

Assistance in dying: Dax's Case and other reflections on the issue

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Abstract

Euthanasia is a Greek word which means a “good death”. In this article, the authors discuss various concepts, such as euthanasia, physician-assisted suicide, mercy killing, and assistance in dying. They argue that involuntary euthanasia is an act of murder, and that to die is to go through the process of dying. The article explains the difference between physician-assisted dying and assistance in dying. The former may flow from the latter, which represents a request for help to die from a particular group of health care professionals. From an ethical point of view, it may appear a matter of semantics, but “assistance in dying” is preferred as a term because it does not carry the same weight concerning judgemental connotations as do the terms “suicide” and “murder”.

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Introduction

Before we look at what has commonly been referred to as “Dax's Case”,^{1,2} what follows is a brief mention concerning the meanings of certain words. Whereas euthanasia in the strict sense of the translation means “a good death”, often writers on the topic use the terms “physician-assisted suicide”, “mercy killing”, and “assistance in dying”. The use of such terms may indicate the writer's position as opponent or supporter of euthanasia. There is no doubt that involuntary euthanasia is an act of murder. So we can avoid a great amount of confusion by calling it “euthanasia” or a “type of euthanasia” since it does not refer to a good death. To die is to go through the process of dying. There is also a difference between the terms “physician-assisted dying” and “assistance in dying”. The former may flow from the latter, which represents a request for help to die from a particular group of health care professionals. It may appear a matter of semantics but “assistance in dying” is preferred as a term because it does not carry as weighty judgemental connotations as do the terms “suicide” and “murder”.

A review of the case of Donald “Dax” Cowart¹

In 1973, Dax Cowart and his father went to view some property near their Texas home. They parked their car in a dry creek bed. This was not uncommon as, in parts of the desert areas in Texas, there aren't roads, or only some dirt roads. After surveying the land, the men returned to their

vehicle. They were unable to get their vehicle started so they started working on its spark plugs. As chance would have it, under the creek bed was a faulty gas line. A spark from the accelerator resulted in an explosion that left Dax Cowart's father dead. Sixty-seven per cent of Dax's body sustained second- and third-degree burns. Prior to this he was a healthy young jet pilot and amateur rodeo performer. Crawling from the scene of the accident he was, by chance, seen by a ranger. He begged him to shoot him. When emergency paramedics arrived he again made this request.

Dax's prognosis for survival was approximately 20%, but his potential quality of life was deeply compromised. He repeatedly requested to die and these requests were all denied. He unsuccessfully attempted suicide by, for example, trying to crawl out of his hospital bed in an attempt to throw himself down the staircase. He was grossly infected by the time he left the hospital and hoped that he would die from sepsis. He didn't. Against his will, he underwent 232 days of treatment in Parkland Memorial Hospital in Dallas. The types of treatment available at that time we might consider as quite “barbaric”. Immersion in tanks of saline, continuous debridement and medications now considered inappropriate were then the best known way to manage such extensive burn injuries.³ Also, at that time, there was a great fear that hospitals might inadvertently be producing “drug addicts”, so analgesia was kept at a minimum.

At the time of his hospital admission, Dax was in a critical condition and his mother was appointed as his proxy

decision maker. So her wishes concerning his care were honoured. Dax's mother held strong religious beliefs concerning life's beginning and end solely to be the will of God. So to even consider her son's request to die was an enigma to her.

Later, and despite the fact that he was deemed competent, his repeated refusal of treatment and requests to die were consistently declined. The accident left him blind and gravely disfigured, with only partial use of his fingers. He later became a millionaire as a result of an out-of-court settlement with the gas company. Dax graduated from law school in 1986. He also became a regular speaker for the Society for the Right to Die. His argument remains that his physicians had been morally wrong to treat him against his wishes. He maintains that he should have been accorded the right to die.

The complexity and difficulty of what became known as "Dax's Case" makes it suitable as the backdrop for a discourse on euthanasia that involves two related facets: the legal and the ethical. As the old adage goes: "What is legal may not be ethical, and what is ethical may not be legal".

Overlaps in the law and ethics

Euthanasia, usually translated from Greek as a "good death" is subdivided into *involuntary* versus *voluntary*, and *active* versus *passive* euthanasia. Active and involuntary euthanasia, as practised by the Nazis in the concentration camps, was no less than a masquerade of a "good death". The victims were killed, clearly against their will. Active, involuntary so-called "euthanasia" is murder. End of discussion.

The legal and moral controversies arise with voluntary euthanasia. A person who, for various reasons, considers that the time has come to exit life can express the conscious and free will to die. In this case, there are two possible scenarios. In the first case, this person takes the necessary steps to commit suicide. No legal system prohibits suicide. The moral permissibility of suicide is a different and debatable issue. In the second scenario, the person is not physically able (or does not have the courage) to commit suicide. Therefore, he or she asks for assistance. Usually this request is made to his or her doctor.

In most countries, assistance in dying is tantamount to murder and, therefore, illegal. Legal practices regarding assistance in dying, however, do vary. Most countries outlaw the practice. In the Netherlands, it is "tolerated" as long as certain conditions are met. In other countries, such as Belgium, Germany, and Switzerland, assistance in dying is lawful if it is practised within the prescribed legal framework.

The third category of euthanasia is referred to as "letting die". There are various circumstances in which this practice may be implemented. For example, the person may be conscious or not. The decision to let die may be in the hands of the patient, the relatives, or the health care team. A terminally ill but fully conscious person may express his or her capacity to refuse any life-sustaining intervention. On the other hand, the health care team may reach the decision that any life-sustaining intervention would be futile. The circumstances may also be one in which a patient, because his or her medical condition has left him or her irreversibly unconscious, is in a permanent vegetative state (PVS).

In considering one of the problems arising in PVS, let us imagine that the patient made a living will and gave advance directives expressing what should be done if he or she were unable to express a choice. If that is the case then, under South African Common Law, a case could be made that the attending health care professional is legally free to withhold or withdraw life-sustaining treatments. However, this has never been ruled on and so it is important to note that, under Common Law, a case *could* be made. Until the legal status of living wills or advance directives is sorted out in the courts, decisions are placed in the hands of a proxy. The proxy hierarchy is as follows: the spouse or partner of the patient, then the parents of the patient, and the oldest sibling. A proxy holds the responsibility of standing up for what he or she honestly believes would be the choice of the patient if he or she were competent.

Both ethical and legal debates concern the difference, if any, between "killing" and "letting die". The legal conundrum shows that, mainly in the USA, the legality of "letting die" is variously interpreted. It is in the interpretation of laws that move towards considerations of the norms of a particular society, the power base of its constituents and, of course, lobbies. These factors will also undoubtedly play a part in informing South African law regarding the matter.

Cases such as that of Karen Quinlan (1975) and Nancy Cruzan (1990) were treated differently.⁴ Karen Quinlan was in PVS and on a respirator; she was being fed through a nasogastric tube. The New Jersey Supreme Court ruled in favour of her parents' request to disconnect the ventilator. The importance that Quinlan's doctors placed on the distinction between withholding and withdrawing life support surprised the Court. The Court applied the right to privacy to allow proxy decision of letting die.

Unexpectedly, Quinlan survived after having been weaned from the respirator. The Roman Catholic nursing staff, unbeknownst to her relatives, implemented the weaning. It is likely that, without weaning, she would have died when the respirator was disconnected. She died after 10 years in PVS.

Nancy Cruzan was also in PVS and being fed through a nasogastric tube. The Missouri Supreme Court overturned the probate court's decision to allow the withdrawal of the feeding tube. This was because, in the eyes of the judiciary, there was no clear and convincing evidence about her wishes not to be resuscitated if she were to be in PVS. In reviewing the Missouri Supreme Court decision, the United States Supreme Court began to recognise the right of a competent patient to informed refusal. The tube was finally removed legally and Cruzan died.

The importance of the Quinlan and the Cruzan cases is that they brought about the legal permissibility of informed refusal and the right to proxy decision making about withholding and withdrawing life-sustaining procedures. In both cases the issue was the artificial feeding. Since food and water are basic human needs, the controversy arose whether artificial feeding is an ordinary or an extraordinary means of sustaining life. In addition, it ignited the debate whether removing the tube would be an act of omission (letting die) or commission (killing).⁵

The legality of assistance in dying is generally recognised. The US state of Oregon, however, enacted the "Oregon Death with Dignity Act".⁶ Oregon's Department of Human Services has the task of auditing a sample of the records regarding each act of assisted suicide on a yearly basis. At variance with the Dutch medical guidelines, in Oregon the right to assistance in dying does not require the existence of any pain, treatable or not.

Rarely mentioned is the fact that, since 1918, the Swiss Federal Government recognises in Article 115 of the Penal Code⁷ that assistance in dying could be motivated by altruistic reasons. This does not mean that euthanasia has been decriminalised. The penal code does not recognise the concept of euthanasia, but admits what is called "murder upon request by the victim". As long as the act is judged unselfish, there is no prosecution because there is no crime.

Most writers objecting to the legalisation of assistance in dying advocate the "slippery slope" argument.⁸ Actually, it is not an argument; usually it is classified as a metaphor for objecting to a particular action on the grounds that, once that action is taken, it will inevitably lead to a similar but less desirable action, which will lead in turn to an even less desirable action, etc. At the bottom of the slope, as we can imagine, lies the end of human morality. In other words, the slippery slope fallacy is committed only when we accept without further argument that, once the first step is taken, less desirable ones will follow. Defenders of a norm shift, on the contrary, show that there is little evidence supporting the danger of the slippery slope. Let us now turn to some ethical aspects of "assistance in dying".

Some ethical components

Needless to say, assistance in dying has its ethical supporters and opponents. Proper argumentation is the lifeline of moral philosophy. All moral theories have strengths and weaknesses. The aim is to offer a fair representation of the arguments of both sides. Broadly speaking, the supporters of what can be called "mercy killing" or "assistance in dying" argue that, since it is done at the request of the person and does not harm anyone, it cannot be morally wrong. Autonomy is respected and beneficence motivates the agency. Some (arguably) add that assisting in dying of, say, a terminally ill person will avail scarce medical resources for others in need.

The opponents refer to many reasons why assistance in dying is morally wrong. Briefly, these views are:

- Killing is always wrong;
- Assistance in killing is against physicians' duty to save lives as articulated in the Hippocratic Oath;
- Respect for autonomy is not served by ending life; and
- If physician-assisted suicide were to become legalised, it would inevitably end in the infamous slippery slope.

Implied in the last of the points set out above is the idea that it is likely that patients will be forced to die under the pressure of relatives or health service funders. Inevitably the spectre of Jack Kevorkian, "Doctor Death", comes to mind.⁹

Where assistance in dying is permissible, it is often restricted to terminally ill persons with excruciating pain that is not responding to pain relief. A paralysed but fully rational and conscious person does not suffer physically, but may be requesting assistance in dying. Should he or she be excluded on the grounds that mental pain does not qualify? Where assistance in dying is accepted, should only a physician practise it? This is mostly the case, but in Switzerland and Germany a layperson is authorised to assist in dying.

Is there a right to die, and is there a duty to die?¹⁰ If there is a right to die, is there a right to be assisted in dying? How should a doctor manage a case when a terminally ill patient refuses treatment that he or she knows will hasten his or her death? If there is a right to be assisted, who has the duty to assist and the right to the conscience clause?¹¹ If there is a duty to die, to whom does it apply, when, and how?

The first assisted death on public record was the Postma¹² case in the Netherlands in 1971. The patient suffered a severe brain haemorrhage that left her partially paralysed, deaf, and with gross speech deficits. She repeatedly begged for death. Her physician daughter injected morphine to induce unconsciousness and curare (a muscle relaxant) to kill her. Her daughter informed the authorities. She was found guilty of murder but was given a suspended sentence. In 1973, the Royal Dutch Medical Association set down guidelines that were accepted by the Dutch prosecutors.

The Hemlock Society¹³ was founded in the USA in 1980 by Derek Humphrey to help people with terminal illness die painlessly and with dignity. The society believes that laws should be liberalised to allow assisting in dying of competent but terminally ill patients. In 1990, Janet Adkins, a member of the Hemlock Society living in Oregon, was diagnosed to be in the initial stages of Alzheimer's disease. She was devastated and wanted to die with dignity before the disease could take its toll. She flew to Michigan where Kevorkian lived and where assisted suicide was not illegal. She was connected to the so-called death machine, the "Mercitron", and died.

Kevorkian was prosecuted for murder by the local district attorney. A local judge dismissed the case but ordered Kevorkian to desist from using his contraption. It is unclear on what grounds the judge's ruling was based, since assisting in dying was not against the law. In 1992, the governor of Michigan signed a law making assisted suicide illegal. In 1994, the Michigan Court of Appeals overruled the state's ban on assisted suicide on grounds of technicalities. The striking of a Washington state law banning assisted suicide followed this. The federal judge Barbara Rothstein held that the Fourteenth Amendment to the US Constitution that protects individual liberties was broad enough to cover women's right to abortion *and* the right of the terminally ill to be assisted in dying.

In *Quill vs Vacco*, the Second Circuit Court of Appeals declared New York's law against physician-assisted suicide unconstitutional, because it is a violation of the constitutional right of equal protection under the law, since it denies help in dying to those without life-sustaining treatment, while permitting it for those receiving such treatment.¹⁴

In 1992, a referendum campaign aimed at toppling California's law banning assisted suicide failed. In 1993, a similar campaign was successful in Oregon; legal challenges delayed the implementation of Oregon's Death with Dignity Act until 1997. Currently, in the vast majority of states, statutes have been retained or enacted that expressly ban assisted suicide. In *Washington vs Glucksberg* (1997), the justices made it clear that there is no constitutionally protected right to physician-assisted suicide. However, they expressed concern about the inadequacies of access to and delivery of palliative care.¹⁵

Terri Schiavo was in the same condition as Quinlan and Cruzan. In 1990, at the age of 27, she went into PVS. In 1998, her husband petitioned the court to withdraw the feeding tube. Florida's Supreme Court refused to hear appeals. A trial court judge ordered the removal. "Terri's Law",¹⁶ enacted in 2003, gave the then-governor Jeb Bush authority to order the feeding tube to be reinserted. The US Supreme

Court refused to hear an appeal brought by Governor Bush. Despite the adoption by the senate of a bill "for the Relief of the Parents of Theresa Marie Schiavo" (2005), the tube was removed and Schiavo died. Commentators have viewed this as an outrageous interference by Congress in medical decisions. The point was that Congress and the courts appeared unwilling to consider the health of the individual and the medical judgement of her physician.¹⁷

There is a striking difference when addressing the decriminalisation of assistance in dying on both sides of the Atlantic. On the North American side, Oregon, Washington¹⁸ and now California¹⁹ are involved on various levels of grappling with existing legislation as well as promoting newer legislation. In Europe, like Oregon, strict guidelines (supported by the national medical associations) are put in place to avoid abuse. Even if assistance in dying remains mostly illegal, it has become largely decriminalised.²⁰ This implies that it is recognised that, in specific conditions, the practice should be permitted.

Arising issues

Returning to Dax's Case, following only the brief time after his admission to hospital, there was never any doubt about his competence. He was an adult, rational, and fully conscious person. At the scene of the accident, he requested assistance in dying. As health care professionals, the paramedics considered that their own personal commitment to the duty to save lives was the right rule to follow, and we do not suggest otherwise. Concerning Dax's desire to commit suicide, he requested that the means be given to him to fulfil his request, as he was not physically able to procure them on his own. There is no legislation that prohibits suicide. The problem seems to be that of involving another in an act that is deemed morally wrong. The US Supreme Court later recognise the legal right to informed refusal of treatment or life-sustaining interventions. For Dax that happened in 1993; 20 years after his ordeal had begun.

The right to die, based on one's personal perception of quality of life, as it was in Dax's Case, was brought to the fore by the case of Larry McAfee in 1985.²¹ At the age of 29, McAfee became almost totally paralysed in a motorcycle accident. In 1989, he decided to file a suit in court for the right to die, because the institution where he was placed did not provide what he judged an acceptable quality of life. He designed a switch to be connected to his intravenous line that would allow him to self-inject a lethal drug by blowing in certain ways into the ventilator. The County Superior Court ruled in his favour. McAfee did not eventually commit suicide, as he was placed in an institution where his quality of life was improved.

Conclusion

It has often been said that, in such cases, it seems as though society gives severely disabled people only three limited, grim choices: to become a burden on their families or friends, to live miserably in a public institution, or to kill themselves. Even the last option is often denied. Is there any difference between a terminally ill patient requesting assistance in dying, given the hurdles of prognostication, and an almost totally paralysed person whose lack of quality of life is unbearable? Why would one oblige to the former's wish and not to the latter?

Like others, Beauchamp and Childress²² remark that, if autonomy is the cornerstone of medical decision making, one has to admit that double standards regulate the granting and declining of patients' autonomy. On the one hand, a patient's informed refusal to life-sustaining interventions is viewed as an affirmation of and respect for his autonomy. That is the moral (and legal) permissibility of letting die. On the other hand, the right to assistance in dying by mutual agreement between the patient and his or her assistant is, with some exceptions mentioned above, unlawful and regarded as morally impermissible. One does not always have the ability to commit suicide. So if one is, for instance, paralysed, one cannot exercise one's autonomy in that regard. Therefore, killing is not the same as letting die. In a widely discussed work, James Rachels²³ agrees. If he is right, the mentioned inconsistency must be redressed.

David Raphael²⁴ asks us to consider an important question: "It is the possibility of actual choice between life and death that gives rise to the most agonising perplexity...Should doctors preserve human life whenever they can, or should they refrain from special efforts when the quality of the extra period of life is, by normal standards, not worth living?"

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