

RELIGION AND END-OF-LIFE DECISION-MAKING

Naomi Cahn*
Amy Zietlow**

This Article analyzes the relationship between religion and end-of-life care. We examine the private role that religion plays in individuals' decision-making processes and the public role that religion plays through state support. We first discuss how the law approaches these issues by looking at both the legal grounding and ratification of surrogates' decisions, and at public funding for hospice chaplains, showing that the law supports an individual's choices concerning the desired impact (or nonimpact) of religious beliefs and practices. We then show how these laws are interpreted and lived, specifically in how surrogates handle end-of-life decision-making, based on empirical data obtained directly through in-depth interviews with those who have experienced the death of their parents. Religion profoundly affects end-of-life decision-making on a personal level, and various laws support religious-based reasoning. On the other hand, the present uncertainties surrounding the application of Hobby Lobby can compound the traumatic experiences of those involved, regardless of their religious (or nonreligious) beliefs and practices. Solutions involve additional legal support for end-of-life conversations.

* Harold H. Greene Professor of Law at George Washington University Law School.

** Affiliated Scholar with the Institute for American Values where she led *Homeward Bound*, a foundation-funded study of Generation X caregiving and grieving. She is ordained in the mainline Evangelical Lutheran Church of America.

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Keith’s father was dying. Keith was the oldest son, but he was emotionally estranged from his father. So were all of his siblings. But as Keith’s father lay comatose in a hospital bed, everyone, including his aunts and his full and half siblings, agreed to name Keith the decision maker. The hospital physician informed Keith of his father’s prognosis, explaining that there was nothing more that could be done to revive him. The medical staff waited for Keith’s directive for whether to remove life-sustaining measures. Here is Keith’s description of how he made his decision:

I prayed on it. You know, Lord, 6:00, it’s going to be your will . . . And I did learn death come[s] when God decides—designated it to come, not when we want to. I was talking to [my dad]. I was holding his hand, telling him I love him. That’s the main thing. Just told him I loved him and kissed him before the doctor pulled the plug.

Keith’s experiences poignantly depict the themes we address in this paper: he used private religious practice as a means to help direct his course of action, yet, at the same time, Keith’s religious beliefs intersected publicly with legal and medical decision-making. While not explicitly acknowledged by Keith, his specific choices on behalf of his father fit into a broader framing of medical care in the United States, where medicine and religion have historically been closely intertwined: consider practices ranging from healing rites to exorcisms, and the role of religious orders in operating hospitals from medieval times to the present.¹ Most

1. Stacey A. Tovino, *Hospital Chaplaincy Under the HIPAA Privacy Rule: Health Care or “Just Visiting the Sick”?*, 2 IND. HEALTH L. REV. 51, 59 (2005); see Robin Fretwell Wilson, *Essay: The Lim-*

medical schools offer courses on spirituality and health,² even though many health-care professionals feel uncomfortable discussing these issues.³ Most patients want some form of spiritual care, and in regards to end-of-life decision-making, religious affiliation can play a determining factor.⁴

Our starting point for this Article is as a contribution to a symposium on Law, Religion and the Family Unit After *Hobby Lobby*, so we use the case as an opportunity for an inquiry into the role of religion and spirituality in end-of-life care, a time when religious beliefs may profoundly affect not just individuals' choices about treatment, but also institutions' provision of care.⁵ We explain how the present legal uncertainties can compound the traumatic experiences of those involved, showing both the private role that religion plays in individuals' decision-making processes, and the public role that religion plays through the state.⁶ Our goal is to show how the legal system both supports individualized expressions of religion, but also has the ability to complicate those expressions.

We first discuss the legal grounding for surrogates' decisions, and then consider hospice care, showing that the law supports an individual's

its of Conscience: Moral Clashes over Deeply Divisive Healthcare Procedures, 34 AM. J.L. & MED. 41, 41 (2008).

2. Laura Landro, *Health Matters: Medicine's Growing Spirituality*, WALL ST. J., (Dec. 8, 2013, 4:32 PM), <http://www.wsj.com/articles/SB10001424052702304854804579236053907496062>; see Christina Puchalski et al., *Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference*, 12 J. PALLIATIVE MED. 885 (2009).

3. Michael J. Balboni et al., *Nurse and Physician Barriers to Spiritual Care Provision at the End of Life*, 48 J. PAIN & SYMPTOM MGMT. 400, 401, 407 tbl.4 (2014), available at <http://projects.iq.harvard.edu/files/rshh/files/barriers.pdf>; Vyjeyanthi S. Periyakoil et al., *No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients*, PLOS ONE 9 (Apr. 22, 2015), <http://www.plosone.org/article/doi/10.1371/journal.pone.0122321&representation=PDF> (citing religio-spiritual beliefs as one of the top barriers physicians name for end-of-life conversations). Studies show that physicians rarely discuss spiritual concerns. See, e.g., Judith E. Nelson et al., *Patient Rate Physician Communication About Lung Cancer*, 117 CANCER 5212, 5212, 5217 tbl.2 (2011).

4. See, e.g., Sarah R. Alcorn, "If God Wanted Me Yesterday, I Wouldn't Be Here Today": *Religious and Spiritual Themes in Patients' Experiences of Advanced Cancer*, 13 J. PALLIATIVE MED. 581, 581 (2010). Surrogates draw support and comfort from their religious beliefs. Kathleen M. Boozang, *An Intimate Passing: Restoring the Role of Family and Religion in Dying*, 58 U. PITT. L. REV. 549, 560-61 (1997); see also PEW RES. CTR., VIEWS ON END-OF-LIFE MEDICAL TREATMENTS 8 (2013), <http://www.pewforum.org/files/2013/11/end-of-life-survey-report-full-pdf.pdf> ("Personal preferences about end-of-life treatment are strongly related to religious affiliation . . .").

5. *Burwell v. Hobby Lobby Stores, Inc.*, 134 S. Ct. 2751 (2014) concerned the impact of the Religious Freedom Restoration Act on a private, for-profit corporation. See generally, Ira C. Lupu, *Moving Targets: Obergefell, Hobby Lobby, and the Future of LGBT Rights*, 7 ALA. C.R. & C L. REV. (2015) (discussing goals of RFRA). State constitutions and mini-RFRAs may also have consequences for end-of-life care, but those consequences are beyond the scope of this paper.

6. Notwithstanding the ubiquity of state statutes directing the surrogate decision maker to consider religious/moral beliefs, the legal issues involving end-of-life care and religion have been studied little. The definitive article is from 1997. See generally Boozang, *supra* note 4. Of course, the impact of religion on other health-care issues has received more attention. See, e.g., Robin Fretwell Wilson, *The Calculus of Accommodation: Contraception, Abortion, Same-Sex Marriage, and Other Clashes Between Religion and the State*, 53 B.C. L. REV. 1417, 1498 (2012). Indeed, "[t]he problem of morality in medicine is anything but straightforward." Elizabeth Sepper, *Taking Conscience Seriously*, 98 VA. L. REV. 1501, 1553 (2012).

choices concerning the desired impact (or nonimpact) of religious beliefs and practices. The second section shows how these laws are interpreted and lived, specifically in how surrogates handle end-of-life decision-making,⁷ based on empirical data obtained directly through in-depth interviews with those who have experienced the death of their parents.⁸ We find that surrogates use religion to guide them in determining what the patient would have wanted, and then to support them through the decision as they move forward. At the end of the essay, we offer some speculation on the potential effect of *Burwell v. Hobby Lobby*⁹ on religious expression at the end of life.¹⁰

I. PUBLIC ROLE OF RELIGION AND SPIRITUALITY¹¹

More than three-quarters of American patients would like spiritual issues discussed as part of their care.¹² In this Section, we explore two ways in which the law recognizes the impact of religion on end-of-life issues.

A. State Guidance on Surrogate Decision-Making

Written directives provide guidance for when a patient is unable to make her own health-care choices, offering a structure for surrogate decision makers. Despite the many reasons for advanced care planning,

7. In a companion article, we address planning for the caregiving process. Amy Zietlow & Naomi Cahn, *The Honor Commandment: Law, Religion, and the Challenge of Elder Care*, 30 J. L. RELIG. 229 (2015) [hereinafter Zietlow & Cahn, *The Honor Commandment*].

8. All names and identifying characteristics of study participants have been changed to protect their privacy.

9. 134 S. Ct. 2751 (2014).

10. In *Hobby Lobby*, the Court summarized the relevant provisions of the Religious Freedom Restoration Act as: “[L]aws [that are] ‘neutral’ toward religion . . . may burden religious exercise as surely as laws intended to interfere with religious exercise.” *Burwell*, 134 S. Ct. at 2761 (quoting 42 U.S.C. § 2000bb(a)(2) (2012)). If the Government substantially burdens a person’s exercise of religion, under the Act that person is entitled to an exemption from the rule unless the Government “demonstrates that application of the burden to the person—(1) is in furtherance of a compelling governmental interest; and (2) is the least restrictive means of furthering that compelling governmental interest.” § 2000bb-1(b), *invalidated by* *City of Boerne v. Flores*, 521 U.S. 507 (1997). “For a burden on religion to count as legally relevant, it must involve actual conflict between a person’s legal interests and his or her religious practices.” IRA C. LUPU & ROBERT W. TUTTLE, *SECULAR GOVERNMENT, RELIGIOUS PEOPLE* 241 (2014) (citing *Burwell*, 134 S. Ct. at 2761) [hereinafter *SECULAR GOVERNMENT*].

11. Defining spirituality and contrasting it to religion is a complex endeavor. *See, e.g.*, Thomas A. Schweitzer, Bruce Ledewitz, *American Religious Democracy: Coming to Terms with the End of Secular Politics*, 23 *TOURO L. REV.* 561, 572–73 (2007) (book review); Hugo Kamya, *Engaging Spirituality in Family Conflict: Witnessing to Hope and Dialogue*, 26 *J. AM. ACAD. MATRIMONIAL LAW.* 15, 18 (2013); *see also* *U.S. v. Seeger*, 380 U.S. 163, 174 (1965) (labeling “the task of discerning the intent of Congress in using the phrase ‘Supreme Being’ a complex one . . . [that] is not made the easier by the richness and variety of spiritual life in our country.”); Evan R. Seamone, *Divine Intervention: The Ethics of Religion, Spirituality, and Clergy Collaboration in Legal Counseling*, 29 *QUINNIPIAC L. REV.* 289, 308 (2011) (“The legal profession largely avoids both religion and spirituality . . .”).

12. Stacey A. Tovino, *Hospital Chaplaincy Under the HIPAA Privacy Rule: Health Care or “Just Visiting the Sick?”*, 2 *IND. HEALTH L. REV.* 51, 51 (2005) (citing Laurel A. Burton & Marcia Sue DeWolf Bosek, *When Religion May Be an Ethical Issue*, 39 *J. RELIGION & HEALTH* 97, 97 (2000)).

most people have not done so; they do not have any of their preferences about end-of-life decision-making in writing, and they have not even spoken with family members or their doctors about their wishes.¹³ Surveys report that among severely or terminally ill patients, fewer than fifty percent have an advance directive in their medical record,¹⁴ as do only twenty-eight percent of home-health-care patients.¹⁵ By contrast, as patients become more involved with health care professionals, they become more likely to have an advance directive: sixty-five percent of nursing home residents and eighty-eight percent of hospice-care patients have filled out an advance directive.¹⁶ While the number of those completing advanced directives remains low, the exposure to end-of-life issues is relatively high. In 2013, forty-seven percent of U.S. adults said that they have had a friend or relative who has had a terminal illness or been in a coma in the past year, and half of that forty-seven percent reported that issues of withholding life-sustaining treatment arose for their loved one.¹⁷ Seventy-eight percent of U.S. adults say that a family member should be allowed to make end-of-life decisions on behalf of a loved one who is unable to communicate his or her decisions.¹⁸

In the absence of patient-completed directives, surrogates draw on a wide variety of other tools, both formal and informal. States generally have laws that establish a hierarchy of default health-care decision makers for any medical decision that must be made while the person is incapacitated. Under these statutes, spouses, sometimes along with recognized domestic partners, are generally listed first. For example, Louisiana law sets out a list of people who can authorize surgical or medical treatment, with priority given to the individual herself, then a court-appointed guardian, followed by family members: a spouse who is not legally separated from the patient; an adult child; the patient's parents; the patient's siblings; then, other relatives.¹⁹ If there are no family members who can act, Louisiana authorizes an adult friend,²⁰ someone who is familiar with the patient's wishes, to act; followed by, among others, an interdisciplinary team of professionals.²¹ Under certain circumstances, then, the treating physician is given discretion to move forward with the medical pro-

13. JM Clements, *Patient Perceptions on the Use of Advance Directives and Life Prolonging Technology*, 26 AM. J. HOSPICE & PALLIATIVE CARE 270, 271 (2009). "Of 306 participants, 77 (25.2%) had a durable power of attorney and 45 (14.7%) had living wills. Of these, 226 (73.9%) responded it was important to make healthcare wishes known to their doctor. Only 36 (15.9%) had done so." *Id.* at 270.

14. WF Benson & N. Aldrich, *Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself*, Critical Issue Brief, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/aging> (last visited Feb. 21, 2016).

15. *Id.*

16. *Id.*

17. Pew Res. Ctr., *Views on End-of-Life Medical Treatments*, PEW FORUM (Nov. 21, 2013), <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments>.

18. *Id.*

19. LA. REV. STAT. ANN. § 40:1299.53A (2015).

20. *Id.*

21. *Id.*

cedure.²² The surrogate is then responsible for making the best decision for the incapacitated person.²³

End-of-life decision making raises a set of distinct issues. The parameters of the decisions authorized, including whether an individual can choose to end life-sustaining treatment and what rights her surrogate has to make the choice on her behalf, have been framed by numerous high-profile court cases over the past few decades.²⁴ While a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment, when another seeks to act on an incapacitated person's behalf, the interests of the state come into play.²⁵ For end-of-life decision-making, many states require clear and convincing evidence for withdrawal of life support, preferring prolonging life as a default. The burden of proof in other states might be the lesser one of a preponderance of the evidence.²⁶

States differ on the substantive standard for how the surrogate must establish the appropriate outcome. Some states use best interests; others use "substituted judgment," a standard based on what the patient would choose if she could speak on her own behalf. Some states have developed a hybrid that allows the surrogate to exercise substituted judgment when the patient's wishes are known, but to make a decision in the patient's best interests where these wishes are unknown.²⁷ Courts consider a variety of written and oral evidence if the surrogate's decision is challenged, such as any information about the patient's preferences, her religious beliefs, etc.²⁸ Relatively few cases involving religion and surrogate decision-making appear in court. When they do, they typically have two elements:

22. LA. REV. STAT. ANN. § 40:1299.53C.

23. See Shana Wynn, *Decisions by Surrogates: An Overview of Surrogate Consent Laws in the United States*, 36 BIFOCAL 10, 12 (2014), available at <http://www.americanbar.org/content/dam/aba/publications/bifocal/BIFOCALSeptember-October2014.authcheckdam.pdf>. For a guide, see THE AM. BAR ASSOC. COMM'N ON LAW & AGING, MAKING MEDICAL DECISIONS FOR SOMEONE ELSE: A HOW-TO GUIDE, available at http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_bk_proxy_guide_gen.authcheckdam.pdf.

24. See, e.g., *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

25. *Id.* at 281–82; Judith D. Moran, *Families, Courts, and the End of Life: Schiavo and Its Implications for the Family Justice System*, 46 FAM. CT. REV. 297, 300 (2008).

26. See Lois Shepherd, *The End of End-of-Life Law*, 92 N.C. L. REV. 1693, 1703–04 (2014). The Louisiana statute does not specify the applicable standard. See LA. REV. STAT. ANN. § 40:1151 (2015). In a few states, surrogates are permitted to make decisions based on the patient's best interests. Shepherd, *supra*, at 1702.

27. Lawrence A. Frolik & Linda S. Whitton, *The UPC Substituted Judgment/Best Interest Standard for Guardian Decisions: A Proposal for Reform*, 45 U. MICH. J.L. REFORM 739, 739 (2012); Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique*, 42 GA. L. REV. 979, 986 (2008) (explaining that states sometimes use a hybrid approach that combines the two); see, e.g., UNIF. HEALTH-CARE DECISIONS ACT §§ 2(e), 5(f) [hereinafter UHCDA]. Indiana, for example, uses a best interest approach. IND. CODE ANN. § 16-36-1-5(d) (2015). While some states explicitly set out the appropriate standard, others, such as Louisiana, are silent.

28. See *infra* text accompanying notes 30–39.

first, family members with conflicting opinions; and second, inadequate documentation (of the patient's wishes).²⁹

States may explicitly require, as part of a substituted judgment standard, that the surrogate act after a review of the patient's religious and ethical beliefs.³⁰ And courts have used the patient's religion—or lack thereof—as a guiding factor. Legal conflicts have been resolved by measuring the fervency and frequency of an individual's historically documented religious practices, such as membership in a congregation, frequency of attendance at worship services, and observance of religious holidays, as supporting evidence for whether the religious beliefs of the individual should be taken into consideration.³¹ Consider two New York cases. In *S.I. v. R.S.*, the patient's siblings claimed that his wife was not acting in accordance with his Jewish faith in terminating treatment.³² The court considered—and evaluated—the patient's own religious beliefs,³³ and considered whether his request that a Jewish ambulance service be called indicated his preference for life-preserving measures.³⁴ Ultimately, the court found that, although the patient did want an Orthodox Jewish funeral, there was no evidence to show he otherwise adhered to Orthodox Jewish beliefs concerning end-of-life care.³⁵ The court upheld the wife's choices.³⁶ In a later case, a judge used a patient's Catholicism as a basis for continuing life-sustaining treatment.³⁷ Although she had executed various advance medical directives, her children disagreed on the appropriate outcome.³⁸ The court engaged in a long explanation of Catholic doctrine on end-of-life care as it applied to New York surrogacy law, ul-

29. Stanley A. Terman, *It Isn't Easy Being Pink: Potential Problems with POLST Paradigm Forms*, 36 *HAMLIN L. REV.* 177, 183–84 (2013).

30. *E.g.*, as New York's provides, "After consultation with a licensed physician . . . , the agent shall make health care decisions: (a) in accordance with the principal's wishes, including the principal's religious and moral beliefs . . ." N.Y. PUB. HEALTH LAW § 2982(2) (McKinney 2015); Borenstein v. Simonson, 797 N.Y.S.2d 818, 828 (S. Ct. 2005) (siblings v. daughter); *see* 755 ILL. COMP. STAT. ANN. 40/20(b)(1) (2015) (directing that surrogates use substituted judgment, based, in part, on "the patient's personal, philosophical, religious, and moral beliefs and ethical values relative to the purpose of life, sickness, medical procedures . . ."). The Uniform Health Care Decisions Act requires that the surrogate consider the principal's "personal values." UHCDA § 5(f). Guardianship law may require similar considerations. *See, e.g.*, MINN. STAT. ANN. § 524.5-313(c)(4)(i) (2015) ("The guardian shall not consent to any medical care for the ward which violates the known conscientious, religious, or moral belief of the ward."). *In re* Guardianship of Tschumy, 834 N.W.2d 764, 775 (Minn. Ct. App. 2013), *aff'd*, 853 N.W.2d 728 (Minn. 2014) (noting the need to consider the ward's religious wishes, even though they were unknown, and authorizing termination of life support systems).

31. *See infra* notes 32–39.

32. *S.I. v. R.S.*, 877 N.Y.S.2d 860, 863 (S. Ct. 2009).

33. Beliefs tend to be defined by theological statements or creeds, whereas S.I.'s religious beliefs were measured by his observed practices. *See* Melinda Lundquist Denton, *Family Structure, Family Disruption, and Profiles in Adolescent Religiosity*, 51 *J. FOR THE SCI. STUDY OF REL.* 42 (2012).

34. *S.I.*, 877 N.Y.S.2d at 865.

35. *Id.*

36. *Id.* at 866.

37. *In re* Zornow, 919 N.Y.S.2d 273, 276 (S. Ct. 2010), *decision clarified*, 943 N.Y.S.2d 795 (S. Ct. 2011).

38. *Id.* at 277.

timately revoking the medical orders that appeared contrary to the patient's religious beliefs.³⁹

B. Hospice

Beyond its support for surrogates using religion as a factor in their decision making, the law provides additional recognition that spirituality plays an important role in end-of-life decision-making through the Medicare Hospice Benefit. Over the last thirty years, end-of-life care has become increasingly associated with hospice, which is a form of intensive palliative care that focuses on end-of-life treatments;⁴⁰ the patient's physical location (at home, in a nursing home or other facility, or even in a hospital) is irrelevant.⁴¹

Under current Medicare rules, hospice care has been limited to beneficiaries whose doctors determine that they have less than six months to live and who agree to not pursue any further life-prolonging treatment related to their disease.⁴² On the other hand, more than ten percent of hospice patients receive care for more than six months.⁴³ The hospice philosophy of care acknowledges that pain can be physical, emotional, financial, relational, *and* spiritual;⁴⁴ thus hospice organizations utilize an interdisciplinary group of specially trained providers—such as nurses, social workers, and chaplains, who respond to, and treat, dying patients' pain and other symptoms,⁴⁵ but do not seek to cure the underlying disease.⁴⁶ Unlike other forms of medical care, hospice considers both

39. In another case involving an intra-family dispute (siblings v. daughter), the court engaged in a long disquisition on Orthodox Jewish end-of-life approaches. *Borenstein v. Simonson*, 797 N.Y.S.2d 818, 830 (S. Ct. 2005).

40. For a brief history of the hospice movement in the United States, see *History of Hospice Care*, NAT'L HOSPICE & PALLIATIVE CARE ORG., <http://www.nhpc.org/history-hospice-care> (last visited Feb. 21, 2016).

41. The National Hospice and Palliative Care Organization estimates that more than 1.5 million patients are served by hospice each year. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO'S FACTS AND FIGURES: HOSPICE CARE IN AMERICA, 2014 EDITION (2014), available at http://www.nhpc.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf [hereinafter NHPCO FACTS AND FIGURES 2014].

42. See Michal Ash & Stephen Arons, *Economic Parameters of End-of-Life Care: Some Policy Implications in an Era of Health Care Reform*, 31 W. NEW ENG. L. REV. 305, 312–13 (2009) (explaining that hospice benefits are available under Medicare, and, while it is not mandated under Medicaid, most states make it available as a benefit); Kathy L. Cerminara, *Pandora's Dismay: Eliminating Coverage-Related Barriers to Hospice Care*, 11 FL. COASTAL L. REV. 107, 124 (2010); *Medicare Hospice Payment Reform: A Review of the Literature*, ABT ASSOCIATES INC. 7 (May 1, 2014), <http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Downloads/MedicareHospicePaymentReformLiteratureReview2013Update.pdf>.

43. NHPCO FACTS AND FIGURES 2014, *supra* note 41, at 5.

44. *Id.* at 3.

45. See, e.g., STEVEN R. CONNOR, HOSPICE AND PALLIATIVE CARE: THE ESSENTIAL GUIDE (2d ed. 2009); Cerminara, *supra* note 42; Kathy L. Cerminara, *Hospice and Health Care Reform: Improving Care at the End of Life*, 17 WIDENER L. REV. 443 (2011); Joshua E. Perry & Robert C. Stone, *In the Business of Dying: Questioning the Commercialization of Hospice*, 39 J.L. MED. & ETHICS 224, 226 (2011); Ryan A. Walsh, Note, *A Matter of Life, Death, and Children: The Patient Protection and Affordable Care Act Section 2302 and a Shifting Legal Paradigm*, 86 S. CAL. L. REV. 1119, 1123 (2013).

46. E.g., Cerminara, *Hospice and Health Care Reform*, *supra* note 45, at 450.

the patient *and* the family as the unit of care. For example, hospice requires the provision of bereavement services to families for at least one year after the death of the patient.⁴⁷

Medicare⁴⁸ sets out two specific requirements concerning spirituality. First, it requires that hospice units assess a patient's spiritual needs⁴⁹ and provide "spiritual counseling."⁵⁰ While the nature of the spiritual assessment is not explicitly defined in the applicable regulations, the notice of proposed rulemaking explained that such assessments "should not be solely related to religious affiliation (or lack thereof)," but should instead be broader, and "might focus on a patient's sense of peace, purpose, beliefs, etc., but may not be warranted for all patients, particularly if they already have an available spiritual/emotional support system."⁵¹ Second, the interdisciplinary hospice group must include a "pastoral or other counselor,"⁵² who is an employee of the hospice.⁵³

Government support for such spiritual counseling may be considered "legally questionable" under the Establishment Clause;⁵⁴ indeed, the

47. (1) *Bereavement counseling*. The hospice must: "(i) Have an organized program for the provision of bereavement services furnished under the supervision of a qualified professional with experience or education in grief or loss counseling. (ii) Make bereavement services available to the family and other individuals in the bereavement plan of care up to 1 year following the death of the patient . . . (iii) Ensure that bereavement services reflect the needs of the bereaved." 42 C.F.R. § 418.64(d)(1) (2014). Although bereavement counseling is required, it is not reimbursable. 42 C.F.R. § 418.204(c) (2014).

48. Congress created the Hospice Medicare benefit in the Tax Equity and Fiscal Responsibility Act of 1982, which became permanent in 1986. *History of Hospice Care*, NAT'L HOSPICE & PALLIATIVE CARE ORG., <http://www.nhpco.org/history-hospice-care> (last updated July 23, 2015). The Medicaid hospice benefit is an optional state plan that tends to follow the conditions of participation as set by Medicare, and its interdisciplinary team requirements include "at least one pastoral or other counselor." 42 U.S.C. § 1395x(dd)(2)(B)(i) (2012). According to the Hospice Directory: "Nearly all states and the District of Columbia offer hospice coverage under Medicaid. In general, Medicaid hospice benefits parallel the Medicare benefit, although there may be some variations in certain states." *Paying for Hospice: Medicare/Medicaid/More Options*, HOSPICE DIRECTORY, <http://www.hospicedirectory.org/cm/about/paying> (last visited Feb. 16, 2016); see 42 U.S.C. § 1395x(dd)(1) (defining "hospice care").

49. 42 C.F.R. § 418.54 (2015).

50. 42 C.F.R. § 418.64(d)(3). Hospices are required to offer counseling services, which consist of bereavement counseling, dietary counseling, and spiritual counseling. *Id.* § (d). On the other hand, hospices receive no payment for bereavement counseling, and no reimbursement when other forms of counseling are treated as "separate services." 42 U.S.C. § 1395f ("[N]o payment may be made for bereavement counseling and no reimbursement may be made for other counseling services (including nutritional and dietary counseling) as separate services."); see Muriel R. Gillick, *How Medicare Shapes the Way We Die*, 8 J. HEALTH & BIOMEDICAL L. 27, 30 (2012).

51. Medicare and Medicaid Programs: Hospice Conditions of Participation, 73 Fed. Reg. 32,088, 32,096 (June 5, 2008) [hereinafter *Hospice Conditions of Participation*].

52. 42 C.F.R. § 418.56(a)(1)(iv); see Elaine Wittenberg-Lyles et al., *Communication Dynamics in Hospice Teams: Understanding the Role of the Chaplain in Interdisciplinary Team Collaboration*, 11 J. PALLIATIVE MED. 1330, 1330 (2008). More than half of hospice chaplains serve as professional volunteers, receiving no payment. *Id.* at 1330–31. In 2001, the National Hospice and Palliative Care Organization developed voluntary recommendations for hospice chaplains' qualifications and practices. *Id.* at 1330. In 2004, the Council for Collaboration, comprised of American and Canadian professional certification bodies for pastoral care, developed common standards for professional chaplains, although many (40%) do not have clinical pastoral counseling training. *Id.* at 1330–32.

53. 42 U.S.C. § 1395x(dd)(2)(B).

54. See, e.g., *Malyon v. Pierce Cnty.*, 935 P.2d 1272 (Wash. 1997) (en banc) (specifically challenging public support for sheriff department's voluntary chaplaincy service); Mary Jean Dolan, *Govern-*

initial notice proposing regulations that would require hospices to include spiritual counseling explicitly addressed this issue, analogizing spiritual counseling to other public payments for nonmedical care when patients' religious beliefs caused them to reject traditional medical care.⁵⁵ More generally, courts have repeatedly found that the Establishment Clause does not forbid chaplains in the legislature,⁵⁶ in the military,⁵⁷ nor in prisons.⁵⁸ Federal hospice regulations specify that spiritual counseling is a core service that should be provided by hospice employees in accordance with the plan of treatment.⁵⁹ Moreover, the mechanism of funding provides some insulation from Establishment Clause claims. First, the government does not pay the hospice chaplains but requires their presence, and the government provides per patient Medicare reimbursement. This is a kind of voucher, beneficiary choice funding, somewhat akin to the school voucher system already upheld by the Supreme Court.⁶⁰ Second, the chaplains are private, not public employees, so not directly analogous to the military and prisons settings, in which the government hires a chaplain and directly pays the salary. Third, however, hospice is akin to the military and prisons in the sense of confinement and immobility; the dying patient and cannot readily go to her own spiritual counselor. On the other hand, the patient or her guardian is permitted to reject

ment-Sponsored Chaplains and Crisis: Walking the Fine Line in Disaster Response and Daily Life, 35 HASTINGS CONST. L.Q. 505, 507 (2008) (noting the paucity of decisions challenging the constitutionality of publicly supported chaplains). On taxpayer standing, see, e.g., Bryan Dearing, *The Future of Taxpayer Standing in Establishment Clause Tax Credit Cases*, 92 OR. L. REV. 263, 321 (2013).

55. The notice of rulemaking explained that "relevant jurisprudence" was not an obstacle to public funding for spiritual counseling. Medicare and Medicaid Programs: Hospice Conditions of Participation, 70 Fed. Reg. 30,840, 30,871 (proposed May 27, 2005) (to be codified at 42 C.F.R. pt. 418) (citing *Kong v. Scully*, 341 F.3d 1132 (9th Cir. 2003)), *opinion amended on denial of reh'g*, 357 F.3d 895 (9th Cir. 2004)). *Kong* held that Medicare payments to religious nonmedical healthcare institutions—the most prominent of which are operated by Christian Scientists—did not violate the Establishment Clause. *Kong*, 341 F.3d at 1141. The opinion noted an earlier case that had upheld a challenge to the original Medicare and Medicaid statutes because they explicitly addressed payment to Christian Scientist sanatoria. *Id.* at 1137 (citing *Children's Healthcare is a Legal Duty, Inc. v. Vladeck*, 938 F. Supp. 1466, 1485 (D. Minn.1996)). See Ira C. Lupu & Robert W. Tuttle, *The Forms and Limits of Religious Accommodation: The Case of Rluipa*, 32 CARDOZO L. REV. 1907, 1919 (2011) ("[T]he Supreme Court has recognized that government has the power to accommodate religion, subject to certain limits.").

56. E.g., *Marsh v. Chambers*, 463 U.S. 783 (1983); *Engel v. Vitale*, 370 U.S. 421, 437 n.1 (1962) (Douglas, J., concurring); see Christopher C. Lund, *Legislative Prayer and the Secret Costs of Religious Endorsements*, 94 MINN. L. REV. 972, 997 (2010).

57. *Katcoff v. Marsh*, 755 F.2d 223 (2d Cir. 1985); SECULAR GOVERNMENT, *supra* note 10, at 253; Ira C. Lupu & Robert W. Tuttle, *Instruments of Accommodation: The Military Chaplaincy and the Constitution*, 110 W. VA. L. REV. 89 (2007).

58. See, e.g., *Rudd v. Ray*, 248 N.W.2d 125 (Iowa 1976).

59. 42 C.F.R. §§ 418.56, .64 (2008). The regulations provide: "The plan of care must specify the hospice care and services necessary to meet the patient and family-specific needs identified in the comprehensive assessment as such needs relate to the terminal illness and related conditions." 42 C.F.R. § 418.56 (2008). See *Medicare Hospice Conditions of Participation Spiritual Caregiver*, NAT'L HOSPICE & PALLIATIVE CARE ORG., http://www.nhpco.org/sites/default/files/public/regulatory/Spiritual_tip_sheet.pdf (last visited Feb. 9, 2016).

60. *Zelman v. Simmons-Harris*, 536 U.S. 639 (2002).

spiritual counseling, and this noncoercive quality is important for both First Amendment and statutory purposes.⁶¹

The law clearly states its parameters and aims for supporting spiritual expression in healthcare and end of life. We wondered, however, how people accessed religious beliefs and practices in end-of-life care. Does the law ratify or channel behavior?⁶² We conducted semi-structured qualitative interviews in order to find out.

II. THE LAW IN EVERYDAY END OF LIFE

Our impetus for conducting a study of twenty-first-century care and grief was to better understand the ways that baby boomers are changing how Americans approach and experience the end of life.⁶³ As the “silver tsunami” approaches, society faces increasing challenges to the caregiving process, due to the combination of longer life spans,⁶⁴ increasing health-care choices and expenses,⁶⁵ and changing family structures. Family caregiving for the elderly tends to rely on the supportive role of a spouse or grown child.⁶⁶ The family structures of the baby boomers will bring new challenges to these two traditional sources of caregiving support. The percentage of older people who have divorced has doubled over the past forty years, with at least half remarrying.⁶⁷ What will happen when baby boomers, with new family structures, confront end-of-life decision-making at the time it becomes a choice of when to die? After a

61. On the other hand, as discussed *infra*, a patient may not experience hospice chaplaincy as non-coercive.

62. See ROBERT C. ELLICKSON, *ORDER WITHOUT LAW: HOW NEIGHBORS SETTLE DISPUTES* (1994); Carl E. Schneider, *The Channeling Function in Family Law*, 20 HOFSTRA L. REV. 495 (1992).

63. Jonathan Vespa et al., *America's Families and Living Arrangements: 2012*, U.S. CENSUS BUREAU (Aug. 2013), <https://www.census.gov/prod/2013pubs/p20-570.pdf>; *Older Americans Month: May 2014*, U.S. CENSUS BUREAU (Mar. 25, 2014), <http://www.census.gov/newsroom/facts-for-features/2014/cb14-ff07.html>.

64. Mary Finn Maples, *Spirituality, Wellness, and the “Silver Tsunami”: Implications for Counseling*, AM. COUNSELING ASS'N, https://www.counseling.org/resources/library/vistas/2008-V-Print-complete-PDFs-for-ACA/Maples_Article_17.pdf (last visited Feb. 9, 2016).

65. Medicare and Medicaid, along with public and private retirement savings and insurance, provide the primary sources of economic support for the older population. Brian O. Burwell & William H. Crown, *Public Financing of Long-Term Care: Federal and State Roles*, U.S. DEP'T HEALTH HUM. SERVS. (Sept. 1, 1994), <https://aspe.hhs.gov/basic-report/public-financing-long-term-care-federal-and-state-roles>. Although the poverty rate for the elderly is lower than for the rest of the population, a drumbeat of reports shows that the overall rate threatens to change, and that blacks and Hispanics experience higher levels than whites. See, e.g., Nari Rhee, *Black and Latino Retirement (In)Security*, U.C. BERKELEY CTR. FOR LAB. RES. & EDUC. (Feb. 2012), http://laborcenter.berkeley.edu/research/retirement_in_security2012.pdf; Nari Rhee, *Race and Retirement Insecurity in the United States*, NAT'L INST. ON RETIREMENT SECURITY (Dec. 2013), http://www.nirsonline.org/storage/nirs/documents/Race%20and%20Retirement%20Insecurity/race_and_retirement_insecurity_final.pdf.

66. See Zietlow & Cahn, *The Honor Commandment*, *supra* note 7.

67. Susan L. Brown, Op-Ed., *“Gray Divorce” Boom*, L.A. TIMES, (Mar. 31, 2013), <http://articles.latimes.com/2013/mar/31/opinion/la-oe-brown-gray-divorce-20130331>; Susan L. Brown & I-Fen Lin, *Divorce in Middle and Later Life: New Estimates from the 2008 American Community Survey*, BOWLING GREEN STATE U., <http://paa2011.princeton.edu/papers/110947> (last visited Feb. 9, 2016); Susan Gregory Thomas, *The Gray Divorcés*, WALL ST. J., Mar. 3, 2012, <http://online.wsj.com/news/articles/SB10001424052970203753704577255230471480276>.

brief explanation of the study, this section looks at how decision makers actually used religion when facing two critical decisions related to death: the choice to enroll in hospice care and the choice to withdraw life support.

A. *The Study*

With the consultation of a board of scholarly advisors, drawn from law, sociology, religion, and public policy, we chose a seven-month period in 2010–11 in the racially diverse, midsize American city of Baton Rouge, Louisiana.⁶⁸ At first glance, the idiosyncrasies of Louisiana law and the comparatively high religiosity of Baton Rouge residents⁶⁹ may seem like stumbling blocks, but the location was chosen for several reasons. Procedurally, conducting the qualitative interviews in person was a top priority. Because one of the principal investigators was the Chief Operating Officer of a nonprofit hospice organization in Baton Rouge, this regional proximity to decedents enabled eighty percent of the interviews to be conducted in person. Of course, our results may not reflect the experiences of those in other communities, but our findings provide insight into how some people engage in surrogate decision-making.

Relatively few studies have been conducted concerning how surrogate decisions are actually made at the bedside. Most of our knowledge of surrogate decision-making comes from either bioethical studies or litigation related to specific medical cases. The bioethical area tends to study how closely medical professionals or surrogate decision makers follow advance directives.⁷⁰ The second source of information—legal conflicts about either who has the right to make decisions on behalf of an incapacitated individual or the decisions themselves—provides some limited, and highly selective, information about disagreements between surrogates.⁷¹

In contrast to these sources, our qualitative research involved interviews with grown children who either served as a surrogate or who observed the role of another family member who functioned as the surro-

68. See U.S. CENSUS BUREAU, CENSUS 2000 PHC-T-29, TABLE 4A. POPULATION IN METROPOLITAN AND MICROPOLITAN STATISTICAL AREAS RANKED BY NUMERICAL POPULATION CHANGE FOR THE UNITED STATES AND PUERTO RICO: 1990 AND 2000 (June 6, 2003), available at <http://www.census.gov/population/www/cen2000/briefs/phc-t29/tables/tab04a.pdf>. Baton Rouge is ranked 66th for numerical population growth. *Id.*

69. *Baton Rouge, Louisiana: Religion*, SPERLING'S BEST PLACES, http://www.bestplaces.net/religion/city/louisiana/baton_rouge (last visited February 17, 2016).

70. Maria J. Silveira et al., *Advance Directives and Outcomes of Surrogate Decision Making Before Death*, 362 NEW ENG. J. MED. 1211–18 (2010), available at <http://www.nejm.org/doi/full/10.1056/NEJMsa0907901#t=articleBackground>. Another study interviewed both physicians and surrogate decision makers as care was being provided to gauge the scope and practice of decision-making within an acute care setting. Alexia M. Torke et al., *Scope and Outcomes of Surrogate Decision Making Among Hospitalized Older Adults*, 174 JAMA INTERNAL MED. 370 (2014), available at <http://archinte.jamanetwork.com/article.aspx?articleid=1813222>.

71. See, e.g., WILLIAM H. COLBY, UNPLUGGED: RECLAIMING OUR RIGHT TO DIE IN AMERICA (2006). Reported cases, of course, represent an extremely small set of actual conflicts.

gate. One-third of the deceased parent figures needed surrogate decision makers because of their incapacity,⁷² a statistic which echoes national studies showing that forty percent of patients admitted to a medical care facility are unable to direct their own treatment.⁷³ Excluding three individuals who indicated the existence of a Do Not Resuscitate (“DNR”) order, none of those interviewed mentioned the completion of an advance care planning document or accessing one. The scheduling of the interviews a year after the death of the decedent gave the surrogates ample time to reflect on their choices (as well as to repress painful memories and rationalize self-interested decisions).

The respondents’ religious upbringing, their families’ religious history, and their current religious beliefs and practices formed a core part of the interview.⁷⁴ No participants identified themselves as having been raised outside of the Christian faith, and virtually all continued to identify themselves as Christians.⁷⁵ Within the Christian traditions represented, the majority are evangelical Protestant Christians, which may have shaped their approach to end-of-life decision-making.⁷⁶ The relative homogeneity of the study population and their greater religiosity may limit what we can surmise related to a breadth of religious traditions and their intersection with medical decision making, however regardless of intensity or lack of diversity, we can analyze the professional or corporate interference in that individual religious reasoning and practice.

72. Thirteen of the deceased had decisions made for them by their spouse. Seven of the deceased had decisions made for them by their grown child, two of those grown children included the significant other of their parent, who did not share in the decision-making role.

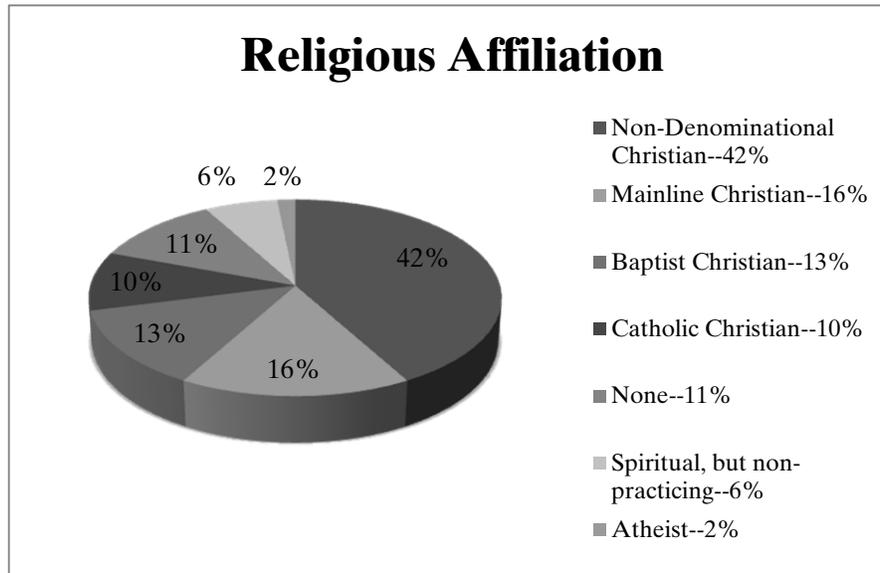
73. Vanessa Raymont et al., *Prevalence of Mental Incapacity in Medical Inpatients and Associated Risk Factors: Cross-Sectional Study*, 364 LANCET 1421 (2004).

74. The interviews were semi-structured, and the explanation of time of death and the decisions preceding that moment emerged naturally in the narrative. Although the focus of each interview was the caregiving and death process, we began by asking each participant about their childhood as a way of easing them into what we suspected would be quite difficult conversations. Later questions were more focused, delving into the moment when they realized their parents were sick, the intricacies of how possessions were distributed, and ending with any advice they would give to others. The semi-structured interviews including questions about religious upbringing, the religious history of their families, and their current religious beliefs and practices.

75. In terms of religious affiliation, nationally, about seventy percent of Americans identify as Christian. *America’s Changing Religious Landscape*, PEW RES. CTR. (May 12, 2015), <http://www.pewforum.org/2015/05/12/americas-changing-religious-landscape/>.

76. See Wendy S. Goffe, *Conform Health Care Directive to Client’s Religious Views—Part 1*, 39 EST. PLAN. 19 (2012), for an overview of religious views related to withholding life-sustaining treatment. See also *Religious Groups’ Views on End of Life Issues*, PEW RES. CENTER (Nov. 21, 2013), <http://www.pewforum.org/2013/11/21/religious-groups-views-on-end-of-life-issues/>, for an overview of additional end-of-life issues.

FIGURE 1



B. Actual Practices

Even before they faced questions of ending life, almost all participants mentioned that religious beliefs had affected their feelings of responsibility towards their parents.⁷⁷ Respondents also discussed early in the interview their faith background as children and how their religious beliefs and practices had evolved in relation to the religious affiliation of their parents. As the parent's illness progressed and joint decisions were made between the parent and families concerning treatment options, the parent included religious beliefs as justification for a particular course of care. Despite disagreement, the family complied with the medical choices of the parent. In joint decisions, the expressed religious beliefs of the parent played a salient role. Once the parent was incapacitated, however, his or her religious beliefs played a less prominent role in what decisions were made, while the religious beliefs and practices of the surrogate assumed more prominence.

Medical professionals⁷⁸ honored the religious framing used by surrogate decision makers as well as the time needed by the decision maker to engage in religious practices that would inform their health-care decision. Medical professionals did not evaluate the salience or sincerity of

77. Indeed, the biblical Honor Commandment is supported in a variety of secular laws. Zietlow & Cahn, *The Honor Commandment*, *supra* note 7. Fifty-five of the sixty-three interviewees spoke of their religious beliefs and practices as informing the care provided.

78. Medical professionals played a key role in instigating when a choice needed to be made, with doctors forcing choices concerning hospice and life support, and nurses providing information and support. *Id.*

the religious beliefs nor measure the frequency or fervency of the historical religious practices, deferring to—and respecting—the surrogate decision makers. In this Section we begin by explaining how religion affected the decision to stop curative treatments and to enroll in hospice care. We then analyze what role religion played in informing the surrogate decision to withdraw life support.

1. *Hospice*

Of the fifty-eight deaths in the study, one quarter occurred in hospice care, either at home or in a hospice inpatient facility. Most of the parents were mentally competent during the discussion concerning admission to hospice, and many called on their religious beliefs for guidance. In making the decision to stop curative treatments and focus on palliative care, the parents and families expressed a sense of closeness to the divine, often expressed as a belief that the parent's or the surrogate's choice fell under God's providence or that God's presence guided the parent or the surrogate to make a choice in the dying person's best interest. God's providence or presence was intuited internally and explained to the other family members as part of the treatment decision process. The individuals or families did not directly refer to theological or biblical texts or seek direct guidance from religious professionals as a way to confirm or support their interpretation of "God's will."⁷⁹

For example, Wanda's mother, Laurie Ann, said that "it was time" for her to stop aggressively treating her lung cancer and that God gave her peace about entering hospice care. Wanda, who was an only child and very close to her mother, debated with her mother about what God really wanted, repeatedly telling her, "If you can fight, you fight." Ultimately, she deferred to her mother's wishes.

In the few families that had formal documentation of their parents' wishes, those directives played a critical role in ensuring the wishes of the parent were followed. Katie was opposed to her mother's choice of palliative hospice care in lieu of surgery to remove a cancerous tumor in her abdomen; however, Katie complied with her mother's goals for care and supported her in transitioning from the hospital to hospice care. During hospice care, her mother completed DNR paperwork.

A few days before her death, Katie's mother had a stroke and was taken to a hospital emergency room, where Katie learned about the DNR order. Her mother's choice about life support reflected her mother's personal character and her general views about God and life. Katie's evangelical background, however, led her to believe that medical interventions should be sought at all costs as a way to allow God to do a mira-

79. Considering more than fifty percent of the respondents could be considered non-denomination/Evangelical and Baptist Christians, this focus on the individual's authority to both access and interpret divine "will" did not surprise us.

cle. When Katie and her sister arrived in the emergency room, they had to make a decision about how the doctors should proceed in treating their mother; the existence of the DNR order circumvented the ongoing tensions and arguments between the daughters over seeking or discontinuing curative care. On the day of her mother's death, Katie recounted a mystical moment she experienced that could not have happened if they had not yielded to their mother's wishes. For Katie, as was true for other families in which there was formal documentation of the parent's choices, even relatively simple advance care planning (such as the DNR order) helped the family members set aside their own preferences, religiously based or otherwise, and focus on the wishes of their loved one.

Once enrolled in hospice care, study participants also noted that they felt that hospice care itself provided spiritual support.⁸⁰ They were not surprised when a hospice chaplain made routine visits as a member of the care team. Chaplains also arrived when a crisis or death occurred and offered a "non-anxious presence."⁸¹

2. *Surrogate Decision-Making*

Surrogates faced a number of health-related decisions concerning treatment interventions. While they were not surprised that choices needed to be made, they still were not explicitly aware of their parents' wishes in terms of treatment options. Because few respondents had formal advance planning documents at their disposal, default rules came into play. No one referred to the law explicitly when it came to designating a decision maker, so the surrogate generally assumed responsibility informally but without challenge. Surprisingly, the religious beliefs of the incapacitated parent were rarely mentioned or specifically considered in making choices to withdraw life support. Instead, the surrogate's own religious beliefs and practices played an important role in the decision to remove life support measures.

In this Section we focus specifically on the respondents and families who faced the decision of whether to withdraw life support measures for the parent on their own. Most respondents used the idiom, "pull the plug," to describe this decision.⁸² Religion came into play in two different ways. First, the religious beliefs of the surrogate concerning the goals of medical care, their understanding of the role of "God's will" in the decision at hand, and an understanding of life after death, informed their understanding of the parent's best interests. Second, the religious practices

80. Only a few interviewees mentioned the role of a chaplain in hospice care explicitly, in part because the length of stay in hospice was short due to the acute nature of the admitting diagnosis.

81. Interview with Katie (February 16, 2012); Interview with Phillip (April 24, 2012).

82. Six of the sixty-three interviewed faced the decision to remove life support.

of the surrogate served as a form of support for discerning what decision to make.⁸³

II. RELIGIOUS BELIEFS

When major decisions about medical treatments were faced, families drew upon their faith beliefs to discern what was in the best interest of the incapacitated parent.

A. “Best Interests”

The key question respondents sought to answer when deciding to remove life support measures concerned the best interests of the incapacitated loved one.⁸⁴ Religious beliefs and practices figured prominently in this assessment, even though respondents did not refer to specific doctrinal statements or theological texts⁸⁵ to support their own or their loved one’s religious beliefs relating to when life ends. This surprised us, considering contentious public debates about when life begins and when life ends frequently draw on formal theological writings.⁸⁶

Many surrogates shared a common theological belief in the concept of mercy, understood to be an unmerited gift of kindness or compassion, and in a merciful God who would be present to relieve suffering. Overall, suffering was not viewed as holding spiritual merit or as something to be endured for the sake of spiritual purification. Respondents sought to relieve suffering without hastening death. Up until the point of withdrawing life support, respondents spoke of a cure as in the best interest of their loved one. Their prayers and hopes focused on a full recovery from illness or injury. One daughter, Courtney, described her shift in thinking when her mother entered hospice care; what she hoped for changed from a cure to a merciful, pain-free life until death. Respondents often used the term “mercy,” with the word serving as a symbol of their religious beliefs. For example, when Sam’s mother came home with hospice care, Sam said that his family prayed, asking God “please just show mercy.”⁸⁷

83. See Elizabeth K. Vig et al., *Surviving Surrogate Decision-Making: What Helps and Hampers the Experience of Making Medical Decisions for Others*, 22 J. GEN. INTERN. MED. 1274 (2007), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2219771/>.

84. While the law often expects a decision based on “substituted judgment,” where that is not known, the surrogate is instructed to use a best-interest standard. See Frolik & Whitton, *supra* note 27.

85. For example, they did not explicitly reference an historical creed, a scriptural commentary, a papal encyclical, or Halakhah.

86. In 2014, these issues resurfaced when teenager Jahi McMath in California and mother Marlise Munoz in Texas were both deemed brain-dead. See Daniel B. Wood & Gloria Goodale, *When Does Life End? Two Emotional Cases Probe the Complexities*, CHRISTIAN SCI. MONITOR (Jan. 19, 2014), <http://www.csmonitor.com/USA/Justice/2014/0119/When-does-life-end-Two-emotional-cases-probe-the-complexities>.

87. Edith, Sam’s mother, had long lived with epilepsy traced to brutal beatings she had received from her parents before being placed in foster care at a young age. For the six years preceding her death, she had been paralyzed, only able to squeeze a finger as a means of communication. Sam’s fa-

Framing his family's decision theologically—using the term mercy—helped Sam understand the goals for his mother's care at the end of her life, especially when his family faced the decision of not inserting a feeding tube and determined that it would be an extraordinary treatment. When all medical interventions could not return his mother to full health, they could still hope for a peaceful, pain-free death.⁸⁸ Kendra's ex-stepfather lived with a chronic heart and lung condition for many years, which eventually required his admission to a nursing home. Kendra watched his physical and mental decline over the years, and as his death neared, she prayed, "Lord, just let it be merciful." She gave thanks to God when he died peacefully in his sleep.

As surrogates considered the best interests of their parent, many respondents framed the choice of withdrawing life-support interventions as "putting it in God's hands." As was true for Keith, whose story opened this Article, belief in God's providence and control became a comfort after he made the decision about his father's life support. As Sam phrased it, there was a sense that "we put it in God's hands and we said if you kept him here this long, if for some reason you're keeping him here, then you'd better do something." From the perspective of the surrogate decision maker, beliefs about God's control of life's length tended to predominate in such statements as "it was a God thing," "God's plan," "God took her," "God planned it," "God does things for a reason," or "if God brings you to it, God will bring you through it." A year after the death, a pronounced sense of God's providence gave comfort to most respondents and allowed the respondents to justify their decision to themselves and to any family members who doubted the decision. Making a decision was easier if it was not ultimately theirs to make. This faith in providence reflects religiosity, on the one hand, but can also be seen as allowing religion to serve as the denial of agency by those who are acting, and as a reflection of the psychic discomfort we all feel when asked to make a life or death decision regarding a loved one. It feels like "playing God," and no one is comfortable with it nor entirely sure that self-interest is not play-

ther served as Edith's main live-in caregiver, with Sam and his siblings checking in each week and providing respite visits for their father.

As Edith's ability to swallow waned, the family faced the difficult decision of whether to use the feeding tube to extend her life. The family recalled the life of their mother as defined by a quick wit and lots of energy, leading their church softball league to many regional victories. The family prayed together and determined that at this point, "what little bit of life was there was no longer" and that "she was basically gone for about five years" before this moment. They decided the feeding tube would only "prolong the inevitable," and would perhaps cause more suffering.

88. Although participants did not necessarily use the word "mercy," that word, as religiously interpreted, accords with the words they did use. For example, Courtney talked at length about her prayers and hopes—how she wanted God to cure her mother, then she just wanted to have God keep her alive when a cure was no longer possible. When she saw that her mother was in pain and that the tumors and cancer that would end her life were the very thing causing her pain and that the medicines could only hold so long, her prayer changed to asking God to let her mom be pain-free and then die.

ing a part.⁸⁹ Believing that one lacks agency, that God is in control, softens the conflict but does not erase it. Moreover, most respondents did not have access to a living will that explicitly communicated the parent's wishes concerning life-sustaining treatment. For those respondents who did think they knew what their mother or father wanted, based on either brief conversations during the hospitalization or through a DNR order, they expressed trust in God's presence with them through the experience without having to use God's will as a decisional crutch.⁹⁰

The surrogate's beliefs about life after death also served as a guide and comfort in the decision to withdraw life support. For example, Jimmy recalled receiving the phone call from the hospital that informed him that his mother was "brain dead," albeit still on life support. Here's how his religion provided support after he visited the hospital:

I knew she'd [already] made it in (heaven) because she had got her last rite before she passed. I wasn't there when she repented, but in order for him (God) to tell me that all is well, then all was well. I was sitting there in Bible Study and I was sitting all to myself, and one of the elders was teaching, and when I looked up, I saw a vision of my mother. This was right after I came down here to see the doctor but I saw a vision of her, and, in the vision, she had—she was real, real, real young, and beautiful. Her hair was long and black and she had a bright, bright light behind her, and she was in a white garment, coming out and reaching out to give me a hug . . . and that kinda eased me. I went to talk to the doctor again and I made the decision. I told 'em, I said, "Saturday, at 2:00 p.m., we gonna pull the plug."

Jimmy's own religious beliefs, and his perception of his mother's relationship with God, gave him clarity to make the medical decision concerning life support.

III. RELIGIOUS PRACTICES

A. Prayer

When the end of a parent's life approached, participants engaged in personal and collective prayer.⁹¹ At the moment of the decision, participants believed that God was present, giving them strength to make the choice. As critical decisions needed to be made, medical professionals did not interfere when respondents engaged in prayer as a way to guide their decision. Respondents also received formal support through hospital chaplains. Keith told the doctors and his family that he needed to go

89. Such self-interest may stem from the discomfort of watching a family member suffer, feeling suffocated by the indefinite duration of responsibility to visit and monitor care, and experiencing concerns over inheritance.

90. See Katie's mother's story and Peter's father's story. See *supra* Parts II.B.1, IV.B1.

91. The relative religious homogeneity of the study population and their greater religiosity provide insight, of course, only into their experiences.

home and “pray on it” before he could make a decision. His prayers focused on asking God to affirm his decision to remove life support. When he arrived at the hospital the next day, the hospital chaplain visited and offered to pray with him. He understood that chaplains only visit when “you lose the person.” Again, he found a quiet place to be alone at the hospital and prayed. Keith then felt that he could let his father go, to be “where God wants him to be.”

Nancy also assumed the role of surrogate decision maker for her single mother. She consulted with her two brothers, her father, as well as her mother’s second husband and current boyfriend of more than ten years. Balancing all their opinions, combined with the heaviness of the decision, led her to pray, “Please God, just take her, because I do not want to have to make the decision to take my mom off life support.” When the medical team gave Nancy and her family a seventy-two-hour window to observe her mother’s condition for signs of improvement before withdrawing life support, she especially appreciated that her mother’s priest, a good friend of the family, came to visit, prayed with the family, administered “last rites,” and agreed to conduct the funeral service. That window of time allowed Nancy to come to peace with the decision to withdraw the life support machines in the Intensive Care Unit (“ICU”) after there were no signs of improvement.

B. Pastoral Care from a Clergy Member

While many of the surrogates drew on their own religious practices and beliefs, some of the respondents also called upon a clergy person for spiritual help. For some, like Nancy, it was the parent’s clergy member who visited. Nancy was Methodist and spoke to her pastor for guidance, but he did not visit. Nancy believed that her mother, as a practicing Catholic, would want her priest to visit to conduct the rites and rituals that Catholics find meaningful at the end of life.

Other clergypersons who visited the hospital served as the pastor for the whole family. For Peter, Pastor Frank (his minister as well as his father’s) was critical in framing the overall experience, as well as the specific decisions to be made. Although Pastor Frank did not refer directly to the religious beliefs of Peter’s father (at least Peter did not recall his doing so), his presence and tacit support of the decision to remove life support gave Peter’s decision theological affirmation.

After a sudden heart attack, Peter’s father, Leonard, was initially comatose but then regained consciousness for a few hours. He was intubated, so he couldn’t speak, but he could mouth words and nod his head yes or no. His family told him the score of the LSU game, and he was able to mouth, “What happened?!?” As they stood around his ICU bed, they took turns rotating closer to speak with him. While Peter waited his turn, he recalled his father saying, “If I die on a golf course, on a racquet ball court—don’t worry. I was happy. I just don’t wanna be stuck in bed.”

A few days later, the doctor sat down with the family to inform them that it was time to make decisions about life support. Peter and his family wanted Pastor Frank to be in the ICU with them as they made the decision. Pastor Frank had frequently visited his father in the hospital, and Peter's appreciation of how close his father was to Pastor Frank brought him a great deal of comfort. On the day of his father's death, Peter remembered "when Frank walked in and saw him there, [Frank] said, 'Boy. If your dad knew he was here, he'd jump off the bed.'"

Pastor Frank helped the family say good-bye. He explained to Peter and his family that sometimes people wait to hear from their loved ones that it is okay to die. He then asked, "Well, Pete, do you wanna go in and just tell your dad it's okay to go?" Giving his dad permission to die had not occurred to Peter or his family, and it made them feel less helpless. Peter walked to his father's bedside and said, "Dad, don't fight any more. We're gonna let you go." Pastor Frank then stayed with the family until Leonard died. Peter explained that the pastor's counsel was critical to allowing his family to sort through all of their complex emotions to reach the result his father would have wanted.

No one in our research mentioned the faith background of the parent, explicitly, in informing their "pull the plug" decision, whereas they were acutely aware of the influence of their own religious background. On the one hand, this omission may tell us that the religious beliefs and practices of the implicated parent did not register during the time of crisis.⁹² On the other hand, perhaps because the interviews occurred a year after the death and the respondent came to talk about his or her experience, the religious beliefs and practices of the respondent were primary during the interview. The semi-structured nature of the interview and the emotional intensity of the narrative during the telling of the time of death did not lend itself to open challenge or probing by the interviewer.

Regardless of why, while the law directs that surrogates use a substituted-judgment rule for patients unable to make their own decisions, surrogates drew on their own religious beliefs and practices; those religious beliefs supported their determinations of what was in their parents' best interests when they could not use substituted judgment. Ultimately, the narratives show that people did not feel that their religious beliefs or practices were silly or burdensome; they did not feel that their religious integrity was questioned; and they did not feel pressure to espouse a certain belief or practice by hospital or hospice chaplains, or by any physicians.

92. This interpretation seems unfortunate considering our culture's high value for substitute judgment and the expressed relief of those respondents who did know the choices of their parent and were able to follow those choices rather than their own.

IV. RECOMMENDATIONS CONCERNING END-OF-LIFE DECISION- MAKING (IN THE SHADOW OF *HOBBY LOBBY*)

So how does *Hobby Lobby*⁹³ play into this? At its core, *Hobby Lobby* considered a government action that was claimed to impose a substantial burden on the religious liberty of a for-profit corporation⁹⁴ under the Religious Freedom Restoration Act (“RFRA”). Our qualitative research in Part II shows the significance of religion, and how it weaves its way into the experiences of individuals and families facing the end of life. No one in our qualitative interviews was aware of the religious beliefs of the hospice organization caring for their loved one.⁹⁵ All respondents assumed that the wishes of their parent, or their opinion of the wishes or best interests of their loved one, would trump those of the hospital and those of the physician for that matter.

Because spirituality can play such an important role in end-of-life decision-making,⁹⁶ legal institutions can take numerous steps to respect the individual’s core beliefs. *Hobby Lobby* might be interpreted to protect an institution’s religious perspective at the expense of quality end-of-life care that honors the individual’s religiously based choices. To prevent *Hobby Lobby* from interfering with a patient’s chosen end-of-life care, the law can develop better approaches that support the individual’s decision-making, regardless of the entity providing care. This can be done by providing more structure at the time of execution of advance directives, providing more structure to surrogates who are making decisions, and providing more training to personnel who are present at the time of advance directive and surrogate decision-making.

As a foundational issue, our study shows the need for more families to engage in end-of-life conversations that address preferences for care, including their religious and moral beliefs about such care—and for those conversations to be documented through advance medical directives. The legal pieces are in place to foster such documentation, and numerous organizations provide easily accessible tools,⁹⁷ but the conversations are

93. *Burwell v. Hobby Lobby Stores, Inc.*, 134 S. Ct. 2751, 2761 (2014).

94. Amy’s experiences with Hobby Lobby stores suggest the depth of the corporation’s religious practices. The stores are closed on Sundays, they have a tradition of posting full page ads on Christmas, and they play Christian hymnody and music in all the stores. See Elizabeth Sepper, *Healthcare Exemptions and the Future of Corporate Religious Liberty*, in *THE RISE OF CORPORATE RELIGIOUS LIBERTY* 305 (Chad Flanders et al., eds. 2015), [hereinafter Sepper, *Healthcare Exemptions*].

95. The two main hospital systems in Baton Rouge, LA are Our Lady of the Lake (Roman Catholic), and Baton Rouge General (Baptist). BATON ROUGE GENERAL, <http://brgeneral.org> (last visited Feb. 18, 2016); OUR LADY OF THE LAKE, <https://ololrhc.com/pages/home.aspx> (last visited Feb. 18, 2016).

96. See NANCY BERLINGER ET AL., *Spirituality and Religion as Factors in Treatment Decision-Making*, in *THE HASTINGS CENTER GUIDELINES FOR DECISIONS ON LIFE-SUSTAINING TREATMENT AND CARE NEAR THE END OF LIFE* 149, 149–50 (rev. ed. 2013).

97. E.g., *Five Wishes*, AGING WITH DIGNITY, <http://agingwithdignity.org/five-wishes> (last visited Feb. 18, 2016); THE CONVERSATION PROJECT, <http://theconversationproject.org/> (last visited Feb. 4, 2016).

not happening.⁹⁸ First, to comply with Medicare and Medicaid, hospitals, hospices, and other medical service institutions must provide information, in writing, to each patient about their right to have an advance directive and the hospital's approach to respecting that directive.⁹⁹ Beginning January 1, 2016, Medicare began reimbursing for doctors' appointments so that patients could discuss various advanced care issues ranging from advanced medical directives (living wills, health-care powers of attorney) to Medicare coverage of hospice and palliative care.¹⁰⁰ Third, service providers are required to offer education for their own staff and the community on issues relating to advance directives.¹⁰¹

As part of these efforts, medical personnel who work with an individual to fill out advance medical directives, or others, such as a Physicians Order for Life-Sustaining Treatment, should explicitly ask about and then explore the impact of any relevant spiritual beliefs as part of a standard procedure for filling out the forms.¹⁰² Clergy and faith communities could themselves undertake to provide more education and discussion concerning end-of-life planning.

An additional issue concerns maintaining the status quo with respect to the Hospice Medicare Benefit; spiritual counseling should continue to be a core service on par with physicians, registered nurses, and social workers. As non-hospice-related palliative care programs proliferate in hospital settings, and the shift to hospice as a predominately for-profit industry continues, the temptation may arise to eliminate spiritual counseling as a required service. The hospice therapeutic model of spiritual counseling reflects best practice in end-of-life care, and echoes what lay people expect when a loved one dies in a hospital setting, or in hospice care in a variety of care settings.

Hospice aims to facilitate the full expression of spiritual beliefs, and practices resonate with the beliefs of the individual patient and family members. The religious or nonreligious beliefs of the individual hospice practitioner or hospice organization should yield to respect for a patient's

98. See, e.g., Harry L. Anderson et al., *End-of-Life Conversations at Dinner*, http://aahpm.org/uploads/microsites/Abstracts_2015/End-of-Life_Conversations_at_Dinner.pdf (last visited Feb. 18, 2016).

99. 42 U.S.C. § 1395cc(f)(1) (2012).

100. Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 Fed. Reg. § 70885 (Nov. 16, 2015) (to be codified at 42 C.F.R. 405, 410-11, 414, 425, 495) <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-28005.pdf>.

101. 42 U.S.C. § 1395cc(f)(1)(E).

102. See Beverly Petersen Jennison, *Reflections on the Graying of America: Implications of Physician Orders for Life-Sustaining Treatment*, 12 RUTGERS J. L. & PUB. POL'Y 295, 322-26 (2015) (recommending inclusion of religious affiliation as part of living will); Karen E. Steinhäuser et al., "Are You At Peace?", 166 ARCHIVES INTERNAL MED. 101 (2006); Terman, *supra* note 29, at 187-88 (offering specific suggestions on options that clinicians can present). An individual might fill out an advance directive that decisions be made in accord with "Roman Catholic" principles. While a court could not decide what that means in the event of a conflict between two different interpretations of Roman Catholic end-of-life principles, this is, of course, not a RFRA issue.

choices. In *Hobby Lobby* terms, the compelling government interest should be in preserving patient autonomy.¹⁰³

V. CONCLUSION

End-of-life care draws on ethics, and those ethics are shaped by many forces outside the law, including religion. Indeed, based on our study participants, religion profoundly affects end-of-life decision-making on a personal level. The law appropriately supported their religious-based reasoning. As advances in medical technology and practice expand our ability to extend life, the number of individuals and families who will need to make nuanced decisions about when that technology is no longer curative or resonate with the individual's definition of life will increase. Protecting the personal religious beliefs and practices of those patients and families will be tantamount to ensuring they have access to a critical source of guidance and encouragement during those liminal times between life and death.

103. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 279 (1990) (“[F]or purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition.”); *see also* *Burwell v. Hobby Lobby Stores, Inc.*, 134 S. Ct. 2751, 2759 (2014) (“We hold that the regulations that impose this obligation violate RFRA, which prohibits the Federal Government from taking any action that substantially burdens the exercise of religion unless that action constitutes the least restrictive means of serving a compelling government interest.”).