

Judicial Decision Making in Areas of Scientific Uncertainty

John B. DOSSETOR*

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* M.D., Ph.D., F.R.C.P. Director, Division of Biomedical Ethics and Humanities, University of Alberta, Edmonton, Alberta.

In this paper two areas of scientific uncertainty will be compared and contrasted for their effect on legal decision making. Section I deals with judicial decisions on paternity, where scientific advances in proving paternity have led to valuable aid for legal decision making. By contrast, Section II considers whether life-prolonging technology, including artificial feeding and hydration by means of a gastrostomy tube, may be discontinued in situations of severe irreversible brain damage but continuing spontaneous breathing, specifically the Persistent (Incognitive) Vegetative State (PVS). Scientific progress in this area has offered limited help in legal decision making, because the underlying fundamental philosophical-theological question has not been addressed: Does continued function of only the mid-brain maintain personhood? ... Is personhood the criterion by which to judge whether human life should continue?

I. WHO IS THE FATHER OF THIS CHILD? THE HLA GENETIC REGION ON CHROMOSOME 6

The term Human Lymphocyte Antigen (HLA) region refers to a region on chromosome 6 where the DNA codes for protein markers found on nucleated cells all over the body. (The HLA markers are not present on the red blood cells, so that HLA grouping plays no part in blood grouping.) The most convenient cell to use is a part of the white blood cells (leukocytes) termed the lymphocytes. (An antigen is any protein that gives rise to an immune reaction resulting in an antibody with which the antigen will combine.)

The HLA region is unique in that there are many possible alternatives for its gene sites. Though no single person can have more than 2 of each, there are 25 or more HLA-A factors and 45 or more HLA-B factors. This diversity for the HLA factors means that, although each person cannot have more than 4 factors for these two HLA sites, they are drawn from a pool of over 70 possible A and B factors. This great diversity of possibilities makes HLA typing valuable in identifying individuals in a population. By contrast, the common blood group gene site has only 3 alternatives, A, B and O. Clearly, HLA factors can identify relationships between individuals with much greater certainty than can the ABO red blood cell system.

In families, all children derive one HLA-A factor and one HLA-B factor from each parent. Further, because the HLA factors are linked together *in linear fashion* on single strands of a pair of chromosomes, the four factors do not get passed on randomly to the next generation. In fact, although each parent has four factors, only two combinations of one HLA-A and one HLA-B factor are passed on by parents, not four as one would expect if linear linkage was not present. Suppose that, in a paternity case, a potential father had HLA-A factors 1 and 2 and HLA-B factors 11 and 12, and that the two combinations carried by his sperm are either 1 and 11 or 2 and 12. The other two combinations of 2 and 11, and 1 and 12, would not be found in his offspring. This linear linkage of an HLA-A factor to a HLA-B factor greatly simplifies analysis of inheritance of HLA factors in a given family.

In paternity testing, the woman is assumed to be the mother of the child. The 4 HLA factors on the cells of the child are then identified and the two factors the child inherited from the mother are determined. That leaves two factors, one HLA-A and one HLA-B, that have

been inherited from the genetic father. If the alleged father does not have these two factors, he is excluded from genetic paternity. If, on the other hand, his cells carry the child's two paternally derived factors, he *could* be the genetic father.

The statistical likelihood (which can never rise to 100% certitude) that he *is* the genetic father is then calculated from the frequency of that particular HLA-A/HLA-B combination in the general population. There are copious tables of combination frequencies for different populations. The calculation uses this data and a starting "prior probability" of biological paternity of 50% (this prior probability of 50% seems reasonable in situations where "she says he is the father, and he says he is not").

Because of the great number of factors in a general population (over 70 for HLA-A and HLA-B) the chances of a randomly selected male having the pair of factors in question is quite small (less than 1 in 20, or 5%). Thus, when the alleged father has both of the child's paternally derived factors, the 50% prior probability will rise to a probability of over 90%. If the pair of factors in question happen to be very rare in the population, the probability could rise to as high as 99.9%.

Although the principle of genetic segregation of HLA factors in families is quite straightforward, its *reliability depends on certain assumptions*, as follows:

1. The "general population" under consideration must not be genetically restricted; i.e. it must not be a human "genetic isolate". In relatively in-bred communities, such as Inuit or Hutterites, or even Northern Amerindians, sharing of combinations of HLA factors may be very much more frequent than in the outbred Caucasoid, Negroid or Mongoloid populations from which population probability statistics are derived. This imposes a limitation on the interpretation of paternity suits when the alleged father comes from such populations.
2. The men who are possible genetic fathers must not include male relatives of the alleged father. In any family, there is a 25% chance that the HLA-A&B antigens of two brothers will be identical. A given HLA-A&B combination, if present on an alleged father's cells, will also be present on the cells of 50% of his brothers, and has a 50% chance of also being carried by the alleged father's own father. Thus, in a case of family incest involving more than one possible male from a family it might be impossible to establish paternity by HLA typing.
3. Genetic "crossing over" must not have occurred between the HLA-A and HLA-B chromosomal subregions in the formation of the particular sperm which led to the child. Crossing over represents a breakdown in the linear linkage mentioned earlier, and has an incidence of about 0.6%.

It should be stressed that *laboratory error* is much more likely to lead to falsely excluding an alleged father (who really is the genetic father) than to falsely imputing genetic paternity. This is because the whole system hangs together on the basis of sharing of cell factors. If the alleged father is to be proven the genetic father, the laboratory tests on all three separate individuals must be technically consistent. Any laboratory error would very likely destroy this required consistency. Conversely, it is very improbable, indeed, that a truly

scientifically inconsistent set of results would be rendered consistent through laboratory error, and thereby falsely impute paternity.

Subsidiary to the use of HLA serology in paternity testing, is the technique of DNA hybridization — also called DNA "finger printing". This technique uses strips of DNA called "probes" from a "library" of such probes. Each probe has been previously isolated by acting on DNA with different digestive enzymes and is valuable only when it has been established that it aligns, or binds, to a genetically significant region of DNA in a test sample. This binding or alignment process is called hybridization.

This technique is under development for paternity disputes, but it does not yet give as reliable information as testing by HLA serology. When further developed, the advantage of DNA hybridization will be that it does not require live cells (such as the lymphocytes used in HLA technology) but only DNA derived from cells, alive or dead. It has already been applied in forensic work in to identify DNA in seminal and blood stains.

Sometimes establishment of paternity is harmful. One instance is when a child loses his or her social father as a result of testing but gains no benefit from the person now identified as the genetic father. This occurs when the genetic father subsequently assumes no social role or responsibility. In private disputes, the gatekeeper for the technology may feel obliged to counsel disputing adults to consider not using the technology, or at least to defer it until the child could not be exposed to possible social or emotional harm or could enter into the consenting process.

In conclusion, HLA paternity testing is accurate and able to underpin most paternity disputes with reliable scientific data. Such data may be used, with some reservations, for judicial decisions when paternity disputes come to court.

II. WHAT IS THE MEANING OF PERSONHOOD? THE PATIENT IN THE PERSISTENT VEGETATIVE STATE

In contrast to the value of scientific technology in resolving problems of paternity, consider the situation of the patient in the following scenario: Mr. F. is aged 54. Four years ago he had a cardiac arrest in association with a myocardial infarction. He fell down suddenly while walking in the street. Within minutes an ambulance picked him up and the medics began resuscitation while en route to the nearest emergency room. On arrival his heart was defibrillated and resumed a regular rhythm. Later, it was judged that he had been without recordable blood pressure for 8-10 minutes. He remained deeply unconscious and dependent upon a respirator for about three weeks after which he had weak but insufficient spontaneous respirations.

After one month, he was breathing sufficiently to be removed from the respirator. For the next four years, to the present date, he has breathed spontaneously. However, he has not recovered consciousness though his eyes are open for periods and he appears to have sleep-wake cycles. His condition may be described as "eyes open unconsciousness". He receives food and fluid by means of a gastrostomy tube which has been surgically inserted

through the anterior abdominal wall. He requires skilled nursing care to avoid skin breakdown (frequent turning of the body) and is incontinent of bowel and bladder. The diagnosis is Persistent Incognitive (or Vegetative) State (PVS).

His wife, who is deeply committed to his care, has become convinced that her husband would not want to have his life prolonged in such a state, which she now agrees is irreversible. Though she is religious, she is convinced that her husband's wishes would be to discontinue all medical therapy, including artificial administration of food and water, now that the prognosis is so painfully clear. She talks to hospital staff and pleads that Mr. F. be allowed to die of dehydration, especially because she now knows that he would not feel any discomfort from such a withdrawal of care. The staff and administration of the hospital oppose her wishes, stating that they are committed to prolonging his life. They point out that he has not sustained a terminal illness, merely one in which he has unfortunately lost all neo-cortical (cerebral cortical) function. They remind Mrs. F. that although his cerebral cortex seems to be irreversibly lost, his mid-brain is functioning and the rest of his body is certainly alive.

Mrs. F. turned to the court for relief. In the legal dispute, she based her claim that her husband be allowed to die a natural death on:

1. Promotion of her husband's autonomy. She was sure that "he would not want this futility to continue, if he were able to express his choice in the matter ..." and that he has been deprived of his right to refuse treatment. Though all other family members agreed, no evidence written by her husband could be found to support this claim.
2. Mrs. F. believed her husband's quality of life was zero and his interests were non-existent. In such circumstances, continuation of medical treatment could not be justified.
3. She argued that hydration and nutrition by gastrostomy is medical treatment.
4. She claimed her rights as her husband's legally appointed guardian entitled her to make a decision to refuse all treatment on behalf of her husband.

It may be noted that Mrs. F. did not claim that her husband was, in fact, already dead and that survival of only the respiratory centre in the mid-brain is evidence that he has suffered death of those parts of the brain that make a body into a person. This claim was not made for three reasons: 1) scientific uncertainties, 2) philosophical uncertainties, and 3) the current state of the law.

The hospital, acknowledging that Mr. F. had a "lethal pathology in a non-progressive" stage, resisted Mrs. F's claim on the grounds that:

1. The Sanctity of Life principle committed the institution to prolonging life;
2. No one really knew Mr.F.'s mind on this matter;

3. Public policy dictated avoidance of "slippery slope" situations which might create bad precedents for future cases; and
4. Hydration and nutrition, even given by gastric tube, constituted the basic elements of care, owed to all persons under all conditions, and were not what is meant by medical treatment.

The clinical condition of PVS was first described by Jennett and Plum in 1972¹ as "wakefulness without awareness" or "eyes-open unconsciousness". In 1988,² Cranford described the condition carefully and indicated how it can be distinguished from prolonged coma, irreversible coma, severe dementia, the "locked-in" syndrome, brain death, and other like conditions. Oboler³ reviewed the criteria for brain death and compared them with PVS, noting the relevant medical and legal literature.

In PVS, the reticular activating system, which is responsible for "waking" the brain, is preserved but not able to interact with the consciousness part of the brain, the cerebral cortex, or cerebral hemispheres, because the latter, being more sensitive to oxygen deprivation, has been destroyed. Though the open eyes wander, they do not fix with purpose or recognition. The gag and cough reflexes are often present, and PVS patients can sometimes swallow involuntarily. Because swallowing is not voluntary, the vast majority of cases have to be nurtured by gastrostomy feedings through a tube. Despite residual vegetative functions the patient is totally and permanently unconscious and is not believed to be able to feel pain. The most famous case of PVS is that of Karen Ann Quinlan. It is estimated that there are between 5,000 and 10,000 patients in PVS in the USA. The longest reported survivor lived 37 and 1/3 years in this state. Thus PVA cases are not terminally ill though they have "lethal pathology in a non-progressive phase".

The degree of certainty about the diagnosis of PVS is less than for the diagnosis of whole brain death. It is not clear how long a period of time should elapse before the diagnosis may be made with certainty, but it is probably 3 months. The Electro-Encephalogram (EEG) is not of absolute value and techniques such as Positron Emission Tomography (PET scanning), in combination with Co-Axial Tomography (CAT scanning) and Magnetic Resonance Imaging (MRI), have not yet provided evidence as to exactly what parts of the brain are alive or dead. More precise neurologic data are needed to better characterize PVS, but until that time, some scientific uncertainty remains.

However, scientific uncertainty is not the fundamental problem. Even greater uncertainty exists philosophically and theologically. Brody⁴ discusses the implications of believing that the individual in PVS is dead as a person. Such a belief implies that, logically,

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1. B. Jennett and F. Plum, "Persistent Vegetative State after Brain Damage", (1972) *Lancet* 1, 734-37.
 2. R.E. Cranford, "The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)", (1988) *Hastings Center Report*, 18, 26-32.
 3. S.K. Oboler, "Brain Death and Persistent Vegetative States", (1986) *Clinics in Geriatric Medicine*, 2: 547-576.
 4. B.A. Brody, "Ethical Questions Raised by the Persistent Vegetative Patient", (1988) *Hastings Center Report* 18, 33-37.

burial could take place even though the body is still breathing⁵ or that direct harm could be carried out on the body (such as by dropping it whilst turning and fracturing a bone). Although these notions are repugnant, according to this belief, there would seem to be moral support for not continuing to feed and hydrate such a body.

The ethical arguments are reversed if it is accepted that the individual in PVS is still alive as a person, though suffering from "lethal pathology of non-progressive type". Although quality of life is zero, the right not to be killed remains. Treatment would continue indefinitely unless other arguments were brought forward based on the patient's right to refuse treatment, or not to be exposed to cruel and unusual treatment without his or her consent. But how much treatment would be extended? If the relatives so desired, would treatment obligation extend to dialysis and kidney transplant, and then ICU care if pneumonia developed? Even if treatment of the patient seems to do good to family members, is one thereby doing good to the PVS patient, also? Boyle⁶ and Grisez⁷ argue that one can do good to PVS patients, though Jonsen⁸ would still assert that decisions that are disproportionately burdensome have no moral authority behind them.

This short account of the PVS is inadequate to do more than highlight the three areas of indecisiveness concerning it:

1. How should the PVS be defined in theological, philosophical and scientific terms?
2. What are the limits of care that should be extended to patients in the PVS? and;
3. Is administration of food and fluid by gastrostomy tube a form of medical treatment?

In contrast to the first interface between science and the law — paternity determinations — it is clear that some problems are so complex that we can look to science only for factual clarification, but not final answers. Meantime, judges will continue to make wise decisions on difficult cases while our technologically advanced society struggles with the meaning of its new scientific creations.

5. R.M. Veatch, "The Definition of Death: Ethical, Philosophical and Policy Confusion", (1978) *Annals of the New York Acad. Sci.* 307, 315.

6. J. Boyle, "Does the Benefit Outweigh the Burden in the Artificial Provision of Nutrition and Hydration?" in *Critical Issue in Contemporary Health Care*, 1989.

7. G. Grisez, "Should Nutrition and Hydration be Provided to Permanently Comatose and other Mentally Disabled Persons?", (1990) *Linacre Quarterly*, May, 30-43.

8. A. R. Jonsen, "What is Extraordinary Life Support?", (1984) *West J. Med.* 141: 358-363.