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ISLAM AND DYING IN THE UNITED STATES

How Anthropology Contributes to Culturally Competent Care at the End-of-Life

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I was on a conference call with hospital administrators, health care providers, consultants, and researchers from the North and Mid-Atlantic States involved in developing a proposal for federal funding that addressed the need to keep patients from being re-admitted to the hospital within thirty days of discharge. This proposal was in response to the 2010 US health care law that authorized the government to fine hospitals "because many of their patients are readmitted soon after discharge" (Rau 2012). This is "part of a multipronged effort by Medicare to use its financial muscle to force improvements in hospital quality" (Rau 2012). On the call it was concluded that the surveys provided to patients in the hospital before discharge about the care they will receive at home and discussions with nurses and medical staff about discharge instructions were inadequate; we needed to understand what was happening at home and in their communities in order to provide a better picture as to why patients are being re-admitted within one month.

As the only anthropologist in the group, I believed that it was critical to realize that patients do not stay in the hospital and, therefore, we needed to better understand how culture and social circumstances impact whether or not they follow their discharge instructions and if they do, to what degree. It is also important to realize that non-compliance is a choice that people are able to make (Campbell et al. 2001). In this instance, many of the involved hospitals' re-admissions were due to class issues and the fact that several of the patients relied on public health care and did not have a private family physician to follow up with after discharge. They often used the emergency room as primary care even though critical care is very costly. At that point I realized the importance of culturally competent health care and taking into consideration people's backgrounds when caring for them and when designing treatment plans. At the time, I was a postdoctoral fellow working with a health care organization in rural Virginia where many of the patients qualified for government assistance. In working with administrators and physicians to

anthropologists and non-anthropologists alike of cultural competence and how the term culture is used in medical education (Carpenter-Song, Nordquest Schwallie, and Longhofer 2007; Kleinman and Benson 2006; Smith-Morris and Epstein 2014), I suggest that cultural competence is often too narrow in practice. As Baker and Beagan (2014) rightly observe, it has been frequently reduced to reference ethnic and racial minorities, which leaves out cultural and social factors and excludes populations that may need special considerations in care. Furthermore, it denies the fact that "individuals belong to multiple cultures, but those cultures are neither coherent, static, nor do they always join together seamlessly" (Baker and Beagan 2014, 581). Arthur Kleinman and Peter Benson write, "One major problem with the idea of cultural competency is that it suggests culture can be reduced to a technical skill for which clinicians can be trained to develop expertise" (Kleinman and Benson 2006, 1673). In the example I gave at the start of the chapter, medical providers needed to consider class in designing treatment plans and follow-up care for many of the patients so that they were not re-admitted to the hospital, and yet this factor was not considered. In addition, just focusing on ethnicity reduces people's identities to a single attribute and simplifies the ways they experience the health care system and society. Identities and experiences are based on a complex network of characteristics including ethnicity, gender, class, religion, sexual orientation, citizenship status, nationality, etc. (Crenshaw 1991; Hall 1996), and people can belong to more than one culture at once or move between cultures with and without ease – all of which can have an impact on health practices and choices.

I address the ways that anthropological approaches can contribute to a broader and more robust understanding of cultural competence in health care and offer a critique of the notion that culture can be "reduced" to a simple skill. To do so, I will discuss some of my interviews and observations with diverse Muslim communities in the D.C. area as well as my work with national organizations that focus on Islamic medical ethics. In this I will disentangle how Islamic beliefs about death, illness, and the body intersect with the US model for end-of-life care, which anthropologists have noted champions technology and views death as a failure for the health care system and medical providers involved in the case (Chapple 2010; Kaufman 2005). My interest in studying Islam and end-of-life care grew out of the fact that there is a rich and burgeoning scholarship on Islamic medical ethics (Brockopp and Outka 2003; Clarke 2006; Gatrad and Sheikh 2001; Moazam 2006), but there is less work on how theological points and ethics are turned into practice in medical settings, particularly in the United States. Detailing religious ethics is not enough if providers are going to truly deliver religious and culturally appropriate care to patients at the end-of-life. It is not productive to assume that there is a coherent Islamic theology, but rather I argue that a more productive ethnographic starting point is to explore the multiple interpretations and ideas that exist among Muslim communities and to allow the discrepancies and differences to come to the fore; this will provide a more holistic analysis of how Muslims understand what Islam says about death, illness, and the body and help illustrate that a general approach to defining cultural competency may be insufficient. Through detailing

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my research, I will elucidate some of the deeper meanings attributed to medical practices in end-of-life care for diverse Muslim patients and their families and demonstrate how ethnography has enabled me to examine the ways Muslims' understandings of death and interpretations of sacred texts are put into practice within a health care setting in the D.C. metropolitan area.

Caring for Muslim Patients: Methodology and Background

My primary site for this research study is the Washington, D.C. metropolitan area, which includes parts of Maryland and Northern Virginia. This is an excellent setting given the region's diverse population and the number of Islamic Centers. As of 2011, there were sixty-two mosques in Virginia, seven in the District of Columbia, and fifty-four in Maryland (Bagby 2011). Virginia ranks in the top ten states in terms of the number of mosques. The majority of Muslims who reside in Virginia and Maryland live in the counties surrounding D.C. (ASARB 2010). The role that religion plays in Muslims' health decisions and practices in the United States must be understood within the context of the anxieties about health care and the end-of-life that proliferate in the political, medical, and public realms.[1] The United States is an aging society. The Administration on Aging predicts that between 2009 and 2030 the population of those over sixty-five will increase from 13% of the population to 19%. The age group of eighty-five plus will increase by 350% in this time (Wiener and Tilly 2002). This trend places added pressure on publicly funded programs for seniors, the health care system, and long-term care facilities. Also, the Pew Forum on Religious and Public Life (2011) estimates that the number of Muslims in the United States will double between 2010 and 2030. Approximately 50,000 Muslims earned permanent residency status in the United States in 1992, and in 2009 this number had increased to 115,000 (Inhorn and Serour 2011, 936). Currently, 65% of the Muslim population in the United States was born abroad, but this number will decrease to 55% as the number of native-born Muslims increases (Grossman 2011). Adult Muslim children will be seeking medical care for aging parents that "is judged to be 'religiously appropriate'" (Inhorn and Serour 2011: 935) and will be making choices about end-of-life care in upcoming decades.

Since 9/11 Islam has garnered a great amount of media attention, and even more so in 2015 with the rise of Islamic State (ISIS), Boko Haram, and the end of the wars in Iraq and Afghanistan. Coverage often frames the religion as repressive and against innovation and modernization. Marcia Inhorn and Carolyn Sargent argue that Islam is generally misunderstood in the West, "In the aftermath of … [9/11] the lack of Western understanding of Islam … has become abundantly apparent … [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" (Inhorn and Sargent 2006, 1). Lisa Henry (2010, 46) writes, "Historically, critics comment, the media has treated Islam as violent and backwards and for Islam to be modern was inconceivable." Lance Laird et al. (2007, 922) note, "Media reports, political rhetoric and legislative action … increasingly focus on

Muslims as an out-group, promoting negative stereotypes of Muslims and Islam. Yet few sources ask how such attention affects the health of Muslims." Laird et al. (2007) ask a key question about how the negative images we see of Islam in the United States impact Muslims' relationships with health care. One female Muslim physician told me that she has had patients who faced discrimination when seeing non-Muslim doctors. In addition, they point out that all Muslims seem to be placed in one group – the "out group" – and little attention is given to the diverse interpretations among Muslim communities in the United States, some of which fall directly in line with many of the policies and best practices in the US health care system.

This is the place where I believe I can contribute the most as an anthropologist and ethnographer – a better understanding of how culture and personal circumstances impact health decision making and practices at the end-of-life for Muslims. Highlighting the diverse ways that Islam informs choices and behaviors can also combat the assumption that populations "have a core set of beliefs about illness owing to fixed … traits" (Kleinman and Benson 2006, 1673). The D.C. area has extremely diverse Muslim communities, and so for my research I have been working primarily with those who have immigrated to the United States and identify as Sunni.[2] Sunnis make up the majority of the Muslim population worldwide comprising 80–90% of the faith's followers (Inhorn and Serour 2011, 935). I conducted extensive ethnographic research in Morocco between 2005 and 2009 on Islam, development initiatives, and reproductive health care for my dissertation (see Hughes 2011, 2013; Hughes Rinker 2013a, 2013b), but upon completion of my PhD I took a postdoctoral fellowship at Virginia Tech and was quickly brought on board to develop projects alongside a health care organization that were aimed at improving the quality of care in rural southwest Virginia. This was a long way from my research in Morocco, but partially due to personal reasons – most notably my partner being settled in the Washington, D.C. area – I limited my job search to the region. The position's advertisement stated, "experience in working in a clinical environment is desired," which my ethnographic research in three health care clinics in Morocco certainly provided me. It also called for someone who is "committed to improving … clinical outcomes." Even though the required research was quite different than my dissertation research, I found the position invaluable because it helped me develop a commitment to improving care for individuals and opened up my eyes to the challenges people face in seeking health care. I continue to cherish this trait as a researcher even after my postdoctoral fellowship ended, and I still promote it to my students as a professor of anthropology and as a mentor (see Hughes Rinker and Nahm 2013).

As is happening in many hospitals across the United States, the health care organization I worked with found that one of its hospitals in particular, located in Appalachia, had a high rate of terminally ill patients without advance directives – documents in which patients' wishes are spelled out (a living will) or a proxy is identified (a power of attorney) – when they were admitted.[3] This is a Critical Access Hospital (CAH), meaning that it is located thirty-five miles or more from

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any hospital or other CAH or located more than fifteen miles from any hospital or other CAH on secondary roads with no highway access (CMS 2014). Given its rural location, the majority of its patients attended one of the three primary care practices in the county, two of which are also owned by the health care organization. There was no specialty care within a reasonable distance. I developed a project to figure out how to make discussions about end-of-life care happen more often within the primary care practices so that when individuals ended up in the hospital at times of serious illness, they would already have documented their wishes and discussed them with their family doctors and loved ones. I collected preliminary data for this study through visiting the hospital and informally interviewing physicians and social workers, interviewing pastors in the local area who provided spiritual care to patients in the hospital, observing hospice nurses as they made home visits in the county and nearby areas, and visiting the two family practices and informally interviewing doctors and nurses when possible. It was while I was conducting this research that I realized the importance of anthropological and ethnographic research to improving health care and creating health policy and to have my work contribute to both scholarly and public discussions. For instance, I discovered that even though the hospital would allow its beds to be turned into hospice beds for a time, the hospice nurses used a completely different electronic medical record (EMR) than hospital personnel. This meant that neither one could view each other's notes about patients, which caused miscommunication between hospice, doctors, patients, and their families. I left the position before the project really got underway, but since then have remained committed to research on health care that is academic, but inherently applied in nature. Following this goal, I wedded my interest in studying Islam and health – as I had for my dissertation research that turned into my monograph and a few peer-reviewed articles – with my newfound interest in end-of-life care in the United States.

I started this project in January 2013[4] just a few months after I began a tenure-track position in anthropology at George Mason University. Given my academic position and my commitment to improving the quality of health care, I decided to design this project so that I can contribute both to scholarly conversations surrounding death, religion, medicine, and ethics and to public debates concerning the end-of-life and Muslim identities in the United States. This means publishing strategically in the future in both academic and professional outlets and being willing to take the time to discuss my project at length – without the academic jargon – with health care providers and administrators. It also means that I have to develop an "elevator pitch" for my project that is suited for those from multiple disciplines and fields and captures my audience's attention in a short amount of time; I have learned in working with medical professionals that is typically all they can spare in their already jam-packed days. This chapter includes data that I collected in 2013 and 2014 primarily through interviews with physicians located throughout the United States who are involved with a national organization, but with international reach, that is dedicated to Islamic medical ethics; practicing Muslim physicians; Imams in the local region; Muslim community members; and

observations of a presentation at a local hospital for medical residents on Islam and palliative care.[5] Other aspects of my ethnographic research include interviews with bioethicists, gerontologists, and Islamic scholars; attending conferences on aging, end-of-life care, death, religion and spirituality, and ethics; reviewing relevant literature in anthropology, public health, religious studies, medicine, and other closely related fields; collecting and monitoring popular media on debates surrounding the end-of-life; interviews and observations at a hospital;[6] and a textual analysis of websites and message boards focused on Islam and dying and of information distributed by health care organizations in the D.C. area on end-of-life care. Ultimately, I suggest that anthropological research on the experiential nature of end-of-life care and on how Muslims view medicine as interfacing with their religious understandings has a critical place in discussions of cultural competency, and in actuality should be made central to academic and public debates about culturally appropriate death.

An Ethnographic Project on Islam and End-of-Life Care in the United States

Through my interviews and observations in my research on Islam and end-of-life care in the Washington, D.C. area, I have found that many contradictions exist. One afternoon I attended a thoughtful and informative lecture given by a Muslim palliative care physician to medical residents in internal medicine at a hospital. The physician discussed some of the major Islamic tenets that the residents should be aware of while caring for Muslim patients as they are nearing death. I sat in the back of the room next to another physician and a few other staff members. The room was full with about twenty-five residents in attendance. The physician explained that he had given this lecture several times to hospice providers and other medical staff at the hospital given that there are a relatively large number of Muslim patients who seek care there. In reading literature about the hospital, I have discovered that it aims to treat the entire person including his or her spiritual needs during a health crisis or just routine health care, so it recognizes that providing culturally competent care can be a way to increase patient and family satisfaction, a means to provide higher-quality care, a way to design treatment plans that people will follow and thus have a higher-quality life and not be re-admitted, and a method to attract new patients. In addition, administrators recognize the ethnically and culturally diverse nature of the local region and therefore, lectures like this one by the physician have a key place in its mission and goals. This whole person approach has been said to lead to better clinical outcomes and higher patient satisfaction (Stewart et al. 2000), thus demonstrating the importance of anthropology (and its methods) to better health practices and management.

At this lecture, the physician recalled a time when an older Muslim male patient was in the hospital with a terminal illness. He was unresponsive. He was not going to return to the quality of life he once had and was being kept alive through machines. This physician was called for a palliative care consultation. He spoke to

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the patient's wife who was by his side. He asked her why she kept her husband alive through the machines. She explained that if she took her husband off of life support it would be considered murder in the eyes of God. The physician returned several times to speak with the patient's wife about different care options to make sure the patient was comfortable and free of pain. He told me that many times patients, or the Imams who will visit the hospital to counsel Muslims patients and families, believe that once life support is started, a patient cannot be removed from it because it would be just like killing the person. This is because it is only God who decides when it is the right time to die. Another physician who used to practice abroad and in the United States but now works full time at a mosque in Virginia explained to me in our interview that the role of the medical provider is to carry out God's wishes. He said, "And the doctor … the patient is God's patient … And God is sending the mercy to him through me [the physician], I'm a carrier in God's mercy, my knowledge … I have no way, I can't withhold it." Several of the Imams and other Muslim physicians that I interviewed for this project all agreed that for every disease God has made a cure, and therefore, all life is God's and we as humans cannot decide when it will end. This is why life support cannot be removed once it is initiated.

During the lecture, the physician recalled that he told the patient's wife that God does not want to burden people and that her husband had physically suffered enough. A verse from the Qur'an states, "God does not charge a soul with more than it can bear" (2, 286). Not only had the patient suffered, but his wife had also had additional emotional and mental stress from seeing her husband's health decline. After several meetings, the wife decided to finally let him be removed from the ventilator and pass away during the Holy Month of Ramadan that year. According to the physician, letting her husband be at peace by unhooking him from the machines was also allowing him to receive extra blessings from God since he was to die during Ramadan. What is interesting in this situation is that what the wife initially understood Islam to say about the timing of death when her husband entered the hospital was the complete opposite of her final action – removing him from the ventilator and allowing him to pass away at the hospital. But, this act did not contradict what the Muslim physician believes about death in Islam. He sees relieving patients' pain and suffering at the end-of-life as an act of compassion if they would never be able to live without the use of machines or would remain unresponsive to stimuli. One Imam I interviewed at a mosque in Virginia, held a similar opinion to the physician if patients are suffering from a terminal illness as compared to having had an accident or experienced an unexpected injury that resulted in them being unresponsive. He recalled one of his worshippers discussing what to do when her aging father fell into a coma after battling cancer,

> So she said what do you think, and [I] said pull the tubes out. Your father is not going to recover. The ICU is for someone who had a motorcycle accident that [may recover] … This is old age. Keeping him like that and you sitting next to him … You stopped your life. That's $10,000 a day [referring to potential

> earnings from a job she left]. Islam does not tell you to waste your money. Take the tubes out. If he [is] meant to live, he will live. If not, that's God's will.

Instead of viewing the removal of a ventilator as murder, if it is medically acceptable it is also a way for God to provide peace to patients and families who have suffered through terminal illnesses or other severe injuries that prohibit the patients from returning to the quality of life they once had.

Another physician at a hospital in Northern Virginia said that one Muslim family told her that the use of opiates to relieve pain often associated with terminal illness was very much against their religion. Imams in the D.C. area have also said this to me. They state it is against Islam to take any type of medication such as morphine because it can alter your state of mind and you may lose your sense of self. They mentioned that when you take narcotics you may not feel like yourself and you may feel "out of it." One Muslim doctor said that while he may not completely agree with this, he understands their line of thinking. You may curse God if you are out of sorts while on medication and blame God for pain or suffering. If you do not feel like yourself, you may speak out against God, which could have ramifications in the future. Another Imam said to me that Muslims are to take nothing more than Tylenol and to try to treat things as naturally as possible. He said,

> Islam does not prohibit medicines … we say yes, but find natural ways of doing it. If I tell you take a Tylenol or take a spoon of honey … [and] both will do the same thing, which one would you prefer? So the honey would be better [because it is natural].

In addition, this Imam emphasized the power of prayer, "So you need a … powerful, powerful prayer … so if he raise [sic] his hand and said, 'Oh my Lord cure my body,' he will cure. This is a given … no exception." However, a Muslim man in his twenties originally from North Africa explained to me that Islam is not against any type of medicine, even those that are considered to be controlled or only by prescription if they are intended to take away pain. Alleviating physical pain is a way for God to unburden Muslims in his opinion and to provide them with some sort of comfort as they deal with approaching the end-of-life. In my research, I have found that there are two major ways of thinking about pain medication. On the one hand, pain medication is against Islam because it could make a person lose a sense of self and potentially speak out against or blame God. (I also found this sentiment among some people in Morocco where I am engaged in a similar project on pain management and palliative care at the end-of-life and Islam.) Moreover, since God has created every disease, he has created a cure. He has provided natural cures and responds to prayer. One the other hand, pain medication is a way for God to help relieve some of the burdens and suffering that Muslims bear during end-of-life care.

The general consensus among Imams that I have worked with is that medical providers are to do everything to try to save a person if they are unresponsive. This

includes using feeding tubes and ventilators if necessary. Muslim physicians have told me that sometimes it is difficult to have patients complete a DNR (Do Not Resuscitate)[7] order even though the medical treatments may be more of a physical burden than the actual illness. One Imam stated,

> In Islam we are discouraged from leaving any directive asking not to provide every possible way to extend life. Because extending a life simply is [the] teaching of the Prophet Mohammed. He said that "If you don't seek treatment of your illness even if with hope of getting cured of 1% then you have killed yourself."

(Some Muslim physicians I interviewed disagreed with this.) A Muslim physician at a hospital in Northern Virginia explained that one Imam who would visit patients in the hospital always preached that patients and families should do everything possible rather than have comfort care, even if medical providers had explained that the patient's condition would not improve. But what struck me is that two of the Imams I interviewed were adamant that patients should return home to die so that they are surrounded by their loved ones; and furthermore, families should take care of patients, not home health services or hospice. However, a chaplain at a hospital near Washington, D.C. said that the hospital administration actually had to step in with several Muslim patients who were nearing the end-of-life because a number of family members and loved ones would come to their hospital rooms, making them extremely cramped, and thus it was difficult for the medical staff to do their jobs.

A Muslim physician in D.C. said during our interview,

> I don't know if you've heard of the statement from the Prophet or the hadith[8] ... that even if you were in the middle of an ocean, you should not waste a drop of water ... the well-being of the community takes precedence over the well-being of an individual.

What is interesting here is that there is a general consensus among Imams in my study that patients and families should request every medical intervention possible, but they do not believe that patients should die in the hospital. The hadith, as told by the Muslim doctor I interviewed, reiterates that patients should not use more resources than necessary, meaning that dying in the hospital may not benefit the community especially if treatment would not be effective. They should return home so that others can use the hospital's resources, particularly if those resources are already stretched thin. While the Imams stated that families should be the primary caregivers given the importance of family ties and progeny in Islam, the Muslim physician who recalled the hadith said that this is not always possible due to financial circumstances. For instance, people may have to work two jobs to make ends meet and would not be able to stay at home to take care of a dying loved one; in cases like this, home health services or hospice care may be absolutely necessary.

Concluding Comments: Studying End-of-Life Care as an Anthropologist

In the above examples taken from my research, I hope to have highlighted some of the contradictions that surround Islam and end-of-life care in the United States that stem from Muslims' varied religious interpretations and understandings, different readings of sacred texts, and the intimate and complicated relationship between religion and culture. My goal for this chapter was not to address my contributions to theoretical discussions and scholarly debates on Islam and end-of-life care, but rather, I wanted to emphasize that there is not a "how-to guide" or "one-size-fits-all" way to provide religiously appropriate end-of-life care. Muslim communities in the United States are extremely diverse in terms of class, ethnicity, nationality, citizenship, social status, and how they identify religiously. Abdulaziz Sachedina, a leading scholar on Islamic ethics, recognizes this when he suggests, "the solutions that are offered in the Qur'an are culture specific and not normative for a timeless application and, therefore, cannot be used as paradigmatic in delivering judicial decisions that recur throughout human history" (Sachedina 2009, 145). These "solutions" are temporally bounded, and in addition, can be applied in different ways depending on geographic location and cultural context. For example, one of the Muslim physicians that I interviewed used to practice in the Middle East. In his experience, it was much more difficult to take a Muslim patient off of life support in the Middle East than he found here in the United States. Anthropologists are trained to tease out the complexities of a situation and to uncover what is not obvious at first glance. My research on Islam and end-of-life care has led me to question how cultural competence can be truly operationalized in the US health care system and whether or not it is too abstract a concept. Because it lacks a concrete definition I ask if it is being put into practice in too narrow and excluding ways.

My interest in health care has opened up many different doors for me. I thought my career trajectory was set and it was a direct path from PhD to tenure-track position. Even though this is how I expected it to go, this did not happen. Unexpectedly my first position was at an interdisciplinary research center designing projects with a large health care organization on topics that I had not addressed in my dissertation research in Morocco and in a completely new location. Looking back on my career path, I think this was the best move that I could have made as an anthropologist. It made me aware of the vital importance of being able to speak to broad audiences and being able to move seamlessly between, and even straddle, the academic and applied worlds. I have come to enjoy explaining ethnography and anthropological theory to those who are not familiar with the discipline – a regular occurrence working in health care. With that being said, it also made me recognize that sometimes there is very little difference between these two worlds and that my work tends to be hybrid in nature – academic but inherently applied. Anthropology can make a difference in health care and policy by putting people at the center of research and putting meaning behind what might be termed by some as just anecdotal evidence.

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