BACKGROUND: BRAIN DEATH, WHERE DID IT COME FROM?

The concept of brain death has been in existence since the late 1960s. Before that, for centuries, human death had practically been considered to be on a par with the cessation of the heartbeat and respiration (Ackerknecht 1968). However, from the 19th century onwards, new possibilities for the treatment of disease emerged. At first, operative inventions and then medicinal ones were developed. These were later followed by technical inventions, such as the ‘artificial kidney’ and the heart-lung machine. In the 1950s the transplantation of organs, particularly kidneys, and the introduction of intensive care, were able to compensate for the failure of vital organs (Schlich 1999).

INTRODUCTION

Innovations obviously create new opportunities. However, they also lead to uncertainties in comparison with the status quo ante. Since its conceptualization began in the 1960s, brain death has been viewed controversially in many cultural settings (Pernick 1999; Schneider 1999; Schönesafert 1999; Schlich 2001), particularly in relation to organ transplantation (Wiesemann 2001; Lindemann 2002; Lock 2002; M anzei 2002). Historical citations have been used by both the proponents and opponents of the concept of brain death, often enough without knowledge of the (con)text, in order to underpin their arguments and/or to discredit those of their adversaries. The most current ones are that brain death was already around in 1800 or, conversely, that it was invented after 1968 to increase the harvest of organs for transplantation (Schlich 1999).

This article summarizes my research, along with that of Bellanger and Steinbrecher, on the development of the debate in Switzerland. It is based on archival sources (i.e. the unpublished minutes of the Schweizerische Akademie der Medizinischen Wissenschaften, or Swiss Academy of Medical Sciences – SAMS, relevant for the three published versions so far of the Academy’s guidelines on the diagnosis of death – 1969, 1983, 1996); oral-history interviews with Swiss physicians from the disciplines of transplant surgery, intensive care medicine and neurology; as well as on systematic screening of the Swiss medical and general press.
Brain death in Switzerland 1960–2000, handling a medical innovation

new criteria for death were urgently needed. As a result, in the course of the 1960s, the concept of ‘brain death’ merged with that of ‘cardiac death’.

Brain death defines the death of a human being as the irreversible loss of consciousness, perceptive faculty, thought, and feeling as well as the loss of those integrating and regulating mechanisms of the body that are controlled by the brain. Cardiac death is more easily understood, for once the heart ceases to beat, a chain reaction sets in leading to the death of one organ after another and, ultimately, to the death of the brain. But for brain death, there is no visually perceptible clarity of the events that mark death. There is no way of viewing the loss of cerebral function with the naked eye. Hence, from the start, new tests for determining brain death have consisted basically of technical measurements. In addition, if considering organ removal for transplantation, these tests have had to be feasible and their results reliable within the confines of time pressure.

THE 1960s: A SCANDAL FOCUSES PUBLIC ATTENTION ON BRAIN DEATH

Most people in Switzerland were not familiar with the concept of brain death until it became associated with the possibilities of organ transplantation. There had been some discussion about the legal aspects of transplantation in the Swiss medical press in the 1960s. But, in the matter of death of the organ donor, this was restricted to traditional cardio-pulmonary arrest which did not seem problematic for, according to one legal expert, ‘we must not be deceived by the effect of the heart-lung-machine. Behind its effect is none other than death in the guise of life and not, as it may appear, life in the guise of death’ (Schwarz 1967). This view was in accordance with the usual practice of explanting organs, mostly kidneys, from ‘non heart-beating donors’. But the situation changed dramatically, for obvious reasons, when heart transplantation started. The first was performed in December 1967 in Cape Town and found an enormous echo in the media. It was immediately followed by a wave of operations all over the world, so that Switzerland’s first heart transplant 16 months later, in April 1969, was already the 126th world-wide.

A scandal ensued after this operation, because the donor’s heart had been removed without prior consultation with his family (Obrecht 1996; Bellanger et al. 2004). The Blick tabloid newspaper and the donor’s relatives launched a massive campaign of accusations against the responsible doctors, stating that they had acted without any authority to do so. The removal of

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organs without obtaining the prior consent of the next of kin was held as an intolerable breach of personal rights as well as of the rights and feelings of piety towards the next of kin. In addition, there were doubts and rumours as to whether, in general, heart donors had been truly dead or if, instead, they had just been placed in the service of science while still alive. As a result, heart transplantation was not only viewed as a sign of hope for the critically ill and as a symbol of medical progress, but also as a potentially risky intervention into the complex fabric of cultural and social values and norms.

Swiss society in the 1960s was not particularly critical of the concept of brain death. Rather, the daily press and some individuals doubted whether doctors truly attempted to save the lives of the terminally ill and the critically injured with utmost care, and with all possible means, because such doctors might have a vested interest in removing and transplanting organs (Schweizer Illustrierte 1969). As one daily newspaper wrote: 'Shock and horror are the reactions when people hear and read about heart transplantation. A young man is bereft of his heart; a defenceless young man is cynically denied life at the hands of doctors craving for glory. Such undercover deals and violations were the thing to do in Hitler's Germany. Nip it in the bud, citizens of Basle and all the rest of you Swiss people. Otherwise, we shall be registered as organ victims whenever we are sick or entering the hospital. Our government should see to it that such operations never occur again.' (National-Zeitung 1969).

As a result, the legitimacy of medical actions became the focus of widespread public attention as did the relationship between doctors, patients and the next of kin. In this situation, doctors actively attempted to influence media coverage. The Schweizerische Ärztezeitung in particular frequently commented on the attitude and coverage of the general press (Anonymous 1969). Doctors were concerned to steer the public debate on the basis of their expert knowledge of the subject. Yet, they barely succeeded in doing so. The fact that informed consent had not been sought from the next of kin was interpreted by many as being a flagrant and deplorable transgression of the discretionary powers of medicine. In view of this tense atmosphere, the Schweizerische Akademieder Medizinischen Wissenschaften in Basle strove to clarify various aspects of transplantation medicine, particularly the determination of death (Schweizerische Akademieder Medizinischen Wissenschaften 1968).

In parallel with recommendations published a few months earlier by the German Society of Surgery (April 1968), and an ad hoc Committee of the Harvard Medical School (autumn 1968), an ad hoc Committee of medical experts appointed by the SAM S (a lawyer was consulted in the interim) produced 'Guidelines for Defining and Determining Death' in eight months (Schweizerische Akademieder Medizinischen Wissenschaften 1969). These were published in January 1969 and sent to public authorities, medical professional associations and hospitals to serve as a basis for decision-making and taking action. In terms of content, (Kommission für Reanimation und Organtransplantation 1968; Ad Hoc Committee of the Harvard Medical School 1968) they stressed the capability and authority of the individual doctor-in-chief responsible for a clinical department.

THE 1980S: BRAIN DEATH BECOMES A 'GOOD DEATH'

Nothing much happened during the 1970s with respect to brain death, neither in the slowly developing field of intensive care nor in transplantation medicine. Towards the end of the decade the problem of organ rejection was resolved from a medically acceptable viewpoint, thanks primarily to the Swiss discovery of an immunosuppressant drug, cyclosporin A. Kidney transplantation in particular became fairly rapidly established, some 120–180 operations being performed annually in the early 1980s. However, in September 1985, after a 10-year moratorium observed throughout the world with the exception of very few centres, a heart was again transplanted, also in Switzerland. Transplantation no longer seemed to be a last resort laden with risks. Instead, it had become a nearly routine possibility of prolonging life in otherwise terminally ill patients. Nevertheless, this success led to a new problem – organ shortage.

The general press now began to give less coverage to doubts about the concept of brain death. Against the backdrop of an operation with the promise of a cure, brain death was frequently presented in a positive light. It was even styled into being 'a good death'. In particular, Swisstransplant (http://www.swisstransplant.org), the co-ordinating centre for organ transplantation in Switzerland, founded in 1985, and the association of patients who had undergone transplantation in French-speaking Switzerland, Les As de Coeur (Aces of Hearts) (http://www.as-de-coeur.ch), always stressed that the
brain death of one human being could make life possible for other human beings.

However, towards the end of the 1980s some doctors as well as nurses became uneasy about dealing with patients who were declared to be brain dead (Arm & Taillen 1990). Like laypeople, they had difficulty in declaring someone to be dead who outwardly showed signs of life, knowing full well that these 'signs of life' were purely artificial, i.e. maintained by appliances and medication. Hence, the diagnosis of brain death unleashed debate, even in medical circles (Leutenegger et al. 1982). A new generation of doctors pleaded for standardizing the procedures within a hospital. As one surgeon put it: 'Such an examination procedure, being clearly defined and documented in advance, regulates responsibilities, makes objective judgement easier, avoids unnecessary discussions, and convinces the next of kin as well as all those involved in the treatment.' (Leutenegger et al. 1982).

When first revised in 1983, the SAM S's 'Guidelines for Defining and Diagnosing Death' (Schweizerische Akademie der medizinischen Wissenschaften 1983) clearly reflected these concerns and showed that the concept of brain death had far more aspects to it in practice than the specialists of the 1960s had expected. In addition, the new version of the guidelines reflected an ongoing transformation of the professional self-understanding of doctors. While according to the first version of the Guidelines of 1969, the accurate diagnosis of death was guaranteed by the authority and responsibility of individual head doctors, now a rather detailed, 'objective' professional and technical knowledge was to assure accurate determination of death.

THE 1990s: NEW ASPECTS ON VARIOUS LEVELS

In the late 1990s, the SAM S Guidelines underwent further revision. The experience of a decade of routine work as well as new technological developments permitted and even demanded that the criteria and diagnostic procedures undergo some further fine-tuning: quite a number of doctors were able to tell stories about people declared 'brain dead' but who had recovered perfectly. There were practical difficulties with the explanatory power of the electroencephalogram, and new tests such as the so-called apnoea-test became increasingly important. In addition, during the 1980s, with the increasing dependence of the diagnosis of brain death on a battery of tests linked to machines, a standardized protocol for diagnosing brain death was appended to the new, third version of the Guidelines in 1996. This was approved by the Academy after more than four years work by a special committee and - for the first time - a consultative procedure that involved all members of the Swiss Medical Association (SAM S 1996). The aim was not only to standardize the procedures within a hospital but to unify them throughout Switzerland. This was in keeping with the trend to standardize many aspects of medical research and practice which began in the 1990s (Timmermann & Berg 2003). Another new feature of the guidelines was that they also provided a precise definition of the diagnosis of cardiac death, a phenomenon that had until then been considered simple and self-evident as compared with the diagnosis of brain death. Given the shortage of organs, some hospitals had resorted to removing organs shortly after a patient's heart had stopped beating (so-called non-heart-beating donors), as had been the case when organ transplantation in humans had been taken up again in the 1950s and 1960s after the very first attempts had failed prior to World War I (Schlich 1998). For this reason, organ removal had to be regulated in the case of cardiac arrest.

Of note is the fact that this third version of the guidelines also delved into the psychological and human components of defining the brain death concept. It included a topic that had been of some interest in the medical and nursing literature from the 1980s. Indeed, nursing staff in particular had repeatedly described the very polarity between the readily perceivable signs of cardio-circulatory failure and the only indirectly demonstrable cessation of brain function by means of appliances as a burden and an irritation at the same time. One straightforward issue was to maintain maximum therapy in the name of beneficence. As a transplant surgeon wrote in a Swiss medical weekly: 'As long as a potential organ donor has not been diagnosed as being brain dead, this person must as a patient be given the absolutely best treatment in keeping with his or her condition. This treatment comprises the maintenance of the circulation while protecting the organs and is not contradictory to the rest of the treatment.' (Laske & et al. 1990). But this did not alter the fact that these therapeutic efforts were only made in order to - potentially - remove organs for transplantation. Now, the preamble of the revised guidelines described exactly this dilemma of doctors who had to decide, while caring for patients unlikely ever to recover, whether organ donation should be considered and whether ap-
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BRAIN DEATH: WHERE IS IT NOW? WHERE WILL IT GO?

For a long time, cardiac death was held to be a dependable and proven concept of human death based on tradition and experience. Until the 1960s, it had been the only concept for determining death. Laypeople as well as medical personnel found the concept of cardiac death logical and reliable. In contrast, the burgeoning concept of brain death was fraught with doubt from the beginning, and in the third revision of the SAM S Guidelines initiated in 2000, the relationship between cardiac death and brain death seemed to undergo a change. These shifts in the appreciation and assessment of various clinical methods of determining death are connected with current modifications in transplantation medicine.

There inclusion of the issue of organ removal in the case of cardiac arrest (non-heart beating donors, see above), already mentioned in the guidelines of 1996, has also brought about an even more far-reaching recapitulation of the criteria of cardiac death. According to the latest draft of the SAM S Guidelines, now out for consultation, the current regulation on cardiac death is inadequate, in fact – when one is under time pressure – the ‘finality of cardiac arrest is clinically far more difficult to determine than is the irreversibility of brain damage.’ On the other hand, ‘the determination of the complete cessation of all brain functions, including those of the brain stem’ is considered to be ‘currently the best criterion for the onset of death’. (Medizinisch-ethische Richtlinien zur Feststellung des Todes mit Bezug auf Organtransplantation 2002). After more than three years of discussion, this process of revision of the Guidelines is still ongoing. The delay is due in part to the fact that the Government decided to include the fourth version of the Guidelines as an appendix to the law on organ transplantation. But there is still a divergence of opinion on the official moment of death, and the comparatively long duration of the whole revision process reflects the complexity of the deliberations of the SAM S Committee which, besides doctors, now includes ethicists and jurists as well as health care personnel (SAM S 2004).

With time the view has developed that brain death should be understood as being the moment of irreversibility in the process of dying and that it should be granted validity and legitimacy within the scope of both organ transplantation and intensive-care medicine. As one senior surgeon put it in an interview conducted with a member of my group:

‘Such an organ removal is a challenging situation, even for us. The moment when you say, fine, that’s it, and the cardiac surgeon removes the heart and the aorta or another...’
major vessel, usually opens a vein and drains the blood, and you can watch, as it were, how the heart stops beating, this is a moment that always gets under your skin. This is when you have to get over it. Of course you do so by way of your knowledge about the certainty of the diagnosis of brain death. If we are not firmly convinced that what we are doing is right, we would surely not be able to cope with the resulting mental distress.

However, the objections to the proposed bill show that the brain death concept is not being accepted as such, namely as signifying the death of a human being. Rather it remains tied in with particular situations of highly 'technological' medicine. For these reasons, the debate about the concept of human death will presumably continue. While the SAMS Guidelines chiefly reflect the medical discourse on brain death, the meaning of 'medical' has gradually widened in the last 40 years in Switzerland, to include no longer just (expert) doctors alone, but all health care personnel and the next of kin involved in transplantation as well as, finally, the potentially concerned citizens. Questions such as the following will still be raised: 'Where does one draw the line between life and death?'; 'What makes a human being a human being?'; 'What then is irretrievably lost with death, even if separate parts continue to be biologically alive?'; 'What do we wish to understand by the term "human death"?'; 'Who should decide the answer to this question and by what criteria should the answer be decided?'

The history of brain death in Switzerland shows that the criteria and tests based on medicine and the natural sciences have obviously not been able to preclude such questions nor to answer them conclusively. The questions asked and the answers found depend far more on cultural contexts that are in a constant state of flux.

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