Approaches to patients and families with strong religious beliefs regarding end-of-life care

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Purpose of review
End-of-life (EOL) decisions with limitations are made daily in ICUs around the world and may involve between 2 and 22% of patients admitted to an ICU. EOL decisions may be affected by numerous factors, including location and religion. This review aims to determine an approach to patients and families with strong religious views.

Recent findings
Different religions have different approaches and beliefs regarding EOL care. Religious people choose more active life-sustaining measures than would nonreligious people. The patient's views on EOL care should be understood, although this is often not possible and the family members' or surrogates' understanding of the patient's wishes is relied upon. This is problematic as the family's wishes may differ from those of the patient. Family members may also have different religious beliefs or have different expressions of their beliefs. Through an open communication with the patient and/or family members, an understanding of the patient's views can be obtained and decisions regarding their involvement in decision making can be taken. Conflicts can be resolved by an interdisciplinary team approach including religious leaders.

Summary
Through proper open communication and understanding of the patient's and/or family's views on EOL care and involvement of religious leaders, decisions can be made regarding how to further care for the patient.

Keywords
communication, end-of-life, interdisciplinary approach, patient beliefs, religion

INTRODUCTION

End-of-life (EOL) decisions are made daily in ICUs and hospitals throughout the world. There are many situations that may trigger a discussion about EOL care. These include irreversible conditions, such as neurological conditions (massive stroke or intraventricular hemorrhage), unresponsiveness to maximal medical therapy and multiorgan failure. The incidence of EOL decisions with limitations has increased over the years and may involve 2–22% of patients admitted to the ICU [1–3].

The spectrum of EOL care was highlighted in the Ethicus study [3] and includes full-continued care, withholding treatment, withdrawal of treatment, active life-ending procedures and brain death. Full-continued care involves all aggressive treatments, including such therapies as mechanical ventilation, vasopressors and cardiopulmonary resuscitation (CPR). Withholding treatment refers to a decision not to start or increase a life-sustaining therapy (e.g., not performing CPR or not starting a vasopressor). Withdrawing treatment refers to a decision to stop a life-sustaining treatment already being given. Active shortening of the dying process refers to a circumstance in which someone performs an act with the specific intent of shortening the dying process; for example, giving an intentional overdose of potassium chloride or narcotics [3].

EOL decisions may be influenced by various variables, including differences in location (Europe, Israel, America) [2,3], different attitudes among caregivers (including physicians and nurses) patients and families [4], and religious and regional differences [5,6].

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Curr Opin Crit Care 2014, 20:668–672
DOI:10.1097/MCC.0000000000000148

KEY POINTS

- EOL decisions are made daily in the ICU.
- Different religious beliefs and affiliations affect EOL decisions.
- Open communication with patients and their families or surrogates.
- Interdisciplinary approach to understanding the patient's wishes and religious beliefs.

PATIENT'S WISHES

One of the problems that physicians face in the ICU is to understand the wishes of the patient regarding EOL care. Very often this is not possible as many patients do not have living wills or advanced directives and because of their condition they are unable to express their wishes. The family's, legal guardian's or healthcare proxy's understanding of the patient's wishes may need to be relied upon. This was highlighted by Cohen *et al.* [7] who noted that the majority of ICU patients (95%) who were dying or were subject to limitation decisions in European ICUs lacked decision-making capabilities. In only 20% of cases, the patient's wishes regarding EOL care were known and the majority of the information came from families. The family's knowledge of the patient's wishes may arise from the patient's previous family discussions or may result from the family member's impression of the patient's wishes. Cohen *et al.* [7] also found that families were more often informed (88%) about EOL decisions than asked about preferences for EOL decisions (25%).

Riessen *et al.* [8] investigated the influence of patient wishes on EOL decisions in a medical ICU and found that of 3401 patients treated in the ICU, 658 (19%) died in hospital. Of the patients who died, 126 (19%) received unlimited therapy and EOL decisions were made in 532 (81%) patients. Of these above cases, 104 (16%) patients made the EOL decision themselves and in 72 cases (12%), an advanced directive was present [8]. A legal healthcare proxy was designated in 8% of cases. The relatives were involved in 541 (82%) cases. When the family, legal guardian's or healthcare proxy are relied upon, it is often difficult to understand what the patient would have wanted and not what the family, guardian or doctor now want or think is best for the patient. Surrogates or family members often choose different therapies than the patient would and project their own views of what they predict the patient's views are [9]. Family members who incorrectly predict the patient's wishes request more active treatments than the patient would request [9].

Curtis and White [10] described a step-wise approach to family conferences. The medical information and condition of the patient is explained. An attempt is made to understand the patient's wishes. The family's or surrogate's desires to be involved in decisions need to be understood. After these areas are clarified, decisions can be made. The value, acknowledge, listen, understand and elicit (VALUE) mnemonic can be used to remember the important principles of physician–family communication [10].

RELIGION

Religion and religious affiliation are important to people both during periods of good health and during times of illness and may also influence EOL decisions [11]. Different religions have different laws regarding EOL care (Table 1). For example, the majority of Protestant Churches accept withholding and withdrawing treatments if found appropriate by the treating physician, but there are diverse beliefs and expressions of these beliefs among Protestants [12].

The Catholic Church, however, allows withdrawal of therapy and alleviation of pain and suffering in the dying process even if life is shortened as an unintentional side-effect, 'the principle of double effect' [6,13]. The principle of double effect permits performing a legitimate act even if the act results in a normally avoided effect, such as alleviating pain even if it unintentionally hastens death [13,14]. Withholding nutrition is controversial [14].

The Greek Orthodox Church adamantly rejects intentional shortening of life even by withdrawing therapy [15,16] and would only allow alleviation of pain if it in no way leads to the patient's death [6]. Greek Orthodox followers believe that a Christian's job is to pray and not to decide life and death matters [6].

Jewish law (Halacha) forbids hastening of death [17,18]. This is because Jewish law maintains that human life is of infinite value and as a result, the withdrawing of life-sustaining, continuous treatments is not allowed [18]. Therefore, withdrawing a ventilator, which is a continuous treatment, would be forbidden but withholding intermittent hemodialysis would be permitted [18]. If the ventilator was on a time switch from the time of initiation of ventilation and can be programmed to stop at certain times, this would convert ventilation into a noncontinuous treatment modality [18]. It is not only the ends that are important but also the means to that end. For example, in a dying patient whose death appears certain (the ends), limiting treatments like chemotherapy would be a permitted

Table 1. The various religions' views on end-of-life decisions

	Withhold	Withdraw	Double effect[a]	Withholding nutrition
Protestants	Yes	Yes	Yes	Yes
Catholics	Yes	Yes	Yes	Controversial
Greek Orthodox	No	No	No[b]	No
Orthodox Jews	Yes	No	Yes	No
Moslems	Yes	Yes	Yes	No

[a]Double effect: alleviation of pain is allowed, even if it unintentionally hastens death.
[b]Alleviation of pain is allowed, if it will in no way lead to the patient's death.
Adapted with permission from [6].

means, whereas withdrawing current vasopressors would not be an acceptable means. When the current vasopressor infusion ends and the syringe needs to be replaced, the treatment becomes an intermittent treatment and may be withheld [18].

Similarly, in the Moslem religion, everything possible must be done to prevent a person's premature death. However, withholding and withdrawing therapy are allowed in the terminally ill patient when the physician is certain that death is inevitable [19,20]. Moslems follow the principle of 'la darar wa la dirar' (no harm, no harassment) [6]. The intent of the physician should be to limit overzealous treatment and not to hasten death [20]. Both Jewish law and Moslem religion consider nutrition to be a basic need that should be continued [18,19].

Religious belief may also provide support for families and staff in the ICU. Brierley *et al.* [21▪] reviewed cases involving EOL care decisions in a pediatric ICU over a period of 3 years. Two hundred and three cases of withdrawal of treatment or limitation of invasive therapy were recommended by the physicians. In 186 cases (92%), there was agreement with family members. In 17 cases (8%), extended discussions with medical teams and local support mechanisms did not lead to a resolution. Eleven (5%) of these cases involved families with strong religious beliefs in divine intervention that claimed that intensive care should, therefore, not be stopped. The cases involved Protestant, Muslim, Jewish and Roman Catholic family members. Five of the 11 cases were eventually resolved with the assistance of religious community leaders and in one case, intensive care treatment was withdrawn following a court order [21▪]. The authors support the idea that most cases can be resolved with extensive dialogue with the families and chaplaincy, deference to the family's beliefs and shared involvement in decision making [21▪].

Within families, different members may interpret religion in different ways, and in these situations it may help to have a representative from the particular religion present [12]. Family members may also vary in the depth of connection to religion. Some may be religious and others may be merely affiliated with a religion. Family members with strong religious beliefs tend to request more treatment in favor of life prolongation and are more reluctant to withdraw life-sustaining therapies [11]. Family members who are merely affiliated with a religion may be influenced more by other factors like cultural influences and tend to choose less aggressive treatments and may be more in favor of withdrawing treatments [11]. This may further complicate EOL decisions in the ICU as the patient may have different strength of religious beliefs than the family members or surrogates.

Shinall and Guillamondegui [22▪] investigated the effect of religion on trauma patients and found that having a religious affiliation was associated with a 43% longer time to death when compared with patients without religious affiliation. This may be explained by the fact that religious patients want more aggressive life-prolonging therapies [22▪]. In this study, a request to see a chaplain was associated with a 24% decrease in the time to death. The chaplain, trained in assisting people to navigate their religious and spiritual issues, may influence the patient's understanding of his condition and assist in understanding the application of the religious principles to that situation. This may influence the quality or speed with which EOL decisions are made [22▪], and may explain the decrease in the time to death observed with this intervention. Spiritual care providers, who provide support for the family's spiritual and religious needs, prepare the families for family conferences and who are involved in understanding the patient's EOL wishes have been shown to increase family satisfaction with ICU care and decision making [23].

Religious leaders (priests, ministers, rabbis and imams) can play a vital role in assisting family members during difficult times and help them understand specific religious laws and views [12,24]. It may also help if a doctor who shares the same religious beliefs speaks to the family.

PHYSICIAN BELIEFS

One of the roles of the ICU physician is to present reasonable treatment options to the patient or the patient's surrogates to enable shared decision making about the best treatment options [25]. The physician's beliefs on EOL care, religious beliefs and associations and psychological factors may affect the presentation of various options. Schenker *et al.* [26] found that clinicians dealing with patients with a high mortality rate did not explicitly inform surrogates about the option of comfort care in over half of the clinician–family conferences. Reasons for not presenting comfort options include the focus of physicians on aggressive treatment of ICU patients and failing to appreciate that comfort care is an acceptable alternative to life-extending treatment [27]. Physicians may also view the ICU as the place wherein maximal treatment is given and may view comfort care as suboptimal care for their patients [26]. As a result of this, discussion about comfort care may only be initiated when the physician believes it is the most appropriate treatment option, and not mentioned initially as an acceptable alternative to full intensive treatment [26]. Psychological factors like the struggle to face death may inhibit physicians from initiating discussion about supportive versus aggressive care alternatives [26]. Physicians may attempt to protect the families from the emotional difficulty of thinking about the possibility of their loved one's death, and therefore do not mention the option of comfort care. This approach may actually lead to increased family distress and adverse bereavement as they are emotionally unprepared to handle the death of their loved one [26]. Bülow *et al.* [11] found that despite the fact that physicians and nurses would want less aggressive measures performed for them, they would provide more treatment for patients who typically wanted more aggressive therapies. It is important that doctors not force their personal beliefs on patients and families.

FAMILY INVOLVEMENT

The importance of family members' satisfaction with EOL decisions was evaluated by Gries *et al.* [28]. Family members were more satisfied with the decision making when they were involved in and supported during the decision making process. This supports shared decision making in the ICU; the patient and/or the patient's family make decisions together with the doctor [28,29]. This is different from the paternalistic approach in which the doctor makes the decision and informs the family about this decision [7]. Johnson *et al.* [30] found that there is a substantial variability in the role surrogates prefer to play in EOL decision making. Fifty-five percent of surrogates preferred to have final control over the EOL decision, 40% wished to share control equally with the physician and 5% wanted the physician to make the decision. The vast majority (90%) of surrogates, who preferred to make the final decision, did so after considering the physician's opinion [30]. Surrogates who had less trust in the treating physician preferred to have more control over the final EOL decision [30] as did surrogates with non-Catholic religious affiliation and male surrogates [30].

Discussion with families needs to be truthful and unhurried and should preferably be done between the same family representative and the same ICU doctor to ensure continuity of information and an understanding of each other. Unfortunately, this is not always possible and families often complain of inadequate discussions and inconsistencies in messages received from different doctors [31]. ICU physicians need to be trained to communicate with families as communication is a vital part of work in the ICU [32].

OTHER FACTORS

It is important for the healthcare workers to appreciate that their values and attitudes may differ from the patient's and family's values. These values are not always based on religion. The Ethicatt study [11] showed that doctors and nurses placed more emphasis on quality-of-life than absolute value of life than patients and families and would not want CPR or admission to ICU if faced with terminal illness. The family may request ongoing care of their loved ones in the belief that they have a debt to pay to the person. In Thailand, children believe they are indebted to their parents for giving them life and may request continued treatments for their parent in order to pay back this debt [33]. Although they may understand that the treatment will not change the outcome, they believe there is inherent value in continuing the treatment. This may lead to conflict with the medical team who believe the treatment is nonbeneficial if they misinterpret this desire as a hopeless effort to change the eventual outcome [33]. It is important for physicians to understand the reasoning on the basis of the process rather than outcome that may be very different [33]. Only with understanding and adequate communication, can the family members' motives be appreciated.

INTERDISCIPLINARY TEAM APPROACH

A part of shared decision making involves utilizing the resources of an interdisciplinary team, including doctors, nurses, social workers and religious leaders.

Interdisciplinary communication may lower physician burnout and assist in family communication and satisfaction [34].

CONCLUSION

Medical practitioners face EOL decisions daily in ICUs. Like ventilation decisions and decisions on fluid management, inotropes and antibiotics, training and experience in EOL decisions are important [32]. Open communication with family members is vital to avoid conflict and improve family members' satisfaction in the EOL decision process [28]. Family conferences should be held often and should include social workers and religious leaders [24] as part of an interdisciplinary approach. It is important to determine what the patient's wishes are regarding EOL decisions, although in most cases the family will be relied upon [7]. Once an understanding of the patient's attitudes toward EOL care is obtained, an understanding of the level of involvement the surrogate wishes to take needs to be clarified and physicians need to be comfortable with different levels of authority [30]. Communication with family members may be complicated when there are cultural differences between the physician and the family members [31]. Religious leaders not only support the family but also help the family better understand their religious viewpoints [12,21▪,24].

No matter what the doctor believes or the disappointment experienced that ICU treatment will not save the patient, the physician needs to keep the guiding principle of Dr Edward Trudeau in mind: 'to cure sometimes, to relieve often, to comfort always' [35].

Acknowledgements

None.

Conflicts of interest

The authors have no conflicts of interest to declare.

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

- ▪ of special interest

1. Sprung CL, Paruk F, Kissoon N, *et al.* The Durban World Congress Ethics Round Table Conference Report: I. Differences between withholding and withdrawing life-sustaining treatments. J Crit Care 2014. [Epub ahead of print]
2. Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. Am J Respir Crit Care Med 1998; 158:1163–1167.
3. Sprung CL, Cohen SL, Sjokvist P, *et al.* End of life practices in European intensive care units: the Ethicus Study. JAMA 2003; 290:790–797.
4. Sjokvist P, Carmel S, Sprung CL, *et al.* Attitudes of European physicians, nurses, patients, and families regarding end-of-life decisions: the ETHICATT study. Intensive Care Med 2007; 33:104–110.
5. Sprung CL, Maia P, Bulow HH, *et al.* The importance of religious affiliation and culture on end-of-life decisions in European intensive care units. Intensive Care Med 2007; 33:1732–1739.
6. Bülow HH, Sprung CL, Reinhart K, *et al.* The world's major religions' points of view on end of life decisions in the intensive care unit. Intensive Care Med 2008; 34:423–430.
7. Cohen S, Sprung C, Sjokvist P, *et al.* Communication of end-of-life decisions in European intensive care units. Intensive Care Med 2005; 31:1215–1221.
8. Riessen R, Bantlin C, Wiesing U, Haap M. End-of life decisions in intensive care units. Influence of patient wishes on therapeutic decision making. Med Klin Intensivmed Notfmed 2013; 108:412–418.
9. Marks MA, Arkes HR. Patient and surrogate disagreement in end-of-life decisions: can surrogates accurately predict patients' preferences? Med Decis Making 2008; 28:524–531.
10. Curtis J, White DB. Practical guidance for evidence-based ICU family conferences. Chest 2008; 134:835–843.
11. Bülow HH, Sprung CL, Baras M, *et al.* Are religion and religiosity important to end-of-life decisions and patient autonomy in the ICU? The Ethicatt study. Intensive Care Med 2012; 38:1126–1133.
12. Pauls M, Hutchinson RC. Bioethics for clinicians: 28. Protestant bioethics. CMAJ 2002; 166:339–343.
13. Evangelium vitae, encyclical letter on the value and inviolability of human life His Holiness Pope John Paul II. 25 March 1995. http://www.newadvent.org/library/docs_jp02ev.htm. [Accessed 24 June 2013].
14. Engelhardt HTJJr, Iltis AS. End-of-life: the traditional Christian view. Lancet 2005; 366:1045–1049.
15. Hatzinikolaou N. Prolonging life or hindering death? An Orthodox perspective on death, dying and euthanasia. Christ Bioeth 2003; 9:187–201.
16. Mystakidou K, Parpa E, Tsilika E, *et al.* The evolution of euthanasia and its perceptions in Greek culture and civilization. Perspect Biol Med 2005; 48:95–104.
17. Rosner F, Tendler MD. Euthanasia. In: Rosner F, Tendler MD, editors. Practical medical Halacha. Jerusalem: Feldheim; 1980.
18. Steinberg A, Sprung CL. The dying patient: new Israeli legislation. Intensive Care Med 2006; 32:1234–1237.
19. Ebrahim AFM. The living will (Wasiyat Al-Hayy): a study of its legality in the light of Islamic jurisprudence. Med Law 2000; 19:147–160.
20. Sachedina A. End of life: the Islamic view. Lancet 2005; 366:774–779.
21. ▪ Brierley J, Linthicum J, Petros A. Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children? J Med Ethics 2013; 39:573–577.
This article highlights how shared decision making, good communication and a multidisciplinary approach can be successfully used in difficult EOL decisions.
22. ▪ Shinall MC Jr, Guillamondegui OD. Effect of religion and end-of-life care among trauma patients. J Relig Health 2014. [Epub ahead of print]
This article emphasizes the importance of religious leaders' involvement in EOL care.
23. Johnson JR, Engelberg RA, Nielsen EL. The association of spiritual care providers' activities with family members' satisfaction with care after a death in the ICU. Crit Care Med 2014; 42:1991–2000.
24. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: 'you got to go where he lives'. JAMA 2001; 286:2993–3001.
25. Wirtz VC, Cribb A, Barber N. Patient-doctor decision-making about treatment within the consultation: a critical analysis of models. Soc Sci Med 2006; 62:116–124.
26. Schenker Y, Tiver GA, Hong SY, White DB. Association between physician's beliefs and the option of comfort care for critically ill patients. Intensive Care Med 2012; 38:1607–1615.
27. Bertolini G, Boffelli S, Malacarne P, *et al.* End-of-life decision-making and quality of ICU performance: an observational study in 84 Italian units. Intensive Care Med 2010; 36:1495–1504.
28. Gries CJ, Curtis R, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. Chest 2008; 133:704–712.
29. Carlet J, Thijs LG, Antonelli M, *et al.* Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium. April 2003. Intensive Care Med 2004; 30:770–784.
30. Johnson SK, Bautista CA, Hong SY, *et al.* An empirical study of surrogates' preferred level of control over value-laden life support decisions in intensive care units. Am J Respir Crit Care Med 2011; 183:915–921.
31. Azoulay E, Chevret S, Leleu G, *et al.* Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med 2000; 28:3044–3049.
32. Spinello IM. End-of-life care in ICU: a practical guide. J Intensive Care Med 2011; 26:295–303.
33. Stonington SD. The debt of life: Thai lessons on a process-orientated ethical logic. N Engl J Med 2013; 369:1583–1585.
34. Carline JD, Curtis JR, Wenrich MD, *et al.* Physicians' interactions with healthcare teams and systems in the care of dying patients: perspectives of dying patients, family members, and healthcare providers. J Pain Symptom Manage 2003; 25:19–28.
35. Gordon AS. End-of-life issues. Caring 2001; 20:6–9.