



Resolving Conflicts over Possibly Inappropriate or Harmful Life-Sustaining Therapies

Introduction

The goal of medicine is to benefit the patient. Conflicts may arise when clinicians disagree with patients and families over whether initiation or continuation of life-sustaining therapies has a reasonable chance of providing benefit. In other words, as the technological possibilities for medical intervention continue to multiply, clinicians and patients alike have an increasingly difficult time deciding whether the application of these technologies is likely to benefit the patient or merely delay the inevitability of death.

As recently as forty years ago, the discontinuation of a life-sustaining treatment under any circumstances was regarded as both unethical and illegal. Since then, however, a consensus has emerged in law and bioethics that competent patients may refuse any unwanted medical therapy, even if their clinicians disagree.¹¹ More recently, the question has arisen in reverse: when may clinicians refuse to provide life-sustaining treatments that are desired by patients and families when the clinicians believe that their use is inappropriate or harmful? At the present time there is no consensus about this more recent question, with ambiguities in both the law and current bioethical opinion.

Fortunately, clinicians are only rarely unable to resolve differing views with patients and families about the appropriate use of life-sustaining technology. While members of the care team may disagree with each other and with the patient or family, the vast majority of these conflicts can be resolved through a process of informal discussions, team meetings, and the assistance of clergy, social workers, ethics consultants, or other mediators. On rare occasions, however, disagreements between the care team and the patient or family over the initiation or continued use of life-sustaining therapy may become intractable. The motivations for insisting upon treatment that is inappropriate or harmful are often complex: clinicians may regard the death of the patient as a personal failure and therefore insist upon treatment indefinitely; families may be unable to accept the impending death of a loved one and insist upon postponement of the inevitable for as long as possible, even at the expense of the comfort and dignity of the patient. When the disagreement is intractable, an approach is necessary for ensuring a fair process that can lead to resolution of the conflict. The purpose of this proposal is to outline such an approach.

The Role of the Children's Hospital Ethics Advisory Committee in Resolving these Conflicts

Conflicts between patients and caregivers are often successfully mediated by institutional ethics committees. As demonstrated by national experience with these committees, the makeup of the committee membership is perhaps the most important factor for ensuring the legitimacy of the mediation process. In recognition of the fact that futility is almost never a solely medical or technical determination, a substantial representation on the committee must be from individuals not associated with the medical or nursing professions, such as former patients or family members of former patients. Among those with a medical background, the membership should have balanced representation among physicians, nurses, social workers, and other clinical professionals. Efforts should be made to attain ethnic and cultural diversity, in order to represent the variety of experiences of health and illness among different groups. The Children's Hospital Ethics Advisory Committee (EAC) meets these requirements, and has

substantial experience in resolving conflicts of this type. It should therefore play a central role in mediating conflicts over the use of possibly inappropriate or harmful life-sustaining procedures.

Case Identification

This pathway is directed at situations where clinicians have come into conflict with patients or surrogates regarding whether it is appropriate to initiate or continue life-sustaining therapy. As noted above, however, the great majority of dying patients have life-sustaining therapy withheld and withdrawn in a timely manner that is perceived to be appropriate by clinicians, patients, and families alike. This pathway is therefore aimed at a relatively small number of cases where the usual mechanisms for decision-making have not been able to resolve the differing views of the patient, family, and clinicians.

Cases for the pathway must meet certain specifications.

1. Patients must be using or considering using therapies generally regarded as life-sustaining. Therapies of this type may include mechanical ventilation, dialysis, cardiac inotropes/vasopressors, ventricular assist devices, or artificial nutrition/hydration. This restriction is intended to limit the application of this policy to serious questions about life and death decisions; this policy should not be used, for example, to resolve a conflict over whether antibiotics should be prescribed for treatment of a viral syndrome, or whether an MRI is necessary to evaluate a headache.
2. In addition, there must be persistent disagreement between the clinicians caring for the patient and either the patient or surrogate over whether the continued use of life-sustaining treatments is inappropriate and/or harmful. For these purposes, treatments are inappropriate when they provide no reasonable possibility of extended life or other benefit for the patient, and treatments are harmful when the additional suffering or other harm inflicted is grossly disproportionate to any possibility of benefit.^[2]
3. Patients and families will be informed about this process as a part of the educational materials made available through the hospital. Patients and families as well as clinicians will have access to consultation about the process as well as the opportunity to initiate the process through the Children's Hospital Office of Ethics and the Ethicist on-call.
4. If the care team is insisting upon the use of a life-sustaining therapy against the wishes of the patient or surrogate, they should provide an ethical justification for its use based upon the expected benefits and burdens of the therapy in the context of the relevant clinical information, and in consideration of the patient's values, preferences, and goals. Often consensus can be reached by focusing on a time-limited trial of therapy, with the understanding that the treatment will be discontinued if certain goals are not met within a defined period of time. Similarly, if the clinical team believes that a life-sustaining therapy desired by the patient or surrogate is either inappropriate or harmful, then the care team must justify this view on the basis of the expected benefits and burdens of the therapy, again in the context of the preferences, values, and goals of the patient. Under these circumstances, the clinicians should emphasize that limiting the use of life-sustaining treatments will not lead to abandonment, or to neglect of the patient's need for symptom control or emotional support. In particular, the availability of clinical pathways for comfort care or consultation from palliative care specialists should be discussed and offered whenever possible.
5. If these measures fail to resolve the disagreement, then the attending physician should seek a second opinion from another experienced and respected clinician, preferably from another institution, and with input from the patient or surrogate whenever possible. The patient or surrogate decision-maker should have an opportunity to meet with this consultant at their request.

6. The case should be referred to the EAC only if, despite these efforts, the patient or surrogate clearly and persistently disagrees with the clinicians' assessment of whether continued treatment is inappropriate or harmful.

Assessing Whether Continued Life-Sustaining Therapy is Inappropriate or Harmful

Once a case is identified as outlined above, a coordinator for the EAC will arrange for evaluation by the Committee. The evaluation has three distinct phases. Depending upon the complexity of the case, these phases may be scheduled to occur sequentially in a single meeting, or the phases may be scheduled to occur separately. Parties that must be involved in the process include:

1. Members of the Committee.
2. Members of the care team, including the attending physician, primary nurse or nurses, members of the house staff, involved social workers, therapists, etc.
3. The patient and supporting individuals. If the patient is unable to attend, as will often be the case for ICU patients, then the patient should be represented by an appropriate surrogate. If the patient does not have an appropriate surrogate, then hospital policies and procedures should be followed for determining who should serve as the patient's representative. In addition, individuals who can be supportive to the patient or surrogate should also be invited, such as relatives, close friends, or clergy. Finally, the patient or surrogate should feel free to bring legal counsel, if desired, and the hospital should provide reasonable assistance in this regard, if requested by the patient or surrogate.^[3]

Meeting Phase One

The first phase of the evaluation should be convened with the Committee and the members of the care team present. The purpose of this first phase is for the Committee to hear the "medical perspective" on the case. This can often be done by a house officer, with attendings and others present to provide details and clarification. Care should be taken to present the social, psychological, and cultural background of the patient as well as the medical issues. At the conclusion of the presentation, the house officer or attending should clearly articulate the basis on which further treatment has been judged to be either mandatory or inappropriate/harmful. The members of the Committee should have ample opportunity to ask questions about the case so that everyone present, including the lay members of the committee, have an adequate understanding of the relevant issues.

Meeting Phase Two

Following Phase One, the Committee should offer to meet with the patient or surrogate and supportive individuals. Members of the care team should attend this meeting only if their presence has been requested by the patient or surrogate. Based on national experience with ethics committees, families will often ask a primary nurse or community physician to attend the meeting with them, both to provide support as well as to facilitate communication with the Committee. In addition, one member of the Committee should be designated as the "moderator," and should structure the meeting so that interactions between the patient or surrogate and the Committee are non-threatening, supportive, and productive. The purpose of Phase Two is for the Committee to hear the "patient and family perspective" on the case. The patient and family should have an unrestrained opportunity to explain their understanding of the illness and the prognosis, their hopes and fears about the future, and their preferences for further treatment. Under the guidance of the moderator, members of the Committee should ask questions that seek to understand the differences in values and interpretation of the facts that have led to the conflict. As much as possible, the Committee should strive to attain the

perspective of the patient or surrogate in an effort to grasp the essential differences that exist between them and the clinicians.

While the involvement of the entire Committee allows for consideration of a wide variety of perspectives, in some cases the patient or surrogate may feel much more comfortable interacting with a smaller group. In these cases a subcommittee should be formed to meet with the patient or surrogate, with responsibility for reporting back to the Committee as a whole.

Obviously, some patients or surrogates may refuse to meet with the Committee. This may be an unfortunate reflection of the loss of trust that often develops between the family and clinicians in situations of conflict. Nevertheless, when good faith efforts have been made to include the patient and family in the process, then their refusal to meet with the Committee should neither be seen as undermining the integrity of the process nor invalidating the Committee's recommendations.

Meeting Phase Three

Following Phase Two, or at another scheduled time, the Committee should meet alone, without either the care team or the patient or surrogate present. The purpose of Phase Three is for the Committee to come to consensus over whether further use of life-sustaining treatment is inappropriate or harmful. The Committee must understand that this determination requires a synthesis of both the medical facts as well as the unique and perhaps idiosyncratic circumstances of the case itself. This may be particularly difficult for some medical professionals, who may be inclined toward an overly reductionistic approach based upon extrapolation from personal experience and the medical literature. Similarly, lay members may be challenged to distance themselves from their own emotional reactions to the case in order to consider the medical realities as presented by the clinicians. In making its recommendations, the Committee should consider the well-being of the patient and family, as well as the need to support the moral integrity of the clinicians and the ethical fabric of the institution.

An important question is whether the Committee should take financial considerations into account in its deliberations. This is especially problematic given the changes in reimbursement that have occurred in healthcare over the past few years. Whereas clinicians and hospitals used to be financially rewarded for over treating patients, they may now benefit fiscally from the under treatment of patients. This shift tends to undermine the credibility of claims by clinicians and hospitals that their reluctance to provide treatments they regard as inappropriate or harmful is not contaminated by financial motivations. Despite these doubts, the Committee should be clear that its deliberations and conclusions will be based solely upon an assessment of the patient's and family's best interests, without consideration of fiscal implications.

The conclusion of the Phase Three deliberations will therefore be one of three outcomes:

1. Lack of consensus,
2. Support for limitations on the use of life-sustaining therapy,
3. Support for initiation or continued use of life-sustaining therapy.

Whatever the outcome, documentation and follow-up on the Committee's recommendations should be modeled after the usual procedures for any type of consultation. As such, a designated representative of the Committee should be assigned to write a synopsis of the deliberations of the Committee in the Medical Record. The synopsis should include a

summary of the salient features of the case that lead to the conclusions reached, and the justification for those conclusions. After informing the attending physician, this representative may meet with the family to review the Committee's deliberations and recommendations. Finally, since the patient or surrogate has legal access to the Medical Record, the attending physician should review this report with the patient or surrogate if requested.

If the Committee Does Not Reach Consensus

If the Committee is unable to reach a unanimous consensus, then alternative approaches to dispute resolution will be necessary. In any case, lack of consensus does not foreclose any options for the care team or patient. Even in the absence of consensus, the process of deliberation outlined above should often lead to fresh insights and strategies for resolution.

If the Committee Does Reach Consensus:

	Patient/Surrogate Insists on Treatment	Patient/Surrogate Refuses Treatment
Clinicians Insist on Treatment	No Conflict	Committee supports patient's view: Section A Committee supports clinicians' view: Section B
Clinicians Refuse Treatment	Committee supports patient's view: Section C Committee supports clinicians' view: Section D	No Conflict

A. If the Committee Supports the Patient's or Surrogate's Refusal of Treatment

Common examples of this type of conflict concern clinician's insistence upon using blood products to treat a Jehovah's Witness patient, or the unwillingness of some clinicians to forego nasogastric tube feedings at the request of a patient or family. If, in these circumstances, the Committee supports the view of the patient or surrogate that further use of life-sustaining therapy is inappropriate or harmful, then the clinicians have several options:

1. Agree to withhold or withdraw the unwanted life-sustaining therapy:
In some cases, the process of deliberation may lead the clinical team to see the situation in a different light, and be willing to forego further use of the life-sustaining treatment.
2. Seek transfer of care:
If the institution or clinicians continue to believe that it is not ethical to withhold or withdraw the unwanted therapy, then they should seek transfer of care to other clinicians or another institution. See below for a discussion of caveats regarding the transfer of care.

B. If the Committee Does Not Support the Patient's or Surrogate's Refusal of Treatment

In this case, the Committee takes the position that foregoing life-sustaining treatment

under the circumstances is not acceptable. In some cases, the institution may be willing to transfer the patient to another facility that would be willing to respect the patient's or the family's wishes regarding the foregoing of treatment. In other cases, the institution might initiate legal proceedings to implement its clinical perspective through a court order. In any case, the patient or surrogate should be made aware of their legal options and the institution should assist the patient or surrogate in reasonable ways to access those options, if they so desire.

C. If the Committee Does Not Support the Caregivers' Refusal to Provide Treatment

If the Committee does not support the caregivers' assessment that further treatment is inappropriate, the clinicians have several options:

1. Continue to provide treatment:
Based upon the deliberations of the Committee, the clinicians may come to see the situation differently. One of the explicit purposes of the process of deliberation is to elicit values and understandings that may not have been articulated in the initial discussions with the clinicians. If this occurs, the clinicians may well be persuaded that continuation of treatment is the most acceptable option.
2. Seek transfer of care to other clinicians or another institution:
If the clinicians continue to believe that further treatment violates their own professional integrity, they may seek to remove themselves from the care of the patient. The nature of the separation will vary depending upon the professional involved. For example, nurses or social workers may be able to remove themselves from the care of the patient simply by asking for reassignments.^[4]

The attending physician, on the other hand, cannot simply ask to be reassigned. For the attending physician to opt out of continued treatment, care must be transferred to another attending willing to accept the case.

If no clinicians can be located within the hospital to assume care, then the patient or surrogate should be informed and permission should be sought to seek transfer of the patient to another facility. If this fails, possible options are not well-defined. On the one hand, physicians have an obligation not to abandon patients under their care, while on the other hand, medical professionals should not be obligated to provide treatments in violation of their clinical judgments, consciences and ethical standards. This pathway therefore does not provide specific recommendations for this possible outcome.

D. If the Committee Supports the Caregivers' Refusal to Provide Treatment

The Committee may support the caregivers' assessment that further treatment is inappropriate or harmful. In this case, it is important for both the clinicians and the Committee to appreciate that withdrawal of life-sustaining treatment against the wishes of a patient or surrogate is not an individual decision, nor even the decision of the care team or Committee, but an institutional decision, affecting all of the professionals who work within the institution. In this light, it is imperative that the hospital administration and legal counsel be involved

in further decision-making. Some of the options that could be available include:

1. *The physician and hospital could attempt to transfer care*

This option is controversial. From a practical perspective, it has the advantage of offering a "solution" to the problem. If the patient is transferred to care providers who are willing to continue the treatments, then some would consider the issue moot. In addition, the process of seeking to transfer the patient to another facility serves as a "check" on the judgment that continued therapy is inappropriate or harmful, since successful transfer might imply a lack of consensus about that judgment within the broader medical community.^[5]

Others would disagree with this perspective, however, especially if continued treatment was considered inappropriate on the basis of being harmful. In this case, some would argue that clinicians would be abrogating their responsibilities to the patient if they allowed such transfer to occur.

2. *Hospital administration could request that the clinicians pursue further attempts at consensus with the patient or surrogate.*

If the consultation process uncovered potential avenues of mediation that might result in consensus between the clinicians and the patient or surrogate, then the hospital might have legitimate grounds for wanting the clinicians to pursue these possibilities. Nevertheless, this option should not be taken by the hospital administration purely to avoid having to make hard decisions about discontinuing inappropriate therapies. In addition, if this option is chosen, the administration needs to explicitly indicate the nature and time-frame of the proposed mediation, and to commit to alternative options if the mediation fails.

3. *Hospital administration and the Office of General Counsel could seek a judicial resolution to the conflict.*

If the consultation process concluded that the patient lacked decision-making capacity, and/or that the patient's surrogate was not acting in the patient's best interest, then one possibility would be to petition a court for its involvement. This would create the opportunity for re-evaluation of the patient's care plan and re-consideration of the advisability of continuing with life-sustaining treatments.^[6]

4. *Hospital administration could sanction the unilateral foregoing or removal of life-sustaining treatments.*

Such action should occur only after informing the patient or surrogate decision-maker of the plan, and only after giving them sufficient opportunity to seek legal advice and possibly judicial involvement, if desired. In some cases, courts have viewed prior deliberations by ethics committees as relevant and legitimate evidence in resolving these disputes. In some cases, the institution may wish to assist the family in obtaining such independent legal advice at the request of the patient or surrogate.

Most importantly, if the Committee supports the judgment of the clinicians, then the institution has an obligation to take good faith and substantive actions toward resolution of the conflict.

1. This right of refusal is substantially qualified when the patient is a minor or incompetent adult.
2. These definitions are adapted from: Tomlinson T, Czlonka D. Futility and hospital policy. *Hastings Cent Rep* 1995; 25:28-35.
3. If the patient or surrogate has legal counsel present during the meetings, then the hospital counsel must also be notified and involved.
4. This is consistent with current guidelines that allow for caregivers to opt out of morally controversial procedures like abortion, while not permitting reassignment for requests not based on moral considerations, e.g., refusal to care for HIV positive patients.
5. This interpretation could be applied to the Baby L case from Children's Hospital in Boston, as described in Paris JJ, Crone RK, Reardon F. Physicians' refusal of requested treatment: the case of Baby L. *N Engl J Med* 1990; 322:1012-1015.
6. This was the approach taken by the institution in the case of Helga Wanglie, as described in Miles SH. Informed demand for "non-beneficial" medical treatment. *N Engl J Med* 1991; 325:512-515.

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Updated August 2, 1999
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