End-of-Life Decisions – Some International Comparisons

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Introduction

Some of the most difficult ethical and legal questions arising in healthcare result from end-of-life issues. Physicians, nurses and social workers can find themselves confronted with problematic situations involving patient and family wishes for end-of-life care as well as professional concerns about continuing to provide medically futile treatment for patients. Palliative care and hospice programs have been instituted in many hospitals worldwide and provide valuable resources for providing end-of-life care (see Figure 1).

The use of hospital ethics committees, ethics consultants and legal counsel can all help to focus specific case discussions in an attempt to provide appropriate resolutions, but the use of these resources is mostly advisory in nature. Final decisions in institutions remain the responsibility of the hospital’s management and attending medical staff, meaning that healthcare executives and medical staff members must develop appreciation for the appropriateness of specific medical interventions at the end of life, even if the patient has executed an advance directive.

Figure 1. International legal status on end-of-life care

<table>
<thead>
<tr>
<th>Country</th>
<th>Law allows for institutional ethics committees</th>
<th>Law allows for advance directives</th>
<th>Law allows for assisted suicide and/or euthanasia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Great Britain</td>
<td>Yes (McLean 2007)</td>
<td>Yes (Toller and Budge 2006)</td>
<td>No</td>
</tr>
<tr>
<td>Canada</td>
<td>Yes (Gaudine et al. 2011)</td>
<td>Yes (Browne and Sullivan 2006)</td>
<td>No</td>
</tr>
<tr>
<td>US</td>
<td>Yes (McGee et al. 2002)</td>
<td>Yes (Lehmann 2008)</td>
<td>Assisted suicide only in five of 50 states</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Yes (der Kloot Meijburg and ter Muelen, 2001)</td>
<td>Yes (Rurup 2008)</td>
<td>Both assisted suicide and euthanasia</td>
</tr>
<tr>
<td>Slovakia</td>
<td>Yes (Glasa et al. 2000)</td>
<td>No (Glacova 2008)</td>
<td>No</td>
</tr>
<tr>
<td>Japan</td>
<td>Yes (Akabayashi et al. 2008)</td>
<td>Yes (Takezako 2012)</td>
<td>No</td>
</tr>
</tbody>
</table>

VOIP = voice over Internet protocol.
Medical care interventions at the end of life have been a rich source of controversy and debate in several Western nations. Withdrawing or withholding life-sustaining treatment (sometimes referred to as passive euthanasia), assisted suicide and euthanasia have drawn increased public attention as both proponents and opponents seek legislative and judicial remedies to more formally establish their positions, both for and against.

Three major themes seem to dominate early twenty-first century discussions of end-of-life care. The concept of medical futility, increased pressure worldwide to constrain the growth of healthcare spending and growing emphasis on the notion of patient autonomy have all served to raise the level of public discourse on end-of-life care.

**Medical Futility**
The concept of medical futility incorporates questions of resource consumption and economics (Darr 2005). When medical treatment might result in an anticipated effect, but yet not be beneficial to the patient, the concept of medical futility would indicate that healthcare providers are not obligated to initiate or continue the treatment. Thus the resources that would ordinarily be expended in the futile treatment are conserved and theoretically would be available for treatment of another patient who might benefit.

The application of the concept often places healthcare professionals in conflict with patients and surrogates who wish certain treatment to be initiated and continued in their belief that the treatment might improve the patient’s situation. The conflict usually arises between the professional’s knowledge of the likely futility of the intervention and the patient or surrogate’s hope for improvement or cure.

Institutional policies and procedures have been developed to navigate complex futility questions in ethics committees. In the United States and the United Kingdom there is open public debate about age as a criterion for healthcare rationing, while in Sweden age prioritization is less visible (Werntoft et al. 2007). Nevertheless, without regulatory guidance, economic pressures will force healthcare providers to closely examine the meaning of life and value of life under the umbrella of medical futility.

As medical futility discussions intensify in the United States and Europe, efforts to legislate end-of-life care will also intensify and legislative actions will reflect public sentiment both for, and in opposition to, end-of-life measures.

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**Economic Pressure**
World economic pressures and human rights concerns impact healthcare systems globally. Governments seek to balance access and quality of care against financing considerations, without violating social norms and creating ethical dilemmas. Healthcare reforms generate concerns for consumers, political parties, religious leaders, insurance companies, regulatory bodies and advocacy groups. Always present in reform discussions are end-of-life considerations and attempts to reduce the use of non-beneficial care.

Without clear national policy and understanding on non-beneficial care, managing and delivering care will be challenged in areas of informed consent, equity, prioritization and quality of life. Providing inappropriate care will be heavily scrutinized in cost-conscious economies, and issues of medical futility will require careful ethical analysis by physicians, administrators, groups and politicians. The right to refuse treatment and the right to die have drawn attention in Europe and in the United States. The circumstances under which
medical futility might be argued and the concepts of patient autonomy versus physician autonomy will generate debate on human rights, equity and transparency.

Patient Autonomy
Arguments surrounding end-of-life issues are somewhat similar to those encountered in discussions of population health: the interests of the individual may differ from the interests of the larger society.

Patient autonomy has been recognized as a first principle of bioethics. This principle holds that patients should be capable of determining their course of medical treatment to include having the ability to refuse unwanted treatment such as ventilator support. If the patient is incapable of communicating his or her wishes to caregivers, a legally recognized surrogate may be empowered to make decisions on the patient’s behalf.

The US Supreme Court addressed patient autonomy in end-of-life decision making when it issued its ruling in Cruzan v. Director, Missouri Department of Health (1990). The parents of a young woman rendered incompetent as the result of severe injuries from an automobile accident had sought permission from a Missouri state court to remove their daughter’s artificial hydration and nutrition equipment when it became apparent that the daughter had virtually no chance of recovering her cognitive abilities. In the majority opinion authored by Chief Justice William Rehnquist, the court ruled that “The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions” (Cruzan v. Director, Missouri Department of Health 1990).

Advance directives, to include living wills and durable powers of attorney for healthcare, may give direction in effecting the patient’s course of treatment. By making a living will, the patient specifies in advance the care that he or she wishes to have rendered in the event that the patient is unable to cogently express his or her wishes. Until a patient reaches the point of being unable to express his or her wishes, the patient may change his or her mind and countermand the intentions expressed in a previously prepared living will.

A durable power of attorney, prepared at the direction of the patient, designates a specific individual to make healthcare decisions on behalf of the patient when he or she is unable to do so. In the United States, holders of durable powers of attorney for healthcare are generally expected to use “substituted judgment” in making decisions for the patient who made the durable power of attorney, meaning that they are supposed to make decisions as they believe the patient would have made the decision himself or herself if they had been able to communicate their desires.

If the patient or surrogate reasonably believes that initiating or continuing certain forms of care or treatment is medically futile in that it will not improve the patient’s condition beyond the then-current state, such treatment generally may be refused or terminated. Some observers have argued that if the refusal results in the patient’s death, the patient has been the victim of passive euthanasia. The more frequently argued position is that a death resulting from foregoing or withdrawing life-sustaining treatment is an example of “double effect reasoning” as noted below (Munson 2012). Withdrawing or withholding life-sustaining treatment when such care is deemed medically futile has generally been accepted as appropriate in the United States, Canada and Europe.

Traditionally, legal authority would seem to favour the patient or surrogate’s decision to initiate or continue treatment over the professional’s wish to deny or discontinue the treatment. Courts in the United States and Europe have seemed to give greater weight to the ethical principle of patient autonomy and the right of self-determination in treatment decisions. But as state legislative action in Texas demonstrates, The Texas Advance Directives Act (1999) specified a protocol for...
resolving medical futility cases in hospitals. The Texas protocol, which follows American Medical Association recommendations for a due process approach, specifies that if a physician refuses to comply with a patient or surrogate’s request for treatment, the matter must be referred to “a hospital appointed medical or ethics committee in which the attending physician does not participate” (Truog 2007). The family is given 48 hours’ notice and is invited to participate in the consultation process. The committee then issues a written report that becomes part of the medical record. If the consultation process fails to resolve the dispute, the hospital and family must make reasonable efforts to transfer the patient to another facility willing to provide the requested treatment. If, after ten days, no such provider can be found, the hospital and physician may unilaterally withhold or withdraw the allegedly futile therapy. The patient or surrogate may seek a court ordered extension, which the law says should only be granted if the judge believes there is a reasonable likelihood of finding another provider willing to offer the treatment in question. If the family does not seek an extension, or the judge fails to grant one, the futile treatment may be unilaterally withdrawn and the treatment team is immune from civil and criminal prosecution (Truog 2007).

Withdrawing or withholding sustaining treatment when such care is deemed medically futile has been generally accepted as appropriate in the United States, Canada and Europe. The natural law ethical principle of double effect holds that if an action will have both bad and good effects, the action may be performed only if the good effect is intended and the bad effect will be an “unintended or indirect consequence” (Munson 2012: 887). Munson states that four conditions must be met:

- The action itself must be morally indifferent or morally good.
- The bad effect must not be the means by which the good effect is achieved.
- The motive must be the achievement of the good effect only.
- The good effect must be at least equally important to the bad effect (Munson 2012).

Assisted suicide involves a patient taking his or her own life with the assistance of one or more persons. Physician-assisted suicide means that a physician caregiver provides the assistance to the patient who is seeking to end his or her own life. The assistance would usually consist of providing lethal doses of medication that the patient would self-administer at the time of his or her choosing.

Although terminology varies somewhat in different nations, unlike assisted suicide, euthanasia involves another person taking direct action to terminate a patient’s life as opposed to the patient taking his or her own life. Euthanasia can further be categorized as voluntary, involuntary or non-voluntary depending on whether the patient has requested or consented to having someone else cause his or her death (Munson 2012). If the patient or surrogate is not actively involved in making the decision to end the patient’s life, the act is considered involuntary euthanasia.

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Some might argue that the administration of terminal sedation is euthanasia, but critics of the latter would argue that the very term “terminal sedation” is a misnomer and that the administration of pain medication is intended to comfort the patient and relieve the accompanying suffering. Although continued administration of pain medication may ultimately result in the death of the patient, adherents to the double effect principle would argue that the intent of administering the sedation is not to cause the death of the patient.
Ethical Theory and Principles
Advocates of assisted suicide and euthanasia advance a number of arguments for their positions. Materstvedt and colleagues (2003) cited a lack of palliative care in certain regions of Europe as a possible explanation for support of assisted suicide and euthanasia. From the ethical principle perspective, supporters of assisted suicide and euthanasia can argue that the principles of autonomy and beneficence support the idea that patients should be allowed to “choose the circumstances” of their death (Doyal 2001) and that if patients wish to die under those circumstances, that is in the best interests of the patients and should be legally permitted.

Opponents of assisted suicide and euthanasia would seem to base their arguments on the ethical principle of nonmaleficence, which Munson (2012: 892) categorizes as “perhaps the most famous and most quoted of all moral maxims in medicine.” The argument under this principle is that any action taken to intentionally end the life of the patient is morally wrong. The theoretical arguments in favour of assisted suicide and euthanasia might be categorized as utilitarian or teleological in that the morality of the act is to be judged by the outcome: the patient’s death is the desired result that validates the act of assisted suicide or euthanasia. Correspondingly, the opponents would argue from a deontological or perhaps Kantian perspective that the acts of assisted suicide and euthanasia are inherently immoral and should therefore be prohibited.

United States Perspectives
A patient or surrogate’s legal right to forego unwanted care and treatment, or to have life-sustaining treatment withdrawn if considered futile, has been generally accepted as permissible, and the US courts have upheld the rights of both patients and surrogates to forego life-sustaining treatment or to have it withdrawn, a distinction that some US courts have rejected (Menikoff 2001).

Elizabeth Bouvia was a 28-year-old patient in a California public hospital who petitioned the state court to have a nasogastric tube removed, which had been inserted and monitored without her consent to keep her alive through involuntary forced feeding (Bouvia v. Superior Court 1986). The California Court of Appeals ruled in her case that “a patient has the right to refuse any medical treatment or medical service…. This right exists even if its exercise creates a life threatening condition.” Despite the fact that Bouvia won her case, she decided not to end her life (Bouvia v. Superior Court 1986). Although the Bouvia decision is not legally binding in other states, its reasoning has been cited in other jurisdictions in support of a patient’s right to self-determination.

The right of a surrogate to have a patient’s life-sustaining treatment withdrawn was decided ten years earlier in a New Jersey appellate court case (In Re Quinlan 1976). The father of a 22-year-old female patient requested the withdrawal of life-support mechanisms from his daughter, who was diagnosed as being in a persistent vegetative state, but his request was opposed by her physicians, hospital and state law enforcement authorities. In a well-publicized and frequently cited decision, the New Jersey Supreme Court relied upon “the constitutional right of privacy” in ruling in the father’s favour.

Assisted suicide is legally permitted in five states. Oregon, Washington and Vermont have enacted statutes that allow for assisted suicide (ProCon.org 2013). In 2009, the Montana Supreme Court ruled that although physician-assisted suicide was not constitutionally protected, state law did not make it a crime for a physician to assist in a suicide (Baxter et al. v. Montana 1999). Two years later, a bill to legalize physician-assisted suicide in Montana failed in the state legislature, leading the bill’s sponsor to admit “…there’s nothing to protect the doctor from prosecution” (Williams 2011). In January 2014, a New Mexico state judge ruled that state law permitted physician assisted suicide (Mungin 2014).
From a federal constitution perspective, the US Supreme Court issued two significant decisions on assisted suicide in 1997. When asked to decide if New York State’s prohibition on assisting suicide violated the Equal Protection Clause of the US Constitution’s Fourteenth Amendment, since withdrawing life-sustaining treatment was permitted in New York, the Supreme Court ruled that the state’s position did not violate the amendment since there is a clear distinction between the two practices:

The distinction comports with fundamental legal principles of causation and intent. First, when a patient refuses life sustaining medical treatment, he dies from an underlying fatal disease or pathology, but if a patient ingests lethal medication prescribed by a physician, he is killed by the medication (Vacco v. Quill 1997).

Prior to the state of Washington legalizing assisted suicide in 2009, the state had a law that specifically prohibited the practice. Opponents of the state’s ban filed suit in federal court arguing that the state’s prohibition violated the Fourteenth Amendment to the US Constitution. The US Supreme Court ruled that the prohibition was permissible since “…our decisions lead us to conclude that the asserted ‘right’ to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause [of the Fourteenth Amendment]” (Washington v. Glucksberg 1997).

Euthanasia differs from assisted suicide in that someone other than the patient takes the action that causes the patient’s death. Euthanasia is not legally permitted in any of the United States.

Since 1991, ballot initiatives in five states have been introduced to legalize euthanasia and assisted suicide. Voters approved measures in Oregon, Washington and Vermont, but other initiatives were defeated in California, Michigan and Maine (Patient Rights Council 2012). A first such initiative in Washington state had been defeated in 1991. A total of 109 legislative proposals have been introduced in 24 states since 1994, but none have been passed by those states’ legislative bodies (Patient Rights Council 2012). Thirty-nine states statutorily prohibit assisted suicide and three additional states prohibit assisted suicide by common law. Four other states are unclear on the legality of assisted suicide (ProCon.org 2013).

**European Perspectives**

A consideration of European national policies on medical futility and end-of-life care reveals some interesting differences to the US perspective. While there is not a legal consensus among European countries on the issue of assisted suicide and euthanasia, the practices within individual nations demonstrate some variability (Spooner 2009).

Definitional differences among European nations further complicate the effort to compare European practices to those of the United States. Gadd (2004: 147) notes that “Although terms such as ‘euthanasia,’ ‘active euthanasia’ and ‘passive euthanasia’ were generally recognized, such terms were not necessarily found in national legislation.” She further noted of the terms that:

…their scope varied widely, for example from the Russian Federation which legally defines euthanasia as ‘complying with the request of a patient to hasten his (her) death with some action or means including discontinuing of life sustaining treatment’ to the Netherlands which defines it as ‘termination of life by a doctor at the voluntary and carefully considered request of a patient.’ (Gadd 2004:147)

As of August 2012, Belgium, the Netherlands and Luxemburg permitted voluntary euthanasia and assisted suicide.
Switzerland permits assisted suicide but not voluntary euthanasia (Burki 2009). All other European nations ban both voluntary euthanasia and assisted suicide.

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Great Britain has never permitted assisted suicide or euthanasia. While the Suicide Act of 1961 decriminalized suicide, the act prohibited assisting suicide. In its final ruling in 2009 before being replaced by the United Kingdom’s new Supreme Court, the Appellate Committee of the House of Lords ruled that the Director of Public Prosecution must issue an “offense-specific” policy identifying the facts and circumstances under which he would prosecute assistance in suicide under the provisions of the 1961 Act (Keown 2012). The appeal grew out of a petition in which a multiple sclerosis patient asked for a determination as to whether her husband would be prosecuted for helping her travel to Switzerland, where assisted suicide is legal, to end her life there.

Legislative efforts in other European nations have failed to legalize either assisted suicide or euthanasia. Schadenberg (2011) reported that in recent years Scotland, Israel and France all rejected attempts to legalize the practices in those nations.

Puppinck (2012) cited the adoption of a resolution against euthanasia by the Parliamentary Assembly of the Council of Europe as the first time, in recent decades, that a European political institution so clearly rejected euthanasia. The resolution came one year after the European Court “asserted that there is no right to euthanasia or assisted suicide under the European Convention” (Puppinck 2012). The Parliamentary Assembly developed a list of principles to govern the preparation of advance directives in the 47 states of the Council of Europe, stating that such documents are often a “back door” for introducing euthanasia or assisted suicide into legislation (Puppinck 2012).

Based in large part on this resolution, the European Court of Human Rights issued a ruling on July 19, 2012, upholding Germany’s ban on assisted suicide (Koch v. Germany 2012).

Several anonymous surveys of European physicians have indicated their willingness to engage in a range of end-of-life practices, especially if requested by a patient. However, the accuracy of such surveys might be called into question based upon physician respondents’ fear of prosecution. As Burki (2009: 447) has written: “… it is a mistake to assume that euthanasia and assisted suicide do not occur under prohibition.”

Canadian Perspective

Assisted suicide has long been prohibited under Canadian law. The Criminal Code of Canada outlaws assisted suicide and provides for incarceration of anyone assisting in a suicide (CBC.ca 2012). Attempted suicide was decriminalized in 1972.

In 1992, a woman from Victoria petitioned the Canadian Parliament, asking the legislators to change the country’s law banning assisted suicide (CBC.ca 2012). The Supreme Court of Canada ultimately ruled against her. However, a June 2012 ruling of the Supreme Court of British Columbia brought the issue of assisted suicide to the forefront of Canadian public policy. In the case of Carter v. Canada (Attorney General), the court granted a constitutional exemption permitting a Canadian citizen to obtain “physician-assisted death” under a number of conditions (Supreme Court of British Columbia 2012), ruling that the challenged provisions of the Criminal Code, when analyzed in light of the Canadian Charter of Rights, “unjustly infringe [on] the equality rights … and the rights to life, liberty and security of the person…” (Supreme Court of British Columbia 2012).
Interestingly, the court suspended the operation of the invalid provisions for one year, most likely to give parliament time to modify the law in conformity with the opinion. The British Columbia Court subsequently reversed the Supreme Court, fully upholding Canada’s laws against “doctor-prescribed death.”

Conclusion

Withholding and withdrawing life-sustaining treatment would seem to be ethically accepted practices in the United States, Canada and the nations of Europe. Although sometimes referred to as “passive euthanasia,” such practices are rationalized as recognition of medical futility, not as intending the death of the patient. As a similar manifestation of “double effect,” the administration of medication for pain or symptom relief is generally considered accepted even though it may have the unintended consequence of ending the patient’s life.

While institutional ethics committees and legally sanctioned patient advance directives might have been expected to facilitate discussion and debate on end-of-life issues, those measures do not seem to have increased public acceptance of assisted suicide and euthanasia. As Figure 1 indicates, while many advanced nations do have ethics committees and advance directives in place, the vast majority still do not legally allow for either assisted suicide or euthanasia.

Assisted suicide is legally permitted in four European nations and in five of the United States. In all, most jurisdictions that recognize the practice have detailed regulations that prescribe the involvement of the “assistants,” the documentation of the patient’s request and the required reporting to legal authorities.

Euthanasia is not legally permitted in any of the United States, but it does have legal recognition in three European nations: Belgium, the Netherlands and Luxemburg. Switzerland permits assisted suicide but not euthanasia.

While appellate courts have demonstrated some willingness to hear constitutional challenges to laws prohibiting the practices, legislative efforts in the United States, Canada and Europe have generally failed to advance the course of legalizing assisted suicide and euthanasia. Legislative bodies have more than likely reflected what they believe to be the will of the majority of their citizenry in refusing to legalize assisted suicide and euthanasia.

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