



Moral Dilemmas

Moral dilemmas of tetraplegia; the ‘locked-in’ syndrome, the persistent vegetative state and brain death

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Lesions of the upper part of the spinal cord, the medulla oblongata or the brain stem have different neurological sequelae depending on their exact location and extent.

High tetraplegia with a lesion at the level of the C3 segment will leave the patient helpless but fully conscious of his situation, and communication is usually possible.

The patient who is ‘locked in’ suffers from a lesion of the pyramidal tract, mostly at the upper pontine–cerebral peduncle–level.¹ Communication is reduced to vertical eye movements and blinking.

The persistent vegetative state is a quite heterogeneous entity, and the underlying lesions are variable. The patient is not comatose, the eyes are open, there are awake-sleep cycles and absence of purposeful movements. There is no communication.

All of these conditions denote a severe neurological impairment of the patient, while brain death has now generally been accepted in most countries as death of the individual.

The moral issues raised by each of these conditions are controversial, and national and local differences may be distinguished. The patient with high tetraplegia, who requests assistance to commit suicide is subjected to the local legal situation. While suicide or attempted or assisted suicide is punishable in some countries (Austria, Switzerland), it is not in others (Germany). But even if it was not a crime to assist suicide from a legal point of view, it is contrary to all medical traditions, the Hippocratic Oath; and is considered ‘unethical’ by the World Federation of Physicians (Weltärztebund).² The general acceptance of physician assisted suicide, however, has clearly increased,³ and criteria have been formulated.⁴ The unresolved key question in each case is: Can this patient be trusted to carry out full responsibility, or is it his wish to die as part of his impaired ability of self determination?

Whilst communication is to a degree possible in those with tetraplegia, and eventually in ‘locked in’ patients, decisions on terminating medical treatment or even withdrawal of life support in those in the

persistent vegetative state (PVS) stand on less safe grounds and greater national differences may be discerned: The causes may be variable, ranging from trauma to hemorrhage, hypoxia and infection. The pathomorphology is a matter of debate.⁵ Findings from the most famous PVS patient, KA Quinlan, revealed severe destruction of the thalamus,⁶ also destruction of white matter and extensive destruction of the cerebral cortex has been reported. The level of consciousness in these patients cannot be clarified, as they are unresponsive. They are certainly not comatose, as they open their eyes, and the kind of pain perception that these patients have is similarly uncertain. Yet, with increasing frequency, courts rule that doctors worldwide should discontinue food and fluids in these patients usually at the request of the relatives. In some countries food and fluids are not considered basic support but part of the medication that can be more easily discontinued from a legal point of view. In their recent article in the *Lancet*, Hoffenberg *et al*⁷ valued withdrawal of food and fluids in PVS as morally identical to giving a drug to these patients that shortens life, since the outcome, death, is the same. Hoffenberg *et al*⁷ see the advantage that organs after actively induced death can be better used for transplantation purposes than those from a patient, who died from starvation and dehydration. Nevertheless, in most countries currently active steps in terminating the life of a patient, who is not dead, is punishable. In the Netherlands active termination of life by a physician is not punishable under certain conditions. A survey in the Netherlands in 1994 revealed, however, that consent of the patient is only obtained in 46%.⁸ The most frequently cited reason was ‘in the best interest of the patient’ or ‘a discussion would do more harm than good.’

In Germany, feelings about giving anybody the right to kill are much more reserved after pitiful experiences with euthanasia prior to World War II. Recently the ‘Kempfen case’ has obtained considerable attention.⁹ In 1990 a 70-year-old female after a transient cardiac arrest was rendered unresponsive, couldn’t swallow and reacted by a facial twitch on

visual, acoustic or pain stimuli. After 3 years of PVS the attending physician and the son agreed to discontinue caloric support, which they documented in a written statement. The patient died 3 weeks later and the case was taken to court by the nurse. The physician and the son were found guilty of attempted minor degree manslaughter and sentenced to a fine. The case proceeded to the highest level, the Federal Supreme Court (Bundesgerichtshof), which annulled the verdict. It did not decide on guilty or not but remitted the case to the lower instance court to ask for evidence that the patient had wanted to be killed either by a written statement prior to the disabling disorder or any other plausible evidence that she would have liked to be killed, as her process of dying was not accelerated by the withdrawal of food but initiated. The explicit purpose of this ruling was to make sure that only the interest of the patient and not the interest of anybody else could be decisive. In cases of doubt the support may not be discontinued. The case is still pending.

In the last few years there has been an increasing number of interest groups around the world, propagating active support of suicide and active termination of life in the proximity of supposedly pending death. As a result, active termination of life is becoming legalized under certain conditions in some parts of the world. Undoubtedly there are singular exceptional circumstances that must be ruled individually. The withdrawal of life prolonging support by medication after the process of dying has irrevocably begun, is for example officially permissible in Switzerland (Schweizer Akademie der Wissenschaften, 5 Nov, 1976 'Richtlinie für Sterbehilfe') and most likely practiced everywhere. By contrast, giving a deadly drug is legally valued differently in most countries. Is the active termination of a life business for the medical profession at all? If societies wanted to put the life of some to the mercy of others, must it be doctors, who associate with killing apart from giving a prognosis? Isn't this violation of a fundamental norm incompatible with the medical profession, which lives on the trust of patients? Hasn't history demonstrated to us that abuse is all but too easy? The Hippocratic Oath: 'I will give no deadly medicine to anyone if asked' should continue to be an integral part of the medical profession.

Brain death

Brain death is a condition fundamentally different from these neurological conditions considered above. The controversy of brain death is the question: does it exist? If so, what are the criteria? As the worldwide conception of brain death differs widely, the recently published second edition of 'ABC of Brainstem Death'¹⁰ is particularly valuable as a source of information. Naturally it is a further version of the British interpretation of brain stem death as brain

death, that has been developed over the last 20 years. It received acute attention in Germany, because a law on organ donation had been passed in Germany on June 25th, 1997.¹¹

The authors state the legitimacy of equating brain death with death of the individual person and proceed to the argument that the vital part of the brain is the brain stem, therefore brain stem death is a necessary and sufficient component of brain death, that should be the adequate criterion for the declaration of death of the individual person. Death itself is not viewed as an event, but as a process, for example as hair and nails still grow for days after cardiac arrest. If we were ready to accept cardiac arrest as an arbitrary marker of death for centuries, in spite of subsequent growth of nails, brain stem death, as a condition inexorably leading to asystole, should also be accepted.

The pitfalls and safeguards are elaborated and the concept of brain stem death is viewed from various angles. Despite all public criticism these criteria of brain stem death are reported to have stood the test of time. Sensational TV-shows of so-called survivors of brain death never provided any serious evidence to question these criteria of brain stem death. So far, once the criteria of irreversible loss of brain stem function were met, there has never been any recovery.

This concept of brain stem death is based on the assumption that consciousness and spontaneous respiration are functions located within the brain stem and are central to the patient's human identity. Once these were lost, the patient may be declared dead and organs may eventually be removed, if feasible.

This is viewed differently in other countries. Generally in the USA and Continental Europe 'whole brain death' is a minimum requirement for the declaration of death on the grounds of brain death. Certainly nobody with a dead brain stem ever has or ever will survive, but is he dead yet? This decisive question led to the precise distinction of primary supratentorial from primary infratentorial brain lesions by the Bundesärztekammer in 1986.¹² In some instances of primary infratentorial brain lesions all criteria of brain stem death are fulfilled, however, not only the EEG may be near normal, but visual evoked potentials can clearly be elicited.^{13,14,15} From the neurophysiological point of view these patients can see when their eyes were kept open, but have no means to react to what they see because of the disconnection of the brain stem. Thus there is no way of ever finding out, what such a patient thinks, what his sentience is. The credo of Pallis and Harley, 'there is no residual sentience above a dead brain stem', even when EEG and evoked potentials remain obtainable, is followed by rhetoric for those who disagree: Is there 'greater hell than an isolated sentience, aware of its precarious existence and with no means of expression?'

Of course this question may equally be posed regarding the persistent vegetative state or even tetraplegia. Pallis and Harley¹⁰ argue that asystole is bound to occur, at the most, a few days after brain

stem death. Since consciousness in their view is irreversibly lost and apnea is present, termination of any special support including respiration is justified in their view.

It is well known, however, that EEG activity after brain stem death in those with primary infratentorial lesions may persist for several days, the interval is variable.¹⁴ Admittedly these cases are rare, but can organs be taken at that point? There are numerous other conditions, which invariably have a fatal outcome, such as glioblastoma, but nobody would argue that organs can be taken from a patient as soon as the fatal condition has been identified.

Many medical societies outside Britain therefore do not accept brain stem death alone as death of the individual person, while the 'whole brain death' concept seems to be more widely accepted in the medical profession throughout most parts of the world.

The general public, of course, is not qualified to follow subtle distinctions of what is sentience and where it may be located. In Germany in 1997 a bill on organ transplantation was passed after the longest discussion in the entire history of the federal Parliament (Bundestag). The debate proved to be a bazaar of lawmakers, who haggled over ill-understood medical aspects of brain death and daily party politics. It soon became apparent that it was not easy to get a majority accepting whole brain death as death of the individual person. A minority within the Catholic church maintained that nobody who believes in the incarnation of Jesus can accept that the soul leaves the body already when only the entire brain is dead.¹⁶ A pregnant 21-year-old after head injury from a traffic accident attracted much national attention when she became brain dead while the fetus was kept alive for several days with the dead mother on a respirator. The fetus died before a cesarean section was possible and the case raised a public debate. Opinion leaders, the Federal Minister of Justice, Mr Schmidt-Jortzig,¹⁷ claimed the supposition of doctors, a corpse could catch a fever or produce a living child, were blatantly preposterous, so in his belief brain death could never mean death of the individual person.

The legislators in June 1997 finally decided not to get involved in details of the diagnosis of brain death, regulating that organs cannot be taken from patients 'unless the irreversible loss of function of the cerebrum, cerebellum and brain stem has been demonstrated according to state-of-the-art rules'. The brain stem death conception clearly had no chance within German society. Obviously public discussion takes different turns in different countries in spite of ready availability of any kind of information everywhere anytime.

'The ABC of brain stem death' by Pallis and Harley 1996, 52 pages, £10.95 gives an international and historical overview. It is a comprehensive and detailed source of information. It should be available to anybody interested in any current aspect of brain death.

Ethical problems

Correspondence on Ethical Problems and Moral Dilemmas is welcome. Editor.

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