
FROM THE GUEST EDITORS

The need for more and better palliative care for Muslim patients

Most individuals facing life-threatening illnesses of any kind in any setting would benefit from palliative care. However, the vast majority of the world's palliative care services exist in high-income countries (HICs) that represent <20% of the world's population. Cancer currently accounts for approximately one in eight deaths worldwide, and in HICs, palliative care patients more often than not have cancer. The incidence and mortality rates for cancer are increasing globally in large measure because of an increase in the average age of most populations. In addition, increased exposure to known cancer risk factors (e.g., tobacco and obesity) are also on the rise globally. Estimates of cancer rates and projections of the future burden of cancer can be obtained from GLOBOCAN 2008 (<http://globocan.iarc.fr>).

The largest increases in numbers of cancer cases and deaths are occurring in low- and middle-income countries (LMICs) where >80% of the world's population resides and where the increase in average age and changes in exposure to cancer risk factors are most pronounced. LMICs, in general, are characterized by insufficient cancer control and prevention activities. As a consequence, cancers in LMICs are usually diagnosed at a later, less curable stage than in HICs. LMICs also have limited capacity for cancer treatment, meaning that cancers are more likely to result in suffering and death, thus rendering palliative care needs in LMICs proportionally greater. Despite the clear and present need for palliative care in LMICs, access to palliative care services in these venues remains severely limited.

Palliative care involves providing comfort and management of symptoms including pain. "Total pain" as conceptualized by Dame Cicely Saunders, founder of the modern hospice movement, includes emotional, psychological, social, and spiritual pain in addition to physical pain. Although evidence is scant on how well countries are addressing total pain (also referred to as "distress"), the national consumption of opioid analgesics for physical pain

provides a "barometer" on palliative care that enables a comparison of the availability of palliative care among the countries of the world. The World Health Organization (WHO) has gone so far as to state that "A palliative care program cannot exist unless it is based on a rational drug policy including... ready access of suffering patients to opioids." As various forms of opioid analgesics are utilized for pain relief, perhaps the most suitable way to compare analgesic use per capita among countries is the measure known as "morphine equivalents" wherein use of all forms of opioids are reduced to a single figure. The morphine equivalents measure is based on data from the International Narcotics Control Board, and this information can be accessed via the Pain Policy Study Group of the University of Wisconsin (see <http://www.painpolicy.wisc.edu/>).

When countries are compared in terms of consumption of total morphine equivalents per capita, it is apparent that there exists a rough correlation between gross domestic product (GDP) and opioid consumption, with most of the world's opioid use occurring in higher-GDP countries. However, within the higher-GDP countries there are exceptions, and opioid utilization is quite variable. In analyzing these data, it became apparent that the higher-GDP Muslim-majority countries (MMCs) of the Arab Gulf (Bahrain, Oman, Qatar, Kuwait, Saudi Arabia, and the United Arab Emirates) are among those using very low amounts of opioid analgesics despite their relative abundance of resources for health in general. It is intriguing to consider what barriers other than financial considerations might contribute to lower opioid usage in a country such as Saudi Arabia. To begin to consider this issue, we examined opioid consumption in the world's 49 MMCs as a window on access to palliative care in these venues. The MMCs cover a very broad range of GDP's.

Recently, a publication proposed a method for estimating the total need for opioids in treating physical pain on a country-by-country basis (Seya et al., 2011).

These authors took into account the needs of 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 non-malignant pain). The study was based on morphine equivalents, and therefore represented use of all forms of opioids. This approach resulted in an “adequacy of consumption measure” (ACM), and the authors defined five tiers of ACM (adequate, moderate, low, very low, and virtually nonexistent). Analysis of 188 countries painted a very bleak global picture with only 7% of the world’s population judged to have adequate access to opioid analgesics. Of the 49 MMCs in the world, none were found to fall into the upper three categories (adequate, moderate, or low consumption) that is, all MMCs were in either the “very low” or “virtually nonexistent” consumption categories. The relatively high-GDP countries of the Arab Gulf are all in a lesser category for opioid consumption than many other countries having much lower GDPs.

There are currently >1.6 billion Muslims living in all parts of the world and representing nearly 25% of the world’s population (www.pewforum.org). Muslims in the world are projected to increase to >2.2 billion by 2030. Approximately 75% of the world’s Muslims live in the 49 MMCs we examined; however, ~25% live in non-Muslim-majority countries of the developing world. Only ~3% of the world’s Muslims live in Muslim-minority countries of the more-developed world (Europe, North America, Australia, New Zealand, and Japan). Muslims are increasing in number globally with 72 of all of the world’s countries having Muslim populations of >1,000,000 today, and this number is projected to rise to 79 countries by 2030. The Muslim share of the United States population is expected to more than double by 2030 and will then exceed 6,000,000. In Europe, there are 10 countries, including Russia, France, and Belgium, where Muslims already represent >10% of their total population, and >25% of new immigrants to the United Kingdom this year are expected to be Muslim.

The barriers to the rational use of opioid analgesics are varied, depending upon location, but certain barriers are common. Barriers to accessing oral morphine include excessively strict national drug laws and regulations, fear of addiction, poorly developed healthcare systems, and lack of knowledge at all levels including healthcare providers. To address and reduce these barriers, changes will need to be effected not only in laws and policies but also in knowledge, attitudes, and behaviors of medical practitioners as well as among patients and their families.

It is certainly recognized by the authors of this article 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 is not monolithic in terms of knowledge, attitudes, and behaviors as these relate to palliative and end-of-life care. Within any given branch of Islam (Sunni or Shia) there is diversity of thought, traditions, and voices. Based on the consumption of opioid analgesics, it is clear that palliative care is severely lacking in MMCs, and this is true not only in the low- and middle-income MMCs (e.g., Bangladesh, Pakistan, Yemen, and the MMCs of Africa) but also in the higher income countries of the Arab gulf cited previously. More research is needed to understand the barriers to the use of opioid analgesics in MMCs, and it is essential that this research be local, as diversity among the MMCs is likely.

Approximately 850,000 deaths from cancer will occur in the MMCs this year. There is a paucity of research on the range of symptoms that accompany these deaths, including those symptoms covered by the field of psycho-oncology. The extremely low consumption of opioids in MMCs is very troubling, because it means that most dying patients in these countries are suffering unnecessarily. 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). Although evaluating the adequacy of treatment of total pain is more challenging than evaluating the adequacy of treatment for physical pain, it would seem unlikely that treatment of total pain as well as management of other physical symptoms would be adequate in a setting wherein adequate treatment of physical pain is lacking.

It has been suggested that some Muslims may perceive suffering as a means of atoning for one’s sins, and to the extent that this interpretation exists among Muslim patients, it may contribute to low opioid usage in MMCs. 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 MMCs. It is likely that there will be a distinctive mix of barriers that vary from country to country even within the MMCs; therefore, 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.

A barrier to palliative care that appears nearly universal is a shortage of adequately trained healthcare workers. Ideally, all healthcare workers would have basic knowledge and skills in palliative care,

with those treating cancer, AIDS, and geriatric patients needing more advanced skills, and those members of specialist palliative care teams requiring expert skills. Although there are educational materials available for healthcare workers in different disciplines (see “Education” at www.ipcrc.net), most of these resources focus on more advanced or specialist skills, and virtually all are in English. Whereas these materials are quite useful in many venues, the inadequate English language skills of some workers in many LMICs render these educational materials of limited utility there. It should be a priority to produce multilingual educational material (probably via translation and adaptation of existing content). The language issue may be of particular importance in training nurses, as it is often the case that their English skills as a group are less advanced than those of the physicians in the same country.

In addition to language accessibility issues, existing educational materials have not generally been tailored so as to include considerations of the religious and cultural distinctions of Muslims. A substantial fraction of the healthcare workers in some MMCs (e.g., Saudi Arabia) are trained in or are from countries having relatively small Muslim populations. Despite the fact that the vast majority of the patients they are treating are Muslims, their training and experience may have left them ill-prepared to deliver high-quality, culturally sensitive palliative and end-of-life care to their Muslim patients. It is important that material in all languages reflect cultural sensitivity and recognize that certain aspects of the Muslim religion and/or culture can have an impact on delivery of healthcare broadly and on palliative and end-of-life care in particular. As part of an effort to address this issue and to build capacity for palliative care services in the Arab world, we have designed a short course for Arabic-speaking nurses that targets all nurses (i.e., not only those working or aiming to work in a palliative care unit, consulting service, home care service, or hospice). The course entitled “What Every Nurse Should Know About Palliative Care” seeks to cover the basics of palliative care and to address certain distinctive issues related to Islam and the Muslim culture that should be understood by all healthcare workers who are treating Muslim patients. One of us (DMA) is Muslim and has served for several years as a clinical nurse coordinator with responsibility for nursing education in palliative care at King Faisal Specialist Hospital and Research Center in Riyadh, Saudi Arabia. The Muslim-centered elements that have been included in the course will be summarized briefly here to provide a glimpse of some of the issues faced by those treating Muslim patients and their families.

Reflective of the strong and extended family structure that is typical in Muslim families, it is thought that most Muslim families would prefer to care for sick relatives at home and that patients would prefer to die at home. Whereas this may well be true, there is little actual research that would directly support this contention. Nonetheless, Muslim families may feel that sending a relative to a hospital without curative intent may be a form of shirking the responsibility of caring for family members at the end of life, as care for the dying has been seen historically as a family responsibility, and death has been managed at home for the most part. However, the lack of home palliative care services in most MMCs may well lead to return trips by patients to the hospital or to extended stays and death in hospitals. More research is needed on this entire topic.

Modesty is a highly regarded value in most Muslim cultures. 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 conducted through a close male relative. We would note that discomfort with a healthcare provider of the opposite sex is not unique to a Muslim culture. 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 tenet of Islam based on the Noble Qur’an is that the timing all events, including the death of every individual, is predetermined by Allah. Accordingly, conversations with patients and families regarding prognosis need to be in general terms describing the usual natural history of the given terminal illness. Nonetheless, the family would likely appreciate being informed (with appropriate caveats) when death appears imminent, so they can be around the patient in his/her final hours and make preparation for the Muslim funeral rites that aim for a speedy burial. Some families may not wish their dying relative to be fully informed regarding his/her illness. Whereas this is certainly not unique to Islam, it is perhaps somewhat more common in Muslim families than in Western families today. When Muslims are sick, their friends and relatives tend to visit, sometimes in rather large numbers for rather extended visits, and Western-trained healthcare workers may find this somewhat odd. Consideration should be given to the point where the visitors are somehow 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 the *Shahadah*,

the foundational statement of the Muslim faith and one of the five pillars of Islam. 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 analgesics may be that morphine-induced sedation could interfere with the ability of the patient to recite the *Shahadah* or hear the Qur'an read.

Another of the five pillars of Islam is the *Salah*, five daily prayers, and patients who are cognitively able are to perform the prayers in sickness and in health. The prayers can be performed even by bedridden individuals. Accommodation of the patient's ability to perform the *Salah* should be made if at all possible. Muslims prefer that the prayer times be in a quiet environment, with the patient facing Makkah. It is desirable to avoid the times of prayers for questions or medical interventions. Another aspect of the daily prayers that has implications in a hospital relates to cleanliness. The required 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 these agents might interfere with the ability of the patient to pray. Some Muslims may even feel that opioid use is *haram* (forbidden by the Qur'an). In Saudi Arabia, a *fatwa* (a legal pronouncement in Islam, issued by a religious law specialist on a specific issue) exists that supports the use of opioid analgesics for relief of physical pain.

Muslim dietary considerations may also come into play in caring for the terminally ill Muslim patient. Ramadan is celebrated by Muslims in the ninth lunar month of the year, and during Ramadan, the *Sawm*, another pillar of Islam, is observed requiring 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, but 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. Injections, transdermal patches (e.g., fentanyl), enemas, and suppositories are permissible however.

Another pillar of the Muslim faith is the *Hajj*, a pilgrimage to Makkah at least once in a lifetime. As Muslim patients approach death, they may well wish to go to Makkah prior to dying. The *Hajj* rites may be quite strenuous for an ailing patient, and 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 ultimately occurs, 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 by the health-care team following the patient's death 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.

A clear barrier to the integration of palliative care into healthcare is the shortage of physicians and nurses with specialized or advanced training in palliative care delivery. Ideally, palliative care would be a part of multidisciplinary case management from the date of diagnosis and not merely appended at the end of life. To achieve this goal, training and capacity building in palliative care should be a high priority of the governments of the MMCs as well as the international community as a whole. It is clear that modules related to cultural and religious distinctions should be added to palliative care training courses and training programs. Such modules would benefit not only those healthcare workers who practice in MMCs but also those working in settings where Muslims are a growing minority (e.g., the United States and Europe).

The paucity of palliative care services in MMCs clearly needs to be addressed, although this is an issue that extends well beyond MMCs, upon which we have focused. 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. These services should also address the issues covered by the emerging field of psycho-oncology in addition to physical symptoms. Were this ideal to be realized in MMCs, the deaths of the >850,000 individuals who die from cancer each year in MMCs as well as those dying from other causes would approach the "good death" that each of us would desire for our loved ones and ourselves.

REFERENCE

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JOE B. HARFORD

National Cancer Institute,
Bethesda, Maryland

DEENA M. ALJAWI

King Faisal Specialist Hospital and Research Center,
Riyadh, Saudi Arabia