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Practicing Physicians and the Role of Family Surrogate Decision Making

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Despite the active and lively discussion being held in the published pages of philosophers and medical ethicists regarding the role of family members in medical decision making, little is known about how physicians who work with patients and their families on a daily basis to make medical decisions approach this challenging issue.[1] We recently conducted and published a survey of physicians that explored their attitudes and preferences regarding this issue.[2] This survey was limited to making decisions for incompetent patients. In the paragraphs that follow we will summarize the results of this survey, discuss interesting findings with moral significance, and explore how the knowledge gained concerning the attitudes and preferences of this group of physicians adds to the ethical debate over the role of the family in medical decision making.

THE CONCEPTUAL FRAMEWORK

Our conceptual framework of surrogate decision making for incompetent patients imagines the degree of the incorporation of interests of the patient's family along a spectrum: at one end, family's interests are rejected, and, at the other end, family's interests are the primary determinants of the decisions that are made. Four distinct models can be identified along this spectrum.

In the *Intrusive Family Interests Model,* family's interests are seen as being in conflict with and as an intrusion into the expression of a patient's individual rights, and should not be considered. In the *Derivative Family Interests Model,* the family's interests should be given consideration in medical decisions if the patient had explicitly stated that the family's interests are important to him or her. Under the *Intrinsic Family Interests Model,* the family's interests are considered in medical decisions whether or not their interests were identified as important by the patient. Finally, in the *Pure Family Interests Model,* patients' interests are not given preferential status in medical decisions; rather, decisions are made to maximize the family's welfare.

Figure 1 is a graphic depiction of this conceptual framework, which shows the inverse valuation of the individual's interests and the family's interests along a spectrum. As the focus of decision making moves from the patient to the family, the focus moves from a more protective role for physicians (toward the patient) to a less protective role. That is, the Intrusive Family Interests Model is the most patient-centered

model, with the most protective role for the physician; and the Pure Family Interests Model represents the most family-centered model, with the least protective role for the physician. Those who favor protective models of medical decision making give proportionately more importance to the prevention of abuse by families and family members who would give undue attention to their own interests in medical decisions. Those who favor more family-centered models give proportionately more importance to the burdens that can be imposed on families by medical decisions.

THE SUBJECTS AND THE SURVEY

For our sample population, we chose critical care physicians because they are commonly involved in surrogate decision making, as well as in "high stakes" decision making that has substantial potential to affect patients' family members. A total of 327 physicians responded anonymously to our mail survey, representing 55 percent of those who were sent mailings. Of the 327 subjects, 25 percent were internists specializing in critical care for adults; 34 percent were pediatricians specializing in critical care for children, ranging from newborns to young adults; and 38 percent were pediatricians specializing in critical care for newborns only. The primary purpose of the survey was to determine which of the four decision-making models the respondents preferred, based on their responses to a series of declarative statements. Responses were ordered on a Likert scale from "strongly agree" to "strongly disagree." Although the survey included a number of clinical vignettes (see table 1) that had been designed to place respondents in a deliberative mindset, and perhaps remind them of scenarios in their own practice in which the interests of family members were potentially relevant, no statement specifically referred to any case. The actual survey items, or statements, that the subjects responded to are found in table 2 and table 3.

One of the secondary purposes of the study was to test our hypothesis that the age of the patients that physicians treat would affect their approach to the interests of family members. To test this hypothesis, we surveyed three physician subspecialties that are responsible for the treatment of three distinct patient age groups.

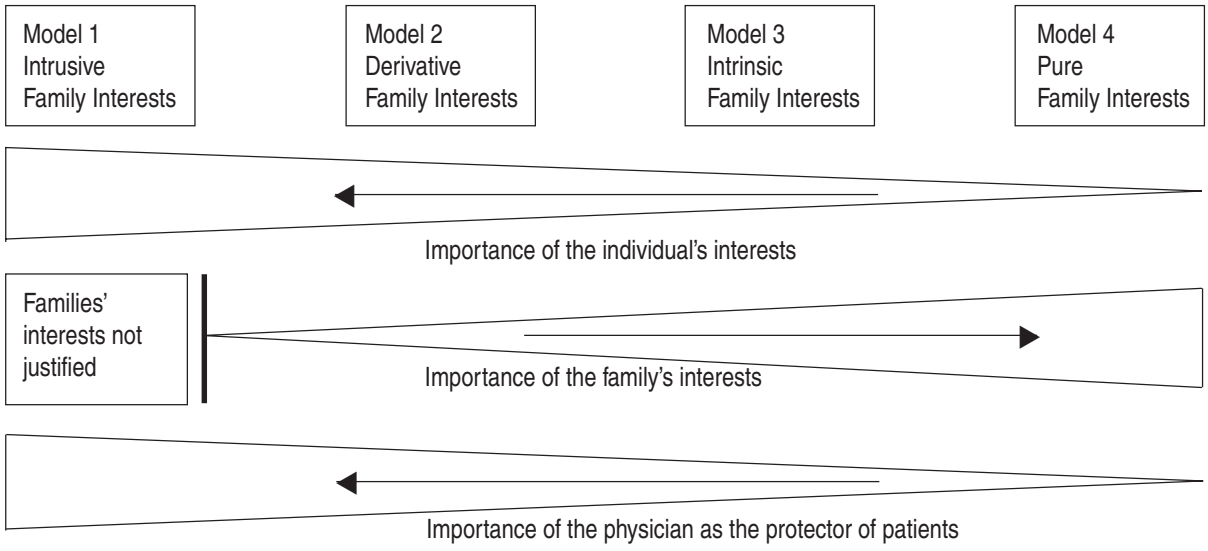

Figure 1. Conceptual model of surrogate decision making by patients' family members.

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On the basis of a logical interpretation of the conceptual framework, we developed a set of categorization patterns to relate the responses to the survey items in table 2 to a preference for one of the decision-making models. Subjects whose responses matched one of the four patterns were categorized as preferring that decision-making model. If a subject's responses did not match one of the categorization patterns, they were not assigned to a pattern. For example, if a subject's responses agreed with the concepts specific to the Intrusive Family Interests Model *and* the concepts specific to the Derivative Family Interests Model, we determined this (prospectively) to be inconsistent with a preference for any of the four models, and we did not categorize the subject's responses. This rigorous algorithm for determining preferences allowed us to successfully categorize 85.6 percent of the subjects. The remaining 14.4 percent were not included in our subsequent analyses.

Table 1
Clinical Scenarios Used in the Survey

Scenario
The husband of a legally incompetent 68-year-old woman with multi-infarct dementia refuses dialysis for her, stating that he has an obligation to think about the needs of his daughter and her family (who has been supporting the patient financially) as well as his wife.
When a family refuses a lifesaving tracheostomy for their nine-year-old son who has a progressive muscular dystrophy, the physician reacts by saying that this would be against hospital policy and asks how they will defend themselves in court.
The parents of an infant with a severe familial cardiomyopathy refuse a heart transplant for her two years after another of their children had been heart transplanted, believing that the strain of caring for two chronically ill children would place their marriage at risk and unfairly impact their other healthy children.
It is discovered that an elderly man, who had been requesting less-aggressive treatment for his 78-year-old wife with Alzheimer's disease who was being treated for pneumonia in the ICU, had recently become engaged to the couple's housekeeper of many years.
A wealthy family refuses surgical intervention for their newborn with newly diagnosed Down's syndrome and duodenal atresia, and requests that the child be treated with comfort measures only, since they prefer not to raise a disabled child.
A man threatens to sue the hospital if they withdraw ventilation from his 20-year-old son who has Duchennes's Muscular Dystrophy and respiratory failure because he cannot bear the thought of losing his son, despite his son's persistent and authoritative requests to have support withdrawn.

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THE RESULTS OF THE SURVEY

Regarding the primary purpose of the study, we found that 61 percent of all respondents preferred the Intrinsic Family Interests Model, 17 percent preferred the Derivative Model, 15 percent preferred the Pure Family Interests Model and only 6 percent preferred the Intrusive Family Interests Model. Our suspicions regarding the effect of physicians' subspecialty on which model they preferred were borne out; internists were most likely to prefer the Intrusive Model and neonatologists were most likely to prefer the Pure Model. However, despite the finding that internists were least likely to strongly incorporate family's interests into medical decision making among the three groups, fully 59 percent of the internists we surveyed preferred either the Intrinsic Model or the Pure Family Interests Model, and only 12 percent preferred the Intrusive Family Interests Model. Further, the items on the survey that explored the exclusivity of the physician-patient relationship indicate that only 12 percent of all of the respondents agreed that physicians have no obligation to anyone in the patient's family, other than the patient.

Of the 327 respondents, 84 percent reported that they at least occasionally were confronted by situations similar to the survey scenarios in their practice; 69 percent believed that proxies from patients' families commonly make decisions that are based, at least partially, on how the decision will affect the family. These findings suggest that the cases and the questions they raise are far from merely theoretical

"thought experiments."

Gender, race, and religion were not found to correlate with the decision-making strategies preferred by respondents. The age of respondents, the percentage of their practice time spent in the intensive care unit, their experience with situations that are similar to the scenarios, and their years of ICU experience all directly correlated with a preference for a family-centered model, but only experience with situations similar

Table 2
Models and the Corresponding Survey Items

Model	Corresponding survey item
1. Intrusive Family Interests	• Surrogates who are family members should not allow the impact of various treatment options on the family to affect their decisions concerning a sick family member under any circumstances. • Surrogates who are family members should consider the well-being of the family as a whole when making decisions for incompetent patients. • The impact of medical decisions on the family must not be given any consideration when family surrogates are making decisions.
2. Derivative Family Interests	• Family interests should be given weight in a decision if the patient had once been competent and stated that she or he never wanted to be a burden on the family. • Family interests should be given weight in a decision if the patient had once been competent and stated that important family interests were more important to him or her than the patient's own life. • Family interests should count in decisions for incompetent patients because most people have an important interest in the well being of their families.
3. Intrinsic Family Interests	• Family interests should matter in a decision, even if it isn't known whether the family's interests are important to the patient. • Family interests are morally legitimate factors in the decision for the family members who act as surrogates, even if family interests are not an important interest of the patient's. • Given the high value placed on good health and longevity, the patient's interests will take precedence over the family's interests in the vast majority of decisions. However, when the benefits to the patient are likely to be small and the burdens imposed on the family are large, then the family's interests should become a critical factor in a medical decision.
4. Pure Family Interests	• Medical illness should give a person preferential status over other members of the family when medical decisions are being made. • All members of the family, including the incompetent patient, should be considered equals with a stake in a medical decision, and the choice that maximizes the welfare of the family as a whole should be chosen. • Medical choices should always be made to maximize the welfare of the family as a whole, even if the welfare of the patient must suffer.

Note: For each concept, the sum of the responses to each item (scored 1 to 5) was calculated. Agreement, disagreement or neutrality was evaluated using the aggregate score for each concept. The scores for negatively phrased items were reversed. Reprinted with permission from G.E. Hardart and R.D. Truog, "Attitudes and Preferences of Intensivists Regarding the Role of Family Interests and Decisionmaking for Incompetent Patients," *Critical Care Medicine* 31, no. 7 (2003): 1895-1900.

to the scenarios remained statistically significant after we subjected them to multivariate testing, which suggests that experience was the underlying concept driving respondents' preference for a particular model among these factors. The only other factors found to correlate with preference for a model after multivariate testing were: how religious the respondents considered themselves (the more religious respondents preferred models that were more patient-centered), and physicians' subspecialties.

We explored respondents' attitudes toward healthcare rationing and found that 48 percent believed that physicians should consider the costs to society of interventions taken on behalf of patients (the dollar costs); physicians who supported healthcare rationing were more likely to prefer family-centered decision-making models.

Questions designed to investigate the level of trust that physicians have in the motives of family members who act as surrogates indicate that 44 percent felt some degree of skepticism regarding the motives of family members; the degree of trust (or lack thereof) did not correlate with the respondents' preference regarding models.

IMPLICATIONS OF THE PRIMARY RESULTS

These findings suggest that physicians in practice — specifically critical care physicians who are routinely involved in making decisions with tremendous consequences regarding patients' survival, quality of

Table 3
Related Attitudes and Peferences and the Corresponding Survey Items Designed to Test Agreement with Each Concept

Concept	Corresponding survey item
The role of the physician as protector of patients	• An important duty of the physician is to defend the patient from others with competing interests.
The exclusivity of the physician-patient relationship	• Physicians have no ethical obligation to anyone in the family other than the patient. • The physician has an obligation to consider the effect of his/her interventions on the family of the patient as well as the patient.
Physicians' perceptions of families' motives	• I trust that family surrogates have good motives when making critical decisions for their incompetent family members. • Physicians should maintain a healthy skepticism concerning the motives of the family surrogate.
Physicians' attitudes regarding healthcare rationing	• It is the physician's duty to save and/or preserve the lives of her patients regardless of the consequences for society (e.g. the dollar costs of treatment). • The physician has an obligation to consider the costs to society of interventions taken on behalf of patients.

Note: For each concept, the sum of the responses to each item (scored 1 to 5) was calculated. Agreement, disagreement, or neutrality was evaluated using the aggregate score for each concept. The scores for negatively phrased items were reversed. Reprinted with permission from G.E. Hardart and R.D. Truog, "Attitudes and Preferences of Intensivists Regarding the Role of Family Interests and Decisionmaking for Incompetent Patients," *Critical Care Medicine* 31, no. 7 (2003): 1895-1900. © 2003 Lippincott Williams & Wilkins.

life, and family — hold preferences and attitudes regarding making medical decisions that are not predicted by the traditional, individualistic standard for making these decisions that has been developed, taught, and institutionalized by the medical profession in the last half century. Our findings support what certain authors, most notably John Hardwig and James Lindemann Nelson, have argued for the last 15 years — that the current standard of purely individualistic decision making that is considered to be orthodox by the medical profession does not serve as an effective model for real patients as they are encountered in the real world, as people accompanied by persons with whom they have strong personal relationships.[3] It is striking that the sizable majority of physicians in our study who preferred family-centered decision-making strategies effectively espoused an approach to decision making not even offered as an option (let alone taught as the standard) in commonly read medical ethics texts or the curricula of American medical schools. How do these physicians justify their preferences? Where do they acquire them? While we did not directly address these important questions in this limited survey, certain clues to the thought processes of the survey respondents will be discussed in subsequent sections. Ultimately we are left to speculate about the meaning of these findings; in an editorial that accompanied an earlier article reporting our results, Lindemann Nelson argued that our survey "gives reason to believe that concern about the moral standing of families in healthcare decision-making is not restricted to a small number of dissident bioethicists or family advocates, but operates strongly in the way in which at least some physicians understand their own responsibilities in the light of moral tensions involved in contemporary health care."[4]

Pediatricians and Internists

Why is it that the pediatricians in our study preferred family-centered decision-making strategies more than doctors in our study who treated adults? It is often said in pediatrics (and family practice, for that matter) that "the family is the patient," but this rather vague maxim may simply reflect the observation that the family serves as informants, caregivers, and surrogate decision makers in the vast majority of pediatric cases.[5] To the extent that it difficult to separate a patient from her or his family as a practical matter, it follows that the family is the patient. The findings of our survey, however, suggest something deeper. Applying the conceptual framework tested in our survey, we find that physicians tended to be less protective of patients' interests and more willing to consider the interests of family members when they treated children and neonates. While the notion that physicians would not protect the interests of infants and children as vigorously as they would an adult may, at first glance, seem offensive, deeper reflection suggests that it may have an ethical basis.

First, as never-competent individuals, young children have not developed the capacity to acquire values, preferences, or personal conceptions of the good life, and so they have no personal values (distinct from the values of their families) to serve. A neonate is in no position to exercise self-determination, and so there is no autonomy to be respected. Consequently, the potential for insoluble conflicts between the patient's interests and the family's interests is greatly diminished and takes on an almost abstract quality that has little relevance in day-to-day medical decision making.

Second, a neonate's future is so dependent on its family's future that, at that point in time, the patient's interests and the family's interests may seem to be completely fused. Studies have consistently reported that the health of patients is directly related to the "health" of the family, across a range of medical conditions.[6] Therefore, to act in the family's interests is to act in the patient's interests, and to act against the family's interests is to act against the patient's interests.

Third, our society entrusts parents with the power to determine what is in the best interests of their child. Traditionally, a high threshold must be met before physicians and the state can challenge and overrule determinations by a child's parents.

Fourth, the authority of parents extends beyond their discretion in determining a child's best interests. In fact, parents are not required by society to always act in their child's best interests. Countless societally

accepted examples of parents acting in ways that are not in their child's best interests exist: deciding not to send Max to baseball camp so that Annie can take piano lessons; choosing to send a child to an inferior school to save money for other purposes; removing children from school to attend a parent's college reunion as a family; to name a few. In essence, society has traditionally allowed parents and families to compromise the interests of children to serve familial goals and purposes.[7] In healthy families, a natural balance develops between the interests of individual family members and the family itself, and society (including the pediatric profession) gives parents wide latitude in raising their children.

Healthcare Rationing

The debate over the proper role of the interests of the family in making medical decisions bears similarities to the debate over the proper role of bedside rationing in making medical decisions. In both cases, the patient-centered ethic of decision making is challenged by the observation that the patient is not the only person affected by these decisions. It has been argued that all parties who will be seriously affected by a medical decision must be considered when such decisions are made, to meet the requirements of distributive justice.[8] It was our hypothesis that, if this was so, we would find a correlation between our respondents' attitudes supporting the rationing of healthcare services and their preferences regarding family-centered decision making. Indeed, not only did we did find a statistically significant relationship between support for bedside rationing and family-centered decision making, but the relationship was the most statistically robust correlation in our results. Fully 89 percent of those respondents who supported the rationing of healthcare services preferred either the Intrinsic Model or the Pure Family Interests Model. We infer from this finding that an appeal to distributive justice is at least part of the respondents' justification for preferring family-centered decision making.

There are, however, some important differences between rationing healthcare services and family-centered decision making that must be developed. "Healthcare rationing" is used to describe a variety of practices, but its unifying theme is a consideration of the monetary cost of medical tests and treatments to society. Close scrutiny of our survey items concerning healthcare rationing reveals that we tested the attitudes of our respondents toward one specific type of healthcare rationing: rationing at the bedside. The essence of rationing at the bedside is that medical professionals use their discretion and professional knowledge to save money (serving the interests of society) while they provide adequate, if not the best, care to their patients. Some see physicians who act in this way as "good citizens" who merely recognize the inevitable necessity of considering cost in decisions regarding healthcare services.[9] To others, these physicians are "double-agents" who are less likely serving society's interests than lining their own pockets, or filling the coffers of a hospital or insurance company.[10] Even granting these physicians the best motivation, critics see the potential risks of rationing at the bedside: by diluting the fiduciary duty of physicians to patients, rationing may erode trust in the medical profession, which remains a critical component of the healing relationship between doctors and patients. One final concern is the fear that physicians might make discretionary determinations without the explicit knowledge of, or involvement of, the patient — which magnifies the possibility that such behavior may limit fair access to care for members of certain groups.

In contrast, in family-centered decision making, patients' interests are balanced against the full range of a family's interests, not just their financial interests. Additionally, the possible impact on the family of a medical decision, while the decision may involve many assumptions and a great deal of uncertainty, is less abstract than a general appeal to the interests of society expressed in dollars. Finally, the decision-making process in these cases will virtually always involve participants other than physicians (that is, members of the patient's family), who will typically be exquisitely sensitive to and aware of potential consequences for the patient and his or her family. The involvement of family members in making decisions will likely serve as a check limiting the opportunity for physicians to unilaterally make decisions that favor the family's interests. Nevertheless, it is possible that physicians might bias medical decisions for the patient to favor the

interests of the family without explicitly disclosing such bias. For example, neonatologists who claim that they are purely promoting the best interests of the neonate may actually be giving parents a range of options that includes sacrificing the interests of the neonate for the interests of the family as a whole.

Protection and Trust

Even the most ardent promoters of family-centered approaches to decision making admit that not all families are healthy and harmonious, and that the potential for some proxies to act with malice toward their family member is very real.[11] It is not surprising, therefore, that 78 percent of the respondents agreed that physicians should protect their patients from others who have competing interests.

Of course, one of the most consistent arguments used to defend a patient-centered ethic in surrogate decision making is that it is foolhardy to assume that all family members will have proper motives.[12] Further, it has been argued that the very nature of families — as close communities with shared values, goals, interests, and identities — makes family members *less* qualified to serve as surrogates, as their close, intertwined relationship with the patient would make it difficult for physicians to detect choices that are driven by factors other than the patient's interests.[13] If this highly skeptical attitude were prevalent, we would expect that physicians in our study who strongly preferred the Intrusive Family Interests Model would not trust the motives of surrogates who were family members. After all, such a mindset suggests that a high degree of suspicion of such a surrogate's motives would be a prerequisite to aggressively protect patients' interests, and that even the tightest scrutiny might fail to detect deviation from exclusive consideration of patients' individual interests. Consequently, we were surprised to find that the degree of skepticism our respondents had regarding the motives of surrogates who were family members did not correlate with their preferences regarding the models for decision making. In fact, only 16 percent of respondents reported that they did not trust family surrogates,[14] while 16 percent were neutral and 55 percent trusted families' motives. These findings lead us to construe an encouraging mindset of physicians in practice — that they generally trust that the families they work with have good intentions as they make difficult decisions, but feel it is their fiduciary duty to protect their patients' interests nonetheless.

Experience and the Family-CenteredEthic of Decision Making

Our data (after it was adjusted for confounding) support the notion that more experienced physicians tend to prefer family-centered decision-making strategies. Why might this be so? One attractive and plausible explanation is that inexperienced physicians are merely expressing the priorities that were clearly established in their medical education. How else would we expect young physicians to handle these admittedly "messy" situations, other than to refer to the principles they have learned in their training? Without other influences, it is entirely predictable that they would rely on the orthodoxy of the principle of respect for autonomy, as established in the halls of medical school, residency lectures, and standard textbooks.

How experience leads to a more family-centered approach calls for even more speculation. Yet we argue that it is precisely experience — phenomenal experience in direct medical care of patients as well as in one's personal life experience independent of professional practice — that leads clinicians to question approaches that are strictly patient-centered, as they struggle to apply these approaches to the morally complex and important scenarios they encounter in real life, as opposed to hypothetical situations from textbooks. The rivalry between an ethic that values decisions made by family members and the prevailing ethic for medical decision making is manifested in such a progression of experience. A realization that patients are not rugged individuals who demand to have their interests "maximized" seems to come with experience. And, with experience, physicians learn to acknowledge the inadequacies of the traditional paradigm of medical decision making and to rediscover the virtue of a more complex, but more realistic, paradigm that includes the patient's family.

This Study and the Ethical Debate Over the Role of Families' Interests in Medical Decision Making

These data suggest that, among American physicians, there is probably not a monolithic acceptance of a patient-centered ethic of decision making that has served virtually as a mantra for medical educators and bioethicists in the last few decades. While it is appropriate to be circumspect in drawing sweeping conclusions from a limited study such as this one, we found that family-centered decision-making strategies may actually be more the rule than the exception, at least in the critical care setting.

Assuming these fairly conservative conclusions to be correct, there is a great deal of work to do and a great number of questions to be answered, including:

- How are such attitudes applied in the clinical setting by physicians?
- It has been suggested that families conceal their consideration of their interests because the medical system actively discourages and stigmatizes anything but the most patient-centered approach. Is this true? Do physicians who support family-centered approaches similarly feel stigmatized and conceal their beliefs?
- What does it mean to take families seriously? Does it mean favoring a family's interests over the patient's interests? Does it mean allowing a family's "usual" decision-making processes to continue, with less interference by the medical community? Does it mean that the medical community should take more responsibility for how the consequences of a medical decision may affect a family's interests?
- What are the attitudes and preferences of the lay public regarding this issue?
- Do today's medical educators adequately prepare young physicians for the types of decision-making situations they can be expected to confront?
- Should the medical system be refashioned to support, perhaps even encourage, family-centered decision making?
- Would the rights and interests of vulnerable patients be put at risk by adopting a system that promotes family-centered decision making?

That so many of the physicians in this cohort confront these issues on a frequent basis argues for explicit and serious consideration of this issue by the medical community. That experiences seem to lead physicians to manage difficult situations in a more comprehensive manner is intriguing, and suggests that prevailing decision-making models may be deficient; however, it is unlikely that experience, trial and error, and intuition represent the optimal approach to improve how decisions are made.

Empirical research can begin to answer some of these challenging questions. Equally important, however, to improving our such processes is open, informed, and structured debate — in medical schools, professional organizations, hospitals, and doctors' offices. Medical ethicists can play a vital role in this process by providing a moral framework that clinicians and families can use to explore how to develop new decision-making paradigms that are designed to serve the needs of patients and their families more fully.

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