

## Religious Advance Directives: The Convergence of Law, Religion, Medicine, and Public Health

### ABSTRACT

Because of the deep interpersonal significance of decisions made at the end of life, it is not surprising that religion has played an important role in patient and family decision making. Specific religious concerns about death and dying have led to religious advance directives. Advance directives offer a case study of models of interaction between religious communities and secular institutions. This paper examines why such directives have been created and how they may affect health care decisions. An analysis of their strengths and weaknesses concludes that specific religious instructions are unnecessary in written directives and may undermine both the religious and health care goals of patients. (*Am J Public Health*. 1993;83:899-903)

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Death and dying are topics of particular concern in contemporary health care ethics. Technological innovations to prolong life have often served merely to prolong dying. The antipaternalism patients' rights movement, which began in the 1960s, empowered dying patients to control the value-laden medical decisions they must make at the end of life.<sup>1</sup> The move toward a principle of respect for autonomy, evidenced in patient self-determination, focuses on the ability of competent adults to control their own health care decisions. However, how these health care decisions will be made when patients become incompetent is sometimes controversial. Public debate about justice and access to care has focused not only on overtreatment but also on undertreatment and rationing of care. All these issues arise in the context of individual patient concerns about humane and compassionate care.

Because the decisions made at the end of life have deep interpersonal significance, it is not surprising that religion has played an important role in patient and family decision making. Specific religious concerns about death and dying have led to religious advance directives. Advance directives offer a case study of models of interaction between religious communities and secular institutions. This paper examines why such directives have been created and how they may affect health care decisions.

### **Religion, Medicine, and Public Health**

Several national surveys have documented that more than 90% of those polled believe in God, more than 40% attend religious services weekly, and 20% consider religion to be very important in their

lives.<sup>2</sup> Religious beliefs significantly affect how individuals view life, death, and health care. There is a long history of interaction between religion, medicine, and public health policy. Much of that history has been less than amicable as medical ethics and law have attempted to balance the free exercise of religion with various secular governmental goals.<sup>3</sup>

Case studies involving religion and medicine fall along a continuum. At one end, several religious communities have tried to remain completely outside the secular legal system. At the other end, some religious communities have recognized the authority of secular law and have tried to work within the system to obtain legally sanctioned exemptions or protection for specific religious tenets. Some closed religious groups who do not believe in medicine remain completely insulated and totally reject medical care. Other, more open religious groups choose to interact with the secular world but do not seek medical care for themselves. Christian Scientists, who believe in not providing medical care to themselves and their children, have tried to use the secular legal system to protect that belief by enacting specific exemptions to child abuse and neglect statutes.<sup>4</sup> Jehovah's Witnesses have sought medical care for themselves and their children but do not consent to receiving blood or blood products; however, although the courts have upheld the right of these adults to refuse blood for themselves, the courts have not allowed

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parents to “martyr” their children.<sup>5-7</sup> Orthodox Jews actively seek medical care but have used the law to set their own standards for the declaration of death and autopsies.<sup>8</sup> The Roman Catholic hierarchy wants access to all facets of health care for themselves but wish to use the law to ban abortions for all citizens.<sup>9</sup> Following a recent Supreme Court case banning the use of peyote in a ceremonial Native American ritual, a coalition of religious groups have proposed a federal religious freedom act to protect religious practices from unwarranted state intrusion.<sup>10</sup>

### *Death, Dying, and Religion*

Religious hospitals, clergy, community groups, and charities have historically played an important and often central role in the delivery of health care. Although secular law and medical ethics have primarily focused on questions of autonomy, empowerment, and patient’s rights, religions are more concerned with duty, obligation, community, and beneficence.<sup>11</sup> Religiously oriented hospice support has been in the forefront of providing care and comfort to the dying and the bereaved family members. Religion traditionally has been a source of response to questions about the meaning of life and the nature of suffering.

Western religions view death and dying within the broad context of the nature and purpose of human existence. Although most of these religions hold a supreme reverence for the sanctity of life as God given, there is also divine acceptance of the notion of a time to live and a time to die.<sup>12</sup> End of life decision making in a religious tradition is influenced by religious law and spiritual teachings and is made in association with family and the faith community. Clergy often serve as important facilitators of health care decisions.<sup>13</sup>

### *The Patient Self-Determination Act and Advance Directives*

The federal Patient Self-Determination Act<sup>14</sup> took effect on December 1, 1991. This act requires all hospitals, nursing facilities, hospice programs, and health maintenance organizations that serve Medicare and Medicaid patients to provide all their new adult patients with written information describing the patient’s right under state law not only to make decisions about medical care but also to execute a living will or durable power of attorney for health care (health

care proxy). This law has rightly encouraged discussion of advance directives for health care in hospitals, homes, churches, and synagogues.

Advance directives are documents that permit individual patients to direct in advance how they want to be treated should an illness or accident incapacitate them later on. Advance directives are generally of two types. A health care proxy allows people to appoint a specific individual (a health care agent) to make health care decisions for them should they become unable to speak for themselves. A living will specifies in writing the kind of treatment that a patient who has become incapacitated does or does not want.<sup>15</sup>

Each type of advance directive has strengths and weaknesses. Living wills specify what medical interventions might be used to postpone death. However, although such specifics help health professionals know the limits of medical intervention, it is difficult, if not impossible, to predict what future illness, condition, or injury will lead to death. Furthermore, the instructions may not match the clinical complexities of the dying state. In such circumstances, the document must be interpreted if it is not to be ignored. But health professionals may be uncertain whether to assume that anything unstipulated is unwanted and thus perhaps withhold measures that may actually be desired, or to assume the opposite and thus subject the patient to unwanted interventions. Because a simple living will does not ordinarily name a particular person to help interpret patient wishes, conflicts between family, physician, and other health care professionals may ensue.

Health care proxies are more flexible and encompassing in form and practice. The designated health care agent is given complete authority to make any decision the patient might have made if still competent. This authority is not limited by narrow stipulations. However, if the agent is unaware of the scope and limits of the patient’s wishes, he or she will be unable to articulate those wishes. For the health care proxy to work, the patient and the agent must discuss attitudes and beliefs about the perceived goals, burdens, and benefits of therapy beforehand and in detail. Another concern is assurance that the agent can be trusted to carry out patient wishes in good faith. Without a specific written directive, health professionals have no independent verification that the agent is making a true substituted judgment of the patient’s beliefs and desires. Because of the strengths and weaknesses

of both living wills and health care proxies, some have advocated combining the documents.

### *Religious Advance Directives*

Formal religious bodies have been concerned about how to relate the autonomy empowering advance health care directives to their own religious perspectives. The general public has focused primarily on using advance directives to ensure that life-support technologies are either discontinued or not initiated. Many religious groups, however, are equally concerned about undertreatment in the form of premature withdrawal, denial, or withholding of desired life-support technologies. These religious groups are less concerned with the “right to die” than with the obligation to preserve life. Religious groups worry about a medicalization of value claims as an attempt to set objective limits on health care and expenditures and thus devalue life.

Several religious groups have decided to use the Patient Self-Determination Act and advance directives to ensure that appropriate “religiously correct care” is given to incapacitated and vulnerable patients. Concerned that treatment might be discontinued prematurely or for reasons contrary to religious doctrine, these groups have created and distributed their own versions of advance directives, expressly stating what treatments must be provided in specific clinical circumstances. To protect religious goals and objectives, religious doctrine is incorporated into a secular legal document.

One such religious advance directive is the Catholic Health Association Affirmation of Life.<sup>16</sup> This directive explicitly states: “I request that no ethically extraordinary treatment be used to prolong my life.” It then goes on to note: “Ethically extraordinary treatment is treatment that does not offer a reasonable hope of benefit to me.” But although these statements seem to imply that Catholic patients wish to place limits on life-sustaining treatment, the document goes on to state: “No treatment should be used with the intention of shortening my life.”

The Massachusetts Catholic Conference created and distributed a specific religious health care proxy in December 1991,<sup>17</sup> the preface to which states:

Catholics who designate a health care proxy should ensure that such an agent will not only act in fidelity to their personal convictions and preferences where there is legitimate freedom, but

will also act in compliance with the *authentic* teaching of the Catholic Church. (Emphasis added)

The introduction to the proxy notes:

Catholics, together with many people of good will, recognize the sacredness of human life from the first moment of conception to the moment of natural death. Hence we expect that every ordinary effort will always be made to preserve and improve life.

From the section on guiding Catholic teaching, the following guidance is then offered:

Respect for unborn human life requires that life-sustaining treatment be extended to a dying pregnant patient if continued treatment can benefit the child . . . .

Nutrition and hydration should always be provided when they are capable of sustaining life.

If questions arise, the document suggests that further moral guidance can be obtained by conferring with one's pastor. The Massachusetts Catholic Health Care Proxy itself states:

I am a Roman Catholic. It is my wish that my health care agent make health care decisions for me consistent with the *authentic* teaching of the Catholic Church and based upon my profound respect for life and my belief in eternal life. (Emphasis added)

The Agudath Israel of America, a religious body representing a group of Orthodox Jews, has developed its own Jewish Health Care Proxy.<sup>18</sup> This document states:

I am Jewish. It is my desire, and I hereby direct, that all health care decisions for me be made pursuant to Jewish law and custom as determined in accordance with *strict* Orthodox interpretation and tradition. (Emphasis added)

Because of questions concerning how to ascertain the requirements of Jewish law, the proxy continues:

In order to effectuate my wishes, if any question arises as to the requirements of Jewish law and customs in connection with this declaration, I direct my agent to consult with and follow the guidance of the following Orthodox Rabbi. If such Rabbi is unable, unwilling or unavailable to provide such consultation and guidance, then I direct my agent to consult with and follow the guidance of an Orthodox Rabbi referred by the following Orthodox Jewish institution or organization. . . . [or to] [F]ollow the guidance of an Orthodox Rabbi whose guidance on issues of Jewish law and custom my agent in good faith believes I would respect and follow.

The Jewish Health Care Proxy also contains directions about postmortem decisions and instructions about organ and tissue donation for transplant and burial of the dead body.

The Rabbinical Council of America, another religious body representing Orthodox Jews, has created an advance directive that combines a specific directive in the form of a living will with the designation of a health care proxy.<sup>19</sup> It also provides a place to designate which source should have primary authority. If there is a disagreement on Jewish law, the document states that "a prominent Halakhic [Jewish legal] authority must be consulted and shall have final authority." There is also a place to name the preferred rabbinical authority.

### *Strengths and Weaknesses of Religious Advance Directives*

On first impression, specific religious health care advance directives appear to be the solution to concerns about religious preferences in health care decision making. Their advantages parallel those of secularly informed advance directives. These documents are a formal mechanism to make known a person's wishes, values, attitudes, and beliefs. Religious groups have quite properly tried to use the secular legal system to express their religious doctrines. The meshing of secular and religious documents serves to add authority and protection to individual and religious concerns. Religious beliefs about health care decision making can be set out within the context of a broader view of the faith community. Specific religious perspectives and ritual matters can be related to specific medical practices. Religious sensitivities can be honored regarding the line between prolonging life and prolonging death and the distinctions between the quality and the sanctity of life. Religious concerns about the premature termination of desired life-support technologies can be articulated. And open and explicit discourse about religion and health care between patients, families, clergy, and the health care team can be encouraged.

Despite their advantages, however, religious advance directives also have significant weaknesses in the specific articulation of religious concerns. Paradoxically, the stipulation of religious limits on health care decision making may, in fact, limit choices and options and serve to *disempower* the very groups who so desperately seek their religious goals. Religious

groups often wrongly assume that advance directives can only be used to limit or terminate care and then only in the case of terminal illness. But like state laws on patients' rights, the Patient Self-Determination Act does not restrict patients' rights to any clinical circumstances but rather provides for self-determination in all health care decisions. Further, health care proxy legislation affirms the right of every citizen to appoint a health care proxy who, in turn, has the authority to make any treatment decisions that the patient, if competent, would have the authority to make. Such decisions include requesting as well as refusing or discontinuing therapies. Limiting the authority of an agent or requiring that agent to seek explicit religious consultations prior to making decisions restricts the range and flexibility of choices and could lead to controversy and confusion.

Living wills, in their attempt to stipulate specific directives, cause additional problems. No written instruction about medical treatment can cover all the circumstances that may befall a patient. Health care professionals caring for incapacitated patients who have executed a living will may have difficulty interpreting the directives in the context of each unique clinical situation. Who has the authority to interpret the living will directives? Physicians may have a specific bias toward particular types and timings of therapies; for example, an oncologist may interpret a living will quite differently than a gerontologist, a surgeon, or a family primary care physician. Similarly, when faced with catastrophic illness, family and friends may have varied rescue fantasies, fears of loss, or past experiences that significantly affect their interpretations. And a religiously informed advance directive may be given yet a different interpretation by the hospital chaplain and personal clergy.

The Catholic advance directives stipulate that significant differences exist between the exercise of "extraordinary treatment" that does not offer "a reasonable hope of benefit" and the promise that "every ordinary effort will always be made to preserve and improve life." The meaning of *ordinary* and *extraordinary* is problematic in a secular context because value judgments may inform the relative burdens and benefits of "appropriate" versus "heroic" care. For this reason, most secular medical ethicists and legal scholars (as well as courts) have abandoned the distinction. In the religious context, such value-laden definitions must be

informed by an even more complex balancing of such issues as the meaning and significance of pain, suffering, salvation, and faith. When does an extraordinary measure become ordinary? What are the scopes and limits of "ordinary effort[s]" to "preserve and improve life"? What does it mean to require nutrition and hydration if they are "capable of sustaining life"? Would this include major surgery to place special feeding and intravenous catheters in patients who are dying?

Religious advance directives that require treatment to be guided by Jewish law are equally problematic. Applying general Catholic and Jewish laws to specific health care decisions is difficult at best. Even more problematic, however, is the requirement to comply with the "authentic" teaching of the Catholic church and to follow Jewish law and custom according to "strict" orthodox interpretation and tradition. What qualifies as "authentic" or "strict" doctrine, and who is authorized to make that determination? Some religious groups have official and authoritative bodies that issue position papers. Some have a central authority to consult on specific cases. Still other religions have no central authority but rather delegate authority to individual clergy or personal conscience.

Religion played a significant role in the well-known right-to-die case of Karen Quinlan.<sup>20</sup> At issue was the right of Joseph Quinlan, Karen's guardian, to represent Karen's wishes and remove the respirator of his 22-year-old daughter, who lay in a permanent vegetative coma. At trial, Mr. Quinlan was noted to be "deeply religious" and a "communicant" of the Roman Catholic church. In arriving at his decision to request discontinuation of life supports, Mr. Quinlan sought confirmation from his parish priest and the Catholic chaplain of the hospital that such action was consistent with Catholic doctrine (moral values). In support of these religious convictions, the New Jersey Catholic Conference of Bishops submitted an *amicus curiae* (friend of the court) brief. Writing for the group, Bishop Lawrence Casey noted:

The request of plaintiff for authority to terminate a medical procedure characterized as "an extraordinary means of treatment" would not involve euthanasia. This upon reasoning expressed by Pope Pius XII in his "allocutio" (address of November 24, 1957) . . . .

Therefore, the decision of Joseph Quinlan to request the discontinuance of this

treatment is, according to the teachings of the Catholic Church, a morally correct decision . . . .

The right to a natural death is one outstanding area in which the discipline of theology, medicine and law overlap; or, to put it in another way, it is an area in which these three disciplines convene.

Although this joint statement of the Conference of Bishops reflects a broad religious consensus in the *Quinlan* case, there was no specific evidence that these views concurred with Karen's own religious beliefs. Nor was it clear that Karen would have required either consultation beyond her own parish priest or a consensus among bishops. The *Quinlan* court did not require any religious consultation. But had Karen created a religious advance directive, such consultation might have been necessary.

Religious conflict concerning interpretation of religious doctrine has occurred in another important right-to-die case. Paul Brophy was a 48-year-old man who, like Karen Quinlan, lay in a persistent vegetative coma.<sup>21</sup> This case focused on the discontinuation of artificially supplied food and hydration rather than a ventilator. Mrs. Brophy, guardian for her husband, was a deeply religious and devout Catholic. In trying to decide what should be done, she consulted her parish priest, who concurred with the decision to discontinue treatment. In the *Brophy* case, however, there was a variance of views held by unconsulted Catholic clergy regarding the acceptability of this decision.

Had the *Quinlan* or *Brophy* cases involved questions of Orthodox Judaism rather than Roman Catholicism, even greater controversy might have arisen. Rabbi J. David Bleich, an expert on Jewish law and bioethics, wrote a critical commentary on the *Quinlan* case.<sup>22</sup> In response to the question of the right of parents to authorize withdrawal of treatment, Bleich stated that, because Karen was still alive, "from the perspective of Jewish law parents have no standing whatsoever in this matter." Rabbi Bleich continued:

Only the Creator who bestows the gift of life may relieve man of that life even when it has become a burden rather than a blessing . . . . Distinction between natural and artificial means, between ordinary and extraordinary procedures, and between non-heroic and heroic measures recur within the Catholic tradition, but no precisely parallel category exists within Jewish Law. Judaism knows no such distinctions and indeed the very vocabulary employed in drawing such distinctions is foreign to rab-

binic literature . . . . The obligation refers in its medical context, not simply to the restoration of health but to the restoration of even a single moment of life.

Although these right-to-die cases revolve around the authority to withdraw or withhold life-support technologies, equally problematic cases arise when the incapacitated patient's family demands specific medical therapies. Religious doctrines that approach a "vitalist" perspective on life may demand life-sustaining technologies that the medical profession would deem futile. Families may demand the use of "all measures available" to sustain life even if such measures can extend that life by only a few hours. Additionally, the family may demand admission to the often limited space in intensive care units.

Further conflicts can arise when disparate religious beliefs and interpretations are held not only by patients and family members, but also by physicians, nurses, social workers, and other health care personnel. Religious hospitals may have their own standard policies that are dictated by a central religious body. Thus, Roman Catholic or Orthodox Jewish hospitals may set constraints on the decision-making authority of patients, families, health professionals, and administrators.

Can religious advance directives assist in resolving the potential ambiguities and controversies of honoring religious wishes within the context of health care decision making? Although religious health care proxies and living wills are well-intentioned, their vagueness or specificity often undermines their intent. Further, specific instructions can serve to limit the authority of the health care agent in carrying out a patient's wishes. The use of specific religious language in advance directives may be more likely to confuse than to enlighten.

## Solutions

The best way to address the advisory role of religious bodies and to ensure that patients' religious wishes are carried out within the health care setting is to use a standard simple health care proxy form. Appointing an agent without adding specific instructions or restrictions permits the most flexibility and ensures the best outcome. Health care agents are bound to make a substituted decision according to the wishes and values of the incapacitated patient. Those wishes and values include religious beliefs. Further, physicians and

health care professionals are bound to uphold the decisions of the duly appointed agents.

Critical to the success of this solution, however, is a detailed discussion between the patient and the agent concerning specific secular and religious beliefs and values.<sup>23</sup> In such a discussion, clinical examples, value scales, and physician and family involvement are helpful in exploring the limits and goals of therapy.<sup>24</sup> In consenting to serve in the role of proxy, the agent should have accepted the responsibility to learn about explicit patient wishes. The lack of narrowly written directives, however, allows the agent the flexibility to respond to unpredicted circumstances and remain true to the patient's beliefs.<sup>25</sup>

If a patient has concerns about whether a specific agent will follow his or her wishes, perhaps a different agent should be considered. If there is concern about whether the agent will be able to decide on the appropriate religious teaching for a given situation, the agent should be instructed to consult with specific named clergy who understand the patient's religious commitments. Stipulating the clergy in a written directive, however, creates problems unless that clergy has had the opportunity to discuss the individual patient's religious views. Further, the clergy must accept the responsibility and be available to advise the agent. Conflicts between the health care agent and designated clergy may also stymie treatment.

The appointment of an unrestricted health care agent and discussion with that agent about the types of care required and the appropriate persons to consult should meet the needs of religious interests. If there is still concern, however, the last solution may be to consider appointing a specific priest, minister, or rabbi—with their consent—to serve as the health care agent. However, many clergy would feel uncomfortable in the position of legally authorized agent rather than of trusted counselor and would refuse to accept such a role.

The goal of advance directives is not to withdraw or withhold treatment from any specific class of persons. On the contrary, health care directives serve to protect the citizens' right to have their wishes honored regarding health care decisions even when they are incapacitated. Adding specific instructions for care, for religious or other reasons, can be both confusing and unnecessary. A health care agent has the authority to ensure that a patient's

wishes to receive or discontinue therapy are respected. The person chosen to serve as health care proxy and the discussions about health care decision making that ensue are more important than any words of instruction that may be written in a directive.

If religious organizations wish to encourage greater attention to religious teachings in making health care decisions, they should abandon the effort to write specific religious directives. Instead, they should assist people in choosing appropriate health care agents and facilitate communication and understanding between patients, agents, and health care professionals. Patients can be encouraged to seek health care professionals and institutions that share their religious values and commitments even while the patients themselves retain autonomy.

## Conclusion

The case of religious health care advance directives serves as a paradigm for the interrelationship of law, religion, medicine, and public health. As medicine and technology advance, the need to distinguish what *can* be done from what *should* be done will be increasingly important. Patient choice will continue to be informed by both secular and religious values. Religious traditions can serve as an important source of guidance, order, purpose, understanding, meaning, solace, and hope. Clergy, in their chaplain role, may help individuals to comprehend, accept, and explain the underlying motivation for their actions. Religious organizations will continue to lead the way in providing and ensuring humane care and comfort. Discussions of health care decision making can serve as an opportunity for law, medicine, ethics, and theology to work together to protect the interests of patients. □

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