

# Palliative Care in the Muslim-Majority Countries: The Need for More and Better Care

Deena M. Aljawi<sup>1</sup> and Joe B. Harford<sup>2</sup>

<sup>1</sup>King Faisal Specialist Hospital and Research Center,

<sup>2</sup>National Cancer Institute,

<sup>1</sup>Saudi Arabia

<sup>2</sup>USA

## 1. Introduction

The need for palliative care around the world is immense. In round numbers, approximately 60 million deaths from all causes will occur worldwide this year. Of all global deaths, approximately 80% will be in low- and middle-income countries (LMIC's). The majority of those dying in LMIC's would be expected to benefit from palliative care, but palliative care services are lacking in most places. Although palliative care is much more than pain relief, palliative care cannot be adequate if pain is going unrelieved. The World Health Organization (WHO) has gone so far as to assert: "A palliative care program cannot exist unless it is based on a rational drug policy including...ready access of suffering patients to opioids." (WHO, 2002). WHO has estimated that 5.5 million people with terminal cancer are not receiving the pain relief they need. In addition, 1 million late-stage HIV-AIDS patients, 800,000 people with injuries lack adequate pain relief (WHO, 2009).

The barriers to the rational use of opioid analgesics are varied depending on location but certain barriers are common. Barriers to accessing oral morphine identified in a survey of healthcare workers, and hospice/palliative care staff in Asia, Africa and Latin America include excessively strict national drug laws and regulations, fear of addiction, poorly developed health care systems, and lack of knowledge at all levels including healthcare providers (Help the Hospices, 2007). Barriers to accessing palliative care in Pakistan, for example, appear similar to those identified elsewhere (Shad et al., 2011). To address and reduce these barriers, changes will need to be affected not only in laws and policies but also in knowledge, attitudes, and behaviors of medical practitioners as well as among patients and their families.

Palliative care involves much more than the alleviation of physical pain but rather encompasses "total pain" as conceptualized by Dame Cicely Saunders, founder of modern hospice care, with total pain including emotional, psychological, social, and spiritual pain (Saunders, 1976; Mehta & Chan, 2008). Issues regarding to spirituality including existential beliefs regarding the meaning of life and extending to include religious beliefs and practices can come to the forefront in patients advanced illnesses (Williams, 2006). Spirituality and religion are coping mechanisms, and where the question has been examined, reports suggest that many patients may wish to discuss their beliefs with their healthcare providers (Ehman et al, 1999). It would appear obvious that for these discussions to be optimally

useful, healthcare providers should possess cultural and religious knowledge and sensitivity relevant to the patients being treated.

A report was recently published on the size and distribution of the world's Muslim populations (Pew, 2009). There are currently approximately 1.6 billion Muslims in the world representing 23.4% of the world's population. This number is projected to increase to over 2.2 billion representing 26.4% of the world's population by 2030. Nearly 75% of Muslims live in the 49 Muslim-majority countries (MMC's). Only about 3% of the world's Muslims live in non-Muslim-majority countries of the more-developed world such as Europe, North America, Australia, New Zealand, and Japan. However, many of the health care workers in MMC's are trained in or sent from these countries having relatively small Muslim populations. As such, their exposure to Muslim perspectives on illness and death may be inadequate.

In this chapter, the current situation regarding palliative care services in MMC's will be reviewed. Special attention will be paid to those features of palliative and end-of-life care that have some distinctive in the Muslim culture that ought to be included in any training of healthcare providers. While these issues are perhaps of most relevance to those healthcare workers in MMC's, these considerations are certainly relevant to those working elsewhere. Seventy-two of the world's countries have Muslim populations of more than one million, and this number is projected to rise to 79 countries by 2030. For example, the Muslim share of the US population is expected to more than double by 2030 and will exceed 6 million, making Muslims roughly as numerous as Jews or Episcopalians in the US today. In Europe, there are ten countries including Russia, France, and Belgium where Muslims represent more than 10% of their total population. In the UK, more than one-quarter of new immigrants this year are expected to be Muslim (Pew, 2011). Muslims live and die in every region of the world (see Figure 1), and so healthcare workers in every region of the world should be prepared to provide them with palliative care and end-of-life care in a culturally sensitive way.

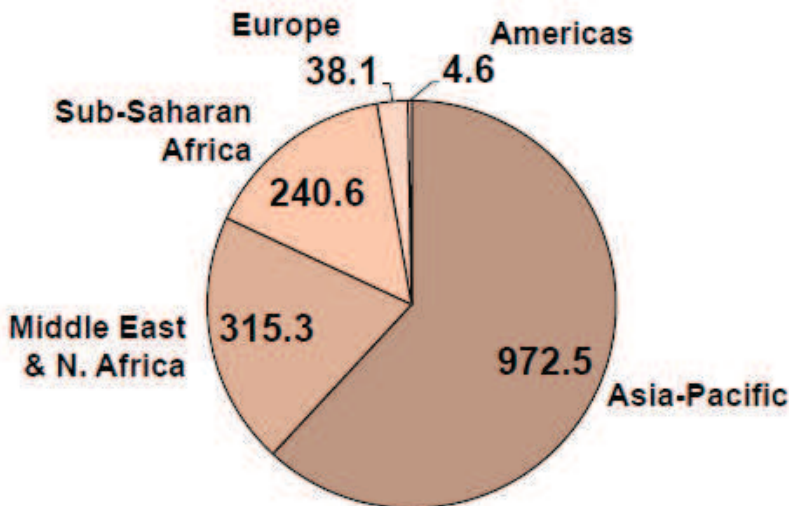


Fig. 1. Distribution of Muslims in the major regions of the world. Numbers shown represent millions of Muslims in each region. (Based on data from Pew Research Center on Religion & public Life: *The Future of the Global Muslim Population*, January 2011).

It is certainly recognized by the authors of this chapter that every human being is unique and that adherents to any religion vary in their beliefs and practices. Islam is no exception. It is a monotheistic religion, but it is not monolithic in terms of knowledge, attitudes, and behaviors as these relate to healthcare more broadly or palliative and end-of-life care in particular. There are two major schools of thought in Islam (Shia and Sunni). Nearly 90% of the world's Muslims are Sunni with most Shia Muslims living in four countries (Iran, Pakistan, India, and Iraq). In certain parts of the world (e.g., Africa), Sufism, which focuses on the mystical elements of Islam exists, and Sufis can be Shia or Sunni. Within any given branch of Islam there is diversity of thought, traditions, and voices. One of the authors (DA) is Muslim and serves as Clinical Nurse Coordinator within the Palliative Care Unit of the King Faisal Specialist Hospital and Research Center in Riyadh, Saudi Arabia, a predominantly Sunni country. This hospital has been at the forefront in developing palliative care services in Saudi Arabia (Gray et al., 1995). Most patients receiving palliative care at this hospital have cancer.

## 2. The current state of palliative care in Muslim-majority countries

The ability to assess the state of palliative care in a given location is a complicated process and the comparison of one location to another even more complicated since comparable data are not always readily available. Guidance for implementing quality palliative care exists, but the application of these guidelines appears to be predominantly at the level of individual organizations seeking to define themselves in terms of quality rather than as an internationally recognized "model of standard care" (Ferris et al., 2007). Outcome measures that have been developed for evaluating palliative care have been reviewed (Jocham et al., 2009). Many of the studies cited by these authors suggest that there is a lack of good quality evidence upon which to base conclusions regarding the appropriate measures for palliative care assessment. Most of the studies covered are from North America and western Europe.

Group as Defined by IOELC	Muslim-majority Countries
No known activity	Afghanistan, Burkina Faso, Chad, Comoros, Djibouti, Guinea, Libya, Maldives, Mali, Mauritania, Niger, Senegal, Somalia, Syria, Turkmenistan, Western Sahara, Yemen
Capacity building	Algeria, Bahrain, Brunei, Kuwait, Lebanon, Oman, Palestinian Authority, Qatar, Sudan, Tajikistan, Tunisia, Turkey, Uzbekistan
Localized provision	Albania, Azerbaijan, Bangladesh, Egypt, Indonesia, Iraq, Jordan, Kazakhstan, Kyrgyzstan, Morocco, Pakistan, Saudi Arabia, Sierra Leone, The Gambia, United Arab Emirates
Approaching integration	Malaysia

Table 1. Distribution of Muslim-majority countries according to the typology of the International Observatory on End-of-Life Care (data from Wright et al., 2008).

Several years ago, the U.S. National Cancer Institute commissioned a survey by the International Observatory on End-of-Life Care (IOELC) of palliative care services within the jurisdictions of the Middle East Cancer Consortium (MECC) and published a monograph containing the results of this analysis (Bingley & Clark, 2008). Four of the members of MECC have Muslim-majority populations (Egypt, Jordan, Palestinian Authority, and Turkey). A summary of the situation analyses conducted by IOELC has also been published (Bingley & Clark, 2009). More recently, the MECC Palliative Care Steering Committee has published country-specific situation analysis for the MECC membership as well as two additional MMC's (Lebanon and Saudi Arabia) (Moore et al., 2011). These situation analyses, while useful, were based on input from a relatively small number of healthcare workers from each jurisdiction.

The IOELC has also published a survey of palliative care services around the world (Wright et al., 2008). The countries of the world that were analyzed were placed by the IOELC into four categories of palliative care activity. The four-category typology depicts levels of hospice-palliative care development with "approaching integration" being the most advanced category. Countries in this category are characterized by a critical mass of activists; multiple providers and service types; an awareness of palliative care on the part of health professionals and local communities; the availability of strong, pain-relieving drugs; an impact of palliative care upon policy; the development of recognized education centers; academic links forged with universities; and the existence of a national association (Wright et al., 2008). Of the 234 countries analyzed by the IOELC, 35 countries (15%) were placed in the "Approaching integration" category. Of Muslim-majority countries that were analyzed, only Malaysia was characterized as being in this most advanced category (see Table 1). Seventeen MMC's were placed in the "No known activity" category, 13 in the "Capacity building" category, and 15 in the "localized provision" category. In general, the countries in Group 4 ("Approaching integration") tend to have higher GDP per capita than in those in the other three groups suggesting that palliative care services might be a prerogative of high-income countries. However, the more wealthy MMC's with GDP per capita in excess of \$20,000 (Bahrain, Brunei, Kuwait, Oman, Qatar, Saudi Arabia, and United Arab Emirates) are absent from Category 4. Five of these countries are in Category 2 ("Capacity building") and 2 are in Category 3 ("Localized provision").

This situation analysis enabled its authors to calculate the ratio of services to the population of the country providing a measure of how many thousands of persons would theoretically be served by each service. These ratios for selected MMC's are provided in Table 2 along with comparators of the United States and the United Kingdom. The MMC with the most favorable ratio was again Malaysia wherein 37 services were identified, and there was an average of 685,000 persons per service. This ration compares to 43,000 for the UK and 90,000 for the US. The least favorable ratio was seen in Pakistan where only 1 service was identified for a population of 157,935,000. With the exception of Malaysia with 37 services, no other MMC had more than 3 services identified. As an example of the disparity in hospice/palliative care services, Egypt with a slightly larger in population than the UK was found to have 3 services whereas the UK had nearly 1400 services.

Palliative care services can take the form of palliative consulting services within a hospital, dedicated palliative beds within a hospital, a stand-alone hospice facility, and homecare palliative/hospice services. One of the principles of a "good death" from the Muslim

Region	Country	Services	Ratio 1:1000's
Europe	Azerbaijan	1	8,411
Western Asia	UAE	2	1,344
	Jordan	2	2,852
	Saudi Arabia	3	8,191
	Iraq	1	28,807
Asia Pacific	Malaysia	37	685
	Bangladesh	3	42,274
	Pakistan	1	157,935
Africa	The Gambia	1	1,517
	Sierra Leone	1	5,525
	Egypt	3	24,678
	Morocco	1	34,487
Comparators	UK	1,397	43
	US	3,300	90

Table 2. Hospice-palliative care services and indicative ratios of hospice-palliative care services to populations in selected Muslim-majority countries with comparison to the United Kingdom and the United States (data from Wright et al., 2008).

perspective would be to have access to hospice services in any location, not only in the hospital (Tayeb et al., 2011). Reflective of the extended family structure that is typical in Muslim families, it has been reported that most Muslim families would prefer to care for relatives at home and that patients would prefer to die at home (Gartrad, 1994; Gardener, 1998; Sarhill et al., 2001), although there has been little or no research on this topic in most MMCs. Muslim families may feel that sending a relative to a hospital without curative intent may be a form of shirking of the responsibility to care for family members at the end of life. In one study, some participants in a survey stated that they preferred to die in a holy place like a mosque or in Makkah or Medina (Tayeb et al., 2011), but this may reflect religious idealism rather than practicality. Historically, care for the dying has been seen as a family responsibility and death has been generally managed at home (Gatrad & Sheikh, 2002). However, the lack of home care services in most MMC's can lead to return trips to the hospital and/or extended stays and death in a hospital. This dilemma may also be exacerbated by the long distances that more rural patients may need to travel to get to hospitals that are usually located in urban settings. Expansion of palliative care and hospice services including access to opioid analgesics in the home setting has the potential of relieving the patient load on in-hospital services.

Another measure of palliative care activity is provided in analysis of the use of opioid analgesics. Palliative care involves, of course, much more than pain relief. Indeed, advanced cancer patients experience a range of symptoms that require medical management. Cancer patients tend to experience multiple symptoms including what has been termed "symptom clusters" i.e., two or more symptoms that present together (Fan et al., 2007; Jimenez et al., 2011). Symptom clustering has also been documented in Muslim patients in Kuwait (Alshemmari et al., 2011). Granting that pain control is not synonymous with palliative care, use of opioid analgesics nonetheless provides a "barometer" for palliative care, and data on

opioid consumption are available. The amounts of opioid analgesics consumed in a year are monitored by the International Narcotics Control Board (INCB), an agency of the United Nations located in Vienna, Austria. There are a number of ways in which opioid analgesic consumption might be compared among countries. The website of the Pain Policy Study Group (PPSG) of the University of Wisconsin (see <http://www.painpolicy.wisc.edu/>) presents data collected by the INCB. Given that there are many forms of opioid analgesics (e.g., fentanyl, hydromorphone, methadone, oxycodone, pethidine, in addition to morphine itself), the PPSG website has converted the quantities of each form into "morphine equivalents". This enables one to compare consumption between countries that may utilize different forms of opioid analgesics for whatever reason. The use of fentanyl transdermal patches has become increasingly popular. For example, over 50% of the morphine equivalents in Egypt and Saudi Arabia and more than 90% of the morphine equivalents in Turkey are fentanyl according to the INCB database for 2008 (see <http://www.painpolicy.wisc.edu/>). Fentanyl transdermal patches are a rather expensive form of opioid analgesics, and it would be of interest to explore the reasons for increasing use of fentanyl in MMC's.

Using the INCB data, countries can be compared for total morphine equivalents consumed per capita. Not surprisingly, the range is very large with most of the world's morphine consumed by countries representing a relatively small fraction of the world's population. In general, there is a correlation between a country's income and its use of opioid analgesics. Indeed, approximately 80% of morphine is consumed by 7 high income countries representing <10% of the world's population. Developing countries, which represent >80% of the world's population, account for <10% of global morphine consumption. In about 150 countries, the use of morphine is severely restricted. Palliative care services in most MMC's countries in the world are indeed quite limited. It is noteworthy, that among the exceptions to the correlation between income and opioid analgesic usage are the relatively wealthy countries of the Arab Gulf where opioid use is low despite a high average income.

Perhaps more meaningful than opioid consumption would be evaluation of consumption of opioids in comparison to the need for pain relief. Recently, a study was published by Seya et al. (2011) that proposed a rough but simple way for estimating the total population need for opioids for treating moderate to severe pain. The authors calculated the needs for terminal cancer patients, terminal HIV patients and lethal injury patients and corrected for the needs associated with pain from other causes (e.g., nonlethal cancers, nonlethal injuries, non-end-stage HIV, surgery, sickle cell episodes, childbirth, chronic nonmalignant pain). The calculation resulted in an "adequacy of consumption measure" (ACM). Based on these methods an ACM of 1.00 or more was deemed to represent "adequate" access to opioid analgesics relative to need. An ACM between 0.30 and 1.00 was considered to be "moderate" consumption relative to need; an ACM between 0.1 and 0.3 as "low" relative to need; an ACM of between 0.03 and 0.1 was deemed to be "very low" relative to need, and an ACM of under 0.03 was deemed to be "virtually nonexistent" consumption of opioid analgesics. The study was based on morphine equivalents and so represented use of all forms of opioids. Globally, this analysis of 188 countries painted a very bleak picture with only 7% of the world's population judged to have adequate access to opioid analgesics. The situation in MMCs was even more grim. No MMC was found to fall into the adequate, moderate, or even low categories i.e., all were in either the very low or virtually nonexistent categories. Figure 2 is based on these data for the fifteen MMCs with the largest populations and ordered in the figure according to decreasing ACMs.

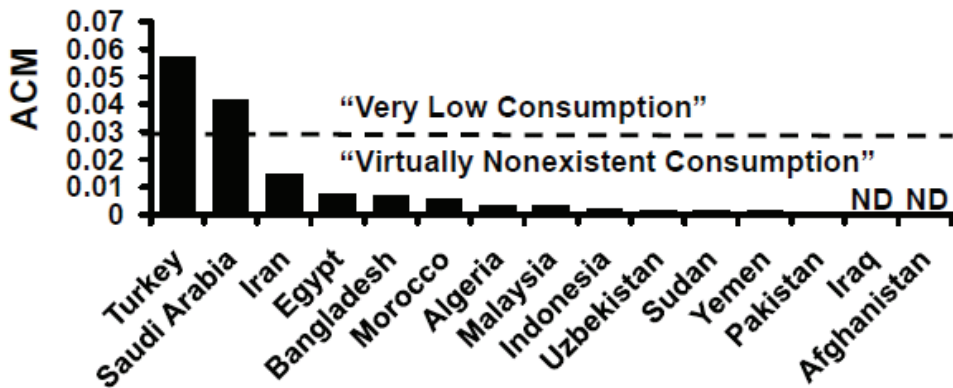


Fig. 2. Consumption of opioid analgesics in the fifteen largest Muslim-majority countries ordered by decreasing ACM. The dashed line represents the boundary between “very low consumption” and “virtually nonexistent consumption” based on the data and definitions of Seya et al. (2011). ACM = adequacy of consumption measure. ND = no data. By comparison, the ACM for the US was calculated to be 2.48.

The extremely low consumption of opioids in MMC's is very troubling because it means that most dying patients in these countries are suffering unnecessarily. Considering cancer patients alone, the MMCs represent approximately 835,000 deaths from cancer (all cancer sites excluding non-melanoma skin) each year according to the GLOBOCAN 2008 database of the International Agency for Research on Cancer ([www.iarc.fr](http://www.iarc.fr)). Physical suffering of cancer patients has been addressed and the prevalence of various symptoms including pain documented (Teunissen et al., 2007). In a small survey of adult patients in Kuwait, pain was the most common and most distressing symptom with 82% of the patients having physical pain (Alshemmari et al., 2010). It is estimated that adequate pain relief can be achieved in up to 90% of patients using existing WHO treatment guidelines available in multiple languages including Arabic (Sepulveda et al., 2002).

There is a paucity of research in MMC's on the barriers to opioid use that might exist in MMC's. As in other settings, the barriers are likely to be a multifaceted and complex mixture of legal/policy aspects combined with lack of knowledge and misguided attitudes on the part of policy makers and healthcare providers in addition to patients and their families. Fear of diversion of narcotics from patients is one concern, but it has been found to be rare or non-existent in one MMC (Malaysia) (Devi et al., 2008). It has been suggested that Muslims may perceive suffering as a means of atoning for ones sins (Al-Shahri & Al-Khenaizan, 2005). To the extent that this interpretation exists among Muslim patients, it may contribute to low opioid usage in MMC's. It should be noted that clearly not all Muslims adhere to this idea, and the linkage of suffering and atonement is not unique to Islam but is also a belief held by some Christians for example. More research is needed to understand the barriers to opioid usage in MMC's. It is likely that there will be distinctions found from country to country even within the MMC's, so local research would be most appropriate. Once the barriers are better understood, educational efforts aimed at overcoming the barriers can be designed, evaluated, and implemented. Since 2006, the INCB has requested

annually that all governments promote rational medical use of opioid analgesics, and there is recognition that pain relief is a component of the human right to the highest attainable standard of mental and physical health or a human right on its own (Help the Hospices, 2007; Seya et al., 2011).

The Global Access to Pain Relief Initiative (GAPRI) is a joint programme of the Union for International Cancer Control and the American Cancer Society to make effective pain control measures universally available to cancer patients in pain by 2020, in line with Target 8 of the World Cancer Declaration. GAPRI's projects are designed to address these key objectives: creating stronger collaboration between cancer and HIV communities around pain treatment; improving the market for essential pain medicines; empowering governments to take the lead in expanding access to pain relief; addressing health systems challenges at multiple levels; and mainstreaming the issue of pain treatment in global health efforts (see <http://www.uicc.org/programmes/about-gapri>).

### **3. The need for additional healthcare workers trained in palliative care**

The need for additional healthcare workers trained in palliative care was recognized for the U.S. in 1994 when the NCI noted, "There are few formally structured programs for training in palliative patient care available in the United States" and issued a request for applications "To stimulate medical schools...to design methodologies for the education and training of health care professionals in hospice and palliative care." Nonetheless, even in the U.S., a minority of medical schools appear to require training in palliative care and to evaluate students in their care of patients with advanced, incurable conditions. Nursing training in palliative care in the U.S. is also inadequate. Although comparable assessments of professional school training in palliative care within LMICs are sparse, it would not appear that the topic is covered even remotely in proportion to the need for palliative care in these venues.

Several years ago, the U.S. National Cancer Institute (NCI) commissioned the U.S. Institute of Medicine to produce a publication entitled "Cancer Control Opportunities in Low- and Middle-Income Countries." (Sloan & Gelband, 2007). Among the statements made in this publication was "Ideally, medical, nursing, and social work students (and other relevant health care workers) will receive training in palliative care and practitioners will incorporate palliative care into routine practice." Unfortunately this is not yet the reality. Contributing to the lack of palliative care services in MMC's is a paucity of healthcare workers with knowledge of the basic principles and specific skills of palliative care delivery.

Recognizing the importance of palliative care education and the advantages of distance learning, the Institute for Palliative Medicine in San Diego, CA, with support from the U.S. National Cancer Institute's Office of International Affairs, has launched a website through which healthcare professionals worldwide can access training resources in palliative care. It is hoped that this web portal [referred to as the *International Palliative Care Resource Center* (IPCRC)] will contribute to the desperate need for additional capacity for palliative care service delivery and palliative care research not only in MMC's but in LMICs more generally (see [www.ipcrc.net](http://www.ipcrc.net)).

An optimal situation would be for all healthcare workers to have basic knowledge and skills in palliative care, those treating cancer, AIDS, and geriatric patients to have more advanced



skills, and those members of specialist palliative care teams to possess expert skills. While there are a number of educational materials available for healthcare workers in different disciplines (e.g., under "Education" at [www.ipccr.net](http://www.ipccr.net)), most of these resources address more advanced or specialist skills and virtually all are in English. While these materials are quite useful in many venues, there are other locations where English language skills of nurses, in particular, are limited so as to render these educational materials of limited utility. It is also the case that educational materials that are currently available have not generally been tailored so as to include considerations of religious and cultural distinctive of Muslims.

As part of an effort to address this issue and to build capacity for palliative care services in the Arab world, a course for Arabic-speaking nurses was created to be pilot tested in Tanta, Egypt. This course targets all nurses not only those working or aiming to work in a palliative care unit, consulting service, or hospice. The course is designed to convey the basic knowledge and skills in palliative care that would be beneficial to all nurses. It is anticipated that subsequent to this basic training, a subset of nurses will be selected for more advanced and ultimately specialist training. The basic skills course for nurses may be of use throughout the Arab-speaking world. In addition, such a course could be adapted to meet the needs of nurses who speak languages other than Arabic.

There have been publications regarding palliative care in Muslim patients that have attempted to address distinctives of Islam and Muslim culture that should be understood by healthcare workers who are treating Muslim patients (Al-Shahri & Al-Khenazian, 2005; Gatrad, 1994; Gatrad & Sheikh 2002a, 2002b; Sarhill et al., 2001; Sheikh, 1998; Tayeb et al, 2010). In one instance, over 250 Muslims in Saudi Arabia were surveyed and some interviewed as to what constitutes a "good death" starting with the elements identified in Western communities (Tayeb et al, 2010). These authors found that participants identified elements in three main domains: 1. Faith and belief; 2. Self-esteem and image to friends and family; and 3. Satisfaction about family security after the death of the patient. Given the centrality of the family in the Saudi culture, it is not surprising that two of the three domains were family-oriented. An attempt has been made to incorporate these and other Muslim-centered elements into the Arabic nursing training in palliative and end-of-life care described above. In most instances, the Arabic-speaking nurses being trained are themselves Muslims as are the vast majority of the patients they are serving. The Muslim-centered elements that have been included will only be summarized briefly here.

Modesty is a highly regarded value in most Muslim cultures. For example, in Saudi Arabia, an *abaya* (full body cloak) and *tarha* (head covering) is nearly universal, and many women also cover their faces. Unnecessary touching between unrelated adults of the opposite sex is considered highly inappropriate. In some cases, a Saudi woman, for example, might be uncomfortable even communicating with an unrelated man and may be more comfortable if discussions with a male healthcare provider were carried out through a close male relative. Once again, we would note that discomfort with a healthcare provider of the opposite sex is not unique to the Muslim culture. It may be more common in Muslim cultures however, and it should not be disregarded in the delivery of care. Asking permission to touch for hands-on medical care may not be the norm for Western-trained physicians and nurses but it would be considered appropriate in the case of a Muslim patient of the opposite sex.

One very fundamental tenets of Islam based on the Noble Qur'an is that the death of every individual is predetermined by Allah, and only Allah knows when that death will occur.

Conversations with patients and families regarding prognosis and life expectancy need to recognize this belief, and be in general terms describing the natural history of the given terminal illness. Nonetheless, the family would likely appreciate knowing when death appears imminent, so they can be around the patient in his/her final hours and be prepared for the Muslim funeral rites that aim for speedy burial.

When Muslims are sick, their friends and relatives tend to visit and sometimes in rather large numbers for rather extended visits. Western trained healthcare workers may find this somewhat unusual, but consideration should be given to the point where the visitors are in some way impeding the delivery of care. Near the end of the patient's life the family may wish to read passages from the Qur'an or recite *Shahadah* that bears witness to Allah being the only God and Muhammad (pbuh) being the messenger of Allah. The *Shahadah* is one of the five pillars of Islam, and it is generally desired that these be the last words heard by and on the lips of the patient in this life. One concern regarding the use of opioid analgesics may be that morphine-induced sedation might interfere with the ability of the patient to recite the *Shahadah* or hear the Qur'an being read.

Some families may not wish their dying relative to be fully informed regarding his/her illness. While this is certainly not unique to Islam, it is perhaps somewhat more common in Muslim families than in Western families today. In some instances, the patients and relatives may be engaging in what has been termed "mutual pretense" (Bluebond-Langer, 1978) i.e., both the patient and his/her family know that the patient is dying but the topic is avoided with each pretending that the other doesn't know the real situation.

Another of the five pillars of Islam is the *Salah*, five daily prayers, and these are to be performed in sickness and in health if the patient is cognitively able. Accommodation of the patient's ability to perform the *Salah* should be made if at all possible. If bed-ridden, the prayers can be performed in bed. Muslims usually prefer that the prayer times be in a quiet environment, and the patient should be facing Makkah. In a hospital located in an MMC, the direction of Makkah would be known, but Muslim patients in a non-Muslim setting may need assistance in identifying the direction to pray and orienting their bed so as to allow them to face Makkah. It is desirable to time medical interventions so as to avoid the time of prayers. Another aspect of the daily prayers that has implications in a hospital setting relates to cleanliness. The clothes and body of the patient should be free of urine, stool, vomit, and blood at the time of the prayers. Washing before prayers may also require that special accommodations be made and assistance rendered. Another concern regarding the use of opioid analgesics may be that morphine-induced sedation might interfere with the ability of the patient to pray.

Muslim dietary considerations also may come into play in caring for the terminally ill Muslim patient. Here again, the basic dietary restrictions of Islam would be less of a concern in a care facility located in an MMC but could be an issue in a non-MMC setting such as in the US or Europe. Ramadan is celebrated by Muslims in the ninth lunar month of each year, and during Ramadan, the *Sawm*, another pillar of Islam is observed. This requires abstinence from food and drink during the daytime. Although the sick can be exempted from the mandate to fast, many Muslim patients will desire to keep Ramadan. Adjustment of meal times is one accommodation that can be made. Perhaps more challenging is that the restrictions of Ramadan may be interpreted to include certain medical interventions relevant to palliative care e.g., oral medications, blood transfusions and intravenous fluids, although

injections, transdermal patches (e.g., fentanyl), enemas, and suppositories are permissible (Al-Shahri, 2002).

Another pillar of the Muslim faith is the *Hajj*, a pilgrimage to Makkah once in life. As Muslim patients come to appreciate that their life is approaching its end, they may well wish to go to Makkah prior to dying. The *Hajj* rites may take days to complete and may be quite strenuous for an ailing patient. Planning for a *Hajj* (or an abbreviated pilgrimage called *Omrah*) is likely to require cooperation between the family of the patient and the palliative care team.

When death of the patient occurs, it is important to assist the family in preparation for burial which is to be performed as quickly as possible. Autopsy is not generally done except for legal or possible public health reasons. Immediately following death, the eyes and mouth of the deceased should be closed, the body freed of all needles, tubes, etc., and the limbs straightened. Generally, members of the family of the deceased perform a ritual washing and shrouding of the body in preparation for burial. The major assistance to be rendered to the family by the healthcare team is the timely completion of necessary paperwork (e.g., the death certificate) so as to release the body to the family as quickly as possible for burial.

#### 4. Conclusions and recommendations

Muslims make up nearly one-quarter of the people on earth and are in the majority in 49 countries. Based either on assessment of available palliative care services or on the consumption of opioid analgesics, it is very clear that palliative care is severely lacking in MMC's. This is true not only in the low- and middle-income MMC's (e.g., Pakistan, Bangladesh, and the MMC's of Africa) but also in the higher income countries of Arab gulf. More research is needed to understand the barriers to the use of opioid analgesics in MMC's. At least one of these barriers may have ties to Muslim concepts of suffering and death, and these can be addressed. In Saudi Arabia, for example, a fatwa (a legal pronouncement in Islam, issued by a religious law specialist on a specific issue) has been issued that supports the use of opioid analgesics for relief of pain.

The paucity of palliative care services in MMC's clearly needs to be addressed, although this an issue that goes far beyond MMC's (Wright et al., 2008). Ideally, these services would encompass consultative services within each hospital, dedicated beds for a palliative care unit, stand-alone hospices, and home-care palliative care and hospice services. The ideal set forth by the IOELC is "integration" into the healthcare system. Were this to be achieved in MMC's, the deaths of the over 800,000 individuals who die each year from cancer in MMC's as well as those from other causes would approach a "good death." This integration would mean that palliative care would be a part of multidisciplinary case management from diagnosis and not merely appended at the end of life.

A clear barrier to the desired integration of palliative care into healthcare is simply the shortage of physicians and nurses with specialized or advanced training in palliative care delivery. Clearly, training and capacity building in palliative care should be a high priority of the governments of the MMC's as well as the international community as a whole. While there are existing educational material and curricula in palliative care (see [www.IPCRC.net](http://www.IPCRC.net) under "Education"), almost all of this training material is in English. It should also be a priority to produce educational materials in other languages (probably via translation and

adaptation of existing content). This issue is of particular importance when it comes to training nurses, since it is often the case that their English skills as a group are on average less advanced than those of physicians in the same country.

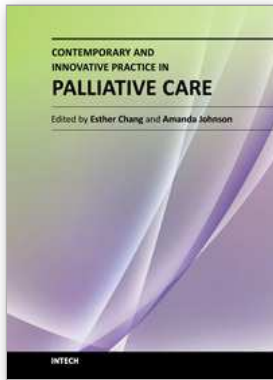
It is, of course, also important that material in all languages, including English, reflect cultural sensitivity and recognize that certain aspects of the Muslim religion and/or culture have an impact on delivery of healthcare more broadly and on palliative and end-of-life care in particular. In some MMC's, many or even most of healthcare workers are either trained in or come from Western countries. Despite the fact that the vast majority of the patients they treat are Muslims, their training and experience in a Muslim-minority setting may have left them poorly equipped to deliver high quality palliative and end-of-life to their Muslim patients. It is clear that modules related to cultural and religious distinctives should be added to palliative care training courses and programs. Such modules would benefit not only those healthcare workers who practice in MMC's but also those working in settings where the Muslims are a minority (e.g., the US and Europe). In many of these settings, the fraction of the population represented by Muslims is projected to rise in the future.

## 5. References

- Al-Shahri (2002). Culturally sensitive caring for Saudi patients. *J. Transcult. Nursing* 13, 133-138.
- Al-Shahri, M.Z. & Al-Khenaizan, A. (2005) Palliative care for Muslim patients. *J. Support. Oncol.* 3, 432-438.
- Alshemmari, S., Ezzat, H., Samir, Z., Sajnani, K. & Alsirafy, S., Symptom burden in hospitalized patients with cancer in Kuwait and the need for palliative care. *Am. J. Hospice & Palliat. Med.* 27:446-449.
- Bingley, A. & Clark, D. (2008). *Palliative care in the region represented by the Middle East Cancer Consortium: A review and comparative analysis*. National Cancer Institute. NIH Pub. No. 07-2630, Bethesda, MD.
- Bingley, A. & Clark, D. (2009). A comparative review of palliative care development in six countries represented by the Middle East Cancer Consortium (MECC). *J. Pain & Symptom Manage.* 37, 287-296.
- Bluebond-Langner, M. (1978) Mutual pretence: cause and consequence. In: *The Private Worlds of Dying Children*. Princeton University Press, Princeton, NJ: 210-230.
- Devi, B.C.R., Tang, T.S. & Corbex, M. (2008). Setting up home-based palliative care in countries of limited resources: A model from Sarawak, Malaysia. *Ann. Oncol.* 19, 2061-2066.
- Ehman, J.W., Ott, B.B., Short, T.H., Ciampa, R.C. & Hansen-Flaschen, J. (1999). Do patients want their physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Arch. Intern. Med.* 159, 1803-1806.
- Fan, G., Filipczak, L., Chow, E. (2007). Symptom clusters in cancer patients: A review of the literature. *Curr. Oncol.* 14:207-282.
- Ferris, F.D., Gomez-Batiste, X., Furst, C.J. & Connor, S. (2007). Implementing quality palliative care. *J. Pain & Symp. Manage.* 33, 533-541.
- Gardener, K. (1998). Death, burial and bereavement amongst Bengali Muslims. *J. Ethn. Migr. Stud.* 24:507-521.

- Gatrad, A.R. (1994). Muslim customs surrounding death, bereavement, postmortem examinations, and organ transplants. *BMJ* 309, 521-523.
- Gatrad, A.R. & Sheikh, A. (2002). Palliative care for Muslims and issues before death. *Int. J. Palliative Nursing* 8, 526-531.
- Gatrad, A.R. & Sheikh, A. (2002). Palliative care for Muslims and issues after death. *Int. J. Palliative Nursing* 8, 594-597..
- Gray, A.J., Ezzat, A. & Volker, S. (1995). Developing palliative care services for terminally ill patients in Saudi Arabia. *Ann. Saudi Med.* 15, 370-377.
- Help the Hospices (2007), Access to Pain Relief—An Essential Human Right. URL: <http://www.helpthehospices.org.uk/our-services/international/resources/developing-services/drugs-and-pain-control/>
- Jimenez, A., Madero, R., Alonso, A., Martinez-Marin, V., Vilches, Y., Martinez, B., Feliu, M., Diaz, L., Espinosa, E. & Feliu, J. (2011). Symptom clusters in advanced cancers. *J. Pain & Sympt. Manage.* 42, 2431.
- Jocham, H.R., Dassen, T., Widdershoven, G. & Halfens, R. (2009). Evaluating palliative care—a review of the literature. *Palliat. Care Res. & Treat.* 3, 5-12.
- Mehta, A. & Chan, L.S. (2008). Understanding the concept of total pain: A prerequisite for pain control. *J. Hospice & Palliat. Nursing* 10, 26-32.
- Moore, S.Y., Pirrello, R.D., Christianson, S.K. & Ferris, F.D. (2011). Strategic planning by the palliative care steering committee of the Middle East Cancer Consortium. *J. Pediatr. Hematol. Oncol.* 33, Supplement 1, S39-S46.
- Pew Research Center on Religion & Public Life (2009). *Mapping the Global Muslim Population*. October, 2009. URL: <http://www.pewforum.org/Muslim/Mapping-the-Global-Muslim-Population.aspx>
- Pew Research Center on Religion & Public Life (2011). *The Future of the Global Muslim Population*. January 2011. URL: <http://www.pewforum.org/The-Future-of-the-Global-Muslim-Population.aspx>
- Sarhill, N., LeGrand, S., Islambouli, R., Davis, M.P. & Walsh, D. (2001) The terminally ill Muslim: Death and dying from a Muslim Perspective. *Am. J. Hospice & Palliat. Care* 18, 251-255.
- Saunders CM. (1976). The challenge of terminal care. In: Symington T, Carter RL, eds. *Scientific Foundations of Oncology*. London, England: Heinemann. p. 673 -679.
- Sepulveda, C., Marlin, A. Yoshida, T. & Ullrich, A. (2002) Palliative care: The World Health Organization's global perspective. *J. Pain Symptom Manage.* 24, 91-96.
- Seya, M.-J., Gelders, S.F.A.M., Achara, O.U., Milani, B. & Scholten, W.K. (2011). A first comparison between the consumption of and the need for opioid analgesics at country, regional, and global levels. *J. Pain & Palliative Care Pharmacotherapy* 25, 6-18.
- Shad, A., Ashraf, M.S. & Hafeez, H. (2011) Development of palliative-care services in a developing country: Pakistan. *J. Pediatr. Hematol. Oncol.* 33, Supplement 1, S62-S63..
- Sheikh, A. (1998) Death and dying—a Muslim perspective. *J. Royal Soc. Med.* 91, 138-140.
- Sloan F.A. & Gelband H. (2007) *Cancer Control Opportunities in Low- and Middle-Income Countries*. National Academies Press (US), Washington, DC.
- Tayeb, M.A., Al-Zamel, E., Fareed, M.M. & Abouellail, H.A. (2010). A “good death”: Perspectives of Muslim patients and health care providers. *Ann. Saudi Med.* 30, 215-221.

- Teunissen, S.C., Wesker, W., Kruitwagen, C., de Haas, H.C., Voest, E.E. & de Graeff (2007). Symptom prevalence in patients and incurable cancer: A systematic review. *J. Pain Symptom Manage* 34, 94-104.
- World Health Organization (2002). National cancer control programmes: Policies and managerial guidelines (2nd ed.), World Health Organization, Geneva, p. 87. URL: <http://www.who.int/cancer/nccp/nccp/en>
- World Health Organization (2009). Access to Controlled Medications Programme. Improving access to medications controlled under international drug conventions. World Health Organization briefing note 2009. URL: [www.who.int/medicines/areas/quality\\_safety/ACMP\\_BrNoteGenrl\\_EN\\_Feb09.pdf](http://www.who.int/medicines/areas/quality_safety/ACMP_BrNoteGenrl_EN_Feb09.pdf)
- Williams, A.L. (2006). Perspectives on spirituality at the end of life: A meta-summary. *Palliat. Support. Care* 4, 407-417.
- Wright, M., Wood, J., Lynch, T. & Clark, D. (2008). Mapping levels of palliative care development: A global view, *J. Pain Symptom Manage.* 35, 469-485.



## **Contemporary and Innovative Practice in Palliative Care**

Edited by Prof. Esther Chang

ISBN 978-953-307-986-8

Hard cover, 302 pages

**Publisher** InTech

**Published online** 10, February, 2012

**Published in print edition** February, 2012

This book is designed to provide a comprehensive insight into the key and most prevalent contemporary issues associated with palliation. The reader will find viewpoints that are challenging and sometimes discerning, but at the same time motivating and thought-provoking in the care of persons requiring palliation. This book is divided into three sections. Section 1 examines contemporary practice; Section 2 looks at the challenges in practice; Section 3 discusses models of care. This book is an excellent resource for students, practising clinicians and academics. By reading the book, reflecting on the issues, challenges and opportunities ahead, we hope it will create within the reader a passion to take on, explore and further develop their palliative care practice.

### **How to reference**

In order to correctly reference this scholarly work, feel free to copy and paste the following:

Deena M. Aljawi and Joe B. Harford (2012). Palliative Care in the Muslim-Majority Countries: The Need for More and Better Care, Contemporary and Innovative Practice in Palliative Care, Prof. Esther Chang (Ed.), ISBN: 978-953-307-986-8, InTech, Available from: <http://www.intechopen.com/books/contemporary-and-innovative-practice-in-palliative-care/palliative-care-in-muslim-majority-countries-the-need-for-more-and-better-care>

# **INTECH**

open science | open minds

### **InTech Europe**

University Campus STeP Ri  
Slavka Krautzeka 83/A  
51000 Rijeka, Croatia  
Phone: +385 (51) 770 447  
Fax: +385 (51) 686 166  
[www.intechopen.com](http://www.intechopen.com)

### **InTech China**

Unit 405, Office Block, Hotel Equatorial Shanghai  
No.65, Yan An Road (West), Shanghai, 200040, China  
中国上海市延安西路65号上海国际贵都大饭店办公楼405单元  
Phone: +86-21-62489820  
Fax: +86-21-62489821

© 2012 The Author(s). Licensee IntechOpen. This is an open access article distributed under the terms of the [Creative Commons Attribution 3.0 License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.