Journal of Dispute Resolution

Volume 1996 | Issue 1

Article 11

1996

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Recommended Citation

Karen A. Butler, Harvesters: Alternatives to Judicial Intervention in Medical Treatment Decisions, 1996 J. Disp. Resol. (1996)

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Harvesters: Alternatives to Judicial Intervention in Medical Treatment Decisions

Karen A. Butler

I. Introduction

The tragic scene is played out in critical care units across the country: a loved one suffers a tragic stroke; a young mother sustains a devastating head injury in a motor vehicle accident; an infant is born with part of a brain. These scenes result in various approaches: the family wants nothing done, the doctor wants to pull out all the stops; the doctor wants to let the person go and the family wants "everything" done; the family and the physician agree to let Dad die with dignity only to have a hospital administrator intervene.

The twentieth century has seen an explosion in medical technology.¹ One need no longer breath to receive oxygen; one need no longer eat to receive sustenance; one need no longer think to be "alive".² With this technology has come fear.³ People fear a life in limbo, kept alive by machine, unable to interact with our environment, nearly as much or more so than people fear death itself.⁴

The United States Supreme Court has recognized the right of a competent, non-pregnant adult to refuse life sustaining treatment. Unfortunately, when the time comes to make these decisions, many people lack the capacity to do so. It is in this situation that many families and/or physicians turn to the courts for help.

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^{1.} Linda C. Fentiman, Privacy and Personhood Revisited: A Framework for Substitute Decisionmaking for the Incompetent, Incurably Ill Adult, 57 GEO. WASH. L. REV. 801, 802 (1989); Support Principal Investigators, A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients, 274 JAMA 1591 (1995) (hereinaster "Support").

^{2.} David K. P. Lee, M.D. et al., Withdrawing Care: Experience in a Medical Intensive Care Unit, 271 JAMA 1358, 1359 (1994).

^{3.} Fentiman, supra note 1, at 802, 804. See also Support, supra note 1, at 1591.

^{4.} Id.

^{5.} Cruzan v. Missouri Dep't. of Health, 497 U.S. 261, 278 (1990). "[A] competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment. . . ." Id. But see Alicia Ouellette, Comment, New Medical Technology: A Chance to Reexamine Court-Ordered Medical Procedures During Pregnancy, 57 Alb. L. Rev. 927, 953 (1994) (discussing the compromise of the constitutionally protected rights of pregnant women to refuse even major surgical procedures which may benefit the fetus).

^{6.} Fentiman, supra note 1, at 803.

^{7.} Id. at 828.

In the past, judicial intervention in decisions to withdraw life support and/or withhold treatment for an incompetent patient was virtually unknown. These decisions were made privately, by the patient's family and physician. Although to a large extent the same is true today, in the past twenty-five years more physicians and families have sought judicial intervention when conflicts arise concerning the treatment decisions for an incompetent patient. It is difficult to imagine a more personal and heart wrenching decision than allowing a loved one to die. Yet not only is judicial intervention cumbersome, expensive, and time consuming, it intrudes into the lives of patients and their families during a particularly emotional and upsetting time. In addition, few judges possess the clinical expertise to decide issues involving complex medical data. Similarly, judges are not familiar with the patient's values, goals, preferences or religious beliefs. Clearly, the courtroom is the least desirable forum for determining these issues.

Various models of dispute resolution have been proposed as alternatives to judicial intervention in making medical decisions for the incompetent adult. 16 These models include forms of mediation as well as arbitration utilizing ethics committees and/or ethical consultants. 17 This article will examine the problem of making medical decisions for those who cannot decide for themselves. Current models of decision making will be examined as well as various proposals for alternative dispute resolution. A proposed New York model will be examined in detail. As America enters the twenty-first century, it is imperative that its citizens formulate mechanisms of dispute resolution that protect the rights of the incompetent patients to dignity and autonomy when such persons are seriously ill and unable to decide for themselves. Alternative forms of dispute resolution may be superior to judicial intervention in meeting the needs of these persons.

^{8.} Id.

^{9.} Id. at 807.

^{10.} Id.

^{11.} Michele Yuen, Comment, Letting Daddy Die: Adopting New Standards for Surrogate Decisionmaking, 39 UCLA L. REV. 581, 582 (1992).

^{12.} In re Jobes, 529 A.2d 434, 449 (N.J. 1987).

^{13.} Yuen, supra note 11, at 605.

^{14.} *Id.*

^{15.} Id. at 610.

^{16.} In re Quinlan, 355 A.2d 647, 668 (N.J. 1976) (discussing ethics committees); Jobes, 529 A.2d at 463 (discussing ethics committees); John LaPuma, M.D. & Stephen E. Toulmin, Ethics Consultants and Ethics Committees, 149 ARCHIVES INTERNAL MED. 1109 (1989) (comparing ethics committees and consultants and suggesting that consultants should mediate disputes while committees should promulgate institutional policy); Yuen, supra note 11, at 627 (proposing arbitration to resolve disputes regarding medical decision making); Fentiman, supra note 1, at 841 (proposing a mediation model of dispute resolution to resolve these disputes).

^{17.} See supra note 16.

II. THE PROBLEM

A. Medical Intervention

Death comes to everyone. To a few, it comes suddenly and completely unexpectedly, but to most, it follows an opportunity for leave-taking and for directing, to some extent, the mode and timing of death. Virtually all people who die in this country will have been under treatment by health care professionals who have, especially in the last four decades, developed powerful means to forestall death. This power is so dramatic that sometimes it seems that medicine aims first and foremost to Physicians realize, of course, that the mission of conquer death. vanquishing death is finally futile, but often they and their patients are quite determined to do all that is possible to postpone the event. Sometimes this objective so dominates care that patients undergo therapies whose effects do not actually advance their own goals and values. Specifically, the drive to sustain life can conflict with another fundamental (and arguably more venerable) objective of medicine -- the relief of suffering. Physicians and others who establish health care policies and practices have come to realize that the attempt to postpone death should at times yield to other more important goals of patients. 18

Americans have developed into a complex, technologically advanced society. 19 Nowhere is the complexity of human existence or the pervasiveness of technology into everyday lives as evident as in medicine. 20 Medical procedures and equipment can work modern day miracles to snatch, at least temporarily, the dying from the jaws of death. 21 However, modern technology often serves not to prolong life, but only to prolong death. Death may be held at bay by a dizzying array of medical weaponry including ventilators, dialysis machines, drugs, transplants, artificial hydration and artificial nutrition. 22 This raises an image of life in limbo, neither dead nor capable of interacting with one's environment 23

^{18.} President's Comm'n for the Study of Ethical Problems in Medicine & Biomedical & Behavioral Research, Deciding to Forego Life-Sustaining Treatment 15-16 (1983) (hereinafter Comm'n Report).

^{19.} Fentiman, supra note 1, at 801.

^{20.} Id. at 802.

^{21.} Id.

^{22.} Id.

^{23.} Id. In 1986 it was estimated that five to ten thousand persons in the United States "lived" in a persistent vegetative (permanently unconscious) state. Lynne Sims-Taylor, Reasoned Compassion in a More Humane Forum: A Proposal to Use ADR to Resolve Medical Treatment Decisions, 9 OHIO ST. J. ON DISP. RESOL. 333 n.213 (1994).

The decision to accept or forego medical treatment is a deeply personal one based on a person's own religious, ethical, and philosophical values.²⁴ In a recent survey, eighty-four percent of Americans stated that they would want life support withdrawn if there was no hope of survival.²⁵ However, decisions regarding any medical intervention are always contextual.²⁶ Healthy persons frequently express the feeling that they would not want to live with a severe disability.²⁷ However, when faced with a disabling illness or injury, people will often accept even the most aggressive treatment, frequently going on to lead productive and rewarding lives.²⁸ What appears to be an intolerable burden to a healthy person may seem like a reasonable accommodation to a disabled individual.²⁹

For instance, consider the case of Stephen Hawking, the renown physicist and Cambridge's Lucasian Chair of Mathematics.³⁰ Hawking, forty-nine, is afflicted with amyotrophic lateral sclerosis ("ALS") or Lou Gehrig's disease, an incurable disease of the central nervous system that has rendered him paralyzed, wheelchair bound and unable to communicate without the help of a computerized synthesizer.³¹ However, Mr. Hawking credits his disability with focusing his energies on theoretical physics and allowing him to develop the science of cosmology, the study of the nature of the universe and the unity of space and time.³² With the help of medical technology, Stephen Hawking has contributed to our knowledge of the universe and of ourselves and continues to be a source of inspiration for the disabled.

B. The Right to Choose

Nonpregnant adults, with capacity, have a firmly established right to accept or reject medical treatment.³³ "[E]very individual of sound mind and adult years

^{24.} NEW YORK STATE TASK FORCE ON LIFE AND THE LAW, WHEN OTHERS MUST CHOOSE: DECIDING FOR PATIENTS WITHOUT CAPACITY 47 (1992) (hereinafter "TASK FORCE").

^{25.} Sims-Taylor, supra, note 23, at 333.

^{26.} Yuen, supra note 11, at 607.

^{27.} Id.

^{28.} Id.

^{29.} Id. See also Marion Danis et al., Patients' and Families' Preferences for Medical Intensive Care, 260 JAMA 797, 799 (1988) (stating seventy-four percent of patients treated in ICU would repeat the experience even if it meant only one more month of life).

^{30.} Stephen Hawking, Is the End in Sight for Theoretical Physics, in BLACK HOLES AND BABY UNIVERSES AND OTHER ESSAYS 49 (1993).

^{31.} Id. at 25.

^{32.} Id. at 22-23.

^{33.} Cruzan, 497 U.S. at 278. (stating that the right to refuse treatment is a Fourteenth Amendment liberty interest). However, the rights of pregnant women to refuse even invasive procedures is far from absolute. See Ouellette, supra note 5, for a discussion of the rights of women to refuse treatment intended to benefit the fetus. A full discussion of this issue is beyond the scope of this article.

has a right to determine what should be done with his own body "34 People have the right to refuse even life-saving treatments that are minimally invasive and which pose negligible risk. 35 Patients' right to determine their own medical treatment prevails over the state's interests in preserving life, preventing suicide, protecting third persons (for example, dependent children) and preserving the integrity of the medical profession. 36 Problems arise, however, when patients are without the capacity to make these treatment decisions for themselves.

C. Medical Decisions for Patients Without Capacity

The determination of patient "incapacity" - i.e., the patient's inability to make an informed decision about healthcare - has critical implications. Patients with capacity have the right to control the course of their medical treatment. Patient's who lack capacity cannot exercise this authority. Their decision-making rights exist only to the extent that others are obligated to honor their previously expressed wishes.³⁷

At the patient's bedside, the physician usually determines if the patient has the capacity to consent to treatment.³⁸ The physician often turns to the patient's family for assistance in determining health care issues.³⁹ As long as the patient voices no objection, no judicial determination of incapacity is necessary.⁴⁰ Only a judicial determination of incapacity can remove the patient's right to object to medical treatment.⁴¹

The problems arise when patients, without capacity, require treatment that, for some reason, the doctor or family believes they might have refused if they had capacity. States have enacted legislation permitting patients to retain some control over health care decisions after they have lost the capacity to do so.⁴² These advance directives fall generally into two types of instruments; the "living will" and the "health care proxy."

^{34.} Schloendorff v. Society of New York Hosp., 105 N.E. 92, 93 (1914).

^{35.} The Court in *Cruzan* made no distinction between artificial nutrition and hydration and other more invasive or heroic medical procedures. *Cruzan*, 497 U.S. at 261. *See also* In re Convoy, 486 A.2d 1209, 1236 (N.J. 1985) (nutrition and hydration no different from more aggressive treatments); Fosmire v. Nicoleau, 75 N.Y.2d 218 (N.Y. 1990) (patient had the right to refuse blood transfusions even though to do so could cause her death).

^{36.} TASK FORCE, supra note 24, at 25.

^{37.} Id. at 27-28.

^{38.} Id. "Capacity" is a limited and specific determination that a person lacks the ability to make a particular decision at a particular point in time. Id. at 83. Conversely, "competence" is a broader, judicial determination, that a person lacks the ability to make all decisions for himself. Id. A detailed discussion of the standards to determine "capacity" and/or "competence" is beyond the scope of this article. See id. at 83-92 for a detailed discussion of the tests for competency and capacity.

^{39.} Id.

^{40.} Id. at 28.

^{41.} *Id*.

^{42.} Id. at 29.

1. Living Wills

Living wills were originally proposed by Doctor Louis Kutner in the 1960's and were popularized by such groups as the Society for the Right to Die. 43 Thirty-eight states have enacted living will statutes. 44 A typical statute allows competent adults to execute a document, witnessed by two disinterested persons, which provides that, should the person become incapacitated and incurably, terminally ill sustained only by "life support," they wish to receive no medical treatment. 45 Potential patients can specify exactly what treatments they wish to receive and what treatment they do not want. 46

Living wills have been criticized as inadequate to achieve the goal of personal autonomy in medical decision making.⁴⁷ A person may be "incurably" ill without being "terminally" ill (i.e., a person in a persistent vegetative state).⁴⁸ Many statutes hold that the living will is not effective unless the person is terminally ill, death is imminent, or the document is drafted in vague terms such as "life-sustaining" treatments. In addition, living wills are specific and inflexible.⁴⁹ A person executing a living will cannot possibly predict the circumstances in which these decisions will be made or which decisions will be perfectly reasonable or which absurd.⁵⁰ These decisions will be largely contextual, depending on the type of treatment, illness and incompetency involved.⁵¹ For this reason, many states have instead legislated the designation of a health care proxy to make decisions for a patient that has become incapacitated.⁵²

2. Health Care Proxy

Thirteen states, including New York, have enacted statutes allowing people to designate surrogate decisionmakers in the event they become incapacitated. ⁵³ The designated person makes health care decisions in accordance with the patient's known wishes, or if these wishes are unknown, in accordance with what the proxy believes the patient would have wanted. ⁵⁴ In New York, the surrogate may make decisions regarding artificial nutrition and hydration only if these wishes are

^{43.} Fentiman, supra note 1, at 818.

^{44.} Id. at 819.

^{45.} Id.

^{46.} Id. at 820.

^{47.} Id. at 823.

^{48.} Id.

^{49.} Id. at 824.

^{50.} Id.

^{51.} Id.

^{52.} Id. at 826.

^{53.} Id.; N.Y. PUB. HEALTH LAW § 29-C (McKinney Supp. 1992).

^{54.} TASK FORCE, supra note 24, at 33.

known.⁵⁵ Health care professionals must honor the decisions of surrogates as if they were the decisions of patients themselves and are protected from liability for doing so.⁵⁶ The designation of a surrogate decisionmaker, unlike a living will, allows health care decisions to be made in the context of intelligent, informed consultation with the health care team in consideration of the patient's beliefs and values.⁵⁷ This flexible approach is clearly superior to the living wills method of advance directive.

Unfortunately, only nine to fifteen percent of the population have executed any type of advance directive. 58 Congress has recognized the utility of advance directives to facilitate decision making for the incapacitated patient. 59 In an attempt to encourage the use of such directives, Congress passed the Patient Self Determination Act ("PSDA"). 60

3. The Patient Self Determination Act

To promote the execution of advance directives, Congress passed the PSDA.⁶¹ The PSDA applies to all health-care facilities receiving reimbursement under Medicare Part A.⁶² This includes most hospitals, nursing homes, hospice programs and HMO's.⁶³ The PSDA provides that patients must be informed, in writing, of their right to execute an advance directive under their state law as well as the institution's policy on implementation of the directive.⁶⁴ Any advance directive must be documented in the patient's medical record.⁶⁵ Though the PSDA is a step in the right direction, unfortunately, it can be anticipated that most adults will still fail to execute an advance directive. Therefore, it is imperative to determine what processes can best be used to resolve disputes arising when the patient has no advance directive and is without capacity to make his own health care decisions.

^{55.} Id.

^{56.} Id.

^{57.} Fentiman, supra note 1, at 828.

^{58. 136} CONG. REC. E943-01 (daily ed. April 3, 1990) (statement of Rep. Levin).

^{59.} Id.

^{60. 42} U.S.C. § 1395cc (West Supp. 1991).

^{61.} Id.

^{62.} Id.

^{63.} Yuen, supra note 11, at 592.

^{64. 42} U.S.C. § 1395cc(f)(1)(A) (West Supp. 1991).

^{65. 42} U.S.C. § 1395cc(f)(1)(B) (West Supp. 1991).

III. STANDING FOR SURROGATE DECISION MAKING

There are, traditionally, two standards for making medical treatment decisions for those persons who cannot decide for themselves. 66 These are the "substituted judgment" and "best interests" standards. 67

A. Substitute Judgment

Surrogates, utilizing the "substituted judgment" standard, attempt to extrapolate what patients would have decided about a specific medical treatment, if they had the capacity to do so, from any evidence indicating the wishes of patients regarding medical decisions expressed before patients lost capacity. Edeally, surrogates are people in a position to know patients, their philosophies, values, ethics, religious beliefs and feelings regarding these decisions. Whether to refuse or allow a specific treatment will depend on the decisionmaker's interpretation of the evidence. The decisionmakers attempt to "stand in the shoes" of patients and decide as they would have decided. This evaluation will, necessarily, be colored by decisionmakers' own values, beliefs and even conflicts of interest with the patient. The evidence of the patient's wishes may fall far short of the types of evidence found in an advance directive.

Substituted judgment has been allowed in some jurisdictions even when the patient has not clearly expressed any feelings regarding medical decisions, since it is felt that the surrogate is in a position to intuitively sense what the patient would have wanted. A parent may understand a child's values because she helped to form them, a child may grasp a parent's values because the parent imparted them to her, and a couple may have developed and refined their views in tandem. For example, New Jersey utilized the substituted judgment standard in the case of Nancy Jobes, a thirty-one year old woman who, as the result of a motor vehicle accident, was in a persistent vegetative state. Mrs. Jobes was fed through a "j-tube", a tube surgically inserted into the abdomen through which she received liquified feedings. Mrs. Jobes' husband sought to

^{66.} Diane E. Hoffmann, Regulating Ethics Committees in Health Care Institutions -- Is it Time, 50 MD. L. REV. 746, 772 (1991).

^{67.} Id.

^{68.} Id.

^{69.} Id.

^{70.} Id.

^{71.} Fentiman, supra note 1, at 848 n.55.

^{72.} Hoffmann, supra note 66, at 773.

^{73.} Jobes, 529 A.2d at 446.

^{74.} Id. at 436.

^{75.} Nancy K. Rhoden, Litigating Life and Death, 102 HARV. L. REV. 375, 438-39 (1989).

^{76.} Jobes, 529 A.2d at 436.

^{77.} Id. at 437.

have the tube removed. The court found that, though Jobes had made some casual references indicating that she did not want to be kept alive like Karen A. Quinlan, Nancy Jobes had left no clear evidence of her desires in such a situation. Never-the-less, the court held that in the absence of evidence of the patient's wishes, the family could still exercise substitute judgment.

[F]amily members are best suited to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but also because of their bonds with him or her. Our common experience informs us that family members are generally most concerned with the welfare of the patient.⁸²

The New York view was expressed by the court of appeals in *In Re Westchester County Medical Center*, 83 where the court rejected the substitute judgment doctrine and declined to allow withdrawal of a feeding tube absent clear and convincing evidence of the patient's wishes. 84 The court held that, for a decision maker to assert the right to forego life-saving treatment on behalf of an incompetent patient, the decision maker must show by clear and convincing evidence that the incompetent person, while competent, held a firm and settled commitment to terminate treatment under these or similar circumstances. 85 The United States Supreme Court has held that a requirement of clear and convincing evidence of the patient's wishes before making health care decisions is constitutional. 86

Where the patient has expressed no preference regarding health care decisions or has never been competent to make these types of decisions, substitute decision making is inappropriate.⁸⁷

^{78.} Id.

^{79.} See In re Quinlan, 355 A.2d 647 (N.J. 1976) Ms. Quinlan was a young woman who, for reasons unknown, stopped breathing and, after resuscitation, was in a persistent vegetative state. Id. Ms. Quinlan's father successfully sought judicial intervention to withdraw the ventilator which kept her alive. Id. at 663 -64.

^{80.} Jobes, 529 A.2d at 442-43.

^{81.} Id. at 445.

^{82.} Id.

^{83. 531} N.E.2d 607, 613 (N.Y. 1988).

^{84.} Id.

^{85.} *Id*.

^{86.} Cruzan, 497 U.S. at 284.

^{87.} TASK FORCE, supra note 24, at 55. See also In Re Storar, 420 N.E.2d 64 (N.Y.), cert. denied, 454 U.S. 858 (1981). In Storar, the New York Court of Appeals considered whether a mother could refuse blood transfusions on behalf of her son, a profoundly retarded man who never had the capacity to make health care decisions for himself. Id. at 66. In deciding that the mother could not make this decision, the court observed that substitute decision making in this case offered little guidance. Id. at 72-73. To attempt to make such a determination would be "similar to asking whether if it snowed all summer would it then be winter?" Id.

B. Best Interest

Where substitute decisionmaking relies on a subjective analysis of what the patient would have decided, best interest analysis focuses to a greater extent on an objective assessment of what is in the best interest of the patient.⁸⁸ The best interest analysis focuses not on what course of treatment this patient would have chosen, but what a reasonable person in the patient's position would decide.⁸⁹ In reaching a determination, the surrogate must weigh the burdens and benefits of treatment and imagine what a hypothetical reasonable person in the context of the patient's particular circumstances would decide.⁹⁰ The surrogate should consider:

- 1. the dignity and uniqueness of every person;
- 2. the possibility of extending or preserving the patient's life;
- 3. the extent of restoration and improvement of the patient's health;
- 4. relief of suffering;
- 5. anything else that a reasonable person in the patient's condition would consider in reaching their decision.⁹¹

The quality of a life, if prolonged, should be considered to a very limited extent. Only when the prolonging of life will result in an existence of pain and suffering or in a permanently unconscious state should quality be considered. It is important that decisionmakers do not instill into the process their own biases about physical or mental disability. Human beings are enormously adaptable and even persons with profound disabilities report a broad range of experiences and possibilities.

^{88.} TASK FORCE, supra note 24, at 55.

^{89.} Id.

^{90.} Id.

^{91.} Id. at 114.

^{92.} Alan R. Fleischman, M.D. et al., Caring for Gravely Ill Children, 94 PEDIATRICS 433, 435 (1994). See also, Rebecca Dresser, Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law, 28 ARIZ. L. REV. 373, 379 (1986) ("[P]eople experiencing various life events, including set backs in their physical and mental functioning may revise their goals, values and definitions of personal well-being."); see also, Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626 (Mass. 1986). "[W]e must recognize that the State's interest in life encompasses a broader interest than mere corporeal existence. In certain, thankfully rare, circumstances the burden of maintaining the corporeal existence degrades the very humanity it was meant to serve . . . " Id. at 635 (allowing withdrawal of a feeding tube in a patient in a persistent vegetative state).

^{93.} Fleischman, supra note 92, at 435.

^{94.} Id.

^{95.} Id. See also HAWKING, supra notes 30-32 and accompanying text (discussing the life of Stephen Hawking).

C. Risks of Erroneous Decision Making

The decision to withhold life sustaining treatment is usually irrevocable. Therefore, the fear of making the wrong decision is justified. Frroneous decisionmaking originates with one or more of the following errors in the decisionmaking process:

- 1. mistaken diagnosis;
- 2. mistaken prognosis;
- 3. mistaken assessment of the patient's treatment wishes in a substituted judgment analysis. 98

There is, at least, a minimal risk of a medical error in diagnosis or prognosis.⁹⁹ However, the area where the risk of error is greatest is in assessing the patient's own wishes.¹⁰⁰

Several studies have attempted to examine the accuracy of surrogate decisionmaker's predictions of what health care decisions a person would make. In one study, the physician's predictions of their own patient's preferences were better than chance alone in only one out of six instances. Chillingly, most doctors predicted that their patients would wish to forego treatment when, in fact, the patient would have chosen aggressive medical intervention. Spouses fared somewhat better, choosing better than chance alone three out of six times. Unlike doctors, spouses were more likely to err on the side of aggressive treatment. Most significantly, both spouses and doctors were more than ninety percent likely to choose for the patient what they would choose for themselves.

^{96.} See, e.g., Lee, supra note 2, at 1359. In a study of twenty-eight patients who had life sustaining treatments withdrawn, fourteen died within twenty-four hours, seven died within days one and seven, and seven survived more than one week. *Id.* Furthermore, only four patients were eventually discharged from the hospital. *Id.*

^{97.} See Fentiman, supra note 1, at 808.

^{98.} *Id*.

^{99.} *Id*.

^{100.} Id.

^{101.} TASK FORCE, supra note 24, at 6-7.

^{102.} Id. at 7.

^{103.} Id. But see Support, supra note 1, at 1594-95 (in a study of 4,301 patients only 47% of physicians were aware that their patients preferred to avoid CPR and half of the patients who were able to communicate in their last few days spent most of that time in severe to moderate pain); Bernard Lo, M.D., Improving Care Near the End of Life - Why is it so Hard?, 274 JAMA 1634, 1635 (1995) (Dr. Lo theorizes that practitioners project their own concept of a "good death" on their patients).

^{104.} TASK FORCE, supra note 24, at 6-7.

^{105 7}

^{106.} Id. at 7 n.6. See also Lo, supra note 103, at 1635. At the very least, these studies underscore the need to initiate some kind of advance directive to assist the surrogate in making these determinations.

In addition to inserting their own values, however unconsciously, into the decisionmaking process, surrogates may also wish to see the patient dead, either because of dislike, avarice or to limit the drain on available resources. For instance, a physician's determination that a patient would want life-support withdrawn may reflect his own desire to free an intensive care unit bed. Also, a family may want to limit the economic and emotional expense of maintaining a loved one on life-support.

Regardless of who the surrogate is, the dangers of erroneous decisionmaking exist. When the physician and family cannot decide on the correct course of treatment, at least one party has misinterpreted the evidence of what the patient would want or what treatment is in the patient's best interest. At this time, it is advantageous for the parties to look to a neutral decisionmaker who has the skills to facilitate the decision making process, protect the rights of the patient and provide a forum for each side to justify their views. This article addresses various mechanisms for review of these life-and-death decisions.

IV. WHO SHOULD DECIDE WHEN THE PATIENT CANNOT

A. Judicial Determination

As medical technology progressed to the point where persons could be kept alive for an indefinite period, courts were forced to forge principles for reasoned decisionmaking in an area where there were no clear answers in existing common law. [12] [T]he radical advances in life sustaining equipment and procedures developed by the medical profession in the last twenty years have taxed the common law process in ways that it has never been tested before. [113] The decisions from the state courts have been diverse. [114] In Massachusetts, the supreme court purported to require judicial review whenever a decision was made to withdraw life-support from an incompetent patient. [115] The court explicitly rejected any nonjudicial determination of the appropriate action by physicians or ethics committees:

^{107.} Fentiman, supra note 1, at 810.

^{108.} Id. at 811. See also, e.g., Lee, supra note 2, at 1360 ("[O]nce life sustaining interventions were withdrawn, most patients were soon transferred to general medical floors.").

^{109.} Fentiman, supra note 1, at 811. See also Yuen, supra note 11, at 588 (noting that it is not uncommon for families to be forced to sell their homes in order to maintain a family member on life-support for an extended period).

^{110.} See Fentiman, supra note 1, at 812.

^{111.} Yuen, supra note 11, at 629-30.

^{112.} See Sol Wachtler, Life and Death Decisions: The Patient's Choice, 205 N.Y.L.J. 39 (1991).

^{113.} Id.

^{114.} Id.

^{115.} Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 433 (Mass. 1977).

We take a dim view of any attempt to shift the ultimate decisionmaking responsibility away from the duly established courts of proper jurisdiction to any committee, panel, or group, ad hoc or permanent. Thus, we reject the approach adopted by the New Jersey Supreme Court in the Quinlan case of entrusting the decision whether to continue artificial life support to the patient's guardian, family, attending doctors, and hospital "ethics committee."

The Saikewitz court noted that "such questions of life and death... require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created."

The advantages of the judicial system in rendering these decisions have been identified as:

- 1. public nature of the proceedings;
- 2. principled decisionmaking;
- 3. reviewability by appellate courts, legislatures and legal commentators:
- 4. impartiality of courts;
- 5. developed body of common law;
- 6. adversarial nature of proceedings;
- 7. availability of tools, such as guardianship, to protect the rights of the patient. 118

Unfortunately, some factors which the Saikewicz court held as benefits to the judicial system are actually detrimental in these cases. For example, the openness of the judicial process exposes what inherently should be private matters to public, even media-style scrutiny.¹¹⁹ In addition, the judicial system is expensive, bureaucratic and time consuming.¹²⁰ Frequently, the decisions are announced months after the patient has either died or left the hospital.¹²¹ In response to these concerns, the New Jersey Supreme Court, as early as 1976, suggested that a more appropriate forum for review of these decisions was a hospital-based ethics committee.¹²²

^{116.} Id. at 434 (citing Quinlan, 355 A.2d at 671).

^{117.} Id. at 435.

^{118.} Yuen, supra note 11, at 600.

^{119.} COMM'N REPORT, supra note 18, at 159.

^{120.} Hoffmann, supra note 66, at 780.

^{121.} Id

^{122.} Quinlan, 355 A.2d at 668. The Quinlan case represented the first judicial review of a "right to die" decision. Susan M. Wolf, Ethics Committees and Due Process: Nesting Rights in a Community of Caring, 50 MD. L. REV. 798 (1991).

B. Ethics Committees

1. History

The New Jersey Supreme Court in *Quinlan*, relying on an article by Dr. Karen Teel, suggested that healthcare decisionmaking was better facilitated in a hospital based ethics committee than in a judicial forum.¹²³ The *Quinlan* court recommended that if an ethics committee determined that "there [was] no reasonable possibility of Karen's ever emerging from her present comatose state to a cognitive, sapient state," life-support could be withdrawn without judicial intervention.¹²⁴ In 1982, it was estimated that approximately one percent of American hospitals had an ethics committee.¹²⁵ Since that time, the number of ethics committees has exploded.¹²⁶ In 1991, the majority of hospitals reported having ethics committees.¹²⁷ To a lesser extent, long-term care facilities have also begun to establish ethics committees.¹²⁸ Support for the ethics committee movement include legislative proposals, judicial decisions encouraging committees, legal and medical commentary, federal guidelines regarding decisionmaking in infant cases as well as a Presidential commission report released in 1983.¹²⁹

2. Composition

The composition of ethics committees is interdisciplinary and may include physicians, social workers, nurses, hospital administrators, clergy, lawyers and ethicists. The New York State Task Force on Life and the Law recommends that mandatory membership should include at least five individuals consisting of at least one physician, one nurse, one social worker, one bioethicist and one lay member of the community not affiliated with the hospital. Other suggested

^{123.} Quinlan, 355 A.2d at 668 (quoting Dr. Karen Teel, The Physician's Dilemma: A Doctor's View: What the Law Should Be?, 27 BAYLOR L. REV. 6, 9 (1975)).

^{124.} Id. at 671.

^{125.} Hoffmann, supra note 66, at 797 n.3.

^{126.} TASK FORCE, supra note 24, at 17.

^{127.} Wolf, supra note 122, at 799. For example, a 1988 survey of New York hospitals showed that 51% of responding hospitals had an ethics committee. TASK FORCE, supra note 24, at 17. Another survey revealed 91% of non-federal Maryland hospitals and 78% of District of Columbia hospitals had committees. Sims-Taylor, supra note 23, at 360 n.160.

^{128.} TASK FORCE, supra note 24, at 17.

^{129.} Wolf, supra note 122, at 798-801. See also Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 50 Fed. Reg. 14893, 14893 (1985) (encouraging the formation of "Infant Care Review Committees" in making health care decisions for disabled infants); COMM'N REPORT, supra note 18, at 169 (recommending the establishment of ethics committees). Such influential groups as the AMA and the American Academy of Pediatrics have also endorsed the formation of ethics committees. Andrew L. Merritt, Tort Liability of Hospital Ethics Committees, 60 S. CAL. L. REV. 1239, 1242 (1987).

^{130.} TASK FORCE, supra note 24, at 18.

^{131.} Id. at 139.

members include lawyers, clergy, and hospital administrators.¹³² In long-term care facilities, the community member should be an advocate for the elderly or persons in long-term care.¹³³

The interdisciplinary nature of the committee represents an advantage over the judicial forum for review of health care decisions. ¹³⁴ Physicians and nurses have clinical expertise to weigh medical facts as well as risks and benefits of proposed treatment options. ¹³⁵ Members of the community are more likely to reflect the values of the patient. ¹³⁶ Social workers may clarify issues regarding community resources available to assist the patient and their family. ¹³⁷ Members of the clergy may assist committee members to identify religious and ethical issues crucial to some patients. ¹³⁸ Thus, the multidisciplinary committee can bring a dimension of knowledgeable, reasoned decisionmaking to their determinations beyond the scope of a judicial proceeding and may provide a forum more amenable to ethical reflection and creative dispute resolution.

The multidisciplinary nature of the committee may also encourage parties to seek assistance with difficult decisionmaking. ¹³⁹ For example, a physician may feel more comfortable consulting with another physician, or a nurse may be less reluctant to bring her ethical concerns to another nurse, or a lay person may feel less intimidated discussing his/her problems with another lay person. ¹⁴⁰ To all parties, a committee meeting within the health care facility itself may seem less formidable and more accessible than a courtroom proceeding.

Though ethics committees may be relatively better decisionmakers than the courts, the current committees include disadvantages. The majority of committee members associate with the health care institution which may produce a danger that committees will act as mere "puppets" of the facility. In addition, though ethics committees represent a multidisciplinary group, the members remain largely homogenous. Members typically are white, middle or upper middle class with undergraduate, if not, graduate degrees. This group may not accurately reflect the preferences of the community whom they

^{132.} Id. at 143-44.

^{133.} Id. at 142.

^{134.} Hoffmann, supra note 66, at 785.

^{135.} Id. See also TASK FORCE, supra note 24, at 140.

^{136.} Hoffmann, supra note 66, at 785.

^{137.} TASK FORCE, supra note 24, at 140.

^{138.} Id. at 140-41.

^{139.} See Michael D. Swenson, M.D., Ph.D. & Ronald B. Miller, Ethics Case Review in Health Care Institutions: Committees, Consultants or Teams?, 152 ARCHIVES INTERNAL MED. 694, 695 (1992) (discussing the advantages and disadvantages of consultants and committees).

^{140.} See, e.g., id.

^{141.} Hoffmann, supra note 66, at 785.

^{142.} Id.

^{143.} Id. at 797 n.158 (citing Diane E. Hoffmann, Does Legislating Hospital Ethics Committees Make a Difference?: A Study of Hospital Ethics in Maryland, the District of Columbia, and Virginia, 19 LAW, MEDICINE & HEALTH CARE 105 (1991)).

^{144.} Id.

purport to represent. For example, studies show that non-college graduates, African-Americans, born-again Christians, and the elderly are slightly more likely than the general public to believe that a person's life should always be saved. ¹⁴⁵ Therefore, recommendations for membership, such as those by the New York Task Force, may be too narrow in scope to achieve their stated goal of producing a committee that reflects the values of the community.

3. Functions of Ethics Committees

Currently committees perform a variety of functions within the health care institution. The American Hospital Association Management Advisory has suggested that certain activities are especially suited to ethics committees:

- 1. directing educational programs;
- 2. providing a forum for discussing ethical issues;
- 3. formulating policy regarding ethical issues;
- 4. conducting retrospective review of "bedside" ethical decisions;
- 5. case consultation and providing a forum for dispute resolution. 146

Indeed, one of the most powerful functions of the committee is the review and formulation of hospital policy.¹⁴⁷

The ethics committee role as a neutral third party in resolving disputes and assisting parties to make health care decisions is the most controversial and, potentially, most important role of the ethics committee.¹⁴⁸

C. Dispute Resolution

There are several advantages to utilizing alternative dispute resolution techniques when deciding the treatment of patients who currently lack the capacity to decide for themselves. Alternative dispute resolution includes processes such as mediation, arbitration, negotiation and numerous hybrid forms. These processes provide several advantages over judicial intervention including:

- 1. maintaining and strengthening ongoing relationships;
- 2. expertise of the third party neutral in the subject of the dispute;

^{145.} Id. (citing TIMES MIRROR CENTER FOR THE PEOPLE AND THE PRESS, REFLECTIONS OF THE TIMES: THE RIGHT TO DIE 12 (1990)). See also Leslie J. Blackhall et al., Ethnicity and Attitudes Toward Patient Autonomy, 274 JAMA 820 (1995) (in many cultures, it is believed that the family, not the patient, should make decisions regarding life support for the terminally ill).

^{146.} Sims-Taylor, *supra* note 23, at 344 (citing AMERICAN HOSPITAL ASSOCIATION, MANAGEMENT ADVISORY: ETHICS COMMITTEES (1990)).

^{147.} See Swenson, supra note 139, at 695.

^{148.} See Merritt, supra note 129, at 1243-44 (recognizing the consultive role of an ethics committee).

^{149.} Fentiman, supra note 1, at 843.

- 3. a sharing of views with the other side;
- 4. increased satisfaction with the decisionmaking process;
- 5. efficiency;
- 6. accessibility;
- 7. decreased cost:
- 8. confidentiality. 150

The use of alternative dispute resolution in health care decisionmaking for the person who cannot decide for himself has the potential to facilitate a continuing relationship between the parties, increase satisfaction of the parties with the decision reached, protect the privacy of the patient and his family, and assist the loved ones of a hopelessly ill patient to be at peace with the decision to withhold or withdraw life prolonging treatment. A timely and economically efficient resolution of these problems may be a humane alternative to judicial intervention for families already emotionally and fiscally exhausted.

1. Committees or Consultants

Currently two methods of case review utilizing alternative dispute resolution have been proposed: ethics committees and ethics consultants. An ethics consultant is an individual with specialized experience that enables him to identify ethical issues and offer recommendations to health care practitioners based on moral principles. A consultant not only "clarifies issues, but solves cases." Most consultants utilize mediation or negotiation in resolving disputes if called upon to do so. Many consultants place classified advertisements in medical journals, offering their services. Ethics consultants may be clinical specialists who actually make rounds, review medical records and are otherwise regularly involved with the patient at the bedside. These clinicians then document their recommendations in the patient's medical record. Other consultants never see the patient, but make a detached recommendation to the attending physician about proposed treatment options.

^{150.} See id. at 843-44, 846.

^{151.} See supra note 16 and accompanying text.

^{152.} John Lapuma & Stephen E. Toumlin, Ethics Consultants and Ethics Committees, 149 Archives Internal Med. 1109 (1989).

^{153.} Id.

^{154.} Id. This presupposes that there is, actually, a correct answer. However, a recent survey of ethical consultants demonstrated wide variability in their recommendations in several hypothetical vignettes. Ellen Fox & Carol Stocking, Ethics Consultants' Recommendations for Life-Prolonging Treatment of Patients in a Persistent Vegetative State, 270 JAMA 2578 (1993).

^{155.} Id. at 1110.

^{156.} Id.

^{157.} Id.

^{158.} Id.

^{159.} Id.

The following are several advantages associated with an ethical consultant in relation to an ethics committee:

- 1. it is easier to call in one person than it is to convene a committee:
- the clinical consultant can gather evidence first hand to facilitate decisionmaking;
- 3. the family and practitioner may be more relaxed speaking to an individual than to a committee;
- 4. an individual may be more likely to consider creative alternatives than a committee ¹⁶⁰

The disadvantages of consultants favor utilizing the services of an ethics committee. The following list highlights the disadvantages of ethical consultants:

- 1. the multidisciplinary membership of the committee is more likely to reflect the values of the community;
- 2. the committee has the power to change hospital policy, if necessary, to facilitate decisionmaking;
- 3. moral and ethical discourse is more appropriately placed in a committee reflecting various disciplines and attitudes within society;
- 4. ethics committees are already in place in most hospitals;
- 5. ethical consultants will cost money, therefore allowing consultant review only for those families who can afford their services. 161

2. Proposed Models of Dispute Resolution

At least one commentator has proposed a hybrid approach to the consultation/committee dilemma. When a seriously ill patient is admitted to the facility, a hospital counselor or case-manager will approach the family to offer the hospital's understanding and support. This representative would offer information relating to the ethics committee's counseling, advice and mediation services. The representative would continue to visit the patient and his family and consult with members of the health care team to identify early conflicts and, sometimes literally, mediate disputes at the bedside. If these informal mediation techniques fail, both parties are invited to resolve their conflicts at a formal mediation session utilizing a different member of the ethics committee. In those cases where successful mediation of the dispute is not achieved, the

^{160.} Swenson, supra note 139, at 695.

^{161.} Id.

^{162.} Sims-Taylor, supra note 23, at 348.

^{163.} Id.

^{164.} Id.

^{165.} Id.

^{166.} Id.

dispute is then submitted to arbitration by the ethics committee.¹⁶⁷ The arbitration would not be binding, but would be intended to reflect the likely outcome of a judicial determination of the issues.¹⁶⁸ The costs of the process would be paid by the hospital.¹⁶⁹

At least one hospital has reported successful utilization of the hybrid approach. 170 Detroit Receiving Hospital in Detroit, Michigan, maintains a Comprehensive Support Care Team whose function is to offer a "comprehensive, holistic and multidisciplinary approach" to patients and their families as they face difficult end-of-life decisions. 171 Members of the team, led by a clinical nurse specialist, accept referrals from physicians and other members of the health care team. 172 Members of the team then make rounds, gather data concerning patients' prognosis and any information concerning the patients' known wishes and advance directives, meet with patients and their families and seek to address their concerns and identify any areas of potential conflict.¹⁷³ Most disputes are resolved informally at the bedside. 174 In the event a decision cannot be reached in this manner, it is referred to the hospital ethics committee. 175 The clinical nurse specialist who heads the team also co-chairs the ethics committee. 176 Because of the priority this hospital gives to this group of patients, staff members express an understanding that facilitating a satisfactory end to life can be as important as saving a life. 177

The New York State Task Force on Life and the Law has proposed a system of dispute resolution utilizing hospital based ethics committees. Every hospital and long-term care facility would be required to establish an ethics committee. The committee would mediate disputes and make health care determinations. In most cases, their findings would be nonbinding. However, committee decisions regarding withdrawal of life support from patients without a surrogate or in cases where a patient without capacity is neither permanently unconscious nor terminally ill, would be binding on the parties.

^{167.} Id.

^{168.} *Id*.

^{169.} Id.

^{170.} Michael Villaire, Margaret L. Campbell: Making an End-of-Life Difference, 14 CRITICAL CARE NURSE 111 (1994).

^{171.} Id.

^{172.} Id.

^{173.} Id.

^{174.} Id.

^{175.} Id.

^{176.} Id. at 113.

^{177.} Id. at 114.

^{178.} TASK FORCE, supra note 24, at 261-65.

^{179.} Id. at 261.

^{180.} Id. at 262.

^{181.} Id.

^{182.} Id.

All decisions of the committee are reviewable by a court of competent iurisdiction.183

D. Procedural Safeguards

Because the consequences of erroneous decisionmaking are critical and because the patient has a constitutional right to make his own health care decisions, certain procedural safeguards must be in place before alternative dispute resolution can replace the judicial process as a forum for deciding health care issues. 184

1. Education

It is imperative that members of ethics committees, with the power to mediate and/or decide health care disputes, be familiar with the components of a reasoned analysis of the issues. 185 Quality decisions and uniformity of the decisionmaking process will be facilitated by educating members of ethics committees in the principles of "substitute judgment" and "best interests" analysis. The members of the committee should be aware of the prognosis and legal implications of certain disease states. 186 The members must also possess an awareness of and respect for the right of a patient to refuse any treatment, even if to do so will cost the patient her life. The committee should, therefore, refuse to mandate any treatment for which there exists clear and convincing evidence that the patient would refuse the treatment if able to do so. 187

2. Due Process

Disputes between caregivers and patient's families resolved by arbitration must contain procedural safeguards to ensure the due process rights of the parties. 188 Wolf has described the current process of dispute resolution by ethics committees as a "due process wasteland." Often, committees meet at the request of the physician without any awareness by the patient or her family that the case is being reviewed. 190 The proposed model of dispute resolution in New York provides procedural safeguards which protect the parties' due process rights:

The committee shall provide the patient or his surrogate with

^{183.} Id. at 267.

^{184.} See id. at 27-28; see also Lee et al., supra note 2, at 1359.

^{185.} Hoffmann, supra note 66, at 768.

^{186.} Id.

^{187.} TASK FORCE, supra note 24, at 82.

Wolf, supra note 122, at 819.

^{189.} Id.

^{190.} Id.

- (i) notice of any pending case consideration concerning the patient. . . and;
- (ii) the committee's response to the case, including a written statement of the reasons for approving or disapproving the withholding or withdrawal of life sustaining treatment...¹⁹¹

3. Immunity

To promote the use of ethics committees in dispute resolution, members of the committee and health care professionals who follow the decisions of the committee must be immune from liability. Fear of liability would not only discourage membership on the committee but would also limit free and open discussion by the parties involved in the decisionmaking process. The New York proposal contains a qualified immunity provision. All parties to the decisionmaking process including members, providers and surrogates are immune from all civil and criminal liability, providing they acted in good faith. For example, deciding to limit life support based on the institution's fiscal concerns is considered acting in bad faith.

4. Judicial Review

The role of the committee is to provide a decisional process that is efficient, accessible, reasoned and protective of the patient's rights. ¹⁹⁷ Decisions of ethics committees should still remain appealable to the courts. ¹⁹⁸ Review by the courts will ensure that the committees are acting in good faith with adequate due process rights in place. ¹⁹⁹ Hoffmann has proposed that courts should review these decisions only if the committee failed to follow appropriate procedure in rendering their decision and overturn the committee's decision only if arbitrary and capricious. ²⁰⁰ Conversely, Wolf believes that all judicial review should be "de novo." ²⁰¹ The proposed New York scheme would allow any party to turn to a court of competent jurisdiction at any time for an order to terminate or institute treatment. ²⁰² Because this is a life and death decision, any restriction of judicial review would be unwise. However, if the committee follows competent

^{191.} TASK FORCE, supra note 24, at 264.

^{192.} Merritt, supra note 129, at 1251.

^{193.} TASK FORCE, supra note 24, at 150.

^{194.} Id. at 266.

^{195.} Id.

^{196.} Id. at 150.

^{197.} Wolf, supra note 122, at 852.

^{198.} Hoffmann, supra note 66, at 795.

^{199.} Id.

^{200.} Id.

^{201.} Id.

^{202.} TASK FORCE, supra note 24, at 267.

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decisionmaking procedures, their decisions should closely mirror any judicial determination

V. CONCLUSION

Advancements in medical technology have given birth to disputes regarding the withholding of life-sustaining treatments. It is well established that a non-pregnant adult has a right to refuse any treatment, even if refusal will result in the person's death. Problems arise when a patient lacks the capacity to make health decisions for herself and has failed to execute an advance directive regarding her care. It then becomes necessary for someone else to decide for the patient. These decisions are frequently made at the bedside by the patient's family and physician. Unfortunately, when they cannot agree, the parties are forced to resort to judicial determination of these sensitive issues. Various commentators have suggested that these types of decisions are better made in a hospital ethics committee using alternative dispute models such as arbitration and/or mediation.

ADR would offer several advantages over the judicial process in resolving these disputes including accessibility, low cost, expertise of the members, confidentiality and allowing a continued relationship between the parties. To protect the rights of the patient, however, concepts of due process and reasoned decisionmaking must be part of the process. Judicial review of the decision should be available to ensure integrity of the decisionmaking body.

Reasoned decisionmaking with respect for the autonomy of the patient and compassion for his suffering tempered by value for his life should guide all bodies and/or individuals called upon to decide for a seriously ill person who can no longer decide for himself. Mediation and arbitration may offer an alternative form of dispute resolution most likely to achieve these ideals.

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