End-of-Life Decisions and Double Effect

How Can This Be Wrong When It Feels So Right?

Rita L. Marker

Abstract. The doctrine of double effect has a firm, respected position within Roman Catholic medical ethics. In addition, public debate often incorporates this doctrine when determining the acceptability of certain actions. This essay examines and assesses the application of this doctrine to end-of-life decisions. National Catholic Bioethics Quarterly 11.1 (Spring 2011): 99–119.

In July 2010, a sixty-two-year-old man announced that he wanted to end his life so that he could help others improve their lives. Having been diagnosed two years earlier with amyotrophic lateral sclerosis (better known as ALS, or Lou Gehrig's disease), he said, "I have a death sentence. It's just a matter of time. I know people are waiting on organs. I am going to die, so why not—while my organs are still viable—go ahead and save five to ten people." He explained, "I feel it is the right thing to do." The man was echoing a common sentiment: how can this be wrong when it feels so right?

The decision to do something because it feels right is as old as mankind.

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¹Ashley Fuller, "Man Tries to Donate Organs—Now," *Cherokee Tribune*, July 24, 2010, http://www.cherokeetribune.com/view/full_story/8877370/article-Man-tries-to-donate-organs---now?instance=home news bullets.

A variation on the man's theme is the premise that the end justifies the means—a premise that has been advanced by a Princeton University professor who has written favorably about the benefit of ending the life of a severely disabled newborn to make way for another child who would bring greater joy to its family.²

Both the rationalization of suicide to donate organs and the justification of infanticide to increase joy are indicative of the depths to which a disconnection from fundamental ethical principles can take individuals and society. They are illustrative of a trend to deny that any ethical and moral absolutes exist.

There have, of course, always been individuals who have sought to deny that there are any true and abiding principles. Others have questioned whether there is any universal truth, and still others have formulated their own theories to justify the actions they want to take. But in recent years there has been an enormous increase in attempts to justify actions that, only a generation ago, were unthinkable. Particularly when addressing end-of-life issues, concerted efforts to rationalize previously repugnant practices have led society down a pathway where what was previously appalling is touted as appealing.

Anyone who is concerned about the direction in which medical ethics is headed has the ability to influence its course. As policy makers have acknowledged, public acceptance is the key to setting policies and permitting practices that will be widely utilized. Therefore, a well-informed public is necessary. And "the public" is made up of individuals—individuals who can, themselves, become informed, and individuals who can make it possible for others to be informed.

At the heart of this is an understanding of what is meant by applying ethics (as opposed to what some call "doing ethics").

Contrary to what many assume, ethics is not religion and ethical principles are not sectarian. Ethics is distinct from moral theology. Moral theology proceeds from the standpoint of divine Revelation and ecclesiastical law. Ethics, on the other hand, proceeds from the standpoint of natural human reason alone.³ For example, "avoid evil" is an ethical principle that can be known by human reason. Another is "do not directly and intentionally kill an innocent human being."

Ethics, therefore, is defined as *the practical normative science of the rightness* and wrongness of human conduct as known by natural reason.⁴ An ethical principle is one that does not change. However, situations to which one applies the principle do change. Another way of expressing this is that an ethical principle applies the truth of all ages to the questions of the present. One such principle is the principle of double effect.

²Peter Singer, *Practical Ethics* (Cambridge, UK: Cambridge University Press, 1979), 134.

³ Austin Fagothey, *Right and Reason: Ethics in Theory and Practice* (St. Louis: Mosby, 1953), 21.

⁴Ibid., 26.

Elements of the Principle of Double Effect

According to the principle of double effect, it is ethically permissible to perform an act that has both a good effect and a bad effect if *all* the following conditions are met:

- 1. The act is good in itself or at least ethically neutral.
- 2. The good effect is not obtained by means of the bad effect.
- 3. The bad effect, although foreseen, is not intended for itself, but only permitted.
- 4. There is a proportionately grave reason for permitting the bad effect.⁵

An example of the principle's application helps illustrate this. Suppose a passerby who is not a good swimmer jumps into a river to save a small child who has fallen in and cannot swim. The rescuer may, in fact, drown. Nonetheless, we recognize this as a heroic deed—one which is justified by the principle of double effect:

- 1. The act itself apart from its consequences is indifferent. It is the mere act of jumping into a river.
- 2. The act has two effects. One is good—saving the drowning child. The other is bad—the rescuer's drowning. But the rescuer does not save the child by means of his drowning. If he makes it safely to shore, the child will be saved. The good effect is not accomplished by means of the bad effect.
- 3. The rescuer is not intending to die. His intent is to save the child. If, on the other hand, the rescuer used the opportunity to rescue the child as a subterfuge to mask his own suicide and intended his own death to occur, his intent would violate the third element of the principle. However, there is no reason to assume that such was his intention.
- 4. There is a proportionately grave reason for the rescuer's actions, since the child's life is at stake. But if the rescuer jumped into the rushing water to retrieve a trivial item, his action could not be ethically justified, because there would not be a proportionately grave reason for his act.

Today, the second and third elements of the principle are under intense attack in the debate over doctor-prescribed death (assisted suicide) and doctor-administered death (euthanasia). And that attack uses, as its largest weapon, an erroneous claim that the principle of double effect is nothing more than an outmoded religious rule, referred to with such labels as the "hypocritical principle of double effect," that gives cover for religious opponents to justify their actions.

⁵ Articulation of the principle of double effect can be found in Thomas Aquinas, *Summa theologiae* II-II, q. 64, a. 7.

⁶Faye Girsh, letter, *Washington Post*, October 17, 2000. Girsh is the past president of the Hemlock Society (now called Compassion and Choices). She is on the advisory board of the Final Exit Network.

Yet the principle, while rooted in Catholic tradition, has long figured prominently as a guide to ethical decision making in secular settings.⁷ Furthermore, although it was explicitly used for the first time by the U.S. Supreme Court in its 1997 decision regarding assisted suicide,⁸ it has a long history of use in American case law.⁹

Even so, attempts to marginalize those who look to the principle as a means of determining the right or wrong of a given course of action are escalating.

Attacking the Principle of Double Effect

Typical of the attacks is a commentary by Jacob M. Appel, a self-described bioethics and medical historian who holds an M. D. from Columbia University and a J. D. from Harvard Law School. In response to an article in the *Archives of Pediatrics and Adolescent Medicine* ¹⁰ that reported that more than 10 percent of parents of children who had died from cancer had considered hastening their children's deaths and that additional families believed physicians had hastened their children's deaths in direct response to their requests, Appel called for "aid-in-dying" to be available for children at their parents' request. He wrote,

Our society needs to drive pediatric aid-in-dying out of the medical closet. In an era of parental rights and child welfare, maybe we are finally ready to grant suffering minors the right to die.

The medical establishment's longstanding and inadequate solution to the suffering of terminally-ill patients, both children and adults, has been to rely upon the *convenient ethical fiction of "double effect."*...

Thomas Aquinas first proposed this moral sleight-of-hand in the thirteenth century. . . .

Yet the challenges of relying upon this clever if hazy principle far outweigh the benefits. Needless to say, many physicians will disagree about precisely when pain control ends and aid-in-dying begins—and the result may be that children continue to suffer.

⁷See, for example, American Medical Association, *Code of Medical Ethics*, opinion 2.20, "Withholding or Withdrawing Life-Sustaining Medical Treatment" (updated June 1996): "Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care. This includes providing palliative treatment even though it may foreseeably hasten death." See also *amici curiae* brief of the American Medical Association, American Nurses Association, and American Psychiatric Association in Support of Petitioners in *Vacco v. Quill*, 521 U.S. 793 (1997), 13a.

⁸ Vacco v. Ouill.

⁹For a thorough discussion of the historical use of the principle of double effect in case law, see Edward C. Lyons, "In Incognito: The Principle of Double Effect in American Constitutional Law," *Florida Law Review* 57.3 (July 2005): 469–563.

¹⁰ Veronica Dussel et al., "Considerations about Hastening Death among Parents of Children Who Die of Cancer," *Archives of Pediatric and Adolescent Medicine* 164.3 (March 2010): 231–237.

¹¹ "Aid-in-dying" is the current euphemism the assisted suicide and euthanasia activists use for doctor-prescribed suicide and doctor-administered death.

Even if the "double effect" approach could guarantee that all afflicted children might die without experiencing any physical pain or corporeal discomfort, which is highly implausible, such an approach would do little to staunch the emotional and existential anguish of the patient or her survivors. . . .

If an unconscious, terminally ill child's views are unknown, or a dying child is simply too young to comprehend death, parents ought to have every right to declare "enough is enough" and to obtain assistance from a physician in bringing a family tragedy to a speedy and decisive conclusion. Moreover, the parents should be allowed to make such a request legally and publicly, without shame or stigma, rather than having to rely on the *sub rosa* tactics of brave but discreet providers.

Granting parents the right to hasten the deaths of their dying children certainly does not prevent either physicians or the courts from intervening in the unlikely event that a caregiver appears to be guided by base and ulterior motives.

In matters of child dying, as in child rearing, an enlightened society should be willing to say that parents know best.¹²

Appel is neither the first—nor the best—known advocate of pediatric euthanasia and infanticide in recent years. The "good" effect of ending suffering for children and their families is viewed by such commentators as a justification for infanticide even though that supposed good effect is brought about by means of the bad effect—the death of the child.

Justifying the Means

Better known and even more vociferous in his promotion of infanticide is Peter Singer. Singer currently holds a chaired professorship in bioethics at Princeton University.¹³ In 1979, he proposed that children with disabilities (which need not necessarily be severe) be killed if the children's deaths would lead to more happiness for their families. Espousing what he referred to as the "total world view," he described a scenario in which a couple plans to have two children, positing a situation in which the second-born child is determined to be replaceable:

Suppose a woman planning to have two children has one normal child, and then gives birth to a haemophiliac child. The burden of caring for that child may make it impossible for her to cope with a third child; but if the defective child were to die, she would have another. It is also plausible to suppose that the prospects of a happy life are better for a normal child than for a haemophiliac.

¹² Jacob M. Appel, "Should Children Have a Right to Die?" *Huffington Post*, March 3, 2010, http://www.huffingtonpost.com/jacob-m-appel/should-children-have-righ_b_484318 .html, emphasis added.

¹³ Singer, formerly a professor at Australia's Monash University, is the Ira W. DeCamp Professor of Bioethics at the University Center for Human Values. At Princeton, Singer who is also an outspoken advocate of animal rights, molds and shapes the views of many future leaders in medicine, law, education, and business.

When the death of a defective infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the defective infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second. Therefore, if killing the haemophiliac infant has no adverse effect on others, it would, according to the total world view, be right to kill him.¹⁴

More recently, Singer affirmed that viewpoint, explaining that it "must be justifiable, in some cases at least, to end the child's life swiftly and painlessly." ¹⁵ As part of his rationalization of infanticide, Singer explained that infants can be killed because they are not yet persons. At one point he had suggested that the window for ending the life of an infant should be within the first twenty-eight days after birth. ¹⁶ However, the time frame has expanded:

Babies become persons when they develop some kind of awareness of themselves as existing over time. That is, when they can grasp that they are the same being who existed previously and who may exist in the future. As for saying exactly when that happens, I can't. I don't think anyone can. Though I would say it happens sometime during the first year of life but not in the first month of life.¹⁷

He predicted that by 2040 the sanctity of life ethic will be proved indefensible and replaced by a new ethic, in which society accepts the view that a person's life does not begin until there is self-awareness and that euthanasia is a "right." ¹⁸

Singer contends that religion has adversely affected people's ethical reasoning. "Religion has a major impact—basically in stopping people from thinking. This is not true of every religion; it's a generalization, but there are some religions, some ways of interpreting religions, that give you the sense that you know the answers. You've got them laid down as dogma or revelation or what your minister or priest or guru tells you, and you stop thinking. That's a bad thing." And while he acknowledges that his being an atheist probably affects his philosophy, he says, "There are some theists who would reach the same conclusions. But it's certainly easier to reach them if you are not religious." 20

Singer boldly asserts his views, clearly rejecting the principle of double effect. He claims that the distinction between an intended effect and an unintended effect

¹⁴Singer, *Practical Ethics*.

¹⁵"Dangerous Words: Professor of Bioethics Peter Singer and His Views on Life and Death Have Challenged the University and the World at Large," *Princeton Alumni Weekly*, January 26, 2000.

¹⁶ Peter Singer and Helga Kuhse, *Should the Baby Live*? (New York: Oxford University Press, 1986).

¹⁷ "Dangerous Words."

¹⁸ Peter Singer, "The Sanctity of Life: Here Today, Gone Tomorrow," *Foreign Policy* (September–October 2005).

^{19&}quot;Dangerous Words."

²⁰ Ibid.

is contrived, saying that a "consequentialist judgment lurks behind the doctrine of double effect" and that using double effect for a decision is a "disguised quality of life judgment." ²¹ When discussing the principle, Singer invariably depicts it as a uniquely Catholic doctrine.

In an article about hospital deaths by intentional overdoses of painkillers and other drugs, Singer called the principle "the Vatican's position" and wrote that "Roman Catholic thinkers ... would do well to examine the consequences of their own doctrines." ²²

Appel and Singer clearly dismiss the principle of double effect. But however great their influence, changes in the policies of professional organizations can have equally great, if not greater, effects on the way health care is provided.

Nurses on the Front Lines

Moral focus is generally directed at the decisions and actions of doctors. Yet nurses are truly on the front lines of patient care. Their understanding of ethical principles and the policies of their professional organizations are extremely important.

A provision in the 2001 American Nurses Association's (ANA) *Code of Ethics* stated, "The nurse should provide interventions to relieve pain and other symptoms in the dying patient even when those interventions entail the risks of hastening death. However, nurses may not act with the *sole* intent of ending a patient's life even though such action may be motivated by compassion, respect for patient autonomy and quality of life considerations." ²³

This statement seems to fulfill the third element of the principle—that the bad effect, although foreseen, is not intended—when it refers to interventions that entail the risk of hastening death. But closer examination reveals that the intent element is distorted. In taking a position that nurses may not act with the *sole* intent of ending a patient's life, the policy implicitly permits actions that are intended to hasten death. Thus, *hastening death is permissible under the policy as long as it is not the only intent*.

Even the most ardent supporters of doctor-prescribed suicide and doctor-administered euthanasia have the ending of patient suffering as their stated intent. Although their stated purpose is ending suffering, it is accomplished by ending the patient's life. Under the ANA's policy, both assisted suicide and euthanasia would be permissible, since hastening death is not the *sole* intent.

²¹ Singer, *Practical Ethics*, 210.

²² Peter Singer, "Theology's Unintended Consequences," *Guardian*, November 17, 2009.

²³ American Nurses Association, *Code of Ethics for Nurses with Interpretive Statements* (Washington, DC: ANA, 2001), 8, cited in Carolyn A. Laabs, "Nurses and Care of Patients at the End of Life: On the ANA Revised Position Statement," *Linacre Quarterly* 77.2 (May 2010): 168–174, emphasis added.

Obviously, this position violates the principle of double effect, because it allows an act based on the intent of hastening a patient's death so long as this is not the only intent.

Apparently, many nurses and the ANA itself originally interpreted the 2001 policy as a strict prohibition on intentionally hastening death. In 2009, a new position statement was drafted, increasing the emphasis on prohibiting an action if its *sole* intent was the patient's death: "The ethical framework of the profession as articulated through *The Code* (2001) explicitly prohibits deliberately terminating the life of any human being. This new position statement reframes the language to state that nurses do not participate in actions with the sole intent of causing death, but do participate in actions with the sole intent of responding to suffering and providing comfort care in the last stage of life." ²⁴ While the official position statement, released in 2010, does not include these sentences, it continues to emphasize that "nurses must uphold the ethical mandates of the profession and not participate in interventions that are directed *solely* toward ending a person's life." ²⁵

As with the 2001 position statement, emphasis on the sole intent of the action is key to the way in which the position statement is interpreted. It lends professional acceptability to participation in assisted suicide and euthanasia because one could reasonably claim that the sole intent in providing the death-inducing drugs is to end a patient's suffering. Even Jack Kevorkian, in justifying his actions, said his purpose was to end patients' suffering.

But ending a patient's life to end suffering violates the principle of double effect because the bad effect (the death of the patient) is the means used to achieve the good effect (relief from suffering).

While the ANA essentially distorts the principle, other nursing organizations and publications have declared the principle to be irrelevant when making decisions about end-of-life care. In answer to the question "Is the doctrine of double effect irrelevant in end-of-life decision making?" Peter Allmark and others from Britain's Sheffield Hallam University Center for Health concluded that the doctrine was, indeed, irrelevant:

The doctrine is irrelevant because it requires there to be a bad effect that needs justification. This is not the case in end-of-life care for patients diagnosed as dying. Here, bringing about a satisfactory dying process for a patient is a good effect, not a bad one. What matters is that patients die without pain and suffering. This marks a crucial departure from the double-effect doctrine; if the patient's death is not a bad effect, then the doctrine is clearly irrelevant. A diagnosis of dying allows clinicians to focus on good dying and not to

²⁴ American Nurses Association, *Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life*, position statement [draft], November 2, 2009, 14–15.

²⁵ American Nurses Association, *Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life*, position statement, June 14, 2010, 31, emphasis added. http://www.nursingworld.org/MainMenuCategories/Healthcareand PolicyIssues/ANAPositionStatements/EthicsandHumanRights/etpain14426.aspx.

worry about whether their intervention affects the time of death. For a patient diagnosed as dying, time of death is rarely important. In our conclusion we suggest that acceptance of our argument might be problematic for opponents of physician-assisted death.²⁶

Allmark and his colleagues make a crucial change in determining that the principle of double effect is irrelevant. Rather than viewing the intended death of the patient as a bad effect, they actually frame the patient's death as a good effect, one that results in eliminating suffering.

A More Gradual Approach

Disparaging and dismissing the principle of double effect can obviously stem from a desire to reject any moral or ethical absolutes. But more specifically, the disparagement is part of the attempts by assisted-suicide and euthanasia activists' to frame double effect as a sectarian principle that has permitted practices that, in and of themselves, are nothing less than euthanasia and assisted suicide in disguise. If the activists can successfully persuade the public that this is so, then they can easily guide sentiment to accept legalized euthanasia and assisted suicide as more honest and, in fact, more patient-controlled ways to end suffering and enhance autonomy for patients and their decision—makers.

Rather than boldly calling for doctor-prescribed suicide and doctor-administered death, the activists gradually alter and distort the way in which legally accepted (although not necessarily ethically acceptable) actions should be understood. Incrementally, they lead unsuspecting opponents of assisted suicide and euthanasia down a path toward acceptance of death on demand.

Discussions and obfuscation surrounding the use of morphine and sedation for pain control provide examples of this.

The Use of Morphine

Both proponents and opponents of doctor-prescribed suicide have often claimed that morphine, if administered in large amounts, will certainly suppress respiration and will, therefore, have the effect of hastening death. Proponents of assisted suicide use this to claim that, since such deaths are inevitable, it is only honest and logical to permit assisted suicide. Opponents state that, while death is inevitable, it is not intended.

In 1994, as challenges to the laws against assisted suicide in Washington and New York states were wending their way through the courts, an article about morphine's deadly consequences was published in the *New York Times*.²⁷ It was written by Thomas Preston, MD, who was identified as a cardiologist and professor of medicine at the University of Washington. No mention was made of the fact that

²⁶Peter Allmark et al., "Is the Doctrine of Double Effect Irrelevant in End-of-Life Decision Making?" *Nursing Philosophy* 11.3 (July 2010): 170–177, emphasis added.

²⁷Thomas A. Preston, "Killing Pain, Ending Life," New York Times, November 1, 1994.

Preston was also, at that time, a member of the board of directors of Compassion in Dying of Washington,²⁸ had previously expressed support for the activities of Jack Kevorkian,²⁹ and was a plaintiff in the case challenging Washington's law that prohibited assisted suicide.³⁰

The article, aptly titled "Killing Pain, Ending Life," was a thinly veiled attempt to persuade readers that physicians were already routinely ending the lives of their patients. Describing his experience with one patient, he wrote that he knew "the morphine drip—a slow, continuous injection of a painkiller into a vein—would kill the patient by gradually curtailing her breathing. Without it she would probably have lived for days or weeks; as it was, she died in eight hours." ³¹

Explaining his actions, Preston wrote, "Medical ethicists have a term for it: 'double effect.' Our intent is to relieve pain; death is (to use the ethicists' jargon) a 'foreseen but unintended consequence.'" He went on to ridicule such reasoning, claiming that what is permitted under the principle of double effect "is undeniably euthanasia, hidden by the cosmetics of professional tradition and language."

The administration of morphine, as he described it,

differs from the popular conception of euthanasia in two ways. The first is time. ... Death is gradual and appears to be of natural causes, and the doctor's absence at the time of death dispels any association between physician and dying. If I administer morphine to a suffering and dying patient to relieve pain, I am legal and ethical; if I say it is to end her life, I am illegal and unethical.³²

²⁸ Preston was identified as a director on the Compassion in Dying of Washington letterhead in October 1994. Defeat of a 1991 Washington State voter initiative (Initiative 119) to legalize both assisted suicide and euthanasia spawned Compassion in Dying (CID). In its initial publicity, the organization was described as "an outgrowth of the Washington State Hemlock Society Chapter," which was formed to offer suicide assistance in "deserving cases." "Ralph Mero: An Omega Interview," *Omega: The Journal of Death and Dying* 29.1 (1994): 6. CID's activities were the topic of a *New York Times* cover story in 1993. Lisa Belkin, "There's No Simple Suicide," *New York Times*, November 14, 1993. The group's activities caught the attention of attorney Kathryn Tucker, who suggested that it might be better for CID to challenge the constitutionality of Washington State's law prohibiting assisted suicide. David J. Garrow, "Nine Justices and a Funeral," *George Magazine* 2.6 (July 1997): 59; and "The Right to Die: Death with Dignity in America," *Mississippi Law Journal* 68.2 (Winter 1998): 413. For more information on the evolution of Compassion and Choices from the Hemlock Society, see Patient Rights Council, "Assisted Suicide and Death with Dignity: Past, Present and Future," part 1 (2005), http://www.internationaltaskforce.org/rpt2005 I.htm#212.

²⁹In 1993, while Jack Kevorkian was on trial for facilitating several deaths, an Ohio newspaper reported, "Dr. Tom Preston, a Seattle cardiologist who helped lead an unsuccessful effort in Washington to legalize assisted suicide, believes more and more doctors who support assisted suicide would 'come out of the closet' if Kevorkian won." Julia Prodis, "Dr. Death' Trial Intrigues Legal Experts," *Beacon Journal (Akron, Ohio)*, August 19, 1993, A6.

³⁰ Washington v. Glucksberg, 521 U.S. 702 (1997).

³¹ Preston, "Killing Pain, Ending Life."

³² Ibid.

But Preston did not stop at pointing out what he considered "euthanasia, hidden by the cosmetics of professional tradition and language." He went on to call for legalized "aid in dying" as a way to empower patients.

He said current practices are controlled by doctors when it should be up to the patient to decide to die. "Where physician-assisted suicide gives the decision to the patient, the morphine drip empowers physicians to initiate and carry out the ultimate act of medical paternalism." His solution? He called for "specific guidelines on who qualifies for aid in dying." 33

Preston's article made several claims. First, it was timed to influence the outcome of the assisted-suicide case pending in the courts. If, indeed, euthanasia was being widely practiced and if those who were administering morphine to dying patients knew that they were euthanizing patients under the guise of acceptability afforded by the principle of double effect, then there was no ethical difference and, thus, there should be no legal difference between it and assisted suicide.

Preston was correct in claiming that if a physician actually intended the death of the patient (as the physician did in the scenario Preston provided), the act would be euthanasia. But the act would not be permissible under the principle of double effect, because the bad effect (the death of the patient) can neither be intended nor can it be the means by which the good effect (the end of the suffering) is achieved.

Preston also claimed that large doses of morphine certainly and inevitably cause death. He—as well as physicians who do not favor assisted suicide and euthanasia—seemed to believe this. This may be because Preston is a cardiologist who has little or no expertise in pain control. However, physicians who are experienced in providing symptom and pain management know that such an assessment is wrong.

Preston's article drew immediate responses from many with expertise in pain management. Blaine Miller, MD, a pediatric anesthesiologist in Minnesota, wrote that Preston "argues that only two factors separate society's approval of pain treatment from euthanasia: stated intent and time" and that he "urges physicians to admit the frequent and covert practice of euthanasia and to assist in developing guidelines for physician assisted suicide." Miller pointed out crucial differences in the reason and manner in which morphine is administered: "Continuous infusion of narcotics provides a constant blood level of medication maximizing pain relief. Because morphine is rapidly eliminated from the body, it is a more rational way of using medication than intermittent dosing." But, Miller continued, "giving large amounts of narcotics, either by a single dose or by continuous infusion, that go beyond pain to the point of unconsciousness and death provides no benefit [to the patient or the family]." 35

Kenneth Prager, MD, chairman of the medical ethics committee at Columbia Presbyterian Medical Center in New York City, pointed out that Preston and other

³³ Ibid.

³⁴ Blaine R. Miller, "There's a Big Difference between Curbing Pain, Causing Death," *Star Tribune (Minneapolis–St. Paul)*, November 26, 1994.

³⁵ Ibid.

advocates of euthanasia and assisted suicide want to blur the critical distinction between mercy killing and the merciful use of drugs that may unintentionally hasten death. And Thomas Quinn, a clinical nurse specialist in oncology at Lombardi Cancer Research Center in Washington, D.C., wrote, "Morphine drips for pain management are supposed to be adjusted to maintain patient comfort, not to intentionally decrease respiration." Quinn said that, in his experience with hundreds of patients who received powerful opioids, "most of these patients were quite alert, many were able to be independent in caring for themselves, a few even went to work with a continuous infusion of morphine or hydrocodone (Dilaudid). Most of these people had cancer, most of them in advanced stages." 37

Unfortunately, myths about morphine are widespread.

Eric Chevlen, MD, a specialist in hospice and palliative medicine and a consultant to the International Task Force on Euthanasia and Assisted Suicide (now called the Patient Rights Council), has addressed common misinformation about morphine use to control pain. Chevlen said many people (physicians included) assume that giving large amounts of morphine to control pain will suppress respiration, but he noted that this is not true. "While morphine and other opioids may suppress respiratory drive in the opioid-naive patient, they do not do so in patients who have been taking the drug for a little while. Almost all terminally ill patients who receive morphine in their final days of life have been receiving it long enough to be tolerant to this effect. One need not invoke the principle of double effect here, because in fact the morphine does not have a double effect in this population." ³⁸

In a book about pain control, Chevlen wrote:

It is commonly believed that aggressive use of morphine and other opioid drugs carries a high risk of killing patients. The myth that morphine and other such drugs are unsafe is caused by failing to distinguish opioid effects in different groups of people. It is true that, when people who do not have pain are given narcotics, the drugs carry the risk of suppressing the respiratory drive, making it so people do not breathe. Even patients who have pain but who are just beginning opioid therapy (called "opioid-naive" patients by doctors) must be dosed carefully to prevent this effect. Fortunately, the body becomes used to these drugs fairly quickly, usually in a matter of a few days or weeks. After that, the sedating effect of the opioid subsides, as does its potential to suppress respiration. Thus opioid doses may usually be raised safely in the patient who has some prior or ongoing exposure to the drug.

Properly prescribed, morphine and other opioids are more likely to extend life than shorten it, because of the terrible physical and emotional toll that pain exacts on the body. Thus, it is far more compassionate and humane—in

³⁶Kenneth Prager, "Legal Euthanasia Imperils Medical Integrity," letter, *New York Times*, November 7, 1994.

³⁷ Thomas E. Quinn, "Legal Euthanasia Imperils Medical Integrity, Pain Management," letter, *New York Times*, November 7, 1994.

³⁸ Eric M. Chevlen, letter to Joseph A. Califano, January 3, 1999; copy on file with author.

other words, it is simply good medical care—to treat pain vigorously, rather than to allow people to writhe in potentially deadly agony.³⁹

Clearly, if provided in an appropriate way by health care professionals who are seeking to control their patients' pain, then morphine is a benefit and a blessing.

While it is important to emphasize that pain medication, appropriately administered, rarely, if ever, will be the cause of death, it should also be noted that if the intervention did have the foreseeable but unintended consequence of hastening death, it would be permitted under the principle of double effect.

Like the misunderstandings and intentional distortion of facts about morphine use, similarly muddy waters surround the subject of rendering patients unconscious when no other means of pain and symptom management is effective.

Sedation for Pain

In discussing the needs of suffering patients, the question often arises, What about the patient whose suffering cannot be controlled? In particular, this question is raised by those who, favoring assisted suicide or euthanasia, claim that there are patients for whom death is the only way to eliminate severe intractable pain. Others argue that doctor-prescribed suicide or doctor-administered death is unnecessary because, in the very rare cases where suffering cannot be controlled, it is acceptable to sedate the patient to the point of unconsciousness.

Proponents of assisted suicide have seized upon this, portraying it as slow euthanasia. Indeed, they made such claims in two U.S. Supreme Court cases.⁴⁰ The Court, however, did not buy their argument.

In 1994, the New York State Task Force on Life and the Law stated, "It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient's death, if the medication is intended to alleviate pain and severe discomfort, not to cause death." ⁴¹ Judicial and medical groups have not been alone in recognizing that sedation can, in appropriate situations, be used to address symptoms that otherwise cannot be controlled.

From the first time the question was explicitly raised, Catholic teaching has held that sedation, even to the point of unconsciousness, is permissible. In 1957, Pope Pius XII, responding to a question about suppression of pain and consciousness, said that such an intervention was permitted "if no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties." The 1980 *Declaration on Euthanasia* affirmed that sedation causing

³⁹ Eric M. Chevlen and Wesley J. Smith, *Power over Pain: How to Get the Pain Control You Need* (Steubenville, OH: International Task Force, 2002), 43, emphasis added.

⁴⁰ See *amicus curiae* briefs and oral arguments in *Vacco v. Quill*, 521 U.S. 793 (1997), and *Washington v. Glucksberg*, 521 U.S. 702 (1997).

⁴¹ New York State Task Force on Life and the Law, *When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context*, report (May 1994), chapter 8, page 163, http://www.health.state.ny.us/nysdoh/provider/death.htm.

⁴²Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (May 5, 1980), III.

unconsciousness was permissible, noting that "painkillers that cause unconsciousness need special consideration" and adding the 1957 caution from Pope Pius XII that "it is not right to deprive the dying person of consciousness without a serious reason." ⁴³

As noted above, legal, medical, and religious institutions have recognized the validity of sedating a patient into unconsciousness when no other intervention can sufficiently address pain and suffering. In recent years, however, problems regarding terminology, appropriate use, and other aspects of this intervention have surfaced.

Palliative Sedation or Terminal Sedation. Articles and discussions about sedating a patient into unconsciousness generally use the phrases "palliative sedation" and "terminal sedation" interchangeably. There is currently no consensus on their definitions.⁴⁴

For the purposes of this discussion, the following definitions are used:

- "Palliative sedation" means the controlled administration of sedative medications given for the purpose of reducing patient consciousness to the minimum amount necessary to render intolerable and refractory suffering tolerable. The minimum amount of sedation may render the patient unconscious. Any decision about nutrition and hydration (food and fluids) is determined separately: withholding or withdrawing them is dependent on whether the food and fluids are being assimilated or whether their provision is exacerbating symptoms (for example, in the case of a patient with kidney failure). Periodically, the amount of sedation is decreased to determine whether symptoms can be controlled using less or no sedation.
- "Terminal sedation" means the administration of sedative medications to render the patient unconscious, coupled with the withholding or withdrawal of nutrition and hydration. The withholding or withdrawal of nutrition and hydration is done without regard to whether the food and fluids would sustain life. Thus, if sedation is total and continuous, a patient with a life expectancy of greater than five to twenty-one days could die from dehydration, not from the underlying disease.

Palliative sedation can be an appropriate intervention and fulfills the four elements of the principle of double effect. The sedation results in a good effect—alleviation of pain. It, like all sedation that controls pain or is necessary for surgery (anesthesia), carries the risk of an unintended bad effect—death. The action (providing necessary pain medication) is good. The good effect is not obtained by means of the bad effect. The bad effect, although foreseen, is not intended for itself but is only permitted, and there is a proportionately grave reason for permitting the bad effect.

⁴³ Ibid.

⁴⁴"Terminal sedation' is a phrase that has appeared in the palliative care literature in the last few years. There has not been a clear definition proposed for this term." Susan Carter et al., "Sedation for Intractable Distress in the Dying: A Survey of Experts," *Palliative Medicine* 12.4 (July 1998): 255–269.

However, there have been a number of accounts of palliative sedation being used when other interventions would accomplish the same good effect without the potential bad effect. Margaret Mahon, a nurse and associate professor at the George Mason University School of Nursing explains: "Too often, palliative sedation is used as a first-line therapy rather than a therapy of last resort. In some units, palliative sedation is used on one-third to one-half of patients. That is far too often." Mahon explains that the patient is awakened after a day or so to see if the symptoms are alleviated.

When palliative sedation is used as a first-line therapy, not as one that is provided only when other interventions are not effective, it violates an element of the principle of double effect, because there is not a proportionately grave reason for its use.

Mahon also explains the difference between palliative sedation and terminal sedation: "Terminal sedation implies, as a colleague of mine says, 'a one-way ticket." ⁴⁶ The nature of terminal sedation—rendering the patient unconscious, coupled with the withholding or withdrawing of nutrition and hydration—violates the principle of double effect. This is not because the patient is rendered unconscious but because nutrition and hydration are withdrawn even though a patient would continue to live if they were provided. Their withdrawal is intended to result in the patient's dying sooner rather than later. If there is no palliative function served by withdrawing nutrition and hydration, then its only effect is to hasten death. This practice is, in effect, a veiled type of euthanasia by omission. The key question is, why are the food and fluids being withheld or withdrawn?

These distinctions between sedation to control pain and sedation coupled with the denial of nutrition and hydration for the purpose of hastening death are rarely noted, and the practice of giving patients the "one-way ticket" referred to by Mahon is becoming more and more prevalent around the globe.

When those who oppose assisted suicide embrace terminal sedation to prevent changes in laws related to doctor-prescribed suicide, they are deluding themselves. Instead of beating back the progression to assisted suicide, they are moving it forward, eventually to a point of no return. In *The Abolition of Man*, C. S. Lewis observed that our desired conquests of nature usually turn out to be nature's conquests of man: "What looked to us like hands held up in surrender was really the opening of arms to enfold us forever." ⁴⁷

Widespread Terminal Sedation. In Belgium, where euthanasia became legal in 2002, researchers found that the use of deep continuous sedation, culminating in death, increased from 8.2 percent in 2001 to 14.5 percent in 2007.⁴⁸

In Great Britain, patient deaths after terminal sedation have escalated, although in many cases no evidence of underlying intractable pain or suffering was

⁴⁵ Margaret M. Mahon, letter, New York Times, January 4, 2010.

⁴⁶ Ibid.

⁴⁷C. S. Lewis, *The Abolition of Man* (New York: Harper Collins 1944), 68.

⁴⁸ K. Chambaere et al., "Continuous Deep Sedation until Death in Belgium: A Nationwide Survey," *Archives of Internal Medicine* 170.5 (March 8, 2010): 490–493.

documented. Many of those deaths followed adoption of what is called the Liverpool Care Pathway. The LCP was formulated to make dying patients more comfortable. However, in actual practice, it has become the topic of intense controversy.

Under the LCP, patients are sedated into unconsciousness, all food and fluids are denied to them, and death takes place in days. An audit of four thousand patients found that, in 2007–2008, 16.5 percent of all deaths were the result of terminal sedation. ⁴⁹ Moreover, the audit found that 28 percent of relatives were not informed that their loved ones were being put on the LCP. ⁵⁰ This situation led columnist Gerald Warner to ask, "Could the most ardent fan of George Orwell have asked for a more classic, totalitarian euphemism than 'the Liverpool Care Pathway'?" ⁵¹ On a positive note, however, Warner wrote, "The medical profession is now concerned and rightly so." ⁵²

Those who call terminal sedation "backdoor euthanasia" are correct. When sedation is routinely coupled with the withholding or withdrawal of food and fluids—as it is in terminal sedation—it intentionally and inevitably leads to death. Attempts to maintain any prohibition against doctor-prescribed suicide and doctor-administered euthanasia by those who support terminal sedation are thus folly. By accepting terminal sedation as ethically appropriate, supporters not only open the door to practices they claim to abhor, but they establish a foundation for those very practices.

A brief review of statements made and practices being promoted by assisted suicide and euthanasia advocates give an indication where this is leading.

Statements by Activists

Promoting the denial of food and fluids as a means of ushering in euthanasia has long been a weapon of euthanasia advocates. Speaking at an international conference of right-to-die activists, Helga Kuhse, a professor at Monash University in Australia, told participants that if people approved of withholding food and fluids to bring about death, they would soon accept a better way. Kuhse stated that once people see how painful death by dehydration is, then, "in the patient's best interest," they will accept the lethal injection.⁵³

⁴⁹Zosia Kmietowicz, "Findings from Audit of 4000 Patients Clash with Doctors' View of Care Pathway for the Dying," *British Medical Journal* 339.7722 (September 19, 2009): 653.

⁵⁰ Daniel Martin, "Report Warns Doctors Snub Families of the Terminally Ill amid Growing Use of 'Death Pathway," *Mail Online*, September 15, 2009, http://www.dailymail.co.uk/news/article-1213498/Report-warns-doctors-snub-families-terminally-ill-amid-growing-use-death-pathway.html.

⁵¹Gerald Warner, "The Liverpool Care Pathway May Be the Slippery Slope to Backdoor Euthanasia," *Telegraph.co.uk*, September 3, 2009, http://blogs.telegraph.co.uk/news/geraldwarner/100008455/the-liverpool-care-pathway-may-be-the-slippery-slope-to-backdoor-euthanasia/.

⁵² Ibid.

⁵³Rita Marker, *Deadly Compassion* (New York: William Morrow, 1993), 94. Kuhse was then a colleague of Peter Singer. In 1988, Singer and Kuhse wrote the book *Should*

Organizations such as the Hemlock Society (now known as Compassion and Choices) have waged an erratic campaign, lurching from promoting the practice of terminal (not palliative) sedation to expounding on its gruesome nature. In its Fall 1999 newsletter, the Hemlock Society printed an advertisement from its Virginia chapter which carried the banner "Terminal Sedation with Refusal of Food and Fluids." The advertisement noted the availability of a videotape presenting "a psychiatrist's view of a method of self-deliverance that can be used for a dignified death." ⁵⁴ The following year, Faye Girsh, who was then president of the Hemlock Society, argued that assisted suicide should be permitted because, with terminal sedation, "safeguards are minimal and expenses often high." ⁵⁵ She continued, "Many would prefer to have a choice of a five-minute death versus a five-day one where hospitalization is required and you turn the color of mustard. Doctors who oppose euthanasia seem to feel comfortable using this hypocritical principle of double effect to provide a gentle death to their patients."

Only four years later, Girsh was back to singing the praises of terminal sedation. After noting that, in the course of speaking throughout the country, she gets more questions on stroke and dementia than on terminal illness, she described two "options" which a person could legally employ to hasten death in such situations. One was terminal sedation. She described it as a situation in which you "will be rendered unconscious and not fed or given fluids while you are in a coma. ... Death is foreseeable and will be a result of the underlying disease, dehydration or the large amount of medication necessary to maintain the coma." Girsh pronounced this to be "acceptable ethically since the intent is to relieve pain or suffering." ⁵⁶

The other method she described was "voluntary stopping eating and drinking" (VSED). According to Girsh, "You should let your loved ones know that you may choose this option if you fear a life of debilitation and helplessness caused by stroke or dementia. ... In most cases death will occur relatively peacefully in five to twenty-one days, depending on your physical condition." ⁵⁷ In VSED, the patient has been eating and drinking without assistance, has no underlying condition that interferes with digestion, and is able to assimilate food and fluids. The sole purpose of VSED is to cause death.

An attempt to enshrine VSED in legislation took place in 2008 when California Assembly members Patty Berg and Lloyd Levine sponsored a bill that would have made it mandatory for health care providers to inform patients with a predicted life expectancy of one year or less that VSED was among their "end-of-life options." ⁵⁸

the Baby Live? in which they proposed the disabled newborns could ethically be left to die without treatment or their lives could be ended by medical practitioners.

⁵⁴ Advertisement, *Timelines* (Fall 1999): 14.

⁵⁵ Girsh, letter, Washington Post, October 17, 2000.

⁵⁶ Faye Girsh, "Stroke and Dementia: Nemeses of a Good Death," *End-of-Life Choices* (Fall 2004): 8.

⁵⁷ Ibid.

⁵⁸ *The Right to Know End-of-Life Options Act*, California Assembly Bill 2747, chaptered September 30, 2008.

However, before its passage, the bill, which had been drafted by Compassion and Choices, ⁵⁹ was amended and the VSED language was omitted.

Endorsement of VSED has now seeped into professional journals. A September 2009 article in a journal for nurses described "options" that occur "routinely in health care settings across the country." The option of VSED lent the name to the article: "Stopping Eating and Drinking." ⁶⁰ This option, according to the author, is not limited to those who are terminally ill but to decision-capable adults who want to hasten dying. The article, which provided the basis for continuing education credits for nurses who chose to seek them, cautioned readers that if they were uncomfortable with participating in VSED and other options, they should refer the patient to a willing caregiver.

Those who have bent, twisted, and demeaned the principle of double effect have reframed it as either an archaic religious mandate with no relevance in today's advanced society or as a principle that can be altered at will. Disregarding the element of the principle that prohibits the good effect from being brought about by means of the evil effect is also apparent in what is now taking place in the context of organ donation. Essentially, advocates dispose of that element and replace it with the assertion that "the end justifies the means."

Organ Donation and Planned Death

Gary Phebus is the sixty-two-year old man from Georgia mentioned at the beginning of this article who announced that he wanted to end his life so he could help others to improve their lives. Phebus's plan was met with approval not only by his family but also by Kaysha Cranon, the public affairs coordinator for LifeLink of Georgia, a nonprofit organization dedicated to the recovery of organs and tissue for transplantation. Noting that there are more than 108,000 people on the national waiting list for organs, Cranon said, "I think it's wonderful that he wants to donate his organs." 62

Phebus said he felt it was the right thing to do. Cranon thought it was wonderful that he wanted to donate his organs. Without principles against which their feelings can be measured to determine the rightness or wrongness of their actions, they have no ethical barrier to prevent them from carrying out death by organ removal—all

⁵⁹ Marilyn Golden, "Facilitating Assisted Suicide Is Not the Way To Go," *Capitol Weekly (Washington D.C.)*, May 22, 2008; and Stanton J. Price, "The Path to Assisted Suicide," *Los Angeles Times*, August 21, 2008.

⁶⁰ Judith K. Schwartz, "Stopping Eating and Drinking," *American Journal of Nursing* 109.9 (September 2009): 52–61. Schwartz is a regional clinical coordinator of Compassion and Choices.

⁶¹ Because Phebus lives in Georgia, where assisted suicide is not legal, his plans could not be carried out in that state. However, if he were a resident of Oregon, Washington, or Montana, where assisted suicide is permitted, nothing in those states' laws would preclude him from carrying out his wish.

⁶² Fuller, "Man Tries to Donate Organs."

for a good cause. That Phebus has a "death sentence" does not change the fact that his death would be hastened if he donated his organs.

Two months before Phebus's story reached the public, two British ethicists made a proposal which would have wishes like his a reality. Dominic Wilkinson and Julian Savulescu set forth a proposal for solving the shortage of organs for transplant when they proposed criteria for "organ donation euthanasia (ODE)." ⁶³ Their proposal calls for the removal of organs from a patient under general anesthesia, with death following removal of the patient's heart. According to Wilkinson and Savulescu, ODE would have many benefits in addition to saving the lives of many recipients of organs obtained in this manner. They say it would also benefit the organ donor who dies of ODE, since

- It would enhance patient autonomy (ostensibly patients would ask to be euthanized);
- It would provide patients with the greatest chance of being able to donate their organs after death;
- It would be a Pareto improvement ⁶⁴ over current practice for treatment withdrawal and would increase the number of quality organs available for transplantation; and
- Suffering or discomfort for patients would be less likely than with withdrawal of life support.

Although the authors described possible drawbacks to their idea—that ODE may lead to a fall in organ donation rates because of community nonacceptance and could lead to killing patients who would not otherwise have died, they forged ahead, concluding that "we should allow people to make advance directives indicating that they would like to be eligible for this alternative. We should encourage and support such altruistic desires." 65

This was not Wilkinson and Savulescu's first foray into a realm where living human beings could be viewed as organ farms. In a 2008 essay, they suggested that "we could allow organs to be taken from people who are not brain dead, but who have suffered such severe injury that they would be permanently unconscious, like Terri Schiavo, who would be allowed to die anyway by removal of their medical treatment." 66 And what was their justification for harvesting organs from people like Schiavo? "We should do whatever we ethically can to stop people burying and burning

⁶³ Dominic Wilkinson and Julian Savulescu, "Should We Allow Organ Donation Euthanasia? Alternatives for Maximizing the Number and Quality of Organs for Transplantation," *Bioethics* (May 2010): http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2010.01811 .x/full.

⁶⁴A Pareto improvement is a change that harms no one and helps at least one person.

⁶⁵ Ibid.

⁶⁶ Julian Savulescu and Dominic Wilkinson, "Death Fiction and Taking Organs from the Living," *Practical Ethics News*, October 24, 2008, http://www.practicalethicsnews.com/practicalethics/2008/10/death-fiction-a.html.

the most valuable human resource. At very least, we should allow the morally virtuous to give their organs just as they wish." ⁶⁷ Notice that Wilkinson and Savulescu have framed their proposal as one which would be for the "morally virtuous."

Belgium has already embraced organ donation coupled with euthanasia. Four such cases described in a medical journal in 2009 involved patients ranging in age from forty-three to fifty years.⁶⁸ All had debilitating neurologic disease, either after a severe cerebrovascular accident or primary progressive multiple sclerosis. According to the article,

The euthanasia procedures were carried out on the date requested by the patient, by three physicians independent from procurement or transplant teams. ... In 2 patients, the liver, both kidneys, and pancreatic islets ... were procured and transplanted; in 2 patients, there was additional lung procurement and transplantation. ... Organ allocation was performed by Eurotransplant (allocation 4 hours before) in Belgium and the Netherlands, the only two countries with euthanasia legislation. ... The involved physicians, the transplant team, and the institutional ethics committee had the well-discussed opinion that this strong request for organ donation after euthanasia could not be waived. 69

The previous year, Belgian physicians wrote about a forty-four-year-old woman who was euthanized for her organs. The woman was described as having "locked-in syndrome." According to the authors, she was fully conscious and able to communicate with eyelid movement. Using that method of communication, she asked for physician-assisted suicide under Belgian law. After examination by a neurologist and a psychiatrist who excluded depression, her cognitive abilities and her dismal medical prognosis were confirmed, as was her willingness to die:

The day before the euthanasia, the patient expressed her will of after-death organ donation. The ethical and legal possibility of combination of the two separate processes, physician-assisted suicide and after-death organ donation, was then considered and agreed by the institutional ethical committee president. . . .

This case of two separate requests, first euthanasia and second, organ donation after death, demonstrates that organ harvesting after euthanasia may be considered and accepted from ethical, legal and practical viewpoints in countries where euthanasia is legally accepted. This possibility may increase the number of transplantable organs and may also provide some comfort to the donor and his (her) family, considering that the termination of the patient's life may somehow help other human beings in need for organ transplantation.⁷⁰

⁶⁷ Ibid.

⁶⁸D. Ysebaert et al., "Organ Procurement after Euthanasia: Belgian Experience," *Transplantation Proceedings* 41.2 (March 2009): 585–586.

⁶⁹ Ibid.

⁷⁰ Olivier Detry et al., "Organ Donation after Physician-Assisted Death," letter, *Transplant International* 21.9 (September 2008): 915.

What Principle Will Guide Us?

Stories of patients who want to die, proposals to speed up the dying process, and the desire to hasten death so that one can donate one's organs—all do, in fact, have an emotional appeal. The human response is to ask why shouldn't we hasten death in such cases? Should we say that, in this or that case, the principle of double effect should be ignored and the action permitted? Should we decide that principles can be coined, that principle "shopping" can take place, and that a newly minted principle can be found to stamp virtually any course of action with a good ethics seal of approval?

The answer, as heart-wrenching as it is, is grounded in the reality that intentionally hastening the death of an innocent human being is wrong. If one were to say that in this case the principle of double effect should be ignored and the action should be permitted, on what principle would subsequent decisions be based?