Terminal Empowerment

socio-political implications of radical mutual assistance amongst the terminally ill

Introduction

This paper explores the possibility that the terminally ill may be able to employ new ways of cooperating in order to bypass the constraints on their right to choose an early humane death respectful of their dignity and sense of identity. "Terminally ill" is also seen as usefully understood in relation to the millions for whom the stresses of living are no longer bearable due to circumstances beyond their control.

Challenge

Few societies, including those claiming to be the most enlightened and developed, tolerate any form of euthanasia. Any "premature" termination of life tends to be reserved for the state, notably where capital punishment or assassination policies are in place. Actions by private citizens, or their organizations, resulting in suicide are criminalized. This includes efforts to assist suicide at the specific request of the person concerned -- however much the request is monitored and witnessed.

There is much documentation on the suffering to which the terminally ill may be subject over periods of months and years. This is not the focus of what follows. This suffering has been the subject of articles -- including articles by journalists (such as Phil Such) documenting the stages in their own terminal illness. The issue has been the subject of television documentaries following particular people through to their death. Such documentaries may include coverage of legal appeals. Perhaps most significantly, there has been extensive coverage of the attempt by terminally-ill Diane Pretty to seek, through the European Court of Justice, immunity from prosecution for her husband from whom she had requested assistance in terminating her life. This was rejected.

Medico-religious complex

Any legal system tends to be the reflection of positions sustained by patterns of interests within the society that sustains and approves of its provisions. The position opposing any relaxation of attitudes to euthanasia, or the right to death, is primarily sustained by the articulation of the arguments of two influential sectors of society: the medical profession and religious groups. The mutual reinforcement of the interests and arguments of these sectors may be described as giving rise to a "medico-religious complex". Like the "military-industrial complex", orginally identified by Dwight Eisenhower, it has a dangerous hold on society in which the amount of unrelieved suffering continues to increase. With respect to the right to death, the legal system is merely the compliant handmaiden of this complex.

Religions: The attitude of religions to death, in many ways their speciality, is curious -- especially in the case of Christianity, given its role in industrialized countries. Many religions are specifically concerned with suffering in the world and its relief. Many religions arose in response to suffering and have symbolism and dramatic tales associated with it. It is a constant theme in the discourse of any priesthood. And yet no religion makes any attempt to respond to the request for relief from the physical suffering of its terminally ill believers. At best religions strongly recommend prayer on the part of the sufferer, relatives or their community. Their priesthoods transfer any responsibility for concrete action to the divine -- in strange contrast to the charitable action with which they choose to be associated to
Christian priesthoods clearly benefit greatly from this total abdication of responsibility to the divine. With respect to the terminally ill, it does however raise serious questions regarding the nature of their position:

- is there some way in which such priesthoods exploit such suffering to reinforce their power in the community, especially if it is only during extended periods of suffering that individuals may desperately call for them -- a window of marketing opportunity for the cynical?
- is there some way in which priesthoods need to enhance suffering in celebration of the power of their deity, as did their predecessors who indulged directly in human sacrifice?
- is there some way in which the suffering of the terminally ill is effectively institutionalized by religions as a modern form of human sacrifice? Are believers effectively expected to sacrifice themselves repeatedly, preferably with maximum pain, to it beliefs? Is this a contributing factor in promoting unchecked population growth -- "sacrifice fodder" to match the "cannon fodder" required by the military-industrial complex?
- is there something unhealthy about the way in which priesthoods have always been intimately associated, in an official capacity, with execution of the death penalty?
- how is it that such priesthoods have themselves been instrumental in determining the death penalty, often by the most painful means (fully involving their communities in the process) -- whether framed as for the 'saviour of a person's soul' or as a means of "exorcising the devil"?
- is the assiduous interest of modern priesthoods in the final moments of death due to their historic association with the infliction of pain through torture in the expectation that through being "Put to the Question" in that way a death bed conversion might be elicited to reinforce their moral authority in the community?

**Medicine:** It is necessarily the case that the terminally ill rely to a great degree on the medical profession and the pharmaceutical products that they prescribe for the relief of suffering. It is curious however that the principles of the Hippocratic Oath make no provision for the relief of suffering in the form sought by the patient -- when the patient desires medical assistance in a humane death. The situation of the medical profession in the period leading up to death also raises serious questions:

- given the fact that up to 90% of a person's health costs are associated with the last months before death [more**], is the medical profession capable of any objectivity whatsoever in recommending pharmaceutical products and treatments that will prolong a life of agony for further days or weeks against the will of the sufferer (whether at the time or in defined in a living will)? (see Tom Nesi *Prolonging life at any cost*)
- to what extent is the medical profession complicit in promoting processes of irresponsible experimentation on humans in the period of their lives when they are most vulnerable?
- to what extent, as many believe, is the medical profession complicit in assisting the death of privileged patients? Are there questionable statistical trends in the period of suffering of terminally ill medical practioners, for example? Or is monitoring such data as problematic for the medical profession as the procedures which allowed Dr Harold Shipman, as a UK family doctor, to terminate some 150 patients without their consent -- making him the world's second worst single mass murderer in history?

The question must be asked in both cases as to whether the medico-religious complex has framed the suffering of the terminally ill primarily to reinforce its own interests. To what extent is it the case that these interests are skillfully cloaked in the highest moral and/or spiritual values -- whether consciously or unconsciously? Indeed, as with the worldwide recognition of patterns of sexual abuse and exploitation by priesthoods, to what extent are such values misrepresented to justify the advantages that the priesthoods derive from the suffering of the terminally ill? To what extent should the medico-religious complex be understood as morally and ethically bankrupt?

**Abdication of responsibility: hand-washing**

With the complicity of the legal system, the medico-religious complex appears to have created a position of total abdication of responsibility with respect to the final suffering of the terminally ill.

In the case of the Christian religion this attitude seems to be a form of role reversal associated with one of the most powerful formative stories of Christianity. With the ceremonial abdication of responsibility by Pontius Pilate (Roman governor) during the trial of Jesus by washing his hands -- he declares his innocence of the blood of Jesus, subsequently to be crucified.

Is it the case that Christianity has been forced through psycho-spiritual dynamics, of which there is as yet little understanding, through what is known as enantiodromia -- to take up the position of the other (the state, embodied by Pontius Pilate) in the dynamic which engendered that religion? Enantiodromia is a psychological term that literally means conversion into the opposite and the subsequent interaction of the two. It is applied especially to the adoption by an individual or by a community of a set of beliefs opposite to those held at an earlier stage. Jung based his theory of compensation on this principle, claiming that the conscious attitude, at times, must be balanced by gaining awareness of certain unconscious processes. [more]

This results in an extraordinary situation in which withholding assistance to the terminally ill is considered acceptable -- especially when it is possible to frame them as "irresponsible" through their failure to seek the benefits of costly pharmaceutical products and surgical processes, or an appropriate religious conversion. In the case of health care systems, people may be placed on waiting lists or in other kinds of queue. This procedural device ensures that no individual is to blame for either the suffering of the person whilst waiting, or their death prior to treatment. Ironically, in the search for indicators of the efficiency of health systems, it is the length of waiting lists that is used, and not any other measure of the "quality of suffering" endured by those to which the medical system fails to respond.

**Contrasts**
**Animals:** The point has been repeatedly made that humans treat animals in terminal pain with greater sensitivity than they do their fellow human beings. Many euphemisms are used to describe the process as applied to pets, domestic animals, or trapped or wounded wild animals:

- putting it out of its misery
- having it put away
- putting down
- put to sleep
- helped it on its way

**Military combat:** The relationship between a soldier and a severely wounded comrade, or even a deadly enemy, has been frequently dramatized. The request of the wounded person is to be "put out of his misery" -- often acting "as a friend". Persuasion may include the argument "I would do it for you under the same circumstances". A distinction may be made between giving the person a weapon with which they can kill themselves, or less frequently (in the event that they are unable to do so), using the weapon on the person. Ironically, this glorification of mutual assistance in dire circumstances might otherwise be termed "friendly fire" were that term not otherwise employed for unintended killing of allies.

**Execution:** There is a long tradition of execution arranged with techniques that may have been selected as humane. Ironically, even with the most sophisticated of these techniques, there continues to be an effort to ensure that several people are involved in the final process so that no specific person can be blamed. Curiously, it is now the state that has the effective monopoly on humane termination technology.

**Suicide:** This is now considered unacceptable, and may even be criminalized -- especially in terms of insurance benefits. However suicide has had an honourable position in many societies and continues to be considered an honourable "way out" for those of "high rank". In Japan, *hara kiri* was the traditional form of honorable suicide, also known by its Chinese equivalent, *seppuku*. As in some modern "behind-the-lines" military operations framed as heroic, it was practiced by the feudal warrior class in order to avoid falling into enemy hands. As in other cultures, it became a privileged alternative to execution, although abolished as an obligation in 1868. In Japan voluntary *hara-kiri* was resorted to after a private misfortune, out of loyalty to a dead master, or to protest the conduct of a living superior. Voluntary *hara kiri* persists in Japan, and was notably used by numerous soldiers as an alternative to surrender in World War II.

**Suicide attacks:** Such attacks continue to be used and acknowledged as an honourable, even heroic, possibility of military tactics -- most dramatically with the Japanese *kamikaze* in World War II. Many features of the tactics of World War I involved what amount to suicide attacks -- "going over the top" never to return. Medals such as the Victoria Cross are awarded for action under fire that can only be described as suicidal if the person is not fortunate enough to survive.

**Fasting to death:** Voluntary fasting to death (passive euthanasia) is a practice adopted by some who have no other means to expedite their own death. It may even be a preferred process. The Natural Death Centre (UK) argues that it is preferable, on balance, to active euthanasia [more]. According to the Hindu perspective, *prayopavesa*, or fasting to death, is an acceptable way for a Hindu to end their life in certain circumstances. It is considered to be very different from what most people mean by suicide: non-violence and use of natural means; only used when it's the right time for this life to end (when the body has served its purpose and become a burden); unlike the suddeness of suicide, *prayopavesa* is a gradual process, giving ample time for the patient to prepare himself and those around him for his death. While suicide is often associated with feelings of frustration, depression, or anger, *prayopavesa* is associated with feelings of serenity [more]. Jainism traces its roots to a succession of 24 Jinas ("those who overcome", or conqueror) The most recent and last Jina was Wardhamana (Mahavir) who founded the Jain community. In 420 BCE, he committed the act of *salekhana* which is fasting to death. Although suicide is deeply opposed by Jains, vows of fasting to death voluntarily may be regarded as earning merit in the proper context. Hunger strikers, fasting to death, are a current form of political protest, notably used by prisoners in Turkey [more] and by Tibetans seeking a solution to the occupation of their country [more]. The abandonment of the elderly in society may force them into a process of fasting to death, whether deliberately or by default, as in the case of the oldest woman in the UK [more]. Traditionally, in some cultures, notably in Asia, the effective abandonment of the elderly -- no longer able to support themselves and who can no longer be supported in communities with minimal resources -- results in their death by fasting. It might however be argued that attitudes of industrialized countries ensure a similar process for people of all ages in countries where many starve to death.

**Deliberate abbreviation of life:** Many may be said to engage in patterns of consumption (unhealthy eating, excessive consumption of alcohol, etc), patterns of addiction (nicotine, drugs, etc), or high-risk recreation (dangerous driving, extreme sports, etc) that in statistical terms (as documented by the life insurance industry) are likely to ensure an early death. As an unconscious death wish, this may be considered a more or less courageous response to the existential challenges of life.

**Self-immolation and auto-cremation:** Suicide by setting oneself alight has been extensively practiced in cultures influenced by Buddhism as a form of protest against religious oppression -- most recently amongst the Falun Gong in China, where 5 people immolated themselves in January 2001 [more]. Voluntary termination of life, or sacrifice of the body (self-immolation) took several forms for Buddhist practitioners in medieval China (for example, drowning, starvation, feeding the body to wild animals, leaping from cliffs or trees) [more]. In 1963, during the Vietnam war, a prominent Buddhist monk Thich Quang Duc immolated himself in protest [more]. In May 1998 a monk Thubten Ngodup immolated himself to protest the Chinese occupation of Tibet. In France, in 1244 after a year-long siege, the Cathars surrendered: 225 of them went willingly to their deaths on a blazing stockade. In January 1969 Jan Palach immolated himself in Wenceslas Square (Prague) in protest against the Soviet occupation of Czechoslovakia -- shortly followed by 24 others. In the Czech Republic, 6 such incidents were associated with the Iraq war in 2003 [more]. In June 2003, 6 Iranian Mujahedden immolated themselves in Paris, London and Bern in protest at the arrest of their compatriots by France.

**Perilous rescue missions:** Operations to rescue a person in extreme danger may involve actions that are a direct and suicidal risk. If
they fail the person is praised posthumously as having "laid down their life" for another.

**Engineered death:** Author Lawrence Durrell (The Alexandria Quartet, 1957-60; The Avignon Quintet, 1974-83) notably explores his interest in gnosticism through death contracts amongst a group of people committed to avoiding the contingency of death. The aim was to consciously accept the inevitability of death and to engineer a situation in which, randomly, one or other would be killed voluntarily but in an unexpected manner (over a period of time) -- with the purpose of outwitting God.

**Suicide pacts:** Such pacts are not uncommon amongst the intelligentsia (for example, Arthur Koestler and his wife), and are now a recognized characteristic of couples [more]. There is current concern in the USA at the phenomena of suicide pacts, notably involving teenagers -- possibly as a form of protest [more]. In Japan there is concern at the phenomenon of group suicides of strangers who have met over the Internet [more]. Group suicide pacts have been extensively documented in relation to cults (Peoples Temple (Jonestown), Ordre du Temple Solaire, Heaven's Gate) [more]. The ambiguity of whether a group suicide pact is entirely voluntary -- or involves some people "murdering" others -- is illustrated by the classic case of the 1000 Jewish Zealots besieged at Masada in the year 73 CE. About to be slaughtered by the Romans, their leader orders that all Zealots are to be killed: 10 men are appointed to kill the others, then 1 kills the remaining 10, and then he commits suicide.

**Suicide bombing:** This is a modern form of terrorist protest, belonging to the tactics of asymmetric warfare, where a person willingly delivers and detonates an explosive charge in such a way that it results in their own death and that of a number of their enemies. Those who use it justify it as a military tactic, a political one, or a mixture of the two. As a political tactic, suicide bombings send a message of impassioned opposition to enemy forces (that the bomber is willing to die for his cause) and a message of desperation to third parties (that the bomber feels the justice of the cause so strongly that he would rather die than submit). When used against civilian targets, suicide bombing often causes fear in the target population [more]. Its history is traced back to the Japanese *komikaze* attacks of World War II.

**Suicide as indicator of a "terminal illness"**

It has frequently been claimed that the intention to commit suicide is an indication of some form of severe mental instability. Many of the cases above suggest that this is a very simplistic way of framing the mindset that is associated with seeking termination one's life. It may indeed be a courageous expression of defiance at conditions in a world that appears itself to be insane and to offer few opportunities for sanity. This is one of the challenges in understanding the dynamics associated with suicide bombing.

It was suggested earlier that the condition of millions in the world -- suffering from hunger, violence, and lack of minimum facilities -- might be usefully seen in relation to the conditions of the terminally ill. It is indeed the case that the probability of survival of many in those conditions is low. As with the terminally ill, they may well prefer death to an unrelieved experience of further suffering without hope of relief. As with "withholding assistance" to the terminally ill, assistance to these millions, whether in industrialized or developing countries, suffers from the same ambiguity:

- **Policy of neglect:** assistance to those in need is withheld, whether deliberately or tacitly, on the grounds that either they deserve their condition (perhaps as evidence of the will of the divine), or that as "basket cases" they deserve to die, or that priority should be given first to the needs of one's own social group
- **Policy of withholding "life support":** assistance is deliberately withheld as a strategy that most quickly encourages a remedy for their condition (perhaps in the light of the will of the divine), whether through their death or through a miraculous recovery

It is to be expected that the millions suffering from this condition of "terminal illness" may, out of desperation, adopt strategies that appear irrational. Suicide bombing is one such strategy. The suicidal actions of "boat people" is another. Both cases indicate a form of empowerment which is extremely challenging for societies priding themselves on their humanitarian values. Just as the engendering of hundreds of "Osama bin Ladens" has been predicted, so an extreme example of a maritime invasion of Mediterranean Europe by hundreds of boats carrying refugees has been explored (in a movie).

An important common feature is the way in which normal appeals for attention to suffering are not heard, or are ignored, or are rejected -- as with the case of Diane Pretty. This suggests that society itself suffers from a matching "illness" in its inability to respond meaningfully to suffering in a timely manner.

**Probable economically-driven responses**

The various approaches above to termination of life (despite the state and its supporting authorities), can usefully be contrasted with the many forms of state-supported death. These range from military action, through capital punishment and assassination, to withholding aid to those in terminal distress. The change in legislation in countries such as the Netherlands and Switzerland, in defiance of the medico-religious complex, is therefore to be welcomed. It is therefore useful to reflect creatively on:

- how countries, through change of legislation, can also derive economic benefit, beyond humanitarian concerns, from providing such facilities
- how such legislative changes may offer significant economic opportunity to developing countries and especially those starved of foreign currencies
- challenges faced by collapsing health care systems, in both industrialized and developing countries, obliged to give priority, and possibly lengthy, treatment to the terminally ill -- under conditions where they are are already faced with the embarrassment of lengthy waiting lists for non-terminal patients: at what point will the economic benefits of allowing some to die early outweigh the strain on already overburdened health systems?
- the probable extension of the activity of international criminal networks to respond to the market represented by the terminally ill, if only through offering drug overdoses (although there are of course environments in which the cost of such drugs exceeds the
• the probable development, in some countries, of the patterns associated with prostitution to include provision of "humane death services" -- perhaps leading to a new form of "soliciting"
• the probable switch in attitude on the part of the pharmaceutical industry once there is recognition of the economic benefits to be derived from providing a "Dieagra" pill to match the unexpected success of the "Viagra" pill, especially if competing non-proprietary substitutes are made available (whether by alternative health practitioners, or through illegal channels)

Radical mutual assistance

It is ironic: that the right to die is the only right of which people cannot be ultimately deprived -- as yet. However, as indicated above, social institutions have done as much as possible to make it difficult to exercise that right. In many ways they derive much of their power from keeping people alive, notably to exploit their economic potential.

It is interesting that there are radical opportunities for engaging with the current legal context to facilitate ability to exercise the right to die. This may be explained by distinguishing the following phases in relation to terminal illness:

• Phase I: Recognizing the challenge of exercising the right to die and the suffering that may be prolonged unnecessarily by failure to do so
• Phase II: The period during which a person is diagnosed as terminally ill, but prior to its constituting a handicap on action, and whilst there is no immediate desire to die. Typically a living will may be made in anticipation of Phase III.
• Phase III: The period of suffering, in an incapacitated state, from the terminal illness -- during which there may be a manifest desire to die.

The tactical opportunity occurs in the relationship between people in Phase II and people in Phase III, and the opportunity of the former to assist the latter.

In the case mentioned earlier, brought by Diane Pretty in 2001 before the European Court of Justice to seek immunity from prosecution for her husband to enable him to provide her with assistance in terminating her life, the obstacle lay in the fact that her husband did not wish to be prosecuted -- for murder [more]. But if a non-relative in Phase II is willing to provide such assistance, he or she may indeed then be subject to prosecution -- if still alive when the case is finally brought to trial. But the legal costs to the state, and the cost of incarceration once that convicted person moves into the dependency associated with Phase III, would quickly become unacceptable to the state -- given the budgetary challenges already faced by the health, legal and penal systems. It is actually an excellent way of transferring the high health costs of Phase III to the state.

As might be expected in the current bankrupt moral climate, the imprisonment and care costs would be a determining factor in changing the law rather than any moral principle. This position is already taken in fact in the treatment of the underprivileged, whether in industrialized or developing societies, as illustrated by Richard Rorty (Moral Universalism and Economic Triage, 1996):

> When a hospital is deluged with an impossibly large flood of victims of a catastrophe, the doctors and nurses begin to perform triage: they decide which of the victims are "medically feasible" - which ones are appropriate recipients of the limited medical resources available. When the American underclass is told that it is politically unfeasible to remedy their situation, they are in the same situation as accident victims who are told that it is unfeasible to offer them medical treatment.

Triage is a system long used by medical or emergency personnel to ration medical help when the number of injured needing care exceeds the resources available to perform care. Triage, when performed in accordance with accepted medical practice, is recognized and sanctioned by the law in most countries [more]. Domestic and international social triage was a theme explored by Joel A. Wendt as candidate for the presidency of the US in 2004 [more].

This line of reasoning has already been anticipated by elderly people who assist their friends to die. The point made by one such person in a BBC interview was that the prison authorities were embarrassed by the challenges of providing facilities for the elderly -- resulting effectively in a form of immunity from prosecution. "Grey Power" becomes "T-ill Power"!

Wider social causes

The examples given above indicate that "suicide bombing" is merely the development of a long tradition of voluntary use of death for symbolic purposes, as a form of political protest, or to exemplify the dignity and significance that people attribute to life. Arguments that those who engage in this form of protest are being manipulated or misled have to be carefully assessed against the quality of the arguments of the vested interests against whose views the protests are made.

It is to be expected that this form of protest will continue to develop in defence of a wider range of social and planetary causes. It may be expected as an aspect of the radical animal rights movement. It may be expected in defence of valued ecosystems and landscapes. It may be expected as part of the protest against particular products (for example, in the light of the image damage to particular brands of soft drink associated with the Jonestown disaster).

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