An Evangelical Critique of Advance Directives

Gregory W. Rutecki, M.D.

Dr. Rutecki is Associate Professor of Internal Medicine at Northeastern Ohio Universities College of Medicine in Canton, Ohio.

HISTORY AND SIGNIFICANCE OF ADVANCE DIRECTIVES

The well publicized legal imbroglios that surrounded Karen Quinlan and Nancy Cruzan's terminal care have led to a brave new era of patient self-determination. That era began on April 14, 1975, when twenty-one year old Karen Quinlan sustained an enigmatic brain injury described as a "chronic vegetative state" which resulted in ventilator dependence. Her family filed a plea in New Jersey's Superior Court to gain legal permission to disconnect Karen from the Ventilator. Karen's mother, sister, and friend testified that Karen often spoke about her desire not to be kept alive by machines.[1] After being weaned from the ventilator, Karen - now spontaneously breathing - was transferred to an extended care facility on June 9, 1976. Nine years later, Karen Quinlan died. She brought the disturbing and very painful questions surrounding end-of-life care, autonomy and persistent vegetative state to national prominence.

Then on January 11, 1983, twenty-five year old Nancy Cruzan suffered irreversible brain injury in a car accident. Again, Nancy's family and friends testified that she would not want to be kept alive in her condition, "just as a vegetable."[2] The Cruzan family petitioned the courts in order to discontinue Nancy's tube feeding during her persistent vegetative state. The discontinuation of nutrition and hydration eventuated in Nancy Cruzan's death on December 26, 1990. The Supreme Court molded Nancy Cruzan's terminal care into a far-reaching paradigm for end-of-life decision-making. In so doing, the Justices acknowledged the right of incompetent patients to refuse unnecessarily burdensome treatment but at the same time emphasized the necessity for written evidence documenting patient wishes which empowered surrogates to make end-of-life decisions.[3] For the first time, America's terminal care vocabulary would include, "clear and convincing evidence," and a "right to die."[4]

The Cruzan family's agonizing choices vis-a-vis the Justices' interpretation of the Constitution eventually culminated in the federal Patient Self-Determination Act (PSDA) (12/1/91) requiring: 1. the provision of written information to patients regarding the right to refuse treatment and the formulation of advance directives under state law; 2. inquiry as to whether a patient has an advance directive and documentation of the presence or absence thereof in the medical record; 3. the provision of education to hospital staff concerning advance directives; 4. compliance with state law concerning advance directives (all fifty states have enacted living will legislation); and 5. maintenance of written institutional policies concerning all of the above.[5]

Advance directives may be defined as instruments which are intended to conclusively establish an individual's preference in writing with respect to the degree of medical care and treatment he or she desires to receive. Advance directives may also be designed to document how an individual would like to be treated or who should make treatment decisions if the individual should become incapacitated and lose the ability to make or communicate medical decisions. Advance directives include written instruments such as living wills, durable powers of attorney for health care, and health care proxies, as recognized by state law.[6]

Response to the PSDA by both patients and health care workers may be characterized as lukewarm at best with approximately 15% of hospitalized patients availing themselves of such documents.[7] Certain groups,

however, have become targeted for more aggressive advance directive implementation and study. One such group, in whom advance directives are already presumed to lead to "good deaths," is comprised of patients with end stage renal disease (ESRD).[8] The rationale for heightened advance directive utilization in this specific group includes the following: ESRD patients sustain a yearly mortality approximating 20%; already dialysis dependent, these patients are familiar with life support; discontinuation of dialysis followed by death may be the second leading cause of mortality in this population; and 50% of ESRD patients who discontinue dialysis and die are deemed incompetent at the time of important end-of-life decisions.[9]

Even though advance directives are generally purported to have multiplied benefits,[10] they concomitantly raise a disconcerting specter. Recently, my thought as an evangelical was crystallized concerning the potential negative fallout of advance directives. My colleagues and I in nephrology completed a questionnaire investigation of ESRD patients and advance directives which resulted in some disturbing observations.[11] In the study, ESRD patients themselves desired a review of personal advance directives as frequently as four times per year. How valid and binding could such end-of-life documents be if they were no more temporally substantial? Prior studies in the same population have shown that over 40% of ESRD patients would allow significant leeway with potential surrogate override of their written advance directive decision.[12] In a document whose raison d'etre is autonomy, nearly one-half of patients would still have "significant others" making decisions potentially quite different from their own. With previous, substantial empiric evidence documenting the inaccuracy of proxy decision-making, there is no guarantee that the surrogate's choice would be in the patient's best interest.[13] In spite of these and other perceived shortcomings of advance directives, the National Kidney Foundation (NKF) has suggested more vigorous implementation policies throughout the U.S. dialysis facilities.[14] With further government involvement in medicine assured in a short-term future, ESRD patients may become an experiment leading to further enforcement of the PSDA in seriously ill populations.

In response to the concerns raised by empiric study, as well as to the pressure brought to bear by the NKF, I propose to develop a Biblical foundation from which to evaluate the pros and cons of advance directives as they confront a multiplicity of end-of-life treatments. I would like then to proceed and contrast the Biblical foundation with the primary secular force driving implementation of advance directives, i.e., autonomy. Finally, I will engage the future implications of advance directives in a mileu of a post-Hippocratic ethos in medicine.

ADVANCE DIRECTIVES: A BIBLICAL-THEOLOGICAL PERSPECTIVE OR A GOD-CENTERED, REALITY-BOUNDED AND LOVE-IMPELLED VIEW OF TERMINAL CARE[15]

The engagement of advance directives within a Biblical world view perspective will discuss the sanctity of human life, a respect for patient freedom, suffering in the economy of existence, and the utilization of advance directive instruments in deciding for or against treatments at the end of life. Each of these four areas will be considered individually throughout the following sections.

> "The first guide we will examine is life, not because it is necessarily more important than the others but because it is foundational to the entire enterprise of medicine." John Kilner[16]

Advance directives may represent the ultimate reduction of agonizing patient and family choice necessarily leading to either life or death. For the Christian, these terminal choices must valuate life as singularly unique since human life is created in the image of God (Gen. 9:5-6; Ps. 8:3-5; 100:3; 139:3ff; Acts 17:25). Other "important mandates (e.g., personal freedom, an end to suffering) must yield when they stand in the way of the sustenance of life."[17]

Christians must place advance directives first and

foremost in the context of Biblical injunctions against killing (e.g., specifically applied to euthanasia or assisted suicide) (Gen. 9:6; Mt. 5:21; Ex. 20:13; Mt. 6:52; John 8:10; Deut.
4:19). All created life shares the imago dei regardless of whether it is still fallen or even belongs to our enemy (Mt. 5:43-45; Rom. 12:20).

> "The grave is also the fruit of sin, an obscene irruption into human experience, severing plans and relationships asunder. Death is the last enemy indeed." Nigel Cameron[18]

Even though physical death is inevitable in our fallen world, the Biblical view of death - in direct contradistinction to that of life -describes death as "the king of terrors" (Job 18:14). This observation is further developed in Ps. 23:4; Isa. 25:7-8; Mt. 10:5-8. To intend or facilitate death is contrary to the Bible which clearly teaches that God alone controls death (Job 1:2 1; Rom. 5:12; Rom. 14:7-8; 1 Cor. 15:20-26; Rev. 21:3-4) and that death is our final enemy. Any intention which actively facilitates death is antithetical to a God-centered, reality-bounded and love-impelled Biblical ethic which mandates the preservation of life. We are only set free from death through Christ's victory and only by His control of death. (2 Cor. 5:8).

As a result, Biblical study makes it abundantly clear that advance directives may never be utilized by Christians as instruments of active euthanasia or as means to a premature or contrived death in any person.

> "A God-centered approach also emphasizes the importance of seeking God's purposes for the world and living in accordance with them. In the context of treatment decisions, this includes recognizing that disobedience may lie in doing too much as well as doing too little. There is no virtue in over-treating 'just to be sure.' One can become so zealous in trying to sustain biological life that one ceases to attend to the God who created it." John Kilner[19]

The utilization of advance directives when deciding against treatment, in some instances however, uncovers the tension between the protection (vide supra) and the inevitability of death. Advance directives have the potential to protect loving surrogates from agonizing decisions and an unnecessary prolongation of the dying process in their loved one.

In this context, advance directive decisions which are made to limit or discontinue terminal care must be fenced in by a Biblical ethic founded on the sanctity of life and then should proceed to consider the following: terminal care decisions must be free of any intention to cause death; they must never be driven solely to end suffering; they must never be used to eliminate suffering by eliminating the sufferer; they must address the moral issue of who is entrusted with treatment decisions for another; they cannot rely on quality of life determinations alone and must remain as clear as possible in the differentiation between terminal and imminent. Such a distinction is essential so as not to lead to an early abandonment of medical interventions and should leave the door open later to the ministry of terminal care appropriate when attempts at cure are exhausted.[20] Vaguely stated advance directives (i.e., no heroic care) must never be permitted to lead to either benign neglect or the absence of compassion.

> "Some people are even remterpretmg the moral mandate to love to include ending life to end great suffering ... Such 'love' is not shaped and guided by God's created reality to reject the ending of life impaired by illness is not to accord erroneously high value to that life; it is to place it outside the realm of valuing." John Kilner[21]

> "It is not medicine's place to lift from us the burden of that suffering which turns on the meaning we assign to the decay of the body and its eventual death. It is not medicine's place to determine when lives are not worth living or when the burden of life is too great to be borne. Doctors have no conceivable way of evaluating such claims on the part of patients, and they

> should have no right to act in response to them. Medicine should try to relieve human suffering, but only that suffering which is brought on by illness and dying as biological phenomena, not that suffering which comes from anguish or despair at the human condition." D. Callahan[22]

By necessity, end-of-life decision making must confront contemporary attitudes towards suffering and place them in Biblical context. Even though we, like Job, cannot completely understand suffering nor are we able to formulate a peffect theodicy, we nonetheless are able to appreciate that suffering "provides us with an occasion to trust and praise God."[23] Commitment to God is required during suffering and is precedent over any attempt to hasten death actively in order to end suffering. Scripture makes it clear (Jas. 1:2-8; Heb. 5:7-9; Phil. 4:11-12; Rom. 8:35-37; 2 Cor. 12:7-10; 1 Pet. 1:5-7; Heb. 12:11) that God is also sovereign over suffering as He is over death and expects care as our Christian response (2 Cor. 1:3-4; Mt. 10:8; Lk. 9:6; Jas. 5:14-16)[24] which precludes both removal and abandonment of the sufferer.

In summary, even though Biblical study does not exclude advance directives per se, any documents addressing care at the end-of-life must make the sanctity of human life an absolute criterion and appreciate that suffering may be relieved but never by any means which hastens death. Furthermore, when decisions are made to abandon curative medicine, medicine as care and ministry must continue and this consideration is often lacking in advance directives.

CONTEMPORARY SOCIETY ATTITUDES AND ADVANCE DIRECTIVES: CONFLICTS WITH THE BIBLICAL FOUNDATION

The PSDA grew out of an effort to increase patient autonomy in end-of-life decision making. Unfortunately, though this prima facie seems to be good, our zeitgeist has confused the concept of freedom as God intended vis-a-vis the contemporary concept of autonomy.[25] Biblical freedom is a means to an end in that Biblical freedom represents being freed for something not from something. Thus, it is a freedom fulfilled in the love of God and neighbor or best described as being free to accomplish righteousness. Autonomy, unlike freedom, represents self-law, and contemporary interpretations of freedom as removal from any spiritual or moral restrictions affects the implementation of advance directives. In contemporary society, autonomy has become an end in itself, a summum bonum and a consistent trump card in a hierarchy of pluralistic values.

Autonomy, as distinct from freedom in the context of advance directives, may be seen in the results of a recent study. Caralis and associates[26] polled 139 patients concerning their perception of autonomy during end-of-life decision making. Nearly half agreed that doctors should assist patients to die; 36% would desire such assistance for themselves. One-fifth would desire euthanasia for suffering, even if the suffering occurred in a proven non-terminal situation! Our empiric study of advance directives in ESRD showed that 40% of patients would allow another to discontinue their dialysis if they had reversible depression.[27] Advance directives motivated by such autonomy would be incompatible with a Biblical exposition of terminal care. Christian health care workers should not only counsel against autonomy as the summum bonum guiding advance directives, but should foster covenant-modeled interaction with their patients as a witness against this most unsettling abuse of terminal care.

THE DANGER OF ADVANCE DIRECTIVES IN A POST-HIPPOCRATIC MEDICAL SOCIETY[28]

Medicine used to be suffused with Christian values and remained a moral enterprise for thousands of years by a marriage of Christianity with Hippocratism. Medical ethics was grounded in two horizontal relationships (doctor-doctor; doctor-patient) and one essential vertical relationship (doctor-God) through a fear of God and a common oath. The loss of the hold the Hippocratic oath had on the practice of medicine in the U.S.A. was first detected with the onset of liberal abortion. It is clear today however that abortion is only a symptom of a worse disease - one that gnaws at the heart of what it really means to be human. Advance

directives represent one aspect of a disturbing evolution of values in that covenantal medical relationships are now contractual; patients pick from a wide variety and blend of values (vide supra) and the only moral ground for medical decision-making is patient or surrogate consent. The moral dimension in medicine is now reduced to individual preference rather than traditional consensus grounded through a vertical dimension.

A review of advance directives in this context of a post-Hippocratic ethos raises some very perplexing issues. Emanuel[29] followed nursing home patients for two years after the completion of an advance directive. After medical record review and physician interview, the authors concluded that in many cases the patient's choices were overridden because their physician disagreed with the wisdom of their choice. On occasion, the override represented the withholding of treatment because the physician decided it would not benefit the patient. End-of-life choices through vaguely worded advance directives may be primarily relegated to physicians who lack a consensus about what it means to be human.[30] When physicians were polled[31] and asked criteria for the selection of patient treatment in the face of limited resources, decision-making criteria would include age (88%), social value (56%) and ability to pay (43.1%). A continued deterioration in medical ethics would make contemporary physicians very poor guarantors of a sanctity of life ethic at a time of terminal decision-making. In reality, the negative aspect of autonomy cuts both ways in that physician autonomy in the era of "The New Medicine" may become as morally unreliable as that of patient autonomy in the Caralis study.[32] A review of the Remmelink report addressing the practice of euthanasia in the Netherlands empirically documents a corrosive effect of assisted death which leads to physician involvement in the "black side" of medicine.[33] With increasing governmental and third party intrusion into the contemporary contract model of medical care, will advance directives become a coercive tool that rations end-of-life care by offering euthanasia as a cheaper alternative to life?

AN EVANGELICAL CLINICIAN'S CONCLUSIONARY OBSERVATIONS

> "Do we want the best medical skills in the world when we secretly fear they may be used to draw out the dying process, holding us on a rack of suffering when we should be left alone to die and experience all God has in store for us after this life? We feel we need protection from that kind of medicine."
>
> N. Cameron[34]

Since most Christian health care workers are involved with advance directives in some capacity, I'd like to posit selected, practical suggestions. These suggestions are "fenced-in" by the Biblical injunctions reviewed earlier as well as tempered by my concern with our contemporary zeitgeist and post-Hippocratic ethos.

When advance directives are utilized, they must be discussed thoroughly with patients and their families and reviewed openly and frequently. Otherwise, advance directives may represent a version of the "moral cop-out."[35] Physicians who practice medicine as technique only without an ethical "vertical dimension" may use living wills as a legalistic substitute for frank ethical discourse. Such documents then may lead either to abrogation of valid physician moral authority or relegate patients to vague end-of-life euphemisms without substance. Advance directives cannot function in a world of "I want everything done" and "nothing heroic." Contractual models of the patient-doctor relationship will make it easier for secular physicians to under-treat patients for economic reasons or to prescribe euthanasia if such terminal "care" is legalized. Covenantal relationships, however, will allow the physician more freedom in discussing the Biblical "pros and cons" of advance directives.[36] The addition of a "values-history" to the directive will force more discussion, reflection, valuation and true freedom in decision making[37] and is essential to rescue advance directives from being a haphazard checklist.

The final and most difficult aspect of advance directives will involve a hefty dose of Christian discernment. When elderly Christian patients seek to avoid a prolongation of the dying process, when should aggressive attempts at cure be abandoned and Christian care substituted? In

the past, I felt that "futility" would become apparent in the course of terminal care.[38] Though many Christians disagree with medicine's ability to define futility, the attempt at a definition grew out of my concern that the elderly were being mistreated by technology with little to no chance of meaningful cure. When the average duration of hospital time from a DNR order to death is only one day on a surgical service; when the average hospital bill is $60,000 more for patients who die with an in-hospital DNR order versus a pre-hospital DNR order,[39] American medicine must be made culpable for relying on science as a panacea in lieu of a recognition of death's inevitability.

Until we can substitute a workable and ethical concept for "futility," Christian health care workers will have to pray for the discernment to recognize the time when they commend the spirit of those entrusted to them to a peaceful end. This is the terrible "gray" area of advance directives that will at least for now remain an agonizing unknown.

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