

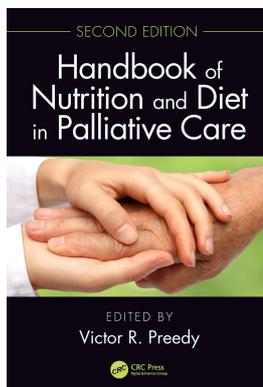
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## **Handbook of Nutrition and Diet in Palliative Care**

Victor R. Preedy

### **Religion, Culture and End-of-Life Issues**

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# 3 Religion, Culture and End-of-Life Issues

*Hans-Henrik Bülow*

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## INTRODUCTION

This chapter presents the rules and points of view of the major religions in the world regarding end-of-life decisions. Many of the references are from intensive care unit (ICU) studies, because that branch of medical science, frequently deals with the ethics of withholding or withdrawing life-sustaining therapy, alleviation of pain, treatment of patients in a persistent vegetative state and whether further therapy will be futile.

This review is an update of a paper from intensive care medicine with a considerably larger list of references than those given here (Bülow et al. 2008). Table 3.1 summarizes the various religions' attitudes and rulings with regard to end-of-life decisions, but not all religions have a ruling/point of view on all of the above-mentioned issues.

## DEMOGRAPHIC CHALLENGES

### Key facts of major demographic changes in the Western world

- The three major religions of the world are Christianity 2.4 billion, Muslims 1.8 billion and Hinduism 1.15 billion.
- Islam (Muslims) is the religion that presently is expanding most from its original areas into a worldwide presence, constituting a constantly growing, larger proportion in many countries.

**TABLE 3.1**  
**The Various Religions' View on End-of-Life Decisions**

	Withhold	Withdraw	Withdraw Artificial Nutrition	Double Effect <sup>a</sup>	Euthanasia
<b>Catholics</b>	Yes	Yes	No	Yes	No
<b>Protestants</b>	Yes	Yes	Yes	Yes	Some
<b>Greek Orthodox</b>	No	No	No	No <sup>b</sup>	No
<b>Muslims</b>	Yes	Yes	No	Yes	No
<b>Orthodox Judaism</b>	Yes	No	No	Yes	No
<b>Buddhism</b>	Yes	Yes	Yes	Yes	No
<b>Hinduism and Sikhism</b>	Yes	Yes	?	?	Some
<b>Taoism</b>	Most	Most	?	?	?
<b>Confucianism</b>	No	No	?	?	No

*Source:* With kind permission from **Springer Science+Business Media: *Intensive Care Med***, The world's major religions' point of view on end-of-life decisions in the intensive care unit, 34, 2008, 423–30, Bülow HH, Sprung CL, Reinhart K, Prayag S, Du B, Armaganidis A, Abroug F, Levy MM.

*Note:* Shows which end-of-life decisions and acts are allowed by the world's major religions. Question marks show that the religion has no official stance on that question.

<sup>a</sup> Double effect. (See Table 3.2.)

<sup>b</sup> Alleviation of pain is allowable, if it will in no way lead to the patient's death.

Healthcare systems have to acknowledge and cope with patients and physicians from many ethnic and religious groups, because the globalization of the world has meant that few countries now consist of homogeneous religious and cultural entities. The challenge in the forthcoming years is that patients and medical teams with different religious, cultural and ethical backgrounds adopt different approaches, even within the same religion (Daar and Khitamy 2001; Pauls and Hutchinson 2002; Sprung et al. 2007).

Islam is *the* example of a worldwide expanding religion with 1.8 billion Muslims (24% of the world's population). About 31% of all Muslims are of South Asian origin – the rest is worldwide (Wikipedia 2017). There are approximately 44 million Muslims in Europe and the prediction is that by 2050, one in five Europeans will likely be Muslim. Likewise, North America is changing. In the United States Hispanics in 2015 represented 17.6% of the population, compared to 6% in 1980 (<http://www.pewresearch.org> 2017). In Ontario, Canada, the number of Muslims increased 142% from 1991 to 2001 and the number of Sikh increased 110% while the Christian community only increased 3%.

Only one religious group is not expanding globally. At the end of World War II there were 800,000 Jews living in the Arabic countries – where they have been present for more than 2000 years. Today they are still in small numbers present in Tunisia and Morocco, but they have been expelled from most other countries on the Arabic peninsula – constituting a few thousand Jews among 280 million Arabs. This is in striking contrast to Israel, where in 1948 lived less than 200,000 Arabs – a population who has now grown to 1 million (20% of the Israel population) (Ziadeh 2017).

## THE VARIOUS RELIGIONS

### Key religious facts on eight major religions of the world

- Christian, Muslim, Greek orthodox and Hebrew points of view are based on holy scriptures, whereas universal scriptures in Far Eastern religions are not available.
- Almost all religions take the point of view, that patients should not suffer and that physicians should alleviate suffering if possible.

**TABLE 3.2****The Doctrine of Double Effect**

- Definition: Nothing hinders one act from having two effects, only one of which is intended, while the other is beside the intention.
- In this context: to relieve pain and suffering with the unintended side effect, that the medication can lead to death.

A variety of substantive medical and ethical judgments provide the justification:

- The patient is terminally ill
- There is an urgent need to relieve pain and suffering
- Death is imminent
- The patient and/or the patient's proxy consents

*Source:* McIntyre A, 2009. Doctrine of Double Effect. In *The Stanford Encyclopedia of Philosophy*. ed. Edward N. Zalta.

*Note:* Explains the term “double effect” where provision of pain relief may lead to a somewhat hastened death and the table also explains under which circumstances such an act is acceptable/allowed.

- There are important differences in patient autonomy among the various religions – but these differences are more based on culture than religious rulings.

**CHRISTIANITY**

Christianity encompasses such diverse groups as Mormons, Jehovah's Witnesses, Lutherans, Roman Catholics, and Orthodox Christians.

**Roman Catholic Perspective**

The Roman Catholic Church's official attitude was published in 1997 during the reign of Pope John Paul II (Catechismus Catholicae Ecclesia 1997). If futile therapy is burdensome or disproportionate to the expected outcome, then withholding or withdrawing is allowed. Despite allowing withdrawal of futile therapy, Pope John Paul II shortly before his death, expressed a firm stand against withdrawing artificial nutrition from patients in a persistent vegetative state – a statement that has raised controversy (Shannon 2006).

In 1980 “Declaration on Euthanasia” allowed alleviation of pain in the dying, even with life shortening as a non-intended side effect, also known as “the double effect” (McIntyre 2009) (Table 3.2), but active euthanasia is never allowed and palliative care is to be offered (Catechismus Catholicae Ecclesia 1997).

**PROTESTANTISM**

Most Protestants will, if there is little hope of recovery, understand and accept the withholding or withdrawal of therapy (Pauls and Hutchinson 2002). However, there is diversity within Protestantism on the question of euthanasia. The Evangelical Lutheran church in Germany has developed advance directives for end-of-life choices but rejects active euthanasia (May 2003), whereas theologians in the reformed tradition, for example, in the Netherlands defend active euthanasia.

**GREEK ORTHODOX**

The Greek Orthodox Church has no position on end-of-life decisions, since the task of Christians is to pray and not to decide about life and death. The Greek Orthodox Church does not allow human decisions on such matters, and condemns as unethical every medical act, which does not contribute

to the prolongation of life. The bioethics committee of the Church of Greece has stated: “There is always the possibility of an erroneous medical appraisal or of an unforeseen outcome of the disease, or even a miracle” (The Holy Synod 2000). Therefore, it is not surprising that the withholding or withdrawing of artificial nutrition is not allowable even if there is no prospect of recovery.

The church also states that should a fully conscious patient request an omission of treatment (that might save him/her) it is the moral obligation of the physician to try persuading him/her to consent to that treatment.

Alleviation of pain is allowable only if the medication with certainty does not lead to death. This is somewhat surprising, since “euthanasia” is actually the Greek word for “good death” which is defined as “a peaceful death with dignity and without pain.”

The actual international meaning of “active euthanasia” is perceived as “mercy killing” and is under no circumstances allowed by the Greek Church.

## JUDAISM

There are three Jewish denominations: reform, conservative and religious orthodox.

The Jewish legal system (*Halacha*) was developed from the Bible (Tanach), Talmud and rabbinic responsa (Steinberg and Sprung 2006). Israeli law was updated in 2006 in order to balance between the sanctity of life and the principle of autonomy. Withdrawing a continuous life-sustaining therapy is still not allowed, but withholding further treatment is allowed as part of the dying process, if it is an intermittent life-sustaining treatment – and if it was the clear wish of the patient (Steinberg and Sprung 2006). This is based on the assumption that each unit of treatment is an independent and new decision; hence it is permissible to withhold it. Thereby you can withhold chemotherapy or dialysis, even after initiation, because such treatment is viewed as omitting the next treatment rather than committing an act of withdrawal.

Food and fluid are regarded as basic needs and not treatment. Withholding food and fluid from a dying patient (or patients with other disorders) is therefore prohibited and regarded as a form of euthanasia. If a dying patient is competent and refuses treatment, including food and fluids, he/she should be encouraged to change his/her mind regarding food and fluid, but should not be forced against his/her wishes (Steinberg and Sprung 2006). The situation changes however, when the patient approaches the final days of life, when food and even fluids may cause suffering and complications. In such an event, it is permissible to withhold food and fluid if this was the patient’s expressed wish.

Based on the moral requirement to alleviate pain and suffering, the law and *Halacha* require providing palliative care to the patient and to his/her family. Treatments include palliative therapy that might unintentionally shorten life, based on the principle of double effect (Steinberg and Sprung 2006; McIntyre 2009).

However, active euthanasia or physician-assisted suicide is prohibited even at the patients’ request (Steinberg and Sprung 2006).

## ISLAM

Islamic bioethic is an extension of Shariah (Islamic law) based on the Qur’an (the holy book of all Muslims) and the Sunna (Islamic law based on the Prophet Muhammad’s words and acts) (Daar and Khitamy 2001), and the primary goal is: “*la darar wa la dirar*” (no harm and no harassment).

For Muslims, premature death should be prevented, but not at any cost, and treatments can be withheld or withdrawn in terminally ill Muslim patients when the physicians are certain about the inevitability of death, and that treatment *in no way* will improve the condition or quality of life (Ebrahim 2000). The intention must never be to hasten death, only to abstain from overzealous treatment.

According to Islamic faith, it would be a crime to withdraw basic nutrition (Ebrahim 2000; da Costa et al. 2002) because such a withdrawal would in effect starve the patient to death.

The Qur'an states that "Allah does not tax any soul beyond that which he can bear" and pain and suffering is a "*kaffarah*" (expiation) for one's sins. However, relieving a patient with painkillers or a sedative drug is allowed even if death is hastened (double effect) (McIntyre 2009), if death was definitely not intended by the physician (da Costa et al. 2002).

The two major branches of Islamic faith, the Shia and the Sunni branches, may differ somewhat, but not fundamentally in bioethical rulings. Nevertheless, the majority of Islamic communities will seek advice from their own religious scholars because the Islamic faith is not monolithic but rather a diversity of opinions (Daar and Khitam 2001).

The Qur'an emphasizes that "it is the sole prerogative of Allah to bestow life and to cause death" and consequently euthanasia is not allowable (Ebrahim 2000).

## HINDU AND SIKH

Hindu and Sikh religions are different, but both are duty based rather than rights based, and they both believe in *karma*, a causal law where all acts and human thoughts have consequences, good *karma* leads to a good rebirth and vice versa. Since Hindu religion does not have a single central authority to secure enforcement in Hinduism (Desai 1988), diverse interpretations, opinions and followings are possible.

Hindus and Sikhs do not die – death is merely a passage to a new life, but untimely death is seriously mourned (Desai 1988). The way you die is important. A good death is when you are old, have said your goodbyes and all duties are settled. Bad death is violent, premature and in the wrong place (not at home or at the river of Ganges).

A do-not-resuscitate order is usually accepted or desired because death should be peaceful (Desai 1988).

There is almost no teaching in Indian medical schools on palliative care and management of death.

The Indian Penal Code from 1860 British India prohibits euthanasia, but there is a long-standing tradition for suicide in certain defined circumstances – exemplified by the rule, that a terminally ill person may hasten death – as a spiritual purification and to ensure no signs of bad death (faeces, vomit or urine).

## CONFUCIANISM AND TAOISM

Bioethics does not formally exist within traditional Chinese culture. The predominant religion in the elderly Chinese population is Buddhism/Taoism, whereas almost 60% of the younger generation claims having no religion, because, Confucianism is not generally considered as a religion by most Chinese people. The moral perspective is primarily Confucianism but also Taoism and Buddhism (Bowman and Hui 2000). Consequently, with this mixture of different religions and philosophies in one population, very diverse opinions and dilemmas can be encountered.

According to Confucian teaching, death is good if one has fulfilled one's moral duties in life, and resistance to accept terminal illness or insisting on futile treatment may reflect the patient's perception of unfinished business (Bowman and Hui 2000).

Taoism is both philosophical and religious. In philosophical Taoism acceptance is the only appropriate response when facing death and artificial measures contradict the natural events. In religious Taoism death may lead to an afterlife in torture in endless hell – where a Taoist might cling to any means of extending life to postpone that possibility (Bowman and Hui 2000).

One thing is common in Chinese culture: The maintenance of hope is very important in the care of the dying, as hope prevents suffering by avoiding despair. Face-to-face interviews with 40 Chinese seniors 65 years of age or older showed that all respondents rejected advance directives (Bowman and Singer 2001). This is problematic seen from a Western (autonomous) point of view because it prohibits the physicians from discussing death in much detail with the patient.

The Chinese are more likely to prefer family-centred decision-making than other racial or ethnic groups. For example, do-not-resuscitate orders in dying Chinese cancer patients were seldom signed by the patient personally (Liu et al. 1999). Moreover, even if a Chinese patient is resigned to death, the children may strongly advocate for (even) futile therapy, because filial piety can only be shown when a parent is alive – and accepting impending death is equalled with removing the opportunity to show piety (Bowman and Hui 2000). Some Chinese patients may think differently. A study in Taiwan showed that cancer patients strongly proclaimed their superior rights to be informed about their disease before their family was informed (Tang et al. 2006).

Euthanasia is illegal in Hong Kong and on mainland China. The first reported case of euthanasia in China caused great debate because the Supreme Court announced the accused physician innocent of a crime, but the topic is seldom discussed in medicine and the law.

## **BUDDHISM**

As with Hinduism, there is no central authority to pronounce on doctrine and ethics. Buddhism is a flexible and moderate religion, and in practice, local customs will often be more important in the relationship between physician and patient than Buddhist doctrine (Keown 2005).

Classically, attitudes towards illness and death may be different for Tibetan, Indian, Thai, Japanese and Western Buddhists, because they are more culturally than religiously based.

Nevertheless, there are basic values shared by most Buddhists. The primary point is that there is no mandate or moral obligation to preserve life at all costs in Buddhism – this would be a denial of human mortality. There are no specific Buddhist teachings on patients in a persistent vegetative state, but maintaining artificial nutrition is a way to keep the patient alive artificially – which is not mandatory in Buddhism. Alleviation of pain, and the principle of double effect (McIntyre 2009), is accepted, but Buddhists strive to meet death with mental clarity. Therefore, some may abstain from analgesia or sedation. Hence, it is extremely important to inquire about specific attitudes that may be deeply held by a Buddhist patient and family who come from a particular culture.

Terminal care should be available and Buddhism supports the hospice movement (Keown 2005). Euthanasia or mercy killing is not acceptable (Keown 2005).

## **GUIDELINES**

### **Key facts of how to cope with religious/cultural challenges**

- There are major differences between the religions' view on palliation, information and end-of-life decisions, but almost universally euthanasia is not allowed.
- Medical teams should early on determine if there is a religious/cultural agenda as well as a medical one.
- Do not guess or suppose that you understand the patient's religious or cultural background. The only way to understand the situation correctly is to ask specifically about the areas you want to know about.
- Independently from the patients' religion and/or pressure from the patients' culture, you must of course adhere to the judicial and ethical rules that you usually work under.

There are five inevitable palliative care questions: What level of life-sustaining therapies? Alleviation of pain? What level of information to patient and relatives? Is euthanasia an issue? What are the final wishes with regard to death and burial?

Medical teams should early on establish their patients' and relatives' cultural background and religious affiliations, before deciding on these five issues.

Many authors (e.g., Daar and Khitamy 2001; Pauls and Hutchinson 2002) have recommended that the clergy of the patient's religion should be involved. If you identify and name differences between

the frame of the patient and that of the medical team, you will most likely minimize the potential religious conflicts and discussions (Hendriks 2012). Never promise beforehand unconditionally to follow religious rulings or advice though, as these may contradict local standards of ethics or care (e.g., keeping a brain-dead patient on a ventilator) or contradict secular law (e.g., abstaining from blood transfusion to a minor patient). Also, be aware, that people who classify themselves as belonging to a religion, do not necessarily attend their church or follow any of the religion's rulings.

Alleviation of pain is almost universally accepted (Table 3.1).

When it comes to information, protestant Reformation which celebrated its 500-year anniversary in 2017 put emphasis on personal freedom and the patients' right to be truthfully informed. In Western countries, this concept is no longer considered a unique feature of Protestant (religious) bioethics (Pauls and Hutchinson 2002). Greece, however, is an example of a Western country with a different view on patient autonomy. Approximately 96% of Greek orthodox believes that communication is important in the final stage of a disease, but only 23% agree that the patient should be informed of the prognosis (Mystakidou et al. 2005). This must be due to culture, because the Orthodox Church has not issued such a statement.

In many Asian cultures, patient autonomy is not an agenda (Bowman and Hui 2000), and death and dying is often viewed as a taboo subject. Discomfort with end-of-life conversations among physicians, the ignorance of patient wishes, no widespread tradition for advance directives and traditional Asian values of filial piety mean that in Asia you may meet a more aggressive stance by default than in the West (Koh and Hwee 2015).

The question of euthanasia is the least complicated religious issue. In Table 3.1, it is evident that euthanasia is almost universally not accepted.

When death is imminent, the question of tending to the dead and burial arrangements will arise. Again, it is important to adhere to the wishes of the patient and the family, because each person may have specific rules based on culture and religion (Cheraghi et al. 2005).

Reaching consensus is a key to success but is not always possible. In those (hopefully few) instances where consensus cannot be accomplished, you must act according to the local rules and ethics of your workplace. You will cause confusion and uncertainty and ruin the work climate within the medical team, if you change your way of dealing with end-of-life issues for each new patient (Brierly et al. 2012).

## ETHICAL ISSUES

### Key facts of ethical challenges in modern medicine

- Religions and cultures have since the 1980s had to adhere to a new reality where advances in medical technology have forced society, religious leaders and people to understand that end-of-life decisions must be dealt with.
- There are presently large differences in the world as to how this issue is dealt with.
- Second- or third-generation immigrants may be very different from their original background and their parents on this issue – as they may have assimilated and adopted the point of view of their new homeland.

The bioethics committee of the Church of Greece has stated: “Modern medical technology has produced unprecedented forms of death or conditions of painful survival incompatible with life; leading to new dilemmas and bringing forth unanswered questions” (The Holy Synod 2000). This highlights the problem that religious leaders have faced during the last 25 years. They have had to contemplate and agree on epoch-making decisions concerning end-of-life decisions. The Pope has issued statements, there have been Islamic international conferences, the Jewish legal system has issued rulings so that cessation of therapy becomes legally possible within the framework of Jewish religious law and Western Buddhists accept organ donation.

Until now, critical care medicine, including other advanced medical measures to keep patients alive, has essentially been a discipline of Western medicine because it demands a highly developed medical and economic system. Far Eastern countries have no established head of the various Far Eastern religions who can adjust and express the religious rulings on these issues during the twenty-first century. Nevertheless, with increasing economic growth, these countries will also have to develop local guidelines covering advanced medical therapy. In fact, India in 2012 issued guidelines for end of life with among other issues a modern approach to informed consent: “The physician has a moral and legal obligation to disclose to the capable patient/family, with honesty and clarity, any dismal prognostic status when further aggressive support appears non-beneficial” (Mani 2012).

Nevertheless, even when there is a clear-cut statement from church leaders, it may be difficult to incorporate the religious perspectives into modern medical decision-making. The Catholic Church allows withholding or withdrawing “extraordinary” therapy, but what is extraordinary? Mechanical ventilation could be ordinary at one stage in an illness, and extraordinary at a later stage of the same illness.

Strict ethnic and religious background is not the only factor that one must take into account, when dealing with end-of-life decisions. Recent immigrants will generally adhere rather strictly to the rules of the religion and culture in their native country (Bowman and Hui 2000), whereas second- or third-generation immigrants will often have adopted the dominant bioethics of their new country (this is known as acculturation) (Matsumura et al. 2002). However, when facing death, many individuals tend to fall back on their traditional cultural or religious background (Klessig 1992).

Not only are patients changing their behavioural patterns when they move to other parts of the world, so are physicians. Although religion is an important part of decision-making, regional differences among physicians of the same religion have been documented too, and these differences are most probably due to acculturation (Matsumura et al. 2002; Sprung et al. 2007). Even a straight religious statement is not necessarily adopted. According to Islamic law one is allowed to abstain from futile treatment, but in Tunisia withdrawing of treatment (Ouanes et al. 2012) or do-not-resuscitate orders (da Costa et al. 2002) is less frequent than in Western Europe – and in both papers this difference is mainly explained by cultural differences.

## KEY MAIN CONCLUSIONS

- Due to globalization medical staff must cope with many ethnic and cultural groups.
- The key to working with these different groups is to ask about and explore attitudes and beliefs, never to assume that you know beforehand.
- If conflicting views make consensus impossible, then the staff must apply local ruling laws and guidelines as their frame for work.

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**TABLE 3.3**

**Checklist to Establish Religious Beliefs, Cultural Affiliation and Family Background When End-of-Life Decisions Are Necessary**

- What do they think of the sanctity of life?
- What is their definition of death?
- What is their religious background, and how active are they presently?
- What do they believe are the causal agents in illness, and how do these relate to the dying process?
- What is the patient’s social support system?
- Who makes decisions about matters of importance in the family?

*Source:* Klessig J. 1992. *West J Med* 157: 316–22.

*Note:* Examples of questions that are suitable to ask when trying to explore patients’ and relatives’ cultural and religious background.

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## SUMMARY POINTS

- Globalization changes many parts of the world, diminishing homogeneous religious and cultural entities. Consequently, the medical staff has to acknowledge and cope with religious attitudes, beliefs and wishes of patients from many ethnic and religious groups.
- In a globalised world, religion and culture also have an impact on how physicians and nursing staff from different parts of the world interact and reach decisions.
- Worldwide patient autonomy often plays less of a role than in Western countries. Here family interactions can play a prominent role regarding treatment and information, very different from the usual Western context.
- Both religion and culture play an important role in end-of-life issues, but most physicians do not know their patients' religious affiliation, which can lead to a complete breakdown in communication.
- To avoid pitfalls, using the checklist in Table 3.3 is one way to explore culture and religion.
- Identify and name differences between the frame of reference of the patient and that of the medical team.
- It has been widely recommended early on to involve the clergy of the patient's religion. However, do not ever promise unconditionally to follow the clergy's advice or rulings, if you seek information, as this may clash directly with local legislation or the usual ethical framework in your workplace.
- By exploring these issues, it is usually possible to reach consensus, but if that is impossible, then the staff must apply the local ruling laws and ethical guidelines.
- In the context of a globalized world the statement of the ethics committee at Stanford University is important: "the key to resolving ethical problems lies in clarifying the patient's interests."

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