# Ethics guidelines for palliative care of terminally ill patients in Islamic Republic of Iran

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## **ABSTRACT**

**Background:** There have been many challenges with clinical interventions and policy decisions to enhance the quality of life and care for patients facing life-threatening illnesses, thus highlighting the need for ethical considerations and guidelines for palliative care of terminally ill patients.

**Aim:** To document the development of guidelines for addressing ethical concerns in the palliative care of terminally ill patients in Islamic Republic of Iran.

**Methods:** The guidelines were developed in 4 phases: a scoping review of existing palliative care guidelines on PubMed, Scopus, Web of Science, Google Scholar, and 2 Persian databases; focus group discussions to improve the drafts guidelines; online opinion poll of 32 experts, including ethicists, religious scholars, psychologists, palliative care specialists, and sociologists; and a national workshop to produce the final guidelines for government approval.

**Results:** We published the "National palliative care ethical guidelines and regulations for terminally ill patients" in Islamic Republic of Iran after endorsement and approval by the High Council of Medical Ethics. The guidelines provides recommendations on 5 main aspects of palliative care: structure, composition and qualification of interdisciplinary teams; the roles and responsibilities of ethics advisors; general ethical principles governing palliative care practice; specific guidelines for psychological, spiritual and religious support; and protocols for ethical decision-making in end-of-life care.

**Conclusion:** Considering the challenges associated with palliative care, it is necessary to provide ethical guidelines specific to the needs of terminally ill patients. These guidelines will serve as a steppingstone towards integrating palliative care into the national healthcare services in Islamic Republic of Iran.

Keywords: Palliative care, end-of-life care, terminally ill, ethics guidelines, spiritual care, Islamic Republic of Iran

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## **Background**

In 1974, after completing a study on death and dying in a Canadian hospital ward, physician Balfour Mount, coined the term palliative care to describe the specific type of integrated care (pain management, counseling, among others) that is necessary in hospital wards where patients are either terminally ill or suffering from advanced life-threatening or debilitating chronic conditions (1). Palliative care is a patient-centred, integrated healthcare method aimed at enhancing the quality of end-of-life care for persons and their families confronting life-threatening or terminal illnesses. Appropriate candidates for palliative care are persons afflicted with various chronic or terminal stage illnesses such as cancer, congestive heart failure, kidney failure, chronic respiratory diseases, Alzheimer's, HIV/AIDS, cerebrovascular disease, neurodegenerative disorders and amyotrophic lateral sclerosis. Specialists in palliative

care engage in ethical decision-making, advance care planning (such as patient-centred advanced directives) and comprehensive care planning, to support ethical issues associated with a person's care (2).

Integrated, ethical care is achieved through the proactive identification and comprehensive management of physical, psychosocial, and spiritual suffering, particularly focusing on pain alleviation (3,4). Persons afflicted with life-threatening and incurable ailments represent a particularly vulnerable demographic within healthcare settings, contending with an array of medical, ethical, psychological, social, financial and religious or spiritual challenges that tend to stress patients rather than alleviate their suffering (5).

The World Health Organization (WHO) defined palliative care as a distinct medical discipline in 1986, with subsequent updates in 2002, 2014 and 2020 (3,4,6). WHO states that palliative care is an approach

dedicated to improving the quality of life for patients, both adults and children, and their families grappling with life-threatening illnesses. Palliative care focuses on identifying and addressing pain and other physical, psychosocial and spiritual challenges associated with end-of-life care and implementing swift procedures to alleviate these challenges.

Palliative care acknowledges dying as a natural process and seeks to provide relief from suffering without hastening or postponing death. It integrates psychological and spiritual support into patient care, assisting individuals to live as actively as possible until the end of life. Additionally, it offers vital support to family members or caretakers throughout the individual's illness and their subsequent bereavement period. This comprehensive approach to palliative care involves a multidisciplinary team and can be initiated early during the illness trajectory, alongside other life-prolonging and supportive treatments.

Mirroring global trends in pandemic levels of non-communicable diseases and/or life-threatening illness, the high prevalence of life-threatening and incurable diseases in the Islamic Republic of Iran generates a substantial burden for healthcare financing and infrastructure (5).

Iranian national data suggests that approximately 0.5 million individuals are afflicted with cancer or cancer-related illnesses, with an annual mortality of approximately 30 000 persons (7). Given the escalating global incidence and burden of cancers (8), we suggest that it is imperative to implement a suite of efficacious and cost-effective palliative care interventions, particularly tailored to the circumstances of low- and middle-income countries such as the Islamic Republic of Iran (9).

Palliative care in geriatrics has additional importance in ageing countries (10). In the Islamic Republic of Iran, only about 8.2% of the population is older than 60 years (11). Quality of life during the ageing process is accompanied by difficulties that include affliction with chronic noncommunicable diseases. According to the World Health Organization (12), the number of individuals older than 60 years globally will nearly double between 2015 and 2050; estimated to reach 22% by 2050. For example, while the population older than 60 is currently 1 in 10 in the Islamic Republic of Iran, the estimated proportion based on these estimates would be around 1 in 3 in only 35 years' time (13). WHO insists that health systems around the world need to evolve so they can effectively respond to the health and well-being of older individuals (12). WHO recently established a global strategic action plan to define new public health frameworks for healthy ageing (13).

In recent years, the Islamic Republic of Iran's Ministry of Health and Medical Education (MOHME) initiated some palliative care programmes such as the National Cancer Registration and Palliative Care Clinics (14). As palliative care continues to evolve across the country, collating and designing appropriate culturally accepted ethical guidelines is necessary to resolve ethical

problems in palliative care practices. The first and main goal of integrating medical ethics into palliative care is to increase ethical sensitivity and understanding of the complex issues involved in end-of-life care .

Currently, Iranian clinicians lack a well-defined set of palliative care ethical standards and guidelines that are culturally sensitive and comply with current national health regulations and the unique religious setting. The first national strategic plan for medical ethics was compiled in 2002 (15) and revised in 2017 (16). In 2008, an additional bioethical guideline was published in the Bulletin of the World Health Organization (17).

To generate a new set of ethical guidelines for Iranian healthcare specialists, we reviewed many of the key issues in principle-based bioethics and classified them into 4 main bioethics categories and themes of acceptance and respect (Tables 1 and 2). In particular, we used frameworks derived from principle-based bioethics regarding sensitive ethical issues related to palliative care (18). Following Gomez-Batiste and Connor (2), we assert that the following 5 key points should be considered when developing a national palliative care plan: (i) the primary goal of palliative care is the relief of pain and pain management using the best available medical evidence and standards; (ii) respect for autonomy and patient's dignity is essential; (iii) palliative care is multidimensional, requiring integrated ethical, physical, psychological, emotional, spiritual/religious and social and economic support systems; (iv) the palliative care plan should be so comprehensive that it includes nonterminal patients with advanced chronic conditions of various types and characteristics; and (v) a specialized, multidisciplinary team should be responsible for all palliative care cases.

#### Methods

We conducted this qualitative study in 4 distinct phases. Initially, we conducted a keyword and term search using PubMed, Scopus, Web of Science, Google Scholar and 2 Persian databases (SID and Magiran). We chose "palliative care", "palliative medicine", "ethics", "ethical guideline", "regulation", and "hospice" as our primary search terms.

Once appropriate research papers and ethical guides were identified using these broad search terms and articles selected and uploaded, we conducted a narrative literature review of the selected texts. In this review, we identified related concepts (such as patient privacy) and converted them into professional guidelines. Our research team generated an outline of related concepts and codes and shared it with colleagues at the Medical Ethics Group of Endocrinology and Metabolism Research Institute (EMRI) before compiling the first draft of the new guidelines.

In Table 3, we present some examples of the various guidelines we consulted to generate the first draft of our document.

Table 1 Bioethics challenges in palliative care

Autonomy	Beneficence/non-maleficence	Justice	Communication
<ul> <li>patient's dignity</li> <li>informed consent</li> <li>decision-making capacity</li> <li>the best possible care and comfort</li> <li>surrogate decision-making</li> <li>right to know</li> <li>truth telling</li> <li>healthcare team honesty</li> <li>patient's preferences and conflicts (of interests) among the patient and caretakers</li> <li>confidentiality</li> <li>privacy</li> </ul>	<ul> <li>quality of life</li> <li>relief of pain is a core ethical duty in medicine.</li> <li>relief from pain is a legal right (WHO)</li> <li>'double effect'</li> <li>end-of-life care</li> <li>the concept of a good death</li> <li>advance care planning (advance directives)</li> <li>respect do-not-resuscitate directive</li> <li>euthanasia</li> <li>physician-assisted suicide</li> <li>futility</li> <li>withhold or withdraw treatments</li> <li>withdrawal of life-sustaining therapies</li> <li>continuity of effective palliative care until end of life</li> <li>vulnerable groups and research</li> </ul>	<ul> <li>scarcity of health resources</li> <li>limiting life-sustaining treatments</li> <li>provider conflict</li> <li>critical care providers</li> <li>scientific knowledge on the subject</li> <li>availability of palliative care</li> <li>home versus hospital versus hospice care</li> </ul>	<ul> <li>spiritual/religious distress</li> <li>social support</li> <li>bedside clinical ethics</li> <li>consult availability</li> <li>effective and compassionate communications</li> <li>pain control and symptom</li> </ul>

Table 2 Attributes of Palliative care

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Respects	Accepts	
Value of life	The reality of death	
Patient autonomy	Truth and transparency	
Human dignity	High-quality care	
Quality of life	Alleviation of pain and discomfort	
Human feelings and emotions	Provide psychological and spiritual care to family members	

Our first draft of the new set of guidelines was discussed and revised through participation in 2 focus group discussions (Flowchart 1). Four medical ethics experts discussed the various selected guidelines and selected concepts and made edits to methodology where necessary. The document was then reviewed again by three other palliative care and nursing experts.

In the next phase, an opinions poll was conducted. The second draft was sent (via email) to 32 experts in medical ethics, palliative care and related disciplines. Based on their comments and feedback, the third draft was prepared for an expert consultative workshop.

In the final phase, 47 experts from different Iranian medical facilities and universities, such as Tehran, Kerman, Isfahan, Shiraz and Qom, conducted a joint workshop to collate feedback on the third draft and complete the final draft of the guidelines. This final document was then presented to the High Council of Medical Ethics for approval (Figure 1).

## Results

The main result of this consultative process was the publication of a new National palliative care ethical quidelines

and regulations for terminally ill patients in the Islamic Republic of Iran. (See reference 19 for link to guidelines in Farsi)

This new set of guidelines consists of 5 main sections:

- Interdisciplinary care team: structure, composition and qualification
- 2. Responsibilities and duties of ethics advisor
- 3. General ethical guidelines for palliative care practice
- Specific guidelines in psychological, spiritual and religious support
- Guideline for ethical decision-making in end-of-life care

The complete guideline is available in Farsi (19) and was published by the Academy of Medical Sciences of the Islamic Republic of Iran in 2021. After certification by the High Council of Medical Ethics of MOHME, the new guidelines in Farsi were shared with all universities nationwide to be used for teaching and practice.

## **Discussion**

The Islamic Republic of Iranian Patient's Rights Charter (20), initiated in 2009 by MOHME, prioritized providing

<sup>\*</sup> Considering the limitation of words in the journal, the full content of the guidelines in English will be available per request.

Table 3 Examples of palliative care guidelines consulted for this review

Guidelines	Website	
<ul> <li>The International Association for Hospice and Palliative Care (IAHPC):</li> <li>The IAHPC Manual of Palliative Care, 3rd edition, 2013</li> </ul>	https://hospicecare.com/what-we-do/publications/manual-of-palliative-care/	
<ul> <li>The Worldwide Hospice Palliative Care Alliance (WHPCA):</li> <li>Building Integrated Palliative Care Programs and Services, 2017</li> </ul>	http://www.thewhpca.org/resources/building-integrated-palliative-care-programs-and-services	
<ul> <li>The National Consensus Project for Quality Palliative Care (NCP), USA:</li> <li>The Clinical Practice Guidelines for Quality Palliative Care:</li> <li>Domain 8: Ethical and Legal Aspects of Care</li> </ul>	https://www.nationalcoalitionhpc.org/ncp/	
<ul> <li>The National Institute for Health and Care Excellence (NICE), UK:</li> <li>Improving supportive and palliative care for adults with cancer</li> </ul>	https://www.nice.org.uk/guidance/csg4	
<ul><li>American college of Surgeons, USA:</li><li>The Statement of Principles of Palliative Care</li></ul>	https://www.facs.org/about-acs/statements/50-palliative-care	
<ul> <li>Swiss Academy of Medical Sciences, Switzerland:</li> <li>Medical-ethical guidelines and recommendations:</li> <li>Palliative Care</li> <li>End of Life Care</li> <li>Decisions on cardiopulmonary resuscitation</li> <li>Advance directives</li> <li>Treatment and care of patients with chronic severe brain damage</li> </ul>	https://www.samw.ch/en/Publications/Medical-ethical-Guidelines.html	
Treatment and care of elderly persons dependent on care		
<ul> <li>GSF:</li> <li>• The National Gold Standards Framework (GSF) Centre in End of Life Care, UK</li> </ul>	http://www.goldstandardsframework.org.uk/	

Figure 1 A schematic view of the research process



comfort for terminally ill patients. It underscores the right of every individual to receive appropriate health care services, with emphasis on ensuring comfort for those nearing death. Comfort, in this context, involves reducing pain and suffering, addressing mental, social, spiritual and moral needs, and allowing dying patients to choose their death companion.

The Charter extends its provisions to allow for surrogate decision-makers if the patient is unable to consent to medical treatments or life-ending procedures. However, if the surrogate decision-maker opposes treatment against medical advice, physicians can seek intervention from relevant authorities. Moreover, if a patient lacks decision-making capacity but can contribute reasonably to some aspects of decision-making, their input should be respected (20).

In 2018, the Medical Council of the Islamic Republic of Iran published a *General Guideline for Professional Codes* of Ethics, comprising 13 chapters and 140 articles. Some of these articles are relevant to palliative care (21). Numerous ethical challenges, including end-of-life care, euthanasia, futile treatments, and truth-telling, have sparked debates in societal and academic circles for decades (22-24). While our new culturally-adapted guideline may not resolve all disputes, it will help healthcare authorities, professionals and biomedical ethicists to understand the unique circumstances surrounding chronic and

terminal illnesses and actionably demonstrate ethical sensitivity to move one step closer to optimal end-of-life related decision-making for patients and their families or caretakers.

## **Conclusion**

Palliative care presents a range of ethical challenges. Taking the initial step of providing novel ethical guidelines and regulations is essential if we are to integrate ethical palliative care into the Islamic Republic of Iran's national health care services.

To ensure the practical success of these guidelines, it is imperative to consider religious and cultural perspectives on the ethics of palliative care. Our guidelines should be evaluated regularly by panels of palliative care and medical ethics experts to add new insights from trials of these guidelines in hospitals and health care facilities.

Ultimately, we believe that establishing an effective palliative care system reduces the burden of end-stage illnesses. Given the shared religious and cultural backgrounds in the region and among neighboring Muslim countries, we assert that regular assessment and evolution of the guidelines should be conducted by a collaborative regional team. Promotion of high-quality primary and palliative care services in the Islamic Republic of Iran is crucial if we are to improve the overall long-term health and well-being of our society.

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**Competing interests:** None declared.

# Lignes directrices éthiques concernant les soins palliatifs dispensés aux patients en phase terminale en République islamique d'Iran

## Résumé

**Contexte:** Les interventions cliniques et les décisions politiques visant à améliorer la qualité de vie et de soins des patients confrontés à des maladies potentiellement mortelles ont posé de nombreux défis, mettant ainsi en évidence la nécessité de tenir compte des considérations éthiques et de formuler des lignes directrices concernant les soins palliatifs dispensés aux patients en phase terminale.

**Objectif:** Documenter l'élaboration de lignes directrices pour répondre aux préoccupations éthiques en matière de soins palliatifs destinés aux patients en phase terminale en République islamique d'Iran.

**Méthodes:** Lesdites lignes directrices ont été élaborées en quatre étapes: une revue exploratoire des lignes directrices existantes en matière de soins palliatifs sur PubMed, Scopus, Web of Science, Google Scholar et dans deux bases de données perses; des discussions de groupe ciblées pour améliorer les projets de directives; un sondage d'opinion en ligne réalisé auprès de 32 experts, y compris des éthiciens, des érudits religieux, des psychologues, des spécialistes des soins palliatifs et des sociologues; et un séminaire-atelier national pour établir le document final en vue de le soumettre à l'approbation du Gouvernement.

**Résultats:** Nous avons publié les « Lignes directrices et réglementations éthiques nationales en matière de soins palliatifs pour les patients en phase terminale » en République islamique d'Iran après avoir reçu l'approbation du Haut Conseil d'éthique médicale. Elles fournissent des recommandations concernant cinq aspects principaux de ce type de soins: la structure, la composition et la qualification des équipes interdisciplinaires; les rôles et responsabilités des conseillers éthiques; les principes déontologiques généraux régissant la pratique desdits soins; les lignes directrices spécifiques pour le soutien psychologique, spirituel et religieux; et les protocoles pour la prise de décisions éthiques en matière de soins de fin de vie.

**Conclusion :** Au vu des défis inhérents aux soins palliatifs, il est nécessaire de définir des lignes directrices éthiques spécifiques aux besoins des patients en phase terminale. Ces dernières faciliteront l'intégration de ce type de soins dans les services de santé nationaux en République islamique d'Iran.

## مبادئ توجيهية أخلاقية بشأن الرعاية الملطِّفة للمرضى المصابين بمرض عُضال في جمهورية إيران الإسلامية

باقر لاریجانی، فرزانه زاهدی، مینا مبشر، فتانه سادات بطحایی، رشا أطلسی، حمیده موسی بور، منصوره مدنی، مهشاد نوروزی

#### لخلاصة

الخلفية: ظهرت تحديات عديدة أمام التدخلات السريرية والقرارات المتعلقة بالسياسات الرامية إلى تعزيز جودة الحياة والرعاية المقدمة للمرضى الذين يواجهون اعتلالات مهددة للحياة، وهو ما يبرز الحاجة إلى وجود اعتبارات ومبادئ توجيهية أخلاقية للرعاية الملطَّفة للمرضى المصابين بمرض عُضال.

الأهداف: هدفت هذه الدراسة إلى توثيق عملية وضع المبادئ التوجيهية لمعالجة المخاوف الأخلاقية في مجال الرعاية الملطِّفة للمرضي المصابين بمرض عُضال في جمهورية إيران الإسلامية.

طرق البحث: سار وضْع المبادئ التوجيهية على 4 مراحل، وهي: استعراض استكشافي للمبادئ التوجيهية الحالية للرعاية الملطِّفة على منصات Scopus و Web of Science و Web of Science و Google Scholar و Web of Science و Web of Science و الأخلاقية وعلماء دين التحسين مسودات المبادئ التوجيهية، واستطلاع رأي عبر الإنترنت شارك فيه 32 خبيرًا من بينهم معنيون بالشؤون الأخلاقية وعلماء دين واختصاصيو علم نفس واختصاصيو رعاية ملطِّفة وعلماء اجتماع، وحلقة عمل وطنية لصياغة النسخة النهائية من المبادئ التوجيهية للحصول على موافقة الحكومة.

النتائج: نشرنا "المبادئ التوجيهية واللوائح الأخلاقية الوطنية بشأن الرعاية الملطِّفة للمرضى المصابين بمرض عُضال في جمهورية إيران الإسلامية" بعد اعتهادها، عقب موافقة المجلس الأعلى للأخلاقيات الطبية عليها. وتقدم المبادئ التوجيهية توصيات بشأن 5 جوانب رئيسية للرعاية الملطِّفة، وهي: هيكل الفرق المتعددة التخصصات وتشكيلها ومؤهلاتها، وأدوار مستشاري شؤون الأخلاقيات ومسؤولياتهم، والمبادئ الأخلاقية العامة التي تحكم ممارسة الرعاية الملطِّفة، والمبادئ التوجيهية المحددة للدعم النفسي والروحي والديني، وبروتوكولات اتخاذ القرار الأخلاقي في إطار الرعاية في مرحلة الاحتضار.

الاستنتاجات: نظرًا إلى التحديات المرتبطة بالرعاية الملطِّفة، من الضروري توفير مبادئ توجيهية أخلاقية مخصصة لتلبية احتياجات المرضى المصابين بمرض عُضال. وستكون هذه المبادئ التوجيهية بمثابة نقطة انطلاق نحو دمج الرعاية الملطِّفة في خدمات الرعاية الصحية الوطنية في جمهورية إيران الإسلامية.

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