News

SOCIETÀ ITALIANA DI NEUROLOGIA (SIN)
BIOETHICS AND NEUROLOGY COMMISSION

SOME BIOETHICAL ISSUES PERTAINING TO THE ANENCEPHALIC NEONATE: DISCUSSION DOCUMENT

This discussion document is the first product of the Bioethics and Neurology Commission recently set up by the Italian Society of Neurology.

The need for a systematic reappraisal of the moral and legal issues that arise in our day-to-day practice as doctors, a need by no means new, has become more pressing in the past ten years in step with the advances of scientific knowledge and of possibilities of intervention. Among the situations that in our discipline raise ethical problems some are, we feel, of particular importance at this time: we are thinking of brain death and the related problems of transplants, the persistent vegetative state, problems bearing on the quality of life and the treatment of some progressive neurological diseases (e.g., the neuromuscular diseases), the preclinical diagnosis of untreatable progressive diseases (like Huntington chorea).

The first topic to be discussed by the Commission has been the anencephalic neonate as possible donor (or rather possible 'source') of organs for transplantation. It may appear to be an extremely specific topic but we do not think that this diminishes its importance: it exemplifies, in fact, a paradigmatic situation, which raises scientific, philosophical and ethical problems, and the attitude to it has implications for other, more common, situations, such as the persistent vegetative state and the dementias.

Now, irrespective of general considerations relevant to the framing of a policy on transplants (and its possible abuses), this particular problem deserves to be discussed in detail. In the past two years it has aroused lively debate in the United States, widely echoed in the American press and public opinion, and has now reached our country.

And it is not only an issue for abstract debate. In some Italian hospitals (in one of them, at least, to our knowledge) neonatologists and neurologists have already been faced with the need to decide what attitude to take when confronted by a neonate with this extremely severe malformation, especially in connexion with the possible explantation of organs.

The discussion in the United States reached white-heat after Leonard Bailey's successful cardiac transplant operation in October 1987 using for the first time the heart of a Canadian anencephalic neonate (baby Gabrielle) at the Loma Linda Medical Center, California. Shortly after (in December 1987) the Center published a protocol entitled “Considerations of anencephalic infants as organ donors”, which proposes a new approach to the care and treatment of the anencephalic neonate with a view to possible explantation. This protocol is the focus of the present debate.

Let us try to summarize the terms of the problem. The driving force behind the question is the expansion of transplant surgery and the consequent demand for infant organs suitable for children with cardiac or other malformations. Although anencephaly is a rare occurrence and likely, according to some, to become rarer, as screening for this malformation during pregnancy becomes more frequent, many surgeons nonetheless consider that the use of these neonates as a source of organs would make a significant contribution in this field. At this point the legitimacy of the practice at once arises. The problems raised by the removal of organs are of several kinds:

1) First there is the definition of death.

In the majority of western countries the concept of 'brain death' has been introduced into the law (or practice). Where the matter has been theorized most exhaustively, as in the USA (see the Report of the Presidential Commission in 1981), death is defined explicitly as the irreversible cessation of function of the entire brain, including the brainstem.

As the law stands at present in Italy, although these terms are not used, the criteria nonetheless clearly refer to cessation of function of the brain in toto. In other countries, as in the United Kingdom, the ne-
cessary and sufficient condition is demonstration of irreversible arrest of brainstem function. This difference in theoretical stance has some practical consequences regarding the criteria of diagnosis of death (the emphasis on the brainstem makes an electroencephalographic examination unnecessary). However, it seems to be proven that brainstem death inevitably involves global death of the brain and hence of the entire organism within a short span of time.

Now, in the case of the anencephalic neonate an exceptional condition obtains: the subject possesses a brainstem (more or less functioning) but no hemispheres. Brain death, understood in the above terms, can occur only if there is permanent cessation of brainstem function. The criteria of diagnosis dispense with the recording of cerebral electrical activity, which in these cases cannot, as a rule, be recorded, and can only be based on apnea and on the absence of all brainstem reflexes. If the anencephalic neonate is capable of breathing at birth, the grounds for speaking of brain death do not exist.

A few authors suggest redefining brain death as cortical death, which would enable anencephalic subjects to be declared dead at birth and allow exploitation of organs to proceed without delay. Others, in particular M. Harrison, do not consider it necessary to modify the definition of death or the related diagnostic criteria but propose creating a special category for anencephalics, that is of “living but brain absent” subjects, from whom it would be legitimate to remove organs without waiting for the occurrence of death in the full sense of the term. This proposal would obviously solve the problem of transplants but would raise a host of legal issues (it would require amendment to the law as it stands) and enormous ethical perplexities. It would clearly be a form of killing of one human being in the interests of others, even though without damage to interests of that individual that he could “subjectively” appreciate. Then there is concern over the possible extension to other categories of patients, such as those in the persistent vegetative state.

2) In the second place there is the form of care of the neonate and the modality of death. As a rule, the care of the anencephalic neonate does not include resuscitation: the subject dies within a few days (in one study only 5% of 181 cases survived one week and the longest survival was two weeks), usually in cardiorespiratory failure, which renders the organs, damaged by anoxia, useless for post-mortem purposes. Hence the idea, put forward first by a group of surgeons in Toronto and endorsed by the doctors of Loma Linda, to give these neonates assisted ventilation immediately after birth or at the first sign of respiratory failure and to watch them for a few days (usually a week), checking twice daily for the onset of brainstem death.

There then arises the theoretical question: for what reason, once assisted ventilation is set up, should brainstem death occur? It should be remembered that in the adult and nonmalformed child brainstem death occurs by a mechanism of intracranial hypertension (with herniation of a temporal lobe or of the entire diencephalon through the tentorial notch); this mechanism is clearly not feasible in the case of anencephaly with the skull absent.

The experience gained at Loma Linda during the six months in which the protocol was applied bore out this doubt: brain death occurred in only two of the twelve cases in the study. Probably for this reason the experience was suspended in August 1988.

There are other, more general, problems relating to the determination of death in children, to which several groups have recently sought to supply an answer, in particular the American Special Task Force, who in 1987 worked out the “Guidelines for the determination of brain death in children”. The Task Force’s conclusion was that it is not prudent to make a diagnosis of brain death in neonates aged under 7 days. Although this opinion is not binding, it clearly creates a further difficulty.

The possibility of misdiagnosing brain death becomes more concrete when one considers that anencephalic neonates often have abnormalities of the optic nerves and of the ear (middle and inner), which may give rise to altered pupillary and vestibulo-ocular reflexes.

3) There are then more properly ethical considerations. In these cases resuscitation is withheld not on therapeutic grounds, as is the case of a patient who is going to die as a result of injury or acquired disease, but from the outset for the benefit of others (the potential recipients or the parents of the donor, who sometimes wish to give their consent and so give meaning to the tragic experience they are living through).

Now, if there is consensus regarding the legitimacy of continuing care after the occurrence of brain death for the time strictly necessary for the removal of organs, there is much more doubt about this situation, in which treatment is instituted pending death solely for the benefit of others, with no possibility of self-determination on the part of the subject and with the possibility, however remote, of causing him suffering.

The question of informed consent of the parents is particularly difficult because, in contrast to the situation in the adult, there is no possibility of the subject having previously expressed his attitude to death and to organ donation. The parents’ decision in this case (as usually in cadaver organ donation by mi-