RELIGION AND ADVANCE MEDICAL DIRECTIVES: FORMULATION AND ENFORCEMENT IMPLICATIONS

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This Article examines the role of religion in the creation and enforcement of advance medical directives. It begins by setting out the principal similarities and differences between the two types of such directives—namely, living wills and health care proxies (or powers of attorney). It then considers the formulation of religiously oriented advance directives and their incorporation of religious doctrine and imperatives. The Article then addresses the impact that the religious views of an individual patient’s treating physician might have on such directives. Finally, the Article analyzes religiously based challenges to the enforcement of advance medical directives, paying particular attention to the Terri Schiavo case and its continuing significance.

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I. INTRODUCTION

Since the mid-1970s, patients in the United States have sought various mechanisms for registering their medical treatment preferences when they are unable to communicate those preferences directly. Such documents are typically described as “advance medical directives” and come in two general forms: (1) living wills, which set forth certain limitations on treatment regimens in specific circumstances; and (2) health-care proxies, which designate some named individual to make any treatment decisions required, usually with little or no specific guidelines in the document itself. At this point, every state has authorized one or both of these types of advance directives, and most of the state-by-state variations are relatively minor.1

That said, certain key aspects of such directives underlay any serious consideration of their uses and limitations. First, these documents must be prepared while a person still has legal capacity, even though they take effect only when that person is unable to make and communicate medical-treatment decisions.2 Second, these documents can be changed or even terminated as long as the person who made them has decisional capacity.3 Third, these documents have no effect on any future medical decisions if their maker has the legal capacity to make those decisions directly.4 For example, assume that a person with a terminal illness wants some medical treatment and can communicate that decision. The fact that this person executed a living will indicating that such treatment should not be provided does not preclude this person from now receiving the treatment in question. Health-care directives, in other words, fill the void in medical decision-making when a patient cannot make such decisions, but are limited to that particular situation.

Beyond these rather fundamental parameters, a thorough examination of advance medical directives would entail analyzing particular state-to-state differences dealing with an intriguing constellation of issues, such as the availability of standard forms on various websites, document execution variations (e.g., notarization versus witnesses), limitations on allowable proxies (e.g., attending physician) or witnesses (e.g., legatees and beneficiaries under intestate succession statutes), accessibility of executed forms in various medical settings, portability from one

2. Id. at 31; see also Living Wills and Health Care Proxies, HARVARD HEALTH PUBLICATIONS (July 1, 2005), http://www.health.harvard.edu/staying-healthy/living-wills-and-health-care-proxies (noting that “[a]s long as [a patient is] able to make and communicate [his or her] decisions, [the patient’s] word supersedes anything [the patient has] written or said to others.”).
3. FROLIK & KAPLAN, supra note 1, at 39; see also Advanced Directives, AM. CANCER SOC’Y, http://www.cancer.org/acs/groups/cid/documents/webcontent/002016-pdf.pdf (last modified June 24, 2015) (“Once you make an advance directive, you may change or revoke it . . . at any time while you are competent to do so.”).
4. FROLIK & KAPLAN, supra note 1, at 31; see also Advanced Directives, supra note 3 (“An advance directive will not affect the type or quality of your care while you can voice your own decisions. It only comes into play when you can’t.”).
state to another, and the like. In keeping with the theme of this Symposium, however, this Article focuses instead on the role that religion plays in the formulation and enforcement of advance medical directives. Section II considers religiously oriented advance medical directives; Section III then addresses the impact of physicians' religious views on advance medical directives; and Section IV analyzes the enforcement problems that arise when religion combines with political aspirations. Section V concludes.

II. RELIGIOUS ADVANCE DIRECTIVES

As noted at the beginning of this Article, the two general types of advance medical directives are very different documents. A living will is a relatively brief declaration that in certain, specific situations—often terminal illness or permanent unconsciousness—death-delaying procedures should not be continued. These directives respond directly to many people's fears of being “hooked up to machines” that serve only to maintain some semblance of biological life that the person making the document would deem unacceptable if there is little realistic hope for recovery or improvement. States employ slightly different definitions for the medical conditions that activate living wills, as well as the scope of treatments and medical “procedures” that may not be commenced or continued. But the key point is that living wills are relatively straightforward instruments that address a fairly narrow set of circumstances and make no pretense of covering every possible situation that might arise in the future, especially in light of ever-developing medical interventions and discoveries.

In contrast, health-care proxies or health-care powers of attorney, as they are often styled, generally provide no guidance about what medical treatments are desired and, instead, simply designate an all-purpose decision maker to assess the medical situation as it arises and, in consultation with the treating physician, to make whatever medical-treatment decisions are required. Some health-care-proxy documents include highly generalized imprecations, such as “continue life at all costs,” but most simply indicate who should be asked about what treatments are desired and establish no real criteria for the designee to follow. Often, there is an expectation that the designee will consider the document maker's own values and objectives in making medical decisions, but there are usually no guidelines that inhibit the flexibility the designee has, and that is the intended result.

Against this inexorably legal backdrop, many religious organizations have attempted to modify one or both of the general advance medical directive formats. These modifications incorporate religious teachings

6. Id. at 212.
or provide guidance to ensure that decisions being made on behalf of incapacitated adherents comply with the religious imperatives that those persons would have undoubtedly followed if they could make those decisions themselves. In addition, some religiously affiliated medical institutions, especially hospitals and nursing homes, may impose restrictions on the scope of permissible medical decisions to take account of their religious teachings and strictures. As one astute commentator noted, there is an essential tension between (1) the empowerment of the individual that advance medical directives seek to enable, and (2) the goal of many religions to ensure compliance with their principles and edicts, observing that “[t]he general public has focused primarily on using advance directives to ensure that life-support technologies are either discontinued or not initiated [while m]any religious groups . . . are equally concerned about undertreatment in the form of premature withdrawal, denial, or withholding of desired life-support technologies.”

To that end, some religious organizations have fashioned advance medical directives that state explicitly which medical treatments must be provided in specific clinical situations. Sometimes, these instructions seem inherently contradictory. For example, a directive created by the Catholic Health Association Affirmation of Life provides that “ethically extraordinary treatment,” which it defines as “treatment that does not offer a reasonable hope of benefit” should not be provided, but then states that “[n]o treatment should be used with the intention of shortening my life.” Similarly, a Roman Catholic Health Care Proxy requires that the document maker be given “food and water to sustain my life, including when provided by artificial means . . . [when] I am reasonably expected to live if given food and water,” but the designated agent may discontinue such treatments “when they no longer provide reasonable hope of prolonging my life.”

Other religiously oriented documents set up standards that may be difficult to apply in particular situations. For example, a group representing Orthodox Jewish rabbis has developed a health-care proxy that directs all medical decisions “be made pursuant to Jewish law and custom as determined in accordance with Orthodox interpretation and tradition.” To this end, the form directs the designated agent to consult with a named Orthodox rabbi and “to comply with his halachic decisions.”

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8. Id. at 900.
9. Id.
10. See id. (internal quotations omitted).
11. See id. (internal quotations omitted).
14. Id. at 3, ¶ 3.
also provides for an alternate named Orthodox rabbi in case the first named rabbi is “unable, unwilling or unavailable to provide such consultation and guidance.”15 Similarly, the Roman Catholic Health Care Proxy previously referenced directs the designated agent to make decisions that “are consistent with authentic Roman Catholic ethical, moral and religious principles,”16 though it does not specify how or by whom the authenticity of such principles is to be determined.17

The inevitable result of such religious-doctrine-incorporation provisions is to limit the discretion of the designated proxy to make medically optimal decisions in any particular clinical situation.18 To be sure, death and dying are tough circumstances to contemplate in the best of situations, and the prospect of facing these issues without the ability to communicate or otherwise direct one’s care makes this context even more unsettling. Incorporating religious imperatives may well provide some degree of comfort and general assurance to makers of advance medical directives, and these imperatives might even encourage certain individuals to undertake the difficult process of discussing their treatment preferences and memorializing their decisions in such directives. These are real benefits that should not be denied or trivialized.

At the same time, however, introducing religious perspectives into a setting that is already fraught with emotions and misgivings might further complicate the task of health-care professionals who must apply these directives in specific contexts. As the previously referenced commentator observed, “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.”19 Accordingly, he concludes, “[t]he use of specific religious language in advance directives may be more likely to confuse than to enlighten.”20 Indeed, how can it be otherwise?

Rather than explicitly incorporate religious views or doctrine in advance medical directives, clients would be better advised to carefully consider their choice of designated decision maker and select someone whose religious outlook mirrors theirs.21 This approach accomplishes much, if not most, of what some religiously oriented advance medical di-

15. Id. at 4.
17. Id.; see also Faroque A. Khan, Religious Teachings and Reflections on Advance Directive—Religious Values and Legal Dilemmas in Bioethics: An Islamic Perspective, 30 FORDHAM URB. L.J. 267, 271 (2002) (“Advance directives are permitted as long as the efforts are sincere and the intentions are to abide by Islamic rules and follow the commands of Allah.”).
18. Grodin, supra note 7, at 901–02.
19. Id. at 901.
20. Id. at 902.
21. Cf. 755 ILL. COMP. STAT. 40/20(b)(1) (2012) (providing that decision makers who are designated statutorily rather than in an advance medical directive should consider “the patient’s personal, philosophical, religious and moral beliefs and ethical values relative to the purpose of life, sickness, medical procedures, suffering, and death.”) (emphasis added).
rectives try to provide, without introducing additional administrative uncertainties.

III. RELIGIOUS VIEWS OF TREATING PHYSICIANS

One of the principal purposes of advance medical directives is to stimulate discussions about end-of-life treatment preferences between a client and that person’s physician(s). But a key variable that is usually overlooked in fashioning this paradigm is the religious views of the physician(s). This omission is important because those views might affect what treatment options are discussed during these critical planning sessions. An important study published in one of the leading U.S. medical journals, The New England Journal of Medicine, explored how the religious views of physicians may shape patient interactions regarding “controversial clinical practices.” This study focused on three such practices, the first of which is especially pertinent to this Article—namely, administering terminal sedation to dying patients. The other two controversial practices, incidentally, were providing abortion for a failed contraception and prescribing birth control to adolescent patients without a parent’s approval.

As a general matter, the results of this study were fairly reassuring: sixty-three percent of the physicians who responded to the mail-in survey believe that “it [would] be ethical . . . to plainly describe to the patient why he or she objects to the requested procedure,” but eighty-six percent believe that doctors “have an obligation to present all possible options to the patient, including information about obtaining the requested procedure,” and seventy-one percent believe that “physician[s] have an obligation to refer the patient to someone who does not object to the requested procedure.” On the other hand, a physician’s personal objection to a particular clinical practice does affect these results. Physicians who object to terminal sedation are more likely than non-objectors (sixty-nine percent versus sixty-two percent) to describe their moral objections and more inclined (eighty-nine percent versus seventy-eight percent) to disclose possible options, and much less likely (fifty-eight percent versus seventy-five percent) to refer the patient to other clinicians. That said, only seventeen percent of physicians object to terminal sedation versus fifty-two percent who object to abortion due to failed contraception and

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24. Id. at 595.
25. Id.
26. Id. at 597.
27. Id. at 599.
forty-two percent who object to prescribing birth control to adolescents without parental consent. Thus, the role of physicians’ personal objections may be less consequential in the context of terminal sedation than in the other two procedures simply because such objections are less common.

Nevertheless, a closer look at the survey results reveals important differences depending upon a physician’s “intrinsic religiosity,” frequency of attendance at religious services, and, to a lesser degree, his or her personal religious affiliation. This study defined the somewhat vague criterion of “intrinsic religiosity” as “the extent to which a person embraces his or her religion as the ‘master motive’ that guides and gives meaning to his or her life.” This characteristic was assessed by asking survey subjects whether they agreed with the following two statements:

a. “I try hard to carry my religious beliefs over into all my other dealings in life.”

b. “My whole approach to life is based on my religion.”

If a physician agreed with both statements, that person was categorized as having “high” intrinsic religiosity. Agreeing with only one statement constituted “moderate” intrinsic religiosity, and disagreeing with both statements categorized the respondent as having “low” intrinsic religiosity.

The percentage of physicians who agreed with the proffered responses for the three controversial clinical practices according to the intrinsic religiosity of those physicians is summarized in the following table.

<table>
<thead>
<tr>
<th>Course of Action</th>
<th>Intrinsic Religiosity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>Physicians may describe their moral objections</td>
<td>56</td>
</tr>
<tr>
<td>Physicians are obligated to disclose all possible options</td>
<td>92</td>
</tr>
<tr>
<td>Physicians are obligated to refer the patient</td>
<td>82</td>
</tr>
</tbody>
</table>

As might be expected, the higher the intrinsic religiosity, the more likely the physician believed it is appropriate to describe his or her personal moral objections, the less likely physician will disclose alterna-

28. Id. at 596.
29. Id. at 595.
30. Id.
31. Id.
32. Information adapted by author. Id. at 598.
tive approaches, and the *significantly* less likely that physician will refer the patient to some other health-care provider who might be willing to comply with the requested clinical practice.

The second criterion—namely, frequency of attendance at religious services—was determined on a monthly basis. The percentage of physicians who agreed with the proffered responses for the three controversial clinical practices according to this measure of religious commitment is summarized in the following table.\(^{33}\)

**TABLE 2: PERCENT OF PHYSICIANS WHO AGREE**

<table>
<thead>
<tr>
<th>Course of Action</th>
<th>Monthly Attendance at Religious Services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>Once</td>
</tr>
<tr>
<td>Physicians may describe their moral objections</td>
<td>51</td>
<td>59</td>
</tr>
<tr>
<td>Physicians are obligated to disclose all possible options</td>
<td>94</td>
<td>89</td>
</tr>
<tr>
<td>Physicians are obligated to refer the patient</td>
<td>84</td>
<td>79</td>
</tr>
</tbody>
</table>

Again as might be expected, the greater the degree of religious commitment, at least as measured by regular attendance at religious services, the more likely the physician believed it is appropriate to describe his or her personal moral objections, the less likely that physician will disclose alternative approaches, and the *significantly* less likely that physician will refer the patient to some other health-care provider who might be willing to comply with the requested clinical practice.

Finally, this study classified the responses according to the religion of the responding physician, and those results are shown in the following table.\(^{34}\)

**TABLE 3: PERCENTAGE OF PHYSICIANS WHO WOULD**

<table>
<thead>
<tr>
<th>Religion</th>
<th>Describe Objections</th>
<th>Disclose Options</th>
<th>Refer Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protestant</td>
<td>70</td>
<td>86</td>
<td>65</td>
</tr>
<tr>
<td>Catholic</td>
<td>63</td>
<td>79</td>
<td>66</td>
</tr>
<tr>
<td>Jewish</td>
<td>56</td>
<td>93</td>
<td>80</td>
</tr>
<tr>
<td>Other (Buddhist, Hindu, Mormon, Muslim, etc.)</td>
<td>63</td>
<td>89</td>
<td>71</td>
</tr>
<tr>
<td>None</td>
<td>52</td>
<td>92</td>
<td>88</td>
</tr>
</tbody>
</table>

\(^{33}\) Id.

\(^{34}\) Id.

\(^{35}\) See id. at 595.
This time, the results are less conclusive, other than the expected result that those physicians who did not identify with any religious affiliation were less likely to describe his or her personal moral objections, more likely to disclose alternative approaches, and more likely to refer the patient to some other health-care provider who might be willing to comply with the requested clinical practice. To be sure, the “Other” category includes individuals from very different religious traditions, and the label “Protestant” may similarly be unduly broad.

In any case, this study shows that physicians’ personal religious affiliations and commitment might affect the flow of information that patients receive—an extraordinarily important facet of the advance medical directive paradigm and a critical component of end-of-life care planning generally. As the study’s authors noted in analyzing the study’s results:

“[Patients] should know that many physicians do not believe they are obligated to disclose information about or provide referrals for legal yet controversial treatments . . . . Patients may not have ready access to information about physicians’ religious characteristics and moral convictions. Thus, if patients are concerned about certain interventions . . . , they should ask their doctors ahead of time whether they will discuss such options.”

Given America’s increasing ethnic and religious diversity, the personal religious views of physicians are likely to become a more important consideration in the years ahead.

IV. RELIGIOUSLY FRAMED ENFORCEMENT CHALLENGES

Advance medical directives respond to several independent phenomena, including the incredible development of new medical technologies and therapies that extend biological life, the fear of health-care providers facing malpractice claims for not doing “everything possible,” the effect of third-party payment mechanisms that mitigate cost as a limiting consideration, and the like. But the history of such directives is also inexorably linked with the specter of family-wrenching litigation over unwanted medical care at the end of life.

The famous In re Quinlan case37 spawned the growth of hospital ethics committees and state statutes that authorized living wills to document end-of-life medical treatment preferences when a patient cannot communicate those preferences directly. The U.S. Supreme Court’s landmark decision involving Nancy Cruzan38 similarly stimulated states to authorize health-care-proxy documents to enable citizens to designate a substitute decision maker in advance, as well as health-care surrogacy statutes that provide a prioritized listing of medical decision makers for

36. Id. at 597.
those who did not prepare advance medical directives themselves. The federal government similarly responded to this litigation with the Patient Self-Determination Act, which requires that adult patients who are admitted to a hospital or nursing home be provided with their state’s advance medical directive forms. The clear thrust of these legislative changes was to promote such directives in lieu of heart-wrenching litigation of these sensitive issues.

To be sure, advance medical directives do not completely forestall the prospect of such litigation, but much of their appeal is that, barring someone petitioning the court to establish a formal guardianship, these documents should be largely self-executing. Such expectations, however, were seriously challenged a decade ago when certain religious communities disrupted the enforcement of advance medical directives even though they did not change the ultimate result. That episode also showed that religion can be particularly disruptive when politically ambitious public officials make common cause with religious adherents.

Terri Schiavo was a twenty-seven-year-old woman who lost consciousness briefly in 1990 and lapsed into a persistent vegetative state from which she never recovered. Like most young people, she did not have an advance medical directive, but Florida’s health-care-surrogacy statute designated her husband, Michael, as her health-care proxy and he sought to have her feeding tube removed. Her parents sought to intervene and were able to enlist various conservative politicians and religious organizations on their behalf. During the ensuing litigation, it was brought out that the Catholic Church (Terri Schiavo was Catholic) at the time Terri lapsed into unconsciousness held that withholding artificial nutrition was acceptable in certain cases. Nevertheless, a papal statement on life-sustaining treatment issued fourteen years after that event also entered into the discussion. This sorry tale consumed seven years of litigation before twenty different judges, as well as a special statute passed by the Florida state legislature that authorized then-Governor Jeb Bush to order the reinsertion of Terri’s feeding tube, which he did. That statute was subsequently declared unconstitutional by the Florida Supreme Court.

45. Id. at 1712.
Even Governor Bush’s brother, then-President George W. Bush, became involved in this case. He encouraged the U.S. Congress to take up Terri Schiavo’s case and flew back to the nation’s capital to sign emergency legislation that was enacted on her behalf. The U.S. Senate actually met in a special emergency session on a Sunday (!) during their spring recess to pass a law that applies only to Terri Schiavo. This legislation did not change any of the underlying applicable statutes regarding advance medical directives or health-care surrogacy, but merely provided that a federal district court had jurisdiction to hear any claim “relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain [Terri Schiavo’s] life.” It further provided that any “parent of Theresa Marie Schiavo shall have standing to bring a suit under this Act.” This federal legislation cautioned that “[n]othing in this Act shall be construed to create substantive rights not otherwise secured” by existing law and that this new law did not “constitute a precedent with respect to future legislation, including the provision of private relief bills.” In the end, Terri’s husband prevailed in every court that dealt with the case and eventually had Terri’s feeding tube withdrawn.

Nevertheless, the entire episode raises questions about the ultimate enforceability of advance medical directives and whether executing such directives is worth the effort entailed if religious considerations can so disrupt their effectuation. A much less publicized but similarly revealing case involved a man named Hugh Finn in Virginia. As the attorneys who represented Mr. Finn reported, lawyers should be alert to possible misuse of religious perspectives, especially when conflicts arise between a family’s priest and the local Catholic parish.

To that end, it is extremely important to note that following the Schiavo case, no new laws or other changes in advance medical directives were made. In other words, the underlying law was clear, but religion—especially when combined with politics—can seriously interfere with the operation of these directives, a troubling prospect that remains unabated to this day.

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48. Id. § 1, 119 Stat. at 15.
49. Id. § 2, 119 Stat. at 15.
50. Id. § 5, 119 Stat. at 16.
51. Id. § 7, 119 Stat. at 16.
54. Hampson & Emanuel, supra note 43, at 975; Annas, supra note 44, at 1714.
Advance medical directives seek to empower individuals to determine their medical-treatment preferences when they have lost the fundamental ability to make those preferences known. Religious concerns can never be completely disengaged from a subject as inherently personal as one’s medical care near the end of life, but such concerns have the potential to erode the efficacy of advance medical directives by (1) complicating the communicative function of these directives, and (2) introducing additional, perhaps preemptive, considerations when family members have differing religious outlooks. While some religious concerns can be addressed through careful selection of a designated medical decision maker, enforcement problems are much less easily accommodated and remain an issue affecting the ultimate utility of advance medical directives.