
Bioethics Outlook

Plunkett Centre for Ethics

Volume 19, No 4

December 2008

Tell me about Mama: Facilitating end-of-life decisions, ethics committees and ethics consultations

Nancy Neveloff Dubler

It is a great honor to join this legislature as it grapples with a fair and just process for decision making at the end-of life¹. These issues are profound and make human consideration difficult and often divisive. Death is in the realm of the ineffable, the domain of man and God or, for those without belief, for man alone. No one is un-ambivalent about death whether a robust afterlife or a void is the postulated next step.

As a bioethics consultant engaged in supporting decisions at the end-of-life, I come to you with a plea from decades of work at a hospital: Structural law is necessary but not sufficient for the development of a compassionate, supportive and successful process of communication and resolution at the end-of-life. Dr Tobin has argued, and I agree, that in the main, proxy appointments are far superior to pieces of paper in giving effect to the prior wishes and supporting the values and desires of the patient. But proxy appointments must be understood as creating the need for a new nest of supports for that person appointed. If this does not happen, then the proxy is abandoned to struggle with the most awesome and burdensome decision of her life. I urge that this legislation not only create a proxy-agent but also address the lonely status of that proxy. A proxy can only be effective and secure within a doctor-proxy relationship that not only empowers the proxy's right to decide but also cherishes the proxy in her struggle. I will argue that creating a proxy agent to decide for the patient is the first step. Creating the supports for that proxy is the next.

In this issue

Nancy Neveloff Dubler's article is the last of three inter-related pieces on the care of people at the end of their lives.

In the first of these three, Daniel Sulmasy argued that advance care plans should be seen as an extension of the tradition of forgoing extraordinary means of care. In the second, Bernadette Tobin argued that one form of advance care plan - the appointment of someone to represent a patient and speak on his or her behalf should circumstances arise in which medical decisions have to be made but the patient can no longer communicate - should be seen as better than another form of advance care plan - a piece of paper or 'living will' on which a patient sets out in advance which treatments he or she would accept or refuse.

In this article Nancy Dubler, of Montefiore Medical Center in New York, argues that it follows that there is now a new relationship in health care to be understood and supported within hospitals and nursing homes: the relationship between the doctor (and other health care professionals) and the 'proxy' who represents the patient. Nancy Dubler's paper was originally given as a talk to the Senate of the Italian Republic in March, 2007.

Bioethics is about stories and I will relate a few as illustrations for my argument. End-of-life decision-making is about patients, family members, close friends, clergy, physicians and medical professionals struggling together to do what is "best" and what is "right". Bioethics assumes that medicine is both a science and an art that the notion of "best" is guided by professional medical knowledge, experience, wisdom and skill; the idea of "right" – for the patient – is the product of the patient's personal history and values, and the religious commitments of the patient in the context of the family.

Medical decisions, especially those at the end-of-life, are made on a crowded stage. It is not only the number of players that complicate the picture but also the fact that each player possesses different stakes and interests – and to each is owed various obligations.

Consider the following case, taken from my case files at Montefiore Medical Centre.

Emma's case²

The patient, Emma, had been transferred to the hospital from home, after having spent six months at a nursing home for rehabilitation following her second stroke in ten years. She lived with her married daughter, Mary, who stated that after Emma's first stroke she and Emma began to talk about what she, Emma, would want for her health care if she could not choose for herself. She was very clear: 'No machines and nothing to prolong my dying.'

This recent admission: After a massive stroke, Emma lost consciousness and had severe breathing difficulties. An ambulance was called. The patient received a breathing tube in the ambulance and was brought to the emergency room (ER). When Emma was reviewed by the intensive care triage team, it was decided that she should not be sent to Intensive Care as she was a patient "in the process of dying". By the time a Bioethics Consultation took place, Emma had been in the ER for two and a half days as there were no available beds in the hospital. The Bioethics Consultant/Mediator was called

because of a "conflict within the family".

Seven members of the family met in a small room near the ER, including one granddaughter, a niece, three daughters, and one son and his wife. The staff included two members of the Palliative Care team, the patient's regular physician in the community (Dr Henriques) and the Ethics Consultant: truly, a crowded stage!

The Ethics Consultant began by asking the medical team and the family, who had been at the bedside since the patient arrived, to introduce themselves. Then she said: "Tell me about Mama", a question that elicited tears and memories, hugs and stories. Then Dr. Henriques, known to and trusted by the family, gave the medical history of the patient. She had been brought into the ER unconscious, in septic shock, with multi-system failure including failing kidneys leading to visible edema as the result of fluid overload. Dr. Henriques first said that there was less than a 20% chance of recovery, then that the chance was about 10%, then revised that to 5%, and finally said, quietly: "She is not going to get better."

Mary, her Mom's legal health care proxy, was convinced that her Mom would not want to live this way. She said that her Mom's favorite TV program had been "ER" and they regularly watched it together. Emma said that her mother had never wanted to be on machines and had "never wanted to be that way". Emma, Mary said, was a deeply spiritual Christian who was not afraid of dying. Everyone agreed with this. Mary wanted to remove the breathing machine immediately. All of the family quietly agreed... but for the patient's son, Joseph.

Joseph said that his mother was a fighter, that she loved life and that she would have wanted every chance. Therefore, he said, he could not agree to the removal of the machine.

Joseph and Mary faced off. Everyone else sat silent.

They all agreed that they did not want their

mother in pain. The Palliative Care service assured the family that the patient was not suffering.

After a while the Ethics Consultant asked Joseph what might help him to bridge the divide between himself and his sister. "Time", he said.

The Consultant then pointed out that, in fact, staff would be reluctant to remove a ventilator in the ER where there was so little quiet and privacy, and proposed that Emma be moved to a private room and extubated on the following day. The palliative care nurse explained that the family should be prepared for the fact that once the patient was moved to a calm setting death sometimes followed swiftly. The Consultant then asked Joseph if this would be acceptable to him. "Yes", he said. But his sister Mary disagreed: she thought her mother should be extubated immediately.

Searching for a solution, hoping to gain some time, the Consultant asked the family if their Mom loved all of her children. All agreed that she did. She then asked whether Mom would want this extra time for Joseph to be comfortable. Mary thought that she would.

So, all the family then agreed that Emma would be moved to a private room and would be extubated the following day according to her wishes. Joseph agreed and said that he and his brother, an Episcopal priest, would begin preparing for the funeral.

This patient was not feeling any pain or discomfort. Had she been, her right to be shielded from suffering might have demanded a different outcome. In this case her legal wishes were clearly presented by her health care proxy and would be honored - but in a way and at a time and place that would be most comfortable and most healing for her family.

In this case the Bioethics Consultant acted as a mediator, that is, an impartial third person who:

- facilitated a negotiation between people in conflict and assisted them to find solutions

that met their interests and needs;

- worked with the parties - in this case the care providers and members of the patient's family - and helped them identify their goals and priorities, to generate and explore the available options, and to exchange information that was necessary in formulating a solution; and
- was an optimist - searching for a solution that could ease the family through the death of the patient.

The doctor-proxy relationship

It is by now commonplace in law and ethics that the physician owes the patient duties of skillful care, information about the options of care and the risks and benefits of those options, and support in the process of deciding. These obligations are central to the doctor-patient relationship, and supported by diverse ethical theories that emerge from an analysis of duties, best consequences and virtuous behavior, all of which support robust doctor-patient interactions. But what if, as in the case of a proxy, the patient is no longer interactive? In that case, all of these duties and obligations of support and communication, I would argue, flow to the proxy.

Consider the following brief tale:

On evening at about 7 pm the Bioethics Consultant found a woman sobbing in the waiting room of the Intensive Care Unit. The young woman, Sara, sat alone by the door. When asked if she could help, the Bioethics Consultant was told that this woman, aged 24, was the granddaughter of a very ill patient, was her only living relative and was her health care proxy. The Bioethics Consultant said, "Tell me about grandma."

Her grandmother, whom she loved deeply, was 94 and until recently, when hit by a boy on a bicycle, had lived alone. Every day she had dressed, put on make up, gone shopping and out to lunch and then on to the Senior Citizens Center.

The accident resulted in complex hip fracture and there had been major complications following the initial surgery. Now the patient was facing her third, and quite risky, surgery for undiagnosed gastro-intestinal bleeding.

The surgical care team had been urging surgery. The geriatric consultant had been suggesting a palliative care plan and hospice. The geriatrician argued that with substantial kidney and cardiac compromise the risk of the surgery was extremely high and the patient's ability to recover very low, if any. He argued that, even if she survived the surgery, she would never return to her prior independent, active life.

The patient had been always been clear with her granddaughter: for her, only the independent life was worth living...those words echoed in her granddaughter's thoughts. The physicians had just come and asked her whether to do this next surgery or not...the choice was devastating.

Proxy appointments are necessary component in any schema of end-of-life legislation. They assure the medical care team, and society, that the person making the decision has the legal right to do so. For the person appointed, however, this obligation is often overwhelming. The patient is generally a loved one for whom the proxy is faced with life and death decisions - an awesome and terrifying prospect. And, unfortunately, the medical care system often deals with the proxy as a sort of junior colleague - requesting a decision as a crisp and tailored response to a set of medical facts. "Shall we do this next surgery on your grandmother?" The compassionate, careful respectful presentation and support that we owe to, and most times provide to, the patient is often absent from the proxy discussions.

Deciding for another may be more difficult than deciding for oneself. Medicine needs to cherish the patient's proxy, to support her, to help her to bear her burden without disempowering her. The relationship of the proxy to the patient is not only a contract. It is a covenant: I will be with you until the end. The relationship between the doctor and the proxy needs the same covenantal commitment: I will be with you until the end.

The remainder of my remarks address the ways in which this covenant of caring can be supported by

developing structures in the hospital to educate staff, to facilitate decisions and to mediate in instances of conflict.

The Major Role of the Bioethics Committee: Education

Bioethics Committees have traditionally engaged in retrospective case review, policy development and education. Some also participate in prospective case consultation, although training in facilitation, dispute resolution or mediation training is needed for this intervention once conflict has emerged.

Bioethics Committees have a long history in the United States. The first was probably the committee, called a Bioethics Committee but more properly a Prognosis Committee, that a Court required in 1976 in the case of Karen Ann Quinlan. In that case, the New Jersey Court ruled that, in order to withdraw a ventilator from Karen who could not make the decision for herself, a committee at the hospital had to declare that the prognosis was "hopeless". Then Karen's father, who had been appointed her guardian, could decide to withdraw care based on what Karen would have wished if she could have told him - a legal standard referred to as 'substituted judgment'. This case was one of the early cases that provided a spur for the development of advance directives as a way of avoiding long, costly and public litigation. In the 80s and 90s, Bioethics Committees spread widely in the United States but are, even now, of most varied quality and skill.

The primary goal of Bioethics Committees is to educate. In the matter of end-of-life care, an enormous literature exists that can help to train health care professionals to facilitate compassionate, culturally sensitive, religiously appropriate end-of-life decision-making. The Bioethics Committee is the natural locus for this training. In order to be effective it must acquire or develop curricula for end of life care, reference the literature, and present training that prepares the staff for the tasks. It can serve as the forum for didactic presentations and, even more valuable, for role plays - an invaluable resource for preparing staff for actual discussion with patients and with family members.

Consider, for a moment, the power of a hospital-wide staff intervention called "Tell me about Mama". The

point of the intervention is to train physicians to ask *about the patient* before ever asking for permission for any particular surgical or medical treatment *for the patient*.... always begin a discussion with the family that makes the patient, otherwise moribund and silent, a part of the conversation. This patient, overwhelmed now by disease, may have been talking, laughing, baking and caring for others just a day or two ago. She must be made present in the conversation. A Bioethics Committee can spearhead the intervention. There is now a vast literature on end-of-life care. Research has documented what patients and families most want in care provided:

- Patients, family, physicians and other care providers consider the following the most important at the end of life: pain and symptom management; preparation for death; achieving a sense of completion; decisions about treatment preferences, and being treated as a "whole person".
- People dying in institutions have unmet needs for symptom amelioration, communication, emotional support, and being treated with respect. Dying at home or in hospice provides a more favorable dying experience.
- Bereaved family members are most concerned about failures in communication and pain control which are more important than decisions about specific treatments.
- Arranging the shift from life-prolonging to more palliative approaches, focused on quality of life and comfort, is best facilitated by a structured approach that assesses the patient's prognosis, physical, psychological and spiritual needs, in the context of supports and patient-specific goals, in discussions that are truthful and support patient choices within clear medical recommendations.
- Advance directives can be helpful in planning for care at the end of life but must be focused more on goals and less on specific treatments. They exist in the context of trust, uncertainty, emotion and hope and are complicated by multiple medical providers and medical institutional contexts. Their use suggests the following lessons: encourage patients and

families to talk; do not contradict other health care providers; be humble; demonstrate respect; do not force decisions, acknowledge emotion and uncertainty; identify loss; offer support; hope for the best but prepare for the worst.

- Advance directives should be part of end-of-life conversations that must become routine and should be linked to (1) enhanced physicians' interpersonal communication skills, (2) a patient-centered model of care, (3) a focus on the quality of the remaining life, and (4) innovative models for introducing these discussions earlier in the care process.

These messages are but a few from the vast literature that an ethics committee can make available to the care team.

Bioethics Consultation

Some Bioethics Committees actually engage in bioethics consultation. Many have rotating sub-committees that involve themselves in prospective cases as a way, according to the classic formulation of the goals of consultation, of improving the quality of patient care by identifying, analyzing, and attempting to resolve the ethical problems that arise in practice.

Patients, families, and health care providers have a right to expect that ethics consultants should be available at hospitals that provide end-of-life care. In the United States this development has been supported by the fact that Joint Commission on the Accreditation of Hospital Organizations, which accredits hospitals for government financing, requires hospitals to have some capacity to address ethical dilemmas. Bioethics Committees and bioethics consultation services fulfill that standard.

Professionals, on committees and consultation services, should be trained to deal competently with the complex issues that patients and families face at the end of life, to facilitate conversations within the context of the law and to refer to and incorporate morally relevant principles. Consultants need to be sensitive to the power that they wield and to the possible conflicts of interest that their positions permit. They must strive to

empower patients and family members to express their values and idiosyncratic history, and to incorporate these values and moral commitments, rather than their own, into the outcome of the consultation. The consultation service must have a means for evaluating their processes, together with measurable outcomes, so that quality can be ensured.

The literature indicates that, in most European countries, Bioethics Committees and bioethics consultation services are not as common as in the United States. The reasons for this can only be speculated upon, but are likely to include: the existence of universal access to care that makes medicine less contentious; the continued existence of an academic and social structure supporting the physician as professor and decider, and the relative lack of litigiousness in society. More simply, the idea has just not caught on in the same way, and has not been mandated by national accrediting bodies.

Whatever the origins, recent articles about care in Norway, Switzerland, Italy, the United Kingdom, Canada, and Germany indicate that Bioethics Committees and bioethics consultation services are less developed in Europe than in the United States. As Italy embarks on this new venture in end-of-life care legislation, implementation may be as important as passage. Creating the possibility of proxy appointments, I would argue, demands attention to what will happen once these become the norm. In end-of-life decision making the *process is as important as the product*.

Bioethics consultation generally situates commonly accepted moral reasoning within generally accepted paths of clinical reasoning, including a plain statement of the initial problem, careful gathering of data, a differential diagnostic assessment, and articulation and confirmation of a justified plan. This approach pays special attention to the goals of medical care, because so much depends on whether or not physician and patient share the same goal.

There are many kinds of clinical ethics consultation but all strive to provide a forum for discussion and a method of careful analysis that promote health care practices consistent with high ethical standards. Consultation should help to create and foster consensus and resolve conflict in an atmosphere of respect. It should honour the participants' authority - patient, proxy and provider - while respecting their values and preferences in the decision-making process. An effective consultation structure is a tool for education and fosters the notion of justice by ensuring that like cases will be treated in similar ways.

Historically, committees began by retrospectively reviewing

cases to gain a common vocabulary and create a shared experience. Increasingly as committee members gain experience with each other and with the ethical norms in their institution, as they become more comfortable with reflective analysis, they are prepared to engage in prospective consultation and to intervene in cases that are just unfolding.

Role of the Mediator: a special sort of bioethics consultation

Bioethics mediation is a process of building consensus. It is designed to be inclusive and empowering. It is one of a category of skills often grouped as dispute resolution. Its goals are:

- to identify the parties to the sorts of disagreements that can develop among care providers, and between care providers and the family as the patient is dying;
- to manage that conflict;
- to maximize the number of options for building consensus; and
- to help parties to reach an agreement on the goals of care, the process of caring and the desired outcome.

Bioethics Mediation uses the clinical substance of mediation and the perspectives of bioethics analysis. One reason it is effective is that there is an armamentarium of skills and techniques in dispute resolution that can be taught in the context of bioethics. These tools include: listening and repeating back to clarify; framing and reframing - a 20% chance of dying may appear different from an 80% chance of living -; complimenting the various parties and emphasizing their positive contributions to the discussion, maximizing options and helping the parties to reach a "principled resolution". In Bioethics Mediation, neutrality equals respect for the patient, the family, and the care providers and an impartial stance regarding what should be the outcome in any particular case. The process is a key part of the product. And the process focuses on respect for the unarticulated values and preferences of the particular patient and family.

Let us return to the case of Emma with which this

discussion began. Emma had been quite clear about her wishes. Her daughter, who was her health care proxy, relayed her wishes. It would not have constituted a principled resolution to ignore those wishes. Emma had been capable of making decisions and had determined what she wanted. But delaying that decision by a few days, when Emma was not suffering, respected both her wishes for her own health care and her deep love for her children.

Now consider Sara, the ethically abandoned granddaughter. The medical team was treating her somewhat as a junior colleague—asking, quite reasonably, what should we do now? But she was not a junior colleague but rather a grieving, loving relative, overwhelmed by the conflicting opinions and suggestions. In a meeting of the entire care team, prior to a meeting with the proxy, all of the physicians agreed that the outcome of the surgery was so uncertain that a less aggressive plan of comfort care at the end-of-life was likely the best for the patient. The risks and possible benefits of the surgery were explained and comfort care and hospice, instead of surgery, were suggested to the proxy. The granddaughter-proxy grieved but was comforted and supported. Furthermore, she was not asked to shoulder the enormous burden of feeling that she alone was choosing between life and death.

In Bioethics Consultation/Mediation the process always begins with the care team. A meeting of that whole team, which may be the first such meeting in the care of the patient, is often instructive. Many times

there is serious disagreement among the members of the medical team which is reflected in confusion, discomfort or conflict among family members. Hope and denial, levels of which always vary among individual family members, inevitably lead to selective hearing and understanding. When different medical messages about prognosis are offered, consensus slips away. Meetings where medical providers hear each other, and subsequent meetings where family members together consider the medical facts and discuss the goals of care, are all simple but powerful means of achieving consensus.

Bioethics Mediation differs from classical mediation in a number of key ways. The mediator/bioethics consultant works for the hospital and knows the staff; she is not a true neutral. As a bioethicist, she must ensure that the agreement fits the rules for a “principled solution”. In Emma’s case this meant that her wishes, as communicated to her health care proxy, should be followed. And the process, which permitted the family to go on together after Emma’s death, was entailed in the obligation of good end-of-life care.

In bioethics mediation, time is of the essence and failure to reach an agreement simply facilitates a different plan. Life and death are often in the balance, emotions run high, and calm and support are as important as knowledge and intellectual skills. Finally, the patient, about whom all are gathered, is generally not present in the room. Thus, let us all begin, *Tell me about Mama.*

Notes

1. Nancy Neveloff Dubler LL.B. Director, Division of Bioethics Montefiore Medical Center, Professor of Family and Social Medicine, The Albert Einstein College of Medicine, Bronx, New York. This paper is based on a talk given in the Senate of the Italian Parliament, March, 2007.

2. Identifying factors have been changed in all cases to protect the privacy of patient and family.

Bibliography

Dubler, NE, Symposium: the doctor-proxy relationship, *Journal of Law, Medicine and Ethics*, 27,1, Spring 1999, 5-81:

Articles:

Post, LF, Blustein, J, Dubler, NN. Introduction: the doctor-proxy relationship: an untapped resource

Zeleznik, J, Post, LF, Mulvihill, M, Jacobs, LG, Burton, LG, Dubler, NN. The doctor-proxy relationship: perception and communication

Kuczewski, M. Commentary: narrative views of personal identity and substituted judgment in surrogate decision making.

Collopy, BJ. The moral underpinning of the proxy-provider relationship: issues of trust and distrust

Fins, JJ. Commentary: From contract to covenant in advance care planning.

Sabatino, CP. The legal and functional status of the medical proxy: suggestions for statutory reform.

Kapp, MB. Commentary: Anxieties as legal impediment to the doctor-proxy relationship.

Alpers, A. & Lo, B. Avoiding family feuds: responding to surrogate demands for life-sustaining interventions.

Powell, T. Extubating Mrs K: Psychological aspects of surrogate decision making.

Dubler, NN. & Liebman, CB. *Bioethics Mediation: a guide to shaping shared solutions*, United Hospital Fund, New York, New York, 2004

Hanson, LC & Garrett, J. What is wrong with end-of-life care? Opinions of bereaved family members, *J Am Geriatr Soc*, 45,11,1997

Hoffman, JC, Wenger, NS, David RB. Patient preferences for communication with physicians about end-of-life decisions, *Annals*, 127,1, July 1, 1997

Larson, DG & Tobin, DR. End-of-life conversations, *JAMA*, 284,12,2000

Post, LF, Blustein, J, Dubler, NN. *Handbook for health care ethics committees*, The John Hopkins University Press, Baltimore, Maryland, 2007

Steinhauser, KE, Christakis, NA, Clipp, EC. Factors considered important at the end of life by patients, family, physicians and other care providers, *JAMA*, 248,19,2000

Teno, JM, Clarridge, BR, Casey, V. Family perspectives on end-of-life care at the last place of care, *JAMA*, 291,1, January 7, 2004

Tulsky, JA. Beyond Advance Directives: Importance of communication skills at the end of life, *JAMA*, 294, 3, 2005

Weissman, DE. Decision-making at a time of crisis near the end of life, *JAMA*, 292,14, 2004

Bioethics Outlook is a quarterly publication of the Plunkett Centre for Ethics, a University Research Centre of Australian Catholic University and St Vincents & Mater Health Sydney.

Telephone: (02) 8382 2869

Facsimile (02) 9361 0975

email: admin@plunkett.acu.edu.au

Editor: Bernadette Tobin

Layout: Paul Stanton

Subscriptions:

<i>Institutions</i>	<i>\$65.00 + 10% GST</i>
<i>Individuals</i>	<i>\$40.00 + 10% GST</i>
<i>Student/Pensioner</i>	<i>\$20.00 + 10% GST</i>

(Airmail & overseas subscriptions additional \$15.00)

Plunkett Centre for Ethics in Health Care, St Vincent's Hospital, Darlinghurst NSW 2010

www.acu.edu.au/plunkettcentre/

ISSN 1037-6410