Palliative Care for Muslims Reference Guide

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Developed May 2023
Latest revisions from June 2026

VHA Home HealthCare
Creating More Independence for Over 100 Years

Disclaimer

This reference guide is intended to be a resource to provide general information related to Muslim practices and beliefs to support end-of-life care needs for Muslims. It is important to be aware that cultural diversity exists amongst Muslims and levels of religious observance may vary between individuals and within families.

About the Collaborators

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This resource was developed based on their own lived experience of providing and receiving care in the community and through consultation with other Muslim community members acknowledged in the contributor's section.

Contributors

This resource is a result of a collaborative effort from various stakeholders including Client and Family Partners, VHA Home HealthCare staff and service providers, and partners from other health and community care organizations.

We thank our stakeholders for answering questionnaires, having conversations, providing feedback and sharing guidance.

We would like to acknowledge the following contributors below:

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Special thanks to Shahina Siddiqui, B.A. LLD of Winnipeg, Manitoba for sharing her personal journey about her son and his palliative end of life process. Sister Shahina provided guidance in several sections of this reference guide. To quote Sister Shahina, "it is important to speak from the heart so that it goes to the heart of the listener" (Siddiqui, 2018).

Additional Credits

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Background and Introduction

Muslims are ethnically, culturally, and linguistically diverse, and not homogenous in their religious adherences. However, despite these differences, there are shared concerns when it comes to health care, end of life practices, and rituals.

A review of published research revealed systemic bias and barriers to equitable community end of life care for Muslims. Community based palliative care is reliant on formal and informal support systems. A select survey of Greater Toronto Area Muslims revealed that over 80% of respondents felt it was very important for formal caregivers to understand Islamic practices. Caregivers need not be "experts" in Islamic values, but their end-of-life care comfort and competency can be built by leveraging appropriate resources.

An Islamic paradigm has been identified but should not be categorized as another cultural care issue. The inclusion of Islamic rituals in end-of-life care is about respecting and supporting client's spiritual needs and adherence to their faith. This facilitates implementation of the **8 domains of palliative care** (National Consensus Project for Quality Palliative Care, 2018). These 8 domains of palliative care are guidelines that support transitioning from life to death.

The goal of this resource is that it will support caregivers with information that will facilitate their provision of care for Muslim clients and families including giving them the information they need to have appropriate conversations with clients and families, to understand client questions and concerns and to support connections to appropriate support systems.

Ultimately this resource is for care providers to understand end of life care for Muslim community members. It is key to discussing with both clients and caregivers what is important to them at end of life. This resource is intended to increase the comfort and competency of care providers regarding rituals related to end of life care for Muslim community members, hopefully leading to improvements in Muslim clients' experiences.

Terms and Definitions

What is Islam?

- The word Islam is Arabic and is derived from two root words: peace and submission. Islam is more than a religion; it is a way of life. All aspects of a Muslim's life are informed by the faith. The followers of Islam are called Muslims

What are the Five Tenets and Rituals of Islam?

1. **Declaration of faith (Shahada):** Belief is the oneness/unity of Allah. Allah is Arabic for God. This is a unique term that has no gender or related physical imagery
2. **Ritual prayer (Salah):** Five daily prayers at regular intervals are mandatory for men and women after puberty
3. **Fasting (Sawm)**: Fasting is expected during the **month of Ramadan** (Islamic Networks Group, 2022)
4. **Almsgiving (Zakat):** Compulsory donations to charity equal to 2.5% of personal wealth annually for those who meet required threshold
5. **Pilgrimage to Mecca (Hajj):** Once in a lifetime for those who are healthy enough and have the financial means to do so will take the sacred pilgrimage to Mecca

Basic Islamic Terms and Definitions

- **As Salaam Alaikum**: An Islamic greeting that means "may peace be upon you"
- **Halal**: The Arabic term to identify what is allowed and *permissible* under Islamic Law. Further information on Halal food can be found on this **Guide to Understanding Halal Foods document (download PDF)** (Toronto Public Health, 2004)
- **Haram:** The Arabic term to identify what is *forbidden* under Islamic Law
- **Fasting:** Abstaining from foods and/or liquids for a specified period
- **Wudu:** A mandatory hygiene required for prayers (exceptions can be made if water is not available)
- **Quran:** Muslim holy book
- **Imam:** An Islamic leadership position. "The Imam leads Islamic prayer and services but may also take on a larger role in providing community support and spiritual advice." (Huda, 2019). **Further information about the Imam role can be found here**

Muslim Practices and Beliefs

Below is some general guidance regarding common practices and beliefs among Muslims. Given the diversity of the Muslim community, not all practices or beliefs may be upheld by all individuals.

Muslim Women

- Women who do not wear the hijab still appreciate the observance of modesty
- Adult Muslim women of sound mind can make their own care decisions
- Many Muslim women do not shake hands with unrelated men
- Many Muslim women keep a different last name than their husbands

Concept of Health

Islamic law requires Muslims to protect their health and strive to maintain a healthy environment. Muslims are expected to:

- Seek medical help
- Take medications as prescribed
- Abstain from anything that is contributing to ill health including intoxicants
- Live a healthy lifestyle including eating, resting and exercising in moderation and following medical advice

Spiritual Care of the Patient

- Muslim patients must have access to family members and friends
- Care should be taken to maintain modesty
- Dietary restrictions should be respected
- Access to spiritual care from own faith is essential
- Personal hygiene is generally a great concern for Muslims so personal hygiene needs should be respected and attended to.
    - For example, Muslim patients can become agitated if their clothing has become soiled. In order to pray, Muslims must have unsoiled clothing, or they may experience emotional or spiritual distress. Chronic bladder issues and the use of diapers are an exception.
- Care providers' role is seen as facilitating medical help and providing companionship
- Muslims eat a halal diet. Having the server announce "*Here is your halal meal*" when caring for a Muslim patient will feel supportive and helpful to the patient

Ethical Framework of Palliative Care

"The patient, his or her family, and the healthcare team are often faced with challenging scenarios in which there are no apparent 'right' answers. Patients, families, and clinicians may face a variety of ethical dilemmas when providing end-of-life care such as complex medical scenarios: deciding to withdraw life support interventions; when to use artificial hydration and nutrition at the end of life; to issues related truth telling and disclosure" (Canadian Hospice Palliative Care Association, 2024).

Social Etiquette with End-of-Life Muslim Patients

- Speak softly, slowly and gently, do not raise your voice
- Music is *not* recommended
- Announce yourself before entering a patient's room
- Keep bedding as clean and dry as possible and keep the patient modestly covered

Concept of Life and Death

- "Death is inevitable marking a transient separation. Life and death are believed by Muslims to be in accord with the will of Allah – the timing of death is therefore predetermined with a fixed term for each human being. Death marks the passing to the *Hereafter* – the ultimate destination" (Kristiansen, M., & Sheikh, A., 2012).
- The Quran describes the time of death as detachment of the soul from the body
- Muslims tend to accept unfavorable outcomes from medical interventions because they believe that only Allah determines the course of illness, recovery and death. Muslims believe physicians are merely a means through whom Allah grants a cure or relief to whom He wills.
- Illness is not seen as a result of God's anger nor is it a punishment from heaven.
- Illness is seen as an ordeal, which brings purification of sins.

Use of Opioids for Pain Control

According to Choong, K. A. (2015):

> "Having compared and contrasted the philosophical underpinnings of secular palliative care with the Islamic notion of death and dying, several important questions come to the fore. First, if pain leads to the expiration of sins and has a higher purpose, can pain relief be taken?
>
> If so, the second question that arises is whether the substance used (i.e. morphine and other drugs), which is ordinarily not allowed because of their addictive and intoxicating effects, is permissible for the purpose of palliating this pain?
>
> Further, if Islam forbids acts that terminate life prematurely, what if the pain medication carries with it the potential to abbreviate life? In addition, can the patient be sedated when emphasis is placed on optimizing their final days?
>
> Opportunities
>
> "Muslim scholars have highlighted that recognition of an inherent value and larger meaning in pain and suffering should not overshadow nor in any way prevent Muslims from seeking pain relief.
>
> In fact, not only are they allowed to avail themselves of such assistance, but efforts in this direction are also obligatory and regarded as highly virtuous (al-Shahri & al-Khenaizan, 2005; Sachedina, 2012).
>
> As emphasized by Sheikh (1998, p. 138), undue pain and suffering "has no place in Islam". Muslims should accordingly seek to benefit from pain relief methods that are available to help lessen their pain and suffering.
>
> Challenges
>
> However, if pain management can have faith-enhancing and faith-preserving qualities, there are challenges that require scrutiny. As Muslims are not generally allowed to consume intoxicating mind-altering substances like alcohol and narcotics."

Suicide, Euthanasia or Medical Assistance in Dying (MAID)

According to Islamic doctrine, Medical Assistance in Dying (MAID), suicide, and euthanasia are forbidden because these acts are seen to betray the trust of life that God has blessed an individual with.

Further, according to Islamic doctrine, Muslims do not own anything in an absolute sense, including life.

Given the diversity of the Muslim community, not all community members may adhere to the full Islamic doctrine.

Additional information regarding the Islamic doctrine on MAID, suicide and euthanasia is outlined below.

"Regardless of the incurable or debilitating nature of a disease, it is never Islamically appropriate to take one's own life or to take a patient's life in hopes of saving him/her from suffering. This stems largely from the fact that preservation of life is one of the primary goals of Islamic law and that Muslims believe in a fixed life term that is pre-ordained by God. As humans, including physicians, we do not know with certainty the natural progression of any given patient's disease. It is impossible to Islamically justify assisted suicide as a method of easing his/her suffering. Rather, we are encouraged to search for treatment, as indicated in this statement from Prophet Muhammad ﷺ: 'Treat sickness, for God has not created any disease except that He has also created its cure" (Sultan, 2017).

Suicide is prohibited in the Qur'anic verse: "And do not kill yourselves [or one another]. Indeed, God is to you ever Merciful."

Palliative care offers an alternative to suicide or euthanasia in the face of a disease with a grim prognosis, painful course, and intolerable medication side effects. It involves methods to minimize discomfort without artificially prolonging or truncating the course of an illness. Interventions to tackle pain, respiratory distress, and depression are integral to proper management of illness at the end of life." (Sultan, 2017).

Medical Research Opinions on DNR and Opioid Use

Do Not Resuscitate

"The Islamic Medical Association of North America (IMANA) believes that when death becomes inevitable as determined by physicians taking care of terminally ill patients, the patient should "be permitted to die naturally with only the provision of appropriate nutrition and hydration." IMANA does not believe in prolonging misery on mechanical life support in a patient in a vegetative state, when a team of physicians, including critical care specialists, has determined that no further attempt should be made to sustain artificial support. Even in this state, the patient should be treated with full respect, comfort measures, and pain control. No attempt should be made to enhance the dying process in patients on life support.

Physicians' religiosity may affect their approach to end-of-life care beliefs. Saeed et al. studied the religious aspects of end-of-life care among 461 Muslim physicians in the US and other countries. Only 66.8% of the respondents believed that DNR is allowed in Islam. The need for education of the public is an essential part of DNR practice. Poor explanation to the family has often led to family dissatisfaction in many cases." (Chamsi-Pasha & Albar, 2017).

* *Families seek counsel with an Imam as required.*

Facing Death and Grief

- Death of a Muslim is always announced with remembrance of Allah: "From Allah we come and to Allah is our return."
- Muslims is inclined to accept death of a loved one without going through classic stages of grief because they believe death is inevitable and the beginning of the eternal life
- The belief in life after death helps Muslims through the grieving and acceptance process
- Muslims find solace in communal prayers, gathering of family and friends and reading of the Quran as well as giving of charity and feeding the needy

Common Practices and Guidance Regarding Death and Death Services

- Many Muslims prefer to die at home
- It is not necessary for an Imam to be present at the time of death as there is no priesthood in Islam
- Arrange to release the body as soon as possible as it must be buried without unnecessary delay
- Cremation or embalming are not allowed and transportation to far off lands for burial is discouraged
- Providing phone numbers for Mosques that provide funeral services with death package would be appreciated
- The body would generally be picked up by the funeral company and transported to a Mosque that has funeral preparation facilities
- The body is washed by family members and volunteers of the same gender. It is then shrouded in plain white cloth and placed in a simple wooden casket. However, some Muslim families do not bury the deceased in a casket
- Viewing is done in some Muslim cultures and not in others
- Prayers are conducted in the Mosque where men and women gather or can be offered at the grave site

Organ Donation

- Families seek counsel with an Imam on this topic as required

Mourning Post Death

- Generally, the prescribed mourning period is three days. During this time, the extended family and community take care of family needs such as meals, shopping, etc.
- For Muslim women who are widowed, the prescribed period of mourning is 4 months, although exceptions are made if she is the sole provider for the family and needs to go back to work
- For Muslim women who are widowed while pregnant, the prescribed period of mourning is until the birth of the child

Participation of Care Team Staff and Friends in Death Rituals

- Inform the family that you would like to visit in advance
- Gifts of flowers are not expected
- People of all faiths are welcomed to Mosque to witness the prayers

- Those participating in Islamic prayers in a Mosque do so on the floor on a carpet. Many Mosques have chairs assigned for visitors. Anyone is welcome to join the funeral procession and attend the burial
- All attendees are requested to wear clothing that covers their full legs, and women are expected to cover their heads. There is no preferred colour for clothing
- Footwear should be removed when you enter a home, building or prayer area
- Some Mosques have separate entrances and sections for men and women

Muslim Personal Care Plan Guide (Incorporating the Best Practice: Palliative Performance Scale (PPS) Tool)

The Palliative Performance (PPS) is a "tool for measuring the progressive decline of a palliative resident. It has five functional dimensions: ambulation, activity level and evidence of disease, self-care, oral intake, and level of consciousness. To score, there are 11 levels of PPS from 0% to 100% in 10 percent increments. Every decrease in 10% marks a fairly significant decrease in physical function. For example a resident with a score of 0% is deceased and a score of 100% is fully ambulatory and healthy" (Quality Palliative Care in Long Term Care (QPC-LTC) Alliance, 2011).

Personal Care 80%-50% (Considerable assistance required)

- If possible, staff or the family attending to this person should be of same gender
- 'Tahara' or Personal Cleanliness is the washing away any blood or other exudates stains on the body or on the bed
- Do not cut a male client's facial hair
- If client is ambulatory, rinse the peri areas with running water (a container to hold the water for rinsing is best practice) after urinating or after passing stools is appreciated. Do not use tissue paper
- Help the client in preparing for daily prayers. Assist them to perform wudu; for bed patients, give wet towels (so they can wash their faces, hands from fingers to elbows, wipe head, behind ears and feet to ankles)
- Assist client to position of choice for prayer
- Dress code for men in minimum from navel down to the knees; and for women, the only parts of the body that could be exposed to non-family male members are face, hands below wrist and feet below ankles. Women wear

head cover called Hijab. For a sick person, his or her comfort should be considered regardless of dress code
- Dietary laws include no pork or pork products like pepsin, gelatin, or lard even in small quantities as ingredients. Yogurt must be identified as Halal. Only halal meat is permissible. Kosher meat is an acceptable alternative if Halal is not available. Fish and dairy products are allowed

Personal Care 30%-20% (Total care required)

- Same as above – modify for non-ambulatory
- Prepare patient for daily prayers, perform wudu for them (damp wash their face, hands from fingers to elbows, wipe head, behind ears and feet to ankles)
- Position client as appropriate for prayer

Personal Care 10% (Imminent death)

- Perform 'Tahara' or Personal cleanliness by washing away any blood or other exudates stains on the body or on the bed
- Perform wudu (damp wash their face, hands from fingers to elbows, wipe head, behind ears and feet to ankles)
- Friends and family will recite portions of Quran & Shahada near the dying person

Personal Care 0% (At time of death)

- Inform the family to follow the instructions given by the nursing or medical team on steps to take for pronouncement **BEFORE** calling the Masjid body retrieval team
- Family will increase Qur'an recitation at the bedside
- Keep the eyelids closed and hold for a few minutes till they set closed
- Straighten arms and legs. Never lay the arms crossed over the chest
- Support family to dampen mouth with swab, & keep the mouth closed by wrapping gauze or a piece of cloth around the chin and the head
- Cover the whole body with a sheet of cloth. At no point and time, the body is to be kept naked or uncovered

How to Perform a Modified Version of Wudu

Wudu is a compulsory act for Muslims to perform mandatory pray.

Steps on how to perform a **modified** version of Wudu are listed below.

This ritual is done with fresh clean water (no soap). The use of wash cloth is permissible.

1. Seek permission from client or family to assist with or perform wudu
2. Damp, wipe, or rinse right hand from fingertips to elbow
3. Damp, wipe, or rinse left hand from fingertips to elbow
4. Damp, wipe or rinse face with water (top down) from forehead to chin
5. Pass damp cloth over head
6. Pass damp cloth behind ears and around neck
7. Damp, wipe and rinse right foot from toes to ankle
8. Damp, wipe and rinse left foot from toes to ankle
9. Dry washed areas when ritual is complete

Resources

Stakeholder Input

Information and feedback were gathered from Muslim clients receiving care from VHA to inform the development of this guide. Specific guidance was provided regarding timing for visits relative to prayer times, perspectives regarding the knowledge and expertise clients felt care providers should have regarding Muslim customs, practices and beliefs.

Feedback was also gathered from VHA team members involved in providing palliative care. Their insights highlighted the benefit of additional cultural and spiritual resources to support client-centred care, which contributed to the development of this resource, and their specific questions helped inform the content included here.

Toronto and GTA Islamic Resource Centres

Brampton and Regional Islamic Centre (BARIC)
Phone: 416-834-0617
Website: https://baric.ca/

Islamic Society of Markham – Jam'e Masjid Markham
Phone: 905-294-7866
Website: https://markhammasjid.ca/

York Region Islamic Centre – Islamic Society of York Region
Phone: 905-887-8913
Website: https://isyr.org/

Islamic Foundation of Toronto (Scarborough)
Phone: 416-321-0909
Website: https://www.islamicfoundation.ca/

Masjid Usman Picerking Islamic Centre
Phone: 905-426-7887
Website: https://masjid.ca/

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