Quality of life and the right to die: an ethical dilemma

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INTRODUCTION

Traditionally physicians have been able to rely almost exclusively on their own judgements when making decisions about their patients’ needs, but health care is increasingly being confronted with patients who demand to make independent judgements about their own fate. As a reflection of this general trend the topic of euthanasia has received increasing attention in recent years and has been the focus of much debate. There is now a growing drive to review the current laws on euthanasia and assisted suicide and it has been reported that 75% of a sample of British public agreed that the law should allow adults to receive help towards an immediate peaceful death, if they suffer from an intolerable physical illness (Dawson 1986).

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Definition of euthanasia

Stedmans Medical Dictionary defines euthanasia as ‘a quiet, painless death’, and ‘the intentional putting to death by artificial means of persons with incurable painful disease’. Collins English Dictionary suggests that euthanasia is ‘the act of killing someone painlessly, especially to relieve suffering from an incurable illness’ and the terms ‘mercy killing’ and ‘assisted suicide’ are commonly used to describe the phenomenon.

Pain, and incurable illness are therefore predominant features in the euthanasia debate, so that the controversy usually revolves around patients who are terminally ill with cancer, and/or suffering intractable pain. However, pain is not the only determinant of poor quality of life. Saunders (1992) notes that requests for euthanasia often seem to come from a hatred of dependence and helplessness more akin to other groups of patients than those with cancer. Newbern and Krowchuk (1994), for example, have...
observed that some elderly people become overwhelmed by a sense of helplessness and hopelessness, which results in their literally ‘taking to their bed’ and refusing to eat. The psychogenic mortality in these cases has been referred to as ‘passive suicide’, in that death occurs when the elder turns his/her face to the wall, and gives up life. Suicidal behaviour in chronic dialysis patients has also been reported by Abram et al. (1971) and this may be manifested by disconnection from the machine, with the consequences of exsanguination, or by withdrawal from dialysis. The problems therefore become more complex when the issues are extended to include the incurably ill or disabled whose condition may deteriorate within a more prolonged life expectancy, but who also feel that life, by their own evaluation, is intolerable.

Suicide and attempted suicide are no longer criminal offences in this country but whether or not this implies a legal right to end one’s life is still in debate. Counselling or assisting suicide remains an offence if conducted on immediacy and intent and health care workers cannot assist actively in the suicidal process. In law counselling, procuring, aiding and abetting are taken as a whole so if health workers knowingly comply with these suicidal wishes then the question must be raised as to whether this can be regarded as a form of euthanasia or ‘assisted suicide’ which would be illegal under the Suicide Act 1961 section 2 (1) (Mason & McCall 1991 p. 329).

This paper attempts to explore the complex ethical and legal issues pertinent to decision making in the situation where a patient is attempting suicide by the refusal of nutrition. A case study approach will be used to illustrate the dilemmas involved.

THE CASE STUDY

Susan was a strikingly attractive 27-year-old who had enjoyed all the excitement and advantages that life could offer. She had been to university, travelled extensively and participated in sports such as skiing and deep sea diving. Being intelligent and quick witted she had achieved a successful career in law and had excellent prospects for future promotion. Susan had just begun planning for her forthcoming wedding to John who was also a lawyer, and they were visiting various hotels to choose a venue for their reception, when an accident occurred and John, who was driving, hit a stationary lorry. Susan had previously stepped out of the car to ask directions and was not wearing a seat belt. She sustained a complete spinal cord lesion at C4 and was paralysed from the neck down with no free movement other than that of her head and neck.

After rehabilitation there followed a period of 15 months where Susan attempted to adjust to life as a quadriplegic. The house was altered to accommodate her needs and an electric wheelchair and a ‘possum’ were provided, but Susan had no enthusiasm for any of the suggestions made by a variety of health care and social workers to occupy the long hours spent in the house. Her main carer was her 65-year-old mother, whose husband had died some 2 years previously, and there were no siblings. However, Susan’s mother had a history of myocardial infarction and poor peripheral circulation and so was limited in her physical ability to cope. There was therefore considerable input from the community nursing services who eventually formed a strong relationship with the family.

Initially John maintained regular contact, but although he experienced considerable guilt and regret at his part in the accident he gradually became more detached from Susan, until 9 months later a visiting work colleague mentioned that he was seeing someone else. Following a confrontation John admitted that while he wished their friendship to continue, he was unable to now consider marriage. Susan was unexpectedly calm at the news and said that she understood, but there was from that time onwards a decided change in her demeanour and she seemed to have lost hope. She started to engage in what seemed like a rather bizarre attempt to recapture the past by insisting on covering her bedroom walls with enlarged photographs of herself undertaking sporting activities, or adopting comic poses and her favourite pastime was to recall episodes from her previous life related to the photographs.

Victor Frankl, in his description of life in a concentration camp, stated:

It is a peculiarity of man that he can only live by looking to the future. And this is his salvation in the most difficult moments of his existence, although he sometimes has to force his mind to the task.

(Frankl 1987 p. 72)
by only taking sips of water. She asked that her wishes for non-intervention should be respected.

**ACTS AND OMISSIONS KILLING AND LETTING DIE**

There are differences of opinion about what constitutes euthanasia, and some authors consider that the term can only be used when ‘direct killing’ is involved (Ramsey 1975). Others employ it when there is ‘direct killing’ but also in some circumstances when the patient is ‘allowed to die’ (Fletcher 1974). Cole (1989) distinguishes between the two concepts and suggests that indirect, passive or negative euthanasia (allowing the person to die) when contrasted with direct, active or positive euthanasia (direct killing) has the underlying difference of being an act of omission as opposed to an act of commission and the law often views these acts differently.

Although it is not legally permissible for a doctor to kill his patients it is sometimes permissible to allow patients to die. The BMS’s *Handbook of Medical Ethics* rejects killing, but in some instances allows the withholding of life saving treatment in the full knowledge that the omission would probably result in an earlier death than would be the case if treatment were given (Clough 1977). The ‘instances’ referred to usually involve treatments such as antibiotic therapy, or attachment to a ventilator, where without intervention it is the natural progression of the illness or condition that would bring about death. The patients in such cases are also generally not physically or mentally able to consent to or decline treatment.

However, in the case under discussion death as a result of a disease process was not the issue since Susan was deliberately refusing nutrition as an attempt at suicide and would otherwise be likely to survive for the foreseeable future. There was also a question of whether nutrition could be regarded as a form of ‘treatment’. In the Judeo-Christian tradition, the sanctity of life is founded on the notion that life is a gift over which we have stewardship but no final control. It is therefore considered that suicide is morally wrong. On this basis Roman Catholic theology from the 16th century is of the view that it is reasonable to require people to conserve their lives by ordinary means such as ordinary nourishment (Gillon 1992 p. 141) and does not regard feeding as ‘treatment’. Mason and McCall (1991) take an opposing view and point out that at one extreme spoon feeding of a reluctant ament can be regarded as invasive, and accordingly improper treatment. At the other extreme the instillation of fluid through a tube can be seen as simple care involving no risk, but it can still be done only as a result of invasion and therefore must be considered to be part of medical treatment.

The dilemma presented to the primary care team was that either they endorse Susan’s decision and through non-intervention watch her die, or they attempt ‘force’ feeding with a naso-gastric tube against her wishes, in order to save her life. Neither proposal seemed either morally or legally acceptable.

**THE NURSE’S ROLE IN ETHICAL DECISION MAKING**

Nurses are directly involved with patients such as Susan on a day to day basis, and whilst ethical decision making has been traditionally seen as the remit of the doctor, the consequences of those decisions largely fall on the nurse who is caring for the patient. Although there is an obligation to carry out the physician’s orders when decisions are medically oriented, there is no evidence that doctors are any more qualified in ethical decision making than nurses and Goodhall (1997) argues that there is no reason why they should have a monopoly over ethical decision making. In reality some medics regard sole decision making in such situations as presenting doctors with an unfair burden (Randall 1993) and there is an increasing emphasis on involvement of the whole team in deciding issues of importance. In the circumstances of this case study decisions were taken using a team approach with each member contributing to the discussion. Nurses, however, have a professional obligation to act in the best interests of the patient (UKCC 1992) and if they are being asked to take part in the analysis of ethical issues they need to be versed in the theoretical philosophies underpinning the ethical debate in order to contribute effectively.

**ETHICAL THEORIES**

The two ethical theories of teleology (consequentialism) and deontology (non-consequentialism) that relate to health care take opposing views about the behaviour or acts that are right or wrong. Consequentialism (of which the best known perspective was developed by the British philosopher Jeremy Bentham and is known as ‘utilitarianism’) claims that the answer to moral questions about which actions are right or wrong ultimately depend solely on the nature of the consequences of those actions or proposed actions. According to this view an act is considered ethical if it produces the greatest ratio of happiness over unhappiness for the community (Gillon 1992). Alternatively non-consequentialism relies on moral rules such as the 10 commandments that make no reference to consequences (Gillon 1992 p. 14). One of the most important deontological perspectives was offered by Immanuel Kant, who suggested that the agent should ‘act only on the maxim through which you can at the same time will that should become universal law’. This principle known as the law of universality represents a fundamental theme within morality as being ‘do as you would be done by’ and prevents people being used as a means to an end, no matter how important that end might be.
Goodhall (1997) argues that closely adhering to one or other of the main ethical theories would have serious shortcomings, as neither are totally appropriate, nor workable in the health care setting. She suggests the use of a combination of the theories and these are reflected in four fundamental principles of health care ethics which according to Gillon (1986) and Beauchamp and Childress (1989) should be considered when ethical judgements are made. These principles are: non-maleficence; beneficence; respect for autonomy; and justice.

The case study will therefore be discussed within the framework of the particular ethical principles seen to be pertinent to the situation.

Non-maleficence and beneficence

Beneficence refers to an action done for the benefit of others, whilst non-maleficence invokes the obligation not to harm others. Beauchamp and Childress (1994) draw a distinction between the two principles by suggesting that in general terms whilst we are morally prohibited from causing harm to anyone, we are not necessarily required to help or benefit those with whom we have no special relationship. Where the relationship is between doctor and patient or nurse and patient, however, then beneficence becomes an obligation.

The Hippocratic oath states that the moral objectives in medicine subscribe to both the principles of beneficence and non-maleficence, i.e. to help sick and suffering people and to do them no harm. In order to fulfill this obligation it may sometimes be necessary to override their wishes. Pelligrino and Thomsama (1988) see beneficence as being independent of, and potentially in conflict with, patients’ preferences. They substantiate this claim by presenting several circumstances in which the patient may have made irresponsible choices and they argue that the caring physician should therefore override the patient’s wishes. Since the professional has superior training, knowledge and insight to determine the patient’s best interests it can be argued that they are like a parent with a dependent and often naïve child. The term ‘paternalism’ is therefore often used as an analogy with the action of the intentional over-riding of a person’s known preferences by another person, the justification being that the action will benefit or avoid harm to the person whose will is to be overridden.

Gillon (1992) presents the alternative view that people’s perception of harm, like their perception of benefit, is idiosyncratic and an integral part of the way they see themselves and their life plan. It is therefore important when applying the principle of noncere to be aware of the individual’s own assessment of what is of benefit or harm from their perspective, and this can be justified on both utilitarian grounds of maximizing welfare, or on Kantian grounds in which respect for persons and their autonomy is fundamental. Susan’s concept of ‘harm’ was to be trapped against her will in a body which she regarded as useless and the greatest benefit in her view would be to be allowed to die.

Beauchamp and Childress (1994 p. 286) charge that where suicide is concerned, failure to intervene seems to symbolically communicate to the potential suicide a lack of communal concern, and works to diminish our sense of communal responsibility. Glass (1988) contends that careful evaluation of suicides almost invariably reveals evidence that the suicide occurred as a manifestation of psychiatric disorder rather than as a rational choice. Many mental health professionals would also subscribe to the view that suicides are almost always the result of maladaptive attitudes, depression or destabilization by crisis, and clients are therefore in need of attention and support. Susan demonstrated no obvious signs of psychiatric disorder but rather a calm determination to have her way. This is in keeping with Hockley’s (1993) observations that in her experience as a specialist in palliative care, many patients requesting euthanasia do not display depression, despair or hopelessness but quite rationally feel that their lives are pointless and want desperately to die.

Autonomy

Hart (1970) argues that if there is such a thing as universal human rights they are secondary to one fundamental human right, notably the ‘equal right of all men to be free’, freedom being in the context of free to exercise his/her autonomy and this generates from the fundamental moral obligation for us to respect each other’s autonomy. Gillon (1992) defines autonomy in its most literal sense as being ‘self rule’ or the capacity to think, decide and act on the basis of such thought and decision freely and independently without let or hinderance. Harris (1994), however, suggests that the individual’s capacity for autonomous choice will be undermined and diminished by four different kinds of defects. These defects are described as follows:

- Defects in the individual’s ability to control her desires or her actions, e.g. in the case of mental illness.
- Defects in the individual’s reasoning, e.g. under the influence of drugs.
- Defects in the information available to the individual upon which she bases her choice.
- Defects in the stability of one’s own desires, i.e. these may change over time.

The legal right to refuse or stop treatment has been recognized as part of the common law right to self-determination since 1914 (Friedman 1986) and the question of competence is the main consideration, competence being the ability or capacity of the individual to understand the nature or the implications of their desires. The initial fundamental issue therefore appeared to be the question of Susan’s competence and Drane (1985) cautions that the required stan-
standards of ‘competence’ to make decisions on medical care should vary with the seriousness of those decisions. Thus the decision to commit suicide by starvation would require a far higher standard of manifest competence to make informed, voluntary, deliberated and autonomous decisions than would less dangerous situations.

Psychiatric considerations are likely to be among the most controversial issues in the euthanasia debate and in the Netherlands official guidelines include mental suffering as a criterion that supports the medical decision for euthanasia, but not in circumstances where there are reasonable prospects for improvement (van der Wal 1993). Depression in terminal illness, for example, can be responsive to both anti-depressant medication and psychotherapeutic intervention. Findings by Chochinov et al. (1995) who studied patients requesting euthanasia showed that following intervention over the course of a 2-week period the majority of patients showed a decreased extent of their desire to die. If Susan was suffering from depression then the associated negative mind set might bias her capacity to make well-considered life and death decisions and treatment from mental health specialists might reverse her despondent view on life.

On this basis two consultant psychiatrists were requested to examine Susan for disordered function. After lengthy examination and discussion they concluded that she was neither clinically depressed, nor had she any psychiatric disorders such that would make her incompetent to reason or make rational choices. She was also fully informed of the consequences of her actions and the primary care team caring for her had tried consistently to find options that would improve her quality of life, including arranging admission to a highly specialized spinal injuries unit for counselling. None of the options offered, however, appealed to Susan’s view of what would make life worthwhile and she refused to participate in anything suggested.

In relation to the stability of the decision over time there was, however, a distinct possibility that the loss of an important relationship had triggered a period of crisis for Susan, to which through time she would adjust and find some inner contentment. A study by Gardner et al. (1985), for example, found that despite the intolerable lifestyle forced upon many tetraplegics they had found meaning in life, and 18 out of 21 sufferers said that they wished to be resuscitated in the event of their degenerating into a coma. However, Harris (1994) contests that the possibility that someone might change their view over time is not an adequate reason to make what is tantamount to an assault on their person. In all other senses Susan had been found to be ‘maximally autonomous’.

Legal considerations

In making legal judgements careful cognisence is taken of the moral values and belief systems on which the society in which it functions are based. The law therefore cannot be seen as a completely different entity to ethical decision making, since ethical concepts are the foundations on which the judicial system is based. In law the principle of self-ownership is firmly established and the concept of informed refusal is now achieving the same legal standing as that of informed consent in the USA and Canada. Pioneering statutory action in this field is to be found in the Medical Treatment Act 1988 of Victoria, Australia, where a patient can refuse treatment on either a general or specific basis and introduces the offence of medical trespass (Mason & McCall Smith 1991 p. 326). In this legislation no distinction is made between terminal or other illness and the right of the patient to refuse treatment is unqualified.

A similar case to that of Susan was cited by Beauchamp and Childress (1994 p. 239). Larry McAfee was a competent adult, paralysed from the neck down as a result of an automobile accident. Being qualified in engineering he devised a self-disconnecting, mouth-controlled mechanism that would separate him from his ventilator, thereby causing his death. He was not terminally ill but found his life as a quadriplegic intolerable. A Georgia court in the USA found that McAfee’s right to refuse treatment and disconnect himself outweighed the state’s interest in preservation of life and in preventing suicide and upheld his right to assistance during the agonal phase. In the further case of Conroy versus New Jersey Supreme Court (1985) in the USA the judge commented that ‘a competent person has the right to decline any treatment, including artificial feeding’ and held that nasogastric tubes were indistinguishable from any other forms of life sustaining treatment. Mason and McCall Smith (1991 p. 334) also cite the case of Farrel where an American court found in favour of autonomy but noted that in the event of conflict the patient had no right to compel a health care provider to violate generally accepted professional standards.

Goodhall (1997) argues that with such judicial trends doctors have little to fear in the legal arena when withholding or withdrawing treatment if the clinical judgement is made in the patient’s best interests, or if acting in good faith on the expressed wishes of the patient. However, they may be at risk for overtreating when treatment was not wanted by the autonomous patient.

THE ETHICAL DECISION

After consideration of all the available evidence it was decided that it would be neither morally nor legally permissible to take away Susan’s little remaining dignity and means of control by overriding her wishes, and she was therefore reluctantly allowed to embark upon her suicidal quest. Starvation, however, is a slow and unpleasant way to die, requiring much strength of will and determination. As her condition deteriorated Susan became dehydrated,
constipated and had severe problems with the drainage of her self-retaining catheter, she was troubled with breathlessness and became increasingly depressed and unwell. After almost 3 weeks of taking only sips of water and no diet she finally relented and agreed to be admitted to the specialist unit that had been previously recommended to her, but her eventual surrender resulted not from a change of heart but rather an inability to cope with any further discomfort.

On her discharge from the unit 6 weeks later she appeared to have resigned herself to her existence and no longer expressed death wishes. However, neither had she found any contentment or optimism for the future. Frankl (1987 p. 107) describes this inner emptiness and discomfort. and she had failed to adjust and progress to pursue different goals that would give her existence some purpose. It was difficult in such circumstances to see how professional intervention could make a difference. 

Frankl (1987 p. 107) describes this inner emptiness and void as an ‘existential vacuum’ stemming from spiritual distress, but suggests that the person can be assisted to find meaning by accepting responsibility for his own life. The objective is to widen and broaden the visual field of the patient from entirely focusing on ‘self’, so that the whole spectrum of meaning and values becomes visible to him. Frankl suggests that it is the therapist’s task to pilot the patient through his/her existential crisis of growth and development so that he/she may gain strength from adversity, and he calls this approach ‘logotherapy’ (Frankl 1987 p. 105).

It remains to be seen whether Susan will at some time be able to make the transition to a meaningful existence in life. For many patients it is only by accepting the inevitable constraints that their condition imposes that they can move on towards a different mind set. Euthanasia presents a rapid but irrevocable solution and if such an option were available then Susan and many like her would not have the opportunity for the spiritual growth and development that Frankl proposes.

CONCLUSIONS

Goodhall (1997) describes the decision making process between overtreatment and neglect as ‘walking a tightrope’. The difficulties encountered in making decisions involving patients who wish to commit suicide have been explored and the principle of respect for patient autonomy would seem to be paramount, with patient competency as the critical factor. The conclusions drawn were that non-intervention in these circumstances would not be regarded as ‘assault’. The question of the right for euthanasia was raised in view of the degree of suffering that ensued in order to end life. The apparent legal contradiction in that an individual may be permitted to commit suicide by refusing treatment or intervention, but not be allowed to make arrangements for death to be carried out in a painfree and dignified way was highlighted.

It would seem likely that whilst ‘mercy killing’ may remain an unacceptable option, assisting the individual to
commit suicide may become a proposition for the future. Health care should no longer only be seen in the sense of physical intervention for disordered function, but there is a lack of understanding or motivation in nursing to address issues of spirituality. A desire in the patient for death could therefore be seen as a failure on the part of the health care services to assist the patient in a psychological and spiritual sense to make the necessary life adjustments.

References


