as the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment will be most likely to be effective in ameliorating or correcting all such conditions.
Failure to treat does not apply when, "in the treating physician's or physicians' reasonable medical judgment,
(A) the infant is chronically and irreversibly comatose;
(B) the provision of such treatment would
   1) merely prolong dying
   2) not be effective in ameliorating all of the infant's life-threatening conditions, or
   3) otherwise be futile in terms of the survival of the infant; or
(C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane." (Public Law 98-457)

3.2 Conclusions

Parents, as surrogates for the infant, should fully share in decision making at every stage. In the same ways in which adult patients are informed, sustained, and consulted about decisions in their own cases, parents should participate in making decisions about infants.

The basic principles governing decisions for newborns should be the same as those for adult patients; i.e., if there is a realistic possibility that the infant could benefit significantly from treatment, it ought to be initiated. This judgment of benefit is arrived at (as in adult cases) by weighing and balancing the full complex of elements listed in Table 4-1, especially

1. the imminence of death without treatment (item 14)
2. the imminence of death with treatment
3. the efficacy of treatment (item 12) and the irreversibility of the illness (item 13), from a broad life perspective
4. a realistic assessment of the prospects for the child receiving the intensive and enthusiastic level of post-hospital care that will be required to realize his full potential—whether this will be from the family (items 10, 23, and 24) or from social institutions
5. the present and prospective quality of life (item 7).
6. the financial burden to the family and to society (Items 10, 26, and 28).

In many cases of seriously ill newborns, residual disabilities make the fourth item especially important. One may argue that the family and/or society have a strong obligation to provide resources to allow the child to develop to her full potential. The President's Commission (1983, 205–207) states the case for this ably. However, if it appears unlikely that this obligation will be met, it is unrealistic to make a decision based on the assumption that it will be. Any attempt to force unwilling parents to live up to what we perceive to be their duty is unlikely to succeed. Prospects for success in persuading society to live up to its duty here may be somewhat greater, if we are willing to work at it, but success is unlikely to come swiftly enough to be of much help to this baby.
If the parents express definite wishes regarding treatment of their newborns (and they should be guided to do so), their judgment should be determinative in situations in which the options are relatively evenly balanced. They may be overruled in some situations, but only when the benefits of the treatment they wish to forego (or the harms of the treatment they are insisting on instituting) are so clear that to carry out their wishes would amount to a form of child abuse.

The authority of parents to volunteer their infants and children for procedures whose orientation is more experimental than therapeutic is sufficiently in doubt that such decisions should routinely be ratified by some carefully chosen third party or parties.

4 Abortion

The issue of abortion extends the questions of the previous section yet a step further. The moral standing of any infant is called into question because of a paucity of any previous moral relationships, but the standing of the fetus is even more questionable in this regard—although recent developments in in utero surgery and diagnostic tests add to the inventory by establishing a physician-patient relationship with the fetus. Current policy with regard to seriously ill newborn infants implies that an independent right to life is subordinated in practice to the moral authority of parents to determine whether this right is exercised or waived; thus any such claim of a right to life for a zygote or fetus will be even more controversial. Whatever limits are placed on the authority of parents to make life-and-death decisions for newborn infants, these are generally regarded as exceeded by the authority of a pregnant woman to end her pregnancy during the first trimester.

Clearly a central question in this debate is whether or not the fetus is to be regarded as an independent member of the moral community, i.e., as a "person" or a "human being" in his/her/its own right. Like the question of demarcating the threshold of death (discussed in Section 1), this is fundamentally a philosophical question: What traits and/or relationships must a being have in order to be considered "one of us," a member of the moral community of persons? This question has been debated at length in philosophical and theological circles for centuries, and it is unlikely that one of the several competing answers will be declared the winner of the debate in the immediate future. Some of the many definitions of the beginning of moral personhood that have been proposed are shown in Table 4-2. However, although the question of the moral personhood of the fetus is certainly a central issue in connection with abortion, it is important to recognize that it does not, by itself, competely resolve the question of the moral justification of abortion.
Table 4-2  Beginning of Moral Personhood

<table>
<thead>
<tr>
<th>Transition Point</th>
<th>Underlying Philosophical Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-conception</td>
<td>Transmigration of souls, reincarnation—the personal identity (soul) exists before and independent of embodiment.</td>
</tr>
<tr>
<td>Conception</td>
<td>Identification of personal identity and/or potentiality with genetic integrity.</td>
</tr>
<tr>
<td>Conception + 14 days</td>
<td>Past twinning limit, assumes that individuation of soul, identity, or life is established once genetic integrity is firm.</td>
</tr>
<tr>
<td>Implantation</td>
<td>Acknowledging the high frequency of spontaneous abortions before this stage; thus individual identity or potentiality is tied with the probability of live birth.</td>
</tr>
<tr>
<td>Organ function</td>
<td>The beginning of &quot;life&quot; is sometimes dated from the initiation of the functioning of certain key organs, such as the heart or the brain. This is an attempt to make the criterion of the beginning of life parallel to the operational criterion of death.</td>
</tr>
<tr>
<td>Quickening</td>
<td>Reflects ancient view that the fetus was inert matter until a certain point and then it &quot;came alive.&quot; The change was usually ascribed to ensoulment. (See next item.)</td>
</tr>
<tr>
<td>Ensoulment</td>
<td>Infusion into the fetus of a soul.</td>
</tr>
<tr>
<td>Viability</td>
<td>Emphasizes possibility of independence as the identifying feature of a person.</td>
</tr>
<tr>
<td>Birth</td>
<td>Emphasizes actual independence, direct relationship as the crucial feature of membership in the moral community.</td>
</tr>
<tr>
<td>&quot;Personhood&quot;</td>
<td>Usually correlated with certain landmarks in mental and social development—such as, a concept of self. Usually based on an analysis of rights.</td>
</tr>
</tbody>
</table>

Even if it were agreed that the fetus is a person with all the "rights, privileges, and responsibilities thereunto appertaining," it would not follow that abortion is never morally justified. The fetus’ physiological ties to the mother may create conditions that pose a threat to the life or health of the mother; thus a plausible case, in terms of a sort of self-defense, might be made to justify abortion.

On the other hand, even if it were agreed that the fetus is not a person but only a mass of tissue, moral arguments against abortion might still be plausible in many circumstances. One of the strongest such arguments would stem from the father’s rights and/or tacit or explicit promises the mother might have made to him. If a couple had agreed to have a child and had taken action to initiate pregnancy based on that agreement, then certain legitimate expectations are created in the mind of the father; thus the mother does not have a right to make a unilateral decision to end the pregnancy.

Another limiting argument rests on the question of whether a person has a right to maim himself without some morally significant justification. Few people feel qualms about piercing ears for aesthetic reasons, but many in our society would think it unjustified to pierce one’s nose or cheek in order to hang jewelry. And if someone proposed to cut off two fingers to achieve the aesthetic result of having four fingers on each hand, or if a woman golfer proposed to remove a breast to
improve her golf swing, or if a man proposed to submit to castration to affect his singing voice, the revulsion with which we would react invokes a moral principle. Similarly, even if the fetus is regarded as nothing more than a mass of cells, it is doubtful that there would be moral justification to remove them merely because their presence is an inconvenience to the mother. Some more serious reason than this would at least be required.

Another important issue that arises in connection with abortion has to do with personal conscience. The law and institutional policies have generally attempted to honor personal conscience even while legalizing abortion by providing that anyone who has moral objections may decline to participate in the practice. However, generally the proviso is added that some arrangement must be made to refer the patient to a provider or institution that will grant her request for an abortion, and many who object to abortion think that even this much personal cooperation is morally wrong. Here is a classic example of a conflict of conscience. Meeting one’s responsibilities to patients may go against personal conscience on this issue. Honoring conscience may compromise duties to patients. This dilemma is even more acute in a community in which some institutions or practitioners to which patients might turn without guidance provide services you would regard as less than fully satisfactory in terms of safety and medical science. In this situation, you must carefully and thoughtfully balance qualms of conscience about cooperating in abortion against duties to protect the interests of patients. Given that the role in abortion in this situation is so indirect and remote, it is hard to avoid the conclusion that the high stakes in terms of patient safety outweigh qualms of conscience regarding abortion.

5 Reproductive Technologies

Current and developing reproductive technologies bring up additional questions of responsibilities toward potential life. If a sanctity-of-life principle were carried to its logical extreme, it would dictate that every ovum of every fertile woman be fertilized and developed to term, for each has the potential to become a person. Only slightly less extreme would be the requirement that technology be developed to enable every ovum that becomes fertilized in the natural course of events to be developed. If life is truly sacred and valuable beyond price, then it follows that every instance of it ought to be promoted—no matter what the cost. And the cost of either of these proposals would be enormous, not only because of the expense of the technology that would have to be developed and used to carry out this task, but also from consequences of the resulting overpopulation of the planet.

11. Roman Catholic moral theology makes the principle explicit. Called the "Principle of Totality," it specifies that inflicting a harm on oneself is justified only when a more serious harm to the organism as a whole is thereby avoided, such as when one submits to surgery to repair a life-threatening condition.
The other pole of reaction to reproductive technologies is to condemn them all because they make "artificial" what is proper only through "natural" means. However, the distinction between the natural and the artificial is exceedingly difficult to draw with precision; when it is clarified, it is not obvious that it can bear the moral weight placed on it. For example, the life of a diabetic is maintained by the artificial procedure of injecting insulin to replace the missing natural production within the body. How is this different, in a morally relevant way, from the artificial juxtaposition of sperm and ovum in a culture medium when the blockage of the fallopian tubes impedes the natural process? To move to a more controversial example, how is the harvesting and fertilization of multiple ova, followed by removing all but one from the culture dish at the blastocyst stage, different in moral terms from the quite common natural process of fertilization of multiple ova and sloughing off most of them in the uterus? Here the natural process is mimicked to preserve the wisdom of nature in avoiding the dangers of ova separation before fertilization and in providing the "fail-safe" and "quality control" advantages of multiple fertilizations.

Of course, the potential for introducing harm to the resulting child by not mimicking nature fully enough needs to be taken quite seriously. Experimentation on human genetic materials is unjustified before these dangers have been reduced to a reasonable level through laboratory studies. Overzealous pursuit of new knowledge (much less of new publications in one’s name) is to be guarded against with extreme caution in an area such as this, where the risks to the resulting child and his or her parents are grave.

Another fundamental issue that arouses moral concern is the allocation of resources. Is there a fundamental "right to reproduce"? Even if there is, what priority should it be assigned relative to other medical needs? These are questions that ought to be worked through to answers before vast sums of money are allocated to this area of research and treatment.

These technologies may bring great benefits to mankind. For one thing, they may help to resolve some of the dilemmas concerning abortion by making it possible to end a pregnancy without necessarily ending the process of development of the fetus. Further exploration into the process of human development may discover ways to prevent genetic diseases that now cause great suffering. However, here as in other areas of experimentation, we must proceed with moral as well as scientific caution.
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2.13 Organ Transplantation Guidelines


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Right to Refuse Medical Care (Capron AM)

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**Abortion**


2.01 Abortion

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I. Medical Aspects (Hellegers AE)

II. Jewish Perspectives (Feldman DM)

III. Roman Catholic Perspectives (Connery JR)

IV. Protestant Perspectives (Nelson JB)

V. Contemporary Debate in Philosophical and Religious Ethics (Curran CM)

VI. Legal Aspects (Finnis JM)

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Prenatal Diagnosis

I. Clinical Aspects (Milunsky A)

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Reproductive Technologies


Reproductive Technologies

I. Sex Selection (Largey G)

II. Artificial Insemination (Frankel MS)

III. Sperm and Zygote Banking (Frankel MS)

IV. In Vitro Fertilization (Mastroianni L Jr)

V. Asexual Human Reproduction (Sinsheimer RL)

VI. Ethical Issues (McCormick RA)

VII. Legal Aspects (Robertson JA)

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