

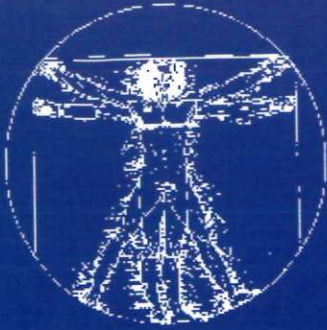
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2000*

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Newsletter, Fall-Winter 2000

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
Published by the Law & Health Care Program, University of Maryland School of Law
and the Maryland Health Care Ethics Committee Network

Fall-Winter 2000

PERSONALITIES AND THE ETHICS COMMITTEE PROCESS

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Have you ever wondered why your ethics committee has a difficult time coming to closure on an issue? Why some members of the committee seem to want to apply clear rules to a case and others are resistant to such a process? Or why some members are always talking and others barely say a word? Your committee's process may have more to do with the personalities on the committee than any structure the committee tries to adopt for purposes of decision making. I became acutely aware of this recently after attending a workshop on group dynamics which focused, in part, on how "personality type" affects one's decision making style. Personality type was measured by the Myers-Briggs Type Indicator, or MBTI. The MBTI "test" was developed in the 1940s building on "Carl Jung's theories about normal personality differences among people."¹ The test is designed to measure one's preferred ways of focusing mental energy, gathering data, making decisions, and dealing with the external world.² The test is frequently used in business and professional settings where people often work in groups and need to learn how to deal constructively with differences.

The Mid-Atlantic Ethics Committee Newsletter is a publication of the University of Maryland School of Law's Law & Health Care Program and is distributed in cooperation with the Maryland Health Care Ethics Committee Network. The Newsletter combines educational articles with timely information about bioethics activities in Maryland, D.C., and Virginia. Each issue includes a feature article, "Network News," a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing and related disciplines.

Diane E. Hoffmann, M.S., J.D.
Editor

Having been a member of several ethics committees, as I sat through this workshop, it became apparent to me that the Myers-Briggs test may offer some helpful insights to members of ethics committees regarding how they approach problem solving and decision making as a group. There even appears to be some overlap between the Myers-Briggs type indicators and the ethical frameworks for decision making discussed in the bioethics literature.

Through a series of either/or ques-

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The information in this newsletter is not intended to provide legal advice or opinion and should not be acted upon without consulting an attorney.

NETWORK NEWS

Maryland Health Care Ethics Committee Network (MHECN)

On December 2, 2000, the MHECN held its fall conference and annual meeting. Dr. Edmund Howe was the principal speaker and facilitator for the conference, "Communication: The Heart of Ethics Consultation." As part of the conference, participants engaged in ethics consultation role playing.

During the meeting, the chair of the MHECN Executive Board, Diane Hoffmann, presented the annual report to the membership. She noted that since the last report in November 1999, MHECN has added 21 institutional members and 13 individual members.

The Network currently has a total of 36 institutional, 20 individual and 2 affiliate members and hopes to increase that number to 47 institutional and 25 individual members by July 2001.

Other Network activities include the recent completion of the Network's first Basic Ethics Education course at Greater Baltimore Medical Center.

Plans for the future include a repeat of this course on the Eastern Shore in late spring or early summer 2001. Progress is also being made on expanding the Network's web site. Basic contact information, as well as selected articles from the Mid-Atlantic Ethics Committee Newsletter can be viewed on the current web site at: http://www.law.umaryland.edu/maryhealth/maec_html.htm

Metropolitan Washington Bioethics Network (MWBN)

The Metropolitan Washington Bioethics Network will meet on Thursday, January 18, 2001 from 4:00 to 6:00 p.m. The topic for discussion will be "Implementing a Palliative Care Approach." The program will be at the Washington Hospital Center. The program planners and speakers are Sue Edwards, Ph.D. and Mary Warfield, M.D. The program will include cases

showing problems in hospitals and other facilities when palliative care is not available, and how it improves when palliative care is an available service. The speakers will discuss models of palliative care services. This will also be the Network's 2001 Annual Meeting. All are welcome.

Virginia Healthcare Ethics Network (VHEN)

The Network is planning for its 2001 educational offering, "Ethics in Healthcare Institutions: New Issues, Controversies, and Practical Considerations" to be held in Charlottesville in October. A statewide survey is planned to identify topics of interest to ethics committees. A second major initiative, chaired by Chuck Hite of Carillion Medical System, is to put together a grant proposal for a statewide program on care at the end of life. Virginia is one of a handful of states without such a statewide program, and VHEN hopes to work with multiple organizations throughout the state to collaborate on programs to (1) develop multidisciplinary palliative care teams (2) foster a statewide dialogue on the issues of death and dying, (3) educate health care professionals and the public about end-of-life care, (4) examine state laws and policies impacting end of life care and educate state legislators regarding issues surrounding death and dying, and (5) serve as a resource for patients, families, health care organizations and professionals, state agencies, and the state legislature to facilitate end of life care. An initial meeting is scheduled for early December in Richmond.

Personalities and the Ethics

Committee Process

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tions, the MBTI provides an individual with a “profile” that shows his or her preferences on four scales:

- (1) Extraversion³ v. Introversion
- (2) Sensing v. Intuition
- (3) Thinking v. Feeling
- (4) Judging v. Perceiving⁴

The extraversion/introversion scale measures where an individual prefers to focus their attention, and where they get their energy. Extraverts focus their attention and get their energy from the external world around them, introverts focus on their inner world. Extraverts on an ethics committee would be those who speak frequently and express ideas readily. Introverts are those committee members who are more reserved. They prefer to think through their ideas thoroughly in their own head before speaking out loud to the committee. In order to take advantage of the type of thinking and strengths of both types of individuals, an ethics committee chair or facilitator needs to know who the extraverts and introverts are on his or her committee. During a discussion, it may be necessary to call on the introverts asking for their opinion about a case or issue before the group. Without such a conscious effort the expertise that these individuals have to offer may go untapped.

The sensing/intuition dichotomy looks at how individuals tend to take in information or gather data from the world around them. Those who are “sensors” prefer to take in information that is real and tangible; they tend to be interested in facts and data with low ambiguity. Intuitives, in contrast, are more likely to pay attention to abstract impressions, to the trends and patterns in a set of data, and to relationships among different facts. They are also more likely than the sensors to come to conclusions quickly and to follow hunches. This dimension of personality type is likely to be evident when ethics committee members are gathering facts about a case or problem. The sensors

want more and more factual data and won't feel comfortable moving forward until they receive the answers to their fact-based questions. Difficulties can come up within a committee when the intuiters are dealing with a problem at a more conceptual level, feeling comfortable without all the facts and the details, while the sensors find this approach too vague and want to wait to move forward until they have all the data they can possibly obtain. The combination of persons with a preference for sensing and a preference for intuiting, however, is a useful one for any ethics committee. There is clearly a need to gather the relevant facts and data about a case before moving forward, but also a need for those who can deal with a problem at a more abstract, conceptual level.

The thinking/feeling preference scale is the one that most quickly brings to mind the bioethics literature and the different approaches of the “principalists” or those who adopt a “caring” perspective when dealing with ethics cases. Those who prefer a “thinking” approach tend to make decisions in a “detached, objective and logical manner.” They strive for an objective standard by which to make decisions. They value fairness and want everyone to be treated equally. Those who prefer to use feeling in their decision making tend to consider the impacts of decisions on the people involved. Their decision making is more values based and subjective. They also value fairness but define fairness as treating everyone as an individual not as treating them each equally. The differences between thinkers and feelers on an ethics committee may become evident in a couple of ways. First, thinkers, because of their objective approach to problems, tend not to take conflict personally and may actually enjoy a good argument. Feelers, however, would rather avoid conflict and seek to create harmony within a group. Thinkers are also the ones who want to rely on bioethical principles or legal rules to resolve issues, whereas feelers will focus more on the relationships between the relevant parties and how they will be affected by any decision that is made. The fact that the

approach of the feelers sounds like the “feminist/caring” approach discussed in the bioethics literature is not too surprising given that the largest gender differences show up on this dimension of the MBTI. According to one source, “studies show that approximately 60 percent of all men in this country prefer thinking over feeling, while only 35 percent of women do.”⁵ These different approaches to decision making in the context of ethics committees can be paralyzing or enriching. If members from both “types” can listen to the other, they can learn to integrate both concepts into the decision making process and, hopefully, come up with a recommendation or process that adequately takes into account both approaches.

Finally, the last set of indicators, judging v. perceiving, measure how individuals prefer to deal with the outer world of people and information. Individuals who are “judgers” are not necessarily judgmental, rather they are individuals who like to live in a planned, orderly way. They like to make decisions and come to closure on issues. Individuals who are “perceivers” are not necessarily perceptive, rather they are flexible and spontaneous. They like things “loose and open to change.” These are the people on your committee who don't like to come to closure and want to keep the options open. This can be frustrating to the “judgers” who feel the need to move on. Sometimes, a committee chair or members of a committee may think they have come to closure on an issue after hearing from most of the committee members, but the perceivers may simply be thinking out loud and have not yet, themselves, come to a conclusion about a particular problem. Understanding these different approaches can help committee chairs be more thoughtful about ascertaining whether the group has, in fact, reached a true consensus on an issue.

Understanding your own committee and the personality types of your members may help you work better together as a group, lessen your frustra-

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Personalities and the Ethics Committee Process

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tion, and even enrich your discussions and the quality of your decisions.

For individuals interested in reading more about the Myers-Briggs Type Indicator, a useful book is "Type Talk" by Otto Kroeger and Janet Thuesen. Also, there are individuals who can administer the Myers-Briggs test to the members of your committee and discuss the results with you and how they can help you improve your functioning.

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¹ Larry Richard, *How Your Personality Affects Your Practice*, ABA Journal (July 1993).

² *Id.*

³ Alternative spelling of "extrovert" used by Myers-Briggs.

⁴ Isabel Griggs Myers, *Introduction to Type* (6th ed.) 1998.

⁵ Richard, *supra* note 1.

The following companies perform MBTI Training:

Otto Kroeger Associates
3605-A Chainbridge Road
Fairfax, VA 22030
703-591-6284
www.typedtalk.com

Type Resources
4050 Westport Road
Louisville, KY 40207
800-456-6284
www.type-resources.com

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Diane E. Hoffmann, Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 515 W. Lombard St., Baltimore, MD 21201-1786.

Case Study from a Maryland Hospital

Joe Chandler is a 65 year old man who had been receiving treatment for symptoms related to colon cancer that has spread to his liver. Joe had two children by his first marriage, which ended in divorce. He has been living with his current partner, Edna Grace, for the past 12 years. He was admitted from home to the hospital's neuro-ICU after Edna found him on the bathroom floor having a seizure. The neurologist determined that he has a 3 by 4 inch metastatic lesion ["at the grey-white interface"] in the right temporal lobe of the brain. He has been started on medication to reduce the swelling in his brain and to stop the seizures, but he continues to have intermittent seizures. A psychiatrist finds him to be lethargic and unable to respond appropriately to questions. The neurosurgeon feels that surgery to remove the lesion in his brain could stop the seizures and allow Joe to improve his mental status functioning, but she cannot predict the degree of cognitive dysfunction that will remain after the surgery, nor how

long any improvements in cognitive functioning would last. Not operating would almost certainly hasten Joe's death.

Joe has no advance directive. Edna states that Joe wanted her to make all his medical decisions, but he did not legally appoint her as his health care agent ("nobody told us about that!"). She is certain that Joe would not want to be kept alive on machines, but that he would want the doctors to try aggressive therapy if it could allow him to regain his mental faculties and have meaningful interactions with others. Since Joe did not legally appoint Edna as his health care agent, Joe's son William (from his first marriage) is recognized as the legal surrogate. Joe's nurse feels William is uncomfortable in this decision making role. Yet, William feels that Joe should be "left alone and allowed to die." You receive a call from Joe's nurse for an ethics consult. How would you proceed?

Response From a Physician/Bioethicist

Joe Chandler is a 65 year old man with colon carcinoma and known liver metastasis who now presents with seizures and lethargy secondary to a solitary brain metastasis. The family is now asked to consider further treatment options.

There are two fundamental components of ethical decision making in the clinical setting. The first is the availability of information that is as clear as the situation permits and that is in language that the patient can understand. This information should describe to the individual his current clinical condition; the risks and benefits of treatment options, including no treatment, and the description of the level of uncertainty that attaches to the different options. The second is an understanding of the individual's stated preferences for treatment; his understanding of the various risks and benefits associated with the different treatment options and the level of risk he is

willing to assume for any particular benefit.

The initial response of one reviewing and commenting on this case may be to focus on the surrogate identity crisis which is doubtless the major dimension. However, the consultant in the case would be wise to encourage the treatment team to be as clear as possible regarding the risks and benefits of the various treatment options and the level of uncertainty associated with them. As described in the case, Mr. Chandler has a terminal illness and the possible treatment options available to him are associated with a good deal of uncertainty. This will assist the patient or surrogate, whomever she may be, to have clear data on which to base a decision. This will help to bring into sharper focus such potentially unclear, qualitative statements as "he would want to be aggressive." The implication here is that the patient would be willing to assume increased risk in order to gain some benefit.

The second major component to ethical decision making is an understanding of the patient's preferences for treatment. It is now an established foundation of decision making in clinical ethics that the person who retains capacity for decision making has the right to accept or decline medical treatments of any and all sorts. This is true even if the suggested treatment is considered life-sustaining or even if the treatment team considers the patient's choice ill-advised and not in the patient's best interest. The condition of Mr. Chandler as described in the case implies that he is incapacitated for decision making. The consultant here should encourage the treatment team to explore thoroughly whether Mr. Chandler has capacity or whether, if they conclude that he does not, it is likely that he might regain capacity as a result of any of the treatments he is receiving. It is *only* when the patient is incapacitated that one should then turn to an agent or surrogate for assistance in decision making.

We are told that Mr. Chandler has not completed advanced directives nor has he appointed a health care agent. The treatment team will then need to

turn to a surrogate decision maker. In this case Mr. Chandler's son, William, has become his surrogate based on the hierarchy set out in the Maryland Health Care Decisions Act. The standards for surrogate decision making are straight forward. The surrogate should base his decision on what is known of the patient's preferences. That is, he should use "substituted judgement." If it is unknown what the patient's preferences might be for any particular decision, then the surrogate is duty bound to act in the patient's best interest. The surrogate should not rely on what he might prefer should he be in similar circumstances, although positing a purely impersonal vantage point in this regard is probably more of a fiction than a reality. In any case, it is an ideal that the surrogate should strive to fulfill.

The case outline raises the question of whether William is in a position to be the most reliable surrogate. We are told that William appears uncomfortable in this decision making role. This is not an uncommon outcome for those who are suddenly thrust in a decision making role especially for difficult decisions regarding end-of-life care or for patients who are critically ill. This, in and of itself, should not disqualify William from the role. However, Edna Grace, because of her twelve year relationship with Mr. Chandler may well be in a better position to be knowledgeable about his preferences. Indeed, we are told that "Joe wanted her to make all his medical decisions" and that "... she is certain that Joe would not want to be kept alive on machines, but that he would want the doctors to try aggressive therapy if it could allow him to regain his mental faculties and have meaningful interactions with others." The challenge now before the treatment team and the clinical ethics consultant is to look more deeply into these comments and into the nature of the relationships that Edna Grace and William had with Mr. Chandler to determine who, in fact, is the appropriate surrogate decision maker from an ethical perspective, the legal aspects notwithstanding.

The ideal envisioned by the law that

family members are in the best position to serve as surrogates for their incapacitated kin is an important one. In cases where an individual has not left advanced directives it is reasonable to look first to family members as those who may be most knowledgeable about this individual's preferences. The complex nature of human relationships and the difficulties experienced by many families however, puts this ideal to the test. Alas, blood is not always thicker than water. Effective and ethical decision making in the clinical setting should always seek to include those who most clearly understand the patient's preferences if the patient is incapacitated or if such a person is unavailable, then one who is committed to acting in the patient's best interest. Difficulties arise when those not so situated are appointed as required by statute or when more than one individual (e.g. two siblings, two children etc.) make similar claims that each is in the best position to know the patient's preferences and that each is requesting conflicting forms of treatment.

William should be invited to describe what he understands of his father's preferences. Likewise, he should be asked to shed light on the statement that Joe should be "left alone and allowed to die." Does he in some way understand this to be what Joe might have wanted? How does he know? His perception of the relationship between Edna Grace and his father should also be explored. The standards for decision making in this context should also be discussed with William. Edna Grace should also be invited to describe the nature of her relationship with Joe and the basis of her understanding of what she understands to be his preferences. If it is found that, as appears to be the case, Edna Grace is the most appropriate decision maker, William should be advised of this and requested to voluntarily transfer this important role while still remaining part of the support process for his father. If he will not, the treatment team should be advised to recommend to Edna Grace that she

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Response From a Physician/ Bioethicist

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undertake to be appointed legal guardian. Duty bound to act in Mr. Chandler's best interest, the treatment team can do no less.

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Response From a Lawyer

Who should decide?

The process of making a decision regarding life-sustaining medical treatment (LSMT) may be subject to a number of traps and pitfalls.

The first trap to avoid is rushing to determine who has the ultimate authority to make this decision. Placing friends and family members of a patient lacking decision making capacity in a hierarchy of decision making authority is often favored by lawyers, administrators, and health care providers seeking an expeditious decision on whether to forego LSMT. Individuals at the apex of the hierarchy are then given a "right" to unilaterally make the decision. This hierarchy has the apparent advantage of delineating who can and cannot make such decisions, thereby seemingly avoiding contentious, time-consuming, and unpleasant disputes among family members and friends about the proper decision.

But while this approach may seem to be an efficient and timely means of obtaining a decision, a hierarchical approach may instead exacerbate tensions among the concerned individuals and ultimately delay or hinder the decision making process. By shutting out individuals from the decision making process, the ground may be sowed for animosity and resentment. Because of the gravity of these decisions and because of the affection and respect felt for the patients at the center of these controversies, a failure to permit all individuals to voice their concerns and views may convert mildly

held opinions into deeply-entrenched positions. Precluded individuals may attempt to undercut the work of authorized decision-makers, even to the point of filing court actions to challenge their authority.

Some health care providers may favor this approach because it seems to clarify their role and lessen their responsibility to get involved in what may be difficult, drawn-out decisions. But to the extent that cooperation and the sharing of information is made unnecessary, they may find that instead they are more frequently drawn into protracted and deep-seated family disputes.

In contrast, a consensus-based decision making model attempts to broaden rather than narrow the decision making circle. By making LSMT decision making a shared responsibility, communication among participants can be facilitated, more material information can be discovered and discussed, the burden of decision making can be shared or relieved, the grieving process can be better accommodated, and tensions and guilt can be explored and reduced.

While a number of states, including Maryland, have established a hierarchical structure for determining who has ultimate LSMT decision making authority, this does not mean that this is the exclusive means for making such decisions or that it must be initially imposed upon the decision making process. This structure provides a means for resolving intransigent disputes among the various interested individuals. It does not, however, preclude these individuals, with the encouragement and support of health care providers, from adopting a mode of decision making more consonant with the patient's interests and their own needs.

The scenario described above, while short on a description of the existing family dynamics, is ripe with the potential for intra-familial conflict that can be stoked by the hasty imposition of a hierarchical decision making model. Although William, Joe's son from his first marriage, is described as being the legal surrogate, Joe's nurse believes William is uncomfortable in this

decision making role. Such a reaction to this responsibility would not be unusual. Ordinarily he might seek help with this decision. But by eliminating any need to consult with others about this decision, he may feel it unnecessary or inappropriate to do so.

Despite his discomfort with this role, William has expressed his view regarding the appropriate decision—Joe should be "left alone and allowed to die." The case study, however, does not indicate whether this is simply William's view of what he (or people in general) would want done under these circumstances or whether, more appropriately, this is a reflection of Joe's prior declarations, wishes, or interests. No indication is provided of whether Joe and William are close, have recently been in contact, or have discussed such decisions. At a minimum, the ethics consult should explore the foundation of William's view.

In contrast, Edna, Joe's current partner for the past twelve years but described as not his legal surrogate, claims to have had such discussions with Joe and would appear to have been closer and in more regular contact with Joe. The nature of her relationship with Joe suggests that she could provide valuable information regarding Joe's declarations, wishes, and interests.

However, there may be no pre-existing relationship or foundation of trust between Edna and William that readily leads to a sharing of information. By immediately recognizing William as the legal surrogate and thus the authorized decision-maker, the likelihood that information will be shared may diminish. This, in turn, can lead to a decision that does not accurately reflect Joe's declarations, wishes, or interests.

Furthermore, there may be an existing antipathy between William and Edna that is exacerbated by an immediate recognition of a legal surrogate. William may resent Edna as Joe's partner, perhaps out of loyalty to his mother. Alternatively, she may be a stranger to him, having spent little time with her prior to this. He may thus be reluctant to address this decision with her, notwithstanding his discomfort in this decision making role.

Similarly, Edna, as the apparently unmarried partner of Joe, may harbor resentment towards William. She may be unhappy that her relationship with Joe has not been formalized and she may be jealous of William's legally recognized status. Having spent the past 12 years as Joe's partner, William's immediate recognition as legal surrogate may enhance her resentment. She may feel that she knows Joe much better than William, and regard William as a stranger to the situation.

Additionally, if Edna is financially dependent on Joe, she may be concerned that Joe's demise will result in the transfer of their shared assets to William. She may thus be concerned that William is acting solely to promote his own interests. Similarly, William may be concerned that Edna is depleting his father's estate and thus question her motives and the reliability of her statements.

Who is the legal surrogate?

The second trap to avoid in an ethics consult is to assume the accuracy of facts asserted by others. There are a number of asserted facts associated with this scenario that should be more fully explored during an ethics consult. For example, whether William's expressed view represents Joe's or William's wishes or interests.

A second asserted fact is that William is Joe's legal surrogate, assuming because Edna is not married to Joe and thus is not his spouse. Under the hierarchical surrogate decision making models found in various states, including Maryland, a patient's spouse is given priority over a patient's adult child to make health care decisions on behalf of a patient lacking decision making capacity. Edna is described as Joe's current partner for the past 12 years, and although their marital status is not specified, the fact that William has been recognized as Joe's legal surrogate suggests that Edna and Joe are not married and thus she is not considered to be his spouse.

However, 11 states and the District of Columbia recognize common law marriages—relationships between a

woman and a man where a marriage license has not been obtained but which possess the requisite indicia of a marital status. Although most states, including Maryland and Virginia, do not recognize common law marriages, when such marriages have been established in another jurisdiction (such as Pennsylvania or the District of Columbia), other states are generally required to recognize them as valid. See *Blaw-Knox Constr. Equip. Co. v. Morris*, 596 A.2d 679 (Md. App., 1991). Thus if Joe and Edna had recently moved from a state that recognizes common law marriages and met the criteria for a common law marriage in that state, the state to which they moved would be obligated to recognize Edna as Joe's spouse. This, in turn, would give Edna decision making priority over William in a state with a hierarchical surrogate decision making model.

Does the patient lack decision making capacity?

Another purported fact that the ethics consult should explore is Joe's lack of decision making capacity and whether this lack of capacity is likely to continue and, if so, for how long. The question of who is Joe's legal surrogate need only be addressed if Joe lacks current decision making capacity. To the extent that Joe has decision making capacity, the law universally recognizes his right to make his own medical decisions, and the views of Edna and William are only relevant to the extent that Joe cares to take them into account when making his decision.

States vary somewhat in their criteria for establishing a lack of decision making capacity. Relatively typical is that of Maryland which states that an adult is considered "incapable of making an informed decision" when the individual is "unable to understand the nature, extent, or probable consequences of the proposed treatment or course of treatment, is unable to make a rational evaluation of the burdens, risks, and benefits of the treatment or course of treatment, or is unable to communicate a decision." (MD. CODE ANN., HEALTH-GEN. § 5-601(1)(1) (2000)).

The reported scenario indicates that a psychiatrist has found Joe to be lethargic and unable to respond appropriately to questions. What is unclear from the psychiatrist's report is whether Joe's mental status is unlikely to improve over time or whether there may be periods of time when Joe will have decision making capacity. The case study indicates that Joe has been started on medication to reduce the swelling in his brain and to stop his seizures. To the extent that such medication is successful, Joe may regain the requisite decision making capacity. The scenario does not indicate whether sufficient time has been given to ascertain the effect of the medication. In addition, the case study indicates that Joe continues to have intermittent seizures. If Joe was evaluated shortly after a seizure, this may explain his lethargy and inability to respond appropriately to questions.

The ethics consult should explore whether Joe's mental status may fluctuate or improve over time, and, if so, require at a minimum a second psychiatric evaluation. There needs to be an assurance that Joe would not be found to have decision making capacity at another time within the parameters of the needed decision.

Is there an absence of an advance directive?

The question of who is Joe's legal surrogate is only germane if Joe does not have an advance directive. An advance directive can either indicate the patient's LSMT choices or appoint an agent to make health care decisions on behalf of the patient. Furthermore, advance directives can generally be either written or oral.

The scenario assumes that there is no advance directive. However, Edna has stated that Joe declared who he wanted as his health care agent, namely, that he wanted her to make all his medical decisions. There is no indication this declaration was made in writing, suggesting that this declaration was made verbally. An issue the ethics

Response from a Lawyer

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consult should explore is whether this constituted a binding oral advance directive.

Also, the case study could be read to imply that Joe made an LSMT choice per se. The reported scenario states that Edna "is certain that Joe would not want to be kept alive on machines, but that he would want the doctors to try aggressive therapy if it could allow him to regain his mental faculties and have meaningful interactions with others." It is uncertain whether Edna has derived this conclusion from statements made by Joe, or whether she has simply deduced this from his character or behavior in general or her own beliefs about what would be appropriate under these circumstances. The ethics consult should also explore the basis and impact of this statement by Edna.

In Maryland, an oral advance directive regarding LSMT or the appointment of a health care agent must be made in the presence of the individual's attending physician and one witness, and documented as part of the individual's medical record, with the attending physician and the witness signing and dating the medical record (MD. CODE ANN., HEALTH-GEN. § 5-602(d) (2000)).

In jurisdictions such as Maryland, assuming that Joe did not make the oral declarations reported by Edna in the manner prescribed, they would not have binding effect. This does not mean they should be summarily dismissed. Instead, they should be considered in conjunction with other indications of Joe's intent. Even if a legal surrogate is appointed, that surrogate should take these declarations into account in seeking to determine Joe's intent or interests. The ethics consult should facilitate the exploration of the nature and manner in which Joe might previously have made an LSMT declaration. If a binding advance directive was not created, the ethics consult should remind anyone acting as the legal surrogate of the importance of considering this information in determining Joe's intent.

Conclusion

By broadening the circle of involved individuals and exploring fully the underlying facts, the ethics consult can promote sound LSMT decision making that is more fully accepted and less subject to subsequent questioning and challenge.

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UPDATE ON NEW MARYLAND LEGISLATION

The Maryland General Assembly's 2000 Session yielded three pieces of legislation of interest to institutional ethics committees. One makes the first change in a decade to the ethics committee law itself; another requires a review of facility procedures regarding oral advance directives and oral revocations of advance directives; and the third gives greater effect to existing emergency medical services "do not resuscitate" orders and, potentially, will lead to a revamping of the EMS/DNR program. All three bills took effect on October 1, 2000.

Senate Bill 100, sponsored by Senator Paula Hollinger, adds a new element of required consultation for ethics committees. Under §19-72(a)(3) of the Health-General Article, an ethics committee is required, "in appropriate cases," to consult with the patient, the patient's family, and the treatment team. Senate Bill 100 adds the requirement, "in a case involving the options for medical care and treatment of a child with a life-threatening condition," that the ethics committee also consult with "a medical professional familiar with pediatric end-of-life care, if a medical professional with this expertise is not already a member of the committee."

An ethics committee that might encounter a pediatric case of this kind

should review its membership to determine if the appropriate expertise exists and, if not, should establish a means of obtaining prompt assistance in the event that a case is brought to the committee.

When Senate Bill 100 was introduced, it contained language that would have made it easier for courts to consider ethics committee recommendations in end-of-life cases, by allowing the committee's written recommendation to be admitted into evidence. This provision was amended out of the bill, however, after the organization representing judges objected to this new exception to the hearsay rule.

Senate Bill 684, sponsored by Senator Andrew Harris, changes the portions of the Health Care Decisions Act dealing with oral advance directives and revocation of advance directives. Under §5-602(d)(2) of the Health-General Article, the Act declares that an oral advance directive "shall have the same effect as a written advance directive if made in the presence of the attending physician and one witness and documented as part of the individual's medical record." The written documentation is to be signed by the physician and the witness. Senate Bill 684 amends this provision to make clear that what is to be documented is "the substance of the oral advance directive," not merely the fact of its creation.

In § 5-604 of the Health-General Article, the Health Care Decisions Act also ensures that patients who have previously created an advance directive, written or oral, are free to revoke it. One means of revocation is by "an oral statement to a health care practitioner." Senate Bill 684 requires that this oral revocation be witnessed and that the "substance of the oral revocation" be documented in the chart. In this respect, the procedures for an oral revocation will parallel those for the creation of an oral advance directive.

House Bill 770, sponsored by Delegate Elizabeth Bobo with ten co-sponsors, resolves a specific problem with the EMS/DNR provision of the Health Care Decisions Act and calls for a broader review of the program.

Under § 5-608(a)(1) of the Health-General Article, “certified or licensed emergency medical services personnel shall be directed by protocol to follow” EMS/DNR orders. The Health Care Decisions Act was silent, however, about other health care professionals who see evidence of an EMS/DNR order; for example, could an EMS/DNR order guide care once a patient arrives at the emergency department, or was a newly issued DNR order required? House Bill 770 makes it clear that all health care providers who see an EMS/DNR order form or a bracelet incorporating an EMS/DNR order may honor it, with the protection of the immunity provision in the Health Care Decisions Act.

In addition, House Bill 770 directs the Attorney General to study the EMS/DNR program and make recommendations to the Legislature in the following areas: simplification of the EMS/DNR form; the applicability of an EMS/DNR order to lay persons who are authorized to use automatic external defibrillators; the scope of the EMS/DNR program, in particular whether it should apply to interventions other than CPR in a manner comparable to a widely praised Oregon form governing life-sustaining procedures generally; and, if the program were broadened, the manner in which it should be structured, financed, and evaluated. Anyone who has suggestions or comments on these topics should send them to Assistant Attorney General Jack Schwartz, 200 St. Paul Place, Baltimore, Maryland 21202, 410-576-7035, (fax) 410-576-7003, jschwartz@oag.state.md.us.

Lone Ranger Consults: Hi Ho Silver

A response to “The Imperative of Training for Ethics Consultation” by Evan G. DeRenzo, Ph.D. in the last issue of the newsletter (Summer, 2000)

I agree with most of what Dr. DeRenzo had to say about the importance of well-trained ethics consultants. I agree

that ethics consultants need special training in clinical ethics, conflict resolution, and at least a working knowledge of the vocabulary of medicine. In addition, I believe that certain personality traits are extremely helpful if not essential: ability to think out of the box, ability to suspend conclusions, ability to deal with uncertainty, empathy, and a genuine caring attitude. While Dr. DeRenzo is correct in pointing out that these skills do not necessarily come with a medical degree, so too a medical degree does not prohibit one from acquiring these skills. These skills are needed to varying degrees depending on the individual consult. In my experience, communication skills are often more important than knowledge of clinical ethics and always more important than a working knowledge of philosophy.

Whether ethics consultations are performed better by well-trained individuals compared to a consult team depends on many factors. The most important factors are the training of the individual consultant compared to the training of each member of the consult team, and the group dynamics of the consult team. A consult team composed of poorly trained members does not get better by the addition of more poorly trained members. To illustrate this, permit me to relate a story from my days as a medical student. In the late 1960s at Northwestern University, a superb internist by the name of Ralph Dolkart was reported to have examined a complex patient with a fever of unknown origin and announced that the patient had endocarditis based on the finding of a faint diastolic murmur indicting aortic regurgitation. This was in the days when echocardiography was still in its infancy. A team of house officers consisting of a chief resident, two interns and three medical students had all examined the patient and did not hear the murmur. The brash chief resident informed Dr. Dolkart that the entire team of six had examined the patient and that none had heard the murmur. He suggested that perhaps Dr. Dolkart was mistaken. Whereupon Dr. Dolkart suggested that he invite the doorman at the hospital entrance to

examine the patient and then there would be seven who could not hear the murmur. Apocryphal? Perhaps, but it make the point that the skill of a consultant or a consult team does not automatically improve by the addition of more members.

Not only does the team not improve by the addition of more poorly trained members, the dynamics of the group may cause the skill level of the team to fall to the skill level of the most dominant or vocal member, group think. The dynamics of group process are often ignored when evaluating the quality of an ethics consult team, yet it is an essential component. The ideal team will be multidisciplinary, so that the team members will have different filters. Similar training and similar backgrounds will often result in similar filters, thus invalidating one of the advantages of using a team. In addition, the team must work in a safe environment. By that I mean, an environment in which the voice of the least powerful member of the team will be heard and respected even if it is against the flow of the group. Consider a team member who says: “I know all of you are heading in the same direction, but I am uneasy about the direction this consult is taking. I don’t know what it is, but it just doesn’t feel right.” It takes courage to articulate such misgivings, and this lone voice in the wilderness must feel safe to speak out. The lone voice must believe that his/her voice will be respected. The lone voice will have learned from previous experiences with the group whether it is safe to speak. The proper response from the group is to stop the current discussion and attend to what this individual has to say. The group should help the lone voice to discover what it is that is causing his/her distress, because he/she may hold the key to the right answer for this consult and because that is the response that is necessary to create a safe environment. It is only in this way that a consult team can take advantage of its multidisciplinary nature. Unfortunately, my experience is that few consult teams are so structured.

Cont. on page 10

Lone Ranger Consults
Cont. from page 9

It is dangerous for consult teams to fail to attend to these group dynamics, because the team may simply be a front for the dominant voice. In that situation, an individual is in reality acting alone, but not taking individual responsibility because he/she is supported by the group. Group think at its worst. The attending physician and the patient or the patient's family, believe that they are getting advice from a group that has reached consensus when in fact they are simply getting the opinion of the dominant voice (not necessarily even the most thoughtful voice) of the group. The attending physician may feel less willing to ignore the advice of the group than if the advice were coming from a single individual. So we have the worst possible combination. Advice that is hard to ignore provided by an individual who does not take personal responsibility for the advice. It is the risk of this kind of group dynamic that I believe has led Mark Siegler, M. D., at the University of Chicago, to reject consult teams and to promote individual consults using the medical model of consultations.

So, I agree with Dr. DeRenzo, consult-team members need special training, but in addition the team must learn to work together to create a safe environment and to avoid group think. A well-trained consultant, Lone Ranger, will usually do a better job than a group that is poorly trained or that is not attuned to group dynamics. Remember, the Lone Ranger was always successful and he never killed anyone—he just shot their gun out of their hands.

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COMMENTS ON CASE STUDY FROM A VIRGINIA HOSPITAL: THE CASE OF BABY CAROL

Below are selected responses to the Case Study, and the Case Comment by Dr. John Fletcher, that appeared in the Summer 2000 issue of the Newsletter. They were compiled from e-mails from the MHECN membership.

Professor Fletcher observes that the legal issues in this case are “impressive.” Indeed they are, and it seems to me imperative that the legal vacuum regarding decision making authority be addressed promptly. Law and custom alike presuppose that protection of the child's best interest involves not only an ethically sound decision making process but also the presence of a decision maker who bears a socially and legally recognized relationship to the child. In this case, those who are present do not have that relationship, and the one who has it is effectively absent.

The people who are pressing to forgo life support on behalf of Baby Carol, the adoptive parents (more accurately, the prospective adoptive parents) have no legal authority to do so. Under Virginia law, as everywhere else, an adoption is not complete, and parental rights do not vest in the adoptive parents, until entry of a court decree. That has not happened. Hence, the birth mother retains legal authority to make health care decisions as the “natural guardian” for her daughter. Yet, the birth mother, having taken psychological but not legally effective steps to relinquish custody of her child, is unwilling or unable to engage the crucial issue of a future care plan.

While everyone agrees that issues of clinical care ought to be resolved as often as possible without judicial involvement, in rare cases litigation is the best way to deal with a seemingly hopeless tangle. Given the high stakes involved for the child, this is, in my view, one such situation. The prospective adoptive parents should find a way under Virginia guardianship law to seek court

ratification of their authority to make medical decisions on behalf of Baby Carol. This step would also allow the court to identify the legal standard in Virginia for parental or guardian authority in situations of this kind. Based on the case law elsewhere, the standard would likely be formulated along the following lines: “[I]n cases where there is a division of medical opinion as to the appropriate treatment for a life-threatening condition [as here between the PICU and NICU clinicians], deference should be given to the decision of the parents [or, here, the guardians] as long as the chosen course of treatment is a reasonable one within medical standards.” In re Mathews, 650 N.Y.S.2d 373, 378 (App. Div. 1996). See also Newmark v. Williams, 588 A.2d 1108 (Del. 1991); 79 Op. Md. Att’y Gen. ___ (1994) (Op. No. 94-028 (May 13, 1994)).

Jack Schwartz, J.D.
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There's a certain dearth of clinical information in the report in the newsletter. There is the implication that baby Carol might be suffering extreme pain and discomfort during episodes of hypoxia, but his suffering is then largely ignored since we can't ask her how she feels. Back in the middle ages, when I went to medical school, we were taught that the safest way to do anesthesia for extremely young infants who needed heart surgery was basically intubation and oxygen and tying them down. It was said, by otherwise excellent clinicians, who should have known better, that the babies were too young to suffer, and wouldn't remember the suffering anyway, so it would be safer not to introduce the added danger of anesthetic agents when doing cardiac surgery on newborns.

Now, in this modern age where we recognize that pain is an issue even in patients who can't speak for themselves, it's been shown that giving anesthetics and pain relief to newborn infants is probably a good thing because infants treated as humanely as one would treat

an older person who could remember the pain and sue the doctor actually decreases the mortality of cardiac surgery in neonates. In other words, these babies are testifying, with their very lives, that they can indeed suffer pain and that suffering pain is bad for their health.

Baby Carol is suffering pain as we speak, not only when she's hypoxic, but all the time. It just gets worse when she gets hypoxic. We get no indication in the case report as to whether her pain and suffering is being addressed as part of the treatment plan. Being a cynic at times, I suspect that her suffering is not being addressed because the PICU staff thinks it's safer not to introduce the added danger of opioid agents when doing long term intensive artificial ventilation on a young baby.

If I've maligned the PICU staff, then I apologize, but if they're not treating baby Carol's pain, then the issue of giving her not only undue suffering, but downright torture, should be at the forefront of this debate rather than the legal niceties of going along with the putative adoptive parents as long as they agree with what the PICU staff wants to do but ignoring them when they disagree with the proposed treatment plan.

I apologize for seeming a bit argumentative and negative, but in addition to my emergency medicine practice, I've been a hospice physician for the past sixteen years or so, and I've seen that treating pain is an issue that is rarely addressed adequately even now, in the twenty-first century.

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CALENDAR OF EVENTS

January

- 5 "Medical Futility and Withholding, Withdrawing Treatment," Frank Ryan, MD, Suburban Hospital. 8:00 a.m. Sponsored by Hospice Network of Maryland. For information call 410-729-4571 or e-mail hospice@aol.com.
- 12 "Communicating Bad News," Alva Baker, MD, Frederick Memorial Hospital. 12:30 p.m. Sponsored by Hospice Network of Maryland.
- 18 "Implementing a Palliative Care Approach," Washington Hospital Center. Sponsored by Metro Washington Bioethics Network. 4:00 – 6:00 p.m. For further information call 202-877-0246.

February

- 6 "Legal Issues in End-of-Life Care," Jack Schwartz, Assistant Attorney General, Maryland General Hospital. 5:00 p.m. Sponsored by Hospice Network of Maryland.
- 7 "Legal Issues in End-of-Life Care," Jack Schwartz, Assistant Attorney General, Northwest Medical Center. 2:00 p.m.. Sponsored by Hospice Network of Maryland.
- 8 "Legal Issues in End-of-Life Care," Jack Schwartz, Assistant Attorney General, Shady Grove Adventist Hospital. 2:00 p.m. Sponsored by Hospice Network of Maryland.
- 20 "Last Hours of Living," Carla S. Alexander, MD, Maryland General Hospital. 3:00 p.m. Sponsored by Hospice Network of Maryland.

March

- 4 – 9 "Developing Healthcare Ethics Programs," Charlottesville, Virginia. Sponsored by The Center for Biomedical Ethics. This 5 day course is designed to facilitate or strengthen the implementation of an ethics program within healthcare organizations. For further information contact Ann Mills at 804-982-3978 or amh2r@virginia.edu.
- 7 "Medical Futility and Withholding, Withdrawing Treatment," Christopher Kearney, MD, Northwest Medical Center. 5:00 p.m. Sponsored by Hospice Network of Maryland.
- 8 "Legal Issues in End-of-Life Care," Jack Schwartz, Assistant Attorney General, Montgomery General Hospital. 12:30 p.m. Sponsored by Hospice Network of Maryland.
- 8 "Gaps in End-of-Life Care," Carla S. Alexander, MD, Mercy Medical Center. 8:00 p.m. Sponsored by Hospice Network of Maryland
- 9 - 10 "Breathtaking Decisions," Appalachian Bible College, Beckley, WV - Sponsored by the Center for Bioethics & Human Dignity, Christian Medical & Dental Association, Trinity International University, West Virginia Network of Ethics Committees, together with Raleigh General Hospital. The conference will discuss issues in managed care, public policy, genetic technology, and end-of-life issues. For further information contact Cindy Jamison at 304-293-7618 or cjamison@hsc.wvu.edu.

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