

Supplement to  
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# Clinical Cardiology™

A Journal for Advances in Cardiovascular Disease

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Prologue

Introduction

Medical Futility

Advance Care Planning

Palliative Care

Education and  
Implementation

## Project GRACE

### Guidelines for Resuscitation And Care at End-of-life

**L. L. Basta, M.D., FRCP, FACC and  
H. D. McIntosh, M.D., M.A.C.C.**  
*Guest Editors*

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# Clinical Cardiology

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Supplement II

## **Project GRACE** **Guidelines for Resuscitation And Care at End-of-life**

L. L. BASTA, M.D., FRCP, FACC, AND H. D. McINTOSH, M.D., M.A.C.C., **Guest Editors**

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## Project GRACE Florida's Panel to Study End-of-Life Care: An Interim Appraisal

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### Prologue

"It was the best of times, it was the worst of times. . ." These infamous words from Charles Dickens' *A Tale of Two Cities* epitomize the situation that exists in much of our country today when it comes to issues pertaining to end-of-life care. At the same time when this country has seen unbelievable advances in medical technology and treatment, we have barely scratched the surface of the ocean of controversy surrounding the needs and desires of patients as they near the end of their lives. Recent, often extensive studies of the problems that often occur in these clinical situations, such as the now well-reported Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT),<sup>1</sup> have shown us how often we, as physicians, do not gather and process the information necessary to acknowledge and follow the desires of our patients, as well as how often we fail to alleviate pain and suffering in these same patients.

Although many in this nation have embarked on a journey to dialogue publicly about these clinically and socially important issues, much of the conversation has been academic, or at least has not reached the attention of the majority of practitioners and, most critically, the public.

The State of Florida offers a vivid example of how early we are in the process of providing patient-directed, complete care to the affected populace. In spite of being the state with the largest number of seniors (estimated at two and a half million age 60 or older), less than 25% of the population has a valid advance directive. No concise estimate of the number of hospitalized patients with advance directives or of home and community patients with do-not-resuscitate orders is available. Education of physicians and other health care providers on end-of-life and palliative care issues is spotty at best and unquantified at least.

Recognizing this void, the Florida Legislature, in 1998, empowered a new body called the Panel to Study End-of-Life Care (The Panel). The Panel was directed to study issues related to the care provided to persons at the end of their lives and specifically (1) to develop methods to ensure that pain management is a goal in each health care setting; (2) to identify barriers that hinder health care professionals from providing satisfactory pain management and palliative care; (3) to determine whether mandatory education in pain management and palliative care should be required as a condition for licensure or relicensure of health care professionals; (4) to assess the current use of advance directives and determine whether changes are necessary to ensure that, once prepared, advance directives will be honored in any health care setting; and (5) to study the regulatory and financial incentives that influence the site or setting of care and of care providers.

The Panel was statutorily mandated to include a number of individuals from diverse organizations including government agencies on health and aging, hospitals, nursing homes, hospice centers, clergy, attorneys, professional organizations including allopathic and osteopathic physicians and nurses, the legislature, and consumer representation. In addition, the Panel selected a formal group of advisors (e.g., ethicists, pharmacists, assisted living facility operators, additional clergy, etc.) as it sought to bring together the vast expertise available in this state to deal with these problems. In order to coordinate and communicate with the concurrent Project GRACE, Dr. Lofty Basta attended the Panel meetings as an advisor and invited the Panel's chair to join Project GRACE as an advisor as well.

In the thirteen months of its existence, the Panel held 17 formal meetings, including 7 throughout the state for specific public input on these key areas. Public input was critical to the members of the Panel as they sought to bring forward new recommendations that would be sensitive to the many cultural and racial concerns on end-of-life care found in our diverse state. Frequently heard themes from the public included concerns with advance directives, such as their confusing language, lack of portability, lack of follow-through from health care practitioners, and need for a "terminal" diagnosis in some circumstances; concerns related to palliative care, particularly difficulties getting pain relief by patients, and misunderstanding by physicians about protection for administering appropriate pain medications; and concerns about regulatory and fi-

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<sup>1</sup>A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses for Outcomes and Risks of Treatments (SUPPORT). The SUPPORT Principal Investigators. *J Am Med Assoc* 1995;274:1541–1548.

nancial barriers to care including un- or underinsurance, lack of reimbursement for palliative and end-of-life counseling or consulting in some circumstances, and concern about conflicting regulations for hospice referral and care.

Based on its public input and after extensive discussion, the Panel brought forth an interim report to the Governor and state legislature with a number of specific recommendations. After additional legislative debate, important changes to Florida's statutes on end-of-life care were passed and became law on October 1, 1999. Among the many changes produced by the new legislation, several will particularly impact the way in which citizens receive end-of-life and palliative care in this state. Do-not-resuscitate orders, for instance, will now be valid not only in the community when filled out, but in hospitals, nursing homes, hospices, and assisted living facilities as well. The law will prohibit health care facilities from having the patient fill out a new advance directive once they have (and provide) a current one. The statutes also add "end-stage condition" as an additional condition that will permit the withholding or withdrawal of life-prolonging procedures. Pain will be encouraged as a "fifth vital sign" in health care facilities and offices. Also created is a new pathway whereby a person in a persistent vegetative state, who has no advance directive and no health care proxy or surrogate, may have life-prolonging

procedures withheld or withdrawn. Physicians and other health care providers will be encouraged to take continuing medical education courses on end-of-life and palliative care through statutory changes, and the Departments of Health and Elder Affairs will both have new roles to play in additional education of providers and the public on end-of-life care.

Even as the above changes are in the process of being enacted, the Panel has completed its formal mission and presented further recommendations to the Governor and legislature for possible action this coming year. Throughout the Panel's time in existence, it has been apparent to all participants that the long journey of bringing dignity and respect to patients nearing the end of their lives is only beginning. The multitude of social, legal, ethical, and, yes, even medical problems which daily interfere with caregiving in these situations will continue to require the explicit attention of all of us interested in making sure that self-directed care is available to all patients. Through the ongoing work of national and state initiatives such as the Panel's work and that of Project GRACE, we must strive to make what has been for many "the worst of times" into at least a "better time," that is, at a minimum one in which the patients know they will have a knowledgeable doctor or health care provider who will respect their wishes regarding end-of-life care and treat them with dignity and compassion.

## Project GRACE (Guidelines for Resuscitation And Care at End-of-life)

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### Introduction

Since the dawn of history, medicine's mission has been wellness for the healthy, healing for the sick, and comfort for those in the process of dying.<sup>1</sup>

During the last half of the twentieth century, thanks to breathtaking advances in medical technology, medicine's primary focus became that of saving lives and fighting death. The insidious medicalization of dying has changed death from an event to be expected and accepted as a natural occurrence to an unwelcomed offense riddled with vexing complexities. Commonly, death is regarded as a conclusion of a battle for the patient, failure of the medical profession, a costly process for society, and an unwelcome event riddled with all sorts of emotions for the family.<sup>2</sup> A multitude of factors have contributed to this transformation. Among these are influence of the news media, social changes in family structure, unrealistic expectations for high technologies, exaggerated promises from the healthcare providers, pursuit of material gain, fear of litigation, and the convenience of having everything possible done to the patient without concern for the financial consequences to the family and/or society at large.<sup>3</sup>

Although high-technology medical advances helped the majority live longer and healthier lives, it proved not to be without serious shortcomings. Aside from the staggering increase in cost(s) for medical care, a quick, painless death from the ravages of acute cardiovascular events has been replaced by a protracted last chapter of life, often with a mindless existence or hopelessly deteriorating bodily functions. For many, such existence robs them of much treasured dignity and valued richness of living. Furthermore, the evolution of closed-chest cardiopulmonary resuscitation (CPR) and effective defibrillation in the early 1960s rendered obsolete the traditional definition of death as cessation of breathing and circulation.<sup>4</sup> Now death occurs only when there is total brain death that includes cessation of all brain stem function.

The new definition of death was intended to enable the timely harvesting of organs suitable for transplanting into waiting recipients. However, it left behind a horde of individuals who have irretrievably and permanently lost high brain function and, therefore, loss of what defines them as persons but at the same time not considered dead (but legally disabled).<sup>5</sup> Also, the ability of assisted ventilation, hyperalimitation, dialysis, and CPR to postpone the official moment of biological death (according to the total brain formulation) have made the process of dying longer. This fate is made even more

likely through the liberal use of CPR and policies that greatly restrict Do Not Attempt Resuscitation (DNAR) orders.<sup>6</sup>

In 1969, during a meeting of the Euthanasia Society of America, Kutner proposed the use of the Living Will (LW) for those who desire to prevent unwanted death-prolonging medical care.<sup>7</sup> The Quinlan Case of 1976<sup>8</sup> and the California Natural Death Act<sup>9</sup> in that same pacesetting year underscored the right of competent persons to articulate, or for their surrogates to enforce, wishes to prevent or withdraw unwanted medical interventions when one becomes unable to express such wishes. Although the debate continued unabated, discussions about end-of-life medical care came to the forefront only recently. Factors that contributed to the heightened interest include in a perverse way, the emergence of Dr. Kevorkian as an advocate for euthanasia, the legislation of physician-assisted suicide in Oregon, and the Supreme Court deliberations about whether American citizens are entitled to a constitutional right to physician-assisted suicide. In addition, the pace is enhanced by the publication of a multitude of excellent new books on the subject and findings in credible research that many dying patients are treated contrary to their wishes and that half suffer from pain that has been ignored or undertreated.<sup>10,11</sup>

It is no wonder, therefore, that many philanthropic organizations have dedicated funds necessary to change the prevailing, wasteful, technology-driven death-denying culture in America. Also, the American Medical Association and its judicial and ethical affairs offices have expressed a renewed and serious interest in changing physicians' knowledge and attitudes about death and dying. Furthermore, the National Institutes of Health (NIH) have allocated research funds to further our knowledge about this weighty subject.

More and more, there is an unspoken realization that this problem does not lend itself to a piecemeal approach but requires a comprehensive, integrated, multidisciplinary approach that includes physicians, lawyers, theologians, ethicists, civic leaders, lawmakers, and the public.

Near end-of-life medical care encompasses a wide spectrum in which the colors merge imperceptibly and often confusingly into one another (Table I). At one end of the spectrum lies the question of when to withhold (not offer) a treatment that may not benefit the patient and when to withdraw an intervention that is deemed not to have achieved its desired benefit. Next is a whole host of medical scenarios in which an organ-replacing, life-sustaining, or life-prolonging intervention that is of potentially marginal benefit may be desired by some patients but not by others. It is this segment of the spectrum on

TABLE I Spectrum of issues considered in the medical treatment of a patient in the last chapter of life

|                   |   |
|-------------------|---|
| Futility          | Withhold further intervention that is not indicated<br>Withdraw treatment that proved useless<br>Do not resuscitate |
| Advance directive | A competent person refuses potentially beneficial treatment including cardiopulmonary resuscitation                 |
| Expectant caring  | Palliative care<br>Unlimited use of pain medications<br>Cessation of feeding and hydration<br>Terminal sedation     |
| Illegal           | Physician-assisted suicide<br>Voluntary euthanasia<br>Involuntary euthanasia  |

which advance care planning (ACP) and/or LW should focus. The next band of colors encompasses an array of medical treatments designed to alleviate pain, suffering, and mental anguish as well as to preserve patients' dignity. When appropriate, terminal sedation and cessation of calibrated feeding and hydration fall into this spectrum of legally and ethically acceptable decisions even though they may predictably hasten the moment of death.

At the other end of the spectrum is physician-assisted suicide (by which the patient controls the means and moment of dying) which is legal in Oregon. Voluntary euthanasia (by which the dying person relinquishes the execution to a health care professional) and involuntary euthanasia (when the patient is put out of his/her misery without consent).<sup>12</sup>

The definition of Medical Futility must remain in the domain of the treating team and be based on strict objective medical criteria and not subject to the treating physician's value judgment. A treatment unlikely to benefit the patient or one that has failed to confer any measurable benefit is deemed futile.<sup>13</sup> Table II describes standards by which determination of

TABLE II Issues involved in the determination of medical futility and DNAR decisions

|  |
|--|
| Domain of physician                            |
| Should be entirely based on objective criteria |
| Functional status                              |
| Probability of benefit                         |
| Magnitude of benefit                           |
| Possible duration of benefit                   |
| "Cost of intervention"                         |
| Safeguards are necessary                       |
| To protect patient                             |
| To protect physician                           |
| Less stringent standard for CPR?               |

Abbreviations: DNAR = do not attempt resuscitation, CPR = cardiopulmonary resuscitation.

futility may be based. We believe that employing the *beyond reasonable doubt* standard and establishing reference guidelines and indemnity ordinances are necessary to have a more realistic approach to end-of-life care.

The Study to Understand Progress and Preferences for Outcomes and Treatment (SUPPORT),<sup>11</sup> based upon the observation of over 9,000 patients who died in five leading centers, underscored the need to rethink the role of an LW in guiding care when the patients lose the capacity to make or articulate their desires and preferences. As shown in Table III, only 35% of patients included in the study had an LW in their hospital records, as did half of those who asked to forego CPR had DNAR orders in their hospital records. Most revealing is the fact that of 688 LWs reviewed, 87% used general language about not wanting to prolong life by artificial means and only 13% went beyond the general statements; 5.2% had specific instructions about the use of life sustaining treatments, and only 3.2% referred to the patient's specific current status.<sup>14</sup> The near irrelevance of many LWs is further complicated by the frequent absence of information about an LW at the time of need. Furthermore, appointed surrogates frequently do not know about the principal's true wishes. Statements such as medical certainty, terminal illness, imminence of death, heroic measures, or artificial means, create impediments rather than facilitate the implementation of an LW.

The whole spectrum of palliative care requires review and revision, as far as the *when, who, and how* to carry it out and for whom to implement it. The objective of palliative care is to provide timely, humane, professional care that preserves dignity and provides comfort. In Oregon, where most patients have access to palliative care, only 22% of Medicare patients die in a hospital. By contrast, over 50% of Floridians die in hospitals. Whether palliative care saves dollars should not be the overriding issue: the best care provided by caring professionals should. The guiding principle should be to meet people's expectations and priorities (Table IV).

The Florida Chapter of the American College of Cardiology (FCACC) recognized that to improve this wide spectrum in a comprehensive, integrated, and effective way requires far-reaching educational programs targeted at medical students, physicians, allied health professionals, and the lay public.

TABLE III Near irrelevance of Advance Directives (AD) and Living Will (LW): Findings from the SUPPORT study

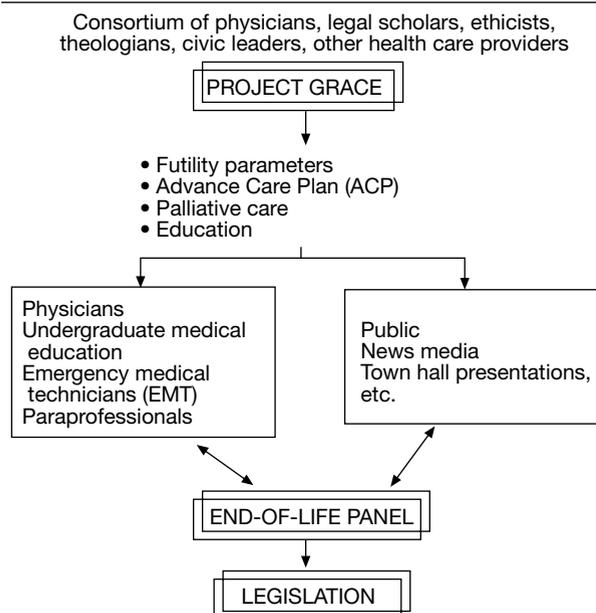
|   |
|---|
| <ul style="list-style-type: none"> <li>• 35% had LW in their records</li> <li>• Even when LW and no DNAR orders were in records, they had a minimal impact on care</li> <li>• Of those asking to forego CPR, less than 50% had no DNAR orders</li> <li>• 87% of LW were in a general, nonspecific language</li> <li>• 13% of LW went beyond general statements</li> <li>• 5.6% had specific instructions about the use of life-sustaining treatment</li> <li>• 3.2% (of 35%) had relevance to the patients' specific situation</li> </ul> |
|---|

Abbreviations as in Table II.

TABLE IV Summary of ordinary people's priorities and expectations from the medical profession during the last chapter of life<sup>15</sup>

- Adequate pain and symptom management
- Avoid inappropriate prolongation of dying
- Achieve sense of control
- Relieve burden
- Strengthen relationship with loved ones

TABLE V How Project GRACE interfaces and integrates with other Florida efforts in changing the culture of dying



Project GRACE (Guidelines for Resuscitation And Care at End-of-life) is a timely endeavor directed toward the noble and necessary goal of transforming the culture of dying for Florida citizens with the hope of establishing a prototype for the nation. Toward this goal four task forces were assembled and each was assigned a topic pertinent to the care of patients at the end-of-life to review and present a report on each of the following topics: (1) medical futility/DNAR, (2) advance care planning, (3) palliative care, and (4) education/implementation. Each Task Force was comprised of at least one member representing each of the following disciplines: medicine, law, ethics, civic service leadership, religion, and medical ethics. National experts were invited to contribute to the effort(s) at

the outset and at the Consensus Development Conference held in Tampa, Florida, on April 24, 1999. The results of these efforts and the recommendations for future actions follow (Table V).

## Acknowledgments

Teams of dedicated individuals contributed to this project. We wish to express our appreciation to each one of them. We are especially grateful to the Fourjay Foundation for providing a grant to underwrite this publication. Also we are grateful to Mr. Wil Mick and Ms. Liz Campos for their valuable contributions.

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## Medical Futility

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### Background and Rationale

For centuries physicians, patients, and families have dealt with end-of-life issues in an appropriate, compassionate, socially responsible manner. When a patient's illness would become overwhelming, life-prolonging efforts were abandoned and the individual was allowed to experience death, a natural part of life, with dignity and comfort. During the course of struggling with the patient's illness, physicians would come to the sad realization that further efforts to extend quality life were futile. The recognition of medical futility by the physician, patient, and family would not in any way diminish the need for care and medical attention. Instead, it would mark a shift in the primary goal of care from the prolongation of life to the provision of physical and emotional comfort. This traditional physician-patient-family decision-making process is now threatened by the erosion of trust that society holds for physicians and by expanding technology, which makes the recognition and acceptance of medical futility increasingly difficult.

The explosion of medical technology has not in any way altered the cardinal goals of medical care: (1) to relieve physical and emotional pain and suffering, (2) to enhance the quality and functionality of life, and (3) to extend the length of life. Technology has brought an amazing array of beneficial treatment choices, but has also led to immense pressure to offer some form of potentially curative therapy. Since there is almost always something that can justifiably be done to treat one or more of the patient's medical problems, the norm has become aggressive treatment until death. In many cases, patients are treated well past the point where treatment may be properly regarded as futile. Even though only a small percentage of patients are treated aggressively beyond futility, the absolute number of people remains large because millions become severely ill prior to death each year. The impact of expensive technology at the end of life is enormous because of technology's ability to prolong dying significantly. The fact that individuals with medically futile conditions can almost always be found in every hospital critical care unit is obvious evidence of the increasing prevalence of continued life-prolonging treatment beyond the point of futility.

In an effort to reduce the inappropriate application of medical interventions to patients who have no potential for benefit, the term *medical futility* has been used increasingly by

physicians and medical ethicists. The rationale has been that reminding doctors and the public that physicians have no ethical obligation to offer or provide futile interventions should result in a reduction in the inappropriate use of technology at the end of life. While the existence of medical futility is as unquestionable as the eventuality of death, the impact of the futility concept on decision making has been hampered by the lack of a clear definition of medical futility. The definition has become increasingly elusive as technology has pushed back the limits of what can be done to prolong both life and the process of dying.

### Twentieth Century Progress in End-of-Life Care

The growing debate over medical futility may be best understood in the context of the significant strides that have been made in dealing with end-of-life care during the past century versus the persistent obstacles to appropriate care that exist as Americans enter the new millennium. Substantial progress has been made in defining the patient's autonomy, the physician's role in dealing with medical futility, and the medical institution's responsibility to patients and physicians.

#### Patient Autonomy

Americans have made progress in end-of-life care by asserting their autonomy through the courts and legislation and have largely thrown off paternalistic decision making by physicians through the realization of a number of patient rights. The right to refuse medical treatment has been supported in common law and by the U. S. Constitution. In a 1914 informed consent case, Justice Cardozo ruled that "every human being of adult years and sound mind has the right to determine what shall be done with his own body."<sup>1</sup> This ruling has been cited in numerous common law cases establishing a patient's right to refuse unwanted medical intervention, even when that intervention is regarded as necessary to sustain life. Other cases have based the right of self-determination on the U. S. Constitution's implied right to privacy and on the liberty interests identified in the Fourteenth Amendment. The right to refuse unwanted, life-sustaining medical treatment gained explicit constitutional recognition in the Cruzan case with the U.S. Supreme Court's assertion that a competent patient has a con-

stitutionally protected liberty interest in refusing unwanted treatment.<sup>2</sup>

Patients have secured the right to refuse life-sustaining treatment even in the setting of nonterminal illness. In the case of Elizabeth Bouvia, a young woman with severe cerebral palsy, but without life-threatening illness, the California Court of Appeals ruled that she had the right to refuse treatment with artificial nutrition.<sup>3</sup> Patients have also used legislative action to establish the option of controlling health care decisions in advance of mental incapacity by completing advance directives or by delegating decision-making rights to another individual who can serve as a health care proxy with durable power of attorney.<sup>4</sup>

Finally, in cases where patients lack decisional capacity and formal advance directives or proxy designations, their right to be free of unwanted treatment can still be exercised through a hierarchy of two decision-making standards: substituted judgment and best interests. The substituted judgment standard requires a surrogate decision maker, usually a close family member, to make the decision he or she believes that the patient would have made, based on past statements made by the patient. The best interest's standard is used when there are no applicable past statements and the surrogate is asked to make decisions based on what is judged to be in the patient's best interest.<sup>5</sup>

### Physicians and Medical Futility

Physicians have recognized both the quantitative and the qualitative aspects of medical futility since antiquity. Hippocrates encouraged doctors to assess the quantitative aspect of futile treatment and to refuse to treat those who are overmastered by their diseases, realizing that medicine is powerless in such cases.<sup>6</sup> Plato, however, emphasized the qualitative nature of futility, believing that the good physician would assess each case, then judge whether treatment should be given. "For patients whose bodies were always in a state of inner sickness, he did not attempt to prescribe a regimen, for that would make their life a prolonged misery . . . medicine was not invented for them and they should not be treated even if they were richer than Midas."<sup>7</sup>

Much of the modern futility debate has centered on futile cardiopulmonary resuscitation (CPR). As CPR has become the standard of care, "do not resuscitate" (DNR) orders have evolved to designate individuals in whom resuscitation is not indicated. More recently, the phrase "do not attempt resuscitation" (DNAR) has been proposed as more appropriate because it "makes clear that many attempts at resuscitation fail" and that "in some cases in which resuscitation is accomplished, the patient is left with severe mental impairment."<sup>8</sup> The common practice of requiring consent for DNAR orders has been questioned. As an alternative, it has been proposed that CPR be considered a specific therapeutic intervention with its own indications. Based upon the principle that doctors have no duty to discuss or provide useless therapy, some have argued that when attempting CPR would be futile, DNAR orders can be written without the consent of the pa-

tient or family.<sup>9-11</sup> Consistent with the concept of qualitative futility, Plunkitt and others have written that "CPR is not indicated unless there is a reasonable hope for a conscious life with a chance that the patient will be able to pursue and achieve some degree of happiness."<sup>12</sup>

While the CPR debate has done much to move the issue of medical futility forward, concern about medical liability has led many physicians to order and attempt futile CPR. They reason that erring on the side of aggressive treatment protects them, assuming they will not be faulted for doing something for the patient in an effort to save or prolong life. However, there is no precedent for the successful suit of a physician for refusing to render resuscitation or other aggressive care in a medically futile situation. "Analysis of the relevant case law lends credence to the argument that a physician's liability for not providing futile CPR is remote and that, in fact, a physician exposes himself to greater liability by providing such treatment. Nevertheless, where unilateral DNAR orders are to be written, it would be prudent to do so under the auspices of hospital or medical staff guidelines for their issuance."<sup>5</sup> In 1993, Drane and Coulehan more broadly defined treatment as medically futile that "(1) does not alter a person's persistent vegetative state; (2) does not alter diseases or defects that make a baby's survival beyond infancy impossible; (3) leaves permanently unrestored a patient's neurocardiorespiratory capacity, capacity for relationship, or moral agency; or (4) will not help free a patient from permanent dependency on total intensive care support."<sup>13</sup> Unfortunately, this comprehensive, succinct definition has not been widely accepted by society or the profession of medicine.

### Healthcare Institutions and Medical Futility

In 1990, Congress enacted the Patient Self-Determination Act which mandated that health care institutions accepting Medicare and Medicaid provide all patients with written information regarding their legal rights to participate in the medical decision-making process and to formulate advance directives.<sup>14</sup> The American Hospital Association's *Policy and Statement on Patient's Choice of Treatment Options* (1995) provided that health care decision making should be based on a collaborative relationship between the patient and the physician and that institutional methods should be established for reasonable assurance that the patient may exercise this authority on the basis of relevant information necessary to make a sufficient voluntary and informed decision.<sup>5</sup> In addition, the Joint Commission on Accreditation of Health Care Organizations has set standards to assist health care facilities in implementing policies with respect to obtaining a patient's informed consent to treatment.<sup>5</sup>

Other supportive innovations in end-of-life care include a clearer definition of the patient's ability to provide informed consent,<sup>15</sup> detailed protocols and guidelines addressing effective palliative care,<sup>16</sup> provisions in several states requiring skilled nursing facility patients to execute advance directives in the presence of patient advocates,<sup>17, 18</sup> and the development of ethics committees to assist in resolving conflicts in patient

care.<sup>19</sup> In addition, much work has been done to craft policies on medical futility at the health facility,<sup>20–22</sup> community,<sup>23, 24</sup> and national levels.<sup>25, 26</sup>

### **Twenty-First Century Obstacles to Futility-Based Decisions**

The controversy over medical futility may be surprising to anyone considering the issues for the first time, given that (1) physicians, patients, and families have historically dealt with medical futility well; (2) significant progress has been made in end-of-life care, as enumerated; and (3) the vast majority of individuals, if asked, express a desire to forego treatment beyond futility. There remains, however, an increasing number of social, cultural, legal, ethical, economic, and medical obstacles to dealing appropriately with medical futility in a way that is consistently in the patient's best interest.<sup>27, 28</sup>

#### **Social and Cultural Obstacles**

American society does not deal well with death and dying. Americans are often poorly prepared psychologically and spiritually for their own deaths or the deaths of loved ones. Cited reasons include fear, denial, Western individualism, lack of understanding of the meaning of life, and lack of acceptance of death as a natural part of life.<sup>29</sup> Discussions about death and dying are uncommon in American families. Most people expect death to occur in the hospital, though they would typically prefer to die at home. Most American children have never seen a dead person and fear death as an unknown, unspoken mystery. The American attitude toward death represents an obstacle to acknowledging medical futility, which requires that individuals face and accept the inevitability of death. This obstacle is greater when coupled with the expectation that technological advances will overcome illnesses, no matter how grave.

Many patients who do acknowledge the limits of medicine and wish to limit their own treatment fail to communicate their wishes prior to catastrophic illness. Inadequate communication represents yet another major obstacle to avoiding over-treatment. A minority of adults communicates their wishes through advance directives (ADs). These often use vague language and are of little utility because they fail to address key issues such as life support, CPR, nutrition, and hydration.<sup>30</sup> Questions have been raised as to the ability of patients to make informed decisions regarding more explicit advance directives because some individuals change their minds over time and choices may be affected by age, race, acute or recent illness, depression, vagueness of the document or its presentation, and reluctance to commit to directives in writing.<sup>31–34</sup> Particular obstacles exist in implementing advance directives in long-term residential health care facilities. Owners often do not want any resident to die in their facility and residents become especially vulnerable to unwanted resuscitation and emergency hospital transport. Even when an advance directive is signed, it is often unavailable.

Although surrogates typically act with the utmost compassion, many are incapable of completing the patient's wishes. Even surrogates with long, intimate relationships with the patient may not be able to predict accurately the individual's choices or may be influenced by personal biases or ulterior motives. Surrogates may have little confidence in the physicians involved in the patient's care or a poor understanding of the medical advice offered. Finally, physicians may be to blame for not communicating effectively and consistently enough to allow surrogates to make appropriate decisions.

#### **Legal Obstacles**

One of the clearest instances of medical futility is that of brain death. The diagnosis of death is uncontroversial when made at the bedside by establishing the irreversible cessation of heart, lung, and brain functions. However, when CPR and life support systems are used, brain death often occurs despite the reversal of cardiac and respiratory arrest. In this situation all brain function has irreversibly ceased, but air is pumped into the chest via a ventilator and the heart has, in most cases, been restarted via CPR. Because such a person is medically and legally dead, any continued or proposed intervention is, by definition, futile.<sup>35, 36</sup> Objections to stopping futile intervention in these patients typically come from families who do not accept that their loved one is dead<sup>37</sup> and from physicians who do not accurately diagnose brain death, but instead continue to regard the patient as alive, albeit severely injured.<sup>38</sup>

"Successful" CPR can also result in a persistent vegetative state. Such individuals have severe, permanent high brain damage to the extent that there is no responsiveness or awareness, and yet low level brain function allows them to breathe on their own, unlike patients with total brain death. An estimated 5,000 patients with persistent vegetative state in the United States at any given time<sup>39</sup> can be kept "alive" for several years with artificial feeding and meticulous nursing care. Some physicians have proposed that the brain death concept should be expanded to include permanently vegetative patients by defining death as the permanent failure of the brain areas responsible for consciousness and cognition.<sup>40</sup> Proponents of this view see the current brain death standard as too narrow and as a legal obstacle to the discontinuation of futile treatment.<sup>41</sup> Expansion of the definition of death, however, has not met with wide acceptance.<sup>42</sup> Hundreds, possibly thousands of patients in persistent vegetative state are allowed to die with dignity by their physicians and surrogates each year. The protracted, inconsistent treatment of many others remains a major problem in the United States in that their treatment beyond futility often perpetuates emotional suffering for families and poses an extremely high cost to relatives and society.<sup>43</sup>

In the absence of advance directives, decisions by surrogates for those without capacity can be legally more difficult. Some states require that surrogates base decisions on convincing evidence of the patient's wishes. When the courts become involved, they understandably look carefully at the patient's medical condition or prognosis before sanctioning surrogate

decisions for nonautonomous patients who have not expressed a clear position of abating treatment.<sup>44</sup> Courts have an easier task when there is clear legal precedent, such as with terminally ill patients or those in persistent vegetative state. The more difficult case is the charged issue of abating treatment for non-vegetative, nonterminally ill patients who lack capacity.<sup>44</sup>

Courts have virtually always supported physicians and medical institutions after the fact, when medical interventions have been withdrawn or withheld in situations of medical futility. However, they have been reluctant to intervene by requiring the withdrawal of futile care when requested by physicians or medical institutions over the objections of families or surrogates. Despite sound legal precedent for futility-based decisions, physicians continue to be more likely to acquiesce to a vocal surrogate who requests that everything be done, possibly due to concern over liability or simply to avoid confrontation.

Significant deficiencies in most living wills (LWs) are likely due to the combination of legal obstacles, insufficient understanding of medical futility, and lack of appreciation for the need and purpose of advance directives by both the lay public and physicians.<sup>45, 46</sup> Recent pacesetter legislation in Florida removes many obstacles toward empowering physicians to deal with medical futility rationally and facilitate the implementation of patient's expressed choices.<sup>47</sup>

### Ethical Obstacles

Physicians have no obligation to offer futile interventions based upon the ethical principle of beneficence, which requires the physician to act in ways that benefit the patient. Since futile interventions lack benefit, there is no obligation to provide them. Furthermore, the ethical principle of nonmaleficence requires that physicians avoid harming patients with futile medical interventions, which often retain their potential for harm. If the proposed intervention is costly, the ethical principle of justice becomes an important consideration. Justice requires physicians to make wise use of health care resources, and costly futile interventions cannot be justified. An opposing ethical argument, however, is the principle of autonomy or self-determination, which holds that adults have the right to make decisions about their own bodies. A common obstacle to futility decisions arises when the patient or surrogate believes his or her right to decide on treatment extends equally to decisions to receive treatment and decisions to forego treatment. This belief sometimes results in inappropriate demands for futile treatment. The treating physician's ethical obligations, however, logically limit the patient's autonomous choices to those options the physician can ethically offer. There remains some lack of consensus as to who should have ultimate decision-making authority.

Logically, the profession that creates a treatment has innate authority and obligation to prescribe its proper use. But unfortunately, medicine's innovations are often widely applied well in advance of guidelines for their use. In some instances, guidelines are never clearly formulated. Meanwhile, decisions to forego futile treatment have been defaulted to patients and

surrogates. This state of affairs has become so common that it now seems out of place for a physician to make a unilateral futility judgment. Unilateral futility decisions can ethically be most easily justified in situations of absolute physiologic implausibility, such as attempting CPR in the setting of progressive hypoxemia from end-stage, chronic lung disease that makes adequate oxygenation impossible despite maximal ventilator settings. Once hypoxemia leads to cardiac arrest, no amount of CPR can improve air exchange. Thus, from a physiologic standpoint, CPR is absolutely futile. Most situations, however, are not physiologically futile. The judgment of futility is, instead, based on a low probability of treatment success and/or an extremely poor quality of life. In these situations, unilateral futility decisions are ethically less defensible, since the pursuit of treatment is based primarily on a value judgment.<sup>47</sup> When futility is based upon a value judgment, the well-informed patient should decide to accept or forego treatment. The rare exception to this is when the likelihood of benefit is extremely low and the likelihood of harm to the patient is significant, such that the physician cannot ethically offer the medical intervention. Finally, whether the patient's autonomous value judgment should be overridden by excessive cost (based on justice) in situations of borderline or definite medical futility remains an unresolved ethical dilemma for society.

Ethical conflicts sometimes occur when patients lack understanding of the meaning of low statistical probability and its full implications. More commonly, conflict arises precisely because patients and physicians may draw the futility line at a different probabilistic point, such as under 5% versus under 1 or 2% likelihood of success. Some patients might require 0% or unprecedented success before agreeing that a treatment is futile. Unfortunately, medical science often does not allow discrimination to such a precise degree of accuracy, since little research has been done in individual prognosis prediction and human physiology is highly variable.

Conflicts can occur when physicians and patients differ on the goals of treatment. An example is the case of Helga Wanglie, a ventilator-dependent patient in a persistent vegetative state. Her physician felt that ventilation was futile because it "could not heal her lungs, palliate her suffering, or enable this unconscious and permanently respirator-dependent woman to experience the benefit of the life afforded by respirator support."<sup>48</sup> Her husband disagreed because Mrs. Wanglie had consistently said she wanted respirator support for such a condition. The physician's goal was to benefit the patient through healing and relief of suffering; the patient's goal, according to her husband, was simply to have her life extended. Because cases of goal disagreement involve value judgments, the patient's values should generally prevail. Based upon the above ethical arguments, an individual who is permanently ventilator dependent, but values such an existence, possesses the autonomous right to choose to continue treatment, regardless of whether others would agree that such a life is of value. If the patient is also in a persistent vegetative state, however, one may argue that it is no longer possible for the individual to derive any value from such treatment because such patients completely lack cognitive perception. A counter argument may be

posed as to the ability to predict with absolute certainty that the individual will remain vegetative forever. Thus, a circular argument ensues, ultimately involving the question of who should decide on treatment in the face of probabilistic futility. Based on past judgments, courts would likely support the unilateral declaration of medical futility by a physician if ventilatory support has already been withdrawn; but would likely rule in favor of the surrogate should the case come to court before withdrawal of ventilator support. Both the individual and society would arguably be better served by resolving such conflicts through a local, bio-ethics committee made up of lay and professional volunteers empowered with a clearer, more widely accepted definition of medical futility.

Ethical obstacles to futility decisions are even greater in cases where surrogates do not have clear past statements by the patient and are asked to make life and death decisions based on insufficient information from the patient. Surrogates commonly err on the side of aggressive care rather than assuming the responsibility for withholding treatment. The most difficult surrogate decisions are controversial treatment choices, such as withholding artificial nutrition and hydration. Though the law and medicine clearly view artificial nutrition and hydration as medical treatments, surrogates may view them as nurturing or palliative, and may have difficulty withholding hydration and nutrition on emotional, religious, or ethical grounds. When attempts at curative and life-prolonging intervention have become futile but conflict arises, the challenge is to achieve consensus of all involved. Unfortunately, many physicians are ill prepared to achieve artfully the consensus required and effective, enlightened bio-ethics committees are often lacking.

### **Economic Obstacles**

A majority of Americans are not directly accountable for their medical expenses by virtue of insurance, Medicare, Medicaid, or indigent status and have no economic incentive to use medical resources judiciously. There is also little incentive for physicians and hospitals to avoid expensive care, since most medical care delivered in the United States is still funded by some version of fee for service financing. The Medicare diagnostic related group (DRG) payment system is intended to provide incentives to reduce hospital costs per admission, since hospitals receive the same reimbursement for like diagnoses, regardless of resources utilized. On the other hand, neither hospitals nor physicians have economic incentives for keeping patients out of the hospital altogether. The result is that there is little incentive to change the fact that most people die in the hospital, where the costs of care at the end of life are greatest. Also, because most patients are accustomed to going to the hospital for serious illness, they often believe that the only alternative for obtaining relief of physical pain and emotional suffering is hospitalization. Most patients are eligible to receive hospice care, regardless of socioeconomic resources, yet patients and physicians too often seem unaware or unwilling to use hospice or other options that involve volunteers for end-of-life care.<sup>49</sup>

Over ten percent of all health care expenditures is spent during the last year of life and a significant portion is spent on hospital care that is futile or of marginal utility.<sup>50-52</sup> Much of this care delivered is in intensive care units, where costs have been estimated to make up 28% of total hospital costs. End-of-life costs are likely to rise exponentially in the future due to expanding technology and the increasing elder population. The number of individuals over 85 years of age is expected to triple between 1980 and 2030.<sup>53</sup> American society faces the serious challenge of addressing how we care for people in the last chapter of life. Not only must we find ways to allow cherished senior citizens a graceful exit,<sup>54</sup> but we must avoid the destructive impact of expensive overtreatment on Medicare and other health care financing systems for our aging population as we enter the twenty-first century.

### **Medical Obstacles**

The absence of a clear operational definition of medical futility and poor communication between physicians, patients, and families remain the most important obstacles to making futility-based decisions. Historically, physicians have been trained to prolong life to the last possible moment and to view death as the enemy. Training programs typically emphasize the success of interventions in treating specific diseases rather than the whole patient.<sup>55</sup> They often provide little or no instruction in recognizing medical futility, communicating futile situations with patient and families, engaging in shared decision making, and achieving consensus.<sup>56</sup> This may be, in part, due to the fact that relatively little research has been done on predicting medical futility in individual patients. The result is that prolonging life beyond medical futility is common and young physicians come away from their training with the idea that it is ethically acceptable, thus, perpetuating the paradigm of overtreatment.

Conversely, physicians must provide aggressive medical care to all individuals in whom medical futility is not present. Physicians must always provide safeguards to prevent inappropriate choices when treatment is not futile. Families sometimes misinterpret an LW as meaning that their loved one wanted to categorically avoid all life support. An individual with an LW might be an excellent candidate for nonfutile, aggressive treatment even to the point of CPR and mechanical ventilation. Such therapy is not in violation of an LW in which a patient has expressed the desire not to be resuscitated in a situation of terminal illness or medical futility. What most current LWs do not but should address are conditions of nonterminal medical futility.

Determinations of medical futility must be restricted to a clearly defined set of circumstances in order to avoid overzealous or excessively liberal application of the concept. To protect against inappropriate futility judgments, a restrictive definition has been recommended that limits judgments to those of physiologic futility, or treatment that is "clearly futile in achieving its physiologic objective."<sup>57</sup> Use of this physiologic definition is much narrower than the concept of whole-person futility, which includes treatment that may have "important physiologic

ic effects which medical judgment concludes (nonetheless) are nonbeneficial to the patient as a person.”<sup>58</sup> Medical futility has been more broadly defined as “care that serves no useful purpose and provides no immediate or long-term benefit.”<sup>52</sup> A number of court cases, however, have failed to recognize the more inclusive, whole-person definition of futility and have ruled in favor of a physiologic definition. Most notably, in 1993 a U.S. District Court ruled that a hospital could not refuse mechanical ventilation for Baby K, an anencephalic infant who suffered repeated episodes of respiratory failure.<sup>59</sup>

The ultimate obstacle to futility decisions is that physicians can never predict prognosis or even death with absolute certainty. As a result, physicians typically hesitate to make life and death decisions based on uncertain data. Because some conditions, by nature, involve more uncertainty than others do, physicians may have particular difficulty in judging that treatment is futile. Examples include advanced age, dementia, severe brain injury, stroke, extreme low birth weight, and congenital defects involving severe mental and physical handicaps. Especially problematic are severe brain injury and the permanent vegetative state, which are clinical diagnoses for which there are no definitive, confirmatory diagnostic tests. Many physicians feel, however, that these diagnoses can be made clinically with confidence if the patient is unimproved after 3 months after a hypoxic brain injury or a cerebrovascular accident and after 12 months following a head injury.<sup>60</sup>

Some physicians appeal to statistical models of medical outcomes to help with prognostic assessment and futility judgments. However, the accuracy of most currently available statistical models is not sufficiently predictive when applied to individual patients, such that physicians often cannot be assured that an individual patient actually has the 95–99% probability of dying generally desired to declare death imminent. Furthermore, existing predictive models appear to be of no greater accuracy than physicians’ clinical estimates of survival.<sup>61–63</sup>

A related obstacle to accurate futility judgments is the overestimation of treatment success at the end of life. The effectiveness of CPR, for example, is commonly overestimated by both physicians and the public.<sup>64</sup> This is to some extent due to the high success rate of CPR (67%) depicted in medical drama on television.<sup>65</sup> In reality, CPR’s true effectiveness is quite limited. With in-hospital cardiac arrest, general survival rates are reported at 10–20%, but are only 10–11% in patients over 65 and 3.5% in patients over 85 years of age. Following out-of-hospital arrest, only 5% of all patients are discharged with intact brain function. Elderly nursing home patients with out-of-hospital arrest only have 1–2% survival.<sup>66</sup> These statistics are not widely appreciated, much less applied consistently in making CPR decisions. One study found that when CPR outcome data were shared with people, it decreased their stated desire for CPR in a variety of medical scenarios.<sup>67</sup>

Patients and families are often reluctant to accept DNAR status due to legitimate concern that the level of medical care for their loved one will be reduced. This obstacle to DNAR decisions is likely to worsen as managed care and nursing shortages increase. A further source of legitimate concern is that physicians are reluctant to give adequate palliative analgesia

and sedation due to personal bias, concern about addiction, or fear of being accused of euthanasia if medication intended to alleviate suffering also hastens death. A further concern is that categorically withholding heroic or investigational therapy from patients who are hopelessly ill may prevent the discovery of new, effective treatments for such individuals in the future. Although it is very reasonable to argue that heroic treatment should be undertaken for the advancement of medical science, the vast majority of futile care goes unanalyzed and undocumented and contributes little to medical knowledge.

Another obstacle to futility-based DNAR decisions is the failure of hospital policy to heed professional guidelines for the appropriate use of CPR. As early as 1974, guidelines published by the National Conference on CPR stated that the purpose of CPR is the prevention of sudden, unexpected death and that it is not indicated in certain situations, such as in cases of terminal, irreversible illness where death is not unexpected.<sup>68</sup> The American Medical Association’s guidelines stipulate that efforts should be made to resuscitate patients who suffer cardiac or respiratory arrest except when administration of CPR would be futile or not in accord with the desires or best interests of the patient.<sup>69</sup> Despite these official recommendations, hospital policies typically mandate full resuscitation unless there is explicit consent for a DNAR order. The result is that physicians are routinely called to the bedside of a frail, terminally ill patient on whom full resuscitation efforts have already been initiated. There is typically no effective, routine system in place for protecting individuals from such trauma, apart from case-by-case application of DNAR orders.

Unfortunately, physicians commonly fail to engage in timely, end-of-life treatment discussion with patients. Early, accurate, consistent, and continuous dialogue is of paramount importance, particularly in situations of medical futility. Failure to counsel patients effectively can be due to many factors, including time constraints; personal dislike of discussing death; misperception that the patient or family does not wish to discuss such issues; the tendency to project the physician’s own values onto the patient; insecurity in disclosing a lack of knowledge about the patient’s prognosis;<sup>70</sup> and the concern that the patient or family may not agree to limit any intervention and instead insist that the physician do everything.<sup>71</sup>

In addition to poor communication between physician and patient, lack of communication between other health professionals involved in the patient’s care, such as nurses and consulting physicians, can cause interstaff conflict.<sup>72</sup> On the same day, one physician may deliver a discouraging message about overall prognosis while another speaks favorably about the slightest improvement in some physiologic parameter. Poor interstaff communication can lead to disconnected, inconsistent medical therapies, while the mixed messages given to patients and families can cause confusion and mistrust.

## Defining Medical Futility

One of the chief problems in end-of-life care is that physicians do not recognize futility early and, thus, miss important

opportunities to address the issue with patients and families. Clearly, an operational definition of futility is needed if end-of-life care is to be improved. Lists of futile diagnoses are inadequate because of the infinite potential combinations of medical diagnoses and the variations in severity of illness among individuals. A logical, stepwise analysis is proposed in Figure 1. Physicians should consider three specific questions: (1) Is death imminent? (2) What is the best possible outcome or recovery that can be hoped for if treatment is maximally successful? (3) What is the probability of achieving the best possible result, or at least a good result? If the answer to any one of the three questions clearly points to a medically futile situation, the patient should be managed with every effort to provide comfort, support, and dignity, but not with continued efforts to cure or merely prolong life. If the answer to any of the three futility-defining questions is borderline, the life-prolonging interventions in question should be weighed heavily against the expected negative impact of treatment, including the emotional, physical, or financial burdens inflicted on the patient, family, and society. Significant negative factors should mitigate against heroic treatment in situations of borderline futility.

Once a medically futile condition has been established, the patient and/or family should be counseled on specific treatment issues relevant to the patient's condition. Counseling

should always address resuscitation status, that is, full resuscitation, limited resuscitation, or DNAR. Other issues that should be discussed include life-sustaining treatments ranging from highly technological measures, such as mechanical ventilation and dialysis, to simple measures, such as intravenous or nasogastric feeding and hydration. In each case, every effort should be made to give the patient and family genuine reassurance that the existence of a poor prognosis would not cause a reduction in the level of palliative and supportive care. Protocols, including specific routine palliative orders, should be implemented immediately to deliver effectively the best possible care for these individuals in their last chapter of life.

Decisions regarding futility must be constantly reevaluated. It is rare for futile situations to become nonfutile, but common for patients to evolve into apparent futility after trials of medical or surgical intervention have failed. Individuals with brain damage are typically in a coma immediately after experiencing brain insult or injury. Most recovery from such situations begins within a few hours or days, while late, miraculous recovery is extremely rare. Such individuals must be constantly reevaluated based on best possible outcome and probability with sensitivity to the pre-event wishes of the patient and the ongoing needs of the family. If futility becomes apparent, all efforts should then be made to involve the patient's family in making choices that respect the rights and wishes of the patient while considering the realistic limitations of medical technology and health care resources.

For clearer illustration of medical futility, specific medical conditions are listed that frequently constitute medical futility (see Table I). Such a list is incomplete by definition and lacks sufficient information to serve as an ironclad rule without individual consideration. Conditions are intended to serve as a benchmark to assist physicians in recognizing futility and in communicating with patients and families. Patients with these diagnoses typically meet at least one of the three futility-defining criteria. For example, death is clearly imminent in an individual with metastatic cancer that is refractory to treatment. Vigorous palliative therapy should be provided, but CPR and life support are inappropriate and any further, futile efforts at obtaining a remission from cancer should be abandoned.

In an individual with chronic, refractory, class IV congestive heart failure, however, premature death is certain but not as easily predicted as being imminent. Such an individual requires a constant reevaluation of the best possible quality of life that short-term recovery can provide and the probability of obtaining such recovery. Intermittent, intravenous inotrope infusions coupled with intensive nursing care have allowed the extension of reasonably high-quality life for months with minimum time in the hospital. Continuing aggressive therapy eventually becomes medically futile when severe symptoms or emotional and financial burdens outweigh the value of survival. A DNAR order may be appropriate early in the course of therapy to allow a sudden, graceful exit and hospice, commonly underutilized for such individuals, can be extremely helpful in supporting a peaceful death in the home environment.

More emotionally charged issues in futility involve newborn children who are found at birth or in utero to have severe

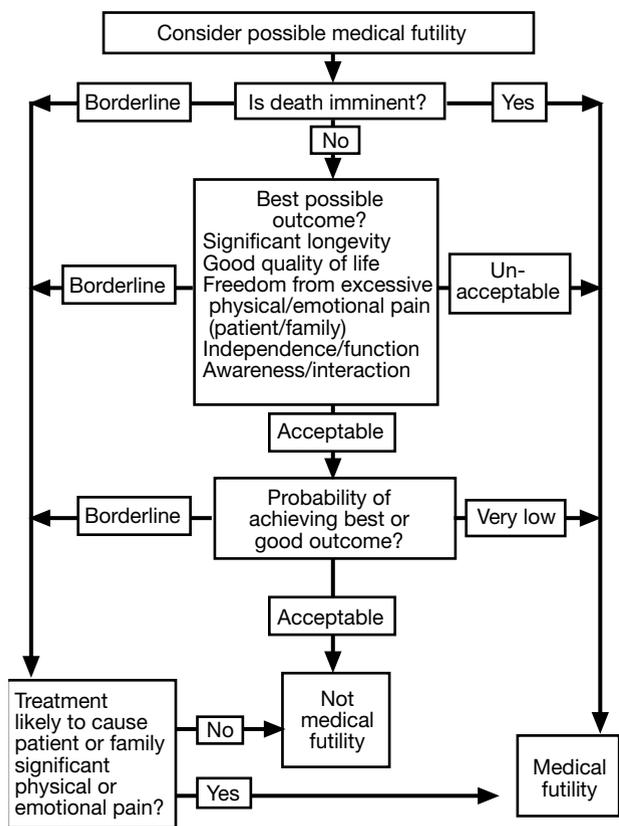


FIG. 1 Recommended clinical pathway for determination of medical futility.

TABLE I Medical futility

| Rationale for futility  |   |   |
|---|---|---|
| I–Death is imminent   |   |   |
| II–Best possible outcome for patient (longevity, quality of life such as freedom from excessive physical or emotional pain for patient or family, independence, function, awareness, interaction) is acceptable |   |   |
| III–Probability of achieving best or even good outcome is very low  |   |   |
| Definite futility   | Frequent futility   | Not futile  |
| Metastatic cancer, untreatable or multiple treatment failures (I, II, III)  | Widespread cancer, incurable (II)   | Treatable cancer with potential cure or significant probability of remission  |
| End-stage congestive heart failure, unable to wean off ventilator or keep out of hospital (nontransplant candidate) (I, II)   | Severe, class IV congestive heart failure, despite maximal medical therapy (nontransplant candidate) (II)   | Congestive heart failure amenable to medical therapy and/or with reversible or treatable underlying cause   |
| End-stage chronic lung disease, on ventilator unable to wean (not heart-lung transplant candidate) (II)   | End-stage chronic lung disease, post respiratory failure, requiring continuous oxygen (nontransplant candidate) (II, III)   | Moderately severe to severe chronic lung disease amenable to medical therapy and oxygen; acute, reversible respiratory failure                          |
| End-stage renal disease with severe, irreversible dysfunction of other organ systems (heart, lung, liver, CNS, or bone marrow); not dialysis or transplant candidate (I, II)                                    | End-stage renal disease with multiorgan system failure, low probability of recovery (III)   | Acute, reversible renal failure and chronic renal failure, transplant and/or dialysis candidate   |
| End-stage liver disease, hepatic encephalopathy or coma (nontransplant candidate) (I, II)   | Severe chronic or acute liver dysfunction plus multiorgan system failure (CHF, renal failure, or respiratory failure) (III)   | Nonendstage chronic liver disease and acute, potentially reversible hepatic dysfunction   |
| Severe myelodysplasia with severe pancytopenia and bleeding and/or infection (I, II, III)   | Myelodysplasia with severe reduction in at least 2 of 3 types of blood cells with infection or bleeding (III)   | Reversible bone marrow failure and chronic anemia amenable to transfusion therapy   |
| Severe, irreversible dementia, totally dependent for activities of daily living, bedfast, disoriented (II)  | Severe or moderately severe and progressive dementia, bedfast or severely dependent or with severe behavioral dysfunction (agitation, hostility) (II)   | Mild or moderate dementia with intact communication and some activities of daily living independence  |
| Severe immune compromise (HIV, organ transplantation, active chemotherapy for incurable cancer) plus incurable, life-threatening infection (I, II)  | Sepsis plus multiple organ system failure (III)   | Severe infection with potential for recovery  |
| Irreversible coma/persistent vegetative state, 1 year after head injury or 3 months after CVA or anoxic brain injury (II, III)  | Severe brain dysfunction (CVA, trauma, infection, anoxia), persistent for 2 weeks with no improvement; severe brain stem or high spinal stroke or injury, irreversible (locked in syndrome) (II, III) | Acute coma or dementia, without severe, irreversible brain injury   |
| Extreme (>90% 3rd degree) burn injury (II, III)   | Extensive burns (3rd degree over much of body); sepsis (II, III)  | Limited but severe burns, skin graft candidate, absent sepsis   |
| Prolonged cardiac asystole or electrical-mechanical dissociation (>10 min), unresponsive to ACLS, (I, III)  | Electrical-mechanical dissociation in setting of severe cardiac disease and cardiac arrest with critical aortic stenosis (I, III)   | Witnessed cardiac arrest post CPR, successful defibrillation and adequate blood pressure, absent end-stage heart or other organ disease (acute setting) |
| Advanced age in ICU with extremely poor prognosis predictive model scores (SUPPORT, APACHE, SAPS, MMP) (III)  | Advanced age in hospital with poor prognosis predictive model scores (SUPPORT, APACHE, SAPS, MMP). (III)  | Advanced age alone (functionally, medically and mentally intact; some independence and interaction)   |
| Absence of neonatal potential for higher brain development (anencephaly) (I, II)  | Congenital defects associated with extreme mental retardation and inability to achieve independence or survive beyond infancy (II)  | Congenital defects with potential for longevity and development (Trisomy 21)  |
| Congenital organ defects incompatible with survival and development (nontransplant candidate) (I, II)   | Congenital defects associated with moderately severe to severe mental retardation plus organ defects  | Congenital defects associated with nonfatal organ dysfunction or transplant candidate   |

*Abbreviations:* CNS = central nervous system, CHF = congestive heart failure, HIV = human immuno suppressive virus, CVA = cardiovascular accident, CPR = cardiopulmonary resuscitation, ICU = intensive care unit.

congenital defects that preclude normal development and longevity. The choice to withhold life support in an anencephalic child appears appropriate to most individuals, for example, but can be extremely emotionally traumatic for the family. Management issues in children born with severe, nonsurgically correctable congenital heart disease or brain defects that predictably lead to severe mental retardation and/or short life spans without imminent neonatal death are even more difficult for physicians and families to resolve. Emphasis on a unified, supportive decision that dispels any feelings of guilt is critical. Elderly patients commonly wish to forego invasive medical interventions, even when futility is not yet apparent, reasoning that they have lived a long life, have accomplished their goals, have come to terms with death, and wish to fulfill personal preferences regarding their own graceful exits. They may choose nonaggressive management for any number of serious illnesses, such as stroke, heart attack, cancer, and even pneumonia. Since surrogate decisions for elderly people are difficult, physicians should take a much more proactive role in obtaining advance directives while individuals are still capable of making decisions for themselves.<sup>73,74</sup>

In dealing with a patient with severe Alzheimer's disease, Doctors Karlawish, Quill, and Meier recommend an approach for working with the patient's family.<sup>75</sup> A "consensus-building process, grounded in dialogue among proxy, other close family members, physician, and immediate caregivers" is recommended. These authors emphasize an evolving dialogue, in which surrogates are asked to verbalize the patient's conditions and perceived wishes, guided by the physician's insertion of appropriate questions that should be considered in advocating for the patient at each stage in the process. Dialogue about futility should center around explicitly stating the goals of therapy in relation to futility judgments, and to clarify which goal(s) cannot be met, or are unlikely to be met, by the proposed intervention. An extremely insightful recommendation is that sometimes it is necessary to postpone the decision making and recommend that the participants take time to think about and discuss key issues.<sup>76</sup> Consensus building takes emotional release, evolution through stages of grief, acceptance, and education, all of which require time and a guided dialogue.

Despite attempts at consensus building, conflicts still emerge. Such conflicts rarely, if ever, stem from lack of desire of either the physician or the patient's family to do what is in the patient's best interest, but typically arise from (1) differences in expectations of outcome; (2) difficulty in dealing with uncertainty in outcome, commonly reflected by requests to do everything; (3) differences in the way benefits and harms are valued; (4) denial or lack of understanding of the severity of the illness by physician, patient, or family; and (5) the tendency for physicians and families to transfer their own values and perceptions to the patient.

To minimize conflict, physicians and patients should engage in shared decision making. Physicians have the most knowledge about expected outcomes of therapy and have the ability to evaluate expected benefits and risks of treatment more accurately and objectively than patients or surrogates. However, physicians should not impose their values, religious

beliefs, fears, tolerance of pain, or ultimate definition of quality life on the patient. The patient and family should make a highly informed decision as to what course of therapy is desired, within the range of reasonable treatments outlined by the physician, with the option to reevaluate and change.

If the physician perceives that the patient or family are making a poor choice based upon their lack of understanding of the likely outcome of therapy, every effort should be made to better advise the patient or surrogate, short of passing judgment on the individual's values. Once it is clear that the patient or surrogate is well informed, every effort should be made to support the decision that is made. Both patients and families tend to feel guilty about such choices, no matter what is chosen, since a choice of one course of therapy necessarily deprives the patient of another and outcomes are never certain. It is the physician's cardinal responsibility to reassure the patient and family that the choice, once made, is the best and most ethical choice for that individual, since it is based upon unique, personal values.

When inevitable conflicts still occur, physicians should learn to assess *why* when a patient wants a treatment that is thought to be futile by the physician. Is it misunderstanding, disbelief, denial, mistrust of the doctor, or is it a difference in the patient's assessment of the value of a possible small duration or chance of survival? The physician should attempt to preserve or restore trust and establish a compromise, when possible.<sup>77</sup> All resources available should be used to resolve the conflict, including input from other physicians as well as ethical and religious consultants. Hospitals should have committees of dedicated professional individuals who are trained to assist physicians and patients when conflicts arise.<sup>78</sup>

Unresolved conflicts should be dealt with by deferring to the patient or family, by recommending that the case be turned over to another physician, or rarely by arranging transfer to another institution. The best way to deal with conflicts is to avoid them through early, continuous communication. Families should be informed of the patient's condition and expected prognosis at the earliest possible time, particularly if the prognosis is poor. When medical futility is not absolutely certain, families and patients should participate in formulating a treatment strategy that might entail aggressive therapy for a finite length of time to give the patient an opportunity to improve against the odds. It then becomes much easier to accept the fact that the chosen interventions have failed and that everything of potential benefit has been done for the patient prior to agreeing that a medically futile situation exists. Physicians must also learn to deliver the message that a particular treatment is futile without implying that such information is giving up all hope, for nothing is ever totally predictable. There is always the hope of minimum suffering and there is the therapeutic benefit of hope itself.<sup>78</sup>

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## Advance Care Planning\*

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Those associated with Project GRACE agree that all adults should be encouraged by their physician(s) and society as a whole to make clear statements, in legally acceptable documents, as to how they wish to be cared for when their health status, as reflected in their quality of life, deteriorates significantly, or if they experience a sudden cardiac arrest.

Thus, addressing end-of-life issues first and foremost requires advance planning.<sup>1, 2</sup> A scenario-specific living will (LW), which is clearly understood by the individual and his/her relatives and caretakers, from family to physicians, is an absolute necessity.<sup>3-5</sup> The following is an outline to help establish such an advance planning document.

### Recommendations for Advance Care Planning

- All information and forms related to Advance Care Planning (ACP) should be written in clear, concise English. If the individual for whom the action(s) implies does not readily comprehend English, the document should be written in the language understood by the individual and then translated into English. The document should be easily read by lay persons and, more important, understood by elderly or ill persons. Readily available trained counselors are needed to explain the forms and guide the individual in his/her decision making and finalization of the document.

- The American Medical Association and other health related organizations should lobby for a Medicare/Medicaid code and an insurance reimbursement code for counseling in ACP.

- Patients (i.e., principals) should be required to discuss the document with any close, caring family and/or their appointed surrogate before signing the document. After such discussion, the surrogate should sign and date the document. The Florida Legislature defined a surrogate as any competent adult expressly designated by a principal to make health care decisions on behalf of the principal upon the principal's incapacity.

- The documents and the planning process should be discussed with the patient's primary physician so that the patient's wishes are clear and acceptable to the physician.

- After such discussion(s), if agreeable, the primary physician should acknowledge the content and date of the document.

- If the physician does not agree with the plan(s), the patient should be informed and the reason(s) should be carefully discussed with the patient, close relatives, and any appointed surrogate. If agreement is not reached, the patient should be referred to another physician.

- It should be made clear that any person executing such a document can delete or change his/her wishes at any time. If a person does change his/her wishes, the individual must inform his/her close relative(s), surrogate(s), primary physician(s), and other care givers.

- The document should be more precise than the traditional, vague language of the current statutory LW. The 1999 Florida Legislature reaffirmed that the term "advance directive means a witnessed, written document or oral statement in which instructions are given by a principal, or in which the principal's desires are expressed concerning any aspect of the principal's health care, and includes, but is not limited to, the designation of a health care surrogate, a living will, or an anatomical gift."<sup>6</sup>

It should be noted that any advance directive made prior to October 1, 1999 (when major changes in the Florida Statutes became effective), shall be given effect as executed provided such directive was legally effective when written.

- The form should provide specific choices that a patient may make, with the opportunity to write in specific desires, including a desire to provide organ donations, as the patient sees fit.

- The LW form should be universal and should be acceptable in all 50 states. There should be a federal law guaranteeing this level of acceptance or a model act which is adopted in all states.

- The LW, stating the terms, should be easily accessible via a driver's license, voter registration card, and/or a national computer registry.

- There should be a specific requirement that LWs be posted on the medical chart in a specific location so that it is easy for medical providers and physicians to locate. The Florida Legislative statute states that "the patient's advance directive shall travel with the patient as part of the patient's medical record."

\*Project GRACE Advance Care Planning Document may be obtained by calling 813/884-3990 or toll-free number 1-877-99GRACE or [www.p-grace.org](http://www.p-grace.org).

- The LW should provide, and the Legislature should support, a waiver of any liability for any physician or any other healthcare provider who renders care or withholds care from a patient, if they reasonably believe that such action is consistent with the patient's wishes as expressed in the LW.

- There should be a penalty for refusing to follow a valid LW.

Recent substantive changes in the Florida laws should enable the wide use of ACP in guiding medical care. Pertinent changes are summarized in Table I. A flow chart for medical decisions regarding advance care planning is provided in Figure 1.

## Recommendation for a Universal Living Will

### Category I: Defines Loss of Functionality, Terminal Illness, Coma, Permanent Vegetative State

The following are examples of scenarios that apply to conditions of terminal illness. In these situations, the individual has lost the ability to communicate, dress, feed, or clean himself/herself, hold urine, go to the bathroom without assistance, is not self-ambulatory, and is unable to make appropriate decisions about daily living matters.

*Terminal illness:* Death is expected to occur even with/without medical intervention(s), or condition is irreversible, or there is no reasonable chance of recovery.

*Coma:* Refers to permanent unconscious deep sleep. There is brain damage, severe enough to render the individual unresponsive and unable to feel or communicate in any way. There is no reasonable chance for recovery by all generally accepted medical standards.

*Permanent vegetative state:* There is permanent brain damage, severe enough to render the individual unaware of self or the environment. The patient has irretrievably lost the ability to meaningfully appreciate, understand, and communicate appropriately. There is no reasonable chance for significant improvement

### Category II: Significant Diseases that Diminish Quality of Life, such as Advanced Senility, Dementia, Massive Stroke, Loss of Speech, Loss of Independence

The following scenarios apply to conditions that, while terminal, do not render the person comatose or in a permanent vegetative state. In these conditions the end of life is near but not imminent. Active intervention is unlikely to improve the length or quality of life materially. Examples of scenarios when these losses may occur are as follows:

*Severe dementia, advanced senility and/or advanced stroke with loss of ability to communicate and loss of an independent life:* In this person, brain damage has been present for a while, such as with severe Alzheimer's disease or multiple strokes. The brain damage is severe enough to make the individual lose his/her ability to recognize others, interact with them, or make

intelligent decisions. The individual is mostly confused, is totally dependent, and has irretrievably lost the qualities which characterized the individual as a person.

It is any condition with total loss of ability to communicate that renders the patient totally and permanently dependent upon others for feeding, personal hygiene, and all daily activities.

*End-stage disease:* Death is expected in the near future with or without treatment.

- Disseminated cancer not responsive to treatment
- End-stage heart or lung disease, provided heart-lung transplantation is not indicated or feasible. (End-stage heart disease when there is loss of response to maximum medical therapy and requiring repeated hospitalization over the previous 3 months); (end-stage lung disease rendering the patient chair bound and needing oxygen around the clock)

- End-stage infection such as with terminal stages of acquired immune deficiency syndrome (AIDS)

- Disseminated infection with an organism resistant to all available antimicrobials (antibiotics)

- End-stage liver disease when liver transplant is not indicated or not feasible

- End-stage kidney disease in conjunction with advanced heart, lung, or liver disease. Dialysis is either not indicated or unlikely to improve the quality or length of life or has been instituted and has not been effective

- End-stage nervous disorder with near complete total body paralysis, near total dependence with no hope for improvement.

*Advanced conditions and disease(s) that diminish the quality of life:* Advanced senility, extreme frailty, total dependence, and unbearable and unrelievable pain. These individuals are particularly susceptible to bone fractures, pneumonia, heart attacks, and strokes.

Conditions and findings that make ordinary activities of daily living impossible, such as:

- Tolerate unbearable and unrelievable pain
- Clean oneself
- Feed and hydrate oneself
- Dress oneself
- Control one's bladder and/or bowel
- Communicate and express oneself
- Ambulate independently
- Make decisions about daily living matters.

With each of the medical scenarios, the patient is given the choice whether to forego specific medical interventions including:

- Cardiopulmonary resuscitation (CPR)
- Life support measures such as assisted ventilation and dialysis, surgery, and other interventions unlikely to change the underlying medical condition
- Blood transfusion intended to treat incidental anemia
- Antibiotics aimed to treat a terminal pneumonia or a concurrent infection except for treatment designed to relieve distressing symptoms (e.g., urinary tract infection causing dysuria)
- Tube feeding and hydration.

TABLE I Guide to 1999 changes in Florida's Living Will law

| Topic  | Old law  | Chapter 99-331 new law   |
|--|--|--|
| Determining capacity of patient  | Attending physician and a consulting physician must evaluate patient | Attending physician alone may determine capacity 765.204(2)  |
| Conditions which will activate Living Will   | Terminal condition or persistent vegetative state                    | Terminal condition or end-stage condition, or persistent vegetative state 765.302  |
| Determining patient's condition  | Attending physician and consulting physician                         | Same 765.306   |
| Applicability to person who never had capacity to execute Living Will  | Not clear whether Chapter 765 could be applied                       | Procedures in Chapter 765 do not apply to persons who never had capacity to designate a health care surrogate or execute a living will—765.102(20)   |
| Requirements in the absence of a written Living Will   | No requirements specified  | Law now specifies additional requirements in the absence of a Living Will. In addition to being in a terminal condition, end-stage condition, or persistent vegetative state, the patient must be both mentally and physically incapacitated with no reasonable medical probability of recovery—765.305(2)(b)    |
| Standard prehospital Do Not Resuscitate Order (DNRO). Department of Children and Family Services (DCFS) Form No. 1896§401.45 | Applied only to emergency medical personnel                          | Now may be honored by:<br>Nursing home staff — 400.142(3)<br>Hospital emergency services personnel — 395.1041(3)(1)<br>Assisted living facility staff — 400.4255(3)<br>Home health agency staff — 400.487(7)<br>Hospice care team — 400.6095(8)<br>Providers of adult family care homes — 400.621(3)             |
| Liability shield for honoring a DNRO   | Only applied to emergency service personnel                          | Expanded to apply specifically to:<br>Nursing home staff — 400.142(3)<br>Hospital emergency services personnel — 395.1041(3)(1)<br>Assisted living facility staff — 400.4255(3)<br>Home health agency staff — 400.487(7)<br>Hospice care team — 400.6095(8)<br>Providers of adult family care homes — 400.621(3) |
| Authority of health care surrogate to authorize organ donation   | No authority   | Health care surrogate may authorize organ donation if the patient previously signed a document evidencing his or her intent to donate or indicated such intent on his or her driver's license — 732.912(2)   |
| Organ donation considered a health care decision   | Not clear  | Law specifically recognizes that the decision to make an anatomical gift is a health care decision — 765.101(5)  |
| Life-prolonging procedures include artificially providing sustenance and hydration   | Not clear, generally understood based on case law                    | Law specifically provides that artificially providing sustenance and hydration are life prolonging procedures — 765.(0)(10)  |

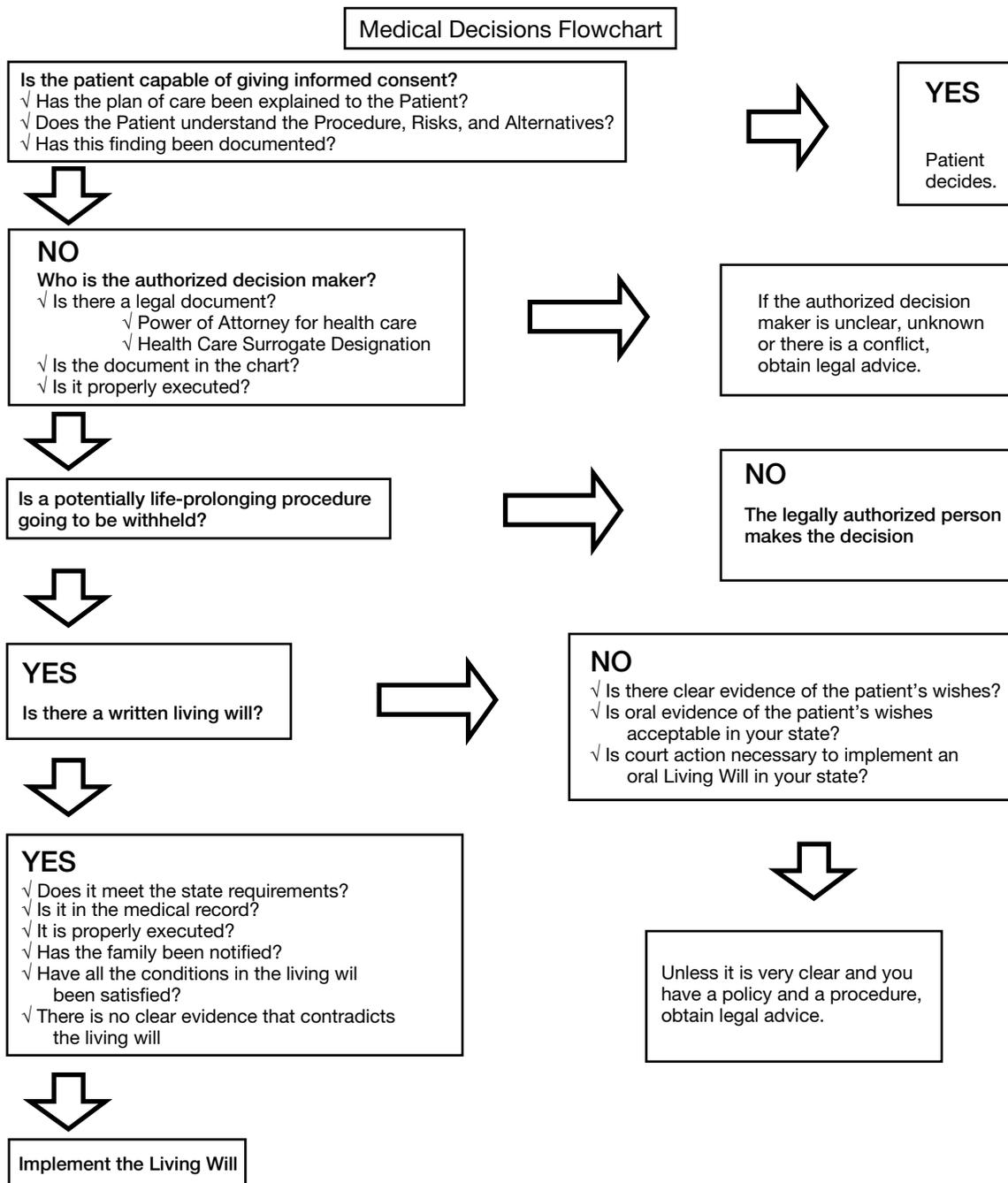


FIG. 1 A Medical Decision Flowchart to guide physicians caring for patients nearing their death. Copyright © 1999 M.D. Geldart, Esq. Reprinted with permission.

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## Palliative Care

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During the early stages of a serious illness, cure is the major goal for all concerned and treatment is generally aggressive. However, if the illness persists and cure appears unlikely, and adverse symptoms and poor quality of life become more dominant, the burden(s) of traditional medicine may appear to outweigh the benefits. This is particularly likely to be so when the therapeutic efforts that were intended to cure, produce adverse symptoms that impair the quality of life and require therapy.

Such a transition period, that is, when the major therapeutic efforts are directed from traditional curative care to symptom control, may be one of the most difficult periods of caring for a patient with life-limiting illnesses, for it is not always easy to determine an individual patient's survival probability and, therefore, to date when the transition period should begin. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) reported that both patients and professionals overestimate the likelihood of long survival.<sup>1</sup> It has been demonstrated that such prognostic optimism tends to prolong the use of potentially curative therapy despite the production of symptoms contributing to an adverse quality of life.<sup>2</sup> So it is not surprising that, as the presence of the illness and therapeutic-induced symptoms continue, the treatment goals of the patient, the goals of the patient's family, and the goals of the patient's physician(s) may diverge.

The treatment that is directed by caregivers predominantly toward the relief of suffering, psychosocial support, and the enhancement of the patient's quality of life has been classified as Palliative Care. Such care is considered indicated not just when an illness is considered terminal but for all patients with advanced chronic illness(es), whether or not they are considered to be imminently dying.

The term *hospice care* is frequently used interchangeably for palliative care. The purist knows that the older dictionaries defined hospice as only a place of rest or shelter, usually maintained by a religious order for pilgrims, travelers, etc.<sup>3</sup> However, in more recent editions of the dictionary (1988), hospice is defined as a homelike facility to provide supportive care for terminally ill patients.<sup>4</sup> The word is still classified as only a noun. Reference to hospice care, where hospice is used as an adjective, is even more recent.

While a number of definitions for palliative care exist, the one developed by the Last Acts Campaign's Task Force on Palliative Care, sponsored by the Robert Wood Johnson Foundation,<sup>5</sup> is considered most timely and inclusive:

“Palliative care refers to the comprehensive management of physical, social, spiritual, and existential needs of patients, in particular those with incurable, progressive illnesses. Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family. The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms, and restoration of functional capacity while remaining sensitive to personal, cultural and religious values, beliefs, and practices.”

The intensity and range of palliative interventions may increase as illness progresses and the complexity of care and needs of the patients and their families increase. The priority of care frequently shifts, as an illness progresses, from curative goals to focus on end-of-life decision making and care that supports comfort and is consistent with the values and expressed desires of the patient.

As with any choice in health care, there exist multiple potential decisions. For the decision to transit to palliative care, the primary decision makers may be the patient, or family members, or attending and/or referring physician, or occasionally even impersonal reimbursement entities such as Medicare, Medicaid, and contracting health plans. The decision to enter into palliative care can occur in a variety of settings such as emergency departments, intensive care units, research centers, HMOs, physician offices, nursing homes (NH), assisted living facilities (ALF), and/or patient homes.

A formalized hospice program is an attractive option for many persons desiring traditional curative care. However, patients who are averse to the word hospice, or who are reluctant to sign forms that redefine their insurance benefits, or who have difficulty acknowledging that they are facing the terminal stages of a disease, should ideally be able to receive palliative services under the guidance and with the support of their physician.<sup>6</sup> However, physician referral to or initiation of palliative care will depend on the physician's knowledge level, values, beliefs, and the availability of community resources.

For the best preparation of patients and families, physically, emotionally, and spiritually, and to assure the highest possible quality of life, it is imperative that discussions regarding palliative care begin earlier in the disease trajectory than typically occurs. The unpredictability of the outcomes of patients with

chronic diseases substantiates the need(s) to begin discussions of treatment options soon after diagnoses.<sup>7</sup>

As a result of an earlier introduction of palliative interventions, in place of the compulsive continuation of traditional care, quality of life may be enhanced and costs may be reduced. A 1995 study by U.S. Healthcare demonstrated that a Congestive Heart Failure Disease Management Program, which provided palliative care to 209 members, positively impacted multiple outcomes for patients and the provider.<sup>8</sup> The program included a case manager, home visits and educational instruction by a nurse, parenteral medication at home (if necessary), 1-year follow-up, and tracking of outcomes.

Much of the discussion on increasing care options for dying persons has focused on physician-assisted suicide. Indeed, the U.S. Supreme Court's consideration of the legality of physician-assisted suicide in 1997, the passage of Oregon's *Death with Dignity Act* which permits physician-assisted suicide, and the recent second-degree murder conviction of Jack Kevorkian has made physician-assisted suicide a more familiar concept than palliative care.<sup>9</sup>

From the limited data available, the factors most commonly involved in requests for assistance in dying are concerns about future loss of control and being a burden to family members as well as a fear of severe pain.<sup>9</sup> Studies asking terminally ill cancer patients and patients with acquired immune deficiency syndrome (AIDS) about their desire for death revealed that such desires are closely associated with depression, pain, and lack of social support.<sup>10-12</sup> Comprehensive palliative care not only manages the physical symptoms of the dying patient, but also helps patients and families deal with the social, psychological, and spiritual aspects of death and dying. Advocates for the legalization of physician-assisted suicide believe that if expert palliative care were available to everyone who needed it, there would be few requests for physician-assisted suicide.<sup>13</sup>

The terms *physician-assisted suicide* and *euthanasia* are widely used, sometimes interchangeably, but crucial conceptual and behavioral differences distinguish the two actions.<sup>14</sup> Both assisted suicide and voluntary active euthanasia are instances of assistance in bringing about the death of another person. In cases of assisted suicide, the person who dies causes his/her own death with the assistance of another person (e.g., another person provides lethal medication for the patient to take him/herself); whereas in cases of voluntary active euthanasia, the person dies because of the direct actions of another person (e.g., death is caused by lethal injection or excessive oral medication).

At present, with the exception of the state of Oregon and despite ongoing efforts at legislative reform in several states, physician-assisted suicide and voluntary active euthanasia are illegal in the United States. Unlike the right to assistance in committing suicide, the right to refuse or to withdraw from medical treatment, even at the risk of causing one's death, is protected by the Fourteenth Amendment's Due Process clause. Furthermore, the right to refuse life-sustaining medical treatment is supported by case precedent (e.g., in *re* Quinlan,<sup>15</sup> *Bouvia v. Superior Court*,<sup>16</sup> *Cruzan v. Director*<sup>17</sup>) and the common laws of most states. Patients [or their duly appointed sur-

rogate(s)] who refuse or discontinue life-sustaining treatment are not seen as committing suicide/(murder), but rather as dying/(accepting death) due to the underlying disease. Physicians who honor their patients' wishes to forego life-sustaining treatment are similarly not seen as assisting in their deaths.

Physicians who care for dying patients may use available pharmacologic tools with the knowledge that they may hasten the time of death. While the physician's primary intent is to relieve the patient's suffering, some medications used for pain management may suppress respiratory function, and as a secondary consequence, or double effect, may hasten the time of death. However, this is a very rare event in the hands of an experienced palliative care physician administering pain medication in accordance with established protocols.<sup>18-22</sup>

Both the courts and the majority of medical professionals endorse increasing access to palliative care, not assisted suicide, as a compassionate and appropriate response to dying persons. The U.S. Supreme Court acknowledged that its refusal to legalize physician-assisted suicide was based in part on the availability of palliative care and encouraged the development of more effective and available palliative care alternatives for dying patients. In fact, the U.S. Supreme Court's ruling may be interpreted as outlining a right to palliative care and a directive to remove institutional barriers to appropriate care at the end of life.<sup>23</sup>

A recent Gallup poll, however, reported that when asked if terminally ill with 6 months or less to live, 9 of 10 adults would prefer to be cared for at home.<sup>24</sup> Nationally, however, nearly 1 of 5 older persons die in NHs<sup>25</sup> with many more dying in hospitals after becoming institutionalized.<sup>26</sup> Of all NH patients, 26% die in hospitals, unless hospice is involved in the NH, then reducing hospital deaths to 1%.

Recognizing that not all people can live and die in one place, health care providers must also be responsible for providing a seamless transition from one level of care to another. Most people do not remain in one location during their last years of life. Regardless of their goal, illness may force them to seek interventions at different institutions of care, such as a hospital, rehabilitation center, skilled nursing facility, or an ALF. While this may be inevitable, the ability for healthcare providers to provide a seamless transition may greatly reduce the ramifications of health problems.<sup>27</sup>

Health care providers historically are poor communicators. This is complicated by the fact that most patients assume that all their health care providers have conferred. However, this is generally not the case and no one, including the patient, assumes responsibility for sharing all pertinent medical history with all the providers. This lack of relevant patient-related data often leads to duplication of services. Another issue encountered is the need to rewrite advance directives and other documents at every level of care. A case manager who follows the individual through the multiple levels of care may limit some of these problems.

All palliative care services need to provide continuity of health care, even between different levels of care. The site of care may not always be a choice that the patient and even the caregiver can control; however, health care providers can min-

imize the negative impact of changing the care site by providing a seamless transition model.

Despite increased societal concern about end-of-life issues, there is no clear indication that care for most patients with chronic illnesses has improved. Increased attention has been given to hospice and palliative medical education; however, in practice, the majority of health professionals have received only sporadic training in the principles and practice of caring for patients with advanced life-limiting illnesses.<sup>28</sup>

In the United States, medical conferences devote minimal time to palliative medicine, and only 5 of 126 medical schools surveyed in 1994 offered a separate course on end-of-life care.<sup>29</sup> The lack of more current data probably bespeaks to the lack of attention directed to such programs by the academic community. Many physicians, nurses, and students acknowledge a lack of skill and confidence in the area of palliative medicine and indicate a desire for more education and training on symptom control and the management of psychosocial and spiritual concerns. Very few continuing education courses in end-of-life or palliative care are conducted for physicians and nurses in practice.

The three medical colleges (University of Florida, University of Miami, University of South Florida) and one osteopathic (Nova University) college in Florida were surveyed about their end-of-life or palliative care education curriculum. In addition, four Florida Colleges of Nursing (Barry University, Florida State University, University of Florida, University of South Florida) were surveyed to determine similar information about their curriculum.

Results of the survey revealed no standardization of education in end-of-life care or palliative care. Medical schools and nursing schools are primarily teaching end-of-life issues in ethics courses, but they offer little clinical instruction in the treatment of patients from a palliative care approach. There was, however, strong interest by individuals in all three medical schools to include additional palliative care education in the curriculum, either at the undergraduate or postgraduate level. Current end-of-life care or palliative care education in the medical schools is primarily possible because of grants (funded by The Robert Wood Johnson Foundation, The Veterans Administration, and The National Cancer Institute) that are time limited and based on available funding opportunities. While there appears to be no standard education, changes in curriculum are being seen; however, it is unclear whether there will be permanent changes, once temporary funding ends.

If the public in general is expected to increase their acknowledgment and acceptance of end-of-life and palliative care, there needs to be acceptance by the health care community that end-of-life and palliative care are integral parts of the health care continuum. This will require uniform education for changes in attitudes, knowledge, and skills of health care professionals in end-of-life and palliative care.

Although one would think that palliative care, as it is typically practiced, is less expensive than conventional medical care, there is little evidence to support this presumption.<sup>30</sup> If one equates palliative care with hospice care and examines the Medicare data,<sup>31, 32</sup> the cost benefits that are seen in the last

few months of life diminish the further from death patients may be.<sup>33-35</sup>

No reports have documented that high-quality palliative care is more expensive than conventional care.<sup>36</sup> According to the U.S. Supreme Court, high-quality palliative care is a right.<sup>37</sup> The cost effectiveness of this form of care should be presented, at least, as not being a financial deterrent to incorporating it into mainstream medicine.

Currently, there is no defined reimbursement plan for palliative care. Palliative care is practiced by a number of physicians and other health care providers in a variety of settings under existing reimbursement models.<sup>38, 39</sup> This is not an ideal situation but it does permit some reimbursement for those involved in palliative care.

Many physicians practice a modified form of palliative care (single-team member with a predominantly medical focus), but are unable to include other disciplines because of the lack of a reimbursement mechanism. The current Evaluation & Management (E&M) codes that physicians use for billing focus on procedures and activities and do not generally recognize time spent, thus the code limits the ability to bill for palliative care services through established mechanisms.<sup>40</sup>

Inpatient palliative care is often provided through the Medicare Hospice Benefits (MHB) inpatient benefit. This has the limitations mentioned previously and other limitations imposed by the inpatient benefit itself; but it is a solution for acute palliative interventions for the small number of terminal patients where inpatient units or contracts exist.

Patients receiving palliative care outside of hospice programs experience many of the same previously cited problems. Obviously, demonstration of cost effectiveness will drive the development of palliative care within Medicare HMOs in a positive direction. In addition, demonstration of good quality outcomes with neutral dollar impact will move this system forward. The use of palliative care should demonstrate both of these, but data are needed. Until this occurs, Medicare HMO patients will have a more difficult time receiving any form of home health care and are unlikely to see any funding of the other disciplines important to high-quality interdisciplinary palliative care.

As palliative care health services are instituted, attention must be directed toward determining the impact of the illness on the lives of the members of the involved family and the influence of the family's response to the illness on the outcome of the patient experiencing the illness. Illness, long-term care, and death are family affairs. The manner in which each person is cared for will influence the cooperation of the members of the family, and ultimately how each member grieves and is able to continue living. Health care providers must recognize diversity in families in terms of ethics, religion, cultural norms, social support systems, financial strata, and health care expectations.

In considering family membership, it is important to recognize, among others, the status of homosexual partners, common-law arrangements, homeless patients, single-parent households, the young single patients, the widowed, and the aged who have never married.

Another societal factor affecting the provision of palliative care is the consideration of whether one lives in close proximity to others or in isolation. The physical provision of care changes with the resident's location. A recent survey in the United States revealed that over 55% of our population lives alone.<sup>41</sup> The isolated resident is more likely to receive health care at a distance from his/her home, and providers need to recognize themselves as strangers to this type of family system.

Caregivers must recognize the word *family* as all encompassing. Those members identified and recognized by the patient will be helpful in identifying the patient's support system; however, that may not include the total membership. Infirm members, who are chronically ill, often consider their closest neighbor, friend, or nursing caretaker more as family than their own blood relatives. The ill patient may have made the decision to receive palliative versus curative care, but the distant family members may not accept or agree with the decision.

To prevent worry, or to spare adult children the expense of frequent trips from work and home duties, the patient may not contact the family at the time of diagnosis, nor during the treatment process. Adult children may question the wisdom of the aged parent and his/her health care providers, even when recognizing their inability to care for the dying in their locale. Even those family members who are totally supportive of the decisions of the patient and health care providers may experience a sense of denial, guilt, shame, and remorse with the thoughts that they should have been more involved earlier.

The number of barriers in the family will increase or decrease depending on the openness of the communications between members, the relationships of the dying member to his/her family, and the trust and honesty with which they have lived. In a closed secretive communication system, lack of knowledge is a barrier and becomes evident concerning not only palliative care but all end-of-life decision making, such as the selected person for health care surrogate, living wills, expenses, desires for particular funeral rites, place of burial, and estate settlements. There are some patients who are unable to speak to their loved ones about dying. There are families who maintain denial, unable to acknowledge the closeness of death of a loved family member.

It takes tremendous energy, effort, and time to care for an ill patient in a home setting. The demands on the caregiver are enormous. Age and/or physical limitations of the caregiver can become a barrier to providing palliative care. However, the caregiver may resist respite care because of feeling guilty that he/she cannot meet the expectations of the patient, health professionals, and family. Those responsible for the palliative care must be concerned not only for the care of the patient but also the ability of the individual caregiver(s) to meet the expected needs for care without causing an adverse personal effect.

There is much that can and must be done by health care providers and society at large to foster palliative care for those with chronic, frequently debilitating conditions. Recommendations<sup>46-48</sup> to attain these goals will be articulated in the chapter to follow.

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## Summary of Task Forces I, II, and III, and Report of Task Force IV Education & Implementation

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### Background

In 1998, after years of discussion, the Florida Chapter of the American College of Cardiology (FCACC) launched Project GRACE for the purpose of developing Guidelines for Resuscitation And Care near the End-of life for our society. It is hoped that these guidelines will be implemented throughout the state of Florida and possibly eventually even throughout the nation.

The guidelines evolved as a result of the dedicated efforts of volunteers organized into Task Forces, who reviewed the appropriate literature, consulted with academic and community leaders, and, after much discussion, consolidated their opinions and recommendations in four Task Forces on major subject-matter areas. These are: Medical Futility, Advance Care Planning, Palliative Care, and Education/Implementation.

The members of Task Force I emphasized that despite difficulties of predicting the time of death or its certainty beyond doubt, medical knowledge now exists that permits prediction of a fatal outcome or medical futility (where life is functionally meaningless) with a high degree of probability. The possibility exists that young people may be involved in accidents or catastrophic illnesses that impair their ability to make rational decisions about their health. And since people are living longer, they are likely to confront health decline and situations in which additional health care may be superfluous or undesirable, or where they are physically or mentally incompetent to make a health care decision. Hence, all individuals should be advised to make legal preparation for end-of-life situations through an Advance Care Plan (ACP)/Living Will (LW). Further, since the individual may at some future date lack the physical or mental ability to make a rational decision, he or she should select in advance a surrogate empowered to act in the individual's best interest in such a situation. Such preparation can protect the individual from undesired and futile therapy and can relieve his or her family from the difficulties of making decisions about limiting or withdrawing care.

Elderly patients often choose to forego aggressive interventions, reasoning that they have lived a long life, have accomplished their goals, have come to terms with death which, although not imminent, may be around the corner, and prefer to make a graceful exit. Such individuals should have the right to request any or all limits to cardiopulmonary resuscitation

(CPR) and life support measures, and establish a Do Not Attempt Resuscitation (DNAR) order. Furthermore, they may prefer nonaggressive management for such illnesses as heart attacks, cancer, and even pneumonia. There is an urgent need to develop legal and social mechanisms for respecting and fulfilling end-of-life choices of these individuals.

Each person is aware of cases where patients have been kept alive for days or weeks when death was certain. When the patient's prognosis is poor and the expected outcome from any medical treatment is likely to be useless or even harmful to the individual, medical futility applies. The physician will use the patient's diagnoses, together with knowledge of the severity of the illness and other individual patient characteristics, to assess the situation and answer three questions:

1. Is death imminent?
2. What is the best possible outcome or recovery that can be hoped for if treatment is maximally beneficial?
3. What is the probability of achieving the best possible result, or at least a good result?

If the answers to these questions point to a medically futile situation, the patient should be managed accordingly.

Task Force II focused on the form and content of the ideal ACP or LW. Although a number of forms are available, it was agreed that none is ideal and that an effort should be made to develop an ideal form. Consideration should be given in that form by the patient to making an anatomic gift of one or more organs after death.

Task Force III noted that Palliative Care is compassionate care that provides psychosocial support of a person with an incurable disease or significant functional limitations. Illness, as well as long-term care and death, are family affairs. Each family cares for their identified patient in a way indicative of their values and beliefs; and the manner in which each person is cared for will influence the cooperation of the family and ultimately how the family grieves and is able to continue living. Health care providers must recognize diversity in families with regard to ethics, religion, cultural norms, social support systems, financial means, and health care expectations, along with other variables.

Florida's varied population offers a challenge to appropriate and even-handed health care discussions. Florida is a state of transients, of tourists, of snow-bunnies here for half a year, singles such as students, divorces/divorcees, single parents, the widowed, and retirees beginning a new lifestyle. The cli-

mate and relatively low taxes attract migrants from northern states and Europe, while geography and a good economy invite immigrants from the Caribbean and Latin America. The result is a multicultural population of diverse ages, economic status, educational levels, marital status, religion, race, and social attitudes.

An example of diversity appears in statistics of deaths each year in Florida's counties, with counties that attract elderly people reporting many more deaths per 1,000 residents. For 1997, even among adjoining counties in the Gulf Coast of Florida, large differences occurred:

| County              | Deaths per 1,000 population |
|---------------------|-----------------------------|
| Hillsborough        | 8.5                         |
| Pinellas            | 14.2                        |
| Polk                | 10.5                        |
| Pasco               | 15.7                        |
| Hernando            | 15.2                        |
| Average for Florida | 10.4                        |

It is evident that to improve palliative care, some areas of the State will require more educational programs than others. Furthermore, the diversity of the State's population indicates that no single standardized program will meet the needs of all residents.

It is a truism to state that the traditional family in America no longer exists. Families move many times and members of many nuclear families live many miles apart. Care must frequently be delivered to homosexual partners, common-law arrangements, single-parent households, young singles, the widowed, the aged who have never married, and the homeless. A frequent occurrence in Florida is the couple who moved from a distance to Florida to retire, then within a year one partner dies leaving a new widow or widower with little connection to the community. A recent survey of the United States reported that over 55% of the population live alone.

It is often difficult for the caregiver to identify the person who serves as part of the family support system. Often the patient who is chronically ill considers the closest neighbor, friend, or nursing caregiver as more of a family than his or her own blood relatives.

Communications with the physician may also be strained where family members lack medical knowledge, do not understand the situation(s), and do not know what questions to ask. They may call the physician at inopportune times and find the response unsatisfactory.

Unfortunately, some physicians lack the knowledge of how to communicate openly with the patient and family. In other cases, they may follow the tradition of guarding the privacy of medical information. Physicians and other healthcare personnel need to communicate what palliative care means and explain the efforts being made to provide comfort and pain relief for the patient. Acceptance of the person identified as caregiver by the patient and family is crucial. The role carries responsibilities, for the caregiver is an influential decision-maker.

Although actions taken by the caregiver may not always be approved by the family, good communications are essential.

Task Force III concluded that it was essential to:

1. Establish a standard educational program of palliative care for physicians, nurses, health care administrators, social workers, pharmacists, and all other health care providers. This basic course should be required in every medical, nursing, seminary, pharmacy, and social work school in the State. The course should address the problems and goals identified in this report.
2. Offer additional courses in each category of health care, such as pain management for physicians, pharmacists, and nurses; social variants for social workers; spiritual care for clergy, and so forth. These courses should be offered as continuing education at seminars, conferences, and educational institutions. Courses on palliative care should be included in programs of continuing education taken each year by thousands of elderly citizens throughout Florida.
3. Use professional magazines in each health care discipline to provide information on palliative care and incorporate educational programs for credit for Continuing Education Unit(s).
4. Develop a single medical record and a case management model that can follow patients through an entire illness.
5. Develop disease-specific protocols to advise clinicians of timely and appropriate transition options to palliative care and support research analyzing quality of life and cost benefits of palliative care.

## Conclusions

It is obvious that the problems discussed earlier require changes in practice, attitudes, and ways of communicating that can be achieved only through additional and improved education. Not only do new courses on end-of-life treatment and palliative care need to be provided and required for physicians and health care providers, but public education through a variety of means needs to be extended. Furthermore, the education of students in medical and other health care schools must emphasize the importance of recognizing medical futility and the importance of palliative and patient participation in their care through ACPs.

We believe, that as a result of the input of all participants of Project GRACE, the following goals should be sought by all wishing to assist our citizens to attain a graceful exit.

1. Seek required courses in medical and nursing schools on medical futility, palliative care, the role and observance of ACPs, including LWs, powers of surrogate, and Do Not Attempt Resuscitation (DNAR). Continuing education courses in these subjects must be provided for health care professionals currently practicing.
2. Promote public information by the Florida media and by private groups, for example, American Bar Association, American Medical Association, American Association of Retired Persons, and others, on ACPs, and encourage assistance to the elderly in completing the required forms.

3. Make available information and forms on ACPs in doctors' offices and hospices, where assistance to patients in filling out the forms can be provided.
4. Promote communication between patient, physician, and other health care providers on the existence and significance of ACPs.
5. Support state legislation that clearly defines an LW and other ACPs, promotes standard forms, outlines responsibility of a surrogate, enhances communications between patients, physicians, and health care providers with regard to ACPs.
6. Seek state issuance of a wallet-sized card for individuals indicating the existence of an ACP, including DNAR, identi-

ty of surrogate, also the development of a state web site where such ACPs can be accessed.

7. Advocate creation of a national registry of ACPs and a national (or international) web site where they can be accessed.

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