

Palliative care and Islamic tradition: the Mauritanian case

SARA MARIA LODI RIZZINI, MASSIMO PIZZUTO

UO Cure Palliative e Terapia del Dolore, Azienda Socio-Sanitaria Territoriale Nord Milano.

Pervenuto e accettato il 13 luglio 2020.

Summary. Multi-ethnicity in European countries is progressively increasing in the last decades, frequently resulting in new challenges related to the communicative gap between occidental and oriental mindset. The oriental thought carries different beliefs, cultural and religious traditions. Palliative care originate from an holistic dimension of occidental medicine to look after people in the last part of their life. This requires, if possible, a continuous research of common ground between patients and health care professionals. Sometimes this research is proved to be really challenging if the common ground isn't shared. Through the available literature we tried to analyze and learn more about the aspects of Islamic culture that could impact on health care operators' decisions that deal with Islamic people affected by terminal illnesses.

Key words. Palliative care, death, culture, Islam, palliative sedation, opioids.

Muslims presence in Europe counts about 5% of the whole population and it's destined to rise in the next decades¹. An increasing proportion of second and third Muslim generation is going to be part of the resident population, as beneficiaries of sanitary and social services, too. Some of them are already patients or caregivers and it's important to know precisely their culture and comprehend how palliative cares are perceived and can develop in such a context.

Leong et al. in 2016 identified in a study the main Islamic precepts that can affect palliative care operators about what happens before and after death, thanks to the direct consulting of an Imam².

Leong's work was organized in form of a survey and submitted to 14 operators (doctors, nurses, social assistants) and then commented by the Imam during a frontal lecture with the participants. A general lack in Islamic teachings emerged from the lessons. In the study were mainly analyzed the following Islamic views on advanced illness:

- **illness:** is felt with "patience and faith"; in Islamic conception sorrow is viewed as the way to obtain mercy and forgiveness; Allah thought about a cure for any illness and humanity, through science, must look for it relentlessly³;
- **analgesic and opioids:** Muslims are encouraged to look for treatments: analgesics, including opioids, are considered acceptable because relief from pain is perceived as virtuous³. In some circumstances devotees may want to be awake and alert for as long as possible to pray Allah. Doctors

Cure palliative e tradizione islamica: il caso mauritano.

Riassunto. La multietnicità nei Paesi europei è negli ultimi decenni in progressivo aumento, causando spesso nuove sfide legate al divario comunicativo tra mentalità occidentale e orientale. Il pensiero orientale ha diverse credenze, tradizioni culturali e religiose. Le cure palliative provengono da una dimensione olistica della medicina occidentale per prendersi cura delle persone nell'ultima parte della loro vita. Ciò richiede, se possibile, una continua ricerca di un terreno comune tra pazienti e operatori sanitari. A volte questa ricerca si è rivelata davvero impegnativa se il terreno comune non è condiviso. Attraverso la letteratura disponibile abbiamo cercato di analizzare e apprendere di più sugli aspetti della cultura islamica che potrebbero influenzare le decisioni degli operatori sanitari che si occupano di persone islamiche colpite da malattie terminali.

Parole chiave. Cure palliative, morte, cultura, Islam, sedazione palliative, oppioidi.

should ask any patient what level of alertness and pain relief they wish for⁴;

- **ritual ablution:** in the impossibility of carry out this ritual in the right place, some patients rely to dedicated kit for dry washing; they can simply consist in sand or a stone, usually kept near the bed;
- **"do not resuscitate (DNR)" status and life sustaining therapies discontinuation:** cardiopulmonary resuscitation operations were introduced with modern medicine and they are not contemplated in any Islamic holy text such as Quran, Sunnah o Hadith⁵. To solve this aspect a dispensation (*fatwa*) was emitted: "if three loyal and respected doctors agree that the patient's conditions are hopeless, all life sustaining equipment can be discontinued or don't even start". This is an aspect vastly debated because of the holy perception of life in Islam, but it seems that lots of Muslims think of DNR status acceptable in certain conditions⁶;
- **suicide/euthanasia:** they are prohibited by Quran;
- **artificial nutrition and hydration:** it's a still debated aspect but it's popular opinion that nutrition and hydration ought to be administered to all patients, unless these treatments cause more damage or don't agree with Islamic law⁷;
- **death ritual:** in the moments preceding death Muslim patients should be able to declare their faith in Islam; after death the patient's eyes should be closed and their body covered. Friends and family should recite one last prayer for the dead.

About what happens after death, the author analyzes the following aspects:

- **mourning:** in Islamic culture loud lamentations could be seen as doubting Allah's will, therefore families usually show moderate behavior in their sorrow: the Quran points for Muslims "to persevere patiently";
- **organs donation:** this is one of the most discussed aspects because Muslims perceive their body as holy. To burn or maim dead people is considered blasphemy. However in Quran is written that "anyone who saves a life, saves all humanity's life"⁸; as of today is strongly recommended to discuss any case, possibly with religious authorities;
- **cremation:** is prohibited in Islamic culture since the burial ritual is very important and complex and it ends with posing the body symbolically with the head toward the Makkah^{2,9}.

An aspect of potential tension between practitioners with occidental training and practitioners who follow Islamic laws could be about the use of sedative drugs in palliative care context. In a 2018 study Muishout et al. analyzed the sensitive aspect of palliative sedation through a semi-structured interview and submitted it to Muslim palliative care operators¹⁰.

From several studies emerged that doctors with a strong religious Islamic background are more inclined to turn down therapies that are perceived as hastening the process of dying. They also seemed to be less likely to discuss therapeutic options with patients¹¹⁻¹³.

As of today palliative sedation is an issue but there isn't any specific document compiled by the Islamic community about such a sensitive topic^{14,15}. The conflict between wishing to appear in front of Allah awake and with a rational mind opposed to being less alert or being sedated is one of the most debated topics. Following these beliefs and according to literature, profound sedation represents a controversial procedure.

General anesthesia is largely accepted because of its "temporary" characteristic. Palliative sedation could be tolerated but only in certain conditions that aren't unequivocally recognized yet. Conscience loss through pharmacological action has a heavy social and religious impact over patients and their families, who can't respect the prayer services required for adult Muslims¹⁶.

Muishout's study asked a group of Islamic doctors living in the Netherlands how they can conciliate religious precepts and palliative care occidental standards: every participant proved to be open to dialogue, even the two with the more orthodox religious drive. Both showed a potential openness toward palliative sedation in selected cases. Only one participant seemed to be reluctant at the thought of denying a patient's chance to pray in his last days before death ("the last five days" prayer) due to palliative sedation¹⁷.

This introduction must not lead to think that palliative care aren't successfully integrated in Islamic countries, in fact they developed rapidly in the African Anglophone regions where HIV infection was wildly

spread, and they developed slowly but steadily in the West and North Africa¹⁸. In Mauritanian rural areas in 2019 a qualitative survey interviewed 33 palliative care operators (doctors, nurses, social assistants), 12 families with recent mourning and 31 community chiefs through 31 interviews and 8 focus groups. The main goal of the study was to verify if palliative care principles and families' and health care operators' beliefs were congruent in the rural areas of the Islamic Republic of Mauritania¹⁹. Three main aspects emerged from the study:

- **life threatening illness:** participants' vision about this topic was profoundly different from the one usually implied in palliative care. The problem is related to the "life threatening" aspect of the diagnosis: the term, in the participants' opinion, required the knowledge of the destiny of every patient. That is, the certainty that a patient in going to die because of a precise illness: this is impossible, since this religion assumes that death isn't related to an illness status but to a divine will. Trying to "foretell" death with a diagnosis of life threatening illness could be seen as pretentious and absurd. Another recurrent idea is that Allah can cure any and every disease and this can heavily impact over health care operators' decisions who feel obligated to use any necessary mean to prolong life, even if disproportionate or invasive in a palliative care vision. Likewise families expect a linear recovery since the start of such invasive therapies, but soon they feel disappointed if this doesn't happen, becoming disheartened and not trusting the health care operators, seeking help for their beloved ones elsewhere;
- **communication:** health care operators who were interviewed admitted their difficulties in communicating bad news in a palliative care context. Informing patients about their health status is considered improper and some of them think that it's not good to inform patients they have cancer, referring again to the idea that only Allah can speak to a man about his destiny²⁰⁻²⁴. This last aspect enhances insecurity within families, who are kept in the dark and don't have the necessary knowledge to look after their beloved. Families are burdened with uncertainties and ambiguities the closer the moment of death is. They see the ending life path not as a process, but as a neat passage from a long disease state (that can potentially last forever, with the right therapies) to death;
- **"good death":** in the palliative care prospect a "good death" consists of the expectation and hope that a person can accept their destiny with patience and faith. All the participants emphasized that having a "good death" is fundamental to be "a good Muslim" and that can happen only arriving to the fateful moment following actively the Quran: praying in mosques, undertaking a Makkah pilgrimage, praying with family at home. Referring to Islamic beliefs analgesic drugs, opioids above all, are perceived as a potential obstacle to a "good death" because they can interfere with patients' sanity.

Health care operators feel like it's their duty to relieve patients' pain but in Mauritania the access to opioids is difficult and scarce and the clinical experience is limited. Family has a fundamental role in concluding the process of dying, through purifying rituals and burial organization so that the deceased is positioned toward the Makkah.

We already said that the Islamic notion of pain is about atonement and a demonstration of patience and faith, which leads to favor pain endurance instead of using drugs that could lessen conscience. Pre-modern and contemporary jurists agree over the fact that the intentional suppression of conscience is prohibited¹⁶, although is acceptable the idea that "necessity overcomes prohibition", for example in surgery, where the use of analgesics is allowed. Therefore reducing the level of conscience, also with opioids, is justified and ethically acceptable only if a severe and urgent motivation arises. Regarding the loss of conscience due to opioids the palliative care operator must remember that, to Muslims, life is marked by religious rituals, like praying five times a day, which is mandatory despite health conditions. In this case shorter forms of prayers exist, which facilitate and prevent some movements (i.e. kneeling or bowing). In the majority of the African countries access to opioids is usually inadequate to satisfy the necessities of the population^{24,25}. In the study emerged how Islamic community chiefs support the importance of pain relief in sick people; if this seems in conflict with the religious beliefs now outlined is because of the scarce access to opioids and limited clinical experience.

In conclusion we could say that orthodox Islamic theology and palliative medicine principles seems to be compatible on a conceptual level. In the last considered study Islam and palliative care blended in a particular context, since rural areas in Mauritania maintain a strong religious identity and socio-economic resources are limited. As a consequence therapeutic approaches are limited, too, even if people keep on searching for different physician due to the lack of trust. It's going to take time before palliative care could be integrated in such contexts, but it's useful to comprehend cultures so different from ours, to be able to embrace and comprehend diversity and grant any patient an approach as much personalized as possible.

Conflict of interests: the authors have no conflict of interests to declare.

Bibliography

1. Pew Research Centre. Europe's growing Muslim population. 2017, Pew Research Centre, Washington, DC.
2. Leong H. How Islam influences end-of-life care: education for palliative care clinicians. 2016; 52: 771-4.
3. Al-Shahri MZ, al-Khenaizan A. Palliative care for Muslim patients. *J Support Oncol* 2005; 3: 432-6.
4. Baddarni, K. Ethical dilemmas and the dying Muslim patient. *Asian Pac J Cancer Prev* 2010; 11: 107-12.
5. Saeed F, Kousar N, Aleem S et al. End-of-life care beliefs among Muslim physicians. *Am J Hosp Palliat Care* 2015; 32: 388-92.
6. Sachedina A. End-of-life: the Islamic view. *Lancet* 2005; 366: 774-9.
7. Isolamy S. Islamic views on artificial nutrition and hydration in terminally ill patients. *Bioethics* 2014; 28: 96-9.
8. Keten HS, Keten, D, Ucer H, et al. Knowledge, attitudes, and behaviors of mosque imams regarding organ donation. *Ann Transplant* 2014; 19: 598-603.
9. Puchalski CM, Dorff RE, Hendi IY. Spirituality, religion, and healing in palliative care. *Clin Geriatr Med* 2004; 20: 689-714.
10. Muishout G, van Laarhoven HWM, Wieggers G, Popp-Baier U. Muslim physicians and palliative care: attitudes towards the use of palliative sedation. *Supportive Care in Cancer* 2018; 26: 3701-10.
11. Seal C. The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care. *J Med Ethics* 2010; 36: 677-82.
12. Cohen J, van Delden J, Mortier F, et al. Influence of physicians' life stances on attitudes to end-of-life decisions and actual end-of-life decision-making in six countries. *J Med Ethics* 2008; 34: 247-53.
13. Padela AI. Islamic medical ethics: a primer. *Bioethics* 2007; 21:169-87.
14. Kluge G, Brewster E, Kuipers S. Waardig dying with dignity, religious freedom and the right of the eldest son. *Medisch Contact* 2012; 67: 748.
15. Choukat A, ter Meulen B, Van Widdershoven G. Palliative sedation objectionable for Muslims. *Medisch Contact* 2013; 12: 1550-1.
16. Zahedi F, Larijani B, Bazzaz JT. End of life ethical issues and Islamic views. *Iran J Allergy Asthma Immunol* 2007; 6: 5-15.
17. Gysels M, Pell C, Straus L, et al. End of life care in sub-Saharan Africa: a systematic review of the qualitative literature. *BMC Palliat Care* 2011; 10: 6.
18. Fearon D, Kane H, N'Diaye Aliou, Sall A. Perceptions of palliative care in a lower middle-income Muslim country: A qualitative study of health care professionals, bereaved families and communities. *Palliat Med* 2019; 33: 241-9.
19. Abdulhameed HE, Hammami MM, Mohamed EA. Disclosure of terminal illness to patients and families: diversity of governing codes in 14 Islamic countries. *J Med Ethics* 2011; 37: 472-5.
20. Assaf GN, Holroyd E, Lopez V. Isolation and prayer as means of solace for Arab women with breast cancer: an in-depth interview study. *Psychooncology* 2017; 26: 1888-93.
21. Lewis EG, Oates LL, Rogathi J, et al. 'We never speak about death'. Healthcare professionals' views on palliative care for inpatients in Tanzania: a qualitative study. *Palliat Support Care* 2017; 16: 566-79.
22. Jassim GA, Whitford DL. Understanding the experiences and quality of life issues of Bahraini women with breast cancer. *Soc Sci Med* 2014; 107: 189-95.
23. Rhee JY, Luyirika E, Namisango E, et al. APCA atlas of palliative care in Africa. Houston TX: IAHPC Press, 2017.
24. Cleary J, Silbermann M, Scholten W, et al. Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in the Middle East: a report from the Global Opioid Policy Initiative (GOPI). *Ann Oncol* 2013; 24: xi51-9.

Corresponding author:
Dott. Massimo Pizzuto
E-mail: massimo.pizzuto@fastwebnet.it