



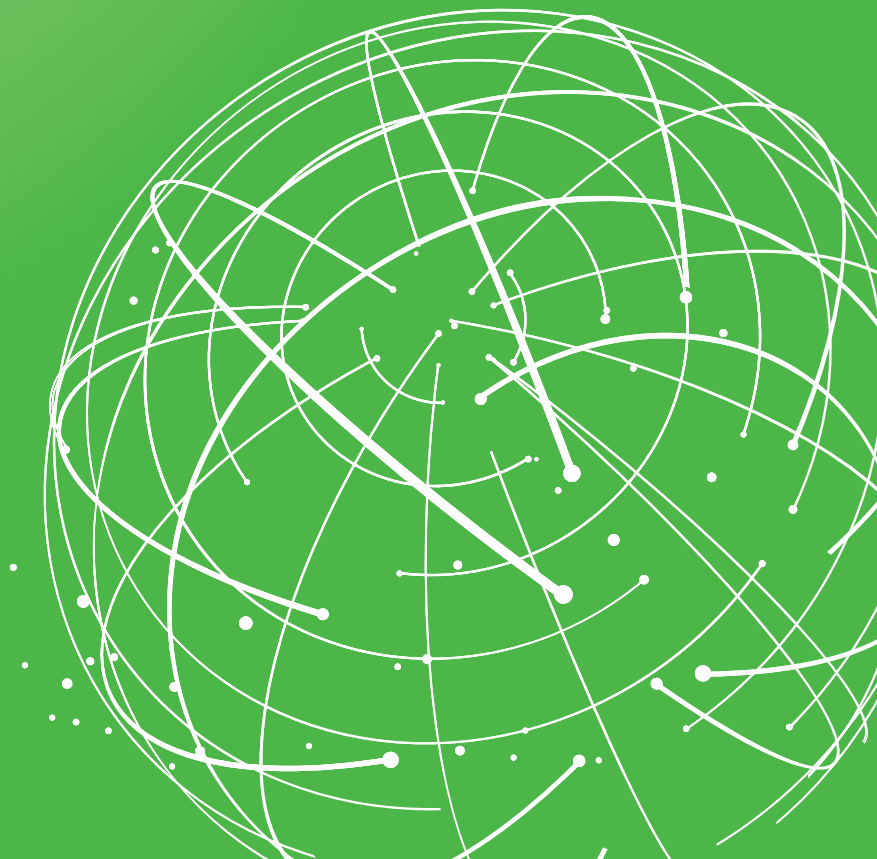
# PALLIATIVE CARE AND ISLAMIC ETHICS

## EXPLORING KEY ISSUES AND BEST PRACTICE

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A Special Report in Collaboration with the Research  
Center for Islamic Legislation and Ethics

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## FOREWORD

Palliative care (PC) is a relatively new medical specialization that embodies a number of universally shared values. Its principal aims are to relieve pain and other distressing symptoms (such as shortness of breath), improve quality of life for people living with serious illness, and provide patients with good end-of-life care. In their attempt to serve these noble goals, and to approach the patient as a whole person, rather than just someone with a health condition, PC physicians face various ethical dilemmas. To provide culturally sensitive PC, patients' (religious) beliefs and moral worlds must be integral parts of the care package.

This study addresses some of the key ethical questions raised around PC from an Islamic perspective. Because Islamic ethics do not work in a vacuum, substantial attention is paid to PC practices worldwide and in Muslim-majority countries. Contemporary Islamic bioethics has not produced a substantial body of research dedicated to PC so, in some areas, we started from the beginning. This report should be seen as exploratory research, to open up new ideas and discourse rather than provide definitive answers.

Our study is informed by research commissioned by World Innovation Summit for Health (WISH) and carried out by YouGov. An online survey conducted in Muslim-majority countries – including Indonesia, Malaysia, Oman, Qatar and Saudi Arabia – asked the general public to evaluate PC services and explored whether considering a patient's religious beliefs and values was an integral part of good-quality PC.

This study does not claim to exhaust all PC ethical dilemmas and issues. It focuses on analyzing ethical issues faced by healthcare professionals, including insight into the moral issues present when treating patients with a Muslim background.

We hope this study will also highlight to healthcare policymakers and legislators the need to develop regulatory frameworks in alignment with the religioethical fabric of Muslim societies.



A handwritten signature in black ink, appearing to read 'A. V. Darzi'.

**Professor the Lord Darzi of Denham,  
OM, KBE, PC, FRS**  
Executive Chair, WISH, Qatar Foundation  
Director, Institute of Global Health Innovation,  
Imperial College London



A handwritten signature in black ink, appearing to read 'محمد غالي'.

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## EXECUTIVE SUMMARY

PC is an integral part of healthcare, and many countries in the Arab world are increasingly offering this care. Experts predict a rise in the demand for PC. There are various reasons for this, including the increase of geriatric populations and prevalence of chronic and life-limiting diseases, which affect adults and children of all ages.

This study focuses on Islamic bioethical perspectives, although other perspectives are considered. As in the WISH 2016 report *Genomics in the Gulf Region and Islamic Ethics*,<sup>1</sup> the structure of this study reflects a specific vision for how Islamic bioethics should engage with PC.

The report is divided into three sections covering:

1. International perspectives, including a historical overview of PC's development, global expansion and evolving scope
2. PC practices in the Middle East, especially Qatar
3. Islamic ethical perspectives on PC and Muslim patients.

As the Islamic ethical discourse on PC develops and matures, PC services for Muslim patients will become more culturally sensitive and eventually effective.

The report draws a number of conclusions and recommendations:

- **PC should be prioritized**  
Various indications show that the need for PC services is increasing worldwide. Ministries of health should fund more PC units and expand PC educational, residency and fellowship training.
- **Islamic bioethical discourse should pay more attention to ethical challenges relating to PC**  
There are very few distinct studies examining the interplay of Islamic ethics and PC. More studies would help address the ethical questions PC healthcare professionals experience with Muslim patients.
- **Current jurisdiction should be updated**  
Muslim-majority countries often lack codified PC laws, national policies and hospital guidelines, making healthcare professionals vulnerable to malpractice and liability charges.

- **Raising public awareness is a must**

If patients and their families knew more about PC, they could always make more informed and better decisions. For instance, raising public awareness about the possibility of expressing one's healthcare preferences through legal documents like Advance Directives or Living Wills (directives that advise physicians of a patient's wishes for end-of-life medical care) can spare the patients, their families and the treating physicians a lot of time and effort trying to regulate the decision-making process around critical issues.
- **Forgoing certain curative treatments can be ethically acceptable**

Beyond life-saving medical interventions whose efficacy is certain, and thus obligatory from an Islamic ethical perspective, curative treatment is generally categorized as an ethically neutral act and thus remains optional. That is why forgoing certain life-sustaining treatments (LSTs) – such as mechanical ventilation and cardiopulmonary resuscitation (CPR) – can be acceptable in some circumstances. Forgoing artificial nutrition and hydration (ANH) is a more controversial issue, but related Islamic ethical discussions are still scarce and immature.
- **Administering analgesics can be acceptable, even if they might have controversial side effects**

A key PC goal is to relieve intractable pain. Certain side effects from doing this can be tolerated from an Islamic ethical perspective. Administering pain medication that induces temporary and partial loss of consciousness is least controversial. Attempts to initiate total and (sometimes) permanent suppression of a patient's consciousness until the moment of death are the most controversial actions.
- **The expressed will of patients should not be overlooked**

From an Islamic ethical perspective, legally competent patients must be the first to be consulted about their health condition, including delivery of bad news. Their preferences and expressed will must be honored, even if their family intervenes.
- **Active euthanasia is not an ethically accepted option**

Contemporary Islamic bioethical deliberations consistently agree that the active termination of a patient's life is unethical. Also, active euthanasia is illegal in many jurisdictions in the Arab and Muslim world, and so the physicians involved run the risk of being prosecuted.

## SECTION 1. INTERNATIONAL DELIBERATIONS AND PERSPECTIVES

Since its origins in the Middle Ages, PC has been tied to religious institutions looking after patients with few resources. Later, specific places were developed to care for those with specific and life-limiting diagnoses.<sup>2,3</sup> Dame Cicely Saunders (1958–2004), who founded the modern hospice movement, championed awareness of the relationship between physical, emotional, social and spiritual suffering. She advocated for holistic care of dying patients to include family and friend caregivers.<sup>4</sup> St. Christopher's Hospice in London, the first modern hospice, founded in 1967 by Saunders, is still a model and source of inspiration for PC professionals around the world.<sup>5,6</sup>

### Global expansion of PC services

In 1982, the World Health Organization (WHO) developed its global Program for Cancer Pain Relief and campaigned to remove legal sanctions against opioid use and importation. In 1989, it formally defined the term 'palliative care' as:

**"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."<sup>7</sup>**

A number of PC networks now exist and collaborate across the globe.<sup>8</sup> Many of these have called for PC provision to be an essential and basic component of healthcare for all.<sup>9</sup> In the US, the PC specialty has expanded rapidly. According to the Center to Advance Palliative Care (CAPC), more than 80 percent of patients hospitalized with serious illness in the US have access to PC through 1,800 hospitals offering PC programs.<sup>10</sup>

The CAPC definition of PC now includes multidisciplinary professionals to support patients and their families. Families themselves are now included, alongside primary and specialist physicians, as vital parts of the PC team. It specifies that PC may be delivered in various settings, and is appropriate for patients with many different serious, complex and chronic illnesses, including: cancer, cardiac disease and heart failure, chronic obstructive pulmonary disease, kidney failure, Alzheimer's disease, and Parkinson's disease. In the

US, PC professionals advocate for, and facilitate, communication that helps patients better understand the nature of their illness, their care options and their physicians' recommendations.

Importantly, while hospice care (which falls under the PC umbrella) is meant for patients expected to live for six months or less, PC is appropriate at all stages of an illness. It aims to help patients live as fully and as well as possible until they die. As medical advances lengthen survival times for the terminally ill, PC can help alleviate disease-related and treatment-related symptoms, and allow the end-of-life period to be better used by patients – often for setting goals, planning care, and discussing an acceptable balance between suffering and living.<sup>11</sup>

Worldwide, there has been increased acknowledgment of the need for PC for cancer patients – and for those with other chronic diseases. By 2011, 136 of the world's 196 countries (69 percent) had established one or more hospice PC services, and 159 countries (81 percent) were either delivering such services or developing the framework to do so. However, only 45 countries (23 percent) had integrated PC with their mainstream service providers.

Despite increased awareness, there remains a huge unmet need for PC in most parts of the world. Differing cultural traditions, varied meanings and understandings of death, dying, and the spiritual value of suffering, undoubtedly shape perceptions. This may represent a major hurdle to the transferability of effective approaches to PC.<sup>12, 13</sup>

## Ethical deliberations

In most of the Western world, the four principles of bioethics – autonomy, beneficence, non-maleficence and justice – are used as a starting point for exploring morally ambiguous and ethically challenging situations in healthcare.<sup>14</sup> Physicians have a duty to uphold each of these principles, while balancing their different demands. Given the potential benefits, burdens and limits of all medical interventions, management of serious illnesses must be approached in different ways.

Worldwide, WHO estimates that more than 20 million people require end-of-life PC every year, primarily as a result of non-communicable diseases.<sup>15</sup> The highest proportion of these people live in low- and middle-income countries.

Access to PC is inextricably linked with medical ethics and human rights.<sup>16</sup> Many international organizations – including WHO, the Senate of Canada, the Committee of Ministers of the Council of Europe, the European School of Oncology, the Worldwide Palliative Care Alliance (WPCA) and Human Rights Watch – have called for the provision of PC as an essential component of



healthcare. The 2014 World Health Assembly resolution on PC noted: "It is the ethical duty of healthcare professionals to alleviate pain and suffering."<sup>17</sup> Just this year, at the 37th Session of the Human Rights Council, the Organisation for the Prevention of Intense Suffering, and International Doctors for Healthier Drug Policies, released a guide outlining the ethical basis of their support for access to opioids as a human rights issue.<sup>18</sup>

Access to quality PC for all who need it includes access to affordable analgesics and to well-informed, trained practitioners. The principle of beneficence demands that healthcare providers develop and maintain their skills and knowledge. Up-to-date training would enable integration of PC into general medical practice, and help debunk the myths about opioid pain medication that are barriers to patients receiving quality PC. Unfortunately, in many settings, historical neglect of suffering, unreliable healthcare delivery methods, and overly strict government regulations based on disproportionate concerns about opioid dependence are obstacles to PC.<sup>19–21</sup> Access to opioid medication for pain control is an enormous problem worldwide<sup>22</sup> – some countries only allow the use of opioids for cancer pain, and outside the Western world, opioid availability is low.<sup>23</sup>

### **Decision-making process: Autonomy, capacity and disclosure of information**

Autonomy in making decisions about healthcare interventions is a prominent guiding principle in Western medical ethics. Underlying that principle is the belief that patients are best able to determine what is best for themselves, if they have the capacity and willingness to do so. Autonomy is the basis for 'informed consent' in the physician–patient interaction. Yet different individuals and societies assign varying degrees of priority to this.

Tied closely to the principle of autonomy is the issue of communicating information about diagnosis and prognosis. Studies done primarily on Anglo-American societies have debunked myths that disclosure of honest prognostic information causes increased patient anxiety, sadness, loss of hope<sup>24,25</sup> or decreased survival times.<sup>26,27</sup> Some studies have suggested that sharing information with family members instead of with the patients themselves, using euphemisms to explain a patient's condition<sup>28</sup> and keeping truth from patients may actually cause more harm than good. Being honest with patients can foster hope and build trust.<sup>29,30</sup> In non-Western societies, however, tradition often dictates an extended and expected role for the family – particularly male family members – in medical decision-making.<sup>31</sup> While Catholicism places highest priority on telling the truth – and thus disclosure of medical information to

patients themselves – in Judaism, withholding information or at least postponing the delivery of bad news, may be considered appropriate in the event that disclosure might risk the patient's health.<sup>32</sup>

It is important to recognize that self-determination and autonomy are dependent on the patient having decision-making capacity. This capacity may fluctuate over time as medical or mental health disorders evolve, or for decisions of varying degrees of complexity and consequence. And while it is always appropriate for the physician to recommend what they believe to be best medically, patients should not be considered to lack capacity because they make a decision contrary to medical advice. Patients have a right to ignore medical advice – and have their own decisions respected.

Finally, lack of capacity to make healthcare decisions – which requires different skills than choices about living independently or handling funds – should not be taken to mean that patients cannot participate in healthcare decision-making at all. It may simply mean that they need more support from surrogate decision-makers.<sup>33,34</sup>

## **Balancing benefits and burdens**

Intimately related to self-determination is the importance of understanding the potential benefits and burdens of treatment options – especially for interventions that cause a disproportionate burden for very limited potential benefit. The physician's duty to protect vulnerable patients becomes increasingly important. The balance between 'patient good' and 'patient harm' presents itself in situations where a patient with a progressive incurable condition (for example, advanced cancer) has limited meaningful treatment options for which greater benefit than harm is anticipated. For example, it is widely considered ethically acceptable for such a patient to forgo further chemotherapy and prioritize quality time over quantity of time, or to avoid excessively 'medicalizing' the final stages of their life.<sup>35</sup>

Patient understanding of their illness and prognosis is also related to the choices they make about treatments of dubious benefit and unnecessary cost. In low- and middle-income countries, patients often come to medical attention only when they have advanced disease, often beyond cure or even significant change. Fearful, suffering, and often inadequately informed patients may impoverish themselves and their family, for what amounts to only a limited, unproven, insufficient fraction of the established standard-of-care treatment.

## Forgoing or withholding life-sustaining treatment

Nowhere is the conflict between beneficence and non-maleficence more evident than in the discussion about attempted resuscitation, which can keep a dying patient 'alive temporarily' with technology.

While attempted resuscitation may be viewed as preserving a life, it may not offer all patients clinical benefit. In the face of incurable and progressive illness, it may well subject a patient to an extraordinary burden of suffering – even cause harm – for very little, if any, benefit since the patient is already dying from their underlying condition.

Initially, CPR was intended for those who suffered cardiac arrest in the context of reversible illnesses and injuries. While CPR became the standard of care, evaluation in a wide variety of clinical situations has revealed that attempted resuscitation may not offer benefits to all patients. In one meta-analysis of cancer patient survival, overall survival to discharge was 6.2 percent, while survival in patients resuscitated on intensive care units was only 2.2 percent.<sup>36</sup> Many serious preexisting conditions, including malignancy, acute stroke, septicemia and hepatic failure may predispose a patient to poor outcome from attempted resuscitation.<sup>37</sup> At worst, resuscitation may simply prolong a painful dying process.

It is also worth noting that attempted resuscitation and intensive care admission in the last week of life for terminally ill cancer patients have been associated with worse quality of life, and increased caregiver depression and regret. There are a number of things that patients with a terminal illness may value more highly than extending their lives, for example: being with family, being comfortable, being mentally aware, and not becoming a burden.<sup>38</sup> Some have suggested that attempted resuscitation should no longer be the default presumption in most hospitals.<sup>39</sup>

Most professional guidelines support the assertion that there is no legal or moral difference between withholding and withdrawing LST.<sup>40</sup> However, for some, withdrawing LST is more difficult than withholding it.

## Principle of double effect

The principle of double effect states that it is permissible to cause harm as an unintended but potentially foreseeable side effect (or 'double effect') of aiming to bring about a good result. It would not, however, be permissible to cause such harm as a *means* of pursuing a good end. Grounded in the ethical principle of proportionality, the unintended but potentially foreseeable negative outcome must be outweighed by the good outcome.

In PC, this means that an intervention, such as giving high-dose opioids to relieve severe end-of-life pain or dyspnea is acceptable, even at the risk of causing foreseen but unintended side effects such as sedation, hypotension and even hastened death. However, this principle forbids using drugs to relieve the distress of a dying patient by intentionally killing them.

This is where we find the distinction from euthanasia, where the intention of administering such drugs is to cause death as a means to relieve suffering. The issue of what is intended in the action is vital. The principle of double effect is key in clinical decision-making by physicians, who cannot let their patients suffer, but do not (and in many countries legally cannot) condone euthanasia.<sup>41</sup>

There are a few important clarifications to be made here. First, satisfactory symptom control at the end of life is not inevitably associated with hastening death. Appropriate use and titration of analgesics is the most effective way of achieving pain and dyspnea control. In the *BMJ* article, Moral Dimensions: Palliative care and the doctrine of double effect, Victoria J. Wheatley puts it in very relatable terms: "Every patient will have a last dose of analgesia in the same way that they will have a last cup of tea. This does not mean that the analgesics (or the tea) shortened their life, merely that they were dying already."<sup>42</sup>

Second, it is important to distinguish between the unintentional sedation that may occur with the use of high-dose opioids for symptom relief (the double effect), and the practice of palliative sedation. Palliative sedation, a tool of last resort, is the use of medication to induce decreased awareness to relieve otherwise intractable suffering at the end of life. It is usually used to treat refractory physical symptoms, including delirium, dyspnea and pain, and its use for existential distress or severe psychosocial distress is controversial. Again, distinction from euthanasia or physician-assisted death is important here, as the desired outcome of physician-assisted suicide and euthanasia is to end life, not to relieve intractable suffering.<sup>43,44</sup>

## Artificial nutrition and hydration (ANH)

Another important ethical tension involves ANH, when a progressive disease has made normal nutrition and hydration impossible. ANH may include using the gastrointestinal (GI) tract to deliver nutrition and fluids into the stomach, or parenteral nutrition in which they go directly into a vein. Both types of ANH can cause complications.

Patients with advanced terminal illness often no longer have functioning GI tracts. In the case of advanced cancer, tumor burden in the abdomen can make it impossible to place a feeding tube. As a result, patients are unable to receive enteral nutrition, or they experience increased discomfort with attempts to

do so. They are also often prone to infection and clotting. Patients with end-stage cancer or heart, liver or kidney disease often have difficulty mobilizing fluid from their bodies, and fluid accumulates in unwanted places such as the abdomen, lungs and extremities. This may cause real discomfort and difficulty breathing. Fluid delivered to the patient through ANH may exacerbate these problems, causing more harm than intended benefit.

In the US, ANH is considered a form of medical treatment rather than a basic care need. As such, it is considered ethically acceptable to refuse, withhold or request withdrawal of ANH. There is some evidence that artificial hydration, in particular, can mitigate symptoms of delirium.<sup>45</sup> However, there is also concern that, for some patients, continued ANH may cause volume overload and unnecessary stress on organ systems that are shutting down, while not alleviating dry mouth or hunger (although most dying patients no longer experience hunger). In addition, studies do not support the theory that there is a survival benefit to ANH in terminally ill or imminently dying patients.<sup>46</sup>

Religious doctrines lead to different perspectives. In Judaism, the concept of the sanctity of life dictates that ANH be provided to sustain life, unless the feeding itself causes undue suffering. In Catholicism, it is presumed that patients will be fed, but not if the procedure of feeding causes suffering or merely prolongs the dying process. For religious or cultural reasons, or sometimes because of a misunderstanding of the potential benefits and harms, families often request ANH for patients who are dying from their disease, not from malnutrition or dehydration. While sensitive communication, education and compromise are crucial, physicians are not obligated to intervene in a way that would be harmful to a patient, even if the patient (or their surrogate) insists.<sup>47</sup>

Currently, most modern PC practice is based on Western values, which may not always be appropriate for the non-Western world. This is, in part, related to a scarcity of local research. But development of an appropriate evidence base is essential if PC is to be delivered in a culturally sensitive manner and for PC advocacy and policy development to progress.<sup>48,49</sup>



## CASE STUDIES: INTERNATIONAL ETHICAL DELIBERATIONS

These case studies shed light on some of the most common ethical dilemmas faced by medical teams.

### Case study 1: Opioid usage

A 72-year-old man with metastatic prostate cancer has received multiple rounds of chemotherapy and hormonal therapy but his disease has progressed. He experiences severe pain and shortness of breath just lying in bed. He has stated frequently and clearly that he does not wish to be intubated.

His pain and his breathlessness are relieved by intravenous (IV) morphine but this also makes him very sleepy. He expresses to the medical team that he doesn't care about the sleepiness, he just can't take the suffering any longer.

His family, devout Catholics, are praying for a miracle and will not allow the medical team to say anything to them about the fact that the patient is dying. They do not want him to suffer, but they are very distressed that he is too sleepy to interact with them. Each time a nurse arrives to administer morphine, the patient's wife blocks them, accusing the medical team of euthanasia.

The medical team decides to switch the patient to a continuous IV infusion of morphine, in a dose equivalent to the amount that has been required to control his symptoms over the past few days. They also order intermittent IV doses as needed in case he has breakthrough pain and breathlessness, despite the morphine drip.

### Case study 2: Patient involvement in care and decision-making

A 49-year-old Muslim woman has pancreatic cancer and has developed an inoperable obstruction of her GI tract. She needs a nasogastric tube to relieve the pressure buildup. She cannot eat by mouth and is not hungry, but enjoys the taste of small amounts of fresh fruit juice. She also has considerable abdominal pain that increases when she puts too much into her stomach. IV hydromorphone makes her sleepy for the first few minutes after each dose, but controls her pain enough for her to enjoy time with her family.

Her husband approaches the medical team outside the room and tells them he wants his wife to receive more chemotherapy. The oncology team has already told him that further treatment won't help her and is more likely to harm her, or even hasten her death. He doesn't want her to know that information – he fears she will lose hope and give up.

The team suggests that they go into the room with him and gently ask the patient what she wants to know about her condition. She expresses her wish to hear all information about her disease and condition. She says she knows her time is limited, as is everyone's time on Earth, and wishes to spend her remaining time with her family around her.

### Case study 3: Artificial nutrition and hydration

A 27-year-old man has primary pulmonary hypertension – a progressive and fatal condition, diagnosed three years ago. Despite aggressive treatment, he now has severe right heart failure with worsening breathlessness, accumulation of abdominal fluid and swelling of his legs. He is on the waiting list for a lung transplant but continues to deteriorate, despite intensive care.

He is becoming increasingly edematous, short of breath and fatigued. He cannot eat, drink or even speak because it makes his breathing more difficult. His family is still hoping for a miracle and an organ donor. The medical staff also hope for a donor, but they know the patient is nearing death, even though they are doing everything they can.

The family requests that the PC team gives the patient sufficient nourishment to keep him strong enough for a transplant should an organ become available. The patient cannot tolerate enteral feeding by nasogastric tube, given the edema of his bowel, and parenteral nutrition increases his pain and other symptoms. The team believes that the artificial nutrition is causing the patient more harm and distress than benefit, in what they believe are his final days or weeks.

## SECTION 2. PRACTICES IN THE MIDDLE EAST REGION

This section focuses on PC services in some Muslim-majority countries in the Middle East (ME) region. The PC revolution in the ME started during the 1990s as part of an international movement, and continues to advance.

Cancer is a leading cause of death in the ME. More than 70 percent of patients with cancer only seek medical attention once their tumor has become incurable, so PC is one of the few available options.<sup>50</sup> Alongside this, there is an aging population. Therefore, tackling inadequacies in PC education and awareness has been prioritized in many ME healthcare systems, including Qatar, Jordan, Egypt, Saudi Arabia, Kuwait and Lebanon. These issues must urgently be considered by the other ME countries too.

For example, in the YouGov survey commissioned by WISH for this report, respondents in a number of Muslim-majority countries were asked to evaluate the PC services provided in their country. Only a minority of the respondents, ranging between 4 percent in Malaysia and 14 percent in Qatar, rated PC in their country as 'poor'. However, few also rated the quality of PC services as 'excellent', ranging between 10 percent in Malaysia and 20 percent in Saudi Arabia.

In the ME and worldwide, PC has not been fully integrated into all healthcare systems, despite evidence that it increases quality-of-life outcomes and relieves suffering at the end of life.<sup>51</sup> In the ME, it is provided by various institutions, ranging from volunteer groups and non-governmental organizations (NGOs), to official hospices and hospital units.

PC professionals struggle to secure funding, establish basic PC education and training facilities, and raise awareness. However, some individuals and institutions in the field have achieved notable successes since the early 1990s. Following the introduction of the first PC unit in Saudi Arabia in 1992, other countries in the Gulf Cooperation Council (GCC) followed. Saudi Arabia, Iran, Jordan and Lebanon now have official PC licensing programs for physicians, while Egypt, Jordan, Oman and Qatar have developed other advanced training programs (such as a specialized Master's or Diploma in PC). Jordan, Oman and Lebanon report having at least one medical school teaching PC as an independent subject, and Egypt and Kuwait report teaching PC as part of other subjects, such as oncology.<sup>52</sup> However, some countries, including Yemen, Libya and Syria, have little or no known PC activity due to political issues affecting the availability of resources, coupled with a lack of education and awareness.

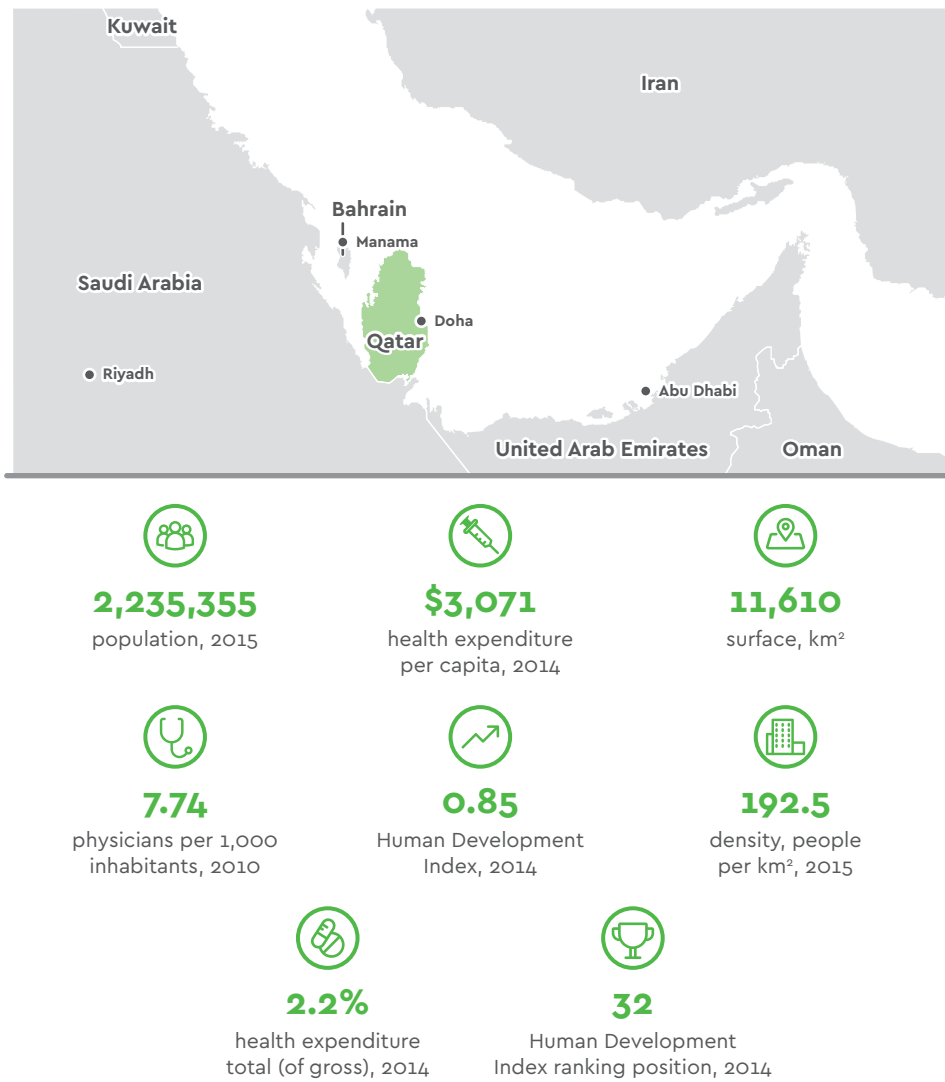
In the following section we review current PC activities and services available in the ME: in Qatar, Saudi Arabia, Jordan and Lebanon.

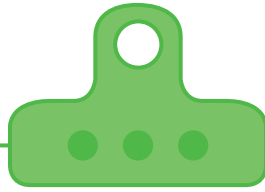


## Current PC services in ME countries

### PC in Qatar

Figure 1. PC services in Qatar





### Palliative care programs

- |                                                          |                                                          |                                                                  |                                                |
|----------------------------------------------------------|----------------------------------------------------------|------------------------------------------------------------------|------------------------------------------------|
| <b>2</b><br>outpatient<br>clinics                        | <b>1</b><br>mixed program<br>(community<br>and hospital) | <b>2</b><br>consultation<br>services (hospital<br>support teams) | <b>1</b><br>hospital<br>PC unit<br>(inpatient) |
| <b>0</b><br>hospices<br>(stand-alone<br>inpatient units) | <b>0</b><br>community-based<br>programs<br>(home care)   | <b>1</b><br>nursing<br>home-based<br>program                     |                                                |

### Payment for PC programs

The health system is public and universal.

	Yes	No
Do patients have to pay for PC?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Do patients have to pay for PC medications?	<input type="checkbox"/>	<input checked="" type="checkbox"/>



### Policies

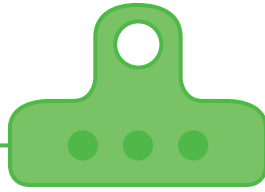
	Yes	No
National PC law?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/> *
National plan or strategy for PC?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
National cancer plan/strategy with a section for PC?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
National standards and norms for PC?	<input checked="" type="checkbox"/>	<input type="checkbox"/>



### Professional activity

	Yes	No
National PC association?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Initiatives promoting PC?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
PC research?	<input checked="" type="checkbox"/>	<input type="checkbox"/>

\*: Null



## Education

1

**medical school**  
with PC education at  
undergraduate level

1

**nursing school**  
with PC education at  
undergraduate level

	Yes	No
PC integrated into any fellowship program?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Postgraduate course for nurses available?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Official recognition as a licensing or advanced training program?	<input checked="" type="checkbox"/>	<input type="checkbox"/>

## Teachers of PC

Full professor	Medicine	2
	Nursing	0
Other professors	Medicine	0
	Nursing	2
<b>Total</b>		<b>4</b>

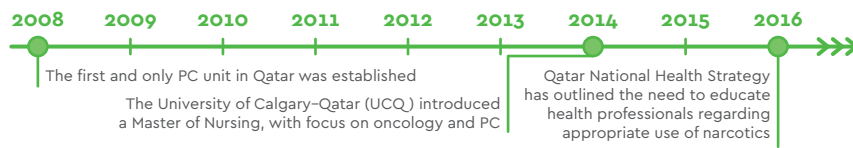


## Availability of medicines

	Yes	No
Codeine	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Morphine	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hydromorphone	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Oxycodone	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Methadone	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Transdermal fentanyl	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Source: Osman et al. Atlas of Palliative Care in the Middle Eastern Mediterranean Region (2017)

**Figure 2. Atlas of PC in the Eastern Mediterranean region**



Source: Osman et al. Atlas of Palliative Care in the Middle Eastern Mediterranean Region (2017)

Qatar's population is expected to grow from its current 2.57 million to 4 million in 2022, when it will host the FIFA World Cup. The elderly population is rising too – from an estimated 2 percent of the total population in 2010, to an expected 20 percent by the year 2050.<sup>53</sup> Alongside this is a high incidence of lifestyle disorders such as diabetes and obesity. End-of-life care services are an increasing priority to Qatar's healthcare system, yet PC in Qatar is still at a developing stage. However, because Qatar faces very few issues with resources, political instability or lack of governmental support, the integration of PC services with mainstream providers should be an achievable long-term goal.<sup>54, 55</sup>

Developments in PC were encouraged by the launch of the National Cancer Strategy for Qatar in 2011 by the then Supreme Council of Health, now Ministry of Public Health. The strategy, based on WHO and global standards, planned to improve access to PC facilities for cancer patients. It included 62 recommendations covering education, prevention, early detection, treatment and ongoing care.<sup>56</sup> Strategy for putting these recommendations into practice lies under the umbrella of the Ministry of Public Health, Hamad Medical Corporation (HMC) and the Primary Health Care Corporation.<sup>57</sup>

Since the launch of the first National Health Strategy 2011–2018, PC in Qatar has evolved from mere printed policies to a functioning unit, affiliated with the Joint Commission International clinical program accreditation. The first local PC unit, with a capacity of 10 beds, was introduced in 2008 by the National Center for Cancer Care and Research which is part of HMC, and the only advanced cancer center in Qatar.<sup>58</sup>

Qatar's National Health Strategy plans to educate health professionals on better use and prescription of narcotics – a response to previously inadequate pain management approaches and restricted opioid administration.<sup>59</sup> All seven essential opioid formulations of the International Association for Hospice & Palliative Care are available in Qatar. However, there are still barriers to prescribing them.<sup>60</sup> As things stand, prescribing opioids to both cancer and non-cancer patients requires a generalized prescription form, valid for just 10 days. For patients who do not have cancer, gaining these forms is relatively easier where general practitioners and family physicians are considered eligible to prescribe them.<sup>61</sup> However, only oncologists and surgeons are authorized to prescribe

opioids for cancer patients – family physicians, pharmacists and nurses are prohibited from doing so. Recent data sets show that Qatar has an estimate of 250mg Defined Daily Doses of opioid consumption per million inhabitants per day.<sup>62</sup>

Advance Directives that include Do Not Attempt Resuscitation (DNAR) orders were initially instituted in the Qatar PC Protocol in 2004 and were finally revised in October 2017. As a result, HMC's policies reflect the legal right of patients to be withheld from life-saving interventions in the case of imminent collapse or medical deterioration. A legally competent patient, aged 18 years or older, and with decision-making capacity, can typically agree on a DNAR order. Initiation of resuscitation against the patient's wishes violates an individual's right to self-determination.<sup>63</sup> DNAR decisions taken by the physician are made only after family meetings and when signing the DNAR is regarded as too difficult for family members alone (often due, in part, to local religious and cultural sensitivities).

HMC, the main health provider in Qatar, has its own DNAR policy. The treating physician considers DNAR whenever resuscitation is determined futile in terminal or untreatable diseases without known chances of survival – for example, advanced stage cancer, irreversible multi-organ failure and severe brain damage. Other measures to maintain the patient's comfort that have been given before cardiopulmonary arrest may continue at the discretion of the treating physician, as indicated on the DNAR form.

In 2014 the Qatar-based University of Calgary introduced a Master of Nursing degree that focuses on oncology and PC services. It gives students hands-on experience and rotations within a hospital PC unit. It also emphasizes the holistic, multidisciplinary nature of the field, centered around providing care for the patients and their families.<sup>64</sup> PC training is also integrated into residency and fellowship training programs as part of HMC's oncology/hematology specialties.<sup>65</sup>

## PC in Saudi Arabia

Saudi Arabia, one of the largest countries in the ME, is considered the regional PC pioneer. The majority of referred PC patients (about 95 percent) in Saudi Arabia have cancer. According to data from the Saudi Cancer Registry, there were 11,946 registered cases of cancer in 2008.<sup>66</sup> This number is expected to increase by 5 or 10 times by 2030 – alongside an aging population.<sup>67</sup>

Since the inauguration of the first PC unit in 1992 at the King Faisal Specialist Hospital and Research Center, PC services across the country have grown. Twenty institutions are now in operation and there are a number of training centers and specialized trainers accredited by international certification

bodies. This accreditation has provided graduates with sub-specialist status and the presence of these practitioners has been at the heart of this policy's success. Hospice care was established in 2018.

In principle, pain-relieving opioids are widely available in all Saudi Arabian hospitals, although pharmacists and physicians are often reluctant to prescribe them. Fatwas (religious advice) issued by Muslim religious scholars are generally accepted as authoritative sources of information that can inspire binding laws adopted by respective governmental authorities. The fatwa issued by the Council of Senior Scholars – known as Fatwa no. 12086 – on DNAR orders played a significant role in streamlining and standardizing some PC practices in Saudi Arabia. More information about this fatwa is provided in the next section.

According to local guidelines, issuing a DNAR order signifies that the patient receives all treatments and interventions to ensure their comfort and dignity, except for CPR. The core of the DNAR policy expressed in Fatwa no. 12086 (namely, three consultants signing the order), is taken up by all hospitals in Saudi Arabia. However, available figures show a high level of diversity in other issues. These include valuing a patient's autonomy, involving the patient and their family in the decision-making process, and considering how each patient's specific circumstances could influence the physician's decision to sign a DNAR order.<sup>68</sup>

Saudi Arabia has official PC licensing programs for physicians and multiple training programs across various hospitals for allied health professionals and nurses. One of the most promising endeavors was the development of separate professional organizations, such as the Saudi Society of Palliative Care, launched in 2013.

In terms of sociocultural acceptance, mass media campaigns around the country have attempted to increase public awareness of PC and related medical services. Physicians and healthcare providers have become increasingly aware of the importance of early referrals too.

The future direction for PC in Saudi Arabia would be to invest more in a specialized and multidisciplinary workforce, encompassing nurses, social workers and pharmacists. The establishment of the Arab Group for Palliative Care is expected to lead and support the development of PC in the region.

## PC in Jordan

Jordan is a relatively small country with an estimated population of about 9.5 million. About 5,000 new cases of cancer are diagnosed each year, 70 percent of which reach the healthcare system at an incurable stage. Therefore, for most cancer patients in Jordan, PC and pain relief are the most realistic and humane approaches.<sup>69</sup>

About 60 percent of the 16,000 deaths that occur each year are likely to require PC.<sup>70</sup> Every dying person is cared for (on average) by at least two family members. This means that more than 29,000 Jordanians would benefit directly from an improved PC system in a given year.

The first PC legislation came in 2003, following frequent communications with the Ministry of Health to boost political awareness. Staff members at Al Bashir Hospital, the biggest government healthcare provider in the country, received PC training.<sup>71</sup> The 2007 WHO Palliative Care Demonstration (a training and awareness project targeted at healthcare professionals) sparked a PC program at the King Hussein Cancer Center. Then, in 2010, as a response to increasing demand, the Jordan PC Society was established to make services accessible to all patients – not just those at the Center. Several workshops and diploma programs soon followed, training more than 1,000 healthcare workers.<sup>72</sup>

In July 2015, Jordan received a grant from USAID to develop four PC projects. These trained healthcare students and professionals, spread PC practice throughout hospitals and universities, boosted public awareness and launched group therapy programs for people with chronic illnesses.<sup>73</sup> There is now an annual PC awareness day, to which the Minister of Health and other important policymakers are invited.

Like other countries in the ME, Jordan has faced significant barriers in the establishment and development of PC programs. Mostly these were due to the low levels of awareness at governmental and professional levels. This resulted in a lack of co-operation, minimal financial support and a shortage of PC staff. Most funding still comes from USAID and, to a lesser extent, private donors, with no substantial contribution from the Jordanian Government.

In terms of education, a Master's level PC nursing program is currently available at the School of Nursing at the University of Jordan. There is also a PC Academic Diploma program at a private university, but with no affiliation to the National Palliative Care Committee in the Ministry of Health. Thus, the academic credibility of this diploma has not yet been recognized. Continuous education and in-service training and fellowships in hospitals are available, and the Kingdom is

in the process of addressing the PC educational gap. Training for physicians in pain medicine as a subspecialty does not exist in Jordan, and only a few physicians practice pain and symptom management – mainly in the private sector.<sup>74</sup>

With regards to pain management, widespread misconceptions about opioids and their side effects have resulted in many barriers to access.<sup>75</sup> This is slowly improving and opioids are generally accessible in the King Hussein Cancer Center. However, when it comes to government-operated hospitals, the uptake remains considerably low.

The DNAR policies and Advance Directives in Jordan correlate with most other hospitals in the ME region. The King Hussein Cancer Center states: "All terminally ill cancer patients are considered eligible, and have the right to, a DNAR directive."<sup>76</sup>

Currently there is one inpatient hospital-based hospice and three stand-alone hospices in Jordan.<sup>77</sup> In 2017, the Health Minister acknowledged Jordan's need to advance comprehensive palliative and homecare services, noting that the Ministry will do "everything possible to further the spread of palliative care". The Director General of the King Hussein Cancer Center also highlighted the role of palliative and homecare in providing comfort for patients and their families, and reducing pressure on hospitals.<sup>78</sup>

## PC in Lebanon

The Lebanese population is estimated at 6.082 million. The country has a death rate of five deaths per 1,000 population (2017) and more than 22,000 deaths a year – most suffer needlessly due to lack of proper access to PC services. While a range of opioids is available, access is poor due to cost, restrictive regulations and a lack of training among healthcare professionals.

At present, most PC patients die in hospitals despite their desire to die at home. This is due to inefficient reimbursement policies that do not support homecare services. Evidently, the implementation of an effective and co-ordinated homecare system would generate considerable savings for the health system.

Lebanon has recently witnessed a period of significant advancement when it comes to PC practice. The country had no PC service providers in 2009, but now has two NGOs providing home-based PC. In 2011, the Ministry of Public Health Lebanon also established the National Committee for Pain Control and Palliative Care which has, in turn, facilitated the development of different PC programs in four hospitals.<sup>79</sup> A national strategy for PC development is currently underway through this committee, which is also working to facilitate



safe access to opioid analgesics.<sup>80</sup> All these factors mean that PC is slowly becoming a recognized specialty in Lebanon. However, lack of adequate funding remains a significant barrier to further growth in the sector.

Advance Directives are currently non-existent in Lebanon, and Living Wills remain non-legally binding. Most patients are unaware they can designate a proxy to make healthcare decisions on their behalf. Many patients do not even know their confirmed diagnoses, and family members often make decisions on their behalf. The survey commissioned by WISH and conducted by YouGov confirms similar attitudes in other Muslim-majority countries. 'Information about life-limiting diseases should be communicated to the patient's family' was the option preferred by most respondents in countries like Indonesia, Malaysia, Oman and Saudi Arabia, with percentages ranging between 40 percent and 66 percent.

To this day, advance care planning remains culturally and socially challenging, with no organized efforts to increase social awareness. Around the country, individual initiatives and active groups work to improve the dialogue around end-of-life care. As for education, two of the seven medical schools in Lebanon have integrated PC into their current undergraduate and graduate medical curricula. However, to date, no formal physician residency training or fellowships in the field are available. A few nursing schools incorporate lectures in PC management into their modules, with the Lebanese University enrolling its first cohort of nurses to a diploma program for PC in nursing in 2016.<sup>81</sup> The Hariri School of Nursing at the American University of Beirut also offers a specialization in pain management and PC for children and adults.



## CASE STUDIES: ETHICAL DILEMMAS IN THE MIDDLE EAST REGION

### Case study 4: The need for PC education and awareness

A case at the National Center for Cancer Care and Research involved an 18-year-old girl with terminal cancer. All lines of treatment had failed and she was referred to the PC unit for support and comfort care. The patient's mother strongly believed her daughter's pain-relief drugs were forbidden by Islam, and was worried that her daughter would be carrying out a sinful action by taking them. She also believed that sugar in the sweets the girl enjoyed eating would exacerbate her illness. The mother wanted to prohibit both pain-relief drugs and sweets.

Without condemning the mother, the physicians were open-minded and initiated multiple counseling and information sessions. These helped the mother understand the importance of the pain relief and her daughter's emotional wellbeing.

### Case study 5: Communicating bad news

Muslim patients and families are often skeptical about accepting a clear-cut prognosis, believing that knowledge of someone's fate is exclusive to God. However, physicians are usually inclined to give precise, honest information – including news of imminent death. Such information may often be met with limited acceptance and statements like: "This is in God's hands, we are not to predict fate."

### Case study 6: Surrogate decision-making

Surrogate decision-making is very commonly seen in the ME region, where close family members are more often directly involved in the patient's care arrangements. Generally, parents, spouses and older children (in descending order of age) have greater decision-making power than the other members of the family. There is often an ethical dilemma regarding the surrogate decision, especially when it contradicts the patient's own opinion.

## SECTION 3. ISLAMIC ETHICAL PERSPECTIVES

In this section, we address the most important issues to healthcare professionals from an Islamic ethical perspective. The relevance of this approach is supported by the results of recent research from a survey commissioned by WISH and conducted by YouGov. The online survey explored the opinion of the general public in Muslim-majority countries like Indonesia, Malaysia, Oman and Qatar about the proposition 'Considering the patient's religious beliefs and values is an integral part of good-quality palliative care'. More than 50 percent of all respondents in these countries either 'strongly agreed' or 'tended to agree' with the proposition. Agreement with the statement was sometimes as high as 80 percent, as was the case in Oman.

Normative bioethical deliberations in the Islamic tradition usually assume two main forms:

- The first consists of perspectives developed by an individual Muslim religious scholar. This falls within the individual ethico-legal reasoning (*al-ijtihād al-fardī*)
- The second is collective *ijtihād* (*al-ijtihād al-jamā'ī*), comprising interdisciplinary or collective reasoning in which religious scholars and biomedical scientists participate.

By the early 1980s, *al-ijtihād al-jamā'ī* began to be institutionalized. The Islamic Organization for Medical Sciences (IOMS) in Kuwait focuses exclusively on bioethical issues and works with two other institutions, whose interest in bioethics is more occasional. They are the Islamic Fiqh Academy (IFA) and the International Islamic Fiqh Academy (IIFA), both in Saudi Arabia.<sup>82</sup> PC is one of the least discussed topics in contemporary Islamic bioethics, and is not comprehensively discussed by institutions or individual scholars.

### Framing palliative care: medical treatment (*tadāwī*)

Recent advances in biomedical science have added new layers of complexity to the concept of medical treatment – in Arabic *tadāwī* or *'ilāj*.<sup>83-85</sup> This is why the concept cannot be approached as one single block. The different types sometimes have blurred borderlines, and ethical judgment naturally varies from one to the other. Medical treatment can be roughly divided into five types:

1. **Predictive** treatment forecasts the probability of developing a certain disease. For example, analyzing one's genetic disposition to cancer.<sup>86</sup>

2. **Preventive** treatment is meant to improve people's health conditions by averting onset of the disease. It includes vaccinations, controlling air and water pollution, and encouraging people to adopt healthy lifestyles. Various secular and religious traditions, including Islam, usually give preference to preventive over curative treatment.<sup>87,88</sup>
3. **Curative** treatment is often perceived as the main function of medicine. It includes pharmacotherapy, surgery, physical therapy and herbal medications.<sup>89,90</sup>
4. **Rehabilitative**, or 'physical and rehabilitation medicine', addresses a wide variety of conditions affecting muscles, brain, spinal cord, nerves and bones.<sup>91</sup>
5. **Palliative** treatment seeks to relieve pain, symptoms and distress for patients with serious illness. It can include end-of-life care.

Ethical dilemmas arise when providing PC would mean forgoing other types of treatment – including curative medicine and medically administered nutrition and hydration. In such cases, should PC be prioritized? Or should curative treatment continue, even if it may increase the patient's suffering, which PC aims to manage and minimize?

The dominant position toward medical treatment (*tadāwī*) in pre-modern Islamic discussions was a general one and did not capture the nuances and complexities of modern biomedical advances, including PC. *Tadāwī* in general was considered either permissible (morally neutral), recommended, obligatory, or morally inferior to having trust in God (*tawakkul*) by forgoing treatment.<sup>92-94</sup>

PC medical teams usually face difficulties when they encounter ethical dilemmas resulting from the possible tension between palliative treatment and curative treatment. Such dilemmas are addressed in the next section on life-sustaining treatments (LSTs). We will then address ethical dilemmas resulting from having two or more relevant but conflicting values that cannot be easily reconciled in the PC setting. For example, administering analgesics that are instrumental to relieve the patient's pain but may impair consciousness or hasten death, or communicating bad news about the approaching death of a PC patient and how to combine truthfulness and compassion in such a context.

## Life-sustaining treatments (LSTs)

LSTs are medical interventions – such as CPR, mechanical ventilation and ANH – that keep a person 'alive' without necessarily reversing the underlying life-threatening condition. LSTs trigger serious ethical dilemmas within the

context of life-limiting illness. If the end of a patient's life is approaching, and physicians estimate that death is imminent, using LSTs can simply prolong pain and distress – contrary to the very aim of PC. Many physicians estimate that the possible curative benefits, if any, of CPR and mechanical ventilation in such cases are quite minimal. Thus, using them would be closer to inflicting harm rather than actual treatment or achieving benefit.<sup>95,96</sup>

The ethical dilemmas in such cases revolve around key questions such as: What is the optimal practice in such cases – for example, forgo LSTs and focus on minimizing pain, or initiate/continue using LSTs? How should the decision-making process be managed in such situations? Muhammad Ali al-Bar, a frequent participant in institutionalized collective bioethical deliberations, stated that these questions are some of the most vexing dilemmas for healthcare professionals working in the Arab and Muslim world, especially for practitioners who do not have an Arab or Muslim background.<sup>97</sup>

In the analysis of the responses given to these questions within the Islamic tradition, we will differentiate between two main categories of LSTs. This is because they are judged differently from an Islamic ethical perspective:

- CPR and mechanical ventilation
- artificial nutrition and hydration (ANH).

Before examining the details of these two categories, we look at some LSTs that have received much less attention. Few religious scholars or biomedical scientists expressed their views specifically about withholding or withdrawing measures like renal dialysis and chemotherapy for patients with terminal diseases. The fatwas bureau at the Kuwaiti Ministry of Awqaf and Islamic Affairs has the view that patients with terminal and incurable diseases can forgo treatment when they contract new curable diseases, even if this new disease could eventually lead to death. The fatwa explains that treatment in such cases remains a matter of probability which makes it optional rather than obligatory.<sup>98</sup> Muslim biomedical scientists are also inclined to adopt a similar position.<sup>99</sup>

## **CPR and mechanical ventilation**

During its 22nd session in May 2015, the IFA discussed the ethical issues related to *not* using CPR and mechanical ventilation in the case of terminal diseases. Participants in this session, like the majority of Muslim religious scholars in general, did not recognize ethical differences between withholding and

withdrawing these LSTs, although withdrawing (*īqāf*) was more frequently used in these discussions than withholding (*imtinā*). Two main positions were held by participants:

- 1. Withdrawing LSTs is forbidden:** Advocates of this position (mainly some individual religious scholars) equated it with intentional homicide (*al-qatl al-‘amd*). The governing perception here is that these LSTs function as a life-saving measure and employing such medical treatments is obligatory from an Islamic perspective. Some religious scholars went as far as saying that this ethical position even applies to 'brain-dead' patients. This was especially the case for scholars who did not consider 'brain dead' as a fully-fledged 'death' from an Islamic perspective. They stressed the sanctity of human life – its preservation an obligation imposed by God. Additionally, they questioned the supposed irreversibility of the patient's medical condition: they said that a physician could make a mistake in diagnosing an illness as 'terminal', and argued that a cure might be developed in time for a supposedly 'incurable' condition (*la yurjā bur’uh*). They also cited the necessity of remaining optimistic – especially for Muslims, who believe in the Omnipotent God.<sup>100, 101</sup>
- 2. Withdrawing LSTs can be acceptable:** Advocates of this position stated that LSTs are not *truly* life-saving measures for patients who are either already deceased or are dying, with no chance of recovery. Therefore, withdrawing LSTs such as CPR is not intentional homicide, but rather is forgoing optional treatment, whose harm usually overrides any possible benefits. The advocates of the second position comprised individual religious scholars and biomedical scientists, in addition to the collective fatwas adopted by some of the above-mentioned institutions. According to the physician, Muhammad Ali al-Bar, almost all physicians advocated this position.<sup>102</sup> In line with this stance, the 1981 *Islamic Code of Medical Ethics* states:

**“In his defence of Life, however, the Doctor is well advised to realize his limit and not transgress it. If it is scientifically certain that life cannot be restored, then it is futile to diligently keep on the vegetative state of the patient by heroic means of animation or preserve him by deep-freezing or other artificial methods. It is the process of life that the Doctor aims to maintain and not the process of dying.”<sup>103</sup>**

The IFA's 2015 session resolved that euthanasia is strictly forbidden. It stated, however, that treatment can be withdrawn if three physicians, who should be competent, and trustworthy, decide that it causes harm for the patient and does not help to improve their health. The resolution added that it is necessary to maintain overall care for the patient through continuing nutrition and

eliminating or minimizing pain as much as possible. The same position was also adopted by the European Council for Fatwa and Research (ECFR) during its 11th session, held in Stockholm in July 2003. Besides the fatwas issued by these transnational institutions, other fatwas issued by national committees in specific Muslim countries like Saudi Arabia and Kuwait also adopted the same position.<sup>104-107</sup> As we discuss below, some of these fatwas had real impact and direct influence on how clinical care was regulated in hospitals.

Advocates of the second position (that withdrawing LSTs can be acceptable) employed various arguments to defend it. For those who recognized brain death from an Islamic perspective, the ethical soundness of withdrawing LSTs such as CPR was straightforward, because there is no benefit to keeping the organs of a deceased person working through mechanical tools. They argued that medical treatment (*tadāwī*) in Islam is not generally obligatory, especially when the efficacy of the treatment is uncertain. In the case of patients with terminal diseases, they added that there is either certitude (*yaqīn*) or preponderant probability (*ẓann rājiḥ*) that these LSTs are futile. They argued that forgoing treatment (*tark al-tadāwī*) in such cases will not raise any ethical complications, and they quoted early prominent religious scholars like al-Ghazālī (c. 1058-1111) to support their position.

Additionally, advocates of the second position listed many possible harms from continuing LSTs in such cases. They spoke about financial harm to the patient, their family and/or the healthcare system because of the high cost of LSTs. They also hinted at the ethical aspects of tying up scarce LST resources that may eventually be needed by a patient with a better prognosis. Another argument concerned the dying process (*iḥtiḍār*) from an Islamic perspective, which is usually characterized by pain and agony. Continuing LSTs would prolong *iḥtiḍār*, which is not in the patient's best interest.<sup>108-112</sup>

Who should be involved in the decision-making process about withdrawing LSTs? And, if there is disagreement, whose decision should override the others?

The collective fatwas issued by the IOMS, IFA and IIFA are silent about these questions, but national fatwa committees and some biomedical scientists expressed the same opinions. Muhammad Ali al-Bar spoke about different parties who must be involved, but he was inclined to entrust the treating physician with the authority to take the ultimate decision. However, al-Bar added that the treating physician should consult with at least two other physicians and that they should all formally sign the decision to be included in the patient's file. Al-Bar stressed that, before implementing the decision, the patient should be consulted, (or their legal guardian if the patient is incapacitated); the patient or guardian should have the right to refuse CPR, along with family members present.<sup>113</sup>

Al-Bar's opinion was premised on a number of fatwas issued in Saudi Arabia by the Permanent Committee for Scholarly Research and Issuing Fatwas (*Al-Lajna al-Dā'ima li al-Buḥūth al-ʿIlmiyya wa al-Iftā'*) and the Council of Senior Scholars (*Hay'at Kibār al-'Ulamā'*). The most relevant piece in this regard was Fatwa no. 12086, issued in 1989 by the Council of Senior Scholars. Besides advocating the position that withdrawing LSTs can be acceptable, the fatwa clearly stated that the authority to take CPR-related decisions is exclusive to a medical team consisting of three physicians. The fatwa stated that the opinions expressed by the patient's family members are not to be considered, because continuing or withdrawing LSTs falls outside their expertise.<sup>114</sup>

Fatwas that supported the second position (for withdrawing LSTs) have been embraced by various hospitals in the Gulf region, which adopted them in their DNAR policies and guidelines. For example, HMC in Qatar, and North West Armed Forces Hospital (NWAFFH) and King Faisal Specialist Hospital and Research Center in Saudi Arabia all adopted Fatwa no. 12086 in their DNR policies. Although their medical teams have the authority to take the ultimate decision, these hospitals also clearly indicated that they always try to involve the patients and their families in the decision-making process.<sup>115, 116</sup>

Despite the richness of these bioethical deliberations, problems and difficulties persist. For example, the deliberations assume the form of fatwas, whose key function is to outline ethically accepted options within the Islamic tradition – to provide opinion, not binding law. Although the fatwas issued by collective bodies are usually more authoritative than those issued by individuals, the very nature of fatwa is that it is a non-binding opinion. Alongside ethical guidance, physicians need clear-cut regulations to protect them from charges of liability in court. This task must be taken up by the respective ministries of health and justice in each Muslim-majority country, in accordance with their own political and sociocultural needs.

### Artificial nutrition and hydration (ANH)

The IFA resolution adopted in May 2015 was general and somewhat vague on certain points. The third item of the resolution reads:

**“It is not permissible to stop treating the patient unless three trustworthy specialist physicians decide that the treatment causes harm for the patient and has no effect on improving his condition. However, it remains significant to continue providing care for the patient, represented in feeding him and removing or minimizing pain as much as possible.”<sup>117</sup>**



One can conclude that the resolution was referring to the possibility of withdrawing CPR and mechanical ventilation, but suggesting that forgoing ANH is unethical. This is echoed by Muhammad Ali al-Bar in the book he co-authored with the Saudi-based cardiologist Ḥassān Shamsī Bāshā, *Contemporary Bioethics: Islamic Perspective*. The authors argued that withholding ANH would lead to a prolonged, terrible death of starvation and dehydration – even worse than euthanasia – and concluded this would be homicide.<sup>118,119</sup>

This conclusion is based on drawing an analogy between withdrawing ANH and a paradigm case mentioned in pre-modern sources of Islamic jurisprudence (*fiqh*): detaining a person and denying them basic necessities of life, especially food and drink, until death occurs. In this paradigm case, the majority of pre-modern Muslim jurists stated that the detainer would be held liable for the death of the detainee.<sup>120</sup> However, the soundness of this analogy can be questioned at various points.

The classical juristic deliberations on this paradigm case, (which is sometimes called *qatl al-ṣabr*), sought to differentiate between various types of homicide – specifically which types would make the perpetrator liable for death penalty (*qiṣāṣ*) or blood money (*diyya*), depending on different factors, one of which was the intention of the perpetrator to terminate the victim's life.<sup>121-123</sup> These classical sources speak about instances where the perpetrator undeniably intended to harm their victim – whereas a physician treating a terminally ill patient has no intention but to minimize the patient's pain. Also, the victim in the paradigm case has a normal health condition, and could have lived further with normal access to food and drink. This cannot be equated with a PC patient who is approaching the end of their life, with no hope of restoring their normal health.

Instead of using homicide (or *qatl al-ṣabr*) as the governing frame, we believe the following Prophetic tradition is more relevant: "Do not force your patients to [consume] food or drinks. Truly, God feeds and waters them."<sup>124</sup> Pre-modern Muslim jurists used to integrate this statement in their discussions on medical treatment (*tadāwī*) to indicate that patients should not be forced to take medication or nutrition because this may cause them harm.<sup>125,126</sup> Some of these pre-modern jurists, such as Ibn al-Qayyim (d. 1350), stated that physicians of their time agreed with this conclusion.<sup>127</sup>

The two PC physicians who contributed to this study argued that the point raised by al-Bar, namely that withdrawing nutrition and hydration would increase the suffering of the patient, cannot be generalized. They stated that the GI tract, the organ in human bodies responsible for taking in food, digesting it to extract and absorb energy and nutrients, and then expelling the remaining waste as feces, becomes dysfunctional in some patients with advanced terminal illness, including cancer and advanced progressive dementia. Also, patients with diseases like end-stage cancer often have difficulty in mobilizing fluid from their bodies, and it eventually accumulates in unwanted places such

as the abdomen and lungs. This means that ANH for such patients may exacerbate these problems. Even providing the benefit of alleviating the symptom of hunger becomes doubtful because most dying patients are no longer experiencing hunger and the organ systems are simply shutting down.

What we want to stress is that the thesis advocated by some voices in contemporary Islamic bioethics – that withdrawing ANH is tantamount to murder – does not stand up to scrutiny. While highlighting some of the problematic aspects and flaws of this thesis, we suggest that more rigorous, in-depth and interdisciplinary discussion is needed to reach evidence-based conclusions. As far as policies and regulations are concerned, management of ANH is much worse than mechanical ventilation and CPR. We are not aware of any distinct policies or regulations, not to mention binding laws, dedicated to withholding or withdrawing ANH that can inform PC physicians about how to do their work without facing possible liability issues.

## Navigating conflicting values

### Administering analgesics: dying without pain or with a clear mind?

As discussed previously, ethical conflicts may arise in the use of opioid drugs to relieve pain. First, such drugs can reduce or remove a patient's awareness, which can be considered harmful from social and religious perspectives. Second, the so-called 'palliative sedation' initiated as the last resort to manage intractable pain near death can entail the risk of 'hastening' death – coming closer, in the eyes of some ethicists, to 'euthanasia in disguise'.

Against this background, this section will address two key questions within the context of PC:

1. How can we strike a balance between achieving the benefit of managing pain and avoiding the harm of suppressing the patient's consciousness?
2. Would the foreseen, although unintended, effect of shortening a patient's life make the administration of pain-relieving drugs or analgesics unethical, despite the benefit of relieving a dying patient's intractable pain?

Concerning pain and pain management, anecdotes about pious and heroic figures in Islamic history speak about the preference they gave to bearing pain, no matter how intense it was, in order to keep their consciousness intact. The story of 'Urwa b. al-Zubayr (d. circa 713) and the amputation of his gangrenous foot – during which he insisted on remaining conscious to "receive God's reward for being patient with these agonies" – is such an example.<sup>128</sup> 'Urwa's story represents the ideal that some Muslims may want to reach rather than

the ethical norm that one must abide by. Both pre-modern and contemporary Muslim jurists agree that intentional suppression of one's consciousness is categorically forbidden. However, they state that the legal maxim "necessity overrides prohibition" (*al-ḍarūrāt tubīḥ al-maḥẓūrāt*) permits it in the case of medical necessity, such as surgery.<sup>129</sup>

Thus, the default rule within the PC context would be as follows: In order to ethically justify the act of reducing a patient's level of consciousness, which is seen as a harm, there should be a proportionately serious or compelling reason, which will be seen as a benefit. In this regard, the so-called 'pain ladder' or 'analgesic ladder' developed by WHO can be a helpful tool in this discussion. It states that a physician would typically start by prescribing the non-opioid painkillers, at the bottom of the ladder, then climb to mild opioids if pain persists, reaching strong opioids at the top of the ladder, if there are compelling medical reasons.<sup>130</sup>

When considering partial and temporary loss of consciousness caused by opioids, PC teams need to keep in mind how vitally important it can be for Muslim patients to perform certain religious rituals. For instance, performing ritual prayer five times a day is obligatory for adult Muslims, no matter how sick they may be – although poor health allows for certain concessions such as performing prayers in a shortened form (*qasr*), combining two prayers at once (*jam'*) or exemption from certain movements like bowing and prostrating. While planning the process of pain management, PC teams need to consider religious rituals that require consciousness to be properly performed.

Continuous deep sedation ('terminal sedation'), which can eventually result in total and permanent loss of consciousness, is the most controversial procedure. It can be argued that terminal sedation does not greatly differ from the general anesthesia in some surgeries, which also induces total loss of consciousness. Especially when it is administered only for the last few hours before death, terminal sedation used to relieve a dying patient from intractable and unbearable pain can be analogous to the general anesthesia used during open heart surgery. General anesthesia has been widely accepted by Muslim religious scholars and so terminal sedation, under certain conditions, can be tolerated too.

There are, however, significant differences between these two procedures. In the case of general anesthesia, while loss of consciousness can be longer than for terminal sedation, this remains temporary. In terminal sedation, loss of consciousness is permanent, continuing until the patient's death. This permanent character of the total loss of consciousness has its own costs at the religious and social level. For instance, the patient is usually recommended to utter the formula of *shahāda*, by saying, "There is no god but God and Muḥammad is the Messenger of God", when one feels that they are nearing death. At the social

level, the patient and the family will be distressed because they will not have the opportunity to be in conscious touch with each other during the very last hours, and to say 'goodbye'. Unfortunately, the very scarce and early-stage discussions on these issues in contemporary Islamic bioethics do not allow us to take a clear position. We believe that more rigorous discussions are needed, where various stakeholders from different backgrounds should be involved before coming to concrete conclusions.

Now, we move to the second question: Would the foreseen, although unintended, effect of shortening a patient's life make the administration of analgesics unethical, despite the benefit of relieving the intractable pain of a dying patient?

In its 2003 resolution on euthanasia, the ECFR classified painkillers that shorten one's life as indirect euthanasia and therefore forbidden.<sup>131,132</sup> In 2004, the IOMS addressed the same question in the 62nd article of The International Islamic Code for Medical and Health Ethics, but concluded that, "the intensified administration of a strong medication to stop a severe pain, although it is known that this medication might ultimately end the patient's life, is not forbidden".<sup>133</sup> However, available publications do not sufficiently detail the deliberations and arguments upon which ECFR's and IOMS's opposing positions were premised. Thus, more in-depth and interdisciplinary research is needed in this area.

Because of its relevance to this debate, we briefly discuss the paradigm case, mentioned in classical juristic sources, of digging a water well. Essentially this case states that creating a well for people to use is a morally good act, but putting the well in the middle of a busy road could lead to injuries or deaths. The unintended harm of causing injuries or deaths cannot be tolerated by arguing that the good act of providing water was the intended one. That is because the unintended harm was always very likely to happen. The ethical judgment would be different if digging the water well was inside a home. Yes, users *may* fall in and come to harm, but it is unlikely and the benefits of the water outweigh this small risk.<sup>134</sup> The appropriate use of analgesics in PC seems to be closer to digging a well inside a home rather than on a busy road.

## **Communicating bad news: truth or compassion at the deathbed?**

As far as the Islamic tradition is concerned, there are certain values to which Muslims in general are to be committed. The virtue of truthfulness (*ṣidq*) is all-important – and compassion for a patient's feelings does not make sufficient ethical ground for lying to them about their diagnosis or prognosis.

Historically speaking, the murder of the Second Caliph of Muslims, 'Umar b. al-Khṭṭāb (d. 644), shows how a physician could deal with the ethical dilemmas of communicating bad news within the framework of Islamic ethics.

The Caliph, having been stabbed by an assassin, was examined by a physician, who advised the Caliph: "Make your will (*awṣī*). I believe that it is just one or two days before you die". The Caliph commented: "He told me the truth and, had he said something else, I would not have believed him." This historical anecdote shows that neither 'Umar b. al-Khaṭṭāb nor the people around him, including family members and prominent Companions of the Prophet, were offended by the way the physician conveyed such bad news.

Literature produced within the Islamic tradition about the etiquettes of the physician (*adab al-ṭabīb*) supports communicating such news to a patient by using gentle words (*luṭf min al-qawl*) such as the aforementioned "Make your will (*awṣī*)". Sensitive, compassionate delivery of bad news – although the words may vary – remains the mainstream recommendation today.<sup>135</sup> According to a tradition attributed to the Prophet of Islam, it is recommended that people who pay a visit to a patient are cautious about their words and select hopeful words because this relieves the patient's agony.<sup>136</sup>

This is in line with what the *Islamic Code of Medical Ethics* states:

**"The Doctor shall comply with the patient's right to know his illness. The Doctor's particular way of answering should, however, be tailored to the particular patient in question. It is the Doctor's duty to thoroughly study the psychological acumen of his patient. He shall never fall short of suitable vocabulary if the situation warrants the deletion of frightening nomenclature or coinage of new names, expressions or descriptions."<sup>137</sup>**

Now, to whom should this bad news be communicated? One would reply: to the patient in the first instance. Within the Islamic tradition, the real owner of the human body is the One who Created it, namely God, but each individual has authority over one's own body, in the capacity of a trustee (*mu'taman*). Based on this understanding, which was couched in a famous legal maxim, "Nobody is allowed to dispose of others' properties without their consent", Muslim religious scholars agree that getting the patient's consent is indispensable before any examination can begin.<sup>138</sup>

Thus, physicians need to be aware that patients have the right to know about their health condition, but equally have the right *not* to know – or to delegate decision-making to someone else. That is why physicians need to enjoy a certain degree of cultural humility and not think that empowering patients means that all information about their health conditions must be communicated to them.

The physician needs to have an exploratory conversation with the patient to get a good idea of what is to be expected from both sides. As long as the patient is able to communicate with the treating physician, priority should be given to the patient's wishes. The opinions of family members should also be considered, although not at the cost of what the patient wants. If the patient is unable to communicate with the physician, the family should be asked to appoint one representative, whose opinion will be sought if there is disagreement among family members.

## ABBREVIATIONS

**ANH**

artificial nutrition and hydration

**CAPC**

Center to Advance Palliative Care

**CILE**

Research Center for Islamic  
Legislation and Ethics

**CPR**

cardiopulmonary resuscitation

**DNAR**

Do Not Attempt  
Resuscitation (order)

**ECFR**

European Council for  
Fatwa and Research

**GCC**

Gulf Cooperation Council

**GI**

gastrointestinal

**HMC**

Hamad Medical Corporation

**IFA**

Islamic Fiqh Academy

**IIFA**

International Islamic Fiqh Academy

**IOMS**

Islamic Organization for  
Medical Sciences

**LST**

life sustaining treatment

**ME**

Middle East

**NGO**

non-governmental organization

**NWAFH**

North West Armed Forces Hospital

**PC**

palliative care

**WHO**

World Health Organization

**WPCA**

Worldwide Palliative Care Alliance

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