# A Process and Format for Clinical Ethics Consultation

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Clinical ethics consultations have become increasingly common in the practice of medicine in North America in the past 30 years.<sup>1</sup> The reasons for this are multiple.<sup>2</sup> Three basic models for these consultations are in use: consultation by committee, by subcommittee, and by individual consultant. Each has its advantages and disadvantages.<sup>3</sup> The background and training of individuals providing ethics consultation has been the subject of considerable discussion.<sup>4</sup> This has led to the publication by the American Society for Bioethics and Humanities (ASBH) of guidelines for hospitals seeking professional expertise in clinical ethics.<sup>5</sup> In addition, the ASBH has produced a Learner's Guide for those involved in ethics consultation.

While there is general consensus that documentation of the ethics consultation in the patient's medical record should always occur,<sup>6</sup> there has been little discussion in the literature of possible formats by which a consultation should be

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Wayne Shelton, PhD, MSW, is Director of the Program on Ethics and Health Outcomes at the Alden March Bioethics Institute, Albany Medical College, Albany, New York, *sheltow@mail. amc.edu.* ©2009 by *The Journal of Clinical Ethics.* All rights reserved. reported in the patient's chart.<sup>7</sup> Rhodes and Alfandre recently described a different method, "a systematic approach to clinical moral reasoning to aid learners and clinicians in their application of ethical principles to the resolution of clinical dilemmas."<sup>8</sup> This method involves structured discussion between the ethicist and the bedside clinicians, but it does not include the opportunity for the ethicist to interact with the patient, family, or other pertinent individuals. In this method, documentation of the discussions and moral reasoning is left to clinicians.

In this article, we will describe an updated method by which an ethics consultation can be conducted that includes direct contact with pertinent individuals, and we will describe how this method serves as a format for documenting the ethics consultation. We will then discuss the advantages and disadvantages of this consultation method and conference method of Rhodes and Alfandre. The method and report format we describe have been developed by the authors in the past 20 years as we have provided bedside ethics consultation and have taught clinicians and graduate students how to do clinical ethics consultations. Our approach was briefly presented as part of a general discussion of ethics consultation in a recent book chapter by one of the authors.<sup>9</sup> This article provides a more detailed description of how ethics consultants may use this method in practice.

We will describe an individual consultant model, in which an ethics consultant works with the healthcare team to reach an acceptable outcome. In hospitals where consultation is done by a subcommittee of three or four individuals from the ethics committee, the process could be quite similar, with one or more individuals collecting the information, followed by a collaborative effort on the analysis and report. Where ethics consultations are done by an entire ethics committee, a different process will be required. Regardless of the process, an ethics consultation should use a method to assure that all relevant information is gathered and analyzed before recommendations are made.

# A PROCESS FOR ETHICS CONSULTATION

#### **The Consultation Request**

In the vast majority of physician-patient encounters, there is agreement about the goals of care and how those goals should be achieved. However, in a few cases, there are value-laden conflicts that create an impasse to moving ahead with a care plan. In other cases there may be no conflict, but questions may arise about the permissibility of a particular course of action. It is in these cases of conflict or uncertainty that ethics consultations are most frequently requested.

A request for ethics consultation usually comes by phone or in person from the individual making the request. Sometimes, however, the consultant may be contacted by an individual assigned to call the consultant such as a ward clerk or medical student. In the latter situation, the consultant should first identify who actually is making the request. It is almost always necessary to speak with that individual right at the outset. Rather frequently, the person initiating the ethics consultation may not be immediately identifiable. The idea for the consult may have come from a nurse, social worker, chaplain, or other clinician, but the formal request is written in the chart by the attending physician or a house officer. Regardless, the initial conversation is usually with that person who made the request.

During the initial conversation with the requestor, our favorite opener is "How can clinical ethics be of help?" The consultant should then get a thumbnail sketch of the patient's history (more details will be learned later), but the primary aim is to articulate the ethics question. This is often the most difficult part of the entire consultation. The caller may say, "Can you help us figure out what to do?" That is not an ethics question, although it may have a value-laden dimension. It often requires some probing to uncover the issue, and whether the issue is an ethical conflict *per se*, or some other issue such as a communication barrier or breakdown. Moreover, the issue identified by the caller may, in fact, not be the real issue that the consultant discovers as he or she digs deeper.

It is imperative to determine whether the attending physician knows about the request for an ethics consultation. Most hospital policies allow ethics consultation to be done over the (very rare, in our experience) objection of an attending physician. Other policies may allow the attending physician to veto a request for an ethics consultation. Still others do not address this issue in written policy. Whether an ethics consultation should proceed without the knowledge or permission of the attending physician is a valid and fundamental question, one that should be clear in written institutional policy. While it is traditional for the attending physician to control almost all aspects of patients' care, we believe that ethics consultation is a unique service that addresses concerns from many perspectives, and we agree with the ASBH that it should be available to anyone involved in the patient's care.<sup>10</sup> This is especially true since such consultations are provided in almost all instances without charge to the patient or insurance company.

However, we believe it is unwise to proceed with a consultation without the attending physician knowing about it. If the requestor says the attending is not aware of the request, the consultant may ask the requestor if he or she is willing to notify the attending. If he or she is not, the consultant may do the notification. It may occasionally be appropriate to not reveal to the attending physician which individual requested the consultation. If, however, the requestor does not want the physician to know about the request at all, we are unwilling to do a formal consult, but will offer to meet with the person calling to help him or her figure out how to cope with the situation. Some consultants may be willing to proceed even without the knowledge of the attending physician. How the ethics consultation process interfaces with the authority of physicians in the hospital setting is again a matter to be discussed and clarified as a matter of institutional policy and procedure.

# **Chart Review**

After receiving a consultation request on an in-patient, the consultant should next review the patient's chart. Often consults are requested on long-stay patients, and in facilities still using paper records, it may (or may not) be necessary to find parts of the chart that have been "thinned out." In many cases it may be helpful to also review the medical record from previous admissions or from the out-patient clinic if they are available. Chart review should generally include the items outlined in table 1. If the consultation is about a patient who is not in the hospital, the process of data collection will necessarily be different, although the information sought is similar.

## **Conversations with Healthcare Professionals**

After collecting information from the requestor and the chart, the consultant should talk with other pertinent individuals. Although listed here in a rational sequence, the consultant may encounter these individuals in any number of different ways, times, and situations. Sometimes the family is present on the patient's unit and it may seem best to speak with them before speaking with others. At other times, important individuals may

# Table 1. Chart Review

- Face sheet with identification and demographic information (note date of birth, medical record number, phone numbers of family contacts, primary physician, nursing home, etc.)
- Admission history and physical, diagnoses, plans
- Nursing intake forms
- Recent progress notes (it may be necessary to scan or review all progress notes)
- Sometimes a concise clinical summary may be found in a transfer note (e.g., when the patient is moved from the ICU to the ward) or an "off-service note" (when the house staff team changes)
- Consultation reports that provide not only the consultant's findings and opinion, but may also give a summary for a long-stay patient, though it is good to compare dates and data with original sources
- Notes from social worker, case manager
- Advance directives, limitation of treatment orders
- On occasion, pertinent lab, x-ray, etc., reports

be unavailable when the consultant wants to speak with them. Regardless, it may be appropriate for the consultant to speak with any of the following staff.

#### Bedside Nurses, Therapists

The nurse caring for the patient that day is usually the best person to inform the consultant of current treatment modalities the patient is receiving (dialysis? pressors? antibiotics? are vent settings high or low?). That person can also provide information about the patient's level of awareness over the past day or two, the patient's interactions with family, et cetera.

# Attending Physician, Residents, Interns, Medical Students

The physicians and students supervising hospital care should have the most detailed information about test results, diagnoses, prognosis, treatment options, and plans. However, each may have been involved in different conversations and may have a slightly different analysis and projection.

# Social Worker, Case Manager, Chaplain

These members of the professional team may also have been engaged in different conversations and may have important information to share about the patient's or family's understanding, values, or wishes.

# Consultants

If the patient's condition has changed since a specialist consultant's report was written, or if the ethics consultant uncovers new information that might affect that consultant's recommendations, it may be appropriate to talk directly with him or her. In addition, the ethics consultant may have specific questions for the medical or surgical consultant, for example, questions about prognosis, that have not been addressed in the consultant's report. Also, there may be questions if the ethics consultant discerns a difference of opinion between a consultant and the attending physician about the patient's prognosis.

# Primary Physician

The hospital attending physician is most often different from a patient's primary out-patient physician; he or she can often provide invaluable information about prior conversations with the patient about values, preferences, et cetera. Al-

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though this seems intuitive, house staff often overlook this very important source of information.

# Clinicians from the Nursing Home

When the hospitalized patient has been previously living in a nursing home, the ethics consultant may want to speak with the long-term care staff, but it may not be clear which individuals will have the information desired. He or she can start by speaking with the nursing supervisor on the patient's unit, or the social worker for the facility, and if they do not know the information sought, they may be able to direct the consultant to someone else who is familiar with the patient.

#### Visiting Nurse

Healthcare professionals who visit the patient at home often have a unique perspective on the patient and family in their home environment, and perhaps in more unguarded moments.

#### **Interactions with Patient and Family**

In addition to these professional caregivers, it is almost always appropriate to see the patient. This may not be so if the issue is about confidentiality, patient's right to know, et cetera. Such ethical issues can often be addressed with the professional care team alone, without involving the patient or family.

"Seeing" the patient may occasionally merely involve observation of the patient to see how he or she looks, what equipment is in place, and so on. But almost always it involves an attempt to converse with him or her.

When we do interact with the patient and family, it is our practice to ask the patient's nurse or resident to introduce us. Sometimes, when the patient and family are aware of the requested consult, self-introduction may be sufficient. Some ethics consultants prefer that the requestor seek consent from the patient or family before the consultant enters the picture. We believe this is not necessary and may occasionally be counterproductive. The patient or family may fear they are being asked to participate in an unwanted legal proceeding. With a direct introduction, the consultant can personally explain his or her role (see below), relieving hesitation and fear. If after the introduction the patient or family declines a consultation, the conversation can be stopped.

The intention of the conversation with the patient may be to elicit additional history, to determine the patient's understanding of the current situation and options, to assess decision-making capacity, or to learn firsthand what the patient would or would not like and why. In addition, it may be possible to learn about relationships between the patient and others, and even to uncover spoken or unspoken coercion.

It is usually important to speak with family members as well, especially if the patient lacks capacity and it is necessary to learn about the patient from the people who know him or her the best. Often, family members are present in the hospital and are easily accessible. At other times, it is necessary to call them on the phone, or to ask a resident or a social worker to set up a time when the ethics consultant may meet with several of them, preferably with one or more members of the clinical team.

When explaining the ethics consultant's role to the patient or family, we often say, "Hello, my name is [name], and I have been asked by [name] to do an ethics consultation. Not everyone is familiar with ethics consultations, so let me explain briefly what it involves. I am a physician [nurse, social worker, et cetera] and have additional training in medical ethics. I get called by physicians or nurses or others when things are complicated and they are trying to decide what is the best thing to do. I don't come in as a judge or jury to say 'Do this or that,' but to be sure we have spoken with everyone, understand the issues, and considered all the ethically permissible possibilities. We work together to try to decide what is best for the patient in a given situation."

Even after this introduction, family members often start interacting with the ethics consultant as if he or she were part of the bedside care team. For example, in response to an open-ended question — "Tell me about your father. What was he like before this illness?" — they often start with the patient's medical history. After listening for a bit, it may be possible to change focus by saying, "That confirms what I have learned from reading vour father's chart. Now tell me more about what kind of person he is. What is his personality like? What kind of work does (or did) he do? What does he like to do in his spare time? Is he outgoing or private? Is he a religious person?" The conversation may help to clarify some of the key issues in clinical ethics consultation, such as consent, surrogacy, substituted judgment, and best interests. It may also serve to provide support for a family in distress who are facing making gut-wrenching decisions for their loved one.

# **Management Conference**

In a large percentage of ethics consultations, it is helpful to arrange a conference. Sometimes this is restricted to the clinical team and the ethics consultant. If the issue is one of confidentiality or disclosure, or if the consultant has learned from the patient or family information that resolves the requestor's concern, it may not be necessary for the family to attend the conference. But more often such conferences include the patient's family, and sometimes the patient, if he or she is able to communicate, plus a few members of the clinical team — typically the attending physician, bedside nurse, social worker, or chaplain. This conference is comparable to the standard "family conference" with the addition of the person or persons doing the ethics consultation. It is important before beginning the conference that it is clear who will be the facilitator. Such conferences can be led by a member of the clinical team (the attending physician or resident), a social worker, or the ethics consultant; the key to their effectiveness is the ability to facilitate such a meeting and to create a comfortable and open setting for candid and respectful communication.

After the ethics consultant has collected as much information as seems necessary, it is time for him or her to analyze the issue and make recommendations. It is not the purpose of this article to discuss the various methods of case analysis used in ethics consultation. These have been well discussed by others.<sup>11</sup>

Our general goal is that the completed clinical ethics consultation report be entered into the patient's chart on the same day as the request is made. In those instances when this is not possible, because of lack of pertinent information or conversations, the consultant should make an entry in the chart, typically in the physician's progress notes, that the consultation is in progress, giving some indication of when it will be completed.

# A METHOD FOR DOCUMENTING THE ETHICS CONSULTATION

Ethics consultation, like all healthcare consultation, requires documentation that a systematic and thorough investigation has been made

into the question or problem that has been presented to the consultant. Currently, there is no universally accepted format by which to record an ethics consultation in the patient's chart. Some ethics consultants write a philosophical analysis, with or without recommendations. Others only write recommendations. Our style is to write a consultation report that will be recognizable by, and helpful to, the clinicians involved in the care of the patient, and will also be understandable by patient or family. Our format includes demographic information, the ethics question, a narrative, an assessment, a discussion, and recommendations. This format is not presented here as the only or even the best method, but in our experience it has proven useful to writers, readers, and students of ethics consultation.

It behooves the consultant to try to put himor herself in the shoes of the reader when composing the report. What have you learned that will be important for the reader to know?

#### **Demographic Information**

Many hospitals use standard consultation forms for paper or electronic formats. If this is not the case, the consultant should document at a minimum the patient's name, date of birth, and location as well as the name and contact information of the individual requesting the consult. It is usually wise to also indicate the source of the information that follows (chart review, list of informants, and so on).

# **Ethics Question**

As indicated above, this may be the most difficult portion of the consultation process. But it is important to document for the reader the question that the consultant will address in the report. This is the initial reason the consultation was called, and may be reframed into another question or problem by the end of the consultation.

# Narrative

The story that the consultant weaves together should be presented to the reader in a clear and logical fashion. This may be done in a fully chronological fashion, but more often begins with this hospital admission and the sequence of events that have led up to the question. In addition, of course, it is important to include past history, both medical and social, and as clear an understanding as is possible of the patient's values and wishes, along with contrary wishes of family members and healthcare professionals (if such is the case).

Some consultants prefer a standardized approach for presenting the story. For example, some may present the history in four paragraphs using the four-quadrant approach of Jonsen, Siegler, and Winslade, namely: medical indications, patients' preferences, quality of life, and contextual issues.<sup>12</sup> This format is often used as a training approach for new or less-experienced consultants, since it offers a step-wise approach that may prevent them from overlooking important elements, but some seasoned consultants also continue to use it.

It is very important that the narrative include all of the information that will subsequently be used in the assessment, discussion, and recommendations. It is contrary to a systematic methodology to add new information in the middle of these later portions of the report, and may cause the reader to wonder about both the history and the analysis. To this end, we recommend that the writer pause after completing the narrative, and review it to ensure that all facts and opinions are clearly expressed.

Some consultants prefer to keep the narrative brief, expecting the reader to be familiar with the facts and issues, relying on other parts of the chart to provide the details. Since we are dealing with important values and nuances of communication, we believe it is important to let the reader know what information is being used to do the ethical analysis. It is not uncommon for hospital charts to be lean or even incorrect regarding social information such as living situation, religious beliefs or practices, or even regarding levels of communication between healthcare professionals and the patient or family. Thus the pertinent information used in the ethics consultation should be clearly documented.

#### Assessment

This is not an essential component of a clinical ethics consultation report, and it is often the most difficult component for our students to master. Nonetheless, we have found it a good exercise to help the consultant to focus on the issues, and to help the reader to see where the process is going and why.

Our goal in writing an assessment is to capsulize in two or three sentences the issues in the case. We would like to see a brief synopsis of the clinical situation (type of illness, condition of the patient, prognosis), plus identification of the ethical issue that will be discussed in the next section of the report, for example, decision-making capacity, surrogacy for an incapacitated patient, consent, interpretation of an advance directive, conflicting wishes or values.

In composing this assessment, students often write a clinical summary that is longer than necessary, redundant to the reader, and fail to properly name the ethical issue. Please see the sample reports in the appendix to more fully understand our goal.

#### Discussion

This is where the ethical issues are fully unpacked and the ethical analysis is recorded. Although it is the meat of the report, it can be surprisingly brief in some instances. We recommend writing this section in two segments. In the first part, which we often call the "generic discussion," the consultant takes the ethical issue(s) identified in the assessment and states the clinical ethics consensus on the issue, or even the range of acceptable standards by which to reach a consensus. This provides a good opportunity for the consultant to introduce the reader to ethics terminology (for example, substituted judgment, best interests) and to teach him or her about standards for decision making, bioethics consensus statements,<sup>13</sup> precedents, and perhaps even legal decisions when applicable. In a separate paragraph, the consultant goes on to apply these standards to the present case.

If more than one ethics issue has been identified in the assessment, it may be clearer to structure the discussion into one section for each issue, addressing the standards and applying them to this case sequentially.

#### Recommendations

After the patient's story has been told, the ethical issue(s) have been identified, analyzed, and applied to this case, it is time to make some recommendations for the healthcare professionals and the patient/family. We generally suggest one to four recommendations, but this suggestion warrants some clarification.

Recommendations are often listed as separate parts of a larger, consistent strategy for moving forward — the two sample reports in the appendix below are examples. Both consultations list three recommendations, all of which are complementary and reinforce a coherent plan around which a consensus had been reached.

Alternatively, when a consensus has not been reached and all of the viable ethical options must be considered, two or more options may be considered that are mutually exclusive because they point to different goals of care. For example, based on the directives of the patient, continued life support, at least for a trial period, and comfort care may be viable options from which a surrogate may choose. However, these seemingly different options often flow from a single, moral perspective - for example, the legitimate surrogate has moral authority, and her choice should be honored. In short, regardless of whether or not a consensus has been reached, specific items listed as recommendations should cohere within a consistent moral perspective.

We have found that in consultations in which we were more actively involved, our ultimate recommendations tend to have been based on a consensus that we have helped to forge. In such cases, it may be appropriate to write in the chart on day one that the ethics consultation has begun and a full consultation note is forthcoming. These are cases in which the ethics consultant needs additional time to help develop an acceptable consensus. Once that is done, a recommendation can be crafted that seems to fit the particular case.

In other situations, a recommendation may be written that is conditional and more theoretical — for example, "if the patient is deemed to have capacity and understands the consequences of her decisions, she may refuse treatment, et cetera." In these cases, the ethics consultant is less involved as a facilitator and is more of an outsider.

Since in almost all institutions ethics consultations are advisory, it is critically important that these recommendations be framed with that in mind. It is inappropriate to write command sentences here (for example, "stop the ventilator," "get a second opinion"). The goal is to lay out the ethically permissible options ("it would be ethically permissible to stop the ventilator in this case"), draw boundaries of impermissible options ("it would be ethically problematic [or impermissible] to allow the patient's son to override her wishes"), sometimes to suggest a rank order for permissible options, or even to suggest new approaches ("a palliative care consultation may help the team meet the patient's expressed goals"). The completed consultation report should be carefully proofread to ensure it is understandable to the reader and free of errors in spelling, grammar, and syntax. In addition, the writer should eliminate words or abbreviations that might be unfamiliar to the average clinician (for example, DMC), or alternatively to define them (decisionmaking capacity). A report that is unreadable or indecipherable to the reader may cause him or her to question the quality of the analysis and possibly ignore the recommendations.

## **COMPLETION OF THE CONSULTATION**

Once the ethics consultation report is completed, the consultant should notify the requestor of his or her analysis and recommendations. This is best done in person or by telephone, but in some instances it may only be possible to enter a note in the progress notes of the patient's record that the consult is completed, and the report may be found in the consultation section of the chart.

Ethics consultation is rarely a one-time event. It is almost always appropriate to do follow-up visits with the clinical team and/or the patient. It is our practice to record follow-up notes in our own computer records on a regular basis. It may occasionally be appropriate to write a follow-up note in the patient's chart as well.

# DISCUSSION AND CONCLUSION

We have presented a method for doing clinical ethics consultations and for documenting the process and the recommendations. Although there are other methods that have been used and accepted, we have found our method to be useful both for analysis and resolution of clinical dilemmas and for teaching ethics to healthcare professionals.

The systematic approach to clinical moral reasoning described by Rhodes and Alfandre focuses on teaching healthcare professionals to identify and analyze dilemmas by themselves, using a principle-based approach, outlined in box 1 and box 2 of their article.<sup>14</sup> Their process occurs in a conference room and does not directly involve the patient or family. The ethicist is a consultant to the professionals, not to the patient or family. This method may have the advantage of increased investment of the professional team in the ethical analysis of individual cases, and it may give them more confidence for management of similar dilemmas in the future. However, we believe the consultation process we have outlined has the following advantages:

- Direct discussion with the patient, family, and out-of-hospital healthcare professionals may help reduce errors of inaccurate reporting or errors of interpretation.
- Observation of body language, tone of voice, et cetera, can allow the consultant a more nuanced understanding of the situation that might not be available to the consultant who speaks only with the professional caregivers.
- Direct chart review may reveal items that might have been overlooked by clinicians, for example, exact wording of an advance directive or documentation by other clinicians (such as a chaplain, or nurses who were not present during the consultation process).
- Recording of the consultant's discussion and recommendations in the patient's chart may more accurately reflect his or her analysis, avoiding errors of interpretation.
- The "generic" portion of the discussion offers an excellent opportunity to teach the clinical team some of the foundational issues and concepts in clinical ethics. This may make unnecessary future requests for ethics consultation in similar situations.
- The substance of the issue(s) may be more clearly documented so that members of the clinical team who were not present for the conference may have a better understanding of the outcome and resolution.

The approach we have outlined can nicely complement informal teaching rounds. We have made a practice of meeting with various ward teams on a regular basis to discuss cases that raise ethical questions for the healthcare professionals. Sometimes these conference room discussions lead to formal ethics consultations, but more often they serve as opportunities to teach clinical teams some of the concepts and precepts in ethics, much as Rhodes and Alfandre have outlined. The additional formal consultations we offer serve to demonstrate the process and content more explicitly. One potential disadvantage of having access to formal consultations is that the clinicians may defer to the consultant rather than addressing their dilemmas more directly.

We do not believe that the variety of approaches to clinical ethics consultation have been adequately discussed or compared. We offer this as one method, hoping to stimulate further discussion. For a sample of clinical ethics consultation reports using this format, see the appendix.

## APPENDIX

#### **Clinical Ethics Consultation, Example 1**

Patient: MR#:	AB, DOB XX/YY/ZZ 012345678
Request: Attending MD:	Dr. C D (neonatologist) Dr. C D
Date:	XX+1/YY/ZZ
Service:	N.I.C.U.
Consult no.:	EC#
Question:	Should we seek a court order to use blood products and/or ECMO (extracorporeal mem- brane oxygenation) on this critically ill child of Jehovah's Witness parents?
Informants:	Patient chart, Dr. D, patient's parents, bedside nurse, social worker

This term infant was born at an outlying hospital about 10:30 PM yesterday to a mother known to have a cervical culture positive for group B-Strep. Soon after birth, she showed signs of possible sepsis and was transported to our NICU about noon today. She has been treated aggressively but has had continued poor oxygenation. This neonate is critically ill and in danger of death if she continues to deteriorate. It is time to consider transfusion and it is approaching time to consider the use of extracorporeal membrane oxygenation (ECMO). Neither of these has yet been done for this child because her parents are both Jehovah's Witnesses and they decline to consent for either of these procedures on religious grounds. Other measures are already in use (inhaled surfactant, experimental nitrous oxide, IV erythropoietin) with the specific intent of avoiding transfusion and ECMO.

ECMO was introduced as innovative therapy several years ago and is now considered the standard of care for several neonatal conditions when they are not responsive to standard or high-frequency ventilatory assistance. This therapy has been available at this hospital for about 18 months. ECMO cannot be used in an infant this size without the use of blood transfusions. Because of their reluctance to impose risky invasive procedures on an unwilling family, Dr. D\_\_\_\_\_ and the director of the NICU have consulted by phone with nationally recognized leaders in ECMO therapy in X City and Y City. They both agree that its use is standard treatment for a child in this condition, and they predict she would have a 70-80% chance of intact survival with its use.

# ASSESSMENT

This neonate is critically ill and will almost certainly die if she does not respond to aggressive treatment within the next few hours. Her parents are unwilling on religious grounds to consent to the use of the next steps in standard therapy. Her physicians are uncertain whether to seek court authorization for additional treatment.

# DISCUSSION

Saving lives and preventing disability in children are two of the primary goals of modern pediatrics and all efforts should almost always be used to achieve those goals. Parental religious objections to the use of specific treatment modalities (e.g., Jehovah's Witnesses' objections to the use of blood products based on their understanding of scripture) are important family and societal values that should not be ignored or overridden lightly. In most situations it is ethically preferable to honor such objections to a point, e.g., to accept a lower oxygen-carrying capacity than one would accept in another child, or even to place a child at slightly greater risk of complications. However, when a child's life is in danger, physicians have been encouraged by society and supported by the courts to impose lifesaving blood products over parental objection. Seeking a court order to use other more invasive therapies or those that are innovative or unproven is even more problematic. Such measures may be ethically appropriate in some situations when there is a high likelihood for survival.

In this case, high-frequency assisted ventilation and other ancillary measures are already in use with continued hopes for improvement without having to use either of the modalities found objectionable by the patient's parents. If these are not effective within the next few hours, however, the physicians are struggling with their competing obligations to save this child's life and to honor her parents' religious beliefs.

If the therapies in question had only minimal chance of success, it would be ethically permissible to honor parental refusal and forgo their use. If, on the other hand, there were a high chance of intact survival with their use, it would clearly be standard clinical practice (with good judicial precedent) to seek the needed court order. Decisions between those extremes are less clear, but most clinical ethicists would recommend that, if the chances of intact survival are significant (10%?, 25%?), a court order should be sought, but only if other measures are clearly not working.

## RECOMMENDATIONS

- It is ethically permissible to continue current measures, and to postpone transfusion or ECMO for a short while in an attempt to honor the parents' objections. However, seeking a court order should not be postponed beyond a point of irretrievability.
- Before that critical point is reached, the appropriate judge should be approached, and he or she should be fully informed of the risks and benefits of both transfusion and ECMO.
- All through this process, the patient's parents should be fully informed of your treatment goals, your reasoning, and your hopes and expectations.

Thank you for asking me to participate in the deliberations about the further management of this baby. If I can be of further assistance, please feel free to call me at home tonight (xxx-xxxx) or at the office (y-yyyy) or by beeper (#zzzz) tomorrow.

[Name and title of ethics consultant]

# **Clinical Ethics Consultation, Example 2**

Patient: MR#: Request: Attending: Date: Service: Consult no.:	AB, DOB XX/YY/ZZ 011111111 Dr. H (hospitalist) Dr. H AA/BB/CC Hospitalists EC#
Question:	Does this patient have decisional capacity and what are her wishes regarding continuing medical treatment?
Informants:	Patient chart, patient, resident, Dr. H, patient's family, bedside nurse

## Medical Indications

This patient is a 68-year-old female with a history of diabetes, coronary artery disease, and chronic renal insufficiency. She had coronary artery bypass surgery on [date] followed by complications, which led to right above-knee amputation. She is now on dialysis 3 times per week, and has a spreading infection on her right leg and an ischemic left leg. She also has a stage 2 decubitus ulcer which without continual turning will likely progress to stage 3. If surgery is done to treat the infection of her right leg, further amputation will be necessary; then further surgery would be required for the ischemia of the left leg. Such a surgical procedure would involve risk of death, and burdens of ICU care and rehab, as well as permanent nursing home care if she survives. Her prognosis is poor.

## Patient's Preferences

The patient is awake and, after long discussion with her and further discussion with her attending physician, there was agreement that she has decisional capacity. She has a history of refusing treatment and continues to refuse medical interventions, including dialysis and being turned. However, she is ambivalent at times, especially when her family is present. She also refuses to agree to a DNR order. When I spoke with her, she indicated one clear point: she wanted to be free of any discomfort.

# Quality of Life

The patient currently requires pain meds to keep her free of pain. She is able to speak, but faces some huge decisions. If she elects to have surgery, she will face risks and burdens, and, if she survives, she will be permanently dependent on others for her care. If she continues to refuse interventions, she will be kept comfortable.

#### Contextual Features

The patient's health has been declining this year. Since surgery, she has been declining further, and is on permanent dialysis. Her closest family member is her uncle. He states he knows her well and that she would not want to accept the risks and burdens of treatment as he as known her in the past.

# ASSESSMENT

This is a patient with a grave prognosis regardless of whether or not she agrees to continued medical treatment, including surgery. Although she is not explicit in her refusal, she refuses medical treatments when offered. Her only explicit demand is to be made comfortable.

# DISCUSSION

It is well established, both ethically and legally, that patients with decisional capacity have the right to make their own healthcare decisions, including the full right to accept or refuse any treatment that is offered. The determination of a patient's decisional capacity is made by the attending physician in concert with others who know the patient.

There was a bedside discussion with this patient that included the attending physician, the ethics consultant, and the family. Following the discussion, there was unanimous agreement that she has capacity. Although she is not explicit in making a decision when asked about her general disposition toward medical treatments, she continues to refuse treatments at the time they are offered. She has refused medical treatment on previous occasions and continues to do during her present hospital stay. However, she is explicit that she wants to be kept comfortable, which is perfectly reasonable. Her family corroborates her general disposition toward medical treatment and they do not believe, based their long-term knowledge of the kind of person she is, that she wants further surgery.

It is not entirely clear that further surgery could accomplish a viable medical goal even if the patient agreed to it. Thus, there would be a high degree of burden associated with any benefit surgery could provide, and, in the long run, the burdens could greatly outweigh any benefit. If the patient were to have a cardiac arrest, even if she survived CPR, her baseline would become even lower, further reducing the chances of any viable medical goals being accomplished. Thus, CPR may involve the risk of causing unnecessary harm to the patient.

# RECOMMENDATIONS

- This patient has decisional capacity and is capable of directing her own care. Her refusal of medical treatments should be respected.
- She desires to be kept comfortable, and all appropriate medical means necessary should be taken to ensure that objective.
- Her physicians are obligated to follow her directives, but to not do procedures that will provide no benefit and only cause the patient burdens. All such options, e.g. CPR in the event of a cardio/pulmonary arrest, should be evaluated in that light.

Thank you for this consultation request. If Clinical Ethics can be of further service, please do not hesitate to call.

[Name and contact information of ethics consultant]

NOTE: These two clinical ethics consultations are based on real patients. Identifying information has been omitted to ensure patient and family privacy. Informed consent for use of these illustrative case reports has not been sought.

# NOTES

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5. Society for Health and Human Values — Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998).

6. See note 2 above, p. 103.

7. "Case Consultation," in *Ethics Consultation*, ed. J. LaPuma and D. Schiedermayer (Boston: Jones & Bartlett, 1994), 3-36.

8. R. Rhodes and D. Alfandre, "A systematic approach to clinical moral reasoning," *Clinical Ethics* 2, no. 2 (2007): 66-70, boxes on page 67.

9. W. Shelton and D. Bjarnadottir, "Ethics Consultation and the HEC," in *Ethics by Committee: A Textbook on Consultation, Organization, and Education for Hospital Ethics Committees* (Lanham, Md.: Rowman & Littlefield, 2007).

10. See note 5 above.

11. D.C. Thomasma, "Training in medical ethics: an ethical work-up," *Forum on Medicine* 1 (December 1978): 31-6; J.J. Fins, M.D. Bacchetta, and F.G. Miller, "Clinical pragmatism: a method of moral problem solving," in *Pragmatic Bioethics*, ed. G. McGee (Nashville: Vanderbilt University Press, 1999); R.D. Orr and D.M. deLeon, "The role of the clinical ethicist in conflict resolution," *The Journal of Clinical Ethics* 11, no. 1 (Spring 2000): 21-30; J. Sugarman and D. Sulmasy, ed., *Methods in Clinical Ethics* (Washington, D.C.: Georgetown University Press, 2001).

12. A.R. Jonsen, M. Siegler, and W.J. Winslade, *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 6th ed. (New York: McGraw-Hill, 2006).

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14. See note 8 above.