Islamic Moral Values and End-of-Life Care: Examining the Intersection of Religious Beliefs and the U.S. Health Care System

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End-of-life care is a central aspect of health care in the United States. Given the country's diverse population, it is crucial to understand different religious perspectives on policies, standards of care, and medical practices. Religious beliefs impact the ways that end-of-life care is perceived and administered to patients of different faiths. This article examines Islamic approaches to end-of-life care within the context of the US health care system. Drawing on data collected through a literature review and interviews with Muslim physicians, imams, and scholars with extensive knowledge of Islam, four areas are identified in which end-of-life recommendations in the US medical care system parallel Islamic moral values: care for aging parents, time spent in the hospital, use of medication, and the preparation of advance directives. We argue that individuals' Islamic beliefs and the initiatives and policies for end-of-life care in the United States are not oppositional and provide insight into how our Muslim participants turn theological perspectives and ethics into health practices.

Introduction

End-of-life care is a critical part of the United States health care system today because individuals are living longer and more people are suffering from chronic health conditions. In the United States, the "oldest old" comprise one of the fastest growing age groups (Kinsella and He 2009).

Given this demographic trend, end-of-life care has become a staple in both medical and political discourse over the past decade in part because of the complex cultural, religious, and ethical issues at stake in providing care for this population.

Research demonstrates that end-of-life conversations between medical providers and patients do not occur soon enough in the United States, often leaving patients unaware of their options and doctors unsure of what treatments patients would or would not have wanted (Kaufman 2005). In 2010, the Obama administration implemented a policy that would allow physicians to be reimbursed by Medicare for discussing options for end-of-life care with their patients. In early 2011, however, end-of-life planning was removed from this Medicare benefit for fear it "would force older adults to hasten their own deaths because they would be encouraged to reject life-extending treatments" (Sharp, Carr, and Macdonald 2011, 275-276). Not reimbursing physicians for end-of-life planning makes it difficult for many to fit this into an already cramped office visit, which usually is scheduled for 15 minutes (Fiscella and Epstein 2008). Such discussions would allow patients to detail their wishes for end-of-life care regardless of what they may be; patients could choose to have life-sustaining treatments or solely comfort care.

In addition, end-of-life conversations may not occur frequently because death evokes people's core religious and spiritual beliefs. Death is unsettling to think about, and people may leave their fate up to a higher power rather than directly confronting the prospect of dying. Ethnic, cultural, and religious pluralism in the United States necessitates consideration of differing approaches to end-of-life conversations and decision making. We seek to build on the anthropological understanding that within a pluralistic society the way health care is provided and received varies according to the cultural and religious identities of providers, patients, and families (Keefe 2006).

To date, there have been few anthropological or ethnographic studies on Islam and end-of-life care, and research on this topic has mainly taken place outside of the United States (e.g., Hamdy 2012; Van den Branden and Broeckaert 2009). Existing scholarship on Islamic ethics and the end of life is abundant in medical journals (e.g., Salman and Zoucha 2010), and there has been much work from the religious studies standpoint

outlining what Islam does and does not permit (e.g., Brockopp and Outka 2003). Our objective is to expand on this literature by offering insight into how Muslims in our study actually experience end-of-life care and examining how theological perspectives are turned into practice. [1] Specifically, this article examines how Islamic principles and Muslim beliefs about death and illness intersect with medical discourse and practices in the United States. Using qualitative research methods, we analyze how Islamic principles—and more importantly Muslims' diverse and varied understandings of them—cohere in the United States with care recommendations, medical standards, policies, and guidelines in four areas: the role of the family in the care of aging parents, length of hospital stays, the use of medication, and the preparation of advance directives.

Ultimately, we argue that Islamic moral values and principles, as expressed by our participants, actually facilitate many of the practices and policies that are advocated by administrators and medical providers within the US health care system, demonstrating a significant overlap between Islamic beliefs and the current health care system. Although the biomedical model of death common in the United States tends to champion technology and view death as failure (Chapple 2010; Kaufman 2005), we demonstrate that Islamic medical ethics do not contradict or prohibit advances in technology or the use of biomedicine at the end of life. Rather, they frequently parallel clinical ethics and the recommended practices of medical providers.

Religion/Spirituality and End-of-Life Care

Anthropologists and health researchers have often called for medical professionals to care for the "whole person," which includes addressing religious and spiritual needs (Kleinman and Benson 2006; Schilder et al. 2001). Daniel Sulmasy writes, "Genuinely holistic health care must address the totality of the patient's relational existence—physical, psychological, social, and spiritual" (2002, 24). He notes, however, that much work remains in understanding the religious aspects of end-of-life care and how to address religious concerns in medical practice and research. Religion is

[1] This research has focused on Sunni Muslims. Data in this article come mainly from those who were born abroad and immigrated to the United States. A future study might focus on Shi'a perspectives.

often considered as "baggage" that needs to be accommodated by providers instead an integral aspect of health care; learning about patients and families' religious traditions can help providers better understand how they are making health decisions at the end-of-life.[2]

The literature shows that religious faith impacts ill patients' health decisions at the end-of-life in the United States and shapes the type of care they request and receive (Lo et al. 2002; Steinberg 2011). Karen Steinhauser et al. (2000) discovered that making peace with God was important for the severely ill in their study of randomly selected Veterans Affairs (VA) patients. The ranking was similar to concerns for mental awareness and not being a burden to anyone, helping others, and having funeral preparations completed. In a multi-site study in the United States, Tracy Balboni et al. (2013) found that terminally ill cancer patients who had the support of religious communities would access hospice care less often and have more aggressive medical interventions towards the end of their life. Balboni and colleagues theorize that religious patients have more hope and believe more in their faith than in their medical providers; patients would not believe their providers when they explained that cancer would end their lives in the near future (Sherman 2013).

Although there is a great deal of research on patients' religious beliefs and how they impact health decisions, Clive Seale notes that, in comparison, there are few studies of the religious faith of medical providers and how faith impacts their decisions regarding the administration of treatment for patients at the end of life. In conducting a survey of medical providers in the United Kingdom, Seale (2010) found that physicians who identified themselves as not religious were less conservative in the treatments they provided to patients and more likely to administer continuous deep sedation until death while also offering services that would not prolong patients' lives. J. Carlet et al. (2004) echoe this position by arguing that religion, ethnicity, and the culture of medical providers

[2] We realize that religion and spirituality are not synonymous (Daaleman and VandeCreek 2000, Sulmasy 2002). One does not need to follow a religious tradition to believe in God (Bruce 1992; Haring 1973). We reference religion along with individual religious beliefs and practices because we are interested in the specific relationship between Islam and end-of-life care in the United States. Both religion and spirituality intersect with the contemporary practice of medicine.

influence their attitudes and how they approach end-of-life care. We cannot forget, therefore, that the religious faith of the medical providers offering the care will also shape how end-of-life care is administered.

Some scholarship on religion and health care in the social sciences and public health suggests that religion lies at the periphery of end-of-life decision making and, as such, must be taken as just one part of the whole context of care (e.g., Marks 2005). This research, however, fails to interrogate the points at which religious belief and practice become inseparable from medical services. We draw on the work of Rosalind Petchesky to argue instead that people often remain "in dialogue with religion" (1998, 305) while undergoing medical care even as they adapt doctrinal perspectives to achieve particular objectives. Our research suggests that religion is never on the margin of individual decision making (if a person identifies as religious) at the end-of-life, regardless of whether decisions are made for oneself or for a family member. Instead, religion is is at the core of how medicine is viewed and health care decisions are made.

Islam, Terminal Illness, and Death

Several scholars of Islam from around the world have carefully considered medical ethics, and there is considerable work on Islamic medical ethics surrounding the end of life (Brockopp and Eich 2008; Bülow, et al. 2008). The Islamic Medical Association of North America (IMANA) has published several papers on ethics to help guide patients and physicians in the United States with their medical decisions (e.g., Khan 1983, Saiyad 2009). The vision of the organization is "to become the recognized leader in national and global healthcare, guided by Islamic values" (IMANAa). Papers by IMANA discuss brain death, medical treatments, resuscitation, and nutrition and hydration during the last days of life, providing a basis from which decisions can be made that follow Islamic principles. For example, one paper answers questions posed by community members about Islamic views on medicine. One member asks what to do after a person suffers a massive brain hemorrhage and is left in a coma with little hope of recovery. In the paper, Hassan Hathout, M.D., answers, "Islam does not encourage prolonging misery in a vegetative state and patients should be allowed to die naturally when nothing more can be done. You should agree with the medical decision. You may seek a second opinion, but insist that hydration and nutrition be maintained until death" (IMANAb).

The papers by IMANA note that for Muslims, as for practitioners of many other faiths, life is sacred. Abdulaziz Sachedina, a well-respected scholar of Islamic ethics, states that Muslims recognize "everyone will face death, and the way we and those we love die is of great individual importance" (2005, 775). In a study of end-of-life care among Muslim Moroccan immigrants in Belgium, Stef Van den Branden and Bert Broeckaert write, "The vision of God as the sole determiner of the life span and the physician as the person who must try to cure the patient, or at least alleviate the pain, can be found frequently in literature on Islamic ethics" (2008, 201). Sachedina says Muslims should "entrust nature to take its own course" (2005, 776); he goes on to say that not recognizing the naturalness of death may lead to the administration of life-extending measures that would not be of any benefit to the patient's health or well-being. These services may in turn cause unnecessary suffering for patients and their families, which Islam discourages.

In presenting our data we show how individuals' Islamic beliefs actually parallel medical discourse and practices in the United States surrounding death. We avoid pitting cultural and religious traditions against medicine and instead trace how religious and medical discourses and practices come together in confronting oftentimes extremely difficult health care decisions at the end of life for oneself or a loved one. We also recognize that we are providing individuals' interpretations of Islam and that Islam is not homogenous. The contradictions and overlaps in perspectives flesh out the intricate relationship between Islam and the US health care system while simultaneously highlighting the multiple and sometimes conflicting interpretations of Islam itself. They also point to the important relationship between religion and culture that must be explored in ethnographic research.

Methods

This article draws primarily on data collected through an extended literature review and semi-structured interviews with individuals who are knowledgeable about key issues surrounding end-of-life treatment, Islam, or medical ethics. We draw on semi-structured interviews that we conducted in 2013 and 2014 with a bioethicist who is also a professor, a gerontologist, three Sunni Imams in the Washington, DC, area, and four Muslim physicians who have an interest in Islamic medical ethics. Most of

the physicians have published on the topic. One continues to practice medicine, two others have moved on to other roles at universities, and one has become a staff member at a mosque. We conducted interviews in the D.C. area if the person was based in the region, or over the phone if not. Interviewees were asked a series of open-ended questions about Islamic principles concerning health, illness, and death; ethical dilemmas related to end-of-life care; their own experiences of caring for or counseling Muslim patients who were terminally ill; the meaning of aging; and what constitutes a "good death."

All participants received and signed informed consent forms prior to the start of the interviews in accordance with the protocol approved by the IRB at George Mason University. With permission, interviews were recorded and later transcribed word-for-word; all participants we reference in this article gave permission to record their interviews. However, all personal identifiers were removed during transcription. We have changed the names of our participants to protect their privacy and have only given general information about the location of their work or mosque. Notes were taken by hand during the interviews to keep track of models they described or complicated concepts they explained in addition to the specific themes discussed.

By bringing together the interviews with a review of relevant literature in anthropology, public health, medicine, and the social sciences, we take a multi-perspective analytical approach to the relationship between end-of-life care and Islamic medical ethics within the context of the US health care system and policies. The research demonstrates that specific circumstances may cause the application of Islamic tenets and medical principles to differ greatly. In the remaining sections, we will examine the four main areas where we found overlap between recommended medical practices, policies, and guidelines for end-of-life care in the United States and the Islamic principles and beliefs discussed by our participants: the role of the family, hospital stays, medication usage, and advance directives.

Findings

The Role of Family in Care

Recent trends in health care in the United States show an emphasis on the importance of family in care for individuals with terminal illnesses. This has been found in other countries as well, as demonstrated by Stajduhar

et al. (2008) in their study of family caregivers in Canada. Families show support for their elders when they are dying, and they view caring for them as a way to show gratitude for being part of their lives (Hayes 2013). In our interviews with Muslims who either cared for dying loved ones at home or cared for terminally ill patients in professional settings, the family responsibility for taking care of ill members was a primary theme.

One imam discussed how his Islamic faith influenced his feelings toward taking care of his parents. In our conversation, he referenced the Qur'an's statements about the importance of taking care of one's parents, specifically as they become older. He said, "When they reach old age don't say '*āuf*' [ugh or oh, meaning you are bothered] . . . show humility as a person." The imam emphasized that children do not recognize all the good things that their parents do for them when they are young. This needs to be acknowledged and then repaid when the roles are reversed, which implies children taking care of parents when their health is failing. He explained that Islam has taught him that he needs to take care of his parents as they age. The imam also believed that it is better to have elderly parents living with their children and having in-home care than sending them to live in nursing homes—unless the family is unable to provide the care that is needed and the patient would suffer more from not receiving particular services (e.g., those that can be provided by skilled providers at extended care facilities). He himself has his aging mother living with his family and strongly believes that since she has moved in with him, she is more energetic and active than if she were in a long-term care facility.

Interestingly, this was a point of contention between the interviews we conducted with imams and with Muslim physicians who work in the United States. The physicians we interviewed had much less conflict with sending patients to live in facilities like nursing homes when necessary because there they receive round-the-clock care, which many families may not be able to provide. This departure could be a result of the physicians' daily experience of working in the US health care system where there is a push for the use of long-term care for those who would not benefit from aggressive treatments.

The imam underscored the special bond that only children can have with their parents and the significance of this bond when children become involved in their parents' care at the end of life. He said that he had an

argument with his wife about this. In response to his wife's complaint about his mother living with them, he responded:

> I said, "Honey, you are my wife, I love you, she is my mother, I love her. My mother cannot have another son. . . . My mom comes number one. You come number two. It doesn't mean I love you number two. I love you as my wife, but my mom is my mom." Islam tell me mom have to be in your house. . . . This is mine. The man is responsible.

This conversation between the imam and his wife demonstrates the impact that his beliefs have on how he treats his mother, as well as the influence of Islam on his beliefs about who is responsible for taking care of aging and ill parents.

The imam views the family as an important element of end-of-life care. Taking care of elders should not be a burden, but a "pleasure." He said, "If [family members] reach old age do not talk to them harshly. Do not even say '*āuf*'. . . lay down your wing of honor before them and make a prayer to God. 'O God, be merciful to them, as they were merciful to me . . .' They are not a burden on society, it's a pleasure for a Muslim to serve his parents." He compares his view of present day American culture to his values as a Muslim. In the United States, he has witnessed aging parents being treated as burdens to the family. Instead of taking in aging family members and caring for them, US society finds it more convenient to place them in nursing homes or other long-term care facilities. He responds to the idea of allowing aging relatives to stay in such facilities by providing a personal example of how he expects to care for his mother:

> [My mother] will be in my house, and she'll be respected, she'll be loved by me and my wife. Because she's also part of that atmosphere. They will say "Now she's old, now, you know, we have a babysitter for her, have someone else to care for her, somebody else to sit down with her." No, we don't do that and that makes a big difference.

The imam's stance that families are responsible for caregiving converges with the US health care system's emphasis on not overusing more expensive critical care facilities while leveraging care from family, community services, and other health providers when curative treatment will most likely not prove beneficial. This is driven in part by the fact that the Centers for Medicare and Medicaid Services (CMS) estimate that approximately one-quarter of annual Medicare spending is on the five percent of beneficiaries who pass away (Adamopoulos 2013). In 2011, for example, Medicare spent $554 billion, and twenty-eight percent of this was on end-of-life care (i.e., on services during the last six months of life). Decreasing the amount spent on critical care—the most expensive—during this time by utilizing other services to provide appropriate treatments and pain management, especially to those with a poor prognosis, is seen by the government as a way to create cost savings (Pasternak 2013).

Length of Hospital Stay

Interviewees suggested it was imperative that terminally ill patients spend as little time as possible in the intensive care unit (ICU).[3] One Muslim physician we interviewed recalled a personal experience as a consultant for an elderly patient who was in the ICU. He describes the situation of the patient as being dire at best. He explained,

> She was on mechanical ventilation and she was on all kinds of support and her son came to me, and he said, "You know, what do you do? What is the prognosis?" And then I shared with him, I told him, "It's not good." He wanted to know, "Why, why, don't I take her home? She'll die in peace at home."

The doctor then discharged the patient to her son, and she died at home.

[3] Approximately 2.5 million Americans died (CDC) in 2013. It is estimated that one in five deaths occur during or shortly after a stay in an ICU (Angus and Black 2004). Aging patients make up a large percentage of overall ICU admissions at 40 percent (Wunsch et al. 2010), and most deaths in the United States take place in an institutionalized setting (Teno et al. 2004).

He said that not every situation goes the way that one did. Sometimes families do everything possible to keep a loved one alive, but this may only prolong the inevitable, which he believed is an approach that Islam does not favor. Along similar lines, another Muslim physician argued that it is acceptable to withdraw a ventilator when it is only prolonging death because it shows mercy to the patient, which Islam highly encourages. Another imam, however, stated that withdrawing life support, once it is started, is considered murder and a sin, but patients or families could refuse it in the first place.

More recently, there has been a move in the United States to remove life-extending measures when they are not advantageous for the patient and allow a more peaceful and comfortable death (Kaufman 2005). At the same time, there are strong tendencies to intervene in end-of-life care in part because removing someone from life support is seen as "giving up" or losing hope by patients, families, and even providers (Chapple 2010; Levi and Green 2010). This tracks with the biomedical model in the United States that champions the use of technology to keep someone alive and views death as a failure.

"Burdening" is a key term when looking at our data on end-of-life care and Islam. In our interview, a Muslim physician and scholar of Islamic medical ethics referenced the verse in the Qur'an that says how it is important not to burden yourself or your family (Qur'an 2:286). He stated that if someone is dying and it is irreversible, then the person may become a "burden" on family members, and even society, if medical treatments are continued that would not result in an improved condition. For him, being a "burden" means that a patient is taking resources away from others at a high cost to the medical facility or the family. In situations where the patient becomes a "burden," he stated, "Being a burden on someone else . . . you're costing everybody too much. That's being a burden on society, and it's, in a sense, burdensome on your family because hospice would be a better situation for them to interact with you than in the ICU."

In contrast to this physician's remarks, a physician and staff member at a mosque in the D.C. area discussed how some Muslims view aging parents as anything but a 'burden.' From his experiences, Muslim families take pleasure in caring for aging relatives whose bodies may be weakening. He said, "They do not mind changing their diapers if they are old, they do

not mind changing their sheets, cooking for them." He stated that Muslim children are less likely to see their aging parents if they remain in the hospital or enter a long-term care facility. This is especially true "during the last few months of life." When there are aging parents involved, Muslim families—from his experience—prefer to have their relatives at home with them, which means they will not stay in a medical facility longer than necessary.

The notion of a "good death" is debatable, but overall, our participants agreed that being surrounded by loved ones is an important part of dying peacefully. The physician and religious scholar mentioned above also works as an ethics consultant for medical facilities and has spent a great deal of time talking with families about end-of-life issues. He explained that in some cases families of patients might request a medical procedure even though it is not ethically warranted. They do this more for themselves than for the patients. The scholar recalled telling families,

> Why do you want this? Ok, so the doctors have told you. Right. That this really isn't going to work. I mean, it's not likely to work and even if this treatment itself, it, in the end won't do anything for you, right? It's not going to make you feel better; it's not going to extend your life. . . . What's the goal here?

This statement emphasizes a point made earlier by one of the Muslim physicians. Spending time in the hospital and having numerous procedures will only increase the chances of dying in an institutional setting, and thus decrease the chances of being surrounded by loved ones at death. Medical treatments may also become a "burden" on the body if they do not improve the quality of life. Several of our participants emphasized the importance of family within Islam and, therefore, preferred that Muslim patients near the end-of-life return home from a medical facility as soon as possible to receive comfort care.

This position intersects with the US health care system's general push to reduce hospital stays and visits to critical care facilities, in part because of the high costs associated with these types of care (Gilmer et al. 2005; Mack et al. 2012). One such example of this is the Primary Care (or Patient Centered) Medical Home (PCMH), which reorganizes family

medicine so that it is "accountable for meeting the large majority of each patient's physical and mental health care needs, including prevention and wellness, acute care, and chronic care" (AHRQ). The goal of this is to provide high quality preventative medicine and to coordinate general and specialized services so that patients do not need to go to the hospital or emergency rooms—which tend to be more expensive—unless absolutely necessary. In a similar vein, many of our interviewees talked about the importance of caring for a patient near the end of life at home by loved ones (with perhaps some health care aides if the family could afford it) instead of going to or remaining in a hospital. This reflects the shift in the US health care system towards seeking care and services outside of more expensive critical care facilities.[4]

Medication

"The saving of one life is as if one has saved humanity" (5:32). This verse in the Qur'an has provided a basis for many advances in Islamic medicine and challenged the idea of only relying on herbal or natural treatments—although some of our participants noted the importance of trying natural remedies before seeking more conventional medical care. Regardless of the imperative to save lives and to limit unnecessary suffering, there are multiple instances throughout the Qur'an where the inevitability of death and the will of God are mentioned with the utmost seriousness.

When discussing hospice and palliative care with one Muslim physician, he explained, "If you are in pain, you are expected to seek relief of the pain. . . . It's not like treatment is forbidden." In interviews, several of our participants explained that Islam facilitates the use of biomedicine. One imam said, "If you are trained since you were a kid that God is the ultimate, then He is the maker of the disease, and He can take away the disease. It's His universe. So then, if you get sick, Muslims don't say, 'Don't go to the doctor.' Go to the doctor . . . to a Muslim doctor." Marcia

[4] We acknowledge that some of the things we discuss in the paper are attempts to encourage certain kinds of approaches, although they are not always seen in practice at present. An example of this is the movement to have more patients pass away at home in light of the large number of people who still die in the hospital in the United States. Hospices have also been fined and forced to pay Medicare because patients are living longer than expected in their care. See Sack (2007) and NHPCO (2010) for examples.

Inhorn and Carolyn Sargent suggest that Islam is "a religion that can be said to encourage the use of medicine, biotechnology, and therapeutic negotiation and agency in the face of illness and adversity" (2006, 1). While Islam does not prohibit the treatment of pain at the end-of-life through medications prescribed by physicians, the imam also spoke to us of the intent of physicians when giving these medications to patients:

> So, we need to be careful what the religion says and what the culture says. The religion says that if you are ill, go seek treatment. And, what it forbids, is that you take your own life. So, sometimes people are so sick, they are in so much pain and agony they'll come and say, "Would you please put me out of this misery, give me some strong medication so I can die." That is forbidden.

Similarly, academic Islamic Studies scholar Abdulaziz Sachedina writes that Islam permits pain-relief and foregoing treatment if an outlook is not positive for the patient, but the patients, families, and providers must be well-meaning.

> In Islam, the killing of a terminally ill person, whether through voluntary active euthanasia or physician-assisted suicide, is judged an act of disobedience against God. However, pain-relief treatment or withholding or withdrawing of life-support treatment, in which there is an intention of allowing a person to die when there is no doubt that their disease is causing untreatable suffering, are permissible as long as the structures of consultation between all the parties concerned about the wellbeing of the patient are in place. (2005, 779)

Medications intended to cure and reduce pain are certainly permitted because they can reduce suffering and bring comfort, which Islam encourages. However, providing or taking medications intended to end a life, such as in involuntary active euthanasia or physician-assisted suicide, as noted by Sachedina, is prohibited in Islam. The intentions of the provider

and the patient play an important role in determining what is acceptable when it comes to medication use.

The Muslim physician who is on the staff at a mosque explained that the outcome is ultimately not in the hands of the patient or the physician, but remains in the hands of God even when the physician is administering medication. He described the Islamic concept of *shifa,* a healing prayer in times of illness, which "means it is from Allah who allows the patient to get better or does not allow him to get better. The doctor prescribes the medicines and these medicines, these medicines ask Allah." The effectiveness of the medication is not the determining factor in the success of the physician in curing or comforting patients; the success lies with the will of God. He expressed further,

> I know also that a lot of people taking the same medicine for the same illness get better, and a lot of people taking the same medicine for the same illness get worse. I know that . . . patient says, "I did my best," all patient's relatives, "We did their [sic] best." Still patient died, why. Because Allah did not close this angle. *Shifa*.

One imam we spoke with shared his opinion that "America is high on drugs," and that the last resort in Islam is to drugs. He told us about the diet of the Prophet Muhammad, which was said to have been "a spoon of honey diluted his [sic] water." The imam expressed that it would be preferable for Muslims to take natural remedies, like honey, to help with their pain and ailments rather than medical prescriptions or over-the-counter medicines. He provided the example of taking honey over Tylenol or Motrin for headaches. However, one Muslim physician at a hospital saw prescription pain medication as a way to unburden patients from physical pain and their families from the stress of seeing them suffer. But in these cases, the physician added that taking such medications must not cause patients to stray from the comfort of their faith and that they must adhere to overarching Islamic values and ethics.

Advance Directives

Our interviewees emphasized that the greatest preparation for death within Islam is the acceptance that everything has been written and

predetermined by God. This includes every life event down to the location, time, and the method of a person's passing (Qur'an 6:61). Several of our participants stated that Islam encourages people to prepare for death, not be afraid, and accept death as a part of life. As noted, one imam insisted that seeing a Muslim doctor is recommended. This way patients and their families will have no doubt that their beliefs and their religious and spiritual concerns will be recognized and addressed properly as they prepare for death or manage end-of-life care. This involves details ranging from having the patient's body facing Mecca (Qur'an 2:144) to discussing with the family the importance of making sure that the patient's debt and any other unresolved issues are taken care of at the time of death (Qur'an 4:12). But seeking a Muslim physician assumes that all Muslims share the same beliefs, which may not be true.

Polly Mazanec and Mary Kay Tyler discuss the importance of "cultural competence," and how competency "demands that nurses look at patients through both their own eyes and the eyes of patients and family members" (2003, 52). They write that "patients from cultures that place value on suffering—for example, those that view suffering as a means to an important end—may need to be supported in their suffering" (57). Some Muslims believe that the greater your suffering in life, the greater your reward shall be in the afterlife (Qur'an 3:195), but one Muslim physician explained that showing mercy is much more important than suffering by citing the beginning of Muslim prayer, "*Bismillah ir-Rahman ir-Rahim,*" which means, "In the name of God, the most gracious, most compassionate." One imam explained that even though Muslims should not seek suffering or allow themselves to be in excruciating pain, it is important to understand that it is all by the will of God.

Since God ultimately determines what happens to the physical human body, death should not be feared in Islam, but rather seen as a natural part of life that we all will experience at some point. Islam promotes embracing and planning for death so that individual and family wishes can be honored, which falls in line with the current recommendation for earlier end-of-life discussions and better planning before reaching the hospital, when it is often too late to make choices about care (Kaufman 2005). Imams and Muslim physicians that we interviewed both noted that a natural death is encouraged and expected in Islam because it is God's decision when one lives and dies. A hadith states, "There is a cure for every malady (except

old age).” Islam recognizes everyone will age and eventually pass away; this is a natural part of life and one that should be expected, but not hastened. This presumption has also been found in many countries in the Muslim world (Takrouri and Halwani 2007).[5] IMANA’s position is that Muslims in the United States are allowed to, and in fact should, have advance directives in place that outline their wishes for end-of-life care.

Some Muslim physicians we interviewed stated that DNRs (Do Not Resuscitate orders) are also acceptable, but in general, the imams in our study argued against this point, emphasizing that Muslims should not hasten death because it is God who decides when you die and all measures should be taken to save a life. They believed that having a DNR means that one wants to bring about death quicker as opposed to allowing it to come naturally without prolonging suffering or misery through interventions that may not work. However, resuscitating patients can be seen as fighting against God’s will in certain cases, especially if the patients will never have the quality of life and livelihood that they once had or would want (Takrouri and Halwani 2007). This is a contradiction in how death can be viewed religiously and ultimately depends upon the context. One imam we interviewed noted that the main responsibility of a patient is to seek care when sick, while the primary duty of the physician is to provide care and to take away pain. The physician, however, should not cause premature death when trying to comfort a patient, as no one is permitted to take a life.

The relationship between physicians and patients has changed with developments in biomedicine. Husain Nagamia claims that “modern medicine has become a commodity” and that “the physician is no longer a confidante, an empathizer, a restorer of confidence, but one who essentially has become a provider of a service” (1996, 100). As is the case with other consumers of medical services, this leaves it up to Muslim patients and families in the United States to decide between religious and more secular influences as they prepare for death. Several of our participants agreed that regardless of the contradictions or tensions, Islam encourages Muslims to plan and to carefully consider their wishes (and how they do or do not follow Islamic principles) for end-of-life care sooner rather than later. This parallels the recognition that providers and policy makers need to figure out

[5] Hadiths are teachings, sayings, or ways of the Prophet Muhammad passed down through a chain of narrators (*isnad*) who were his companions.

ways to have more Americans complete advance directives so that their wishes for end-of-life care are documented.[6]

Discussion: Key Intersections between Islamic Beliefs and the U.S. Health Care System

Our open-ended interviews indicate that there are significant overlaps between how health care is delivered in the United States and the ways that Islam approaches medicine, health, and dying. When asked about the relationship between the US health care system and Islam, one Muslim physician based in DC stated, "There is no difference." He emphasized that Islam and the US system prescribe many of the same things when it comes to caring for dying patients. In our research two key themes emerged regarding US health policies and standards concerning end-of-life care: the need for more cost-effective care at the end of life and the need to better prepare for death through documenting one's wishes (in writing and verbally with family and loved ones).

Cost-Effective Care

Health researchers and providers alike argue that fee-for-service reimbursement has caused the US health care system to be fragmented and disjointed. Health care providers are paid according to the quantity of services they render instead of the quality of those services. This leads to exponential increases in the cost of care without an increase in the quality of care (Hughes et al. 2011). There are numerous debates occurring at local and national levels about how to provide high quality care at a lower cost to both the facility and patients. Providing more efficient care outside of an acute care hospital setting could be a key piece of the cost puzzle (Angus 2004; Hughes et al. 2011). Some studies have shown that families in the United States are generally dissatisfied with the quality of care received by their loved ones who pass away in the ICU (Levy 2001), while others argue that if certain services could take place outside of the hospital at other facilities, the costs of health care might decrease (Roberts, Maxwell, and

[6] For example, In the United States there is the National Healthcare Decisions Day each year on which local and national organizations encourage individuals to complete advance directives so that their wishes are honored, whether it is to do everything possible to extend life or not resuscitate. See http://www.nhdd.org/ for more information.

Gross 1980). As previously noted, a significant portion of Medicare spending each year is on end-of-life care. Even though an increase in medical care at the end-of-life is expected, research illustrates that aggressive treatments are occurring at increasing rates, even though they do not prolong or improve the quality of life (Adamopoulos 2013). Because of this trend, patients remain in the hospital for longer periods or return more frequently. To encourage better longitudinal care, Medicare has begun penalizing hospitals that have a high number of readmissions shortly after discharge (Rau 2012).

In several of our interviews, we noticed that the comments Muslim participants made regarding what is permitted, encouraged, or prohibited in end-of-life care and in regard to caregiving also referenced ways to make care more cost-effective. Many of the experiences they recounted parallel the suggestions being put forth by policy makers and health care administrations to lower the costs of care by moving patients through hospitals in a more timely fashion and discouraging the overuse of services. For example, the imam with the aging mother noted that Islam encourages people to take their loved ones home from the hospital as soon as the doctor allows them to do so. They should not stay longer than necessary and instead should be cared for by family members (or a home health service when this is no longer possible). A former IMANA board member not only echoed this point but also stated that this depends on the context. His wife quit her job so that she could take care of her ailing mother full-time, but this was because he was able to afford the cost of the lost income. For those who are not financially stable, this may not be an option; nevertheless, it is still encouraged. He agreed with the imam in that Islam encourages sons and daughters to take care of their elderly parents given they were their main providers as children. Similarly, the imam noted that Muslims should not remain in the hospital until their deaths because this could decrease their quality of life; rather, they should die surrounded by loved ones in the comfort of the home.

The Muslim physician in DC stated that Islam does not condone individuals overusing resources when there may not be enough for everyone—this includes using treatments that would not improve the quality of life for a person who is dying. Instead, even the terminally ill should only use the services appropriate for their condition so that medical providers can tend to other patients and enough resources will be available for everyone. A key critique of the current health care system is that patients

and families may overuse services by wanting everything possible done in order to save a life, even if the outcome would not change. Or different physicians may prescribe the same services to a patient, albeit for differing purposes, because they did not consult with each other first. This limits access to both facilities and providers and makes hospital beds unavailable for those who need them (Berenson and Docteur 2013). One physician stated, "I don't know if you've heard of the statement from the prophet or the Hadith. . . . 'Even if you were in the middle of an ocean, you should not waste a drop of water.' . . . [The] well-being of a community takes precedence over the well-being of an individual." For him, a key religious principle is not to waste already thin resources in order to preserve some for others who need them, including medical services, resources, and providers. In addition, although it is permissible to take medication to dull pain rather than to cure, providers should not prescribe and patients should not consume excess amounts of medication that may hasten death. Natural remedies, as discussed by one imam, may also be used in place of prescriptions for comfort or as painkillers. All of these principles, either combined or taken separately, encourage patients to use the health care system only when needed, and not in excess, thus helping to lower the costs of services for themselves and the medical facility.

More controlled use of the health care system can curb costs and allow facilities to invest the financial resources needed to provide higher quality care. Part of providing quality care in the United States is being able to care for the whole person and offering culturally competent care to patients. These aspects of health care are the foci of initiatives at national, local, and organizational levels (Chin 2000; Purnell 2013). Policy makers and providers have given great attention to the need to offer high quality care that follows patients' religious and spiritual beliefs, which requires some medical services to be altered or transformed from how they are traditionally delivered in the US health care system.

Preparing for End-of-Life Care

End-of-life care is an extremely sensitive yet urgent matter in the United States. Interest in the subject has grown as academics, medical professionals, and the public are realizing that patients may not receive quality end-of-life care because they may be unaware of their options (Kaufman 2005). Many argue that the conversation about end-of-life care between patients and providers does not occur soon enough. Patients often

do not know what they want, and when the end of life nears, doctors—both primary care physicians and those in the hospital—are unclear about which services to provide or withhold (Meyer 2011). This compromises the quality of end-of-life care and the ability to provide patients with the care they desire.

Advance directives, either in the form of a durable power of attorney or a living will, allow people to specify health care preferences or designate someone to speak for them (Castillo et al. 2011); however, relatively few people (approximately two in five) in the United States have an advance directive (Span 2009). Approximately 50 percent of individuals aged 65 and older have an advance directive, and this decreases to 30 percent for those between the ages of 55 and 64 (GAO 2015).[7] A Muslim physician and former leader of IMANA noted that Islam encourages followers to have conversations with families and providers about their wishes for care and to document their preferences in an advance directive. Because everything is pre-determined by God, including death, Muslims should accept that they are mortal. Death will happen and it is best to be prepared for it. Several Muslim physicians noted that medical providers are only the facilitators of God's will, and God has bestowed upon them the knowledge that is necessary to treat disease and to heal. As noted, IMANA has developed an Islamic advance directive template that can be found on their website and social media. It provides religious direction concerning care, pain, death, and mortuary customs and can be modified after meeting with an attorney or to conform to state law. While some Muslims may view a DNR as contradictory to God's will—and the imams that we interviewed emphasized this—the Muslim physician based in D.C. explained that using resources wisely and not wasting them are more important virtues. He referenced a verse from the Qur'an: "O Children of Adam! Wear your beautiful apparel at every time and place of prayer; eat and drink, but waste not by excess, for Allah does not love those who waste" (7:31). If resuscitation will only prolong a life of low quality and suffering, and if

[7] The 2015 report by the Government Accountability Office (GAO) also breaks down advance directive completion in terms of ethnicity and income (although this is for the overall number of advance directives and not specific to age categories). It was found that those who identify as White have a higher completion rate than those who identify as Black, Latino, or Other Races, and those with an income of over $75,000 are more likely to have an advance directive than those with lesser incomes.

there is little to no chance of recovery, the doctor explained that it is not to be done.

One imam stated that it is preferable for Muslim patients to see Muslim doctors so that religious practices are upheld during the end-of-life. They can then be confident that their religious beliefs and concerns will be taken into consideration over the course of care. Nevertheless, our participants reiterated that it is imperative for Muslims to realize that they are not the ones who determine the place and time of death, and they should, therefore, make preparations well in advance. Research has shown that advance directives may not be completed as frequently as they should be because people do not accept that their lives will end, that it is a natural part of the life cycle. This recognition of mortality within Islam and the subsequent need to prepare for death falls in line with the push by medical professionals, advocates, and researchers to have patients formally document their preferences for care.

Participants in our study explained that while God is the only one who creates life and ends life and physicians are only the facilitators of His will, it is not appropriate to cause unjust suffering to patients particularly if the medical treatments would be greater physical burdens than the ailments themselves. Some research has suggested that better end-of-life preparation could decrease health care costs because documented wishes would reduce the medical resources expended for patients who do not desire extensive medical treatments or if treatments would not improve their conditions. Therefore, Islamic teachings can support the larger movement to encourage the use of advance directives in preparation for the eventuality of death.

Conclusion: Parallels between Islam and Biomedicine in End-of-Life Care

Our research is consistent with increasing demands for more culturally competent health care in the United States. People are seeking end-of-life solutions that recognize their cultural and religious backgrounds (Kagawa-Singer and Blackhall 2001). The Pew Forum on Religion and Public Life (2011) has estimated that the number of Muslims worldwide will double between 2010 and 2030. This is also the case for the United States where it is projected that the number of Muslims will increase over the next twenty years from 2.6 million in 2010 to 6.2 million in 2030

because of immigration and larger family size (Pew Forum 2011, 15). In addition, the United States is an aging society. According to the Administration on Aging, between 2009 and 2030 the 65 and older population will grow from 13 percent to 19 percent, and those who are over the age of 85 will increase by 350 percent (Wiener and Tilly 2002). As a reflection of the general population, it is likely that in the near future more adult Muslim children will seek medical care for their aging parents.

Initiatives by some governmental and health care organizations in the United States designed to enhance the quality of health care—including end-of-life care—parallel the concerns of many members of diverse Muslim communities who evaluate health care from the standpoint of their religious practices. The beliefs and values of the participants in our study emphasize similar preoccupations regarding how end-of-life care is perceived, even as they illustrate how religious values are embodied in the context of providing for the sick and dying.

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Life-prolonging religious values in end-of-life medical decisions were associated with fewer clergy-congregant conversations about considering hospice (adjusted odds ratio [AOR], 0.58; 95% CI 0.42-0.80), P < 0.0001), stopping treatment (AOR 0.58, 95% CI 0.41-0.84, P = 0.003), and forgoing future treatment (AOR.Â Objective: We aimed to examine clergy knowledge of end-of-life (EOL) care and beliefs about the role of faith in EOL decision making for patients with serious illness. Design: Key informant interviews, focus groups, and survey.Â They employed a moral framework to determine the appropriateness of EOL decisions, which weighs the impact of multiple factors and upholds the importance of God-given free will. Religious Issues. Religion, or an organized system of beliefs that typically relates to one's faith and trust in a higher power, is a defining characteristic of the way many people live and make decisions. A person may base a number of life choices on religious views, but when aspects of a person's life conflict with religious ideals, it may be difficult to reconcile the two, and doubt and distress may result.Â A recent study, which examined the correlation between religious beliefs and mental health concerns, suggested that the type of god one worships may have an effect on one's mental and emotional health.