

# Perceptions of palliative care in a lower middle-income Muslim country: A qualitative study of health care professionals, bereaved families and communities

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## Abstract

**Background:** Palliative care has been successfully integrated into many Muslim-majority countries, most frequently in urbanised areas with developed health care systems. Less is known as to how the concept of palliative care is perceived by Muslim populations and health workers in rural, resource-limited contexts.

**Aim:** This study seeks to explore whether the principles of palliative care are congruent with the perspectives of health professionals, families and communities in rural areas of the Islamic Republic of Mauritania, in West Africa.

**Design:** A qualitative research design was employed underpinned by a constructionist paradigm. Data were collected through 31 interviews and 8 focus groups. Data were analysed using thematic analysis.

**Setting/participants:** A total of 76 participants were recruited from across rural Mauritania; 33 health care professionals, 12 recently bereaved family members and 31 community leaders. Data collection occurred during training events in the capital and visits to villages and rural health posts.

**Results:** Three major themes were identified. First, there is a perceived lack of congruency between an illness which limits life and the strong belief in destiny. The second theme describes the perceived barriers to communication of issues relating to palliative care. Finally, a good death is described, framed within the interplay of religious faith and cultural practices.

**Conclusion:** The palliative care ethos is viewed positively by the majority of participants. The need to understand and respect a Muslim individual's faith does not diminish our obligation to personalise palliative care provided for them and their family.

## Keywords

Africa, culture, Islam, palliative care, qualitative research

### What is already known about the topic?

- The ethos and practices of palliative care are widely considered as congruent with orthodox Islamic theology.
- Palliative care has been successfully integrated in Muslim-majority countries.
- There is a need to acknowledge and respect religious beliefs in providing palliative care.

### What this paper adds?

- This study demonstrates a number of challenges and barriers to building palliative care capacity in Muslim-majority, limited-resource contexts.

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### Implications for practice, theory or policy

- The need to understand and respect a Muslim patient's faith does not diminish our obligation to personalise palliative care provided for a patient and their family.
- Communication in palliative care needs to balance the creation of a safe space in which patients and families can express themselves as they desire and receive appropriate information for them to better plan for the future.

## Introduction

Palliative care aims to improve the quality of life for patients with life-limiting illnesses and their families.<sup>1</sup> It remains absent or restricted in much of the world. In Africa, the majority of progress and integration has been in Anglophone regions with high levels of HIV.<sup>2</sup> Countries in West and North Africa, many of which have Muslim-majority populations, have experienced a slower development of palliative care.<sup>3</sup> Research has documented how Islamic beliefs and practices pertain to palliative care issues.<sup>4–7</sup> However, such generalisations of a universal image of Islam can lead to stereotyping and prejudice.<sup>8,9</sup> Islam does have much which unites its global adherents; however, there are ethnic, cultural and social differences in beliefs and practices.<sup>4,10,11</sup> There is therefore a gap in understanding how idiosyncrasies of individuals' and communities' interpretations and practices of Islam impact upon how palliative care is perceived in resource-limited Muslim settings. The Islamic Republic of Mauritania in West Africa, a lower middle-income country with a predominantly Muslim population,<sup>12</sup> is an example of such a context.

## Palliative care in Mauritania

The nascent provision of palliative care in *Mauritania* involves the National Oncology Centre, located in the capital city,<sup>13,14</sup> and a not-for-profit palliative care association. This study reports on research carried out in conjunction with a programme to build palliative care capacity in rural Mauritania.<sup>15</sup> The aim of this study was to better understand the local perceptions of life-limiting illnesses, end-of-life care and a good death.

## Methods

### Design

A qualitative research design was employed underpinned by a constructionist paradigm.<sup>16</sup> Data analysis followed the thematic analysis approach.<sup>17</sup>

### Setting

The palliative care capacity building programme ran from May 2016 to June 2017. A total of 74 rural health professionals, identified by the palliative care association and

the ministry of health, received training in the foundations of palliative care, over three cohorts. Activities included centralised training in the capital followed by work-place mentoring visits.

### Research team

D.F. was medical director of a palliative care association, and a PhD student exploring the experiences of Mauritanian women with breast cancer. H.K. has a PhD in anthropology; her research interests include Mauritanian children's experiences of chronic illness. N.A. was a palliative care nurse and trainer; his interests involve the motivations of palliative care volunteers. A.S. was a palliative care advocate and virologist; he is interested in the experiences of Mauritians with HIV.

### Recruitment

A purposive sampling strategy was employed in conjunction with the palliative care capacity building activities. First, 33 of the 74 rural health professionals attending the training participated in the study. Second, of these 33 participants, 10 received mentoring visits in their rural health posts (eight nurses and two doctors). During these visits, the mentees identified bereaved family members ( $n = 12$ ) and respected community leaders ( $n = 31$ ), who were approached and informed of the study by N.A. or H.K.

### Data collection

Following informed consent, individual semi-structured interviews and focus groups were carried out (Tables 1 and 2). All health professional participants ( $n = 25$ ) in the first cohort of training participated in focus group discussions carried out during the training. From the first cohort, 10 participants were selected to be trained as trainers, all of whom were interviewed individually. An additional 11 participants from the two subsequent training weeks were interviewed. During the mentoring visits to rural health posts, the seven mentees were interviewed on a second occasion, three recently bereaved family members were interviewed, and six focus groups were held with those recently bereaved or community leaders. Focus groups and interviews were moderated and carried out by H.K. and N.A. Focus groups lasted between 37 min and 1 h and 57 min, and interviews between 20 min and 1 h 16 min.

**Table 1.** Demographic data for focus groups.

Focus group	Participants	Location	Gender distribution	Duration	Number of participants
1	Rural health care professionals (during training)	Capital	8 men, 5 women	1 h 30 min	13
2	Rural health care professionals (during training)	Capital	8 men, 4 women	1 h 20 min	12
3	Family members recently bereaved	Rural	1 man, 8 women	1 h 30 min	9
4	Respected members of the community including 4 imams and 1 village chief	Rural	10 men, 0 women	1 h 52 min	10
5	Respected members of the community including 1 imam, retired army officer and a retired teacher	Rural	5 men, 0 women	1 h 2 min	5
6	Imams	Rural	2 men, 0 women	37 min	2
7	Respected members of the community including 2 imams, 1 local politician, 1 village chief and 1 retired professor	Rural	5 men, 0 women	48 min	5
8	Respected members of the community including 3 imams and 2 representatives of a youth organisation	Rural	7 men, 2 women	1 h 47 min	9

**Table 2.** Demographic data for semi-structured interviews.

Participants	Number of interviews	Location	Gender distribution	Role	Number of participants
Rural health care professionals	1	Capital	7 men, 7 women	11 nurses, 3 doctors	14
	2	Capital and rural health posts	6 men, 1 woman	7 nurses	7
Bereaved family members	1	Rural health posts	3 women	–	3

Interviews and focus groups were held in French, Pulaar or Hassaniya, with the use of translators as required. The topic guide, created by H.K. and D.F., covered the principles of palliative care,<sup>1</sup> and the roles of health professionals, communities and the family in caring for individuals with palliative needs. Field notes were recorded during data collection. Data saturation was considered to be achieved when no new information emerged.

### Data analysis

All interviews and focus groups were audio-recorded, transcribed and translated into French. Data analysis was carried out concurrently with data collection and followed the thematic analysis approach.<sup>17</sup> The software NVivo for Mac was employed. Following familiarisation with the transcripts, the authors D.F. and H.K. independently performed line-by-line coding using a coding framework which was modified by consensus through regular meetings. The initial codes were then inductively employed to identify the major themes.

### Ethical considerations

Research ethical approval was obtained (Ministry of Health Department for Non-Communicable Diseases; ref:

18042016). Participants gave signed consent for their individual anonymised data to be published.

## Results

The identified themes relate to several core concepts of palliative care (Table 3).

### Theme 1: life-threatening illness

A diagnosis of a life-threatening illness is a central concept in the definition and practice of palliative care; however, the views of participants diverged from palliative care orthodoxy.

#### *'It is God alone who knows'*

The label of a life-threatening or life-limiting disease is perceived as problematic for the participants. They suggest that such a position requires a knowledge of the individual's destiny, knowledge belonging to God alone. Death is unrelated to illness, it is exclusively controlled by God, who dictates the date, place and manner of an individual's death:

In Islam, I cannot say that your father is going to die. Why? ... I'm not God. I cannot decide anything. I'm simply just a nurse

**Table 3.** Themes and sub-themes.

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Theme 1: Life-threatening illness: 'Illness does not lead to death and health does not extend life'

- a. 'It is God alone who knows'
- b. 'There is no illness for which God has not made a cure available'

Theme 2: 'Information which gives hope is better than a truth which cuts the hope'

- a. 'It's very difficult when you talk about death'
- b. 'They never tell the truth of the illness'
- c. Approaching end of life

Theme 3: A good death

- a. Their own death
  - b. The role of health professional
  - c. The role of family and community
- 

... when you're a Muslim it's forbidden. Islam forbids telling someone 'this gentleman will pass away, will die'. (Nurse, focus group 1)

Stories were shared demonstrating the perceived arrogance and foolishness of attempting to predict death:

There was one person who was very ill and another who was only a little bit ill. We thought that it would be the first who was going to die because his situation was more serious, however it was the second person who died. The first was cured and he is still here. (Nurse, focus group 2)

### *'There is no illness for which God has not made a cure available'*

Every disease has a cure, as supported by the frequently cited hadith 'There is no disease that Allah has created, except that He also has created its treatment'.<sup>18</sup> However, the cure may be either unavailable in the local setting, found outside of modern medicine, or may not yet have been discovered. Many participants, therefore, refuted the concept of a life-limiting illness because they perceived it as analogous to an incurable illness:

All the healers are marabouts ... in Islam there is not a disease that does not have a cure. For any disease, there is its treatment but perhaps it is not yet discovered. This is why the marabout always has the courage and intention to cure the person. (Nurse, interview)

The potential existence of a cure influences many of the health professionals' clinical decisions, who prioritise the prolongation of life in the majority of circumstances. They perceive an obligation to exhaust all avenues of investigations and treatments when caring for patients with serious illnesses. The probable benefits, costs, and the patient's and family's views are not routinely considered. One nurse described a good death as dying while having an intravenous perfusion, a sign to the family and community that everything possible had been done to prolong life.

The expectation of a cure also impacts the family's experiences of care. They consider that correct, timely treatment will result in a quick, linear recovery. Limited signs of improvement lead the family to doubt whether the health professional knows the cure, or whether it is locally available. This often results in them consulting a traditional health practitioner or seeking care in the capital or a neighbouring country.

### **Theme 2: communication**

Good communication skills are considered as essential to providing high-quality palliative care.

#### *'It's very difficult when you talk about death'*

Health professionals acknowledge that the communication of issues relating to palliative care is difficult and frustrating, especially the communication of bad news:

It's too hard for them, they would surely have such stress that they'd die suddenly. (Nurse, interview)

Many health professionals consider that it is inappropriate to inform patients of serious diagnoses, such as cancer. Those who would consider disclosing such information are anxious that it could damage their relationship with the community:

You can lose it all by announcing bad news. You can lose the trust of the people. People now have a lot of confidence in me, but if I tell this news to someone, the person will inform his friend. He will say 'watch out', he is no longer serious because he told that person that their illness will not get better and they will die. You see what can happen if you tell people bad news. It is very difficult. (Nurse, interview)

Many community members and bereaved relatives agree that serious diagnoses should not be disclosed to patients, with some arguing that non-disclosure is an Islamic teaching:

It's not good to inform a patient that they have an incurable illness, it is prohibited in Islam. The patient must be counselled and comforted. (Imam, focus group 7)

### *'They never tell the truth of the illness'*

Many family members perceive widespread barriers to communication in medical consultations. They perceive these brief encounters as antagonistic and frustrating. Little or incorrect information is provided, and there is no space for questions:

They never tell the truth of the illness, even if it is serious. They should tell you the illness is this, you can expect this ... They hide the truth ... (Bereaved family member, focus group 3)

The health professionals' manner of communication, heavy on euphemisms, leaves families unsure of the problem and how to best care for their relative. Family members are left to construct their own understanding based on their own observations; for example, the perceived lack of benefit from their onerous financial expenditures. Repetitive prescriptions and appointments are interpreted as implicit messages that there is no available cure for the disease:

Often, the doctors do not give information. They don't say that they can't cure the patient, but we come to understand this. The doctor gives a prescription and tells you to come back in one month. Sometimes the patient returns to see the doctor and he gives him the same prescription and gives a further appointment a month later. This is a clue to make you understand that the disease cannot be treated. (Community member, focus group 3)

A minority of families described being informed that further treatment was futile. One recently bereaved wife described interpreting this information as there being nothing more to be done for her husband, irrespective of any change in her husband's condition. This resulted in her husband suffering extreme pain prior to his death, with no attempts to access symptom control.

### *Approaching end of life*

Participants consider it relatively easy to accept the moment of death, especially when it follows a prolonged illness. However, the moments preceding death are characterised by ambiguity and uncertainty. Families perceive that health professionals refuse to acknowledge when a patient is approaching the end of life. This lack of openness creates a vacuum of information, which families attempt to fill themselves. They weigh the potential advantages and disadvantages of further investigation and treatment, being less encumbered with the

philosophical and religious constraints expressed by the health professionals:

My aunt was in the hospital. We did lab tests, we did everything. They [the doctors] were unable to tell us what illness she had. So, when we had no more money, we decided to bring her home. It was at home where she rendered her soul. (Family member, focus group 3)

This transition from curative to palliative care is not easy for their relatives. They fear that the palliation of a patient could be seen by others as motivated by greed; not wanting to spend their money searching for a cure. Therefore, the acknowledgement of end of life by someone external to the family can help the situation:

... my aunt was with her children [at the hospital]. An old Maure [Hassaniya speaker] woman looked at her, then called me over ... she told me it was better to take her home than to leave her there. I asked her why and she told me that this one is no more a person of this life. I disconnected the infusions, and I told her children that we were bringing her home. (Bereaved family member, focus group 3)

### **Theme 3: a good death**

A good death in Mauritania relates to the expectation, and hope, that an individual will accept their destiny with patience and faith.

#### *Their own death*

Participants unanimously agree that being a Muslim is the most important feature of any death, and the foundation of any hope of being rewarded in the afterlife. Subsequently, many participants expressed the wish to die while actively following Quranic commands, such as praying in a mosque or completing the Hajj, the Islamic pilgrimage to Mecca. A good death is not, however, limited to spiritual well-being. Freedom from pain, being at home surrounded by family and having repaid all debts are considered as important characteristics of a good death:

For us, the good death is in the context of being Muslim. We say that the good death is someone who dies in good circumstances. That means that they die in the mosque, or that they die while praying in their own homes. That is a good death. (Nurse, interview)

To die with dignity is to die calmly. It's to die without pain. It's to leave while communicating with the family and that's it! For me, it is firstly to die without pain. (Nurse, interview)

Ensuring financial security for the remaining family members is also important. Participants wish to avoid leaving the family in debt, and they may decline certain

treatments to limit the financial burden on the family. Others try to make things as easy as possible for their family, for example, buying and storing their own burial shroud while they are in good health. This concept of always being prepared for death is reinforced by the perceived unpredictability of death. For some older members of the community, this may mean refusing to travel far from their village in case they die far from where they wished to be buried.

### *The role of health professional*

Pain is described as a common experience for patients with palliative needs in Mauritania and is a potential barrier to a good death. Health professionals perceive that they have an obligation to manage pain. However, they have little or no access to opioids, and limited practical experience. Some health professionals report that a minority of their colleagues propose that good Muslims do not require strong analgesia and justify withholding analgesia because of the eternal spiritual benefits of pain. This practice was unanimously rejected within our sample:

We should not let someone suffer. I think it is a crime to let someone suffer on the pretext that it eliminates sins ... Unless the person said not to. (Nurse, interview)

### *The role of family and community*

The family is responsible for ensuring the dignity and cleanliness of the dying person, with intimate care provided by close family members. As the end of life approaches, the wider family and community encourage the patient to recite the 'Shahada', the Islamic creed stating that there is no god but Allah and that Muhammad is the messenger of God:

When he is in the last moments, he must be clean and wearing clean clothes. The people who are around must be clean and well dressed. We say the prayers for him. If he can, one of the recommendations is for him to say the 'Shahada' at the last moment of life. If 'La illaha Ilala' [the first phrase of the Shahada] is the last word said by the patient, he will go to heaven. He is told to say that. (Imam, focus group 6)

After death, family members close the deceased's eyes and mouth, and arrange the body to face Mecca, wrapped in a clean shroud. The arms and legs should be extended and in line with the body. Burial should be carried out within 24 h, following which the family and community research whether the deceased had any outstanding debts to be repaid and seek to repay these. One participant described how their community collectively chose to delay informing the state employer of the death of an

employee, so that the family could continue to receive the salary until all their debts had been repaid.

## **Discussion**

Palliative care is established in many Muslim-majority countries and much of its principles are congruent with orthodox Islamic theology. This study provides an understanding of how the principles of palliative care are perceived by health professionals, families and communities in a resource-limited Muslim country, with both perceived congruences and incongruences.

### *Religious faith as an escape from incurability*

The belief that only God can know the circumstances of a death permits health professionals to continue in their avoidance of speaking of death or incurability.<sup>6</sup> We propose that in Mauritania the concept of destiny encapsulates more than this foreknowledge of events. God is also perceived as causing events; in this case, the death of an individual.<sup>19</sup> This is, however, not explicit due to an unwillingness to appear impolite and apportion blame to God. This reluctance is not limited to a religious position; it is also influenced by life experiences. In these resource-limited settings, diagnoses and prognoses are less certain, and life and death remain unpredictable.<sup>20</sup> In response to these limitations, there is a unifying pursuit of relatively active, aggressive attempts to prolong life.<sup>21</sup> Elsewhere, in developed Islamic countries, the availability of advanced health care technologies has forced a debate on the withdrawal of life-supporting treatment and advanced directives.<sup>22</sup> These issues do not feature in our data. Rather, patients who require high levels of technology tend not to survive long, therefore reinforcing the acceptance that the moment of death is determined only by God.

### *Constructing a space for culturally appropriate communication*

Appropriate and sensitive communication between health professionals, patients and families is essential for good palliative care.<sup>23,24</sup> Our findings suggest that there are widespread challenges in communication: the absence of patient-centred communication in medical consultations, the non-disclosure of diagnoses and the lack of acknowledgement of end of life. The professional-centred care is evident in paediatric services in Mauritania and elsewhere in West Africa.<sup>25,26,27</sup> The tendency to conceal serious diagnoses has been documented in multiple Muslim and/or African contexts.<sup>28-31</sup> This lack of clarity and openness in communication is known to lead to miscommunications and difficulties for the families.<sup>32</sup> An implicit manner of communication is not, however, limited to health professionals. Patients and

their families frequently employ the same style with euphemisms to gently communicate with each other their own understanding and concerns regarding a situation.<sup>26,33</sup> This delicate manner of communication allows the family to bridge the apparent contradiction between disclosing the diagnosis and maintaining hope.<sup>18</sup>

### *A broader conceptualisation of a good death*

Spiritual well-being is a prominent feature of a good death for many cultures, irrespective of any dominant religion.<sup>23</sup> In Mauritania, life is considered as a preparatory stage for the hereafter, consistent with Islamic theology.<sup>19,34</sup> There is, however, an emphasis on the interval period between death and the day of resurrection, termed the *Al-Barzakh* or the barrier.<sup>6</sup> Many Mauritians believe that it is during this period of time that the future destination of an individual is decided.<sup>35</sup> This concept does not feature prominently in the literature on a good death for Muslims.<sup>34,36</sup> It is present in religious beliefs among Moroccans; however, it is limited to a waiting time between death and the after-life and does not have the potential to alter the final destination.<sup>37</sup> This latter purpose, however, features in research from other African contexts, such as Catholic populations in Ghana<sup>38</sup> and the Xhosa in South Africa.<sup>39</sup> In Mauritania, families exploit this concept to positively influence the quality of a deceased relative's death. It is relevant in situations of an unexpected death of a relative, who may not have planned for their death. It is also employed in a family's decision to conceal a life-limiting diagnosis from a patient. Such non-disclosure would inherently threaten to impede an individual's ability to prepare themselves for death; however, this is compensated for by the family appropriating this responsibility.

### *Pain and opioids*

The level of opioid consumption in much of Africa and the Arab world is insufficient to adequately manage the existing pain.<sup>13,40</sup> The existing literature has explored the barriers to its use in Muslim communities.<sup>4</sup> However, many of these philosophical concerns are less prominent in our findings, perhaps due to the absence of strong opioids and only limited availability of weak opioids in rural settings. In our sample, community leaders, including imams, emphasise the health professionals' obligation to employ all available methods to relieve suffering.

### **Implications for practice**

Mauritania holds a strategic geopolitical and social position, where the Arab world meets Sub-Saharan Africa. The study can, therefore, help enrich the road-maps pioneering palliative care integration in this region. For the wider audience, it suggests that the acknowledgement and respect

for a Muslim patient's faith is an important component, and not a barrier, to providing holistic, personalised palliative care. Finally, assumptions of orthodoxy should be replaced with honest and open conversation of the beliefs and wishes of the patient, including any specific requests.

### **Strengths and weaknesses of the study**

The study was strengthened through the use of mixed methods of data collection and recruitment reflecting different languages, geographical regions and roles in society. Participants were open to talk about issues relating to palliative care and their struggles with certain aspects perceived as good practice in other places such as truth-telling. The opportunity to interview several participants on two occasions facilitated the member checking of themes and further exploration of topics identified in the initial interviews.

The study has several limitations. First, Imams were consistently identified as community leaders and were represented in all the community leaders' focus groups. There is therefore the possibility that their presence hindered the openness of the other focus group participants. Second, more males participated than females. This partly reflects the demographics of service providers in rural Mauritania, where it is more socially acceptable for males to work in rural areas away from their families. Third, no patients were recruited to this study and it would now be worthwhile to explore their views of palliative care.

### **Conclusion**

The compatibility of Islamic theology with the principles of palliative care has been established at a conceptual level. This study describes its compatibility in a particular Muslim context, in which the perceptions of palliative care have been constructed through an amalgamation of Islamic theology and the fragility of life in a low-resource setting. We have demonstrated how faith is combined with certain cultural-specific traits to construct a response to some of the principles of palliative care. The process of introducing palliative care at a national level in Mauritania is underway, and this research informs the future integration of palliative care within the health services. Advocacy is in tune with the cultural paradigm and is better able to unite policy makers, families, patients, religious leaders and health professionals to agree on the importance and need of palliative care for Mauritania. Finally, we look forward to witnessing how a Mauritanian-flavoured palliative care service provision can be a model for others.

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