GIPPEC

GLOBAL INSTITUTE OF PSYCHOSOCIAL, PALLIATIVE & END-OF-LIFE CARE

Palliative Care for All: A GIPPEC Symposium on Palliative and End-of-Life Care for Muslims

January 18, 2018

Proceedings Report

Authors: Afnan Naeem, Ahmed al-Awamer, Lesley Chalklin, Aasim I. Padela, Shabbir Alibhai, Abdulaziz Sachedina, Abdullah S. Aljoudi, Ebru Kaya, Shahina Siddiqui, Ahmed Jakda, Gary Rodin

Affiliated with:

UNIVERSITY OF TORONTO

UHN Princess Margaret Cancer Centre

Supported by:

The Princess Margaret Cancer Foundation UHN

Global Institute of Psychosocial, Palliative & End-of-Life Care (GIPPEC)

700 Bay Street, Suite 2303, Toronto, ON M5G 1Z6
http://www.gippec.org/

Published May, 2018

Copies of this report can be downloaded from www.gippec.org.

Authors

Ms. Afnan Naeem
Graduate Student, University of Toronto; GIPPEC Research Trainee

Dr. Ahmed al-Awamer
Palliative Care Physician, University Health Network (UHN)

Ms. Lesley Chalklin
Project Manager, Princess Margaret Cancer Centre & GIPPEC

Dr. Aasim I. Padela
Director, Initiative on Islam and Medicine; Associate Professor, University of Chicago

Dr. Shabbir Alibhai
Senior Scientist & Lead of the Older Adults with Cancer Clinic, University Health Network (UHN)

Dr. Abdulaziz Sachedina
Professor and IIIT Chair in Islamic Studies, George Mason University

Dr. Abdullah S. Aljoudi
Chair of Ethics Committee, Imam Abdulrahman Bin Faisal University, Saudi Arabia

Dr. Ebru Kaya
Palliative Care Physician, University Health Network (UHN)

Ms. Shahina Siddiqui
Executive Director, Islamic Social Services Association, Canada

Dr. Ahmed Jakda
Provincial Clinical Co-Lead, Ontario Palliative Care Network

Dr. Gary Rodin
Director, GIPPEC; Head of Dept. of Supportive Care, Princess Margaret Cancer Centre

CONTENTS

SYMPOSIUM AGENDA

8:00-8:30	**Registration & Networking (coffee and tea will be served)**
8:30-8:40	**Introduction and Welcome** Gary Rodin, Director GIPPEC and Ahmed al-Awamer, Palliative Care Physician
8:40- 9:25	**Religious and Ethical Issues on End-of-Life Care for Muslims** Abdulaziz Sachedina, Professor and IIIT Chair in Islamic Studies, George Mason University
9:25- 9:45	**End-of-life is not the end of life: Reflecting on my experience with Muslim patients at the end of their life** Abdullah Aljoudi, Chair of Ethics Committee, Imam Abdulrahman Bin Faisal University, Saudi Arabia
9:45- 10:35	**Keynote Speaker: Islamic Theological Constructions of Human Dignity and Quality-of-Life: Implications for Decision-Making and Healthcare Near the End-of-Life** Aasim I. Padela, MD Director, Initiative on Islam and Medicine; Associate Professor, the University of Chicago
10:35-10:50	**Break**
10:50-11:20	**Advance Care Planning** Ahmed al-Awamer, Palliative Care Physician and Ebru Kaya, Palliative Care Physician
11:20-11:50	**OPCN Update and Adopting Culturally Sensitive Care** Ahmed Jakda, Provincial Clinical Co-Lead, Ontario Palliative Care Network
11:50- 12:15	**Hydration and Nutrition at the End-of-Life** Shabbir Alibhai, Senior Scientist and lead of the Older Adults with Cancer Clinic, UHN
12:15-1:15	**Lunch**
1:15-1:45	**Palliative Care for Muslims: Diversity and Gender Consideration** Shahina Siddiqui, Executive Director of the Islamic Social Services Association
1:45 -2:20	**Reflecting on Knowledge Gaps and Healthcare inequities in Palliative and EOL Care for Muslims** Aasim Padela, MD Director, Initiative on Islam and Medicine; Associate Professor, the University of Chicago
2:20-2:30	**Patient Story**
2:30-3:15	**Panel Discussion – Strategies to Improve Palliative Care for Muslims** 1. Aasim Padela, MD Director, Initiative on Islam and Medicine; Associate Professor, the University of Chicago 2. Abdulaziz Sachedina, Professor and IIIT Chair in Islamic Studies, George Mason University 3. Ebru Kaya, Palliative Care Physician, Toronto General Hospital, UHN 4. Shahina Siddiqui, Executive Director of the Islamic Social Services Association 5. Shabbir Alibhai, Senior Scientist and lead of the Older Adults with Cancer Clinic, UHN 6. Moderator: Ahmed al-Awamer, Palliative Care Physician, Princess Margaret Cancer Centre, UHN
3:15-3:30	**Break**
3:30- 4:50	**Small group discussion**
4:50-5:00	**Closing**

PLANNING COMMITTEE

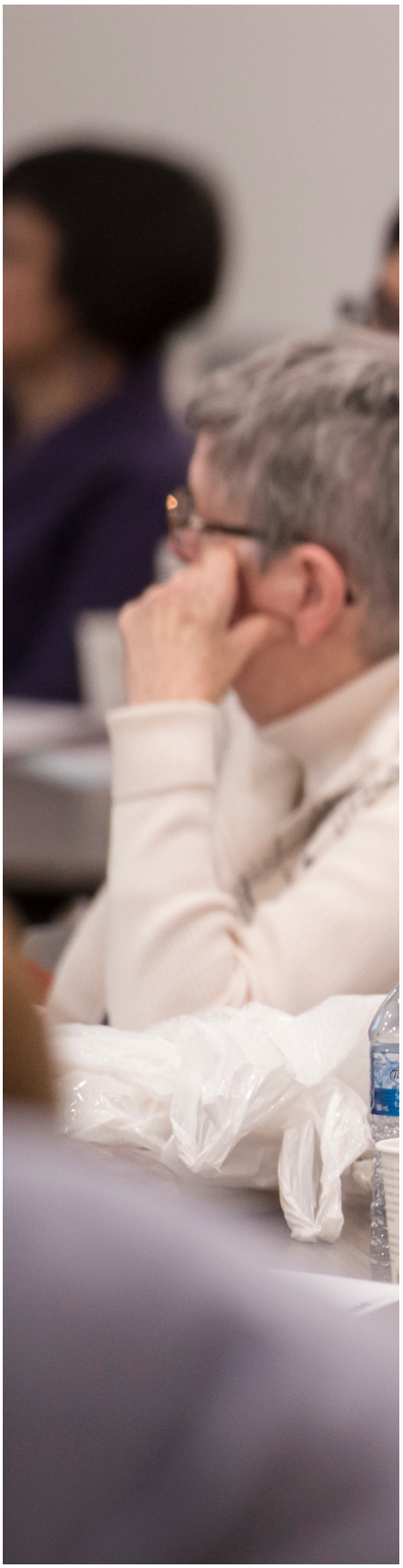
The Symposium topic was proposed to the Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC) by Dr. Ahmed al-Awamer, a palliative care physician in the Department of Supportive Care at Princess Margaret Cancer Centre, University Health Network.

Dr. al-Awamer led the planning of the symposium under the auspices of GIPPEC, with input from leaders and scholars in the field, who also participated as speakers (see Appendix A for Speakers List and Biographies). Coordination of the symposium was carried out by Lesley Chalklin, Project Manager at the Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC).

EXECUTIVE SUMMARY

There is no area of medicine in which culture and religion is more important than in palliative and end-of-life care (PEOLC). Although PEOLC has been recognized as a basic human right, the majority of those in need of such care, particularly in low and middle-income countries, do not have access to such care. Although death and dying are universal experiences, personal, religious and cultural values shape what is considered to be a good life, and a good death. However, there has been a relative lack of attention to the modifications to PEOLC that are needed to embrace the cultural and religious needs of patients with life-limiting illnesses.

The Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC) is committed to a vision of global outreach, gathering and working together with scholars, educators and clinicians from diverse disciplines, to ensure timely, appropriate and culturally sensitive PEOLC. On January 18, 2018, imams, chaplains, administrators & policy makers, physicians, health care providers, and scholars gathered at a GIPPEC symposium in Toronto, Canada, one of the most culturally diverse cities in the world, to explore palliative and end-of-life care for Canadian Muslims, a minority population with unique needs in this domain.



BACKGROUND

Palliative and End-of-Life Care for Muslims

High-quality PEOLC is a basic human right, but personal, cultural and religious values, beliefs, and traditions may have an enormous impact on the perceived quality and appropriateness of such care. Little is known within PEOLC about Muslims' views of a "good death" and their perspective of what constitutes high-quality PEOLC. This gap in knowledge can lead to misunderstanding and conflicts among health care providers, dying patients and their families resulting in inadequate care. A good understanding of the religious and cultural beliefs and traditions of patients is needed to clarify their impact on family decision-making, and accommodations regarding privacy, gender, nutrition, and aggressive treatments at the end-of-life, and death. Planning for PEOLC must also take into account how Muslim religion and cultural beliefs fit in our health care system and to identify and the barriers in access to high quality PEOLC for the Muslim community.

The lack of a culturally sensitive model for PEOLC creates a health disparity for Muslim patients and limits their appropriate access to it. Contextualizing high-quality end-of-life care for Muslims and identifying the barriers and facilitators to Muslims in Canada and internationally receiving it is needed to address this disparity. This challenge has become more urgent, as the number of Muslims worldwide is now estimated to be over 1.6 billion and expected to double by 2030.

1. SYMPOSIUM SUMMARY

GIPPEC is devoted to promoting and developing interdisciplinary research that addresses the medical, psychological, social, legal, ethical, cultural, and religious problems related to psychosocial and palliative care of individuals with advanced and terminal disease. The Planning of Palliative Care for All: A GIPPEC Symposium on Palliative and End-of-Life Care for Muslims was facilitated by GIPPEC, and is tied to the Institute's aims to:

1) Generate and disseminate meaningful evidence to inform clinical practice, health policy and public awareness locally, nationally and internationally;
2) Inform the public debate regarding controversial medical, legal and ethical issues related to death and dying;
3) Support local, national and international research collaboration and education;
4) Build capacity in research and education.

Planning of the symposium was led by Dr. Ahmed al-Awamer and coordinated by Lesley Chalklin, with input from the speakers and researchers invited to present on the topic. The symposium attendees were a mix of health care providers in PEOLC, spiritual care providers, community organizers and policy makers.

1. SYMPOSIUM SUMMARY

Goals of the symposium were to:

- Characterize the religious and cultural beliefs and traditions of Muslim patients and their families at the end-of-life.
- Describe the current state of PEOLC available for Muslim patients in Canada.
- Identify the barriers to providing high-quality PEOLC in Canada and discuss the clinical and system applications to remove barriers.

Anticipated Outcomes:

- Identify accommodations in PEOLC that improve its quality for Muslims.
- Develop and disseminate a report to heighten awareness and share findings locally and internationally.

1. SYMPOSIUM SUMMARY

1.1. Religion and Culture in Palliative Care

Dr. Abdulaziz Sachedina outlined the importance of teamwork and interaction among social workers, families, ethicists, chaplains and healthcare providers, considered through a case study of the rules of engagement for all concerned parties in ethical deliberations in PEOLC.

1.1.1. Ask "How can we help?"

Dr. Sachedina noted that there is often no absolute answer to questions that arise in PEOLC related to religion and culture. However, he emphasized the need for a universal language among healthcare providers in PEOLC that should include "how can we help?" He stressed the need for teamwork and rules of engagement on how health care providers (HCPs) should interact with patients and their families, how they should involve families, and how different disciplines in the hospital system can work together.

1.1.2. Muslims Are Culturally Diverse

The Muslim community of patients and HCPs is diverse, with multiple sects and theological schools of thoughts. Not all Muslims are religious and many Muslim patients have little or no Islamic perspective as it affects PEOLC. There are also cultural differences among Muslims from various cultures, with differences of opinion and practice. Ethicist and Islamic scholars continue to struggle over the differentiation between ethically obligatory and optional treatments at the end-of life, from an Islamic perspective.

1. SYMPOSIUM SUMMARY

1.1.3. Prima Facie Obligation to Treat

A core Islamic teaching in the context of PEOLC is that "harm cannot be done," but the definition of such harm is unclear. Harm may be physical, psychological, or familial and must be weighed against benefits. Deliberations about "withholding" or "withdrawing" life-sustaining treatment are essentially about weighing the Islamic principle of *manfa'* (benefit = beneficence) against that of *madarra* (harm = maleficence). Muslim jurists have been mathematical in their judgements about this, such that that action must be taken if benefit outweighs harm by even one per cent. When a patient is in a coma, with an irreversible medical condition, the critical question becomes: "will the patient be harmed incrementally by cessation of treatment." Professor Sachedina stated that, unlike the common medical presumption that physicians have a "duty to treat" in all circumstances, Islamic law limits the duty of the physician to the "duty to cure" only and physicians are not obligated to provide futile treatment (Sachedina, 2018).

Please See Appendix B for an example of a relevant case study and proposed treatment.

1. SYMPOSIUM SUMMARY

1.2. Islamic Theological Constructions of Human Dignity and Quality-of- Life: Implications for Decision-Making and Healthcare Near the End-of-Life

Dr. Aasim Padela detailed the theological foundations of dignity that are relevant to the quality of life of Muslim patients.

1.2.1. Islamic ethical-legal views on moral status of seeking medical care

Opinions in Sunni jurisprudence have been based on the general rule that seeking medical treatment is permissible but non-obligatory, although more recently it has been considered by some to be obligatory, even when its therapeutic effect is uncertain. Treatment is clearly considered to be obligatory when it appears to be certain to save life (Ghaly, 2010). A fatwa (i.e. a contextualized juridical ruling) issued at the Council of the Fiqh Academy's seventh session in 1992 outlined that medical treatment is:

- Obligatory, if neglecting the treatment may result in the person's death, loss of an organ or disability, or if the illness is contagious and a harm to others;
- Recommended, if neglecting the treatment may weaken the body;
- Optional, if not covered by the preceding two cases;
- Reprehensible, if there is a risk that the treatment may provoke complications that are worse than the illness itself (Ghaly, 2010)

1. SYMPOSIUM SUMMARY

1.2.2. Theological Constructs of Human Dignity and Quality of Life

Drawing on Sulmasy's (2013) dignity framework, Dr. Padela outlined the typologies of human dignity in the Islamic tradition, which are found in scripture. These were identified as the following:

1) Intrinsic
- 'Worth' or 'value' that human beings have, simply because they are human
- Attributed to all human beings
- Not diminished by illness

2) Attributed
- Conferred upon others: skills, virtues, power, position
- Created value; always by choice
- Conferred by Allah (God)

3) Inflorescent
- Expressed in behaviours/actions/states of being that evidences excellence and living out of intrinsic dignity
- Being able to worship God and do beneficial work that results in afterlife rewards

1. SYMPOSIUM SUMMARY

Additionally, Dr. Padela emphasized that human dignity incorporates two concepts: inviolability (*hurma*) and sanctity (*karama*), which are key concepts in understanding quality-of-life constructs in Islam. Inviolability (*hurma*) extends beyond death. In other words, the dignity of a deceased person is the considered same as if the individual were alive. Sanctity (*karama*) conveys the meaning of honour and refers to the special status of humankind above all of God's creation, while inviolability carries the meaning of sacredness and prohibition. Inviolability and sanctity are closely related in that violating bodily integrity compromises human sanctity and conversely, preserving sanctity entails preservation of bodily integrity. The Islamic tradition gives wide berth and grounds for limited interventions at the end-of-life; an "Islamic" theology of care would focus on servicing the God-man relationship and building up dignity in end-of-life decision-making (Padela, 2018).

1.2.3. Counsel for Healthcare Providers: a theology for end-of-life care & quality of life

Overall, Dr. Padela's counsel for healthcare providers in PEOLC is that there should be an emphasis on preserving human dignity and limit "indignities in care," and that inflorescent dignity (as described above) should be built up and supported at the end-of-life through the provision of spiritual support to patients.

From an Islamic theological perspective, the concept of quality-of-life at the end-of-life may possibly be tied to the notion of a human as a *mukallaf* --a person who

1. SYMPOSIUM SUMMARY

is morally accountable to God. *Mukallaf* status in Islam represents the theological premise that "an individual has the cognitive faculty to recognize God and thereby can benefit his afterlife by performing religious practices (worship) or other meritorious actions willfully" (Padela & Mohiuddin, 2015). This can be used as a quality-of-life assessment measure in end-of-life clinical decision-making (Padela & Mohiuddin, 2015). Overall, individuals with the potential of being *mukallaf* have maximized quality-of-life because they have retained the potential to perform deeds that can benefit one's afterlife. If an illness or injury does not threaten an individual's *mukallaf* potential, that patient's ultimate quality-of-life is not threatened (Padela & Mohiuddin, 2015). Notably moving outside of the Islamic sphere, the construct, since it is linked to consciousness and potential for willful action, may be useful for considering quality-of-life and goal setting more broadly.

Dr. Padela emphasized that "preserving physiological life is not a worthy goal in and of itself." He asserted that the goal of care should be to maximize the chance for an individual to regain this status of *mukallaf* when it has been lost due to illness, and to preserve the cognitive functioning of an individual who has the potential to become *mukallaf* in the future.

1. SYMPOSIUM SUMMARY

1.3 End-of-life is not the end of life: Reflecting on experience with Muslim patients at the end of their life

Dr. Abdullah Aljoudi presented on what the term end-of-life signifies for Muslims. He noted that in Islam, life is seen as a continuation; the end of this life is a continuation to another life. Decisions at the end-of-life stage therefore have great significance for the after-death spiritual life. Dr. Aljoudi presented two cases, which can be found in Appendix B, on issues faced in PEOLC by Muslim patients.

1.4 Advance Care Planning (ACP)

1.4.1 Defining ACP

Dr. Ebru Kaya defined advance care planning (ACP) as a process of *reflection* and *communication* regarding the progression of disease and the end-of-life. She noted that many Canadians have not heard of ACP and some patients do not discuss end-of-life issues with their family members because they fear it will be burdensome for them.

> **Reflection**
> Reflection begins the ACP process, as individuals consider their values and address such questions such as : what is important in life,what gives life meaning,what quality-of-life in the context of healthcare, and whether or not there is a life-sustaining situation that would be unacceptable to them.

1. SYMPOSIUM SUMMARY

Communication

Effective communication is key for ACP and it can be spoken or recorded, and not necessarily written. This requires patients to reflect and to talk to people who are important to, especially substitute decision-makers (SDMs) and healthcare providers (HCPs), so that their values and issues of importance are known to them. Communication between patients and their substitute decision-maker (SDM) is essential to ensure that treatment decisions are concordant with the values and wishes of patients.

1.4.2 Why is ACP important?

ACP completion has been found to increase patient and family satisfaction with care and the likelihood of dying in a preferred place and to decrease caregiver distress, trauma, hospitalization, and admission to the ICU and overall health care costs (Temel et al., 2010; Wright et al., 2008). Overall, ACP completion improves the access to palliative care.

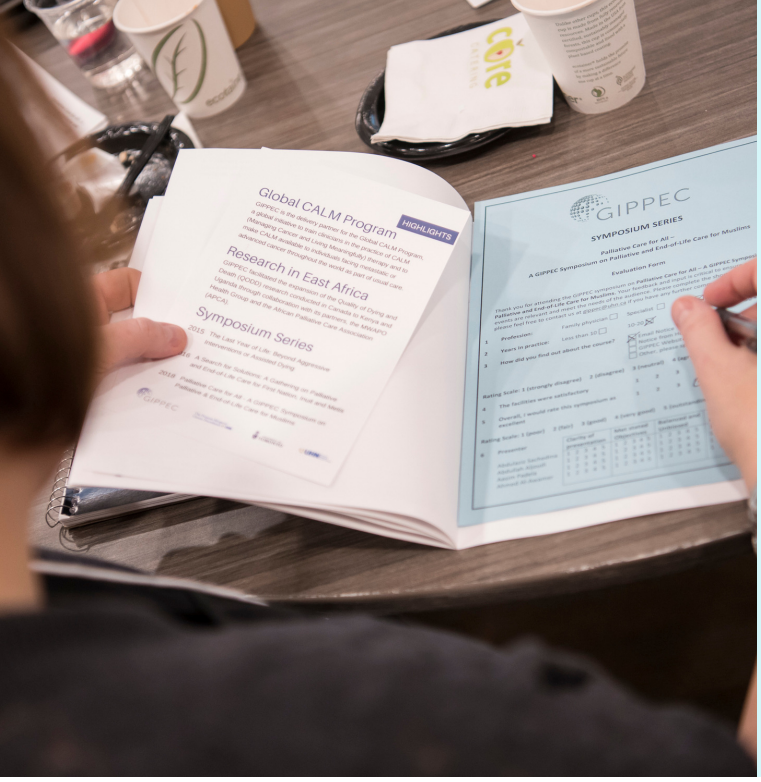
ACP laws differ among Canadian provinces. Under Ontario Law, ACP is part of the Health Care Consent Act and ACP does not constitute consent for treatment. Consent for all treatments based on patients' current health condition must come from a capable person, not a document or any other ACP. Informed consent requires an understanding by the patient or SDM of risks, benefits, side effects, alternatives and the consequences of treatment refusal.

1. SYMPOSIUM SUMMARY

1.4.3 Gaps in ACP for Muslims

Dr. Ahmed al-Awamer emphasized the importance of ACP and its role in improving the access to palliative care. He described the current gap and barriers that exist for the Muslim community in this area. Health inequality in palliative care could result from the lack of clear communication and understanding. In fact, there is no translation or concept of ACP in languages spoken by the Muslim population. Dr Al-Awamer noted that that ACP is similar to the concept of *the will* in Islam (*wasiyyah*), which Muslims are expected to complete. It is a recognized duty in Islam that each person should have his/her own will. Dr. al-Awamer stated HCPs can build on the concept of the will in communicating ACP, making it relevant to the understanding of ACP and that stories and videos can be used to improve ACP communication.

Dr. al-Awamer noted that power differentials, social pressures and conflict among family members can affect their ability to reach consensus in ACP. Confidence in health care decisions can also be undermined by racism, discrimination, affecting the communal experience of trust in the system of health care. Patients who fear being judged may not share their beliefs with medical staff. Dr. al-Awamer outlined that solutions to better ACP for Muslims will require engaging the community and religious leaders and deconstructing myths, anxieties, and questions around ACP. In this aspect, technology could be an effective avenue for engaging the Muslim community and improving communication in ACP.



1. SYMPOSIUM SUMMARY

1.5. Ontario Palliative Care Network (OPCN): Updating and Adopting Culturally Sensitive Care

Dr. Ahmed Jakda introduced the Ontario Palliative Care Network (OPCN), which is an organized partnership of community stakeholders, health service providers and health systems planners responsible for the development of a coordinated, standardized approach for the delivery of hospice palliative care services in Ontario (OPCN, 2018).

The mandate of the OPCN is three-fold:

1) To be a principal advisor to government for quality and coordinated hospice palliative care in Ontario
2) To be accountable for quality improvement data and performance measurement and system level coordination of hospice palliative care in Ontario
3) To support regional implementation of high-quality, high-value hospice palliative care

The OPCN also has various action areas for provincial planning in palliative care for priority populations. These action areas are as follows (OPCN, 2018):

1. SYMPOSIUM SUMMARY

Figure 1: OPCN Action Areas (Jakda, 2018)

A	• Enhancing Patient and Caregiver Engagement in Palliative Care
B	• Aligning the Planning for Palliative Care Across the Province
C	• Enabling Early Identification of those Who Would Benefit from Palliative Care
D	• Establishing Palliative Models of Care that Enable Adoption of the Quality Standard
E	• Identifying and Connecting Palliative Care Providers
F	• Building Provider Competencies in Palliative Care
G	• Measuring and Reporting on our Progress

1. SYMPOSIUM SUMMARY

1.6 Hydration and Nutrition at the End-of-Life

Dr. Shabbir Alibhai outlined the ethical challenges that have arisen with modern approaches to hydration and nutrition, such as feeding tubes, intravenous fluids, and total parenteral nutrition (Alibhai, 2017). The use of these interventions at the end-of-life must take into account the key Islamic ethical principles of the sanctity of life and that God is the Arbiter of the beginning and end-of-life.

1.6.1. Duties, rights, and illness

It is an Islamic duty to prevent harm and illness (*al-darar*), to seek out treatment for illness, to preserve life, and to prolong life. Prolonging life takes precedence over preserving quality-of-life, although this principle has limits. Although suffering may be seen as a trial or test from God, HCPs are nevertheless obliged to minimize suffering (Alibhai, 2018). Artificial nutrition and hydration can best be understood within a broader duty to feed the sick, which encompasses a social duty to eradicate hunger and to assist with preparation of food and/or feeding those who cannot care for themselves (Alibhai, 2008).

1.6.2. Artificial Nutrition and Hydration (ANH)

From an Islamic perspective, artificial nutrition and hydration (ANH) is best considered within a framework that considers its likely impact on life according to Dr. Alibhai. If ANH is considered life-prolonging based on best medical evidence, then it is theologically considered obligatory medical treatment by all major Muslim schools of thoughts. Conversely, if ANH is likely to shorten life,

1. SYMPOSIUM SUMMARY

then it should not be provided. Finally, ANH is considered obligatory to provide when oral feeding is not feasible and feeding is considered not to be harmful. However, palliative care units typically do not support ANH. Dr. Alibhai concluded by asking to what extent current palliative care unit policies regarding ANH and other interventions are based on moral/ethical framework or on concerns about resources/staffing (Alibhai, 2018)? He suggested that a critical examination of this policy is warranted to determine whether it is reasonable and ethically justified since it may mean that many Muslim patients would not be willing to go to palliative care units (Alibhai, 2018).

1.7. Patient Care for Muslims: Diversity and the Cultural Iceberg

Ms. Shahina Siddiqui emphasized the diversity of the Muslim population and the importance for HCPs of cultural competence, cultural humility, and cultural safety. Ms. Siddiqui presented 'The Cultural Iceberg' model, made up of: 1) behaviours and practices, 2) attitudes, and 3) core values. The model suggests that only a small portion of culture are visible and equally significant or greater components of culture are unobservable (i.e. intrinsic) (Language & Culture Worldwide, 2015). Ms. Siddiqui suggested that healthcare practitioners tend to engage in behaviours and practices, that are the observable tip of the iceberg. They may not take into account the underlying force of history, religion, educational systems, the media, family, and economics (Language & Culture Worldwide, 2015). Ms. Siddiqui provided helpful pointers for HCPs in responding to diversity; these can be accessed in Appendix C.

1. SYMPOSIUM SUMMARY

1.8. Reflecting on Knowledge Gaps & Healthcare Inequities in Palliative and EOL Care for Muslims

Dr. Padela identified gaps in knowledge regarding the health care of Muslim patients. He noted that there is a lack of knowledge about the ways in which religion and culture affect Muslim patients' health. This gap is found because religious affiliation is not routinely captured in national databases and health surveys. Dr. Padela observed that the public (i.e. patients) often rely on Muslim physicians for Islamic end-of-life principles, although research shows that many Muslim physicians lack knowledge in this area (National Survey of Muslim American Physicians, 2013). In addition, there may be a lack of communication and intrinsic knowledge gaps between HCPs and Islamic scholars.

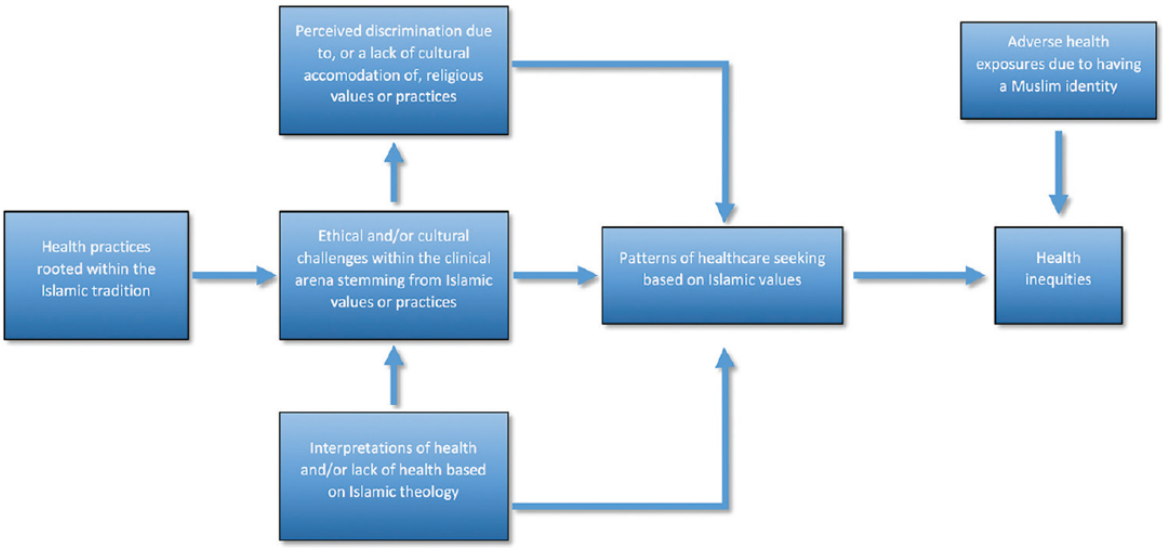
Padela & Zaidi (2018) have found six mechanisms (listed below) through which Islamic identity and/or practice may contribute to health inequities in care for Muslim patients. The pathways of these mechanisms are outlined in Figure 2 (taken from Padela & Zaidi):

1) Interpretations of health and/or lack of health based on Islamic theology
2) Ethical and/or cultural challenges within clinical realm, stemming from Islamic values or practices

1. SYMPOSIUM SUMMARY

3) Perceived discrimination due to, or a lack of cultural accommodation of religious values or practices
4) Health practices rooted within the Islamic tradition
5) Patterns of health-care seeking based on Islamic values
6) Adverse health exposure due to having a Muslim identity. (Padela & Zaidi, 2018, p.3)

Figure 2: Mechanisms through which Islamic identity might contribute to health inequities (taken from Padela & Zaidi, 2018)



2. EMERGING THEMES

Over the course of the symposium, specific themes emerged from presentations, informal conversations, and question-answer periods. These themes helped shape the recommendations drawn from the symposium. The themes are not meant to be exhaustive, but aim to capture the nature of the dialogue around PEOLC for Muslims.

2.1. CONCEPT OF DEATH, ILLNESS & SUFFERING IN ISLAM

There is generally a positive outlook on death in Islam, as it is seen as the will of God. To Muslims, illness is not seen as a wrath but as a normal consequence in life. This is reflected in the powerful Quranic verse, *'to God we belong and to Him is our return'.* Speakers mentioned that this verse serves a valuable purpose in grief and counselling. The Muslim belief is that the time of death is pre-determined but known only by Allah. Death is seen as departure of the soul to the afterlife and a meeting with God; therefore, decorum plays an important role. Death is always announced with remembrance of Allah and Muslims may accept the death of a loved one without going through classic stages of grief (Siddiqui, 2018). Visiting the sick is highly recommended in Islam, and visitors are viewed as a source of comfort for the patient and his or her family. Therefore, Muslim patients are likely to receive many visitors during their stay at the hospital, although the visits may need to be (and in fact are recommended to be) of short duration (Islamic Social Services Association, 2018).

Muslims are required to protect their health, and to maintain a healthy lifestyle as a religious duty (Siddiqui, 2018). Suffering is not seen as an ordeal which may bring expiation of sins. The sick are given dispensation from religious obligation of Islamic law, according to the severity of their illness (Siddiqui, 2018).

2.2. ISLAMIC BIOETHICS

2.2.1. Body as Sacred Property of God

Both Dr. Padela and Ms. Siddiqui discussed the Islamic idea that the body is seen as a trust from God. Hence, the body is to be handled with respect and kept covered at all times (Siddiqui, 2018). After death, the eyes must be closed, the body straightened, and tubes or catheters removed. During an individual's life, the body is seen as a trust between the individual and God, rather than a gift from God (Siddiqui, 2018). Unlike secular ethics, ownership of the body by Allah shapes the the concept of autonomy in Islamic bioethics.

2.2.2. What is a life worth living according to Islamic bioethics?

Dr. Padela noted that the *utility* of life may be related to the discharge of religious duties. A life of worth or merit is a life devoted to God, with worship and good works as the core purpose of existence. A life of benefit is thus related to practicing good works. Yet death is not to be feared for a Prophet tradition tells us that there can be goodness in death and we should have a good opinion of meeting God once we depart this world.

2.3. THE NEED FOR TEAMWORK

Many speakers stated that decision-making should happen in teams and Dr. Ahmed Jakda stated that imams should work with patients to help them understand and know what they are and are not allowed to purse in PEOLC.

2.4. PRIVACY FOR GENDERS

Modesty is a highly valued principle in Islam, although ensuring privacy among genders is an acknowledged gap in health care (Padela, 2012). Muslim patients may prefer same-gender nurses for personal hygiene or lifting and bathing; if none are available, a family member or friend can be present. Some patients may not be willing to shake hands with the opposite gender; healthcare providers should take their cue on this from patients. If a patient offers his or her hand, then it may be assumed that he or she is willing to shake hands. Women who do not wear a hijab may still appreciate and observe concerns of gender-privacy. Male staff should announce themselves before entering a room to give the female patient time to cover herself, except in the case of a medical emergency.

2.5. SPIRITUAL NEEDS & ACCOMMODATIONS

Muslims pray five times a day. The need for space to pray and recite the Quran was mentioned by various speakers, as well as by community members participating in the symposium. Ms. Siddiqui indicated that spiritual care for Muslim patients could include:

- Attendants constantly reciting the declaration of faith
- Constant companionship for the dying
- Reminders of hope and of Allah's mercy
- Forgiveness for the dying
- Encouragement to forgive and resolve conflicts with loved ones
- Maintain personal hygiene and cleanness to perform the prayers

2.6. ACCESS TO PALLIATIVE CARE

2.6.1. Advance Care Planning (ACP): Lack of Knowledge, Engagement, and Barriers

A problem in the Muslim community is that individuals are expected to plan for death but access to ACP is hindered by barriers in health care, time constraints of HCPs, perceived lack of communication skills and training, and lack of knowledge of patients about treatment options and prognosis.

2.6.2. Hydration and Nutrition Barriers

The panel discussion highlighted that the desire of Muslim patients for hydration and nutrition services can be a barrier to appropriate PEOLC Muslim patients. For example, the wish of Muslim patients to continue tube feeding and/or intravenous or subcutaneous fluids can prevent transfer to a palliative care unit (Alibhai, 2018).

3.0 RECOMMENDATIONS

Facilitated small-group discussions on research, policy, education & practice formulated the recommendations outlined hereafter.

3.1. RESEARCH

Overall, research recommendations focused on identifying barriers and gaps in palliative care for Muslims. and short-term and long-term solutions. Potential stakeholders should be involved, including patients, families, research bodies, imams and scholars, chaplains and ethics committees, clinicians and students with interests in PEOLC and Islamic Bioethics.

Specific research recommendations included:

1) Identifying barriers to culturally sensitive care in in-patient, out-patient and community settings
    - Determining whether ACP should be modified for Muslim patients
    - Map out DCM process of Muslims at end-of-life

2) Identifying current state of Muslim palliative care preferences and needs
    - National statistics on place of dying preferences
    - Bereavement and counselling needs
    - Capabilities of hospices in providing palliative care to Muslim patients

3.0 RECOMMENDATIONS

3) Appraising sources of information about Islamic resources
- Reliable and updated review of fatwa (ruling from Islamic law) regarding brain death and end-of-life care ethics

4) Building appropriate tool-kits for health care providers, including:
- Competencies in palliative care for Muslims
- Training (scenario and case-based approaches to see different approaches)
- Vocabulary (public, medical, and religious)
- Assessment tools regarding level of spirituality and spiritual distress

5) Developing, delivering, and evaluating training programs
- Identifying educational and training needs of healthcare providers working with Muslims
- Developing and validating culturally sensitive tools and instrument
- Examining whether generic training in empathy, communication, etc. satisfy the needs of Muslim populations

3.0 RECOMMENDATIONS

3.2. POLICY

Participants engaging and critical discussion about policy measures, recognizing that certain gaps exist in the current policy landscape. The landscape was discussed in terms of Canadian views and values of multiculturalism, and the need to ensure cultural safety in our healthcare system. For example, regulatory colleges should include knowledge of cultural safety concepts when training students. Lack of data was identified as the primary factor acting as a gap in informing policy such as the number of Muslim patients dying, their needs, and disparities faced at death.

Some conference participants questioned the need for culture-specific policies suggesting that, existing policies must be inclusive and recognize the values of different faiths and cultures, coined by some as cultural humility. Existing policies must be grounded in cultural humility and accommodate the multicultural nature of our society and patient population. Opportunity for 'new' policy practices can be implemented through ongoing and highly prevalent unmet needs among the Muslim population, such as a dedicated space for prayer. Prayer spaces can be incorporated as part of 'multi-faith' or spiritual rooms, existing in some hospitals at present. The existence of such policies should be translated to patients and families so that they are aware of such implementations.

3.0 RECOMMENDATIONS

3.2.1. Policy Gaps

A number of policy gaps were identified upon discussion including:

1) Lack of data and statistics on the number of people dying and their unmet needs
2) Limited access to Muslim/spiritual/cultural expertise
3) Lack of uniform training standards for chaplains
4) Limited access of bioethicists to Islamic scholars and experts

3.2.2. Policy Targets

The participants identified the following policy targets to improve palliative care for Muslims:

1) Improve the cultural literacy of hospice staff through proactive measures and tools
2) Develop partnerships with communities and health care teams
3) Integrate minority patient representatives and diverse staff at healthcare facilities

3.0 RECOMMENDATIONS

3.3. EDUCATION & PRACTICE

Overall, conference participants recognized that a public health approach should be taken to address the education needs of the Muslim community, patients, and families. There was consensus that it is crucial to partner with local community resources and to identify informal decision-makers who may have influence. Local champions should be identified who can facilitate and champion education on issues such as advance care planning (ACP).
Educational priorities identified by participants included:

1) Education of HCPs in culturally competent care for minorities on:
    a. Religious and spiritual needs of Muslims and their impact on decision-making
    b. Communication tools to explore patients' preferences and care needs.
    c. Power imbalances between HCPs and patients

2) Education of patients, families and the community adapted to diverse learning styles and non-English speakers with regard to:
    a. The role of cultural navigators
    b. Resources on advance care planning
    c. End-of-life issues

3) Role of Imams and other spiritual leaders in practice

IN CONCLUSION

The Muslim community has unique needs in PEOLC that require a team-oriented approach to address with engagement of patients, families, scholars, and HCPs. Decision-making requires attention to the needs of patients and family members as well as to Islamic theological and bioethical considerations. Gaps in communication between HCPs and Islamic scholars may limit patients' familiarity with their rights and obligations at the end-of-life. The Muslim community faces many barriers to optimal PEOLC and these may by amplified by increasing discrimination and Islamophobia. More research is needed to identify the needs of Muslim patients and to address barriers to optimal PEOLC. HCPs should be encouraged to practice cultural humility and be to mindful of the specific needs and diversity of the Muslim population.

REFERENCES

Al-Awamer, A. & Kaya, E. (2018, January). Advance Care Planning. Presented at GIPPEC Symposium. Toronto, Canada.

Alibhai S. Nutrition and Hydration at the end of life [PowerPoint slides]. Presented at GIPPEC Symposium. 2018 January. Retrieved from author.

Alibhai, S. M. (2008). The duty to feed in cases of advanced dementia. Journal of Religious Ethics, 36(1), 37-52.

Aljoudi, A. (2018, January). End- off- life is not the end of life: Reflecting on my experience with Muslim patients at the end of their life. Presented at GIPPEC Symposium, Toronto, Canada.

Arbour R, AlGhamdi HM, Peters L. Islam, brain death, and transplantation: culture, faith, and jurisprudence. AACN advanced critical care. 2012;23(4):381-94.

Chamsi-Pasha H, Albar MA. Western and Islamic bioethics: How close is the gap? Avicenna journal of medicine. 2013;3(1):8-14.

Cuthbertson v. Rasouli. 2013 SCC 53

Daar AS, al Khitamy AB. Bioethics for clinicians: 21. Islamic bioethics. CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne. 2001;164(1):60-3.

Gatrad AR, Brown E, Notta H, Sheikh A. Palliative care needs of minorities: understanding their needs is the key. BMJ: British Medical Journal. 2003 Jul 26;327(7408):176.

Ghaly M. Islam and disability: Perspectives in theology and jurisprudence. Routledge; 2009 Dec 22.

Jakda A. Ontario Palliative Care Network: Provincial Planning and Patient Preferences [PowerPoint slides]. Presented at GIPPEC Symposium. 2018 January. Retrieved from author.

REFERENCES

Laird LD, Amer MM, Barnett ED, Barnes LL. Muslim patients and health disparities in the UK and the US. Archives of disease in childhood. 2007;92(10):922-6.

Language & Culture Worldwide. (2015). The Cultural Iceberg. Retrieved from https://www.languageandculture.com/cultural-iceberg

Ontario Palliative Care Network (OPCN). (2018). Structure and Mandate. Retrieved from https://www.ontariopalliativecarenetwork.ca/en/node/31881

Padela AI, Mohiuddin A. Ethical obligations and clinical goals in end-of-life care: Deriving a quality-of-life construct based on the Islamic concept of accountability before God (taklīf). The American Journal of Bioethics. 2015 Jan 2;15(1):3-13.

Padela AI, Zaidi D. The Islamic tradition and health inequities: A preliminary conceptual model based on a systematic literature review of Muslim health-care disparities. Avicenna Journal of Medicine. 2018 Jan 1;8(1):1.

Padela AI. Human Dignity and Quality of Life: Islamic theological constructs and implications for palliative and end-of-life healthcare [PowerPoint slides]. Presented at GIPPEC Symposium. 2018 January. Retrieved from author.

Padela AI. Knowledge gaps and healthcare inequities in palliative and end-of-life care for Muslims [PowerPoint slides]. Presented at GIPPEC Symposium. 2018 January. Retrieved from author.

Padela AI, Curlin FA. Religion and disparities: considering the influences of Islam on the health of American Muslims. Journal of religion and health. 2013;52(4):1333-45.

Padela AI, Gunter K, Killawi A, Heisler M. Religious values and healthcare accommodations: voices from the American Muslim community. Journal of general internal medicine. 2012 Jun 1;27(6):708-15.

REFERENCES

Padela AI, Qureshi O. Islamic perspectives on clinical intervention near the end-of-life: We can but must we? Med Health Care Philos. 2017 Dec;20(4):545-559.

Sachedina A. End-of-life: the Islamic view. Lancet. 2005;366(9487):774-9.

Sachedina A. Religion and Culture in Palliative Care [PowerPoint slides]. Presented at GIPPEC Symposium. 2018 January. Retrieved from author.

Sarhill N, LeGrand S, Islambouli R, Davis MP, Walsh D. The terminally ill Muslim: death and dying from the Muslim perspective. The American journal of hospice & palliative care. 2001;18(4):251-5.

Siddiqui S. Palliative Care for Muslims: Diversity and Gender Considerations {PowerPoint slides]. Presented at GIPPEC Symposium. 2018 January. Retrieved from author.

Sulmasy, D. The varieties of human dignity: a logical and conceptual analysis. Medicine, Health Care and Philosophy. 2013 Nov; 16(4): 937-944.

Tayeb MA, Al-Zamel E, Fareed MM, Abouellail HA. A "good death": perspectives of Muslim patients and health care providers. Annals of Saudi medicine. 2010;30(3):215-21.

Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA. Early palliative care for patients with metastatic non–small-cell lung cancer. New England Journal of Medicine. 2010 Aug 19;363(8):733-42.

Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, Jackson VA, Block SD, Maciejewski PK, Prigerson HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. Jama. 2008 Oct 8;300(14):1665-73

APPENDIX A: SPEAKER BIOGRAPHIES

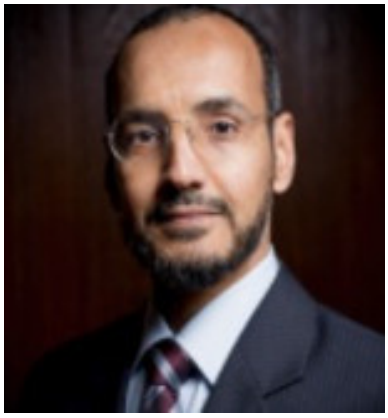
Dr. Ahmed al-Awamer

Dr. al-Awamer is an Assistant Professor in the Department of Family and Community Medicine at the University of Toronto. He is a physician and educator in the Department of Supportive Care at Princess Margaret Cancer Centre in Toronto, Canada. After completing his medical degree, Dr. al-Awamer obtained a Master of Health Science (MHSc) degree in bioethics from the University of Toronto. In his various roles, Dr. al-Awamer directs the PM oncology palliative care fellowship program and leads education at the Princess Margret Cancer Centre, Canada's largest academic cancer center. He is the head of the Curriculum Committee at the University of Toronto's palliative medicine residency program (YAC). He has published and delivered conference papers nationally and internationally about palliative care and ethics. Dr. al-Awamer's research focuses on developing and transforming the palliative care model for Muslims and palliative care education.

Dr. Abdulaziz Sachedina

Abdulaziz Sachedina, Ph.D., is Professor and IIIT Chair in Islamic Studies at George Mason University in Fairfax, Virginia. Dr. Sachedina, who has studied in India, Iraq, Iran, and Canada, obtained his Ph.D. from the University of Toronto. He has been conducting research and writing in the field of Islamic law, Ethics, and theology (Sunni and Shiite) for more than two decades. In the last ten years, he has concentrated on social and political ethics, including interfaith and intrafaith relations, Islamic biomedical ethics and Islam and human rights.

APPENDIX A: SPEAKER BIOGRAPHIES



Dr. Abdullah Aljoudi

Abdullah Aljoudi, MD is a Consultant in Family and Community Medicine, Chair of the Ethics Committee, Head of the Research Support Unit, and Assistant Director of Academic Affairs at King Fahd Hospital of the academic medical center of Imam Abdulrahman Bin Faisal University. He received a MBBS degree from King Faisal University, a diploma in Epidemiology from King Saud University, Arab board certificate in Community Medicine, Clinical Teacher Certificate from the University of Toronto, and Bioethics Fellowship from Harvard Medical School. He has published in peer-reviewed journals including the Lancet and contributed to the Encyclopedia of Islamic Bioethics. He is interested in discovering the similarity and differences between secular and Islamic bioethics in theory and practice.

Dr. Aasim Padela

Dr. Aasim Padela is the Director of the Initiative on Islam and Medicine, Associate Professor of Medicine in the Section of Emergency Medicine, and a faculty member of the MacLean Center for Clinical Medical Ethics at the University of Chicago. Dr. Padela is a clinician-researcher and bioethicist whose scholarship lies at the intersection of community health and religion. He utilizes diverse methodologies from health services research, religious studies, and comparative ethics to examine the encounter of Islam with contemporary biomedicine through the lives of Muslim patients and clinicians, and in the scholarly writings of Islamic authorities. Through systematic research and strategic interventions, he seeks (1) to improve American Muslim health outcomes and healthcare experiences, and (2) to construct a multidisciplinary field of Islamic bioethics.

APPENDIX A: SPEAKER BIOGRAPHIES

Dr. Ebru Kaya

Ebru graduated from Guy's and St. Thomas's Hospitals Medical Schools, London, UK in 1998 and entered her career in internal medicine and later went on to specialize in palliative care. She has been working at UHN since 2007. She is currently the site lead physician for palliative care at Toronto General Hospital and education co-lead for the clinical fellowship program in palliative care at UHN. She is the Hospice Palliative Care Ontario – Advance Care Planning co-lead for the Toronto Central LHIN and is a Director-at-Large for the Canadian Society of Palliative Care Physicians. She participates in numerous committees and has extensive publications and presentations at local, provincial, national and international conferences.

Dr. Ahmed Jakda

Dr. Ahmed Jakda is the Provincial Clinical Co-Lead of the Ontario Palliative Care Network, the principal advisor to the Ministry of Health and Long-Term Care on Palliative Care. He is also a family physician who specializes in palliative care. He completed his training in Family Medicine and Fellowship in Palliative Care at The Ohio State University. He is dual board certified in family medicine and palliative care, through the American Board of Hospice Palliative Medicine, and the College of Family Physicians of Canada. His clinical practice is located in the Grand River Regional Cancer Centre in Waterloo-Wellington. He is an Associate Clinical Professor with McMaster University and the University of Western Ontario, and has research interests in health system policy, data analytics, and change management.

APPENDIX A: SPEAKER BIOGRAPHIES

Dr. Shabbir Alibhai

Dr. Alibhai completed medical school training in 1993 and went on to specialize in internal medicine and geriatric medicine. He obtained a Master's in Clinical Epidemiology, all at the University of Toronto. He is currently on staff as a geriatrician and researcher at the University Health Network and a previous Research Scientist of the Canadian Cancer Society. As of June 2015, he has been the Medical Lead of the Older Adults with Cancer Clinic at Princess Margaret Cancer Centre. He is also an Associate Professor in the Department of Medicine, the Institute of Health Policy, Management, and Evaluation, and the Institute of Medical Sciences at the University of Toronto. He has a long-standing personal and educational interest in religious biomedical ethics, focusing on end-of-life issues and comparative bioethics. He has lectured internationally and published articles and book chapters on Islamic and comparative religious biomedical ethics as well as on artificial nutrition and hydration. He has been featured in multiple media interviews, has helped produce materials on conscientious objection regarding physician-assisted suicide, and is a local expert on Islamic bioethical issues. His primary research interest is in cancer in older adults.

Ms. Shahina Siddiqui

Shahina Siddiqui is the founder and Executive Director of the Islamic Social Services Association based in Winnipeg and the Chair of Islamic History Month Canada. She is active in the community as a member of the RCMP Commissioner's National Advisory Committee on Diversity as well as the RCMP Commanding Officers' Diversity Committee, D-Division in Manitoba. Ms. Siddiqui has served with several NGOs and community organizations in Winnipeg. In addition to her work with various organizations, Shahina contributes as a freelance writer, spiritual counsellor and public speaker.

APPENDIX B: CASE STUDIES

CASE STUDY 1: OBLIGATION TO TREAT

Dr. Sachedina presented a case demonstrating the concept of harm in relation to the prima facie obligation to treat (Sachedina, 2018):

Mrs. Zahra Awad's husband is hospitalized with terminal cancer and in recent days he has fallen into a coma. Mrs. Awad does not practice Islam and has practically no connection with the Muslim community and its institutions in her locality. Most of her family lives abroad. Her husband, a little more religious than her, has left a living will specifying very clearly that if he falls into coma that the attending physician should not revive him (DNR). Moreover, he instructed that extraordinary care should be suspended and life-support equipment should be switched off in that situation. A heated argument took place between Mrs. Awad and the HCPs when Mrs. Awad refused to let the hospital staff switch off the life support equipment (LSE). The attending physicians insisted they should simply follow her husband's advance directives.

How should the Ethics Committee respond to this situation? What would be your advice to Mrs. Awad? To the hospital administration?

Proposed Treatment

- A distinction is made between OPTIONAL and OBLIGATORY treatments, as medically understood;
- The question of QUALITY OF LIFE is raised cautiously since it is incompatible with the distinctions and rules connected with forgoing life-sustaining treatment;
- The Islamic bioethical principle of "No harm, no harassment" is evoked and discussed to establish a presumption in favour of providing life-sustaining treatments for the terminally ill patients.
- During the deliberations, the use of life-sustaining treatments comes up in light of the strong probability that occasionally these interventions violate patient's interests.

APPENDIX B: CASE STUDIES

CASE STUDIES 2 & 3: END-OF-LIFE ISSUES IN MUSLIM PATIENT CARE

Dr. Aljoudi presented the following two cases of patients at the end-of-life that raised common issues faced by Muslim patients (Aljoudi, 2018):

Patient 1

The patient is a 35-year-old Arabic-speaking woman with strong faith in the Will of God (Allah). She is illiterate with no knowledge of English. Her husband is away at work day and night and is absent from care discussions, yet he is the decision-maker. The patient and her husband think differently about receiving palliative care at the hospital or being discharging from the hospital and continue the palliative care at home.

Issues Faced in Care

The patient faced communication problems that made it difficult to clarify her wishes (e.g. did she want to stay in the hospital or leave?). She came from a paternalistic community, where her husband was the decision-making and was now in an individualistic setting where she was expected to be involved in decision-making. The healthcare team did not communicate the patient's poor prognosis to her or to her husband, and on her husband's request, she was unsafely discharged when care was still needed. The interfaith chaplain had visited the patient, but was unable to communicate with her. Before her discharge, the local imam was consulted and after interacting with her concluded that she wanted to speak about light-hearted topics.

APPENDIX B: CASE STUDIES

CASE STUDIES 2 & 3: END-OF-LIFE ISSUES IN MUSLIM PATIENT CARE

Patient 2

The patient is a 60-year-old American Muslim, who settled in the U.S. as a young refugee from Palestine He is an engineer by profession and a non-practicing Muslim. However, at the time of the DNR signature, he 'woke up' and realized his faith. At the end of life, Muslims must prepare themselves for another life. The patient therefore requested a copy of the Quran (Holy Book of Muslims), and cried whilst reciting the Quran. He then wanted to know whether or not DNR was permissible. An interfaith chaplain was consulted, but failed to meet the patient's spiritual needs and therefore a Muslim chaplain from another hospital was consulted and, with the help of the ethics committee, a DNR order was requested.

Issues Faced in Care

A psychiatrist was consulted because the patient was seen crying upon reading the Quran. The staff interpreted crying as depression, although many Muslims cry out of joy when reading the Holy Book. He has been Muslim in name only for many years, but a medical event "woke him up" and triggered a spiritual experience.

APPENDIX C: RESPONDING TO DIVERSITY

Responding to Diversity (Siddiqui, 2018)

- Know your biases
- Look at your policies, procedures, mission statement – are they inclusive?
- Do you have diversity in your: staff, Board, Volunteers?
- Do you have access to diverse resources?
- Is your programming inclusive?
- Do you ever ask your co-workers to teach you about their culture?
- Compassion and respect is the key
- Acknowledge trust issues impacting Muslims (Islamophobia, trauma, media stereotyping)

Diversity Considerations (Siddiqui, 2018)

- Be careful not to base assessments and interventions on stereotypes and personal biases
- Be aware of the interconnection between diversity dimensions
- How religious, cultural, acculturated are the Muslim families you work with?
- Expect varying levels within one family
- How does this impact family dynamics?
- Acknowledge trust issues impacting Muslims (i.e. Islamophobia, Media Stereotyping, Trauma and Vicarious Trauma)

APPENDIX D: CAREGIVER EXPERIENCE AT PRINCESS MARGARET CANCER CENTRE, TORONTO, CANADA

The symposium featured a speaker who was a member of the Canadian Muslim community (identified as Speaker X). Speaker X outlined the barriers she faced as a caregiver navigating the palliative and end-of-life process when her husband was diagnosed with terminal pancreatic cancer. The speaker was a middle-aged widow, mother of six children, and visibly Muslim (i.e. wearing a headscarf). She and the family were newcomers to Canada from the Middle East.

The speaker identified various **challenges** she and her family faced in the hospital, such as:

- Lack of access to a local imam or a religious figure to help her make decisions
- Not being informed about the lack of resuscitation policies in hospital
- Wanting to keep up with the five daily prayers while in the hospital, but not feeling able to discuss with staff that she required prayer space and wanted to pray
- Lacking familiarity with hospital procedures and Islamic requirements/obligations at the end-of-life

Some **positive experience** the speaker outlined as a caregiver involved in the process included:

- The support and assistance of family (her sister, specifically), and community members
- Open communication between family members and wishes
- Referral to the palliative care unit within three weeks; before the onset of delirium, the family was able to have a picnic with the patient
- The family maintained a positive outlook, and lived each day with the patient (her husband and father of six children) to the fullest

APPENDIX E: CONNECT WITH GIPPEC

Facebook
https://www.facebook.com/gippec

Twitter
@GIPPEC

Website
www.gippec.org

Youtube
GIPPEC (https://www.youtube.com/channel/UCPvt_GXpwmZVv6UviCpK3Uw)

E-mail
gippec@uhn.ca

Please note that symposium recordings are available on GIPPEC's YouTube Channel via the following link:

https://www.youtube.com/playlist?list=PLkpGgwi9E_4lfbVnulF7hBJspmWw3AoC8