Supporting Muslim Patients During Advanced Illness

Nathan A Boucher, DrPH, PA-C, MS, MPA, CPHQ; Ejaz A Siddiqui, MIS; Harold G Koenig, MD, MHS

ABSTRACT

Religion is an important part of many patients’ cultural perspectives and value systems that influence them during advanced illness and toward the end of life when they directly face mortality. Worldwide violence perpetrated by people identifying as Muslims has been a growing fear for people living in the US and elsewhere. This fear has further increased by the tense rhetoric heard from the recent US presidential campaign and the new presidential administration. For many, this includes fear of all Muslims, the second-largest religious group in the world with 1.6 billion adherents and approximately 3.5 million in the US alone. Patient-centered care requires health professionals to look past news headlines and unchecked social media so they can deliver high-quality care to all patients. This article explores areas of importance in the context of advanced illness for practitioners of Islam. These include the conditions needed for prayer, the roles of medical treatment and religious authority, the importance of modesty, the religious concordance of clinicians, the role of family in medical decision making, advance care planning, and pain and symptom management. Initial recommendations to optimize care for Muslim patients and their families, informed by the described tenets of Muslim faith, are provided for clinicians and health systems administrators. These include Islamic cultural awareness training for staff, assessment of patients and families to determine needs, health education and decision-making outreach, and community health partnerships with local Islamic institutions.

INTRODUCTION

Adherents to the Muslim faith are a vulnerable group in health care today, subject to potential discrimination because of the widespread negative public view of Muslims. Clinicians and administrators alike, particularly in the US, can benefit from enhanced knowledge about the Muslim faith. The US has its roots in supporting the freedom of religious practice as stated in the First Amendment of the US Constitution. However, worldwide violence perpetrated by people identifying as Muslims has been a growing concern for US citizens. This tension has been further exacerbated by the rhetoric heard during the 2016 US presidential campaign and from the new presidential administration. Since the World Trade Center attacks of 2001, concerns have evolved into a generalized fear of an entire religious group practicing Islam. Clinicians and systems are not insulated from the undercurrent of discrimination against Muslims.

Islam is the world’s second-largest religion with 1.6 billion practitioners worldwide and approximately 3.5 million in the US. Supported by provisions of the 2010 US Affordable Care Act, clinicians and hospital systems are evolving to deliver care that is more patient-centered and equitable. Projections indicate a doubling of the US Muslim population by 2030. A growing and aging Muslim population will have care needs related to chronic and terminal illnesses.

Discrimination in Health Care Settings

Muslims have reported discrimination in health care settings, including denial of services, on the basis of their religion. An Economist poll of 1000 adult US citizens found that Muslims face “a great deal” (39%) of discrimination in America. Respondents reportedly perceived discrimination to be higher for Muslims than for Christians (23%) reporting “a great deal” and 16% reporting “a fair amount” of discrimination) or for Jews (33% and 11%, respectively). Muslims are also more likely to report depression as a result of discriminatory verbal insults compared with those not subjected to such treatment. The Institute of Medicine described racial and ethnic disparities in health care as arising from broader historic and contemporary social inequality, influencing clinician bias and prejudice.

Patient-centered care requires us to look past past news headlines and unchecked social media to deliver high-quality care to patients. In the setting of chronic, serious, or terminal illness, Muslim patients—like any ill patient—require care that meets them where they are, supporting medical as well as psychosocial needs.

Religion is an important part of many patients’ cultural perspectives and value systems that come to the forefront during advanced illness and near the end of life when mortality must be addressed. Yet religious needs are minimally met, if at all, in contemporary US health care. Evidence suggests that health care professionals’ willingness to explore patients’ spiritual needs during advanced illness is low, and this may stem from a lack of spiritual care knowledge and training. Ignorance about Muslim culture in this regard has negative implications for shared decision making, psychosocial support, and management of disease. One pilot intervention involving a one-hour educational intervention delivered by a Muslim chaplain demonstrated improved knowledge of Islamic teachings regarding end-of-life care among participating palliative care clinicians. Additionally, the available research may reflect presumptions that being Muslim means rejecting biomedical innovation and health education when the opposite may be true. Assessing and attending to religious and spiritual needs of patients with...
advanced and terminal illness is supported by the National Consensus Project and the Institute of Medicine in the US, and by the World Health Organization.

We address areas of importance in the context of advanced illness for Muslim patients. These areas include prayer, medical treatment values, role of religious authority, modesty, medical decision making, advance care planning, and pain management. Recommendations to optimize care for Muslim patients and their families include Islamic cultural awareness training for health care staff, assessment of patients and families to determine needs, and community health partnerships with local Islamic institutions. This review is provided to familiarize the reader with tensions at the intersection of Islam and Westernized healthcare in advanced illness contexts.

There is, of course, variation between individual Muslim patients and families. Clinicians and administrators can acknowledge and assess this variation by engaging with their patients, and asking them about their religious and spiritual needs.

Considerations for Muslim Patients and Families

The Sidebar: Case Vignette illustrates the case of a female Muslim patient with advanced illness who encounters challenges in adhering to her faith and practice during an acute care hospitalization. Real-life patient concerns and responses listed support a collaborative approach in caring for a Muslim patient.

DISCUSSION

The Sidebar: Recommendations for Culturally Sensitive Care to Muslim Patients with Advanced Illness details seven areas in which clinicians can address Muslim patients’ spiritual and religious needs.

Prayer

Prayer and one’s preparation for prayer play a central role in Muslim religious practice as one of the five pillars of Islam. The five pillars are profession of faith, prayer while facing toward the holy city of Mecca (in Saudi Arabia), fasting during the holy month of Ramadan, giving of alms (or zakat) to the poor, and pilgrimage to Mecca at least once during one’s lifetime. Notably, each pillar is strongly connected to prayer and devotion, a source of strength important to recovery from illness. Maintaining personal cleanliness and a clean space to pray in healthcare settings in the midst of illness are particular challenges. This is an important concern for Muslim patients with advanced illness who spend a good deal of time in hospitals, clinics, and other healthcare environments.

Muslims will generally wash their hands, face, and feet in preparation for prayer (known as wudu). Tayammum, touching both hands to clean sand and sweeping them over the face and hands, can be done if the person is too ill for the standard wudu ritual washing.

The availability of certain items, such as prayer rugs, and an acknowledgment and understanding of the importance of prayer, have been identified by some

<table>
<thead>
<tr>
<th>Case Vignette</th>
</tr>
</thead>
<tbody>
<tr>
<td>A 44-year-old Muslim woman is admitted for management of complications related to lung cancer with metastasis to her spine. She lives an independent life and is considered a financial supporter for her family. In her current state, she is becoming dependent on others, losing independence in simple activities, and is concerned about the well-being of her children. Her husband provides minimal emotional support.</td>
</tr>
<tr>
<td><strong>Patient's concern:</strong> Pain control, inability to get halal (prepared per Islamic law specifications) meals, and not getting enough nutritious food to regain strength.</td>
</tr>
<tr>
<td><strong>Response:</strong> With staff input, the imam (an Islamic leader) counsels her on the benefit of pain control to relieve suffering under the circumstances. She is advised by the imam to start consuming all types of fruits and vegetables as well as nutritious drinks and fish from the hospital menu.</td>
</tr>
<tr>
<td><strong>Patient's concern:</strong> That her surgical case is being delayed because of her faith.</td>
</tr>
<tr>
<td><strong>Response:</strong> Hospital staff along with the Muslim chaplain are able to comfort her and explain the factors related to the delay.</td>
</tr>
<tr>
<td><strong>Patient's concern:</strong> If paralyzed after surgery, her hygiene will not be properly cared for.</td>
</tr>
<tr>
<td><strong>Response:</strong> The imam reminds her to have faith in Allah and have hope because she is in a competent medical facility. The imam reminds her that by Allah’s will all her postsurgical care, including her hygiene requirements, will be taken care of by hospital staff and her family members. The treating clinician and nurse indicate their support. The imam prays with her and comforts her by indicating that special healing prayers will take place during Jummah (Friday noon prayer) by the hospital’s Muslim community.</td>
</tr>
<tr>
<td><strong>Patient's concern:</strong> Support from her available family member, her husband.</td>
</tr>
<tr>
<td><strong>Response:</strong> The imam, with a hospital social worker, helps to link her husband to the Muslim community and social work supports so that he can be more resilient and supportive.</td>
</tr>
</tbody>
</table>
Muslims as ways to assist adherence to religious practice while ill in health care facilities.23-26 Turning immobile Muslim patients’ beds toward Mecca for prayer, making Qur’ans readily available, and replacing wall-hanging crucifixes (in traditionally Catholic hospitals) with crescents (a symbol of Islam for some adherents), if the institution will allow, have also been described as ways to make clinical space more welcoming for prayer and Islamic faith.27

Medical Treatment

Science, medicine, and faith are not separate in Islam. Indeed, a legacy of scientific and medical advancement is owed to the Islamic world.28 Although the Arab Muslim influence on modern medicine is not often highlighted, Muslim faith generally welcomes innovations in healthcare.29 Muslims are expected to seek treatments for curable disease and to view incurable disease as God’s will.30 Some Muslims may not wish to consider the withdrawing of care or organ donation from their loved ones.31 However, withdrawal of futile life support in the context of inevitable death is permissible, provided it is done with informed consent.32 Islamic law allows patients to refuse futile treatment, but it also forbids passively or actively causing death to self or others.33 In the setting of incurable disease or terminal illness, Muslims’ views may vary depending on religious and social contexts. It is advised to ascertain the views of patients and families/surrogates and to seek out Muslim clerics, imams (a mosque’s prayer leader), or chaplains when possible for clarification and help with family communication.34

Role of Religious Authority

It can be a challenge for religious Muslims to navigate the decidedly secular US health system and the approaches to care that characterize it. Muslims may wish to consult their imam or other knowledgeable Islamic practitioner for guidance in medical decision making.35 Although this person may not have any particular medical knowledge, this practitioner is called on to help with health care decisions, especially in the setting of severe illness.36-38 There is evidence that patient and family requests for religious guidance increased after the 9/11 attacks in New York City because of increased stress from discrimination.39-42 Muslim chaplains, when available, can help patients reconcile faithful practice and health care decisions in advanced illness.27 Additionally, and importantly, fatwas, or authoritative religious rulings by Islamic jurists, provide guidance for Islamic adherents regarding treatment or other health decisions.5-37 Spiritual assessment plays a critical role in determining patients’ and families’ needs during advanced illness,50 but knowledge of Muslim religious authorities’ power is also critical to a broader understanding of how decisions are made.

Modesty

Modesty for women in Muslim practice transcends that of members of the opposite sex. Physical modesty for women, usually involving the physical covering of the body, signifies respect for self and devotion to and respect for Allah—one of the five pillars of Islam.37-38 Modesty in dress applies to men as well, but Muslim women are more iconic for their modest attire.39 Modesty in one’s affairs—language and actions—applies to both men and women and shows respect for society, interpersonal relationships, and Allah.50-51 This includes refraining from vanity as well as unlawful or hurtful behavior. Although some non-Muslims may view aspects of this requirement to be extreme, such as Muslim women’s wearing of the hijab (head/body cover variations), knowledge of its purpose is important in understanding Islam and, ultimately, providing culturally sensitive care. The experience of advanced or terminal illness adds another layer to this culturally and religiously embedded behavior, particularly for women. Losing the ability to be independent and care for others, requiring instead to be cared for in institutional settings, makes control of one’s body and its image much more important.52

Gender concordance of clinicians is linked to modesty as well. A Muslim woman or man may require that the treating clinician be the same sex as themselves.40 Honoring such a preference, a preference that may be shared by non-Muslims as well, will allow for optimal patient assessment and relief of suffering in advanced illness. Although a religious context may be discussed here, a patient’s requirement or preference for gender concordance may reflect his/her culture, religion, or simply preference.

Recommendations for Culturally Sensitive Care to Muslim Patients with Advanced Illness

• Prayer: Make the clinical space more welcoming for prayer and Islamic faith, such as by turning immobile Muslim patients’ beds toward Mecca for prayer, making Qur’ans and prayer rugs readily available, and removing any non-Islamic religious symbols.
• Medical Treatment: Avoid assumptions about Muslim patients’ desire for medical treatment. Frankly explore the treatment options with patients and/or surrogate decision makers.
• Role of Religious Authority: Invite patients, if they wish, to consult their trusted religious leaders as they make decisions about their care.
• Modesty: Keep patients draped and provided with gowns or other materials to maintain modesty. Ask patients about their preference for same-sex clinicians and provide, if able. Otherwise, explore the patient’s preference for a trusted chaperone to be present during examination or treatment.
• Advance Care Planning: Ask Muslim patients about their preferences for care should they become unable to make their own decisions and document these preferences in the medical record.
• Pain Management: Assess patients’ pain adequately, describe the options available to relieve pain, and discuss the benefits and side effects of available treatments. If pain medication is desired or not, document the patient’s choice in the medical record.
• Address Mental Health Needs: Advanced illness is associated with many emotional and mental health issues. Identify these issues and use the patient’s religious faith to help address those needs. Resources are available in this regard.1

Health Decision Making and Advance Care Planning

The Muslim faith and the cultures in which the Muslim faith is practiced influence the way health care decisions, including advance care planning, are made. For example, Muslim families often share health decisions for individual family members, in effect rejecting the concept of autonomous decision making typically encouraged in US health care.41,42 An imam may assist decision making as well through counsel and interpretation of Islamic teachings.32 Additionally, patients may prefer or request that a treating clinician is also Muslim and understands the characteristics of their faith.3 Deliberating on such a request may not be possible in some settings; however, advance care planning done truly in advance of serious illness may allow time for patients to seek a suitable Muslim clinician. Whereas life, death, and suffering is determined by Allah according to the Qur’an (57.22), the Islamic Medical Association of North America, for example, encourages the use of advance care planning to prepare for future illness. Furthermore, Muslims are permitted to refuse treatment in the context of incurable diseases and to not have undesired treatments given to them.43

Pain Management

First, optimal communication and supportive, empathetic care is essential in assisting pain treatment.44 Building on this necessary foundation, there are certain considerations for Muslim patients. Although a Muslim patient may very well desire pain management and although Islamic teachings view relief of suffering as virtuous,45 some Muslim patients may view suffering as a way to atone for their past sins. Counsel from an imam can assist this process and understanding. Furthermore, drugs that make thinking or decision making more difficult are generally eschewed, but may be accepted if the medical utility is explained to patients and families.24 Obtaining informed consent before the administration of pain medication, although not a standard process in most US health care facilities, working collaboratively with local imams and facility staff to respond to patients’ needs.50 Actively determining Muslim patients’ and families’ needs should be a standard practice in health care institutions. Prayer needs, modesty requirements, approaches to decision making, need for a Muslim chaplain or liaison, and dietary requirements (ie, halal [prepared per Islamic law specifications] or vegetarian meals) are among a Muslim’s concerns during a hospital stay or care during advanced illness. Directly asking and documenting these needs or obtaining answers via other screenings (eg, during registration, questionnaires on electronic tablets) will help Muslim patients of any age feel more welcome in US health care systems where secularization is usually the norm.

Community partnerships to improve the care of Muslim patients can also be encouraged. Partnering with mosques or Islamic centers or key community leaders, such as imams, can ease the tensions between the Muslim faith and Western-style health care delivery.32,33 Acknowledgment of the US population’s religious diversity can be accomplished without personal or professional compromise, if that is a concern, by putting support and referral processes in place for Muslim patients with advanced illness.32 Resources offered by organizations such as the Islamic Medical Association of North America (https://imana.org) may be useful to hospitals or medical practices looking to improve the services delivered to their Muslim patients.

Responding to religious and spiritual diversity acknowledges the role that one’s faith can play in coping with illness and making health care decisions and aligns clinician/health system practices with health care standards regarding cultural competence.53 A critical step toward truly patient-centered care is honoring the possibility, and reality, that patients and families are often guided by faith in the context of largely secular health care.

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

Acknowledgment

Kathleen Louden, ELS, of Louden Health Communications provided editorial assistance.

How to Cite this Article


References

1. First Amendment to the United States Constitution, Bill of Rights (Dec 15, 1791).
6. Shah SM, Ayash C, Pharaon NA, Gany FM. Arab American immigrants in New York: Health care and...