

**MEDICAL DECISION-MAKING FOR
UNKNOWN and UNREPRESENTED PATIENTS**
A Report Submitted to the Harvard Ethics Leadership Group
by the Community Ethics Committee

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The Community Ethics Committee was created under the auspices of the Harvard Ethics Leadership Group and functions as a part of the nonprofit Community Voices in Medical Ethics, Inc. The Committee was developed to serve both as a policy-review resource to the teaching hospitals affiliated with Harvard Medical School and as an educational resource to the varied communities from which the members come.

The volunteer members of the Committee are diverse as to age, socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Committee members, during all or part of this study, included:

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SETTING

Hospitals and the caregivers within them are facing an increasingly frequent ethical challenge – who should make medical treatment decisions for Patients unable to speak for themselves and who are unknown and unknowable to the hospital staff, even after diligent search efforts are made and no one is found either to represent them or to describe their values and goals of care? Especially when, after the initial medical emergency has passed, medical treatment decisions must be made that may either prolong or curtail a life, who should make those decisions and how should those decisions be made? An attendant question arises from those forced to make these hard choices – “What does the wider community think about such complex questions?”

A good example of this challenge is presented in a narrative published in a Perspectives piece in the February 2015 issue of the *Lancet*. Using a prepaid cell phone, a gentleman called 911 twice from a boarding house where he had lived for less than a week. Emergency medical services found him gasping for air; treatment for an allergic reaction did not help; and attempts to intubate him failed. He had been without a pulse for ten minutes before emergency access to his airway was established. After the medical team stabilized him, he spent two weeks in the hospital’s ICU before being transferred to a medical floor of the hospital. He had lost all cortical function, confirmed by repeated brain imaging and brain activity scans. Having had a tracheostomy, he was sustained by a vent but no other life-sustaining interventions were required. His care – his food, clothing, housing, medications, direct care services, social connections, indeed his very life – was supported entirely by the hospital and the individual caregivers there. Careful and protracted efforts were made to find co-workers, family, and friends who would be able or willing to speak for the Patient. Those efforts failed thoroughly and completely. For the purposes of medical decision-making, he was friendless and, although some family members were located on a distant continent, they were not willing to speak to the medical team or make any medical decisions. No one professed to know him well enough or felt a strong enough personal connection to make medical treatment decisions on his behalf. He was unknown and unrepresented.

Discussion among medical team members roiled about whether he should be transitioned to “comfort measures only.” What would he have wanted? Are an individual’s values preserved or compromised by continuing to provide mechanical supports when all cortical function is lost? Is the institutional statement “we err on the side of life” always ethically supportable? Should the institution continue to provide arguably burdensome medical care to avoid any liability for “giving up too soon?” What is owed to this Patient? What kind of society do we aspire to be? Is there anything solid upon which to base a medical decision or is it all shifting sand?

In this case, and in others presented to the CEC as it considered this issue, the Patient had absolutely no one to make decisions for him and the medical team had no way of finding out anything about what values might have supported a particular medical decision. Although one could not say the Patient held no values, what those values might have been as they applied in general to medical decision-making and in particular to life-sustaining treatment decisions were unknowable and not discoverable by cultural research or conjecture. The hospital social support team members spent significant amounts of time and resources speaking with those who knew him, even those who knew him only in passing, in an attempt to obtain some insight into his possible values, even if only a glimmer. He had successfully gone “off grid” in every way a person can be “invisible” in this society and that became the only glimmer of insight gained into what was important to him and what he was successful doing. He was unknown and unknowable.

Without a surrogate or Representative decision-maker, the medical team is “stranded” and must proceed to treat the Patient based upon institutional and professional biases. It is true the Court system provides a process for appointing a surrogate decision-maker through a Guardianship proceeding. The Guardianship process in Massachusetts is challenging, however, and is avoided to the extent it can be avoided. Both because of a limited pool of trained and available Guardians (there is no funded Public Guardianship system within Massachusetts) and because of the delays inherent in any deliberative Court process, the appointment of a Court-appointed Guardian to make decisions for an unknown and unrepresented Patient is a solution of last resort.

In situations where the Patient is unable to communicate, the question “What would the Patient have wanted?” is answered by a representative or surrogate – someone who has standing to speak for the individual Patient if s/he cannot. Typically, Patients enter the hospital setting with a decision-making surrogate already named – either a formal proxy who is appointed in an advance directive document or an informal decision-maker who is deemed suitable by default due to blood relation or relational proximity. On rare occasions, a Patient already has a Court-appointed Guardian in place to make medical treatment decisions when s/he cannot. No matter how they obtain their authority to decide, all surrogates are required to make decisions based upon a “substituted decision-making” standard, meaning they are not to make decisions based upon what they would want for themselves but, rather, they are to make decisions based upon what they believe the Patient would have wanted. Such a substituted decision-making standard assumes the surrogate knows the individual and knows the medical decisions which would have been made by him or her. Those decisions are often, although not always, based upon religious, cultural, educational, and experiential perspectives. When the Patient’s individual wishes are unknown either because the treatment option to be decided upon was unanticipated or the individual never had decision-making capacity, a different decision-making standard is employed. The question to be answered transitions from “what did this person say s/he wanted?” to “what would be in the best interests of this person in this particular situation?” It is a decision-making standard which requires imagination and empathy in addition to careful thought.

No matter which decision-making standard is applied, both are predicated upon knowledge of the individual. Substituted judgment requires some understanding or memory of the individual’s articulated desires while best interests requires some understanding of the individual’s values and social structure. These standards are excruciatingly difficult to apply when there is some consanguinity or affinity with the Patient. These standards are perhaps impossible to apply when there is absolutely no knowledge of the individual who is in medical extremis and for whom a life-or-death medical decision must be made.

Again the question arises - is there anything solid upon which to base a medical decision or is it all shifting sand? We are confronted by this question during one of the most challenging of situations: a Patient is no longer responsive; his or her medical condition is often changing and always tenuous; and individual values to be applied to a particular medical decision are, more often than not, unknowable.

This Report describes what the Community Ethics Committee thinks about how medical decisions should be made for individuals who are unknown and unknowable and who have no one to make medical decisions for them. Should such individuals receive life-sustaining treatments as an ethically supportable default decision? Should Patients with no decision-making Representative be treated differently from those with a Representative? Should the mere possibility of medical benefit be the primary justification for medical interventions based upon a Patient's "best interests"? Who should make medical decisions for a Patient who is unknown and unknowable?

The question of "who" should decide is asked in the context of limited Court resources – if the process to appoint a Guardian is unreasonably delayed and/or results in the appointment of an inadequately trained Guardian, who should be the one to make medical decisions when timeliness and medical sophistication are required? The question of "what should be done" is asked in the context of limited institutional resources – does it matter if the careful stewardship of medical resources becomes a salient factor in making medical treatment decisions for unknown and unrepresented Patients, and in that context, which life-sustaining treatment options are ethically supportable and which are not?

INTRODUCTION

The Community Ethics Committee (CEC) is a group of volunteers living in the Boston metropolitan area who are members of the broad demographics of the populations served by the Harvard-affiliated teaching hospitals. The CEC provides reports and opinions on topics brought forward by members of the Harvard Ethics Leadership Group – representatives of the various ethics services within the Harvard teaching hospitals. The need for such a consultative group has been evident for a long time, since the few community members on hospital ethics committees are unable to represent multiple communities. Solicitation for membership on the CEC has been cast widely through community, business and religious groups, with a specific application process to ensure selection of a dissimilar but effective working group.

CEC members are diverse as to age, socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Eight members are women and eight are men; we range in age from our teens to our seventies. Some of us have advanced degrees, some have high school diplomas. Among members past and present are a high school administrator, a high school teacher, and a high school student; a rabbi, an imam, a Muslim female attorney, and a professor at a Protestant seminary. Some of us are individuals with disabilities and others are parents with disabled children. Two are retired, one from a large Boston law firm. We are students and writers and small business owners. We volunteer in our communities, including on an Institutional Review Board and in local health care facilities. We belong to eight different religious traditions, including atheism, and we are fluent in several different languages. Most of us have attended the annual Harvard Clinical Bioethics Course, where the original members first met in 2007 and began the conversation as the Community Ethics Committee. Since 2011, the CEC has been part of the nonprofit corporation, Community Voices in Medical Ethics, Inc., which was established in order to enhance the CEC's mission to bring the issues of medical ethics into the community as well as to include the community's voice in the dialogue already occurring in health care institutions, government, and academia.

PROCESS

The Committee met throughout 2014 and most of 2015 to educate ourselves about the dilemma created by Patients entering the health care system who are unknown and unknowable and who have no one to make decisions for them. We heard narratives from many different sources – several of the Harvard teaching hospital medical team members shared their dilemmas in treating Patients without representatives and the moral distress that arises when trying to make decisions congruent with a Patient’s values and goals of care when those values and goals of care are completely unknown and unknowable. We heard from care team members working in inner city clinics as well as those providing services to the developmentally disabled. We also heard from those working in the Veterans’ Administration hospital setting. Lastly, we had the privilege of discussing the development of a special mental health court in the Maryland judicial system with the Honorable Gail E. Raisin (Retired) who initiated a separate docket of cases to help those who had no personal advocate. The Committee was able to hear care team members’ real and troubling anguish at doing their best to treat individual Patients, most with complex medical needs, all in the context of institutions with differing approaches and with limited financial resources resulting from free care requirements under the Hill-Burton Act. Based on our group discussions and in order to obtain everyone’s viewpoints in an anonymous format, we developed a survey that solicited Committee members’ thoughts on the questions asked by the various medical teams who had presented and on the questions raised at our meetings. Some of the responses from that survey are included in this Report. The Committee also distributed a survey among the public and some of those responses are also included in this Report. The Committee benefited from the special insights of one of its members, Paul McLean, who was focused on this issue as a project of his Fellowship year with the Center for Bioethics. (His individual conclusions, which differ from the CEC’s group recommendations, are posted on the blog found at medicalethicsandme.org.)

TERMINOLOGY

Although our response will highlight some of the additional complexities of this topic, the CEC was presented with two questions – WHO should make medical decisions for Patients who are unable to communicate their wishes and who have no one to make medical decisions on their behalf and HOW should those decisions be made?

The CEC has found that the first step in any review of a topic must involve defining our terms. Surprisingly perhaps, the Committee struggled with the question “who are we talking about?” We concluded the most comfortable and concise phrase to use in this Report was “Unknown and Unrepresented Patients.” The Patients we were focused on are those who are unknown both to the medical staff providing care and to the community from which these individuals come; unknowable even after a diligent search to obtain information; and unrepresented without anyone willing or able to step forward to make medical treatment decisions during their hospitalization and continued care.

When focusing on who we were talking about, “patients without surrogates” and “incapacitated and alone” were phrases that we also considered but “surrogates” was a word with child-bearing connotations and “incapacitated” was a word with legal connotations that made it inaccessible to many. Although the phrase “unbefriended patients” is used widely in the literature on this topic, we concluded the term “unbefriended” carried a pejorative sense that was not helpful. In many ways, “unbefriended elders” were those who actually had friends and family years ago but who had the misfortune of outliving them all.

The Committee found that deciding upon the best word to describe the substitute decision-maker was also problematic. The individual or group chosen to make decisions was not necessarily acting in the role of “friend.” Instead, our discussions frequently focused on the need for someone who could advocate for the Patient’s interests – an individual or group who would actively promote the Patient’s welfare, someone who would be on the Patient’s “side.” We were talking about a Patient needing a substitute decision-maker who would make medical decisions in the same way the Patient would have – in a word, a representative of the Patient. In the end, we felt most comfortable using the phrase “Unknown and Unrepresented Patients” when addressing this topic.

ANALYTIC FRAMEWORK and DISCUSSION

To answer the questions “who should make decisions?” and “how should medical decisions be made for unknown and unknowable Patients who have no one to speak for them?” the Committee used a loose analytic framework of “who,” “what,” “when,” “where,” and “how.” The discussion which follows tracks our conversation over the months that we spent on this topic.

WHO are the Stakeholders?

The **Patient** needing a medical treatment decision is unknown and unknowable. She is not necessarily elderly. She has not always been unknown or socially invisible. She was someone who had a family life at one time, lost now to the alienating effects of mental illness or substance abuse, trauma or just old age. She might have been incarcerated; she might be carefully living “under the radar,” perhaps as an individual without documentation. In all events, as she comes to this medical decision-making moment, she is a Patient who cannot express either her needs or wants and cannot make an informed medical decision; she has no one to speak for her or act on her behalf; she is unknown and unknowable.

The law goes to great lengths to ensure no one loses their autonomy when making medical decisions and statutory structures are in place to ensure a Representative can be identified to make medical decisions for an individual who is incapacitated and unable to speak for themselves. The law in all fifty states allows any competent individual to appoint someone to make healthcare decisions for him or her. With a document called a Health Care Proxy or an Advance Directive or Health Care Power of Attorney, an individual while competent can appoint a representative to make decisions in situations of temporary or permanent incapacity. On occasion, specific directions are given within the document to help the Representative make difficult medical decisions. When such a document does not exist or is not found, a decision-maker can sometimes be identified and empowered based upon a statutory hierarchy of interested persons. Such a listed hierarchy does not exist in Massachusetts and physicians here usually rely upon the informal input of family members and close friends as those individuals are identified by the treating physician and care team members.

Every state has a statutory procedure in place to appoint a Guardian to represent another person who is incapable of making medical decisions for themselves. Those Guardianship proceedings vary but little across state lines, with many states adopting a Uniform Probate Code providing standardization both in the procedures required to obtain appointment as a Representative and in the scope of authority granted to that Representative. Unfortunately, due in part to budget constraints within the Massachusetts Court system, the procedural delays (sometimes months and

months) and lack of trained Guardians (Massachusetts has no public guardianship system in place) result in many hospitals and institutional caregivers eschewing the pursuit of a Guardianship appointment for a Patient who is unknown and unrepresented. And because many end-of-life medical treatments fall into the category of “extraordinary medical procedures” in Massachusetts, a Guardian may be required to seek additional Court approval before a decision can be made to withdraw artificial nutrition and hydration or ventilator support and sometimes before a DNR order can be entered. While the statutory protections are in place to protect individuals from losing their autonomy entirely, the result is that a Guardian in Massachusetts has limited authority to make medical decisions.

The **Representative** of a Patient who needs a medical decision to be made is not necessarily an individual. The best substitute decision-maker for this unknown and unknowable Patient may be an individual or it may be a group of individuals. The Committee acknowledged that whoever steps in as a Representative decision-maker will be biased – whether that decision-maker is appointed by the Patient beforehand or is authorized by a Court or is acknowledged by relational proximity or is a separate decision-making body. A fully-informed Patient makes decisions that are necessarily affected by the Patient’s knowledge of their disease, their confidence in the medical prognosis, and the breadth of their experience. Medical team members are biased by their individual caregiving experiences as well as by the requirements of their professional standards of conduct. They are also affected by the sometimes unspoken institutional biases of “we always err on the side of life” or “remember to steward our resources carefully.” Court-appointed Guardians typically are accountable to uphold a governmental mandate to preserve life. Biases abound among those involved in medical decision-making and most assuredly, the Patient’s Representative is no exception.

The integrity of the Representative is premised upon their ability both to know their medical treatment biases and to disclose those biases. In a “shared decision-making model,” all the stakeholders – medical team members and the Patient or Representative – work together to balance the benefits and burdens of treatment options in the context of prognostic uncertainties. Typically the purview of the Patient/Representative is to articulate the individual’s overall goals of care (based upon cultural, religious, familial, and ethnic values) and the expertise of the medical team is to present medical treatment options which best accomplish those goals of care (based upon professional expertise and experience). In the case at hand, when the Representative does not have any way to know the Patient, the Representative must become an advocate for the Patient in his or her most vulnerable moments. Most certainly, the burden on the Representative decision-maker is heavy.

The **Physician** who is providing medical care for the unknown and unrepresented Patient must often provide that care within an emergency or ICU setting and frequently is called upon to make extemporaneous decisions without the ability or time to consult with others. The physician’s role in helping Representatives make medical treatment decisions rests on his or her medical expertise. The physician’s judgment is required to make both prognostic determinations and treatment recommendations upon which medical decisions are based. Arguably it is the physician’s professional assessment of the feasibility of obtaining good medical outcomes that determines what is in the best interests of the Patient. It is for this reason, many conclude the unknown and unrepresented Patient’s treating physician is the logical default decision-maker and some states have statutorily named the treating physician as the decision-maker in these situations. Although relying upon the treating physician to be the default decision-maker

arguably makes for an “easy” answer to the question “who should decide?,” other interests are at stake which must be addressed including the need to maintain public trust through transparency and accountability. The Committee was also concerned about the effectiveness of medical decision-making residing in one individual, where checks and balances to individual biases do not exist.

Other **Care Team Members** are stakeholders in how medical decisions are made for unknown and unrepresented Patients. They are the caregivers who must provide sometimes intrusive medical treatments for a Patient who, without a Representative, may be maintained for long periods of time in an ICU or in a consciousness-deprived state because of an institutional bias to prolong a Patient’s life, regardless of its quality. Or they are the caregivers who acknowledge that vulnerable unknown and unrepresented Patients often have no advocate for continued therapeutic care and are, as a result, perhaps allowed to die prematurely. The moral distress on both ends of the spectrum is real and troubling.

And lastly, **Society** has a stake in how these medical decisions are made. We as a community must contend with at least two primary social interests in this area of decision-making for unknown and unrepresented Patients – how we treat the least among us affects us all and we should treat Patients without decision-making Representatives the same as we treat Patients with Representatives. Both societal interests fall under the umbrella of “due process” – substantive due process where fundamental rights must be protected and procedural due process where fairness must be protected. The issue of how medical decisions are made for unknown and unrepresented Patients affects society as a whole and mechanisms must be in place to protect our societal values of justice and mercy.

“As a person with a severe disability (quadriplegia), I would not be able to trust any stranger to value my life as much as I do . . .”
Public Survey Respondent

WHAT

Medical treatment decisions must be made by someone during the time when institutional care is provided to an unknown and unrepresented Patient. The CEC discussed at length what the context of those medical decisions would most likely be. We acknowledged that the legal requirements for and the primary goal of emergency medicine are to save and stabilize all individuals in medical need, whether a decision-making Representative is present or not. Only “when the dust settles” and the treatment decisions are either therapeutic (with the primary goals of prolonging life and restoring prior or acceptable functionality) or palliative (with the primary goal of comfort care), does the question arise of what medical treatment decisions are best for this particular Patient. Frequently, as the medical care “steps down,” the next tier of decisions must be made in an intensive care unit.

Based upon the numerous narratives that the Committee heard from caregivers, the medical decisions being made for the unknown Patient which create the greatest moral distress fall into three categories – life-prolonging, life-sustaining, and palliative treatments. **Life-prolonging** medical treatment decisions include treatments with a discernable burden and a limited benefit. Examples of such life-prolonging treatment decisions include excising a malignant tumor when the life-expectancy after the surgery would remain less than six months or authorizing toxic medications such as chemotherapy, again when a life-expectancy remains at less than six months. **Life-sustaining** medical treatment decisions include treatments with a significant burden and an

indeterminate benefit. Examples of such life-sustaining medical treatment decisions include initiating long-term dialysis or performing a tracheostomy with the expectation that the Patient will need long-term ventilator supports. **Palliative care** includes treatments without a primary goal of therapeutic cure or long-term physical maintenance but instead are undertaken with the goal of diminishing the unknown Patient's pain and suffering, both physical and existential, while forgoing burdensome medical interventions. No matter in what category these treatment options fall, medical decisions must sometimes be made quickly and they must always be made knowledgeably and with the Patient's best interests at the forefront.

A concern expressed by Committee members was the interventional "creep" that occurs even with the best of intentions – one medical treatment decision leads to another that leads to another. A life-prolonging decision can provide the time needed for the Patient to respond to therapeutic interventions, through a "trial of therapy." Such life-prolonging treatment decisions can, unfortunately, lead to life-sustaining treatment choices which can strand Patients, both those known and unknown, on mechanical supports for prolonged periods of time, well past when the therapeutic benefit might have been attained. For example, the decision to provide artificial nutrition and hydration for a Patient may seem innocuous enough. A Representative might well receive a recommendation to remove a naso-gastric tube (a short-term measure) and give consent to the surgical insertion of a g-tube (a long-term measure). While on first glance, that escalation of medical treatment is a "good" decision, motivated by the Patient's best interests to prolong his or her life, the placement of a g-tube often leads to the need for other interventions such as antibiotics to fight infections and physical restraints to limit self-extraction of the tube. And, although academic ethical discourse concludes that withholding and withdrawing medical treatments are ethically equivalent, the two actions are not emotionally equivalent and, once a life-sustaining treatment is begun, the stopping of that treatment is fraught with significance for caregivers and Representatives alike.

In the world of institutional Patient care, the transition from therapeutic interventions to palliative care can be challenging. The institutional ethos is clearly to save lives, often by intervening with the best technological resources at hand. The institutional goal of care is to rescue and to restore. Transition to palliative care stops the technological mandate to intervene and redirects those salvific goals of care into the provision of "comfort measures." Such a transition seems to signal defeat and failure. It is no wonder that the choice to transition to palliative care is sometimes challenged by caregivers and perceived as premature or unnecessary.

In an ideal world, a decision-making Representative must possess: (a) the ability to understand the benefits and burdens of accepting and rejecting the proposed medical treatments (to provide true informed consent) and (b) knowledge of the Patient sufficient to advocate for his or her values (to achieve the Patient's individual goals of care). Representative decision-making is challenging enough when the Patient is known and loved and an essential part of a functioning family unit. Such decision-making when the Patient is unknown and unknowable is well-nigh an impossible task, completely without comfort or confidence.

" . . . we are talking about any patient who lacks decision-making capacity who requires care that needs informed consent – whether that is life-sustaining treatment, end-of-life care options, or other treatment situations – chronic or acute." CEC Internal Survey Respondent

WHEN

Although the immediate medical crisis may have passed and the unknown Patient may be physically stabilized, the Representative must often make therapeutic treatment decisions quickly. Life-prolonging and life-sustaining interventions are not usually those which can wait for protracted Court proceedings or on formal institutional mechanisms to provide decisional certainty. The fluidity of the Patient's medical situation necessitates a decision-making Representative who is informed and available to make a complex medical decision quickly and thoughtfully.

The straightforward answer to “when” these ethically challenging decisions must be made is whenever the medical treatment decisions mark a transition. When life-prolonging treatment converts into life-sustaining treatment and when life-sustaining treatment converts into palliative care, those are the points at which Patients who are unknown and unrepresented most need someone to advocate on their behalf. Certainly at the earliest possible moment, but no later than these transition moments, this is when the Committee's recommended Medical Decision-making Team should be included, informed, and involved. (The Committee recommends that a formal ethics committee consult be initiated at the same time.)

WHERE

The decisions which we are discussing – medical treatment decisions for an unknown and unrepresented Patient – are most frequently but not always made in an institutional setting. The Committee learned that without a Representative, unknown Patients cannot be transferred outside of a hospital setting because less intensive settings such as a skilled nursing facility or medical group home do not receive governmental funding to treat a Patient without a Representative. As a result, unknown and unrepresented Patients who have complex medical needs are sometimes stranded in hospitals for months at a time, pending Court appointment of a formal Representative or until the Patient's situation changes. Unknown and unrepresented Patients whose care needs are not as complex face dangerous discharge decisions, sometimes discharged and abandoned to the streets. In either setting – hospital or street - the lack of a Representative can result in a sub-optimal place of care.

“I know our discussions have focused primarily on the hospital setting but it seems like the same issues would arise in nursing home, group home, and home care situations as well. I think wherever the need for informed consent and the lack of decision-making capacity intersect would be situations where a decision-maker is necessary.” CEC Internal Survey Respondent

HOW

Once a Representative decision-maker is identified and agrees to serve, the medical decisions to be made must be made according to established legal and ethical standards. The legal and ethical standards uniformly applied to medical decision-making focus on a Patient's autonomy as exercised through informed consent. Without informed consent granting prior permission for the invasion of an individual's personal space, most medical care would be categorized as an “unauthorized touching” (the tort of battery). When someone other than the Patient makes medical decisions, that interest in autonomy continues and the requirement of “substituted judgment” is mandated of Representatives, no matter how they are appointed. What did the Patient say he or she wanted?

But of course, when a Patient is unknown and unknowable and without a formal decision-making Representative, the Committee recognized that there can be no “substituted judgment.” By definition, this Patient has no one to step forward and shed light on what he or she liked or disliked; what sensitivities may have been held physically, culturally, religiously, emotionally; what personal connections existed at one time to make life meaningful and rich. Without “substituted judgment,” the Representative must rely on a determination of what is in the unknown Patient’s “best interests.” From a purely medical perspective, that “best interest” decision-making standard examines what treatments would give the Patient the best chance of survival, with the least pain and suffering. From a Patient-centered perspective, however, without any information about what the Patient “as a person” would choose, the best interests decision-making standard is impossible to apply in these cases.

The Committee considered numerous methodologies that have been used to ascertain and advocate for an unknown Patient’s “best interests.” A policy promulgated by Brigham and Women’s Hospital proposed a decision-making standard they call “Synthetic Judgment” which stated in pertinent part –

the goal being “to reach a synthetic (as opposed to a substituted) judgment of what the patient would probably choose or want. This should not represent the judgment of a single caregiver but should be a consensus of what a group of people from multiple disciplines directly connected with the patient’s care believe that the patient would be likely to choose. If, following this process, there is no consensus on a care plan and the options include invasive treatment or withholding life-sustaining treatment, consultation with the Office of General Counsel is necessary to determine whether a court-appointed guardian should be obtained.”

The Committee concluded that the Brigham & Women’s policy reflected the best standard for medical decision-making for unknown and unknowable Patients and based its recommendation on this kind of “composite” judgment standard.

RECOMMENDATIONS

As has been noted above, the Committee focused its review on two particular aspects of medical decision-making for unknown and unrepresented Patients – who should serve as a decision-making Representative when no one can be found and how should medical decisions be made for someone unknown and unknowable once a Representative decision-maker is in place?

WHO SHOULD DECIDE?

The Committee concluded that a small group within the institutional setting should be the unknown Patient’s Representative decision-maker. We called that group the Medical Decision-Making Team.

During our many discussions about the topic, we acknowledged that, even though most Representative decision-makers rely almost exclusively upon the recommendation of the treating physician, that physician should not make those key decisions alone. We concluded the best methodology for reaching a balanced, well-considered, and unbiased decision lies in a Representative composed of a team (the unknown and unknowable Patient's Medical Decision-Making Team) making medical treatment decisions based on consensus after synthesizing their several different perspectives, reaching a "composite judgment" on which to base the decision on the unknown Patient's behalf. The Committee then discussed at length what kind of group should make these decisions and what decision-making tools may already be in place or could become alternative recommendations.

We looked at what other states have done to address this issue and found that many solutions have been suggested but few have been given the funding mandate needed to accomplish the lofty goals of adequate representation of unknown and unknowable Patients. Some states have developed Public Guardianships so that there is a well-trained pool of advocates to represent these Patients. Many states (but not Massachusetts) have a default surrogate list to facilitate identifying a Representative for the Patient. (The Committee chose not to address specific concerns about the Massachusetts Guardianship process in this Report.) In some states, the physician becomes the decision-maker of last resort based upon such a surrogate list. "Transition authorization panels," "interdisciplinary teams," and "limited healthcare fiduciaries" have been proposed to make limited decisions for Patients, including decisions about transitioning Patients who are ready to be discharged from an acute care setting to a skilled nursing facility and transitioning Patients to hospice care. (Thanks are due to Thaddeus Pope, J.D., for sharing his expertise in this regard.)

The Committee looked at other creative avenues of specialized decision-making. We examined the medical decision-making process instituted in Massachusetts for disabled children in foster-care, technically under the custody of the Department of Children & Families. In those cases, an ethics committee consult is required along with a second medical opinion. We also discussed whether a specialized docket could be created within the already-existing Probate Court system so that unknown and unknowable Patients would have a "fast track" to experienced Guardians and judges who are not squeamish ruling on medical decision-making cases. We also were attracted to a recommendation that included the creation of a Medical Decision-Making Court which would stand within the existing Superior Court system and operate much like the Superior Court Business Litigation Session which was established in Massachusetts to facilitate the Court's disposition of complex business cases. The creation of a specialized Court-within-a-Court was an attractive way to address a broad spectrum of medical decision-making cases, including cases involving unrepresented Patients and cases involving medical futility.

After lengthy discussion and much self-education, our recommendation finally came down to four over-arching societal interests: expediency, cost, effectiveness, and justice. Creating a Medical Decision-Making Team from within the hospital's human resources addressed expediency – these are people already on-site and available to make decisions in a timely way. Including professional caregivers on the Medical Decision-Making Team addressed concerns about cost and effectiveness as well – other than paying for the time needed to consult on the unknown Patient's care decision, no new costs would be required since no "outside" staff or systems would be involved. The Team would include staff already involved in the unknown and unknowable Patient's care, familiar with the issues surrounding that individual's transitions and the likely repercussions of the medical treatment decisions to be made.

The societal interest remaining for the Committee to consider was justice. Recognizing that without a formally appointed Guardian involved in the decision-making process, the Patient's interests were in danger of being overlooked, the Committee discussed at length how best to incorporate the unknown Patient's perspective. The challenge was to ensure the Patient's "voice" could be heard – finding someone who could speak for the Patient as a strong advocate, sensitive to articulating what the individual's values might have been. We looked at the possibility of including a member of the hospital's Patient and Family Advisory Council but, in the end, the Committee concluded that the best internal advocate on the Medical Decision-Making Team for the unknown and unknowable Patient would come from the hospital's chaplaincy program.

Why chaplains? Chaplains provide not only "life cycle counsel" to Patients and families but they possess the professional skills necessary to be an integral member of an interdisciplinary team. They are trained not only in the spiritual needs of a particular Patient but his or her psycho-social and emotional needs as well. They regularly address a Patient's fears, anxieties, and guilt, in the context of oftentimes complex family relationships. As one of our atheist-identified members noted, chaplains maintain their integrity by being value-neutral. The Committee acknowledged that spirituality is broader than religion and chaplains are trained in diverse world views. The Common Standards for Professional Chaplaincy focus not on denominational or specific religious world views but rather on the elements of pastoral care. These standards require chaplains to "provide effective pastoral support that contributes to the well-being of Patients, their families, and staff;" and "provide pastoral care that respects diversity and differences including, but not limited to, culture, gender, sexual orientation and spiritual/religious practice." Finally, the standards require chaplains to "support, promote and encourage ethical decision-making and care." Perhaps of most importance, chaplains are outside of the primary revenue source of the institution, meaning a medical decision made by a chaplain on behalf of an unknown and unknowable Patient is not tied to the hospital's financial "bottom line". The chaplain does not get paid more or less if the Patient lives or dies. That freedom from institutional bias was significant to the Committee in seeking to maintain trust in the integrity of the decision-making process.

The Medical Decision-Making Team, as envisioned by the Committee, would be ad hoc – a team called upon early in the unknown and unknowable Patient's care to become a participant in decision-making as soon as necessary medical treatment decisions are required. (The Committee understands that consent is not required during emergency care nor is it required during routine medical care. Consent is required, however, when medical treatment decisions are being made that involve invasive, life-prolonging, life-sustaining, or palliative interventions.) The Medical Decision-Making Team would ideally be composed of (1) the Patient's attending physician and (2) a healthcare professional who is not directly involved in the Patient's care (preferably another physician to provide peer review) and (3) a member of the hospital's chaplaincy office. The Committee recommended that any hospital policy which would establish such an ad hoc Medical Decision-Making Team would explicitly state that the chaplain's voice carried great weight, as he or she is speaking on behalf of the unknown and unknowable Patient.

"Two doctors, one palliative, one standard. One hospice nurse. One medical social worker.
No lawyers. No one religious."
Public Survey Respondent

"I would never trust a group that was non-religious. Their interest would only be cost savings.
I want all Herculean measures."
Public Survey Respondent

HOW SHOULD MEDICAL DECISIONS BE MADE?

Once the Medical Decision-Making Team is assembled, the actual medical decisions should be made from the perspective of “doing right” by the unknown and unknowable Patient. Being an idealistic group, the Committee holds that one of the primary goals of any personal interaction, including in medicine, should be to treat each other well - with respect and compassion. As we have discussed earlier in this Report, a Patient comes to a doctor with certain goals of care based upon their values, experiences, and understanding of their condition. The treating physician comes to the Patient with medical treatment options available to accomplish those goals of care. The dilemma here is that an unknown and unknowable Patient does not articulate any goals of care – he or she is, however, in need of health and healing. Such an unknown Patient’s care team comes to the bedside with a full armamentarium of medical treatment options - many of which may be life-prolonging and life-sustaining but not necessarily life-enhancing.

As has also been addressed earlier in this Report, the standards a Representative must use to make medical decisions on behalf of someone else are legally mandated – the Patient’s substituted judgment must be employed when wishes are known and the Patient’s best interests standard must be used when explicit prior decisions have not been articulated but the Patient’s values and interests are known. The conundrum escalates when even best interests are impossible to discern. What then?

The standard for medical decision-making for an unknown and unknowable Patient must include a mechanism for their voice to be heard, even if it is a guess, a composite view based upon whatever small glimpses of values and interests can be gained from an examination of the unknown Patient’s life. Such a composite decision-making standard would be predicated on procedural due process – considerable efforts must be expended to obtain information about the unknown Patient and to locate people who are or were involved in that Patient’s life. Substantive due process must be protected as well – considerations must be taken into account to ensure biases are minimized and medical treatment decisions are made with a view of protecting the unknown Patient’s physical integrity.

The Committee was impressed by the stories of hospital social work staff who are given the task of tracking down any and all possible leads to glean some information about the Patient. This due diligence included entry into now-abandoned apartments, contacting people with even the remotest of ties to the unknown Patient, making repeated calls to absent family members if they are found. And the effort to create some composite picture of the unknown Patient often continued for weeks and months! The sustained effort to obtain some glimpse into the individual’s values and interests is valuable and valued in the quest for creating this composite decision-making standard. It provides the procedural due process needed to protect the unknown Patient’s physical integrity – the right to informed consent before medical interventions are performed. (This sustained due diligence to find out as much as possible about the Patient also provides a level of protection from liability which the Committee understood was needed for good decisions to be made.)

Substantive due process prohibits the government from infringing on fundamental constitutional liberties. In this context, the difference in medical decision-making between a court-appointed Guardian and an ad hoc Medical Decision-Making Team is profound and vitally important. The Guardian must uphold the government’s bias toward sustaining life at all costs. The Medical Decision-Making Team is attempting to replicate the individual’s constitutional liberty to autonomous consent, free of bias to the extent possible. The Committee was troubled upon

learning that Patients without Representatives are far more likely to spend a longer time in an ICU, receiving more aggressive care, than those Patients with Representatives. The Patient's medical circumstances were not as determinative of the length of an ICU stay as was the presence or absence of a Representative. Like Patients are not being treated alike.

As a result, representation for medical decision-making becomes key to protecting the physical integrity of the unknown and unknowable Patient. The recommended Medical Decision-Making Team's composite decision-making standard is necessary so that treatment decisions for unknown Patients are not governed by the technological imperative to treat at all costs. The option of allowing an unknown and unknowable Patient to stop treatment and begin palliative care (with hospice care implied) must be available, just as the oversight to ensure adequate treatment is necessary to protect those who could benefit and recover.

The Committee understands it is not looking primarily at legal standards for decision-making. We are, in fact, an ethics committee! While the law sets the floor for decisions and behavior, establishing the minimum of what must be done, ethics opens the skylight and looks at what should be done. In a Green Paper Technical Report for the Essex (UK) Autonomy Project entitled "Best Interests decision-making under the Mental Capacity Act," Justice Hedley is quoted in a decision saying:

"If one asks what has to be taken into account in considering the best interests of any human being, the answer is a very wide ranging one: his health, his care needs, his need for physical care, and his needs for consistency. There is, of course, more to human life than that, there is fundamentally the emotional dimension, the importance of relationships, the importance of a sense of belonging in the place in which you are living, and the sense of belonging to a specific group in respect of which you are a particularly important person."

The consideration of emotional ties and relational connections is perhaps the most important basis for a composite decision-making standard. In the end, the Committee was protective of the unknown and unknowable Patient – wanting to be sure that the evaluation of an unknown Patient's best interests includes more than the status of their medical condition, but also includes an ethical standard of medical decision-making that ensures such a one's relational life is taken into account. The Committee concluded that an ad hoc Medical Decision-Making Team, using a composite decision-making standard, would best be able to assess the unknown and unknowable Patient's needs and to advocate for those needs to be met, so that what should be done is done.

"I would hope that an advocate would work closely with the care providers to determine the best course of care for my situation. This advocate could be within the hospital setting but not a medical provider (perhaps a social worker, clergy, etc.), or could be a neutral person outside of the hospital setting – assigned by the courts or some outside board. In any case, I would hope the person advocating for me would be thoughtful and thorough in their decision-making, reasonable in their expectations of treatment cost/benefit ratios, and motivated by what is best for me (without financial or other institutional pressures)."

CEC Internal Survey Respondent

THREE SIDE NOTES

The Committee's discussions included three additional side notes that are important to include in this Report. First, we understand the puzzlement that might arise at the Committee's recommendation to specifically include chaplaincy with a weighted voice on an unknown Patient's Medical Decision-Making Team. Second, although not explicitly stated in our recommendation, the Committee encourages the initiation of an ethics committee consult early on in the unknown Patient's treatment. And third, we note the close ties between our discussions regarding medical decision-making for unknown and unrepresented Patients and Medical Futility, with lessons learned that carried a particular impact our recommendation. These three aspects of our discussions were weighty enough to deserve separate treatment here.

Chaplaincy

A short narrative might be in order. The Committee was asked to present its views on medical decision-making for unknown and unrepresented Patients at a May 2015 conference on "Making Decisions for Others" at the University of Arkansas Medical School and three Committee members attended and spoke. We met others wrestling with these challenging issues and we were struck by the composition of several of the ethics committees outside of our limited geographic area. Many institutional ethics committees located outside of the bioethicist-rich Northeast corridor are headed by and comprised primarily of chaplains. These individuals are compassionate, knowledgeable, value-neutral, and innovative representatives of both their institutions and the Patients within their communities. We were struck by their professional skill at advocating for Patients' needs while working within the institutional system. These encounters opened our eyes to the value and the strength of incorporating the chaplains' voice into those ethics discussions where the Patient's voice is unheard and unknown.

In making its recommendation to specifically include a representative from the chaplaincy office, the Committee assumed a non-judgmental professionalism and a value-neutral stance could be maintained. The weighted voice of the chaplain on the Team was meant to enhance the creation of the "composite judgment" standard which we thought would be most effective in ensuring an unknown and unknowable Patient would be treated with mercy and justice.

During a recent Harvard forum on decision-making, Charles Bosk discussed his recent book "What would you do? Juggling Bioethics and Ethnography," and noted that writing the book:

"grew out of my puzzlement: where did ethics experts come from, what made them legitimate, how is it that the secular ethics experts never acknowledged the religious ethics experts? What role in fact did chaplaincy play? . . . [Most patients] don't say "Get me a bioethicist;" they do say "Get me a chaplain.""

Ethics Committees

Without any reservation, the Committee respects the work the Harvard teaching hospitals' ethics committees do to address ethical complexities which arise in the context of the provision of patient care within an institutional system. More often than not, the ethics committee members are trained in bioethical discourse and understand the philosophical underpinnings of bioethical analysis. Most are health care workers within the institution. Some are community members and some are chaplains. An ethics committee consult is an invaluable tool when ethical dilemmas arise and an ethics committee consult often provides another "voice" to the discussions surrounding treatment options and accomplishing a Patient's or families' goals of care. Our Report recommends enlisting the aid of the ethics committee as soon as transitional medical decisions are needed for unknown and unrepresented Patients – the perspectives of the committee will only enhance and strengthen the care provided to such a Patient. The Committee did not explicitly suggest an ethics committee member participate on the Medical Decision-Making Team but there is no reason to presume

exclusion from the Team if that were necessary or advisable. The roles are arguably different and the Committee chose a representative from chaplaincy as a way to be sure there was an institutional participant on the Team whose voice could be weighted to speak to what the Patient would likely have wanted.

Medical Futility Lessons

We found the dilemmas surrounding medical decision-making for unknown and unrepresented Patients are related to dilemmas surrounding medical decision-making for Patients subjected to treatments which are medically futile. Both situations involve the need for a strong Patient-centered voice and both involve situations where care-giving decisions are sometimes overwhelmed by the technological imperative to treat at all costs. The Committee spent a great deal of time and effort analyzing both situations. We learned something from our recommendation with regard to Medical Futility that affected our recommendation here.

At the time of our Report on Medical Futility, we recommended the creation of an independent decision-making panel that would exist outside of the institutional setting. We noted when we reviewed the issue of Medical Futility,

“ . . . Unless an effective and efficient [] dispute resolution mechanism is in place, our society will continue to suffer. And most importantly patients suffer – their dying process is prolonged for no apparent therapeutic or curative purpose with substantial harm done to caregivers, family members, and patient alike. No matter whether decisions are made by court or committee, even if all cases [] could be decided reasonably and well, with the patient’s best interests protected, efficient resolution by any authoritative institutional group may come at the potential expense of public trust and confidence. Decisions made by either courts or medical institutions’ internal review boards are suspect because the stakes are high, core values differ, and the power disparity of the stakeholders is extreme. Rarely does anyone feel particularly comfortable when a court or authorized expert panel or ethics committee mandates withdrawal of life-support for a terminally ill child, for example, against the wishes, hopes, and demands of frantic and grief-stricken parents. Another approach must be found that includes safeguards and provides an open process that considers cultural, religious and patient values and welcomes participation by surrogates acting in the patient’s best interest.”

CEC Report on Medical Futility, January 2013, page 14.

Over time, the Committee has found our recommendation for the creation of an outside decision-making body to be “ideal” but not practical. With limited governmental and institutional resources available to fund a separate decision-making panel, the hospitals are left to rely on institutional policies and their own internal decision-making practices. The Committee felt strongly that we did not want our recommendation on medical decision-making for unknown and unrepresented Patients to lie fallow. By recommending an in-house Medical Decision-Making Team, we have to some extent stepped away from the “ideal” to ensure a practical solution that can address decision-making for these most vulnerable of Patients. It is our hope that the chaplain’s participation on the Medical Decision-Making Team will provide a weighted voice of advocacy and compassion, taking into account factors in addition to physical well-being.

In all the years of its existence, the Community Ethics Committee's discussions and recommendations have focused on the "Patient in the bed." This inquiry was no different. An effective and efficient voice needs to be found for each unknown and unknowable Patient and we trust the creation of an ad hoc Medical Decision-Making Team, comprised of the attending physician, another care team member, and a hospital chaplain, will provide that voice. Even if "only" a composite of the Team's understanding of this unknown and unknowable Patient, the medical decisions made by the Team will provide a previously voiceless Patient with a voice and that is precisely what the Committee hopes for.

A NOTE OF THANKS

To the physicians, nurses, social workers, and medical staff who so generously gave their time and invaluable insights to the Committee, we are grateful.

REFERENCES and RESOURCES

A bibliography of articles, books and resources used by CEC members in our discussions and review of this topic will be provided separately.

EXECUTIVE SUMMARY –**Report on Medical Decision-Making for Unknown and Unrepresented Patients**

Throughout 2014 and most of 2015, the CEC met with many different health care providers who posed two questions: Who should make decisions and how should decisions be made for patients who are unknown, whose values are unknowable, and who have no representative?

Typically the purview of the Patient/Representative is to articulate the individual's overall goals of care (based upon cultural, religious, familial, and ethnic values) and the expertise of the medical team is to offer treatment options which best accomplish those goals of care (based upon professional expertise and experience). When the Representative does not have any way to know the Patient's express wishes or personal values, the Representative must become an advocate for the Patient in his or her most vulnerable moments. The Committee concluded that, although the treating physician's perspectives and recommendations carry great weight, leaving a crucial medical decision to the treating physician alone was not supportable. In answer to the question who should make a medical decision for an unknown and unrepresented Patient, the Committee recommends the Patient Representative should be a three-member Medical Decision-Making Team. The Team would be comprised of the treating physician, a medical professional not directly involved in the Patient's care, and a representative from the hospital's chaplaincy office. Weight should be given to the chaplain's perspective, whose pastoral value-neutral professional training would enable them to be an effective advocate for the Patient.

For Patients who have expressed their wishes regarding particular medical decisions, Patient Representatives must make decisions based upon a substituted judgment standard. For Patients who have never been competent or who did not express their wishes with regard to particular medical decisions, Patient Representatives must make decisions based upon a best interest standard. Using either a substituted judgment or best interest standard to make medical decisions for someone else is challenging. When that "someone else" is completely unknown and their values are completely unknowable, the decision-making standard is not firmly established and is especially challenging. The Committee suggested that a "composite decision-making standard" be employed by the Medical Decision-Making Team, based upon the distinct perspectives of the treating physician (providing a medical prognosis, balancing treatment benefits and burdens), another medical professional (providing peer review of sorts and a balance to a technological imperative to treat), and a chaplain (providing advocacy for the Patient based primarily upon compassion). The recommendation is based, in part, on the Synthetic Judgment Standard promulgated by policy at Brigham & Women's Hospital.

The Committee recognizes its recommendation is based upon assumptions about chaplaincy training and the ability of chaplains to be effective Patient advocates as participants on a Medical Decision-Making Team. To bring in someone outside of the institutional medical setting to serve on a Medical Decision-Making Team was beset with practical challenges including expediency, transparency, and liability. The chaplaincy service offers the best alternative to provide a person "in house" who is trained in both medical decision-making and compassion. The composite decision-making standard to be applied to the medical decisions made by the Team will provide a previously voiceless Patient with a voice and that is precisely what the Committee hopes for.