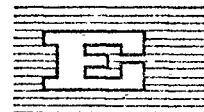


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COMMISSION ON HUMAN RIGHTS

HUMAN RIGHTS AND SCIENTIFIC AND TECHNOLOGICAL DEVELOPMENTS

Protection of the human personality and its physical and
intellectual integrity, in the light of advances in
biology, medicine and biochemistry

Report of the Secretary-General
(continued)

PART TWO. DEVELOPMENTS IN MEDICINE

I. ORGAN TRANSPLANTATION

112. Successful surgical transplantation of certain organs from one human being to another has become possible in recent years. The most important surgical difficulties have been surmounted, and the development of effective immunosuppressive measures, which are needed for post-operative success, is well advanced. Transplantation of organs from one human being to another raises a number of legal, ethical and social issues, however. In a statement furnished to the Secretary-General by the International Commission of Jurists, the Montreal Assembly for Human Rights of 1968, which discussed, inter alia, "new dangers caused by scientific developments", called for an examination of "the profound implications of artificial transplants".

1. The question of the risk run by living donors in transplant operations, viewed in the light of the likely benefit of each operation

113. If the health of living donors in transplant operations is not to be unduly endangered, the range of natural organs which can be taken from them is limited. "The employment of living donors", the report of the Danish Ministry of Justice Committee concerning Legislation on Transplantation states, "is possible only in respect of tissue or organs that can be excised without considerable risk to the life or health of the donor". 169-170/ In this connexion Drs. A. de Coninck, P. Dor and J. R. Fagnart emphasize that "only one pair organ or one tissue capable of regeneration may be taken from one donor". 171/ Defining the organs which can be transplanted from a living donor the report of the Danish Ministry of Justice Committee states: "Without long-term risk all that can be taken from living people is certain tissues such as skin, bone marrow and pieces of bone, and of vital organs a single kidney". 172/

114. All writers dealing with transplants point out that each operation represents a certain physical risk for living donors. Thus, John Holden Th.D. writes that "one must bear in mind the physical ... risk to the ... donor of an organ in transplantation". 17 Speaking about nephrectomy operations, Dr. E. Pillen said: "we ... risk the health of a well person in the future and the later prognosis is still unknown". 174/ Drs. A. de Coninck, P. Dor and J. R. Fagnart indicate that "the immediate risk to the donor and the permanent partial disability resulting from the removal of the organ must be taken into account". 175/ The report of the Danish Ministry of Justice Committee

169-170/ Report of the Ministry of Justice Committee of 12 October 1966 concerning Legislation on Transplantation, and Act No. 246 of 9 June 1967 concerning Removal of Human Tissues (National Health Service of Denmark, 1968) (hereinafter referred to as "Report of the Danish Ministry of Justice Committee"), p. 11.

171/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, Etude sur le problème de la recherche expérimentale sur l'homme et son application aux greffes d'organes (Brussels, Conseil de l'Ordre des médecins du Brabant, 1971), p. 18.

172/ Report of the Danish Ministry of Justice Committee, p. 11.

173/ John Holden Th. D., "Some ethical considerations in the transplantation of organs", Existential Psychiatry, vol. 1, No. 2, p. 175.

174/ E. Pillen, "Theoretical and practical considerations of the low-voltage and zero EEG", paper prepared for the First World Meeting on Medical Law, Ghent, 23 August 1967, p. 5.

175/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., pp. 18-19.

concerning Legislation on Transplantation states that, even if organs and tissues "can be obtained without long-term risk to the donor, it must be borne in mind that every anaesthetization and operation implies a certain - if slight - acute risk of physical injury or fatal termination". 176/

115. The physical risk which the donor faces in a transplant operation may threaten his life. Speaking about the removal of one of a pair of organs, Henry K. Beecher writes: "Such a situation falls into the category of 'statistical mortality', for all major surgical procedures have their own mortality rates. When enough operations are carried out, even the removal of one of a pair will lead to death". 177/ Dr. Gerald Cook, a surgeon at Toronto's Westerns Hospital, stresses that "there is the chance the donor will die on the operating table or as the result of a 'post-op' complication". 178/ In this context Dr. C. A. Richard points out: "There is a statistical risk to the donor. Take kidney transplants, for instance: it is recognized that with nephrectomy operations the death-rate is about one in a thousand". 179/ Danger of fatal terminations also threatens donors of other organs and tissues. Thus, a well-known example is that of a young man of 30 years of age, a skin donor, who died from massive pulmonary embolism ten days after the operation. 180/

116. Besides the fact that the living organ donor undergoes a more or less dangerous operation, the possibility always exists that he may later suffer disease or injury of the remaining pair organ. Dr. Herman L. Blumgart, Professor of Medicine at Harvard Medical School, writes:

"A donor not only loses the factor of safety and reserve provided by the second kidney, but also undergoes all the consequences of a major abdominal operation. One can conjure the problem of a teenage girl who donates a kidney to her identical twin and at the same time loses the added factor of renal safety before she has passed through periods of life, such as pregnancy, when renal infection or other damage may occur". 181/

176/ Report of the Danish Ministry of Justice Committee, p. 11.

177/ Henry K. Beecher, "Scarce resources and medical advancement", Ethical Aspects of Experimentation with Human Subjects, Daedalus, Spring 1969, p. 306.

178/ Cf. I. G. Castel and G. S. Scharpe, "Minors, consents, and organ transplantation", paper prepared for the Third World Congress on Medical Law, Ghent, 19-23 August 1973, p. 5.

179/ News Bulletin of the International Federation of Surgical Colleges, No. 7 (May 1967), furnished by the Federation (hereinafter cited as "News Bulletin"), p. 31.

180/ CIOMS Round Tables: 1. Biomedical Science and the Dilemma of Human Experimentation (Paris, Council for International Organizations of Medical Sciences, 1968) (hereinafter referred to as "CIOMS Round Tables: 1. Biomedical Science ..."), p. 52; and Paul-Julien Doll, "L'homme mis en pièces et les droits de l'homme: transplantation d'organes", Besançon University, Fourth Besançon Colloquium, Human Rights in France, 17-19 January 1974, p. 9.

181/ Herman L. Blumgart, "The medical framework for viewing the problem of human experimentation", Ethical Aspects of Experimentation with Human Subjects, Daedalus, Spring 1969, p. 265.

"The risks", Dr. C.A. Richard stresses, "to which a person with only one kidney is exposed in the event of injury or illness are increased". 182/

117. M. F. A. Woodruff, Professor of Surgical Science at the University of Edinburgh, noting certain long-term risks entailed in sacrificing one of a pair of healthy kidneys, "calls attention to the possibility of life insurance companies refusing to grant policies to potential donors or weighting the premiums of actual donors". 183/

118. The Federation of Neurosurgical Societies points out that "exceptionally a sarcomatous tumor of the brain can develop after e.g. a kidney transplantation, having a very doubtful prognosis". 184/

119. As far as the size of the risk of the living donor of a kidney is concerned, although doctors' figures differ to a certain extent, they agree that while the risk is not great it is not negligible. Speaking at the CIOMS Round Table Conference on Biomedical Science and the Dilemma of Human Experimentation, Professor J. Hamburger said:

"The operation of nephrectomy, of ablation of a kidney, involves in a healthy subject an immediate operative risk of about 0.05 per cent and a remote risk - that of having only one kidney which may become damaged by an accident, cancer, or tuberculosis - of 0.12 per cent ... That amounts to the risk from driving a car for 20 kilometres every day during non-holiday periods. The risk is thus low, but it is not nil." 185/

120. Attention is drawn to the fact that living donors face also some psychological risks. "The psychological risks for the donor", Gerald Leach writes:

"Start with the true 'volunteer' nature of his sacrifice. 186/ A family will often select a donor from among themselves, even before a live transplant has been suggested. Such heavy pressures may be put upon that donor that he is made to feel he has murdered his sick relative if he refuses. In other cases a donor may 'volunteer' out of a sense of duty: 'I dread doing it but I ought to love my brother enough ...' In yet other cases donors have been left feeling that they killed their relative when they have given a kidney but the transplant failed." 187/

182/ News Bulletin, p. 31.

183/ M. F. A. Woodruff, "Ethical problems in organ transplantation", British Medical Journal, 1964, vol. 1, p. 1458.

184/ Information forwarded by the Federation of Neurosurgical Societies on 16 January 1974.

185/ CIOMS Round Tables, 1. Biomedical Science ..., p. 43.

186/ On the voluntary character of organ donations, see also paras. 140-213 below.

187/ Gerald Leach, The Biocrats, rev. ed. (Harmondsworth, Middlesex, Penguin Books, 1972), pp. 306-307.

Speaking about transplants between identical twins, I. G. Castell and G. S. Sharpe pointed out that:

"In two cases, the donee did die ultimately so that the healthy twin ironically did undergo some emotional suffering as a result of his brother's death - the prevention of which was the 'benefit' intended by the surgery although presumably no guilt feelings existed." 188/

121. Another aspect of psychological risk is a possible sense of mutilation and of organ deprivation of the donor. "Maybe the person concerned", Dr. G. E. Schreiner writes, "feels a sense of organ deprivation - he may feel that something is missing when he has a scar to show for a missing kidney". 189/ The donor will "proceed through life with one kidney - ever cognizant of the fatal results should injury or disease affect his one remaining organ". 190/

122. In the report of the Danish Ministry of Justice Committee concerning Legislation on Transplantation the mental strain to which all concerned with a transplantation operation are exposed is emphasized. 191/ J. Russell Elkinton points out the possible disruption of the mental and emotional health of the potential donor and of the patient's family. He writes:

"I know of a patient's brother who declined to donate his kidney - with resultant severe emotional trauma; I know of another family torn apart by a mother giving a kidney to her child against the wishes of the husband and father. Such psycho-social complications occur in many difficult clinical situations but never more so than in this one of transplantation of organs." 192/

123. On the other hand, the probability of success of kidney transplants from living donors is moderate at present. Dr. C. A. Richard estimates it at 40 to 50 per cent. 193/ Speaking about probability of success with a renal graft, Professor J. Hamburger said:

"In our group, taken as a whole since we began these operations, we have succeeded completely for more than a year in 55 per cent of cases - a figure that rises to 75 per cent if operations in the last two years only are taken into account. Everywhere in the world, indeed, there has been an improvement in techniques and results." 194/

188/ I. G. Castell and G. S. Scharpe, op. cit., p. 4.

189/ G. E. Schreiner, "Problems of ethics in relation to haemodialysis and transplantation", in: G. Wolstenholme and M. O'Connor, eds., Law and Ethics of Transplantation, a Ciba Foundation Blueprint (London, J. and A. Churchill Ltd., 1968), p. 132.

190/ I. G. Castell and G. S. Scharpe, op. cit., p. 5.

191/ Report of the Danish Ministry of Justice Committee, p. 11.

192/ J. Russell Elkinton, "Moral problems in the use of borrowed organs", The Annals of Internal Medicine, vol. 60, No. 2, February 1964, p. 312.

193/ Cf. News Bulletin, p. 31.

194/ CIOMS Round Tables, 1. Biomedical Science ..., p. 43.

124. In view of risks faced by living donors, doubts have been expressed whether they should be used. "For the first time in the history of medicine", F. D. Moore notes, "a procedure is being adopted in which a perfectly healthy person is injured permanently in order to improve the well-being of another". 195/ J. Russell Elkinton points out that the question may be raised whether it is legitimate for physicians to subject a healthy person to this risk of possibly shortening his life by 25 or 30 years in order to extend another's life by 25 or 30 months or less. 196/ F. D. Moore writes, that there are some laboratories which have viewed this matter with such misgivings that under no circumstances have they used tissues from volunteer human donors. 197/ "Has the doctor ... the right to make himself the accomplice of a man who wishes to accept a risk to his own person in order to prevent the death of another person?", Dr. Richard has asked. 198/ In this connexion Professor J. Hamburger said at the above-mentioned CIOMS Round Table Conference:

"Thus on one hand is a risk for the donor of 0.12 per cent and on the other a probability of operative success of as much as 75 per cent. In such circumstances, have we the right to accept the voluntary gift of the donor? You know the tradition says no, both moral tradition and legislation in most countries holding that it is not permissible to carry out an operation - in this case a nephrectomy - on a subject when it is not for the benefit of the subject himself. But in recent years, I think, everyone has come to agree that in the particular case of the graft of an organ to save a human being about to die such a tradition should not be maintained. All the thinkers and doctors who have dealt with the problem find nothing illegitimate in accepting that a subject should take a reasonable risk to save someone dear to him." 199/

125. At the same conference the necessity for elaboration of the ethics of risk was stressed. The Permanent Observer of the Holy See to the United Nations, H. de Riedmatten, said:

"While it is of vital importance that there should be a healthy ethic of risk to restrain what needs to be restrained, it is also essential that risk should be given its fully human and positive significance by a consciously objective effort of moral thinking." 200/

126. In the light of risks for living donors, the role of the doctor performing a transplant operation is of primary importance. Speaking about the necessity for taking a reasonable risk, Professor J. Hamburger said:

"But if these are the conclusions of the different meetings that have been held, it is necessary that the doctor should verify two things: first, that there is a reasonable balance between the risks and the probability of success, and second, that the volunteer is a real volunteer. Balance of risks means that it should be verified that the donor does not present additional risks from some defect in his health, and that the recipient offers compatibility conditions auguring well for the success of the operation." 201/

195/ F. D. Moore, "New problems for surgery", Science, vol. 144, 1964, p. 388.

196/ J. Russell Elkinton, loc. cit., p. 312.

197/ Cf. F. D. Moore, loc. cit., p. 388.

198/ News Bulletin, p. 32.

199/ CIOMS Round Tables, I. Biomedical Science ..., p. 43.

200/ Ibid., p. 78.

201/ Ibid., p. 44.

Each renal transplantation must be preceded by careful weighing of the danger to a living donor against the probability of success of the graft in the recipient. "Concern for the recipient has to be matched by concern for the donor", Herrman L. Blumgart stresses. 202/ "The benefit to the recipient must outweigh the sacrifice of the organ by the donor", Drs. A. de Coninck, P. Dor and J. R. Fagnart point out. And Professor David Daube writes:

"First, there must be no other way of achieving the curative end - no other ways actually available, that is; a surgeon available, that is; a surgeon need not be deterred by the reflection that, if haemodialysis machines existed in adequate numbers, his patient might be helped by that method. And, secondly, from a study of pros and cons, the plight of the prospective recipient must emerge as heavily outweighing the danger and loss to be incurred by the donor. Indeed, the promise for the recipient, the rate of success, short-term or long-term, must also be taken into account, just as would be done in any operation, but here, of course, the standard would be far more exacting because of this singular feature that the transaction involves a healthy person. No doubt these balancing considerations are extraordinarily difficult, but they are unavoidable." 203/

127. Touching upon renal transplantation, Herrman Blumgart writes:

"The success of renal transplantation is greatest the closer the degree of the donor's consanguinity, ranging from identical twins to siblings, parents, relatives, and others wholly unrelated ... The physician acting singly or as a member of a group must translate ... scientific and ethical problems into readily understandable terms as he serves as counsellor for the interested parties." 204/

128. Professor Daube emphasizes the difficulty of the doctor's position in weighing the risks, damage and benefits vis-à-vis the two sides, the donor's and the recipient's. He writes:

"In a blood transfusion the risk to the donor is negligible and the damage easily repaired ... But transplantation of a kidney or an eye from a living donor is different. ...

"To judge the respective positions of donor and recipient is a hard undertaking. Some limits may be taken as fixed. No plight of a patient can warrant putting a donor to death. That rules out the use of unpaired vital organs such as the liver. As soon, however, as we get beyond these obvious decisions, we are apt to run into grave dilemmas; how do you evaluate one or two or five years of life in the recipient as against what the removal of a kidney means for the donor? Does age come in, or personal conditions? I think the law would have to be generous and leave the verdict to the rectitude and good sense of the doctor." 205/

202/ Herrman L. Blumgart, loc. cit., p. 265.

203/ D. Daube, "Transplantation: acceptability of procedures and the required legal sanctions", in: G. Wolstenholme and M. O'Connor, eds., Law and Ethics of Transplantation, a Ciba Foundation Blueprint (London, J. and A. Churchill Ltd., 1968), pp. 194-195.

204/ Herrman L. Blumgart, loc. cit., p. 265.

205/ D. Daube, loc. cit., pp. 195-196.

129. The doctor considers the donor's risks in the light of the recipient's benefit, and the latter justifies the character of transplant operations which are more or less experimental. Drs. A. de Coninck, P. Dor and J. R. Fagnart write:

"The recommendations of the Committee on Ethics of the Academy of Medicine with regard to non-therapeutic experiments on human subjects can be adapted to the fact that the violation of the physical integrity of a person is justified in this case by the benefit to the patient rather than by scientific progress." 206/

Professor Daube points out:

"We should indeed exclude an experiment in the sense that the outcome is simply uncertain; that would be too close to a purely scientific probe which ... belongs to a different plane. Where relief is to be hoped for ... this is not a mere experiment and the pros and cons must be carefully examined. As regards this calculation also, the law would have to be open and to rely on the conscience of the surgeon." 207/

130. The necessity for balance between the risks of the donor and the probable success of the transplant is emphasized in the views of Governments on the subject.

131. The Government of Argentina states:

"Before deciding to transplant an organ from a living donor, the permanent or temporary benefits which the operation may procure for the recipient must be weighed against the handicaps suffered by the donor such as unnecessary mutilation in cases where the transplant from a living donor can be replaced by a transplant from a corpse or by treatment not involving surgery, the risk of subsequent damage to the donor's remaining pair organ, regret at having authorized the operation and the psychological effect which mutilation may produce." 208/

132. The Government of Australia has furnished comments by Professor Sir Macfarlane Burnet of the University of Melbourne, in which it is pointed out that "there must always be a small but by no means insignificant risk to a living donor, and unless there is a special bond of affection between donor and patient the use of volunteer donors should be deprecated". 209/

133. In the information from the Government of Austria it is stated:

"Even where in a specific case the donor's free consent is given it is obvious that the matter ought to be decided against the background of the principle of relativity. For the encroachment upon the donor is so heavy that even with the latter's free consent it is justified only if his risk is limited, on the one hand, and prospects are good that the organ transplantation will in all probability actually help the recipient, on the other hand. Of course, there arises at once the question concerning borderlines. But this problem certainly cannot be answered generally as the situation is likely to differ strongly from case to case." 210/

206/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 18.

207/ D. Daube, loc. cit., p. 196.

208/ Information furnished by the Government of Argentina on 30 May 1974.

209/ Information furnished by the Government of Australia on 8 July 1974.

210/ Information furnished by the Government of Austria on 21 November 1974.

134. Subsection 1 of section 47 of the Czechoslovak Order No. 42 of 13 June 1966 specifies that the donation of tissues or organs may be accepted only if, in the opinion of an expert committee, the operation is likely to be successful and if the benefit to the receiver outweighs, from the social point of view, the harm to the donor. 211/
135. In the comments of the Japanese Government on the subject, it is stressed that "transplants must be prohibited if there is a possible risk inviting death of the donors, even when the donors gave their consent to such transplants". 212/
136. In Norway the Act of 9 February 1973, No. 6, relating to transplantation of organs, hospital autopsies and surrender of corpses, emphasizes that a transplant operation "may only be undertaken when it can be performed without involving any direct risk to the donor's life or health". 213/
137. The Government of Romania states:
- "Organ transplantation cannot be permitted except in special medico-surgical centres offering the possibility of examination and treatment of the highest technical order and efficiency and after consultation with a Committee of unquestionable competence capable of establishing an unbiased balance between the hazards for the donor and the success of the transplant. ... Transplantation should represent the last chance of survival for the recipient, after the exhaustion of other possible therapeutic means. Scientific interest alone cannot warrant transplantation. The donor's consent cannot be taken into account except when accompanied by competent medical approval duly authenticated, in which mention should be made that vital and functional hazards for the donor do not argue against the transplant, even in case of next of kin, but the more so if consent was given for profit." 214/
138. The Government of Sweden considers that:
- "A balance must always be struck between the advantages of a transplant operation for the recipient and the hazards involved for a living donor. According to a draft law on transplant operations which is at present being studied in the Ministry of Health and Social Affairs, no surgical operation should be carried out on a living donor if there is a risk of the operation causing serious injury to the donor." 215/
139. The Government of the Union of Soviet Socialist Republics has stated:
- "The risk run by living donors in transplant operations (kidneys, skin) must be minimal, and the transplanted organ must not cease to function; the donor must therefore be carefully examined beforehand. Where there are counter-indications, the surgeon does not have the right to transplant organs, even with the donor's consent." 216/

211/ Cf. Use of Human Tissues and Organs for Therapeutic Purposes, A Survey of Existing Legislation, (Geneva, WHO, 1969), p. 18.

212/ Information furnished by the Government of Japan on 22 March 1974.

213/ Information furnished by the Government of Norway on 15 April 1974.

214/ Information furnished by the Government of Romania on 29 April 1974.

215/ Information furnished by the Government of Sweden on 12 March 1974.

216/ Information furnished by the Government of the Union of Soviet Socialist Republics on 25 July 1974.

2. The question of free consent as applied to living donors in transplant operations

140. In view of the serious risks run by living donors in transplant operations, their knowing, intelligent and truly voluntary consent for organ transplants has been stressed as being of paramount importance. Professor David Louisell states:

"Normally, a surgeon faced with a serious threat to the life or health of his patient under circumstances when the patient cannot be consulted may undertake the necessary procedures without explicit consent if there is no strong reason to believe that the patient would not give his consent. But it is hard to imagine that the defence of emergency would be available in the transplantation area, at least in an action brought by the donor. Because of the time factor necessarily involved in preparation for a transplant, and the lack of benefit to the donor, the defendant physicians would be unable to claim an imminent threat to the donor's health that had to be eliminated even in the absence of his explicit consent. Physicians should obtain specific consents for such serious procedures as organ transplants." 217/

141. The question of consent is important because, in a kidney transplant, the donor is required to undergo a major operation and in addition loses the factor of safety and reserve provided by a second kidney in the event of accident to the remaining kidney.

142. Attention is drawn to the fact that, before giving his consent, the potential donor must be fully informed by a physician as to the nature of the operation and its consequences, and the risks involved. Professor J. Hamburger stressed at the CIOMS Round Table Conference on Biomedical Science and the Dilemma of Human Experimentation, that the donor must "be fully aware of the exact dangers he is running". 218-219/ Drs. A. de Coninck, P. Dor and J. R. Fagnart write:

"The doctor must be sure to provide adequate information ...

"Information given to the donor should be appropriate to his psychology and intellectual capacity and the presence of a witness is a desirable safeguard for the doctor who has to give the information. One way of bringing home the implications is to tell the donor of the attitude of insurance companies to anyone who has undergone a nephrectomy, for example." 220/

143. Speaking at a congress of the Belgian Association of Hospitals, Mr. Bosman, Secretary-General of the Commission of Public Assistance of Liège said:

217/ David W. Louisell, "Transplantation: existing legal constraints", in: G. Wolstenholme and M. O'Connor, eds., Law and Ethics of Transplantation, a Ciba Foundation Blueprint (London, J. and A. Churchill Ltd., 1968), p. 83.

218-219/ CIOMS Round Tables. I. Biomedical science ..., p. 44.

220/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 19.

"First and foremost, the donor must consent to the transplant in full knowledge of the risks he is running and the damage he may suffer ... He must also be warned that an organ of his is being removed for someone else's benefit. Any doctor who carried out such an operation, without the full knowledge of the donor, on the pretext that the organ was being removed for analysis, for example, would be guilty of a breach of trust." 221/

144. The British Medical Association prescribes that:

"Consent should be obtained from the donor after a full explanation of the procedure involved, and the possible consequences to the donor. Where appropriate, the donor should be advised to discuss the procedure with his or her relatives, his religious advisers, and other persons of standing, who, in turn, should be given every facility to meet the medical attendants if they so wish." 222/

145. The Ad Hoc Committee on Organ Transplantation of the Netherlands Red Cross Society emphasized that the donor should be given sufficient information: "The information given to the prospective living donor must concentrate on the health hazards and the social consequences of his donation. As these can sometimes be considerable, they should be weighed before the decision is made". 223/

146. Professor Woodruff pointed out that physicians giving information to the donor must also explain to him "the very considerable chance that his sacrifice will turn out to be of little or no benefit to the patient". The necessary informed consent "is possible only after full and frank discussion". 224/

147. At the fourth Besançon colloquium on human rights in France, Paul-Julien Doll said:

"Informed consent presupposes a full briefing. The donor must be given a detailed explanation of the risks he is running, the economic and social consequences of his sacrifice and the possible complications. The doctor is not expected to use technical medical terms; he should convey the information in intelligible and straightforward language." 225/

148. If a patient cannot give his consent - particularly if he is unconscious - neither a relative nor the doctor is authorized to give consent as long as the person is alive, even when he is kept alive by external reanimation measures. 226/

221/ M. Bosman, "Implications juridiques et morales des prélèvements et greffes d'organes", paper prepared for the Congress of the Belgian Association of Hospitals, Liège, 5 May 1968, p. 6.

222/ British Medical Journal, 18 April 1970, supplement, appendix III, p. 2.

223/ Summary of the Report of the Ad Hoc Committee on Organtransplantation (The Hague, Netherlands Red Cross Society, May 1971), p. 7.

224/ M. F. A. Woodruff, loc. cit., p. 1458.

225/ Paul-Julien Doll, loc. cit., p. 6.

226/ Cf. W. Spann and E. Liechardt, "Rechtliche Probleme bei der Organtransplantation" (Legal problems in organ transplantation), Münchener Medizinische Wochenschrift, vol. 109, No. 12 (24 March 1967), pp. 672-675.

149-150. The Danish Ministry of Justice Committee refers to the psychological pressure which may operate upon a potential donor to secure his consent to a transplant:

"The question of absolute voluntariness is particularly important. Transplantation treatment is already so well known that a situation might well arise for members of a family towards a patient who is in need of a transplant, if the assistance of a living donor is the sole acceptable method. This forced situation might well become accentuated in keeping with the development of better methods of type determination, whereby it may happen that only one person in the closest family circle will be found suitable as a donor. Physicians today are already trying to take measures against such a situation by using psychiatric assistance. But notwithstanding all caution it will scarcely be possible to avoid the possibility that the use of living donors in the long or the short run will lead to grave problems for both donor and recipient ... 227

"... the situation, especially where the donor problem has arisen within a small family circle where the tissue indications have pointed out a few, or perhaps only one, as being suitable for the role, might imply such an actual pressure upon him or them that it is doubtful whether there was anything really voluntary in the decision." 228

151. Professor Woodruff stresses that there "must be no threats or bribes, open or implied, and whenever possible, the patient should be kept in ignorance of the fact that transplantation is under discussion ... until a decision is made to proceed". 229

152. At the CIOMS Round Table Conference on Biomedical Science and the Dilemma of Human Experimentation, Professor Hamburger pointed out that "the offer should be at the free will of the volunteer; it is for the doctor and for the organization dealing with the problem to verify whether there has been pressure from the family or elsewhere, such as the promise of payment". 230 If such pressure has been exerted the donor's offer should be refused. Drs. A. de Coninck, P. Dor and J. R. Fagnart suggest: "If the doctor has any doubts about the donor's having given his consent freely, he can always refuse the donor's offer on some medical pretext such as tissue incompatibility, for example. The donor will then be protected from the reproaches of his friends and acquaintances." 231

153. Practice shows that pressure upon the donor is most often exercised by his family. "The ideal organ source in the absence of an identical twin", Professor T. E. Starzl said at a London conference on organ transplantation, "is and probably will continue to be the familial donor - a parent, offspring, or sibling. This fact alone introduces the possibility of intrafamilial pressure, which in its most malignant form might be directed towards a specific family member on the basis of his or her presumed expendability". 232 Dr. C. A. Richard stressed that: "Family blackmail may exist

227/ Report of the Danish Ministry of Justice Committee, pp. 11-12.

228/ Ibid., p. 19.

229/ M. F. A. Woodruff, loc. cit., p. 1458.

230/ CIOMS Round Tables: 1. Biomedical Science ..., p. 44.

231/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 19.

232/ G. Wolstenholme and M. O'Connor, eds., Law and Ethics of Transplantation, a Ciba Foundation Blueprint (London, J. and A. Churchill Ltd., 1968), p. 132.

in fact without ever being spoken of, and it must be recognized to exist very clearly between identical twins, in whose case it would be surprising if one refused to save the other." 233/

154. Dr. Henry Miller says that some doctors in the United Kingdom, consider that "the request for a member of the patient's family to sacrifice a kidney imposes such unfair moral pressure on the relatives that it is absolutely unethical". 234/ On the other hand, as Professor John Bruce pointed out,

"... many parents and relatives are only too willing to sacrifice a kidney for someone dear to them. There is, therefore, a great moral obligation on the surgeon not to persuade them, or even over-persuade them, in circumstances that make refusal impossible without loss of face and a lifetime of remorse, which is no other than moral blackmail." 235/

155. It is also stressed that the living donor's informed and voluntary decision to give one of his organs should be guided by a rational approach. Professor Hamburger has pointed to the necessity "to determine whether the desire of the donor is stable, well-balanced and rationally motivated. The donor must be mentally healthy and emotionally stable". 236/ He has also emphasized that the donor "should have a reasonable motive for wishing to donate his kidney; that is why, at Paris and at many other centres, we have adopted the habit of considering a volunteer acceptable if he is a relative of the patient to be saved and unacceptable if he is not". 237/

156. Professor Woodruff has drawn attention to the fact that many offers "can be dismissed at once on the ground that the would-be donor is merely making a dramatic gesture without any real appreciation of the issues involved". 238/ As Drs. A. de Coninck, P. Dor and J. R. Fagnart point out, "the donor's consent must be obtained in a form which guarantees his psychological maturity, mental stability and freedom from external pressure". 239/ This would explain the necessity for psychological screening. The donor's voluntary offer "should be subjected to a careful psychiatric examination", Dr. C. H. Richard stresses. He continues:

"In practice, only psychologically stable volunteers are accepted whose decision is the outcome of reflection and not the result of a passing emotion. Nevertheless emotion and affection are factors which cannot be eliminated, and their strength will be all the greater the closer the kinship between donor and recipient, particularly between parent and child." 240/

233/ News Bulletin, p. 32.

234/ Henry Miller, "The ethics of biomedical research and the newer biomedical technologies", in CIOMS, 7th Round Table Conference, Recent Progress in Biology and Medicine - its Social and Ethical Implications (Geneva, WHO, 1972), p. 64.

235/ News Bulletin, p. 16.

236/ G. Wolstenholme and M. O'Connor, eds., op. cit., p. 14.

237/ CIOMS Round Tables: 1. Biomedical Science ..., p. 44.

238/ M. F. A. Woodruff, loc. cit., p. 1458.

239/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 19.

240/ News Bulletin, p. 32.

157. Professor Hamburger considers that psychological examination should be mandatory:

"... mental balance must be required and ... therefore, there should be a psychological, if not a psychiatric, examination to verify that the volunteer is in full possession of his mental faculties. This psychological examination seems to us to be mandatory, both to verify that the decision is free and to say to the volunteer that if he wishes to withdraw his offer of his kidney nobody will ever know that he himself is responsible for that decision and the doctors will assume full responsibility towards the family. The examination will also ensure whether the mental balance of the donor is fully satisfactory." 241/

158. Describing the practice in France, M. Bosman stated:

"Not only must the donor be closely related to the recipient and express a strong desire to be a donor, but also he must be given a psychological examination in order to ensure that he is capable of deciding freely, that his resolve is firm and that his motive is objective." 242/

159. Paul-Julien Doll, emphasizing the necessity of psychological screening, said at the Besançon colloquium on human rights in France:

"For such an act to be freely undertaken requires the self-possession of an adult, which excludes neurotic motives and hasty decisions taken under the stress of emotion. A psychological test appears desirable.

"With regard to the psychology of the donor, I cannot do better than quote Professor Hamburger's definition of the psychiatrist's task: to 'distinguish' between volunteers whose decision has been duly reflected upon, is stable and based on a normal psychic balance and psychically unstable subjects whose decision may have a pathological character or may have been unduly influenced by an uncontrolled fit of emotion; the latter must be eliminated." 243/

160. Speaking about psychological screening, Gerald Leach writes:

"But even this safeguard can still leave very nasty dilemmas, for while the family is being psychologically screened it must also be medically screened to find the most tissue-compatible donor. What happens when the most medically suitable donor is not the most psychologically suitable, and vice versa? Some transplanters have said that they put the psychological considerations first at all times, even if this means making the patient wait longer in the queue. But the temptation to ignore the psychological results when they clash with the medical one must be enormous. As far as I know no one has made the calculation, but it is a fair guess that the truly voluntary, psychologically safe, well-matched living donor must be a very rare specimen indeed - far rarer than a suitable dead donor." 244/

241/ CIOMS Round Tables, 1. Biomedical Science ..., p. 44.

242/ M. Bosman, op. cit., p. 7.

243/ Paul-Julien Doll, loc. cit., pp. 6-7.

244/ Gerald Leach, op. cit., p. 307.

Some authors insist that there should be further safeguards for the donor such as a written form of consent and witnesses. Thus, M. Bosman pointed out:

"It is nevertheless desirable, despite the absence of any legal requirement, that before removing the organ the doctor should establish beyond doubt that the person concerned or, if he is incapable, his legal representative has given his consent, by asking him to prepare and sign a written authority." 245/

David W. Louisell has stressed that "properly witnessed signatures of donors on carefully prepared consent forms are wise precautions". 246/ Paul-Julien Doll also spoke in favour of these safeguards:

"If the doctor wishes to safeguard himself, he will do well to obtain the consent of the donor in writing or at least in the shape of a statement before witnesses. The donor should be allowed the opportunity to change his mind." 247/

161. The majority of authors recognize that the consent emanating from subjects not capable or free - such as children, the mentally ill and prisoners - is, in principle, not valid.

162. Speaking about children, Professor J. Englebert Dunphy has pointed out:

"In regard to children we are on somewhat tenuous ground. Although organs have been taken from children before the age of consent, and although court orders have been obtained authorizing such action, there is considerable doubt in the minds of many as to whether this should be generally accepted." 247A/

Professor Woodruff rejected donors who were minors on the grounds that "they are young people with as yet undefined responsibilities". 248/ Professor David Daube is also quite categorical in this respect: "Children should on no account be donors, and there should be no cheating by maintaining, for example, that the child would suffer a trauma if he were not allowed to give his twin a kidney or whatever it might be." 249/

163. At the Third World Congress on Medical Law, David A. Frenkel said:

"Can one really believe that an incompetent can give full or informed consent? Does one believe that a child 7 or even 12 years old is capable of understanding the risks and consequences of losing a kidney? Undoubtedly the consent is not that of the person but of his representatives. By the acceptance of their consent one gives them a real right over the body of the incompetent, which is not too far from slavery. One of the logical outcomes of free consent is that the consenter should have the right to withdraw at any time. How can this principle be applied in the case of the incompetent? His guardians who consented instead of him are sometimes those who are interested in the transplantation." 250/

245/ M. Bosman, op. cit., p. 6.

246/ David W. Louisell, loc. cit., p. 84.

247/ Paul-Julien Doll, loc. cit., p. 6.

247A/ News Bulletin, p. 44.

248/ M. F. A. Woodruff, loc. cit., p. 1458.

249/ D. Daube, loc. cit., p. 198.

250/ David A. Frenkel, "Consent of and for incompetents (i.e. minors and the mentally ill) to medical treatment", paper prepared for the Third World Congress on Medical Law, Ghent, Belgium, 19-23 August 1973, p. 5.

164-165. The Ethical Group of the Ad Hoc Committee on Organ Transplantation of the Netherlands Red Cross Society pointed out that "in principle minors are not eligible as living organ donors". 251-252/

166. In the report of the Danish Ministry of Justice Committee concerning Legislation on Transplantation it is stated:

"It is the opinion of the Committee that the lowest age at which a person may validly consent to such an important operation upon himself for the benefit of others should be put at 21 years. Under certain circumstances, however, there may be such weighty reasons for allowing a person under 21 years to be a donor that it has been considered best to leave open a possibility for deviating from the age rule." 253/

167. Speaking on minors' consent at the fourth Besançon colloquium on human rights in France, Paul-Julien Doll said:

"Minors are not allowed under the Civil Code to perform the acts of civil life unless emancipated, so that the question of the consent of minors raises special problems. Obviously a minor cannot validly consent to the removal of an organ for transplant. In theory, at any rate, only his legal representative can give such consent. But such consent would, by definition, be unjustifiable since it would be to the disadvantage of the person concerned, save in the exceptional case where the life of a brother or sister, particularly a twin, was at stake. A legal representative therefore cannot in theory consent to the removal of a kidney from a minor.

"There has been a good deal of discussion on this delicate point ... One thing seems certain: a young man of eighteen cannot be treated like a new-born baby and forbidden to express an opinion on such a serious matter as mutilation. Once a minor's intellectual development reaches a certain stage, his will and not that of his legal representative should prevail." 254/

Touching upon the unconscious and the insane, he stressed: "No operation for the removal of an organ can be performed in such a case and the consent of the legal representative must be regarded as void." 255/

168. "Presumably", the Danish Ministry of Justice Committee concerning Legislation on Transplantation points out:

251-252/ Summary of the Report of the Ad Hoc Committee on Organtransplantation
(The Hague, Netherlands Red Cross Society, May 1971), pp. 19-20.

253/ Report of the Danish Ministry of Justice Committee, pp. 19-20.

254/ Paul-Julien Doll, loc. cit., pp. 7-8.

255/ Ibid., p. 8.

"There is general agreement now that transplanted material should not be procured from persons who in one way or another are deprived of their personal liberty, even if the formal voluntary nature of the consent otherwise has been secured ... Presumably the sole imaginable exception will be where the person concerned is very closely related to the patient." 256/

169. Professor Woodruff criticized the idea of accepting offers of kidneys from members of such captive groups as individuals serving a sentence of imprisonment and considered that the only exception is possible for "someone who has committed a serious crime, and, after sober reflection, wants to make such a sacrifice as a sort of act of atonement". 257/

170. Professor David Daube has said:

"No person under any restraint whatsoever should be allowed to give consent. That rules out persons in prison ... It might perhaps be objected that pressure in the family or on the part of acquaintances can be far greater than any pressure a decent prison administration would bring to bear on inmates. That is probably true but, ironically, in this case as in many others, we must be far more careful about criminals than about ordinary citizens in free life ... The pressure in one's family or circle belongs to the normal burden and dignity of social existence - which we deny to prisoners. Some day we may re-think our entire system of treatment of criminals, but then we should do it openly; it would be fatal to lower standards in an indirect manner, however laudable the purposes. At the moment I submit we have no choice." 258/

171. At the fourth Besançon colloquium on human rights in France, Paul-Julien Doll said:

"In principle, it cannot be admitted that a prisoner, doubtless impelled by a desire to obtain a reward in the shape of a remission of sentence, should be allowed to volunteer to have an organ removed ...

"A person condemned to death has the right to insist that, until the sentence is carried out, his physical integrity should be respected.

"In the case of a person condemned to life imprisonment, consent would appear to be impossible, seeing that under article 36 of the Penal Code, such persons are deprived of all civil rights." 259/

256/ Report of the Danish Ministry of Justice Committee, p. 19.

257/ M. F. A. Woodruff, loc. cit., p. 1458.

258/ D. Daube, loc. cit., pp. 197-198.

259/ Paul-Julien Doll, loc. cit., p. 7.

172. Drs. A. de Coninck, P. Dor and J. R. Fagnart summarize the criteria of free consent of living donors in the following way:

"The doctor is required to satisfy himself that the donor's consent fulfils all the criteria of understanding and freedom from obligation. To that end he must:

- (a) obtain it in writing before witnesses;
- (b) refuse to accept consent from a subject in a physical, mental or legal condition such that he cannot fully exercise his right to choose;
- (c) refuse to accept an organ offered for sale;
- (d) give the donor a detailed explanation of the immediate risks and the long-term consequences of the removal, in the widest sense, medical, social and psychological;
- (e) employ every available psychological or psychiatric device to reveal possible hidden motives not prompted by altruism;
- (f) make the preparations for removal in such a way as to allow the potential donor with suspect motives to speak freely without exposing him to some psychological difficulty, even if he withdraws his consent." 260/

173. In the information received from Governments, the necessity for obtaining the donor's free consent to give his organ for transplantation is stressed.

174. The Government of Argentina states:

"The donor of an organ must fully understand what he is doing and have thought his decision over, after a detailed explanation of all the inherent risks for him and all the limitations on the possible benefit to the recipient ...

"To amplify the foregoing paragraph, it must be remembered that freedom of choice involves understanding and reflection; for that reason every care must be taken to avoid transplants from donors in an acutely emotional state with imperfect understanding of the consequences of the operation both for the donor and for the recipient, or who have not been allowed sufficient time to think the position over calmly." 261/

175. The Government of Austria has pointed out:

"As for transplant operations of non-vital organs ... the criteria to be observed should be free consent and relativity. It is understood that a donor's bodily integrity is violated by the removal of a human organ. From the human rights aspect, too, such a violation can be accepted only on the grounds of free consent. The encroachment upon human rights is so considerable

260/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., pp. 20-21.

261/ Information furnished by the Government of Argentina on 30 May 1974.

that compulsion would in no event be justified and consequently there cannot be the question of weighing interests. Nor is it possible to derive from the aspect of social responsibility under human rights an argument to substitute for the donor's free consent ...

"The new Austrian Penal Code, which will come into force on 1 January 1975, provides that a bodily injury is not unlawful if the injured person consents thereto and the injury as such is not contrary to morals.

"The principle of free consent emphasized in the foregoing, however, cannot be applied in all circumstances. This is true for a case where the envisaged donor has lost consciousness (e.g. after an accident). In such instances the donor's free consent must be substituted for by a declaration of consent of other persons." 262/

176. An Italian law of 26 June 1967 prescribes:

"The 'enlightened consent' of the donor is required; the latter must be of age, of sound mind, aware of the therapeutic limitations of the transplantation, and must understand the personal consequences which his donation involves. A magistrate verifies whether these conditions are satisfied and whether the donor has given his consent in a free and spontaneous manner, and then registers the declarations of the donor in writing. The document drawn up is subject to cancellation at any time up to the time of the surgical operation." 263/

177. In the comments of the Japanese Government on the subject, it is maintained that "in cases of transplants from living donors, the consent of the donors is indispensable. Procedures to be followed in relation to the giving of consent should be ... defined". 264/

178. In Norway, the Act of 9 February 1973, mentioned in paragraph 136 above, provides:

"From a person who has given his written consent thereto, organs or other biological material may be removed for the treatment of disease or physical injury suffered by another person ... Before consent is given, the donor must have been informed of the type of operation proposed and the risk entailed. The medical practitioner is under an obligation to ascertain that the person concerned has understood the material content and the significance of such information ... it is an indispensable condition that the donor's consent to the operation is given of his own free will. A potential donor must not be subjected to pressure or persuasion from any quarter ... In several instances in other countries the question has been raised as to whether persons admitted to institutions - for example, inmates of establishments run by the prison service - may give their consent to operations for the removal of transplant

262/ Information furnished by the Government of Austria on 21 November 1974.

263/ Cf. Use of Human Tissues and Organs for Therapeutic Purposes: A Survey of Existing Legislation (Geneva, WHO, 1969), pp. 17-18.

264/ Information furnished by the Government of Japan on 22 March 1974.

material. In such cases there can be no complete guarantee of the consent being entirely voluntary - the inmate of such an establishment may act as he does in the hope of obtaining certain advantages as a result of giving his consent ... Therefore ... persons admitted to institutions of this nature should not be used as donors, unless the donor is a close relative of the recipient in question." 265/

179. The Government of the Republic of Viet-Nam states: "The free consent of the living donor is absolutely essential. The risks involved in the operation must be very clearly explained to him." 266/

180. The Government of Romania states: "The donor's consent should be given in full awareness of the hazards for his own health associated with this act (i.e. after a complete medical screening). The donor should enjoy full legal mental capacity for giving this 'consent'." 267/

181. According to a draft law on transplant operations which is cited by the Government of Sweden, "the consent of a living donor must be given voluntarily before the surgical operation takes place. The responsibility of judging whether the consent is given voluntarily should be borne by the surgeon who decides that the operation shall take place". 268/

182. The Government of the Union of Soviet Socialist Republics points out that: "A living, capable donor may consent to the transplant of kidneys or tissues to near relatives (direct lineal ascendants or descendants, brothers and sisters, spouse). The donor's consent to the transplant of an organ must be freely given." 269/ The Government of the Ukrainian SSR is of the same opinion. 270/

183. It has been said that:

"The ... concept [of informed consent] is relevant to the decision as to the circumstances in which a healthy identical twin or other immunologically very similar person should sacrifice a paired organ - the kidney - to save the life of another. To attempt to lay down any general rules for such a delicate and highly personal situation would be an unprofitable exercise, and the only solution to such a problem is to be found in the collective judgement of the subjects - donor and recipient - immediately concerned and the several physicians who would normally be involved in explaining the implications of such a decision." 271/

265/ Information furnished by the Government of Norway on 15 April 1974.

266/ Information furnished by the Government of the Republic of Viet-Nam on 21 March 1974.

267/ Information furnished by the Government of Romania on 29 April 1974.

268/ Information furnished by the Government of Sweden on 12 March 1974.

269/ Information furnished by the Government of the USSR on 25 July 1974.

270/ Information furnished by the Government of the Ukrainian SSR on 23 October 1974.

271/ E/CN.4/1173, p. 23.

3. The question of consent as applied in cases of transplants from the dead -
advance consent of the donor and consent of his relatives

184. Transplantation from the dead has certain advantages in comparison with that from living donors. Among these the Danish Ministry of Justice Committee concerning Legislation on Transplantation drew attention to the following:

"On account of the doubts involved in the use of living donors - even in situations where the risk factor for the donor is moderate - the procuring of tissue or organs from dead bodies has long been in practice ...

"Moreover, by no means all patients will be in such a situation that a suitable living donor is available.

"Excision of a cornea or a whole lung, for instance, can only be made from a living donor with considerable invalidity as the consequence, for which reason cornea transplantations are made almost exclusively from deceased persons, and the recently attempted lung transplantations were all made from dead bodies.

"Transplantation of vital organs like heart valves, whole hearts, liver, intestines and pancreas of course can only be performed from the dead.

"A further development of transplantation treatment must therefore necessarily presuppose the possibility of taking tissue and organs from the dead for the purpose." 272/

185. Dr. Lillehei, professor of heart surgery at Cornell University, United States of America, has maintained that organs taken from a single dead person can in theory save the lives of 17 people. 273/

186. One of the principal problems in transplantation from the dead concerns the attitude of the deceased and his family to the performing of the operation; it is the issue of consent. Who has and should have control over the decisions made about the use of the corpse? Are the wishes of the deceased to be followed? What if he has expressed no wishes? Is the human body a social property to be used for socially beneficial purposes or do the deceased or family members have some rights and obligations in connexion with it?

187. The majority of authors agree that a person has the right to control the disposition of his body after death. M. Bosman has stated:

"Just as a man disposes of his living body, so in the same way and subject to the same conditions can he decide how his dead body is to be disposed of. He can decide that his remains are to be buried or cremated or given to a school of anatomy to further the progress of science, or he can decide that one or more organs may be removed." 274/

272/ Report of the Danish Ministry of Justice Committee, p. 12.

273/ Centre d'étude des conséquences générales des grandes techniques nouvelles, Bulletin No. 53 (October 1969), p. 8.

274/ M. Bosman, op. cit., p. 10.

Drs. A. de Coninck, P. Dor and J. R. Fagnart point out: "The right of a person over what will be his dead body is of the same nature as the right he holds over his living body and is a consequence of human freedom." 275/

188. It is generally agreed that the characteristics of the consent should be the same as those for consent to be a donor while alive. In the report of the Fifth Bethesda Conference of the American College of Cardiology it is pointed out: "It is essential to obtain adequate, informed consent from the individual before death ... before procuring organs and tissues for transplantation or for other medical purposes." 276-277/ The Danish Ministry of Justice Committee states that the declaration of intention on the subject should be made by an adult and mentally sound person and goes on:

"The Committee considers that the positive wish which in itself independently must provide the reason for performing an operation, must be present in writing and that the deceased when making the declaration must satisfy the same requirement as to age as that for consent to be a donor while alive, i.e. must be 21 years of age." 278/

189. It has also been stressed that a person should not sell organs of his cadaver but may only give them for scientific or humanitarian purposes. Thus, M. Bosman said:

"If a person decides to give his body to a school of anatomy or to permit organ or tissues to be removed, his decision must not be tinged with any thought of monetary gain. A man cannot 'sell' his dead body or part of his dead body. A man's body is a thing that cannot be put up for sale, a thing that is extra-patrimonial ... A man is forbidden to sell his dead body, not only for purely human and ethical reasons but also because a man who contracted to sell his dead body would find himself from that moment bound by a contract which would restrict his freedom and his rights over his body to a wholly unacceptable degree. For example, from that time onwards he could no longer change his mind and decide to be buried or cremated." 279/

190. As the analysis of the legislation of approximately 30 countries shows, the consent may be expressed during a person's lifetime in a written document or may be expressed orally before death occurs. 280/ The most elaborate provisions concerning the form of consent are found in the Uniform Anatomical Gift Act of the United States, which has been adopted, with insignificant changes, in all 50 States. 281/

275/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 25.

276-277/ The American Journal of Cardiology, vol. 22, December 1968, p. 14.

278/ Report of the Danish Ministry of Justice Committee, p. 20.

279/ M. Bosman, op. cit., p. 10.

280/ Cf. J. de Moerloose, "A survey of international and national codes and legislation in selected areas", in CIOMS, Eighth Round Table Conference, Protection of Human Rights in the Light of Scientific and Technological Progress in Biology and Medicine (Geneva, WHO, 1974), p. 338.

281/ Cf. Centre d'étude des conséquences générales des grandes techniques nouvelles, Bulletin No. 70 (June 1973), p. 10.

These provisions are:

"Section 4 ...

- "(a) A gift of all or part of the body ... may be made by will. The gift becomes effective upon the death of the testator without waiting for probate. If the will is not probated, or if it is declared invalid for testamentary purposes, the gift, to the extent that it has been acted upon in good faith, is nevertheless valid and effective.
- "(b) A gift of all or part of the body ... may also be made by document other than a will. The gift becomes effective upon the death of the donor. The document, which may be a card designed to be carried on the person, must be signed by the donor, in the presence of 2 witnesses who must sign the document in his presence. If the donor cannot sign, the document may be signed for him at his direction and in his presence, and in the presence of 2 witnesses who must sign the document in his presence. Delivery of the document of gift during the donor's lifetime is not necessary to make the gift valid." 282/

191. It is agreed that the person who has given the authorization to use his cadaver's organs for transplantation has the right to revoke this authorization. At the London conference on organ transplantation, Dr. Wasmuth stressed that "such authorization for removal or use of a person's body, tissues, organs, members or parts thereof ... may be revoked by the person executing such authorization at any time prior to his death". 283/ In the report of the Ad Hoc Committee on Organ Transplantation of the Netherlands Red Cross Society it is pointed out that "the nature of the consent to organ-removal implies that the donor may revoke his consent during his lifetime". 284/ The relevant provisions of the United States Uniform Anatomical Gift Act read:

"Section 6 ...

- "(a) If the will, card or other document or executed copy thereof has been delivered to a specified donee, the donor may amend or revoke the gift by:
- (1) the execution and delivery to the donee of a signed statement,
or
 - (2) an oral statement, made in the presence of 2 persons and communicated to the donee, or

282/ National Research Council, Medical-Legal Aspects of Tissue Transplantation: A Report to the Committee on Tissue Transplantation from the Ad Hoc Committee on Medical-Legal Problems of the Division of Medical Sciences (Washington, D.C., June 1968) (furnished by the National Academy of Sciences of the United States of America), p. 41.

283/ G. Wolstenholme and M. O'Connor, eds., op. cit., p. 159.

284/ Summary of the Report of the Ad Hoc Committee on Organtransplantation, (The Hague, Netherlands Red Cross Society, May 1971), p. 7.

- (3) a statement during a terminal illness or injury addressed to an attending physician and communicated to the donee, or
 - (4) a signed card or document found on his person or in his effects.
- "(b) Any document of gift which has not been delivered to the donee may be revoked by the donor in the manner set out in subsection (a) or by destruction, cancellation, or mutilation of the document and all executed copies thereof.
- "(c) Any gift made by a will may also be amended or revoked in the manner provided for amendment or revocation of wills, or as provided in subsection (a)." 285/

192. It is generally felt that if the deceased person has not expressed his wishes the transplantation can take place with the consent of his next of kin. Summarizing the legislation of various countries, Dr. J. de Moerloose writes that the direction of the next of kin "can be made by the spouse, any of the deceased's children who is 21 years of age or over, the parents, the brothers or sisters, and, finally, the person lawfully in possession of the body. Any such direction is normally waived only if the de cuius had during his lifetime expressed an objection thereto". 286/ Drs. A. de Coninck, P. Dor and J. R. Fagnart write: "It is generally agreed that, if the deceased has not expressed his views, his family has the right to do so ... As the law stands at present, removal of an organ without the authority of the family is an offence and could give rise to an action for damages." 287/ The same view was expressed at the Third Congress on Medical Law in 1973:

"Often when the time comes to obtain the authority the patient himself is unable to give it. He is incapable of giving his consent advisedly because of his ignorance of the total absence of risk to himself and his unawareness of the considerable therapeutic and social benefits involved.

"It should therefore be sufficient if the consent of a relative is obtained. The present view is [that consent] to the removal of an organ can be given by the deceased's spouse, or failing that his parents, his children, if they are of age, or failing all these his nearest relatives." 288/

193. The British Medical Association recommends:

"The deceased person should preferably have given recorded positive consent in his or her lifetime. Failing this, the donor should be known not to have expressed opposition and in every case the positive consent of the next of kin should be sought ... Inquiry must also be made as to likely objection

285/ National Research Council, op. cit., p. 42.

286/ J. de Moerloose, loc. cit., p. 339.

287/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 26.

288/ A. Andre and others, "Problèmes juridiques et transplantation rénale, critères de la mort et relations avec les magistrats", paper prepared for the Third Congress on Medical Law, Ghent, 19-23 August 1973, pp. 2-3.

by any other relative, as this constitutes a bar ... 'Any other relative' should be interpreted in the widest sense, though it should be sufficient to make such inquiry of the nearest available relative ... It is also necessary to bear in mind the additional obligations in respect of minors." 289/

194. The United States Uniform Anatomical Gift Act contains the following provisions concerning the rights of the relatives of the deceased:

"Section 2 ...

" ...

"(b) Any of the following persons, in order of priority stated, when persons in prior classes are not available at the time of death, and in the absence of actual notice of contrary indications by the decedent, or actual notice of opposition by a member of the same or a prior class, may give all or any part of the decedent's body for any purposes specified in section 3:

- (1) the spouse,
- (2) an adult son or daughter,
- (3) either parent,
- (4) an adult brother or sister,
- (5) a guardian of the person of the decedent at the time of his death,
- (6) any other person authorized or under obligation to dispose of the body,

"(c) If the donee has actual notice of contrary indications by the decedent, or that a gift by a member of a class is opposed by a member of the same or a prior class, the donee shall not accept the gift. The persons authorized by subsection (b) may make the gift after death or immediately before death." 290/

195. In case of conflict between the wishes of the decedent and those of his relatives, the former prevail. Professor Paul Coste-Floret points out: "The next of kin cannot take decisions which go against the wishes of the deceased or the patient. Heirs and families cannot make dispositions which conflict with those of the de cuius. The wishes of the deceased must always be respected". 291/ In the report of the Ad Hoc Committee on Organ Transplantation of the Netherlands Red Cross Society it is stressed that "the

289/ British Medical Journal, 18 April 1970, supplement, appendix III, p. 2.

290/ National Research Council, op. cit., p. 40.

291/ Paul Coste-Floret, "La greffe du coeur devant la morale et devant le droit", Revue de science criminelle et de droit pénal comparé, 1969, No. 4, p. 803.

permission given by the donor may not be revoked by the next of kin after his death". 292/
In its conclusions on the question of amending the Human Tissue Act 1961, the Advisory Group on Transplantation Problems of the United Kingdom pointed out:

"An individual's wishes as to the disposal of his own organs after death should have absolute primacy and override all others. This is broadly the position under the Human Tissue Act 1961, but it is to be hoped that any amending legislation would present this more definitely." 293/

196. In the report of the Danish Ministry of Justice Committee it is stated:

"If there has been a declaration of intention by an adult and mentally sound person, and if there is no reasonable doubt that the intention has been maintained, it is also obligatory on the surviving relatives to allow the deceased's wishes to be fulfilled if there exists a need that can be satisfied by so doing. Conversely, it is the opinion of the Committee that a definite statement by the deceased that he did not wish his body to be subjected to operations of the said kind after his death must be respected by the relatives, i.e. they must not give permission for operations in conflict with the wishes of the deceased. This applies with singular clarity in cases where the wishes of the deceased were governed by his religious belief." 294/

197. Speaking about the need to launch a campaign to secure the enrolment of a panel of volunteers who have contracted in life to give their organs for transplant purposes after death, the British Medical Association gave the following analysis of the two possible systems, namely, "contracting out" and "contracting in":

"To assume tacitly that consent has been given unless the contrary is clearly stated seems too arbitrary a decision to many thinking people, particularly because the pressure of the time factor means that the search for the donor's decision must be perfunctory at best. To be valid, consent must be willingly given and should be an informed consent. There must be some doubt about this always being so when the consent is obtained under the pressures of time and tragedy, of grief and imminent, or immediate, bereavement ... The Blood Transfusion Service provides a model of 'contracting in' as an alternative. It seems likely that a campaign launched to enrol potential organ donors, particularly if directed at young people, would produce an immediate response. The names and identification details of these volunteers could be recorded on a central computerized register of organ donors. Telex linkage between hospitals and the central register would enable prompt ascertainment of whether or not the victim of a fatal accident or illness had enrolled as a donor." 295/

292/ Summary of the Report of the Ad Hoc Committee on Organtransplantation
(The Hague, Netherlands Red Cross Society, May 1971), p. 7.

293/ Advice from the Advisory Group on Transplantation Problems on the Question of amending the Human Tissue Act 1961, (mod. 4106 (London, HM Stationery Office, 1969), p. 4.

294/ Report of the Danish Ministry of Justice Committee, p. 20.

295/ British Medical Journal, 18 April 1970, supplement, appendix III.

198. The majority of Governments which have furnished information to the Secretary-General on the subject consider that the advance consent of the donor or his relatives is necessary for the performance of the operation or at least that there should be no objections to it.

199. The Government of Argentina states:

"The written consent of the donor, particularly where given before a notary public, should be regarded as sufficient even if it conflicts with the wishes or formal objections of the donor's surviving relatives. Where the donor's consent is not explicit, the consent of the relatives must be obtained, unless an emergency makes it impossible for that to be done in time." 296/

200. In the comments of Professor Sir Macfarlane Burnet of the University of Melbourne, forwarded by the Government of Australia, the opinion is expressed that:

"Young and healthy people should be persuaded to carry a consent card. If that consent is on record, any further consent by relatives or others should be unnecessary. Removal of the organ as soon as possible after death is urgent and delay over formalities needs to be reduced to a minimum." 297/

201. In the information from the Government of Austria it is stated:

"First of all it is understood that a transplant operation of a vital organ may be carried out only in cases where the organ donor is dead in the medical sense. In such circumstances it is a matter of course that the declaration of consent should come from the nearest relatives. It should be stipulated that other persons cannot give such consent ... The underlying reason is that whereas in the case of vital organs the donor must already be dead in the moment of the transplant operation and his personal consent is therefore excluded, this is not so for non-vital organs.

"There are no objections from the fundamental rights aspects to an individual giving his consent in advance to transplantation of his organs after his death." 298/

202. In the Act on use of a dead person's tissues for medical purposes of 8 July 1957, No. 260, furnished by the Government of Finland, it is stated that:

"Tissues from a dead person may be removed from the corpse for curative reasons regarded indispensable for the patient, in a hospital designated by the National Board of Health, unless there is reason to believe the dead person would have been opposed to the removal or that his or her nearest relatives would oppose the removal." 299/

296/ Information furnished by the Government of Argentina on 30 May 1974.

297/ Information furnished by the Government of Australia on 8 July 1974.

298/ Information furnished by the Government of Austria on 21 November 1974.

299/ Information furnished by the Government of Finland on 21 May 1974.

203. The Government of France refers to the following two laws:

"The decree of 20 October 1974 provides that, in hospital establishments listed by the Ministry of Public Health, if the doctor-in-charge decides that scientific or therapeutic considerations require it, autopsy and removal of organs may be carried out immediately unless the family objects. However, in accordance with joint instructions issued by the Ministers of Justice and Public Health, the application of this decree is confined to persons who die from an accident, excluding victims of crime, suicide or industrial accidents.

"The law of 7 July 1949 expressly authorizes the immediate removal of cornea transplant material at the place of death in cases where the deceased has made a testamentary disposition bequeathing his eyes to a specialized establishment." 300/

204. The Government of Luxembourg refers to the Law of 17 November 1955 according to which:

"The operations in question require the consent of the next of kin, in due order of succession up to and including the relatives of the second degree, and of the spouse. This consent can be dispensed with if the deceased authorized the operation in writing before his death. Where he expressly refused it before his death, his refusal cannot be over-ruled even with the consent of the relatives and the spouse." 301/

205. In Norway the Act of 9 February 1973 relating to transplantation provides:

"From anyone dead who has already made either a written or verbal decision to that effect, organs or other biological material may be removed for the treatment of disease or physical injury suffered by another person.

"Even if such a decision has not actually been made, an operation of the type described may be performed on a person who dies in hospital or who is already dead on admission to hospital, unless either the deceased or his next of kin have raised any objection, or there is reason to assume that the operation would be contrary to the general outlook of the deceased or his next of kin, or that other special reasons would argue against the operation."

Also relevant is the following comment of the Committee which drafted the Act:

"As a rule the deceased has made no statement as to his wishes in the matter, neither in favour nor against. To make lawful removal (of organs, tissues, etc., by operation) conditional upon the advance express consent of the deceased might have unfortunate consequences. Such a requirement might lead to the medical practitioners feeling themselves bound to discuss the question

300/ Information furnished by the Government of France on 21 January 1970.

301/ Information furnished by the Government of Luxembourg on 14 May 1974.

with their patients, even if the latter had not themselves brought up the subject. In the opinion of the Committee this would be unacceptable, both on humanitarian grounds and on the grounds of medical ethics.

"Taking into account the fact that people in general now have much greater understanding for these problems, it must be possible to base a statutory provision on the assumption that the large majority would be favourably disposed towards organs and other biological material from their own bodies being used for the purpose of transplantation. Such an assumption in respect of consent to an operation of this nature must naturally give way to any statement which has been made by the deceased objecting to operations for the purpose of transplantation; this applies equally in cases where the general outlook of the deceased is known and such an operation must be assumed to be contrary to it." 302/

206. The Government of the Republic of Viet-Nam points out that "the consent of the donor during his lifetime and the consent of his relatives are absolutely essential". 303/

207. The Government of Romania states:

"Consent given during one's lifetime is certainly valid in case of a favourable medical decision by the transplant committee. If the individual dies without having given consent, it is necessary to obtain the next of kin's consent provided it is given in due time, in accordance with the legislation of each individual country.

"Nevertheless, in the case of a decision strongly affirming compatibility, taken by the transplant committee in favour of saving the life of a patient, the organs of the deceased will be employed even if the consent of the next of kin is not forthcoming, if waiting for consent may imperil the life of the graft ..." 304/

208. The Government of Singapore refers to the Medical (Therapy, Education and Research) Act, 1972, according to which advance consent of the donor or the consent of his relatives is required. 305/

209. The Government of the Republic of Sri Lanka points out in respect of the practice in that country: "In the case of transplants from the dead, advance consent of the donor is obtained. This applies to eye and heart valve donations." 306/

302/ Information furnished by the Government of Norway on 15 April 1974.

303/ Information furnished by the Government of the Republic of Viet-Nam on 27 March 1974.

304/ Information furnished by the Government of Romania on 29 April 1974.

305/ Information furnished by the Government of Singapore on 13 March 1974.

306/ Information furnished by the Government of Sri Lanka on 5 March 1974.

210. The Government of Sweden says:

"Surgical intervention in the body of a dead human being in order to obtain biological matter may not take place without the advance consent of the deceased or his family according to Swedish legal principles. Limiting such intervention to cases where consent has been expressly given will probably mean, however, that biological material obtained from deceased persons will be far from adequate ... Therefore, the principle applied in Sweden at present is that if sufficient material cannot be acquired in any other way, the humanitarian point of view and the urgency of being able to help an ill human being should take precedence over the fact that there has not been time to ascertain the wishes of the deceased or his relatives. This principle has recently been called into question. A memorandum prepared by the Ministry of Health and Social Affairs concerning, inter alia, transplant operations discusses whether the relatives of the deceased should be informed of a transplant operation, thus giving them an opportunity to oppose it. The memorandum will be sent for comment to relevant authorities and organizations. The official attitude to these problems will then be finalized in a draft law the Swedish Government is considering presenting to the Riksdag." 307/

211. The Government of the Ukrainian Soviet Socialist Republic says that "organs may be transplanted from a dead person with the consent of his next of kin". 308/

212. The Government of the Union of Soviet Socialist Republics points out that:

"To obtain the advance consent of a living donor to the transplant of organs after his death would be unethical. If a living person has spontaneously expressed an objection to the use of his organs and tissues for transplants, after his death, his wishes must be respected. In other cases organs may be transplanted from the dead with the consent of their relatives." 309/

213. The Government of the United Kingdom states that, under the Human Tissue Act, 1961, the authorization by the person lawfully in possession of the body may be given for the removal of parts of the body for therapeutic purposes "if it can be established that the deceased expressed a wish (in writing or orally in the presence of two witnesses) that parts of his body should be so used after death. Alternatively, the person lawfully in possession of the body can authorize the removal of organs if after making such reasonable enquiries as are practicable he has no reason to believe either that the deceased had expressed any objection or that the surviving spouse or any surviving relatives object". 310/

307/ Information furnished by the Government of Sweden on 12 March 1974.

308/ Information furnished by the Government of the Ukrainian SSR on 23 October 1974.

309/ Information furnished by the Government of the USSR on 25 July 1974.

310/ Information furnished by the Government of the United Kingdom on 8 August 1974.

4. The right to life as applied to donors in transplant operations which a donor cannot survive, viewed in the light of suggested new medical definitions of death

214. Recent advances in artificial circulatory and respiratory maintenance techniques, on the one hand, and the need to remove a heart soon after death if it is to be used for transplantation on the other, have called into question the medically traditional and judicially accepted criteria of death as the cessation of respiratory and cardiac functioning. A dilemma has faced surgeons who have performed organ transplants from the dead. On the one hand, the prospects of a successful operation recede as the condition of the organ to be transplanted deteriorates. On the other hand, a transplant cannot be performed until the donor can be said to be dead in an accepted sense, given the fact that death takes place in stages. As a result, there is a trend towards recognizing the cessation of brain functioning as a new definition of death.

215. The National Research Council of the United States of America states: 311/

"The concept of 'brain death' instead of the classic determination that death has occurred once the pulse cannot be felt or a heartbeat heard has led to a great deal of discussion and soul searching.

"The crux of the whole matter is that the shorter the period of time organs are without an adequate supply of oxygen the greater the probability that the organ will function in another person's body. Were this not true, there would not be the great urgency to insure that the organs to be transplanted continue to receive oxygen as long as possible and are rapidly removed once oxygen in adequate amounts is no longer available to the organ."

Dr. C. Walton Lillehei, Chairman of the International Committee on Heart Transplantation of the American College of Chest Physicians, has stressed that "success of the [heart] transplantation operation is decreased if the surgeon waits too long after cerebral death has occurred". 312/ The report of the Danish Ministry of Justice Committee concerning Legislation on Transplantation stresses that:

"Some tissues and organs are highly sensitive to complete interruption of blood supplies: the removal of such tissues and organs for transplantation must begin quickly after death has occurred. Sometimes it is also necessary for artificial means to be resorted to in order temporarily to maintain a circulation of blood in the organ or the whole body." 313/

311/ Information furnished by the National Research Council of the United States of America on 25 November 1969.

312/ Information furnished by the American College of Chest Physicians and published in its journal, Diseases of the Chest, vol. 55, No. 1, (January 1969), p. 64.

313/ Report of the Danish Ministry of Justice Committee, p. 12.

216. A report of the Division of Medical Sciences of the National Research Council of the United States of America states:

"The problem of defining death has received considerable attention in recent months. The traditional criteria of death, namely the inability to maintain cardiac and respiratory function, are largely inadequate in light of the widespread availability of methods to support both systems artificially." 314/

217. Professor Jan Nielubowicz, Chief of the First Department of Surgery, Warsaw Medical School, has said:

"In cadaver transplantations, for the sake of the graft the time of ischemia /i.e., diminution of the blood supply/ should be maximally reduced. In this type of transplantation the point is to determine the moment at which the autopsy and the take of the kidney can be started.

"...

"In our times the progress of medicine and surgery has brought the modern resuscitation which can maintain the circulation and respiration of a severely injured man for hours and days." 315/

218. The Declaration of Sydney adopted by the Twenty-second World Medical Assembly in August 1968 states: 316/

"Two modern practices in medicine ... have made it necessary to study the question of the time of death further: (1) the ability to maintain by artificial means the circulation of oxygenated blood through tissues of the body which may have been irreversibly injured and (2) the use of cadaver organs such as heart or kidney for transplantation.

"... clinical interest lies not in the state of preservation of isolated cells but in the fate of a person. Here the point of death of the different cells and organs is not so important as the certainty that the process has become irreversible by whatever techniques of resuscitation that may be employed ..."

219. In this connexion Professor David D. Rutstein of the Harvard Medical School stressed:

314/ National Research Council, op. cit., p. 13.

315/ News Bulletin, p. 21.

316/ Declaration of Sydney, 1968 (text furnished by the World Medical Association on 14 March 1974).

"Death is not a simultaneous, instantaneous event for all of the organs of the body. Some organs die earlier than others - the brain being the most vulnerable. It is evident that the heart must be 'alive' and free of disease at the time of transplantation if it is to be useful to the recipient. The selection of the heart donor, therefore, cannot be based on his 'total death' in the usual sense - that is, a lack of any spontaneous activity and the complete absence of cerebral, cardiac, and pulmonary activity and of spinal reflex function." 317/

220. A trend therefore exists in some medical circles to establish a new medical definition of death, and the suggested definitions stress cessation of cerebral function, sometimes referred to as "brain death", and "irreversible coma". For instance, a statement of conclusions adopted on 14 June 1968 by the CIOMS Round Table Conference on Heart Transplantation, organized at Geneva by the Council for International Organizations of Medical Sciences with the assistance of UNESCO and WHO, states: "The choice of the donor should be guided by the following three considerations: ... 3. Complete and irreversible cessation of cerebral function". The criteria for establishing cessation of cerebral function are then set out. 318/

221. A detailed and well-known proposal of criteria for establishing the cessation of cerebral function has been offered in a report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. 319/ These criteria have been summarized as follows:

- "(1) Unreceptivity and unresponsivity. There is a total unawareness of externally applied stimuli and inner need and complete unresponsiveness. Even the most intensely painful stimuli evoke no vocal or other response, not even a groan, withdrawal of a limb, or quickening of respiration.
- "(2) No spontaneous muscular movements or spontaneous respiration or response to stimuli such as pain, touch, sound, or light. After the patient is on a mechanical respirator, the total absence of spontaneous breathing may be established by turning off the respirator for three minutes and observing whether there is any effort on the part of the subject to breathe spontaneously.

317/ David D. Rutstein, "The ethical design of human experiments", Ethical Aspects of Experimentation with Human Subjects, Daedalus, Spring 1969, p. 525.

318/ CIOMS Round Tables: 2. Heart Transplantation, Geneva, 13-14 June 1968 (Liège, Desoer, 1969), p. 51. On page 48 of the report of the conference, the following remark by Professor E. Zander of the Académie Suisse des Sciences Médicales appears:

"The complete and irreversible cessation of cerebral function constitutes 'cerebral death' and - this is important - such cerebral death automatically results in the death of the entire organism. Artificial respiration can retard the death of the other organs for days or weeks, but cannot prevent it."

319/ Journal of the American Medical Association, vol. 205, No. 6, (5 August 1968).

- "(3) Complete loss of reflexes and muscle tone. The pupil is fixed and dilated and will not respond to a direct source of bright light. Ocular movement (to head turning and to irrigation of the ears with ice water) and blinking are absent. There is no evidence of postural activity (decerebrate or other). Swallowing, yawning, vocalization are in abeyance. Corneal and pharyngeal reflexes are absent. As a rule the stretch of tendon reflexes cannot be elicited. Plantar or noxious stimulation gives no response.
- "(4) An unequivocal isoelectric EEG tracing recorded under the best technical conditions, even with stimulation of the brain.
- "(5) All of the above tests should be repeated at least 24 hours later with no change. If the patient is not hypothermic (temperature below 90F (32.2C)) or under the influence of central nervous system depressants, such as barbiturates, then there is irreversible cerebral damage. Since there is no substitute for the judgment of the physician, alone or in consultation, brain death can be diagnosed by points 1, 2 and 3. The electroencephalogram (point 4) provides confirmatory data, and, where available, it should be used." 320/

222. These criteria have been gaining acceptance in medical circles since they were formulated. A report of the Task Force on Death and Dying, of the Institute of Society, Ethics and the Life Sciences, states that these criteria:

"Meet the formal characteristics of 'good' criteria... The criteria are clear and distinct, the tests easily performed and interpreted by an ordinary physician, and the results of the tests generally unambiguous... We can see no medical, logical, or moral objection to the criteria as set forth in the Harvard Committee report. The criteria and procedures seem to provide the needed guidelines for the physician. If adopted, they will greatly diminish the present perplexity about the status of some 'patients', and will thus put an end to needless, useless, costly, time-consuming, and upsetting ministrations on the part of physicians and relatives." 321/

Speaking of heart transplants, the report of the Fifth Bethesda Conference of the American College of Cardiology, 28-29 September 1968, includes the following.

"Prolongation of viability of the donor heart by extraordinary means, including respiratory assistance, vasopressors and cardiotoxic drugs, is justified in the donor to provide the recipient with a favourable organ capable of supporting the circulation... When brain death has been declared on the basis of rigorous clinical and laboratory standards, then cardiac removal is ethically acceptable." 322/

320/ Frank J. Ayd, Jr., "What is death?", paper read at the American Medical Association's second National Congress on Medical Ethics, Chicago, 5 October 1968, p. 6.

321/ "Refinements in criteria for the determination of death: an appraisal", Journal of the American Medical Association, vol. 221, No. 1 (3 July 1972), pp. 50-51.

322/ Cardiac and Other Organ Transplantation in the Setting of Transplant Science as a National Effort: Fifth Bethesda Conference of the American College of Cardiology (New York, 1968), p. 12, furnished by the National Research Council of the United States of America.

Again, article 1 of a resolution adopted by the Executive Council of the American College of Chest Physicians in Washington D.C. on 7 October 1968 reads as follows: "1. The American College of Chest Physicians supports the concept of brain death in transplantation donors. Brain death is a medical, not a legal, determination." 323/

223. Some authors believe that a new definition of death and its criteria should be enacted into law. "It seems that a new, legal definition of death will be necessary", Dr. Rudolf Bystricky has said. 324/ A report of the Commission on Medical Malpractice, prepared under the auspices of the United States Department of Health, Education and Welfare, stated that it was the Commission's belief that the question of the legal definition of death was of such importance that the definition should be enacted into law only by the Congress of the United States. 325/ Professor Hamburger has said:

"I ... hope that legislation will establish the definition of death in the case of these subjects surviving artificially and give authority to stop the machine when it is certain that the subject is really dead. At such time, if it is certain that the subject is really dead - in accordance with the new definition - I believe that organ grafts can be removed from the body, as after death by cardiac arrest, this being a special case coming under the legislation and regulations at present in force. On the other hand, I think that there is no question of authorizing such a removal before death on the sole ground that the prognosis is considered to be hopeless." 326/

224. An attempt at a legislative resolution of the problem was made in 1970 when the State of Kansas, United States of America, adopted "an Act relating to and defining death". This statute served as a model for legislation adopted in Maryland in 1972 and now pending in a number of other States. 327/ The statute has been said, WHO reports, to be "an encroachment on the responsibility of the physician" and "directed more towards the interests of a prospective recipient of an organ transplant than to those of the involuntary donor". 328/

225. In the field of national regulations dealing with new criteria of death, mention should also be made of Circular No. 67 of 24 April 1968 of the Minister of Social Affairs of France concerning the implementation of Decree No. 47-2057 of 20 October 1947 concerning autopsies and the removal of organs; 329/ Ordinance No. 18 of the Hungarian Minister of Health for the implementation, in respect to organ and

323/ Text furnished by the American College of Chest Physicians on 15 October 1969 and published in its journal, Diseases of the Chest, vol. 55, No. 1, p. 63.

324/ Rudolf Bystricky, "Quelques remarques sur la révolution scientifique et technique et les droits de l'homme", in: René Cassin, Amicorum discipulorumque liber, I. Problèmes de protection internationale des droits de l'homme (Paris, A. Pedone, 1969), p. 26.

325/ United States Department of Health, Education and Welfare, publication No. (OS) 73-88, 16 January 1973, pp. 31-32.

326/ CIOMS Round Tables, 1. Biomedical Science ..., p. 52.

327/ Cf. Alexander M. Capron, "Determining death: do we need a statute?", The Hastings Center Report, February 1973, p. 7.

328/ E/CN.4/1173, p. 21.

329/ International Digest of Health Legislation, vol. 19, 1968, pp. 628-629.

tissue removal and transplantation, of Law No. 11 of 1972 on health; 330/ and Italian Ministerial Decrees of 11 August 1969 and of 9 January 1970, promulgated in pursuance of section 5 of Law No. 235 of 3 April 1957 relating to the removal of parts of the body of a deceased person for the purpose of therapeutic grafting. 331/ These regulations describe the criteria for establishing death on the basis of cessation of cerebral function and the procedure for certifying death.

226. As is pointed out and illustrated by the World Health Organization, the criteria of the above-mentioned Harvard Committee are "not universally accepted". 332/ Since 1968 some experts have been emphatic regarding the limitations of the electro-encephalograph, and serious doubts have been cast on the possibility of objectively determining the death of the brain. At the Symposium on Science Policy and Biomedical Research organized by CIOMS with the assistance of UNESCO and WHO in 1968, Dr. J. Naffah, Professor at the French Faculty of Medicine, Beirut, stated that brain death "can only be established by the introduction of deep cortical electrodes, and the danger of implanting deep electrodes makes it impossible to establish any criteria". 333/ Dr. H. Bloch, Director of Research, CIBA, Basle, Switzerland, said: "The example of prolonged reversible comas should make us aware of the shortcomings of any rules we set up and should caution us on the question of transplanting organs". 334/ Dr. B. Rexed, Director-General, Socialstyrelsen, National Board of Health, Stockholm, observed: "There have been comas of six months that were reversible". 335/

227. Professor David D. Rutstein states:

"This new definition of heart donor eligibility that substitutes 'irreversible brain damage' for 'total death' raises more questions than it answers. Does acceptance of this concept mean that it is no longer necessary to treat, for example, the senile patient who would meet such criteria? How do eligible donors differ in principle from totally feeble-minded individuals? What are the implications for the inheritance of property if the heart of an intestate donor is kept beating with a pacemaker while the search for a recipient goes on and the donor's wife dies during the interval? Does this new definition of death for the heart donor open up new channels of criminal activity that will lead to the burking of patients to increase the supply of eligible donors?" 336/

330/ J. de Moerloose, loc. cit., p. 355.

331/ International Digest of Health Legislation, vol. 22, 1971, pp. 125-126, and vol. 24, 1973, p. 168.

332/ E/CN.4/1173, p. 22.

333/ Proceedings of the Symposium on Science Policy and Biomedical Research, Paris, 26-29 February 1968, UNESCO, Science Policy and Documents, No. 16 (Paris, UNESCO, 1969), p. 51.

334/ Ibid., p. 50.

335/ Ibid., p. 49.

336/ David D. Rutstein, op. cit., p. 526.

At the aforementioned CIOMS Symposium on Science Policy and Biomedical Research, Dr. Rexed said:

"We feel that it is essential for people likely to be affected by this situation to decide; if a new definition of death were to be rejected by public opinion, it would set off a crisis of confidence." 337/

228. Drs. A. de Coninck, P. Dor and J. R. Fagnart point out: "Any legal definition of death may quickly become obsolete in view of the constant progress of science." 338/ The American Medical Association, meeting in Anaheim, California, in December 1973, reaffirmed its opposition to any "inflexible" statutory definition. 339/

229. The trend towards substituting cessation of cerebral function for failure of the cardiac and respiratory functions as the medical criterion of death has given rise to concern in certain quarters. For instance, the International League for the Rights of Man has furnished a copy of Civil Liberties, volume 2, No. 1, published by the Civil Liberties Union of the United States of America, which maintains that:

"Individual Americans and their next of kin are on the verge of losing all legal rights to: (a) any part in determining the simple fact of whether an individual is actually alive or dead; ... and (d) any defense against contributing one's life (under new definitions of death) to the expedience of medical experimentation."

Other material furnished by the League stated that "the increasing use of the concept of brain death, rather than heart death, to determine termination of life, may ... create a situation in which individuals are being used ... perhaps even prematurely, as organ donors".

230. Fear undoubtedly exists in lay circles that some over-zealous transplantation surgeon may operate before the donor actually dies. The existence of such concerns has been recognized within the medical profession. Thus, at the discussion on surgical ethics, with special reference to the problems arising from transplantations, organized by the International Federation of Surgical Colleges and held in Warsaw, Professor Gustav Giertz, Chief of the Urological Department, Karolinska Institute, Stockholm, Sweden, said: "I have difficulty in believing that general opinion will ever, whole-heartedly, accept the view that relatives who still show some definite signs of life are regarded as dead". 340-341/ Dr. Calne has said:

"I am sure we would all agree that there comes a time when it is in the interests of the dying person and the relatives to 'turn off the switch'. But the point that is important is whether this is being done because one is looking for a kidney rather than because it is in the interests of the patient who is dying." 342/

337/ Proceedings of the Symposium on Science Policy and Biomedical Research, p. 49.

338/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 24.

339/ Cf. Alexander M. Capron, "To decide what dead means", New York Times, 24 February 1974.

340-341/ News Bulletin, p. 28

342/ G. Wolstenholme and M. O'Connor, eds., op. cit., p. 72.

231-232. In a statement furnished on 11 April 1970 by the Secretary-General of the League of Arab States, it is pointed out in connexion with recent progress in heart-transplanting operations: "If clinical death has not taken place at the time the heart is taken out of the body that would mean that a person was arbitrarily deprived of his life".

233. The aforementioned report by the Task Force on Death and Dying of the Institute of Society, Ethics and the Life Sciences summarized the causes of concern in the following way:

- "(1) problems with concepts and language;
- "(2) reasons behind the new criteria and the relationship of organ transplantation;
- "(3) problems concerning the role of the physician and the procedures for establishing the new criteria; and
- "(4) fears concerning possible further undatings of the criteria." 343/

234. In view of this concern, it has been emphasized that a most rigorous procedure must be followed before an organ transplantation where the donor cannot survive. The above-mentioned Declaration of Sydney (see para. 218) states:

"This determination [of death] will be based on clinical judgement supplemented if necessary by a number of diagnostic aids of which the electroencephalograph is currently the most helpful. However, no single technological criterion is entirely satisfactory in the present state of medicine nor can any one technological procedure be substituted for the overall judgement of the physician. If transplantation of an organ is involved, the decision that death exists should be made by two or more physicians and the physicians determining the moment of death should in no way be immediately concerned with performance of transplantation." 344/

The necessity of the participation of a plurality of physicians in the determination of death and their non-participation in subsequent transplant operations is also stressed in a statement by the CIOMS Round Table Conference on Heart Transplantation, in 1968, 345/ in the guidelines on heart transplantation of 1968 of the American Medical Association, 346/ in a legal commentary that is included in the report of

343/ "Refinements in criteria for the determination of death: an appraisal", Journal of the American Medical Association, vol. 221, No. 1 (3 July 1972), pp. 50-51.

344/ Italics in the text.

345/ CIOMS Round Tables: 2. Heart Transplantation, Geneva, 13-14 June 1968 (Liège, Desoer, 1969), p. 51.

346/ Cf. Statement on heart transplantation, Journal of the American Medical Association, 3 March 1969, vol. 207, No. 9, p. 1705.

the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, 347/ in the rules of 1969 of the Swiss Academy of Medical Sciences 348/ and in a resolution of 1970 of the International Association of Democratic Lawyers. 349-350/

235. Some of the Governments which have expressed their views on the subject consider that surgeons should proceed in transplant operations according to a new definition of death; others do not recognize new definitions of death. The Governments emphasize that the right to life, as applied to donors in transplant operations which the donors cannot survive, must be strictly respected.

236. The Government of Argentina states:

"Before organs are removed from a presumed corpse, two doctors not forming part of the surgical team which is to carry out the operation must certify, on the basis of the presence and persistence of specific symptoms, that the nervous system is irreversibly damaged." 351/

237. In the comments of Professor Sir Macfarlane Burnet forwarded by the Australian Government it is pointed out: "I should accept the view that when cerebral function has ceased, the medical profession and the community has no obligation to maintain visceral functions by artificial means. The legal definition of death should be modified to make this clear." 352/

238. The Government of Austria has written:

"Transplant operations involving a vital organ must be guided by the principle that human life must not be jeopardized in order to save possibly another individual's life. This results from the principle of equality of human life inherent in traditional human rights, which is reflected, for instance, by the fundamental rule of equality of human beings." 353/

239. In the information received from the Government of Norway, the Act of 9 February 1973 Relating to Transplantation of Organs, Hospital Autopsies and Surrender of Corpses is cited, according to which, before the operation "may be undertaken, death shall be confirmed by two medical practitioners neither of whom

347/ Cf. Journal of the American Medical Association, vol. 205, No. 6, (5 August 1968), p. 87.

348/ Cf. Henri Anrys, Les professions médicales et paramédicales dans le Marché commun; Champ d'activité, accès, règles professionnelles, ainsi que les grands problèmes contemporains d'éthique (Brussels, Larcier, 1971), p. 430.

349-350/ "Résolutions sur le progrès technique et les droits de l'homme", adopted by the Ninth Congress of the International Association of Democratic Lawyers, Helsinki, 15-19 July 1970, p. 2.

351/ Information furnished by the Government of Argentina on 30 May 1974.

352/ Information furnished by the Government of Australia on 8 July 1974.

353/ Information furnished by the Government of Austria on 21 November 1974.

performs the actual operation ... The operation must not be carried out by the medical practitioner who treated the deceased during his final illness". In the comments of the Committee which drafted the Act it is said, inter alia:

"The Committee feels that the question of establishing the exact point of time at which death occurs is a purely medical question which must be determined on the basis of the professional insight and the methods of examination generally recognized in the medical field at any given time. The definition of death as such does not lend itself to regulation by statute."

The Government continues:

"The Committee therefore points out that administrative provisions must be drawn up pursuant to this section. It is suggested that one must proceed from a new definition of death instead of the usual one which is based on the criteria of the heart having stopped and breathing having ceased. The new definition is termed 'brain death' by some and rests on recognition of the fact that the individual is dead when the brain has been completely and irreversibly destroyed.

"One of the members of the Committee, Professor Erik Enger, lists the six criteria which must be satisfied before it is possible to accept a confirmation of death which is based on the total destruction of the brain: No. 1. Coma, i.e. deep unconsciousness with no reaction to external stimuli (light, sound, pain). No. 2. Known medical record with history of intracranial morbidity. No. 3. Cessation of spontaneous respiration. No. 4. Absence of pupillary reaction to light and of other cerebral nerve reflexes. No. 5. Isoelectric EEG, with curve recorded under specific conditions. No. 6. Cessation of circulation in the brain, assessed by cerebral angiography carried out under specific conditions." 354/

240. The Government of Romania states:

"Ascertaining of the actual death and taking of organs for transplantation should be based on objective medical findings - breathing, EKG and, especially, EEG; and recorded in a legal written document which will represent the principle document for permitting the intervention." 355/

241. The Government of Sweden states.

"Declaration of death on cessation of cerebral function is not accepted in Sweden. Transplant operations which require that the heart of the donor is still functioning are thus not permitted. In Sweden the principle applied is that every ill human being is to be given adequate treatment as long as there is 'hope' ... Actually, there is no doubt that a human being whose cerebral function has ceased can be described as dead. However, it does not follow from this that the concept of cerebral death should be accepted.

354/ Information furnished by the Government of Norway on 15 April 1974.

355/ Information furnished by the Government of Romania on 29 April 1974.

The requirement of being absolutely sure may under no circumstances be neglected. One imperative condition for the introduction of the concept of cerebral death must therefore be the absolute assurance that it is possible to establish cerebral death. The official Swedish view is that the methods available for establishing the cessation of cerebral function do not satisfy these requirements. On the contrary, it has been found that there are indications that one or other method is sometimes unreliable, even if it is considered that the combined findings of several such methods could determine if cerebral function has ceased or not." 356/

242. The Government of the Ukrainian Soviet Socialist Republic points out that in that country doctors continue to fight for the patient's life until biological death occurs." 357/

243. The Government of the Union of Soviet Socialist Republics states:

"In the USSR doctors fight for a person's life until biological death occurs. Transplants of organs from living persons are therefore not allowed (except in [cases where a living, capable donor may consent to the transplant of kidneys or tissues to near relations])." 358/

244. The Government of the United Kingdom points out that:

"A doctor's duty is to ensure that his patient receives the best medical attention available but a potential donor's prospects of recovery must not be prejudiced by steps taken in the interests of the recipient ... Before organs are removed death should be certified by two doctors, one of whom should be at least five years registered, each independent of the transplant team and without regard to the possibility of a transplant ... The overriding factor at present is ... the legal requirement that life is extinct." 359/

5. The dignity of the human person, viewed in the light of the existence of techniques for the artificial prolongation of certain bodily functions after cessation of the cerebral function

245. Technological advances have forced upon the patient, the patient's family, the medical profession and society at large the question of when the treatment should be stopped of a patient whose brain is dead, but whose heart is beating, and who is breathing, as a result of improved methods of resuscitation. Such procedures have made possible heroic efforts to "save" the gravely ill or severely injured, which however may leave the patient capable of what may be regarded as a less than fully human existence. A great number of such patients are maintained only by intensive care and by extensive interventions. These patients have prompted a concern for the quality of the life which medicine is preserving in these cases and for the dignity of the human person in whom signs of life are only artificially sustained.

356/ Information furnished by the Government of Sweden on 12 March 1974.

357/ Information furnished by the Government of the Ukrainian SSR on 23 October 1974.

358/ Information furnished by the Government of the USSR on 25 July 1974.

359/ Information furnished by the Government of the United Kingdom on 8 August 1974.

246. "Is it scientifically and morally legitimate to continue to keep alive what may be called a 'heart-lung-kidney preparation' by means of resuscitation procedures, when there is convincing evidence that a complete return to life is impossible?" asked Dr. Jonchères at the CIOMS round table conference on heart transplantation. 360/ Speaking about cases where people in coma are "kept alive in a purely vegetative state, even when the brain is dead", Dr. Aujaleu said: "I was not disturbed by this until I realized that these people were being kept alive in order to provide organs for possible transplant operations. This procedure raises the gravest moral problems." 361/

247. At the Eighth CIOMS Round Table Conference on Human Rights, Henry K. Beecher pointed out that:

"With progress in medicine, technical decisions become easier while moral problems become increasingly significant and difficult.

"Two yardsticks must be recognized: the one measuring the welfare of the individual; the other the welfare of science, which is to say, in the best sense, the welfare of society.

"(a) It is clear beyond question that a time comes when it is no longer appropriate to continue extraordinary means of support for the hopelessly unconscious patient ...

"(b) A strong case can be made that society can ill afford to discard the tissues and organs of hopelessly unconscious patients." 362/

248. In practice it often happens that physicians keep a patient alive artificially although there are signs that his brain is dead. They are unwilling to risk violating the law or being accused of murder. This is especially true if the patient is in a hospital where the action might be discovered and reported. Professor Lhermitte has referred to:

"The extreme scrupulosity of those who have to decide whether a human being is finally dead and certify as much. If", he stressed, "I feel that they may have erred, it is certainly not in certifying death prematurely but on the contrary in keeping human beings artificially alive for hours and sometimes days." 362A/

360/ CIOMS Round Tables: 2. Heart transplantation, Geneva, 13-14 June 1968 (Liège, Desoer, 1969), pp. 43-44.

361/ Proceedings of the Symposium on Science Policy and Biomedical Research, Paris, 26-29 February 1968, UNESCO, Science Policy and Documents, No. 16 (Paris, UNESCO, 1969), p. 47.

362/ H. K. Beecher, "Definition of death: the individual's right to be let alone", in CIOMS, Eighth Round Table Conference, op. cit., p. 113.

362A/ Quoted by Leon Depaule, "Le droit à la mort", Fourth Besançon Colloquium, p. 6.

Very often these decisions, it was remarked, "are based not on the patient's need, but on the guilt feelings of the family and the doctor's professional pride". 363/

249. In this connexion it has been emphasized that death, like life, should be achieved with maximum dignity and that there are times when one should not be keeping people "alive" in the sense of merely ticking over on the end of a machine.

250. Robert S. Morison writes:

"There is an implicit indignity in the conception of the meaning of human life revealed by overvigorous efforts to maintain its outward, visible, and entirely trivial signs. It is not breathing, urinating, and defecating that makes a human being important even when he can do these things by himself. How much greater is the indignity when all these things must be done for him, and he can do nothing else. Not only have means thus been converted into ends; the very means themselves have become artificial. It is simply an insult to the very idea of humanity to equate it with these mechanically maintained appearances." 364-365/

He believes that in this case a physician should reason in the following way:

"To be candid about it, the trajectory of this patient's life has now reached its final stage of decline. Virtually everything that once made his life a pleasure to himself, a delight to his friends, and an asset to society has now disappeared, never to return. All that remain are the least dignified of his interchanges with the environment, and even these in their least dignified form. I am sure from previous conversations that this man would not wish to remain in this subhuman condition, and I will therefore withdraw all treatments that would prolong life and continue only those that will prevent restlessness and pain, fully recognizing that such measures will also hasten the end ... By thus fulfilling the wishes of my friend and patient, I restore to him the dignity of controlling, to the extent possible, the circumstances under which he returns to an inanimate state." 366/

251. The possibility that a patient in irreversible coma will be kept "alive" artificially causes anxiety for patients and possible eventual patients. Professor Ruth Russell points out: "It is axiomatic that the elderly have a right to live out their lives in dignity. The corollary of this is also true: each has the right to die in dignity. Today vast numbers are being denied this right." 367/

363/ Cf. Sybil Baker, "Life or death? Who decides? Experts unsure", Sunday News (New York City), 27 January 1974.

364-365/ Robert S. Morison, "The last poem; the dignity of the inevitable and the necessary, The Hastings Center Studies, May 1974, p. 64.

366/ Ibid.

367/ O. Ruth Russell, "The right to choose death", New York Times, 14 February 1972.

252. On 25 April 1973 the Connecticut Medical Society approved a resolution suggesting that a healthy person should be entitled to sign a statement asking not to be kept alive by artificial means or heroic measures. The sample form attached to the resolution concluded: "I value life and the dignity of life so that I am not asking that my life be directly taken but that my dying not be unreasonably prolonged nor that dignity of life destroyed ..." 368/

253. It seems to be generally felt that the dignity of the human person must be observed to the end and that all "heroic" means of treatment should be discontinued after cessation of the cerebral function. Speaking at the Conference on Ethical, Philosophical, Political and Social Implications of Scientific and Technological Development, organized by The Center Magazine in 1969, Professor Kurt Reinhardt said:

"I am opposed to prolonging life that is no longer a life, which is so frequently being done in our hospitals today, perhaps for experimental purposes and at astronomic costs to the family. I know that comatose patients, ninety years old or older, have been kept alive for weeks, even months; and it was not a life, it was a living death. I am opposed to the active practice of euthanasia, but in a case like that, I would be in favour of letting nature take its course. I would remove all the tubes and pull out the plug." 369/

254. H. P. Lewis also wrote that:

"Traditional approaches to the ... useless prolongation of life must be reshaped in the light of today's treatment alternatives. Extraordinary means to preserve life should be employed only when recovery - far above a vegetative level and without intolerable suffering - is a realistic hope for the patient. When brain death can be verified, all efforts toward the maintenance of life should cease, for the ability to sustain a semblance of life does not necessarily lead to the recovery of meaningful life." 370/

255. A report prepared for the American Friends Service Committee states:

"We believe human life is a gift that is meaningful only as long as the receiver is able to function as a person. The quality of the potential life left to the dying person must be a consideration constantly before concerned physicians and society to help guide their actions in specific cases.

368/ "Physicians back the right to die", New York Times, 26 April 1973.

369/ The Center Magazine, November 1969, p. 36.

370/ H. P. Lewis, "Machine medicine and its relation to the fatally ill", Journal of the American Medical Association, vol. 206, No. 2; (7 October 1968) pp. 387-388.

"We approve withholding therapy or withdrawing the supportive therapy that is keeping an unconscious person alive if, by evidence of brain death or such other evidence as the medical profession deems valid, it is the best judgment of the medical profession that the patient's brain is irreparably damaged and he will never recover consciousness." 371/

256. Professor J. Englebort Dunphy stressed the importance of "the respect for the integrity of the patient; his 'wholeness' and his dignity must be taken into consideration and given precedence over a mere surgical tour de force". 372/

257. At the first World Meeting on Medical Law in Ghent in 1967, Dr. E. Pillen pointed out:

"There is the worth of the human being in general, and his death can be theological, spiritual, social and medical. But in certain circumstances it seems to be conceivable that one could establish the moment when life ceases to have any human value for the patient himself, who is already on the threshold of death. We often observe a clinical situation (for example, in terminal hepatic coma after a long cardiac arrest, or in severe brain injury) where the medical criteria are such that the prolongation of life by extraordinary means is not only vain, but signifies for the family, the hospital and society that a fortune must be expended in hopeless attempts at resuscitation. The only effect of the artificial means is a fragmentation of death. Indeed brain death is followed by neurological death and ends in conventional death."

He considered patients of the type under discussion "living cadavers" and that three experienced physicians - a neurologist, a neurosurgeon and a reanimator - can make the decision to stop the machines and all extraordinary means of treatment. 373/

258. At the CIOMS Round Table Conference on Biomedical Science, Professor Hamburger said:

"It seems on scientific grounds obvious that a number of subjects in terminal coma still have heart beats induced artificially but are scarcely any more than physiological heart-lung preparations, whose nervous centres in particular have been totally and irreversibly destroyed. These subjects are in fact dead, and it can almost be considered immoral to carry on with a heart-lung preparation that is no longer comparable with a living human being in the fullest sense." 374/

371/ Who Shall Live? Man's Control over Birth and Death - Report Prepared for the American Friends Service Committee (New York, Hill and Wang, 1970), p. 70.

372/ News Bulletin, p. 43.

373/ E. Pillen, "Theoretical and practical considerations of the low-voltage and zero EEG", paper prepared for the First World Meeting on Medical Law, Ghent, 23 August 1967, pp. 1-2, 8.

374/ CIOMS Round Tables, 1. Biomedical Science ..., p. 52.

259. At the Eighth CIOMS Round Table Conference, Dr. Henry K. Beecher stressed that "the unconscious patient with overwhelming brain damage can be maintained only by extraordinary means. When it becomes evident that the brain is dead, there is an obligation to discontinue extraordinary supports", although the termination of extraordinary care even for just reasons, with death to ensue, can have a shocking effect on observers. 375/

260. Professor L. Cotte supported, at the fourth Besançon colloquium on human rights in France, the point of view of Dr. R. P. Riquet, who wrote:

"Once it is demonstrated that the patient is fundamentally incapable of resuming spontaneous organic functioning or recovering some form of consciousness, the doctor is entitled to abandon his heroic but futile efforts ... Matters may reach such a pitch of absurdity and cruelty that it is not only permissible but preferable, and even advisable, to switch off a machine which is artificially maintaining circulation and respiration in an organism that has ceased to be a human being because of brain death." 376/

261. It has been said that "to maintain needlessly the functioning of what has become in fact a physiological preparation is to prolong the distress of the patient's family and possibly to divert skilled personnel and specialized equipment from those who would derive real benefit from them". 377/

262. It has been stressed that the cessation of resuscitative measures applied to a patient in irreversible coma has no connexion with euthanasia. Thus, Walter W. Sackett, a physician and member of the Florida House of Representatives, pointed out that the concept of "'death with dignity' implies permitting a person to die a natural death without the application of all the heroic modalities known to modern medicine". Euthanasia or mercy killing has nothing to do with this philosophy, he stresses, because those terms imply the application of some positive method of ending a life. 378/
At the Third Congress on Medical Law, Dr. Philip H. Addison said:

"The physician in charge of the patient, after consultation with his colleagues, must make the final decision as to when resuscitative measures should be stopped. Shortening of the life of a patient suffering from irreversible coma should not be regarded as euthanasia because in such a case there is no demonstrable medical indication of pain or suffering. To permit a patient suffering from irreversible coma to die and to apply euthanasia have quite different legal concepts in their motivation even if for the patient the result is the same." 379/

375/ H. K. Beecher, loc. cit., p. 112.

376/ L. Cotte, "Le droit à la mort", Besançon University, Fourth Besançon Colloquium, Human Rights in France, 17-19 January 1974, p. 24.

377/ E/CN.4/1173, p. 22.

378/ Science News, 19 August 1972, p. 118.

379/ Philip H. Addison, "Voluntary euthanasia", paper prepared for the Third World Congress on Medical Law, Ghent, Belgium, 19-23 August 1973, p. 7.

263. Some authors and groups have expressed the opinion that it is permissible to apply life-prolonging treatment to a patient in irreversible coma in the interest of an organ recipient. Thus, Professor M. F. A. Woodruff, speaking about the situation when a physician dealing with a transplantation operation is informed that life-prolonging treatment will be ceased, has said:

"I can do two things: ask them not to switch off for another ten minutes so that I can take out the kidney first or let them switch off the machine and wait till they pronounce the patient dead before I take out a kidney. I can't see that it makes the slightest difference to the neurosurgical patient which I do, and the extra time may make a difference to the kidney recipient ..."^{380/}

Robert M. Veatch has pointed out:

"Presumably if one is dealing with a corpse, the moral imperative would be to preserve the organs for the benefit of the living in the best possible condition - by continuing the respiration process until the heart could be removed. We would find no moral problems with such behaviour; in fact, one would say that it would be morally irresponsible to run the risk of damaging the tissue."^{381/}

264. The report of the Danish Ministry of Justice Committee states that it is "sometimes ... necessary for artificial means to be resorted to in order temporarily to maintain a circulation of blood in the organ to be transplanted or the whole body"^{382/} It will also be recalled that, speaking specifically of heart transplants, the report of the Fifth Bethesda Conference of the American College of Cardiology includes the following:

"Prolongation of viability of the donor heart by extraordinary means, including respiratory assistance, vasopressors and cardiotoxic drugs, is justified in the donor to provide the recipient with a favourable organ capable of supporting the circulation ... when brain death has been declared on the basis of rigorous clinical and laboratory standards, then cardiac removal is ethically acceptable."^{383/}

265. In the report of the Ad Hoc Committee on Organ Transplantation of the Netherlands Red Cross Society it is pointed out:

"The question is asked in practice, if it is permissible to apply life-prolonging treatment to a dying patient solely in the interest of organ transplantation. Some groups consider this not impermissible in view of the important consequences for the waiting recipient and provided that the dying patient experiences no inconvenience from these measures."^{384/}

^{380/} G. Wolstenholme and M. O'Connor, op. cit., p. 99.

^{381/} Robert M. Veatch, "Brain death", The Hastings Center Report, November 1972, p. 12.

^{382/} Report of the Danish Ministry of Justice Committee, p. 12.

^{383/} Cardiac and Other Organ Transplantations in the Setting of Transplant Science as a National Effort: Fifth Bethesda Conference of the American College of Cardiology (New York, 1968), p. 12

^{384/} Summary of the Report of the Ad Hoc Committee on Organtransplantation (The Hague, Netherlands Red Cross Society, May 1971), p. 9.

266. Circular No. 67 of the Minister of Social Affairs of France states that if, after death has been confirmed, the removal of an organ for therapeutic purposes is envisaged, resuscitation procedures may be continued, in order to ensure that the blood supply to this organ is not prematurely cut off. 385/ There is no single point of view on the subject as far as Governments are concerned.

267. The Government of Argentina states:

"After irreversible brain damage, the only reason for continuing resuscitation measures or procedures to maintain functions such as respiration and circulation, would be that their continuance was essential for keeping the transplant organ in a good condition until removal." 386/

268. The information furnished by the Government of Austria contains the following passage:

"In this context it should not be overlooked that the application of medical knowledge and skills and techniques is not an end in itself but should serve man in an optimum manner for the restoration of his health. From the point of view of human dignity and the essence of human rights unlimited employment of technical devices for prolonging an individual's naked life without a chance to restore him to health cannot by any means be advocated. Nor should we forget that such an artificial prolongation of life may cause suffering to the individual concerned. Therefore it should be seriously contemplated whether besides the right to life we should recognize a right to death. In such cases where the individual is unconscious and, according to medical experience, will not regain consciousness it is certainly not inept to doubt the reasonableness of prolonging bodily functions by technical devices. For man's consciousness and the resulting possibility of expression are such specific elements of the human being that their loss destroys the human personality, and it is very questionable whether such a case can still be considered 'human life'." 387/

269. As pointed out in paragraphs 242 and 243 above, in the Ukrainian SSR and in the USSR doctors fight for a person's life until biological death occurs.

270. The information of the Government of the United Kingdom contains the following passages:

"Where a patient's bodily functions have been sustained by artificial means before cerebral function ceased and he is being considered as a potential donor, the artificial support may be continued for longer than would be the case if attempts to maintain life had been abandoned, in order to keep the kidney in good condition until the surgeon is available to remove it.

385/ Cf. Use of Human Tissues and Organs for Therapeutic Purposes: A Survey of Existing Legislation (Geneva, WHO, 1969), p. 14.

386/ Information furnished by the Government of Argentina on 30 May 1974.

387/ Information furnished by the Government of Austria on 21 November 1974.

"Where it has been established that cerebral function has ceased and there is no prospect of recovery, life support measures would be discontinued. From this point onwards, concern to maintain the usability of kidneys in the interest of the transplant recipient, would appear to justify continuing such of those measures as may be considered necessary for a longer period." 388/

6. The question of publicity given to the identity of the persons involved in transplant operations

271. Due to the availability of more developed media for mass communication and due to the progress of organ transplants, especially heart transplants, which clearly possess great news value, there is a particular need to ensure that relevant information is spread in a responsible manner. The question is being asked what particulars the media should give concerning those who are involved as donors or as patients in these operations. This issue touches upon the right of the individual to dignity and to freedom of expression and action.

272. In practice, transplant operations are often accompanied by non-scientific, sensational articles in the press. Mr. W. F. Deeds spoke in the United Kingdom Parliament about "the manner in which some news of some transplant operations has been presented, with a wealth of garish detail and garnished with what Fleet Street's critics categorize as trivia". 389/ At the Tenth International Congress of Diseases of the Chest, held in Washington in October 1968, it was admitted that "there have been instances of irresponsible reporting, both by the press and physicians, particularly in reference to sensationalism rather than an educational approach". 390/ S. J. Hessel wrote that "the need for money and willingness to participate in an experimental procedure transcends the usual confidentiality of patient-physician". 391/ Irvine H. Page pointed out:

"The introduction of payment for television interviews, picture rights, and ultimately organs themselves will surely lead to demand by the donor and recipient for their share of the booty. I can well imagine the minds of the greedy and unscrupulous are already working full tilt ...

"That confidentiality and the ancillary privacy have been grossly breached in the past few years is evident ... What purposes the frantic publicity has served is difficult to discern. Surely it has not been educational. To some of the public it has been entertaining while to others revolting. Building of celebrities has been indisputable ... Whether it will bring more money for research and a heightened interest in it, no one knows, and if it does, at what price?" 392/

388/ Information furnished by the Government of the United Kingdom on 8 August 1974.

389/ Ibid.

390/ Diseases of the Chest, vol. 55, No. 1, (January 1969), p. 63.

391/ S. J. Hessel, "Heart transplants and public information", New England Journal of Medicine, vol. 278, 4 April 1968, p. 797.

392/ Irvine H. Page, M.D., "The ethics of heart transplantation", Journal of the American Medical Association, vol. 207, No. 1 (6 January 1969), pp. 111-112.

273. Professor Fox has written that:

"The extensive, often theatrical coverage of transplantation has ... created certain problems for the medical profession and for the recipients and donors involved. It has invaded the confidentiality and privacy to which the physician and patient, individually and collectively, are ethically entitled. It has encouraged physicians, or put them under pressure, to report their clinical trials to the lay public before submitting them to the trained judgement and criticism of colleagues through channels such as professional publications. In the eyes of some physicians, it has facilitated self-advertising, competition, and commercialized behaviour on the part of certain members of the profession in ways that many feel violate the universalism, disinterestedness, and collectivity-orientation of the medical and scientific community. Furthermore, numerous medical spokesmen have expressed the opinion that the publicity transplantations have received may have 'misled' the general public in two key regards. On the one hand, it may have given them a 'too optimistic' impression of the present state and promises of transplantation; on the other, by excessively emphasizing the role of the physician as a 'taker of organs', it may have undermined public trust in his function of healer and guardian of life ..." 393/

274. The trend within the medical profession seems to be in favour of protecting the privacy of the donor, his family and the patient. To publish the names and addresses of donors or recipients is considered an unjustifiable and an unwarrantable intrusion into private life. The report of the Ad Hoc Committee on Organ Transplantation of the Netherlands Red Cross Society states that "the most stringent measures must be taken to protect the anonymity of donor and recipient, as this is in the best interest of the patients and their families". 394/ The Executive Committee of the International Society of Cardiology says:

"We deplore the fact that in recent times medical and surgical experiments have become matters of public entertainment and even sensationalism. Such a trend can only bring discredit to the profession as a whole and indirectly misrepresent to the public, who are not in a position to judge the implication of such developments, the dangers and limitations inseparable from such procedures in their initial phase." 395/

393/ Renée C. Fox, "A sociological perspective on organ transplantation and hemodialysis", New Dimensions in Legal and Ethical Concepts for Human Research, Annals, New York Academy of Sciences, 169, 2 January 1970, pp. 16-17 of Reprint No. 7 of Harvard University Program on Technology and Society.

394/ Summary of the Report of the Ad Hoc Committee on Organtransplantation (The Hague, Netherlands Red Cross Society, May 1971), p. 10.

395/ Statement by the Executive Committee of the International Society of Cardiology of 9 May 1968, forwarded by CIOMS on 20 October 1969.

275. The World Medical Association stresses a provision of the Declaration of Geneva of 1948 ("I will respect the secrets which are confided in me, even after the patient has died") and a provision of the International Code of Medical Ethics of 1949 ("A doctor shall preserve absolute secrecy on all he knows about his patient even after the patient has died, because of the confidence entrusted in him"), which were reinforced by two resolutions of the 27th World Medical Assembly (1973) strongly reaffirming the importance of medical secrecy in the patient-doctor relationship. 396/ The World Federation of Neurosurgical Societies points out that it is not "right to publish the names of persons involved in transplant operations" 397/ The World Federation of Scientific Workers maintains that "publicity and medicine are incompatible". 398/ In the resolution adopted by the Executive Council of the American College of Chest Physicians on 7 October 1968, it is emphasized that: "The name of the donor must not be revealed for the protection of all parties concerned". 399/

276. In connexion with recent practice Irvine H. Page states:

"I cannot agree that most scientific reports should be made to peer groups through the usually slow process of publication while those that have dramatic aspects need not do so. This allows a degree of permissiveness that will be abused. Such a guideline invites drama and entertainment but not clear thinking and critical analysis." 400/

277. On the other hand, in the above-mentioned issue of Civil Liberties (see para. 229) it is maintained that "individual Americans and their next of kin are on the verge of losing all legal rights to ... information on whether organs have been or will be taken". Material contributed by the League also stated that "the increasing secrecy over the identity of the organ donor ... may ... create a situation in which individuals are being used unwillingly [and] unknowingly ... as organ donors".

278. It has been maintained that some information should be supplied to the public, the more so because public support for medicine implies an obligation to inform the public of its activities, but that this information must be released by the responsible officers without prejudicing the interests of donors and recipients. Mr. W. F. Deeds emphasized in the United Kingdom Parliament: "We may deplore the capacity of some newspapers to obscure a small candle of truth by unnecessary pyrotechnics of their own. But we should not lose sight of the small central frame." 401/

396/ Information furnished by the World Medical Association on 14 March 1974.

397/ Information furnished by the World Federation of Neurosurgical Societies on 16 January 1974.

398/ Information furnished by the World Federation of Scientific Workers on 5 March 1974.

399/ Diseases of the Chest, vol. 55, No. 1 (January 1969), p. 63.

400/ Irvine H. Page, loc. cit., p. 112.

401/ Parliamentary Debates (Hansard), vol. 785, No. 132, p. 872.

The report of the Ad Hoc Committee on Organ Transplantation of the Netherlands Red Cross Society states:

"In the first place it is considered essential that both donor and recipient as well as their families should be as fully informed as possible about the operation to be performed. Only then can the patient, fully realizing the risks and possibilities, take his decision. In the second place the nurses, who are in close contact with these patients and their families, should be accurately informed about the situation ... In the third place, to secure future public co-operation on transplantations, it is very important to give extensive and honest information about the developments (including failures). Nevertheless, the Information Group of the Ad Hoc Committee has set limits as to the information to be given by the news-media ..." 402/

279. In addition to the critical remarks quoted above, Professor Fox has pointed out that the press has played a positive role in respect of organ transplantations:

"The degree and kind of attention that the mass media have accorded to organ transplantation has ... publicized the need for live and cadaver donors, introduced the lay public to the new conception of 'brain death', and helped families and local communities to raise funds for prospective organ recipients. In the opinion of at least one investigator, by dramatizing unsolved medical problems, most notably rejection reactions and tissue typing, the press has helped to interest more researchers to work in these areas." 403/

280. The Executive Committee of the International Society of Cardiology has stated:

"While it is not possible to control the behaviour of those who seek instant publicity, the Council of the International Society of Cardiology feels that a lead must be given by responsible members of the profession. One method of ensuring more ethical behaviour and avoiding extremes of anxiety or misplaced hope is to suggest strongly that no new procedures, either medical or surgical, are released to the lay press before being published in the reputable medical journals after full scientific evaluation.

"The International Society of Cardiology, through its Council, feels strongly that the profession as a whole should support this view in the interests firstly of the patient and secondly of their standing dignity."

402/ Summary of the Report of the Ad Hoc Committee on Organ Transplantation
(The Hague, Netherlands Red Cross Society, May 1971), pp. 9-10.

403/ Renée C. Fox, loc. cit., p. 20.

It fully supported the opinion of the Conseil National Français de l'Ordre des Médecins of 3 May 1968 that, in future, to avoid the diffusion of erroneous information "announcements of such experiments should be the subject of an official bulletin, which respects medical ethics and avoids distress to relatives and the creation of an emotional public reaction". 404/

281. In the "Ethical guidelines for organ transplantation" of the Judicial Council of the American Medical Association it is stated:

"Medicine recognizes that organ transplants are newsworthy and that the public is entitled to be correctly informed about them. Normally, a scientific report of the procedures should first be made to the medical profession for review and evaluation. When dramatic aspects of medical advances prevent adherence to accepted procedures, objective, factual, and discreet public reports to the communications media may be made by a properly authorized physician, but should be followed as soon as possible by full scientific reports to the profession." 405/

282. Irvine H. Page has written:

"I can see only trouble ahead if we continue the abuse of the principles of confidentiality and privacy. To stop it will require the long-term co-operation of the press, lay and medical editors, hospital employees, and chiefly a firm stance by the principals involved. We should not expect absolutes in human behaviour and no one expects a perfect performance but this is a far cry from what is happening. We need not capitulate to the pleading, threats, and insults hurled at us by the uninformed and unthinking. Rather, let us maintain the code of behaviour we as physicians know is right." 406/

283. Several Governments have expressed their views on the subject.

284. The Government of Argentina writes:

"From various standpoints, any publicity about the medical personnel involved in operations of this kind or about the identity of donors and recipients is undesirable. Both the operating team and the hospital director must take great care to avoid all contact with the lay press and to withhold the name or names of those concerned as well as any technical information about the case or related cases, from all except scientific reviews and periodicals." 407/

285. The Government of the Republic of Viet-Nam states that "publicity should be avoided. It merely disrupts the private lives of the persons concerned". 408/

404/ Statement by the Executive Committee of the International Society of Cardiology of 9 May 1968, forwarded by CIOMS on 20 October 1969.

405/ Journal of the American Medical Association, vol. 205 (1968), pp. 341-342.

406/ Irvine H. Page, op. cit., p. 112.

407/ Information furnished by the Government of Argentina on 30 May 1974.

408/ Information furnished by the Government of the Republic of Viet-Nam on 21 March 1974.

286. The Government of Romania writes: "The names of the persons could be revealed ... with their consent." 409/

287. The Government of Singapore writes that no publicity is given "to the identity of the persons involved in transplant operations ... unless the individual consents to or requests it". 410/

288. The Government of Sri Lanka asserts that no publicity is given in the cases in question in that country. 411/

289. The Government of Sweden writes:

"As regards preventing the revelation of the identity of persons who are donors or recipients involved in transplant operations, the general secrecy regulations governing all medical treatment are applicable, and these are regarded as adequate safeguards against such information being communicated by the institution concerned to unauthorized persons." 412/

290. The Government of the United Kingdom writes:

"Publicity can distress recipient patients and relatives of both donors and recipient patients. Recipients in the post-operative stage should be spared needless suffering caused by this.

"The present practice in the United Kingdom usually is for the hospital to respect the wishes of the donor's relatives and of the recipient and his relatives if, as is normally the case, they prefer to remain anonymous. Nevertheless, although this may secure the anonymity of the subject as far as the hospital and surgeons are concerned, the press do regard transplants as matters of public interest. Persistent enquiries, information from inquests and deduction from other evidence often make it impossible to protect the identity of the subjects for more than a brief period. There is the possibility that press intrusion at a time of grief may dissuade relatives from giving permission for organs to be removed for transplant." 413/

409/ Information furnished by the Government of Romania on 29 April 1974.

410/ Information furnished by the Government of Singapore on 13 March 1974.

411/ Information furnished by the Government of Sri Lanka on 5 March 1974.

412/ Information furnished by the Government of Sweden on 12 March 1974.

413/ Information furnished by the Government of the United Kingdom on 8 August 1974.

7. The post-operative rights of a living organ donor, or of anyone undergoing experimental procedures, in terms of medical care, and a donor's post-operative rights, if any, in relation to the organ recipient

291. Another problem concerning transplant operations arises in connexion with the rights of living organ donors. A presentation of this problem is made by Professor Renée C. Fox of the University of Pennsylvania:

"The social status and role of donor ... are unclearly defined and somewhat anomalous and marginal. For ... the donor is neither sick nor a patient in the conventional sense of these categories, although he does undergo hospitalization for major surgery entailing the removal of a vital organ. Given the unprecedented nature of the donor role, it is not surprising that physicians express uncertainty over the proper way to define the donor and to relate to him. Is he more a patient, or is he a member of the medical team, by virtue of the life-saving therapeutic contribution he makes? How much psychological as well as physical care and attention from the medical team does he need and should he have in the immediate post-operative weeks? Should he be treated exactly the same way as the usual post-surgery patient? What, if anything, does the medical team owe him in a long-range sense? Is he entitled to continuing medical care over the years from the team that removed his kidney and handled his convalescence? In the future, should he be 'somebody else's patient' for all but direct complications of the kidney incision? Can it be said that 'even though the donor has lost something materially he has gained something spiritually which is greater', and that therefore he is sufficiently compensated to exempt the medical team from further professional concern about him? These and other aspects of the responsibilities, obligations, rights and exemptions defining the donor-medical team relationship are still not fully worked out.

"Finally, the post-transplant relationship between live donor and recipient also seems to be characterized by certain ambiguities and strains ..." 414/

292. It is stressed by the authors that existing ethical rules do not reflect the rights of organ donors and that it is necessary to elaborate special rules concerning these rights in order to give guidance to physicians. Thus Drs. A. de Coninck, P. Dor and J. R. Fagnart point out:

"The introduction of a third person (the donor) into the doctor-patient relationship creates problems which cannot be solved by reference to the usual rules, since the latter cater for no one except the doctor and his patient, whose direct personal interest can be established fairly easily." 415/

414/ Renée C. Fox, loc. cit., pp. 20-21.

415/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 18 (emphasis supplied).

In the opinion of Professor David Daube,

"Undeniably ... there is a very special problem in transplantation from the living, because of this terrible element that a healthy donor suffers injury, either temporary - in blood transfusion - or permanent. This is a novel and unique feature: the role of the donor fits into no orthodox category, it needs working out, and plainly very special safeguards are required." 416/

Having mentioned the law on transplantation of kidneys from living donors promulgated in Italy in June 1968, to which further reference is made in paragraph 299 below, Professor Hamburger said at the CIOMS Round Table Conference on Biomedical Science and the Dilemma of Human Experimentation:

"I think that this law is an important example. I think that at present all countries where kidney grafts are commonly and successfully carried out should have regulations protecting the rights of donors and also of the medical profession. At the moment, there is on the whole some illegality in their position."

He submitted the following resolution, which was unanimously adopted by the members of the Round Table:

"The members of the Round Table Conference organized by CIOMS,

"Having discussed the conditions governing a renal transplant from a living donor,

"Express the wish that, in countries where centres exist capable of carrying out such operations but where they are forbidden by law, regulations should be established specifying the conditions in which the voluntary gift of grafts can be accepted." 417/

293. It has been maintained that a living organ donor should have the right to medical care as far as all the consequences of donating an organ are concerned. The Federation of Neurosurgical Societies gives the following answer to the question concerning the donor's right: "in terms of medical care: affirmative". 418/

294. The Government of Argentina points out:

"The donor is entitled to medical care for injury or illness which results directly or indirectly from a mutilation performed to remove a transplant organ ... The subjects of other experiments must be informed beforehand of all the risks, direct and indirect, to which they expose themselves in submitting to the experiment and must be told of its purpose, scope and results; they too are entitled to medical care for injury and illness resulting from the experiment in question." 419/

416/ D. Daube, op. cit., p. 194 (emphasis supplied).

417/ CIOMS Round Tables: 1. Biomedical Science ..., pp. 45 and 96.

418/ Information furnished by the Federation of Neurosurgical Societies on 16 January 1974.

419/ Information furnished by the Government of Argentina on 30 May 1974.

295. The Government of Romania states:

"The donor's and recipient's rights to medical care should be regarded as permanent for all the consequences of interventions, as long as the latter can be considered as of outstanding scientific interest. The special centres assigned and authorized to perform these interventions should be provided with special funds ...

"When these interventions become perfected ... generalized and routine, the rights to medical care are those enacted by the ... legislation of the respective country." 420/

296. The Swedish Government writes:

"As far as expenditure etc. is concerned in connexion with transplant operations, reimbursement should be paid for travel and treatment costs and lost income from employment, necessitated both by the investigation of a certain person's suitability as a donor and by the transplant operation itself." 421/

297. In the information from the Government of the Ukrainian SSR and the USSR it is pointed out in this respect that "compensation laid down by law is payable by the State". 422/

298. The Government of the United Kingdom has stated:

"Any person in the United Kingdom who has given one of his organs for transplantation and who subsequently requires medical care will receive the benefit of the same Health Service facilities and treatment as any other person with the same symptoms." 423/

299. It has been proposed that the donor or a person undergoing experimental procedures should have the right to some insurance in the event of his disablement resulting from his donation or the experimental procedures. Professor R. Cortesini, who took part in elaborating the Italian law on transplantation of kidneys has pointed out:

"The donor of the kidney is entitled to the insurance rights envisaged by law until he leaves the hospital ...

"From both medical and social points of view we believe it would be fair to extend the insurance beyond the intervention, in order to provide a pension for the donor in case his remaining kidney is injured." 424/

420/ Information furnished by the Government of Romania on 29 April 1974.

421/ Information furnished by the Government of Sweden on 12 March 1974.

422/ Information furnished by the Government of the Ukrainian SSR on 23 October 1974, and information furnished by the Government of the USSR on 25 July 1974.

423/ Information furnished by the Government of the United Kingdom on 8 August 1974.

424/ R. Cortesini, "Outlines of a legislation on transplantation", in: G. Wolstenholme and M. O'Connor, eds., Law and Ethics of Transplantation, a Ciba Foundation Blueprint (London, J. and A. Churchill Ltd., 1968), p. 173.

Summarizing Italian legislation on the subject in 1968, he said:

"The socio-economic aspects, which I believe are quite important, are the following: the living donor has a special insurance, he does not pay hospital fees, and he is fully protected by the insurance in case of future disease affecting the kidney. The reason for this is that the State recognizes his donation and gives him special protection." 425/

In this connexion Professor Hamburger expressed the following opinion:

"We must congratulate Professor Cortesini, who was at the origin of that Italian law. He was, I think, right in stressing an important practical point in the law that perhaps deserves to be considered in other kinds of experiment - that is, protection by official insurance of the donors, who in the case in point are donors of renal grafts but who could also be healthy subjects or ill persons undergoing an experiment involving some risks." 426/

300. Speaking about the right of the donor to medical care, Paul-Julien Doll said at the fourth Besançon colloquium on human rights in France:

"I venture to suggest that when the time comes for legislation on the subject of transplants from living donors, it should stipulate, on the model of the Italian law, that any consequences prejudicial to the donor should be borne by society provided the operation took place in accordance with the legislation in question, particularly as regards the obtaining of consent." 427/

The information received from the Government of Norway includes the following passage from the book of Professor Enger Transplantasjoner ("Transplant Operations"):

"In a case of accident or subsequent illness related to the operation undertaken, there should be some scheme ensuring financial compensation for the patient or his relatives in the event of disablement or death. Only in very rare cases would there be any need for such benefits, but to make them possible could be the expression of society's recognition of those who in this way place their physical integrity at the disposal of their fellow human beings." 428/

The United Kingdom Government has pointed out:

"In connexion with discussions which are taking place on the setting-up of a panel of bone-marrow donors, the suggestion has been put forward that some sort of provision should be made to compensate them for any possible ill-effects resulting from bone-marrow donation but no decision has yet been taken." 429/

425/ CIOMS Round Tables: 1. Biomedical Science ..., p. 54.

426/ Ibid.

427/ Paul-Julien Doll, loc. cit., p. 6.

428/ Information furnished by the Government of Norway on 15 April 1974.

429/ Information furnished by the Government of the United Kingdom on 8 August 1974.

301. At present donors seem nowhere to have any guaranteed right to medical support in case of future complications resulting from their donations. In this connexion J. E. Murray cites the following episode:

"The donor, a 23 year-old intelligent person, asked a very pointed question: would the doctors at the Peter Bent Brigham Hospital be willing to take care of him medically for the rest of his life if he gave his kidney? We stated that we neither could nor desired to make a guarantee of that sort; we were there to help his brother and if he (the prospective donor) could help his brother, we felt that the chances of success were quite good." 430/

302. There are different opinions as far as the rights of the donor to the recipient are concerned. Some authors feel that such rights exist. For instance the paper of Paul-Julien Doll which was cited above includes the following passage:

"A Swiss author - Professor Bucher - has made a suggestion worth considering: should not a proper contract be concluded between the donor and the recipient? Should it not be the accepted thing that the recipient should bear the cost of the operation, and of any post-operative treatment in the event of complications? Should he not undertake to indemnify the donor and his heirs against later complications or death? (Largiader, Organtransplantation, p. 73).

"This would seem fair but completely contrary to the requirement of confidentiality, since in theory the donor and the recipient should not know each other unless they are related." 431/

The Government of Argentina points out that financial expenses connected with the operation incurred by the donor should be borne by the recipient or the medical institution concerned. This point should be ascertained before the operation. 432/ The Government of the Republic of Viet-Nam states that "in such cases post-operative rights should be guaranteed before the operation". 433/

303. On the other hand it has been maintained that the donor should not have any rights in relation to the recipient. In a study by Renée C. Fox and Judith P. Swazey, "The courage to fail: the sociology of organ transplantation", it is said:

"The relationship between the donors and the recipients of organs, for example, is an extreme version of a common social interchange: the giving and the accepting of a gift. All gift exchanges take place within a framework of social obligations to give, to receive, and to repay. The gift of an organ is no exception, rather, the same obligations are felt with extraordinary intensity by everyone involved. They are felt with particular severity in the case of the live kidney transplant in which the

430/ G. Wolstenholme and M. O'Connor, eds., op. cit., pp. 17-18.

431/ Paul-Julien Doll, loc. cit., p. 6.

432/ Information furnished by the Government of Argentina on 30 May 1974.

433/ Information furnished by the Government of the Republic of Viet-Nam on 21 March 1974.

donor is usually a close relative of the patient. The emotional trauma involved, whether or not a transplant is made, can be severe for donors, recipients, and other family members. Because transplant teams have become very aware of these emotional ramifications of the gift of an organ, they may refuse a donor on psychological grounds, fearing that in a particular family the donation will bind the giver and the recipient in an intolerable relationship of dependence, domination, or gratitude." 434/

It has been said that as a rule donors derive a moral compensation from their donation. Speaking about kidney donors, Professor Hamburger said:

"In our experience none of these donors regret their decision, even after the recipient has died. For instance one of these donors, a sister-to-brother transplantation, wrote a long letter in which she explained that she thought that she had something more than before, having increased the quality of her life by giving the kidney. We received several similar letters." 435/

A relevant event has been referred to by J. E. Murray:

"We had one 14-year-old girl who gave a kidney to her twin and the twin subsequently died. She came from a small community in the Middle West and everyone knew all the details. Many newspaper articles criticized the doctor, the family and the young girl. The family naturally felt badly about the outcome and resultant public opinion, yet they themselves and the donor were delighted they had done it - they feel it has added something to all their lives." 436/

The Federation of Neurosurgical Societies states that "The donor should have no rights in relation to the recipients". 437/ The World Federation of Scientific Workers points out that "a gift cannot be taken back". 438/ M. Bosman stresses that one of the limits set by Belgian legislation on transplantation is:

"That the donor is prohibited from surrendering any part of his body for a pecuniary consideration, whether agreed with the doctor of an establishment which is approved for the preparation, conservation and supply of the material concerned or with the person who benefits from that material." 439/

According to Italian legislation, any negotiation for remuneration in cash or in kind is forbidden and nullifies the donation act, and whoever acts as a middleman is to be punished by imprisonment and a fine. 440/

434/ Harvard University Program on technology and society, 1964-1972: A Final Review (Cambridge, Massachusetts, Harvard University, 1972), pp. 45-46.

435/ G. Wolstenholme and M. O'Connor, eds., op. cit., p. 16.

436/ Ibid., p. 18.

437/ Information furnished by the Federation of Neurosurgical Societies on 16 January 1974.

438/ Information furnished by the World Federation of Scientific Workers on 5 March 1974.

439/ M. Bosman, op. cit., pp. 5-6.

440/ R. Cortesini, loc. cit., p. 173; and Use of Human Tissues and Organs for Therapeutic Purposes: A Survey of Existing Legislation (Geneva, WHO, 1969), p. 18.

The Government of Norway comments as follows:

"The Committee [which drafted the Act of 9 February 1973] has discussed the question of whether the draft Bill should include a provision prohibiting consent in return for payment. The practice of buying and selling human organs is an objectionable practice and should not be approved. However, it has been decided to let the matter stand without any explicit provision being included in the Bill. Doubtful borderline cases might arise. There cannot be any objection to the recipient promising to recompense the donor for any loss of earnings, nor to his offering to meet the costs of a convalescent stay after the operation. As a rule the donor is related to the recipient. It would therefore be difficult to ascertain whether [there existed] any form of gratuity, assumed to apply equally in other cases. Nevertheless, if the medical practitioner has reason to suppose that there is any question of the sale of human organs, he should refuse to accept the act of consent." 441/

In the information from the Governments of the Ukrainian SSR and the USSR it is stated that "a living organ donor has no post-operative rights in relation to the recipient". 442/ The Government of the United Kingdom has written:

"The donor has no rights in relation to the recipient. If a prospective donor or his relatives attempted to set conditions to the use of his organs it is most unlikely that the surgeon involved would be willing to proceed.

"There have been press reports of relatives of deceased donors attempting to obtain money from recipients or their relatives but no direct confirmation of these reports has been received." 443/

441/ Information furnished by the Government of Norway on 15 April 1974.

442/ Information furnished by the Government of the Ukrainian SSR on 23 October 1974, and information furnished by the Government of the USSR on 25 July 1974.

443/ Information furnished by the Government of the United Kingdom on 8 August 1974.

II. RADICAL MEDICAL TECHNIQUES IN GENERAL: THE RISING COST OF MEDICINE

1. The question whether advanced medical techniques for the prolongation of life should be applied to some patients as long as the cost involved curtails the provision of less sophisticated medical care, or the provision of other social benefits, for the many

304. Recently developed radical medical techniques which prolong the lives of people suffering from terminal illnesses, such as organ transplants and haemodialysis, are very expensive and to use them a large cadre of specially trained personnel is required. A report of the United States Department of Health, Education and Welfare has predicted that the yearly cost of terminal kidney disease therapy in 1980 may reach \$1 billion. 444/ It has been estimated that if all the new patients suffering from kidney failure in Britain got immediate kidney transplants at £1,000 a time the yearly bill would be approximately £2.5 million. The cost of providing kidney machines for all of them would be about £30 million a year after twenty years, when over 10,000 staff would be treating 23,000 patients. 445/ A French political economist has calculated that the present cost of treating all those waiting for haemodialysis would already equal that of all other health services put together in his country. 446/ Therefore, the above-mentioned techniques cannot be applied to all sick persons who could benefit from them and the problem arises if anyone should benefit from them at the cost of less sophisticated medical care for the many.

305. This problem is being widely discussed and studied by many private and public agencies in different countries. The most typical questions asked are: How will we confront the moral and economic dilemma posed by our most dramatic successes in the biomedical sciences? In a world in which hunger is rampant, in which treatable diseases remain untreated, in which the simplest of health care is lacking for millions, what are our justifications for those therapeutic measures that are so costly both in manpower and money? Is the Hippocratic Oath outdated by the fact that the consequent practice of ethical principles conflicts with other requirements of human society, e.g. those of an economic nature? Should the cost of treating the less serious illnesses of the many be limited in favour of such large-scale funds for the treatment of the life-endangering illnesses of fewer people? 447-448/ Is the extra life span and a degree of rehabilitation worth the discomfort, the psychological hazards, the long hospital stay, the enormous cost, and the tying up of a large part of a hospital staff when other patients need care? Can we afford to spend \$75,000 for one heart transplant or \$15,000 for a kidney, while each year thousands of children die of

444/ Lawrence K. Altman, "Costs of kidney therapy: two fundamental questions raised", New York Times, 23 January 1973.

445/ Gerald Leach, The Biocrats: Implications of Medical Progress, revised edition (Harmondsworth, Middlesex, Penguin Books Ltd., 1972), p. 258.

446/ Alfred Pletscher, "Roche and the human problems of biomedical progress" The Challenge of Life, Biomedical Progress and Human Values, Roche Anniversary Symposium, Basel, 31 August-3 September 1971, Basel and Stuttgart, 1972, p. 27.

447-448/ Alfred Pletscher, loc. cit., p. 27.

malnutrition? 449/ Are these high peaks of modern surgery - transplants and artificial organs - an inordinately extravagant way of trying to avert death, when scarce, expensive skills should be used in this way when they could be better used elsewhere? 450/ Is the choice between research on an artificial heart for the old and preventing rheumatic heart disease in the young? Between dialysis units and neighbourhood health centres? How many individuals could be rehabilitated with glasses, hearing aids, or dental care for the cost of one heart transplant or one kidney unit? 451/ Where do the rights of society come into the picture when physicians, funds and hospital beds used to keep terminal patients alive are in short supply? Can society justify the costly treatment in view of other pressing medical needs? 452/

306. The opinions of the authors trying to solve these problems are divided.

307. Physicians, in particular those who practice the radical-medical techniques, usually justify employing them in treating patients. Professor Amitai Etzioni, together with his colleagues at the Centre for Policy Research, has conducted a study of two hundred physicians in New York City in this respect. His conclusion is:

"The study of cost-consciousness shows that most physicians are relatively unconcerned with the costs of treatment to the patient, less so when there is an insurance scheme, and least of all when the costs can be charged to the Government. Most doctors take the moral position that, since they are entrusted with the health of their individual patients, no other considerations should enter." 453/

308. Touching upon dialysis units, Dr. Blumgart writes:

"In the United States, approximately six to eight thousand uremic patients could benefit from such treatment, although treatment facilities are available for only a thousand or so. To create a nationwide network of treatment centres would cost \$25,000 or more per case per year for the presently untreated seven thousand patients and would require a large cadre of trained personnel. If one includes the patients with acute kidney disease, the number of people requiring dialysis might reach forty thousand, with a cost of \$10,000 to \$15,000 per patient. To supply sufficient facilities for treatment for all might involve the sacrifice of other social benefits." 454/

449/ Francis D. Moore, Transplant, the Give and Take of Tissue Transplantation, quoted in William A. Holen, "Most of us see only the surgical tip of the iceberg", New York Times Book Review, 5 March 1972.

450/ Gerald Leach, op. cit., pp. 341, 271.

451/ Who Shall Live? Man's Control over Birth and Death - Report Prepared for the American Friends Service Committee (New York, Hill and Wang, 1970) (hereinafter referred to as "Who Shall Live?"), p. 25.

452/ Jane E. Brody and Edward B. Fiske, "Ethics debate set off by life science gains", New York Times, 23 March 1971.

453/ Amitai Etzioni, The Genetic Fix (New York, Macmillan, 1973), p. 177.

454/ Herrman L. Blumgart, "The medical framework for viewing the problem of human experimentation", Ethical Aspects of Experimentation with Human Subjects, Daedalus, Spring 1969, pp. 264-265.

309. In a study prepared by a working party of the American Friends Service Committee it was stated:

"Resources for medical needs and medical research are not unlimited. A single heart transplant costs \$20,000 to \$50,000; a kidney transplant approximately \$10,000. Thirty million dollars will buy the artificial kidney units needed to prolong the lives of victims of kidney failure. The Government has stepped up its efforts to perfect an artificial heart, for which many millions will be needed. Each of these expenditures can be justified." 455/

But the report stresses the other uses, benefiting more people, for which the money involved could be used 456/ and continues: 457/

"The need for medical research and experimentation is clear. But here, too, we have choices to make. A substantial portion of medical research funds and facilities in recent years has been invested in efforts to prolong life in the aging or dying and to seek cures for specific diseases, mainly in the elderly. The value of every such programme can be documented in human terms. But the problem remains: How do we allocate medical research resources between the needs of the aging and those of younger persons so that the quality of life may be enhanced for all?

"In this connexion we are confronted by a number of profound social and moral considerations. It is desirable to keep increasing the life span of the general population? To what limit? If we could make it possible for people to live to be well over one hundred, should we? Would the added years be fulfilling and productive for the individual, his family, and society? Or would we simply be adding to the unhappiness of an ever-increasing number of people, compounding the problems of an already overburdened society, and aggravating the population crisis? Should additional millions be spent on helping the elderly to live longer, or should the money be spent on improving the quality of the life span we have already achieved?"

310. Speaking about the implications of the artificial heart at the Eighth CIOMS Round Table Conference, Dr. Gellhorn said:

"It has been estimated that each installation can be made for the price of about \$25,000 (1973 dollars) and that as many as 50,000 candidates would be available each year in the USA for an annual cost of 1.25 billion dollars. In the majority of instances, the cost of the artificial heart will be beyond the reach of the individual patient and therefore the programme will largely, if not entirely, be supported by tax money. One-and-a-quarter billion dollars is a pittance when compared with the expenditures for military purposes, but if a proportion of the gross national product has been allocated to health, then costs for a programme must be considered in assigning priorities." 458/

455/ Who Shall Live?, p. 74.

456/ See para. 305 above and footnote 451.

457/ Who Shall Live?, p. 76.

458/ Alfred Gellhorn, "Advances in medical terminology: their moral and ethical implications", in CIOMS Eighth Round Table Conference, op. cit., p. 250.

311. At the United Nations seminar on the realization of economic and social rights contained in the Universal Declaration of Human Rights, held at Warsaw in August 1967, it was pointed out that the plans which the State must draw up and carry out for the promotion of economic, social and cultural rights may entail decisions in respect of favouring some groups and individuals over others in the medical field. 459/

312. Dr. Dwight E. Harken considers it more important to care for a larger number of less hopelessly ill patients:

"... balancing the use of considerable resources for a few transplants, against obligation to treat ailing people and extend heart surgery techniques, ... I have elected the rehabilitation of a fair number of people while attempting to improve prosthetic valves, coronary circulation and mechanically assisted circulation." 460/

313. Dr. George E. Schreiner thinks that doctors should not spend the taxpayers' money to find new expensive treatments:

"There's no rationale for doing medical research if there is no intention to deliver the fruits to those who need it. Americans, for example, are spending hundreds of millions of dollars to combat the group of diseases known collectively as cancer. Now is the time for Americans to ask if they are willing to spend the money to deliver such a cure - if one is ever found - to tens of millions of victims, because the existing body of medical knowledge clearly suggests that a cancer cure will not be in the form of 10-cent pills but therapies costing each patient thousands of dollars." 461/

314. Dr. René Dubos, bacteriologist at Rockefeller University, United States of America, believes that there is no need to "become excited about a few hundred organ transplants when every day in New York City 30,000 children are exposed to the possibility of permanent handicaps from lead poisoning and no one is doing anything about it". 462/

315. At the Roche Anniversary Symposium, Lord Zuckerman pointed out:

"No one in his senses could suppose that with the world as it is, with most countries contending with a rate of population growth that threatens their economic and social development ... the resources which they demand justify those extremes of surgical practice represented by techniques such as heart transplantation. These developments are the vested interests of medical or scientific enthusiasts, not of the people at large or of social scientists or of Governments ... By and large more would be made happy if more mundane medical problems were solved first, and equally society would become healthier were we able to deal successfully with the simpler matters ... Indeed, if all new medical research were to stop now and the resources it uses put into the further application of the knowledge we already have enormous gains could still be achieved in the public health of the world." 463/

459/ Report of the seminar, ST/TAO/HR/31, para. 54.

460/ Cf. Herrman L. Blumquet, loc. cit., p. 266.

461/ Lawrence K. Altman, loc. cit.

462/ Jane E. Brody and Edward B. Fiske, loc. cit.

463/ Lord Zuckerman, "The doctor's dilemma", The Challenge of Life: Biomedical Progress and Human Values, Roche Anniversary Symposium (Basel, Birkhäuser Verlag, 1972), pp. 430, 432.

316. Estimating cost effectiveness of radical medical techniques, Gerald Leach writes:

"Though medicine has traditionally put its greatest efforts into life-prolonging ... for the health and wealth of society less dramatic goals can often be a relatively far better bargain.

"The point about cost-effectiveness is that it is only a method for guiding future developments, not for banning present established procedures ... No one is suggesting that it should be used to tell doctors not to investigate and treat a critically ill patient because it would cost too much. No one is talking about running down existing programmes, like kidney machines, on the same grounds. No one is talking about halting research into this or that. All cost-effectiveness is about is deciding where to expand our future horizons for care and research." 464/

317. Some Governments answer positively the question whether the application of advanced medical techniques to patients is justified. The Government of Luxembourg has pointed out that "the doctor is not entitled to let economic considerations influence his decisions about surgery or treatment". 465/

318. The Government of Romania believes that the application of advanced medical techniques is justified and sometimes indispensable. The problem of financial difficulties connected with their application in some countries could be solved with the help of international funds which States might create. A well-organized international co-operation in the field is necessary because there may be emergency cases. Although at present the application of advanced medical techniques is not widespread, special centres for this purpose should be developed in the countries concerned, and resources should be allocated to cover the expenses connected with their application. 466/

319. Information from the Government of the Union of Soviet Socialist Republics states:

"In the USSR citizens have equal rights irrespective of their nationality, race or place of residence in all aspects of economic, administrative, cultural, social and political life, including the provision by State health institutions of free, qualified medical assistance available to all." 467/

320. The information from the Government of the United Kingdom contains the following passage:

"In the United Kingdom, it is for the Regional Health Authorities to decide the allocation of funds between different health needs in their areas and for individual clinicians to decide which patients to treat and how to treat them within the available facilities. In general, costly procedures are not ruled out because of their expense if they are known to be effective. Many treatments which later benefit large numbers of patients at a reasonable cost are developed from advanced and initially expensive techniques originally available only to a relatively few patients." 468/

464/ Gerald Leach, op. cit., pp. 353, 352.

465/ Information furnished by Luxembourg on 16 March 1974.

466/ Information furnished by Romania on 29 April 1974.

467/ Information furnished by the Union of Soviet Socialist Republics on 25 July 1974.

468/ Information furnished by the Government of the United Kingdom on 8 August 1974.

321. The Government of Argentina states:

"National policy on this subject should be based on the principle that an individual's rights stop where those of his neighbour begin, especially when the rights concerned belong to the community as a whole; the attitude which is adopted in a particular case should depend on the availability of resources and the possibility of alternative treatment." 469/

322. The information from the Government of Norway contains the following passage:

"The debate on this question has become highly topical in Norway in recent years where it may clearly be seen that the various public health budgets threaten to exceed all stipulated limits. It looks as if there is still a long way to go, however, before it will be possible to develop an apparatus for management and control in this field, should it be decided that such an arrangement is desirable. International co-operation is probably an absolute necessity here." 470/

323. In the information from the Government of Sri Lanka it is pointed out that "cases of chronic nephritis are not put in the kidney unit. Procedures that would benefit many are advocated". 471/

324. The World Health Organization gives the following résumé of the problem:

"A question that has been much discussed is whether interventions that are very costly in terms of skilled manpower and expensive equipment, but which are designed to confer benefit on only a few individuals, are justifiable from the point of view of a cost/benefit analysis. Many more people, it is argued, could benefit from simpler measures more widely accessible, at the same cost. That such simpler measures should be applied as widely as possible is undeniable, but the whole history of biomedical science shows that advances that will ultimately benefit all are necessarily first tried on a very small sample of the whole." 472/

469/ Information furnished by the Government of Argentina on 30 May 1974.

470/ Information furnished by the Government of Norway on 15 April 1974.

471/ Information furnished by the Government of Sri Lanka on 5 March 1974.

472/ E/CN.4/1173, p. 24.

2. The criteria which should apply to the choice of recipients, if any, of advanced medical techniques for the prolongation of life and to the choice of recipients of organs available for transplantation while these are scarce

325. Since only a few people can benefit from radical medical techniques when they are extremely expensive, when there are only a limited number of donors and centres for transplantation and only sufficient dialysis machines to serve a fraction of the afflicted, crucial dilemmas arise in connexion with the selection and rejection of patients. The following questions arise: How does one select those patients whose lives are to be spared? On what basis should the allocation of expensive treatment be decided? 473/ How can a limited organ supply be fairly used in the face of an overwhelming need and demand? 474/ Under what circumstances may the patient be considered morally entitled to accept the sacrifice that a donor offers? 475/ On what criteria will those "worthy of treatment" be selected?

326. "Shall machines or organs" Dr. Fletcher asks, "go to the sickest, or to the ones with most promise of recovery; on a first-come, first-served basis; to the most 'valuable' patient (based on wealth, education, etc.); to the one with the most dependants; to women and children first; to those who can pay; or should lots be cast, impersonally and uncritically?" 476/ Who should live, who should be allowed to die and who should choose? 477/

327. Stressing the difficulty of this problem, Professor Amitai Etzioni writes:

"The matter is much more difficult than the decision to turn off a life-maintaining machine that artificially prolongs the existence of a terminally ill, comatose body, though even this decision is one that many doctors find very disturbing. Decisions about who shall be allotted an organ and thus a very good chance to lead a normal life, and who shall be refused and condemned to die, are as agonizing as those that have to be made on a sinking ship when the lifeboats are too few to carry all the survivors. However, the medical decisions are more tragic, because the mortality rate is quite predictable." 478/

328. Furthermore, the question has been asked whether to let one person die in order to save another:

473/ Lawrence K. Altman, "Artificial kidney use poses awesome questions", New York Times, 24 October 1971.

474/ Jane E. Brody and Edward B. Fiske, loc. cit.

475/ News Bulletin of the International Federation of Surgical Colleges, No. 7 (May 1967), furnished by the Federation (hereinafter referred to as "News Bulletin"), p. 27.

476/ J. Fletcher, "Our shameful waste of human tissue", in D. R. Cutler, ed., The Religious Situation; 1969 (Boston), p. 252.

477/ Gerald Leach, op. cit., p. 258.

478/ Amitai Etzioni, op. cit., p. 26.

"Suppose you have a terminally ill patient being kept alive by machine -- the only one you have -- and another patient turns up. This one has a good chance to get better -- but, to do so, he needs the machine. Do you transfer the machine? And, if you do, have you in fact killed the patient by taking it away? 'Everybody is willing to turn the machine on', said the Reverend Granger E. Westberg, 'but nobody is willing to turn the machine off. The doctor needs some help in making this decision'." 479/

329. Dr. Blumgart has pointed out that in practice the present selection of beneficiaries is often arbitrary, and to an important degree it is based on the ability to pay. Unless they are rich, qualify for special benefits, or live in areas where the authorities help pay for expensive care, many patients simply cannot afford the price of radical medical techniques. 480/ In this connexion, Dr. Belding H. Scribner has stressed that such expensive treatments:

"are not going to work if to be eligible for State aid you have to sell your house and give up your job. In some States patients have refused treatment, thereby committing suicide, rather than become paupers in order to qualify for public financial assistance ... Washington and Maryland have redefined medical indigency to avoid such a possibility." 481/

Considering the implications of an artificial heart a panel composed of United States specialists in various fields emphasized that "its availability should not be based upon ability to pay". 482/

330. Most of the authors agree that patients should be selected first and foremost on medical grounds. Gerald Leach writes:

"It might seem fairest to choose on a queue system, but unfortunately anyone at the head of the queue will have had kidney disease for longer than the newcomers and will probably be in a worse medical condition. Just because machines are scarce and must be used on patients with the greatest chance (a) of surviving a long time and (b) of surviving with least physical or emotional distress, selection must first of all be on medical ... grounds. Most doctors start narrowing the choice by only considering candidates between puberty and 55 who are not suffering from any additional disease that cannot be easily controlled. ... on medical grounds alone (with or without psychological ones) doctors can nearly always pick out a natural winner ... without any need to start considering difficult social criteria. If they cannot it is rarely difficult to tighten the medical criteria and then have them -- and them only -- assessed by colleagues, who know nothing about the rest of the patient's background." 483/

479/ Albert Rosenfeld, The Second Genesis: the Coming Control of Life (New York, 1969), p. 80.

480/ Herrman L. Blumgart, loc. cit., p. 264.

481/ G. Lawrence K. Altman, loc. cit.

482/ Albert R. Jonsen, "The totally implantable artificial heart", The Hastings Center Report, vol. 3, No. 5 (November 1973), p. 2.

483/ Gerald Leach, op. cit., p. 258.

331. In his paper prepared for a conference on ethical and legal problems of organ transplantation sponsored by the Ciba Foundation, Dr. H. E. de Wardener of Charing Cross Hospital Medical School, London, wrote:

"When we have decided that we have a place we then choose the next 'suitable' patient to be brought to our notice unless we already have such a patient in our care. Such a patient must be showing signs of gradual deterioration in spite of a low protein diet. 'Suitability' is a conveniently elastic word. In this context some would say not unreasonably that any patient with terminal renal failure is suitable for intermittent haemodialysis. Because of the shortage of facilities, however, we have to make a choice and most of us narrow our choice to patients between puberty and the menopause who are not suffering from some additional disease or from a generalized disease which dialysis will not control. Most of us would avoid starting treatment on patients in a moribund or agonal state. It is clear that a variety of conditions control the definition of what is 'suitable'. Some are directly concerned with the patient's comfort and happiness. For instance, children are not treated, for it has been found that if dialysis is begun before adolescence, puberty is unlikely to develop. However, most of the factors which influence a decision about a patient's suitability are related to the probabilities of his having a prolonged survival once treatment is started. For instance, a patient aged 60 years who, in addition to his renal failure, suffers from diabetes or has had a myocardial infarct, is considered to be less suitable than a young person who only suffers from renal failure." 484/

332. The report of the Fifth Bethesda Conference of the American College of Cardiology contains the following passage:

"Serious questions of distribution of scarce, life-saving resources arise in heart, liver and kidney transplantation and in the use of the artificial kidney. By analogy with the other situations, the heart should go to the patient likely to derive the greatest benefit, that is, to the patient in whom the likelihood of a successful transplant is greatest; and, case by case, this must be a medical decision. While ethical, social, economic, legal and theologic considerations necessarily influence medical judgement, such decisions should be based on a full consideration of all factors involved in the potential success of the transplant. In the individual case situation, the decision is properly made by the responsible physician." 485/

333. The importance of medical grounds is also recognized by Professor Paul A. Freund of Harvard University, who stresses the "capacity to benefit from the treatment and not succumb to complicating ailments"; 486/ Dr. Scribner, who indicates in particular

484/ H. E. de Wardener, "Some ethical and economic problems associated with intermittent haemodialysis", in G. Wolstenholme and M. O'Connor, eds., Law and Ethics of Transplantation, a Ciba Foundation Blueprint (London, J. and A. Churchill Ltd., 1968), pp. 107-108.

485/ Cardiac and Other Organ Transplantation in the Setting of Transplant Science as a National Effort: Fifth Bethesda Conference of the American College of Cardiology (New York, 1968), p. 15.

486/ Paul A. Freund, "Introduction to the issue Ethical Aspects of Experimentation with Human Subjects", Daedalus, Spring 1969, p. xiii.

that the person to be treated by dialysis must be under forty and free from cardiovascular disease; 487/ Dr. G. E. Schreiner, who believes that in dealing with the uraemic patient one should act "on the basis of where most good can be done"; 488/ Henry Miller, who thinks that the doctor should "be guided chiefly by the clinical prospect of benefit"; 489/ Dr. C. A. Richard, who points to "the areas offering better or poorer chances of success" and to "possible compatibility with the donor"; 490/ and Drs. A. de Coninck, P. Dor and J. R. Fagnart, who point out: "The decision that a kidney transplant is indicated for a given patient must be based on medical criteria."49

334. It is also pointed out that in selecting patients for radical medical techniques attention should be paid to psychological grounds. Drs. A. de Coninck, P. Dor and J. R. Fagnart consider that medical grounds in the wide sense of the term include psychological ones. Dr. Blumgart writes:

"The stresses suffered by patients and by spouses who carry out the home dialysis procedures are great. Depression, anxiety, frustration, repressed hostility, and conflict quite frequently produce serious crises and turmoil. These emotional and personality factors are important considerations in selecting recipients." 492/

335. Dr. H. E. de Wardener points out that the patients concerned should be "in their right mind and likely to be co-operative". 493/ In this connexion the case of a nineteen-year-old girl is cited who was admitted to hospital nine times for a total period of eight months during the seventeen months she was on a kidney machine. The girl was a disastrous failure on intermittent dialysis because she was badly selected, lacking the intelligence and willpower to adhere to any strict diet. Dr. David Kerr, who dealt with the case, had the impression that nearly half the patients with renal kidney failure attending his clinic would be equally unsuitable candidates for this therapy and that the troubles of the clinic would really begin if they ever had facilities to meet all comers. Therefore, one of his main selection criteria was a "trial by ordeal" on a strict diet. Candidates were started on it several months before they might get a machine and if they could not stick to it they were refused. 494/

336. Other doctors stress that psychological stability, emotional maturity and a determination to make the treatment work are essential qualities. Dr. Shaldon has emphasized such requirements as emotional stoicism, self-control and average intelligence.

487/ Cf. G. E. Schreiner, "Problems of ethics in relation to haemodialysis and transplantation", in G. Wolstenholme and M. O'Connor, eds., op. cit., p. 128.

488/ Ibid., pp. 127-128.

489/ Henry Miller, loc. cit., p. 65.

490/ News Bulletin, p. 31.

491/ Drs. A. de Coninck, P. Dor and J. R. Fagnart, op. cit., p. 17.

492/ Herrman L. Blumgart, loc. cit., p. 265.

493/ H. E. de Wardener, loc. cit., p. 107.

494/ Cf. Gerald Leach, op. cit., pp. 261-262.

Brighter patients are often very hard to train because they are reluctant to accept the unnatural aspects of the procedure and are often extremely anxious; patients with below-average intelligence are often unreliable and irresponsible enough to endanger their own lives. 495/

337. Serious problems arise when there are several or many patients satisfying medical criteria for radical treatment. In this case, an attempt may have to be made to judge the human worth of the patients. "The question of the criteria by which the relatively small number of beneficiaries should be selected", the WHO states, "is a difficult one. Inevitably a choice may have to be made, even in the most developed countries, between a number of potential beneficiaries of limited and highly expensive facilities". 496/

338. The preference of doctors in such cases to treat patients who have young children is mentioned by Dr. H. E. de Wardener 497/ and Dr. C. A. Richard. 498/ Attention is also drawn to such factors as the "social usefulness" of the patient, his responsible position, 499/ whether he is a contributor to the economics of the community, a churchgoer, a married person. 500/ But some think that these criteria are uncertain. Dr. G. E. Schreiner writes that:

"A rather difficult philosophical position arises should there be any change in the status of a patient. If you really believe in the right of society to make decisions on medical availability on these criteria you should be logical and say that when a man stops going to church or is divorced or loses his job, he ought to be removed from the programme and somebody else who fulfils these criteria substituted. Obviously no one faces up to this logical consequence." 501/

In this connexion, Gerald Leach points out:

"For my part, I should like to see these guidelines built round the concept of human, not intellectual or economic loss. The death of a parent of a young family, no matter how 'inadequate', is a more damaging loss than the death of a great poet or prime minister, even though the latter may be mourned (at a lower level) by millions of times as many people. Besides, as hardly anyone seems to have pointed out, the poet or prime minister - or anyone else chosen on his potential value to society rather than to his family - is likely to lose his potential when he goes on a machine. Do you save a prime minister so that he can become a backbencher?" 502/

The World Federation of Scientific Workers believes that the life of "certain specially talented persons ... exceptional people engaged on work which benefits humanity as a whole" should be prolonged. 503/

495/ Ibid., p. 263.

496/ E/CN.4/1173, p. 24.

497/ H. E. de Wardener, loc. cit., p. 102.

498/ News Bulletin, p. 31.

499/ Henry Miller, loc. cit.; C. A. Richard, loc. cit.

500/ G. E. Schreiner, loc. cit., p. 128.

501/ Ibid.

502/ Gerald Leach, op. cit., p. 261.

503/ Information furnished by the World Federation of Scientific Workers on 5 March 1974.

339. The panel which considered the implications of the totally implantable artificial heart (TIAH) came to the conclusion that the so-called "social worth criteria" are fraught with serious insufficiencies as ethical criteria. It recommended that "medical criteria" defining patients who can best physically benefit by TIAH be employed and, while recognizing that social worth often affects medical judgements, urged that every effort be made to reduce this influence. 504/

340. The above-cited book by Gerald Leach contains the following passage:

"More recently several people have ... proposed selection by lottery. Though this would eliminate all subjective judgement values of 'worth', it is nevertheless the most unfair system imaginable. To allow dice to choose between people would not only condemn some very 'worthy' people at the expense of others; it would be a kind of treason against human compassion and responsibility." 505

341. At present, the choice of beneficiaries of heart transplants and of other life-extending procedures is made by doctors and hospital administrations in whose care patients find themselves. The responsibility for the decision is usually accepted by the head of the service, with or without the assistance of a small committee. To spread the load of responsibility some of the hospitals have lay and medical committees through which the claims of potential patients are filtered, as for example, the layman's panel at Seattle founded by Dr. Scribner in 1960. 506-507/

342. There is much disagreement in respect of such panels. Amitai Etzioni, one of their supporters, believes that "there is no reason why the individual doctor's notion of societal utility should overrule that of the community itself", because he suspects that "for quite a few M.D.s a movie star is more valuable than a professor, a 'breadwinner' more valuable than a childless housewife, and a white middle-class person like themselves more valuable than most others. Hence there is a real need for the community to formulate its preferences, as is done on committees that decide who will get kidney dialysis". 508/ On the other hand, Dr. G. E. Schreiner feels "that this is a device to spread the responsibility to people who by experience and education are really less equipped to take the responsibility than the physicians in charge of the case". 509/ Dr. H. E. de Wardener is of the same opinion. 510/ In this connexion Gerald Leach writes:

"Today most doctors reject the use of panels out of hand, and for good reason. A small panel is bound to have the built-in biases of its members, with the policeman favouring pillars of the community, and so on. Who selects the selectors? A large panel, on the other hand, though it would smooth out these biases, becomes totally unworkable. But above all, there is the insuperable

504/ Albert R. Jonsen, loc. cit., p. 3.

505/ Gerald Leach, op. cit., p. 260.

506-507/ G. E. Schreiner, loc. cit., p. 128.

508/ Amitai Etzioni, op. cit., pp. 180-181.

509/ G. E. Schreiner, loc. cit., p. 128.

510/ H. E. de Wardener, loc. cit., p. 106.

problem that someone who knows all the social and medical circumstances of each candidate has to brief the panel and will therefore almost certainly feed them his own biases. That someone, of course, can only be the doctor the panel is designed to replace." 511/

343. Touching upon the role of administrative services in selecting patients for radical medical treatment Eugène Aujaleu said at the Eighth CIOMS Round Table Conference:

"The reply to that is simple. Administrative services should confine themselves to issuing very general instructions (such as 'patients most likely to benefit from methods not yet universally available'); they should not go beyond that, and should leave the choice of beneficiaries to the doctor." 512/

344-345. Information from Argentina states:

"The following criteria require combined consideration before a decision can be reached about the use of radical medical techniques or transplants: (a) criteria concerning the beneficiary: (a1) need, judged by the risk the patient would run if the proposed technique was not used, (a2) recovery prospects, judged by the benefit he might obtain if it was, and (a3) the safety factor, judged by the risks the patient would run if the technique was used; (b) criteria concerning the donor: (b1) the safety factor, judged by the risk of injury, disease or physical or mental disturbance which the donor might run as a result of the mutilation caused by the removal of the transplant organ; and (c) criteria concerning the technique itself: (c1) technical feasibility, (c2) cost-effectiveness, and (c3) priority over other medical and health measures." 513-514/

346. The Government of Austria has pointed out:

"It must be a primary objective of Governments to see to it that, in the sense of equality of human life, all individuals - irrespective of their financial situation - should be able to enjoy such a medical treatment. It cannot be accepted that selection is made among the persons who might be saved by the application of special techniques. It is held that there does not exist any criterion that could be applied for this purpose. In fact, the practical problem is how this medical care can be secured for all who stand in need of it." 515/

511/ Gerald Leach, op. cit., p. 260.

512/ Eugène Aujaleu, in Rôle du pouvoir exécutif et des organes administratifs dans la responsabilité pour la protection des droits de l'homme", in CIOMS Eighth Round Table Conference, op. cit., pp. 292-293.

513-514/ Information furnished by the Government of Argentina on 30 May 1974.

515/ Information furnished by the Government of Austria on 21 November 1974.

347. The Government of Luxembourg believes that "the criteria in question are both scientific and humanitarian". 516/

348. The Government of Norway has pointed out that:

"The majority of the problems involving a choice of this kind will arise in public hospitals, which must be bound to follow certain non-discriminatory principles. Criteria such as sex, social position or race must not be allowed to be taken into account in choosing whom shall receive help. But Norwegian legislation does not list any special sanctions against violation of these principles when the choice is made as to who is to be helped. Even so, certain practical considerations argue against basing this choice on the principle of absolute equality of status - for instance, age may well play some part as a criterion of choice." 517/

349. The Government of the Republic of Viet-Nam states: "It is extremely difficult to lay down criteria. Social, economic and emotional factors are involved; also, criteria which are valid for one country may not be valid for another." 518/

350. The Government of Romania considers that beneficiaries of advanced medical techniques should be first of all young people and persons of high esteem or endowed with certain creative possibilities such as famous inventors, scientists and statesmen. 519/

351. The Government of Sweden considers that "when it comes to the question of which persons are to be given treatment when resources are scarce, one brief comment can be made: the choice must obviously be made on the basis of medical judgement". 520/

352. As it is pointed out in paragraph 319 above the information from the Union of Soviet Socialist Republics mentions the provision by State health institutions of free, qualified medical assistance to all.

353. The Government of the United Kingdom believes that "these criteria are a matter for clinical judgement and both physical and social factors would have to be taken into account. The main consideration would be the patient's ability to benefit from the treatment but some weight may also be given to other factors, such as the situation of any dependants". 521/

516/ Information furnished by the Government of Luxembourg on 16 March 1974.

517/ Information furnished by the Government of Norway on 15 April 1974.

518/ Information furnished by the Government of the Republic of Viet-Nam on 21 March 1974.

519/ Information furnished by the Government of Romania on 29 April 1974.

520/ Information furnished by the Government of Sweden on 12 March 1974.

521/ Information furnished by the Government of the United Kingdom on 8 August 1974.

3. The manner in which medical treatment shall be allocated in those countries or areas where the point has been reached, or is imminent, where the economy cannot accord to every sick person the entire range of available medical treatment from which he could benefit

354. The problems arising from the fact that expensive radical medical techniques can be applied only to a few persons is part of a larger problem of allocation of medical treatment in general in countries or areas where it is economically impossible to apply to every sick person the entire range of sophisticated drugs and procedures from which he might benefit. Dr. Karl Evang, former Director-General for Health Services of Norway, writes:

"Even the richest countries cannot offer optimum health services to individuals and communities in prevention, cure and rehabilitation in the combined field of somatic, mental and social disease. We are faced with the unpleasant, for psychological as well as political reasons perhaps insurmountable, task of stating priorities which would automatically exclude certain types of patients from an optimum type of service. In the rich countries, renal dialysis, open heart surgery and treatment of alienated young people are not made generally available. In the poor countries, even some very modest claims for health services cannot be met because of lack of resources - or should we rather say because money has to be spent for other purposes which are regarded as more important." 522/

355. Apart from expenses due to bad management and to justifiably increased salaries for nurses and physicians, a main reason why medical costs have risen, and will continue to rise, is increased use of scientific instruments and methods. 523/ Complete treatment of every person who is ill will far exceed the capacity of a given economy to supply it and whatever crash national programmes are adopted, enough skilled physicians, nurses, technologists and hospitals cannot possibly be made available to apply these techniques to the entire population. 524-525/ Hence the problem of allocation of available resources and of determining to what extent full treatment of ill persons of a given country can be afforded.

356. This problem has two sides. On the one hand there is the question of reallocation of available resources between different services, not limited to the medical sphere. Amitai Etzioni writes:

"If we are going to have one destroyer less, one less, then most research programmes could be comfortably funded. So when we talk about allocations we not only have to ask about allocations inside medicine, but between medicine and other national services. Even if there is no change in defense spending, we spend eleven billion dollars a year on cigarettes. Surely one could argue that those monies could be spent more profitably." 526/

522/ Karl Evang, M.D., "Health for everyone", World Health, November 1973, p. 6.

523/ Cf. Vannevar Bush, Science is not Enough (New York, 1965), p. 147.

524-525/ Ibid., pp. 147-150.

526/ Amitai Etzioni, op. cit., p. 177.

Speaking at a meeting organized by the World Council of Churches in Zurich in June 1973, Spyros A. Doxiadis said:

"My feeling is that we, in the health professions, have been too ready to accept as final the percentage from the national budget given for health services and we have been only arguing about the better use of this percentage. This is too timid an attitude. I think that, in collaboration with our colleagues concerned with education and welfare, we should be pressing our Governments for a larger percentage of the national budget for these three services. And if asked, we should individually and collectively say that this increase should be at the expense of the percentage allocated to 'defence' which in some countries may mean 'aggression' and in others 'suppression'. Whatever it means it is money spent in preparation to kill." 527/

357. Other services apart from "defence" are also indicated in this connexion: "When livers, limbs, endocrines and even hearts are added to kidney replacements, the load will be beyond anything we can conceive. Society will have to decide whether it wants life and health more than motorways and moon-rockets, and may well prefer the former." 528/

358. On the other hand, the question about allocations inside medicine arises. Gerald Leach writes:

"Families accept that they cannot buy everything they want; we must realize that the same is true of our lives and health as a total community.

"... Is medicine for averting death at all costs, or, at the other extreme, for coping with all the minor and not so minor ailments that assault the vast majority who are not threatened by death yet? Transplants or psychiatry? Kidney machines or contraception? Of course, it is for the whole range, but very broadly where should the emphasis be?" 529/

Kerstin Anér stressed at the above-mentioned consultations in Zurich the necessity of:

"Choosing between saving a few lives by extremely expensive and well-publicized techniques, and saving many or relieving many by dull, uninteresting techniques with no limelight at all ... choosing between solving social problems by social means, or by medical and biotechnical means. It will mean putting a price-tag on every new medical invention. It will mean, alas, putting a price-tag on many human lives. But since this will merely bring to light a practice that is going on all the time, I think it should be done just the same." 530/

527/ Spyros A. Doxiadis, "Social and ethical problems in caring for genetically handicapped children", paper prepared for Consultations on Genetics and the Quality of Life, Zurich, 24-28 June 1973, p. 4.

528/ Gordon Rattray Taylor, The Biological Time Bomb (New York, 1968), p. 211.

529/ Gerald Leach, op. cit., p. 353.

530/ Kerstin Anér, "Genetic manipulation as a political issue", paper prepared for Consultation on Genetics and the Quality of Life, Zurich, June 1973, p. 11.

359. In their attempts to solve the problem of allocation of medical resources, authors emphasize the necessity of taking into consideration the interests of those in greatest need, of spreading simpler medical techniques, and of developing research in those fields in which wide masses could benefit.

360. Dr. John H. Bryant writes:

"One of the most difficult questions to be faced in health care has to do with how to decide whom to serve when resources are inadequate to serve all ... Justice would be met by using some of the health care resources to meet the special needs of those in greatest need. The principle is made operationally practical by assessing the needs of defined populations, setting priorities in terms of health problems and population groups, developing programmes that represent best use of resources in caring for those problems and population groups and, in the course of doing so, reach individuals in greatest need. ... They can then be cared for to the extent that resources are available." 531/

361. Speaking at the Eighth CIOMS Round Table Conference, Marie-Pierre Herzog said:

"The medical profession is faced with the problem of the cost of medical care and surgery. Western medicine - however spectacular its achievements - is dear and makes only feeble attempts to be otherwise ... Look at the gap between the average doctor and certain virtuoso hospital teams or laboratories and you will see that a far-reaching choice exists which is both moral and political in the broadest senses ...

"... over-population combined with all sorts of improved medical techniques ... makes it all the more necessary to work out a simpler type of medicine." 532/

362. Considering priorities of allocation of medical resources, Gerald Leach points out:

"The greatest of all the challenges with which medical progress is confronting us stems from a simple fact. We cannot afford it... we have to decide what expensive luxuries should be restricted so that everyone can have the necessities ...

"Of course, general hospitals are a vital part of medical care, but they are to a large extent a service to the acutely ill, to those whom death may threaten. They hardly touch what one doctor has called the major causes of ill health in advanced countries today - 'a confusing mixture of disease, maladaptation, faulty relationships, poverty, poor education, ignorance, obstinancy, fear, virtue and vice'. No specialist or hollow-eyed houseman in the hospital can peer into this tangled undergrowth of ill health. It can only be penetrated by a network of local services based on the family doctor and community health

531/ John H. Bryant, M.D., "Health care and justice", Christian Medical Commission, Sixth Annual Meeting, Ecumenical Institute, Bossey (Geneva), 2-6 July 1973, p. 33.

532/ Marie-Pierre Herzog "Les fondements éthiques et moraux des droits de l'homme dans leurs rapports avec le progrès biomédical: réflexions préliminaires", in CIOMS Eighth Round Table Conference, op. cit., pp. 16, 18.

centres - a network which forms the base of the health-care pyramid and only passes on the minority of cases (seldom more than 10 per cent) that require special tests or acute treatment to the hospitals.

"We have to back this grass-roots kind of medicine heavily in the future." 533/

563. Dr. Irvine Page and Professor Renée C. Fox note a growing conviction that a more just and equitable system of medical care should be established and more resources should be committed to providing healthy living conditions and adequate medical care to the poor and deprived. 534/

364. Touching upon research, Lord Zuckerman believes that emphasis should be placed in future on "enquiries into the control of reproduction; further research on the safety of new drugs; further work on the crippling ailments of old age - and not such advanced old age - such as the different forms of arthritis and even backache; further research into alleviation of pain; further research on the common cold ... even if at the expense of further research into such heart-rending conditions as mental defect in the young or the treatment of drug addition in society's 'drop-outs'". 535/

365. Charles Elliot, senior research associate of the Overseas Development Group at the University of East Anglia, United Kingdom, believes that a strategy to design as equitable a system as possible should include the following steps:

"Step 1. Protect the entire population from major communicable diseases.

"Step 2. In the poorest countries, spend the remaining public resources on environmental and sanitary improvement in those areas where low density makes participation impossible. In the less poor, cover the same population with the simplest mother and child care." 536/

Professor B. Cvjetanović, Chief Medical Officer, Bacterial Diseases, at the World Health Organization, stresses the importance of cost-effectiveness and cost-benefit analysis in the achievement of the most efficient allocation of resources for the control of communicable diseases. 537/

366. Stressing the complexity and difficulty of the problem of allocation of medical resources, Professor Amitai Etzioni writes:

533/ Gerald Leach, op. cit., pp. 326, 354-355.

534/ Cf. J. H. Page, "The ethics of heart transplantation", Journal of the American Medical Association, vol. 207, No. 1 (1969), pp. 109-113; and Renée C. Fox, loc. cit. p. 13.

535/ Lord Zuckerman, op. cit., p. 432.

536/ Charles Elliott, "Financial resources: present and future", in Human Rights in Health, CIBA Foundation Symposium 23 (new series) (Amsterdam, London, New York, Associated Scientific Publishers, 1974), p. 9.

537/ B. Cvjetanović, "Cost-effectiveness and cost-benefit aspects of preventive measures against communicable diseases", in ibid., pp. 187, 195.

"... the allocation systems of societies are not accidental; they are an integral part of the societal structures. Thus, in most societies, the more affluent get better medical services than the large middle groups and the working classes. This is not a slight oversight that can be readily corrected. The same is true for differences between the upper and middle classes. When people say 'Let's reallocate', they are talking about very far-reaching social changes. Therefore, even national health services, such as those in Israel, Britain or Sweden, have not changed the fact that money buys the best service. And to bring about in the United States, for example, even the degree of egalitarianism that exists in the medical services of these countries, public perspectives, values and power relations must change drastically." 538/

367. Some authors propose that a country concerned about the allocation of medical resources should create a special organ to deal with the problem. Thus, Lord Zuckerman said at the Roche Anniversary Symposium:

"There never will be enough resources to permit the exploitation of all medical fashions or to cater for the demand an uninformed public makes for both old and new medical service. The more rapidly new medical fashions and technologies emerge, the worse the position will become ... It is unthinkable that Governments, either through advisory or executive boards they might appoint, should decree that medical knowledge should progress along these rather than those lines ... Priorities should be set by the medical profession itself, but within a sophisticated framework of governmental information which takes into account not just the amount of money that can be made available either from public or private sources for the direct application of the fruits of new medical knowledge, but also the consequential social costs that may have to be borne given a successful 'break-through' in the control of some particular disease ... I do not suppose that any easy way will ever be found for the determination of priorities in biomedical research and biomedical development. But I should certainly like to see priorities set by a body of men who, while not taking any active steps to suppress new work, made it plain which lines of research counted most from society's point of view. The main criterion which I should like to see guide the decisions of such a body would be the old-fashioned one of the greatest good for the greatest number." 539-540/

368. At the Eighth CIOMS Round Table Conference, Dr. Alfred Gellhorn emphasized that:

"The public introduction of advanced medical technology should not be left solely to the discretion of the manufacturer who has a profit motive, or to the physician-researcher and his teaching hospital which gains prestige and renown for development and/or use. To meet the moral and social issues raised by advanced technology a tribunal which can act as a citizens' advocate as well as a weigher of scientific evidence may be needed to make strong recommendations on policy." 541/

538/ Amitai Etzioni, op. cit., p. 178.

539-540/ Lord Zuckerman, op. cit., pp. 431-432.

541/ Alfred Gellhorn, loc. cit., p. 250-251.

369. An important role in allocating medical resources is assigned to existing panels and committees dealing with application of radical medical techniques. At the CIOMS Round Table Conference on the social and ethical implications of recent progress in biology and medicine, Amitai Etzioni said:

"Allocative decisions are best made, not from the viewpoint of the concerned individuals or their advocates or the medical practitioner, but from a broader perspective. Social considerations should enter via such mechanisms as legislation (which would determine whether more funds should go toward the treatment of children or of the aged, to research on cancer or sex-change surgery, etc., etc.) and committees composed of doctors, theologians and elected citizens. Such committees should decide who makes the decision as to who gets access to scarce resources, and they should draw on community values and public discussion rather than on individual preferences." 542/

370. In the report of a consultation on genetics and the quality of life which took place in Zurich in June 1973 it is pointed out that though in vital decisions on social policy:

"Parliaments and Governments should take the responsibility of looking into the relevant social and ethical issues, not leaving them entirely to the doctors, counsellors, parents, or other people directly involved ... hospital committees are needed to decide on how resources (of people, material, space, etc.,) should be used for different patients and groups of patients ... In so far as such questions lie within the competence of the hospital itself, they should be decided by a team as widely representative as possible, including not only medical (and scientific) personnel on all levels but also ... representatives of the patients (often their parents)." 543/

371. The Governments which expressed their views on the subject believe that the question of the manner of allocation of medical resources should be dealt with by the Governments concerned.

372. The information from the Government of Argentina says:

"The State, acting through the competent authorities, should lay down a policy of priorities based on the criteria set out in paragraph 345 above; nevertheless, whenever the patient or his family are able and willing to pay for treatment, their right to obtain it should be respected." 544-545/

373. In the information from the Government of Ghana the following three fields are indicated to which priority should be given:

542/ Amitai Etzioni, op. cit., p. 182

543/ Genetics and the Quality of Life: Report of a Consultation Church and Society/Christian Medical Commission, Zurich, June 1973, SE/53 Study Encounter, vol. X, No. 1 (Geneva, World Council of Churches, 1974), p. 21.

544-545/ Information furnished by the Government of Argentina on 30 May 1974.

- "(i) Priority should be given to the use of multi- and inter-disciplinary approaches for the development of the basic infrastructural services and amenities particularly in the rural areas.
- "(ii) The development of a network of basic health services with efficient referral systems for optimum coverage of the population with special emphasis on services for health promotion and health protection.

In the allocation of resources and the provision of services, priority attention should be given to maternal and child care, the care of the family and the labour force.
- "(iii) Within available resources, hospitals providing various ranges of medical care should be developed and expanded at all levels."

The Government of Ghana continues:

"It is quite obvious that in a number of developing countries the economic and manpower situation will have a very strong influence not only on the level and quality of services that can be provided but also the range of services.

"Regional co-operation is therefore strongly recommended as a solution to this problem.

"Thus, for the treatment of cancer for example, a centre which will serve a regional or sub-regional group of countries could be set up in one country.

"... Ghana and many other countries with similar problems will continue to depend to a variable extent on external resources for the strengthening, development and expansion of health care delivery systems.

"International agencies and voluntary organizations should give as much support and assistance as possible to developing countries.

"Assistance is envisaged at two levels. First, direct assistance to individual Governments or national health authorities for the development of national projects and programmes; secondly, assistance to regional groupings for the types of activities described above.

"It is also envisaged that assistance and support will take several forms.

"Assistance could be in the form of training national staff for national or regional projects, provision of personnel to fill posts where national personnel are not available, but such assistance should have a counterpart training component. The supply of equipment, etc. and the development of suitable and appropriate information and data processing systems are also worth considering." 546/

374. The Government of Luxembourg states: "The question should be settled by the country's authorities with the collaboration of the medical profession." 547/

375. The Government of the Republic of Viet-Nam believes that "those responsible for the nation's health should establish a system of priorities which takes account of the unevenly distributed needs of the population". 548/

376. The Government of Sweden states:

"Where questions of priority arise they should for the time being be dealt with at the national level. Apparently, these questions are not of particularly high priority at the international level. Other medical problems are much better suited to international co-operation. In the first place these problems should be tackled and solved at national level according to the priorities established by each individual Government." 549/

4. The question whether there is a point beyond which intensive methods to keep incurably ill or very elderly patients alive should no longer be applied

377. The traditional ethical imperative is that everything feasible must be done to prolong the life of the sick as far as possible, but it has been maintained that an officious, prolonged and excruciating application of advanced medical techniques may infringe upon the rights of the sick, if they are in agony, without hope of recovery. The questions asked are these: Is the physician obliged to maintain human life as long as possible, whatever the circumstances? If not, when not, why not, and who is entitled to set these limits? Should the patient be given a voice in his own fate? Should existing laws be changed to safeguard human rights in the light of the progress of medicine and biology?

378. Jean Jonchères has summarized possible attitudes of a physician towards a patient in the state of agony in the following way:

- "(a) Employ the appropriate medication rigorously in order to prolong life as far as possible; this conduct is perfectly ethical and in keeping with the doctor's duty if any hope remains: prolonged acute illness, major hyperthermia, septicaemia, for example.
- "(b) Supplement the treatment proper with analgesics at the risk of hastening death if the patient is definitely incurable, but act with restraint if there is any possibility of cure.
- "(c) Confine treatment to the relief of pain in order to bring about 'a gentle and peaceful death' if all therapeutic measures have been exhausted." 550/

547/ Information furnished by the Government of Luxembourg on 16 March 1974.

548/ Information furnished by the Government of the Republic of Viet-Nam on 21 March 1974.

549/ Information furnished by the Government of Sweden on 12 March 1974.

550/ Jean Jonchères, "Euthanasie", in CIOMS Eighth Round Table Conference, op. cit., p. 118.

Although there is some controversy, most doctors appear to feel that extraordinary methods to prolong life place an intolerable burden on the patient, and they usually do not apply them in case of terminal patients in the state of agony. Radical medical techniques are withheld from a patient and he is allowed to die. 551/

379. The headlong advances of medical science make the issue constantly more complex for patients and their families. As far as terminally ill patients are concerned, Harry C. Meserve writes:

"We do not fear death itself. We know that it is a part of life and nature. What most of us fear is the process of dying, which is so often in later years prolonged, painful, debilitating and undignified. Most of us cherish the hope that we may be able to die ... without the tragic sense of running down and losing our grip that is the real sadness of sickness and old age." 552/

380. But it often happens that even if the doctor feels the intensive treatment cannot achieve worthwhile results other than mere prolongation of an unsatisfactory level of existence, and even if the patient might be presumed to share these feelings, pressures from members of the family may lead to continuation of prolongation procedures. Dr. Robitscher writes:

"Families, animated by both love and guilt, seek to preserve life and postpone the inevitability of a final separation. The family sees the doctor as the healer and the prolonger, and the doctor is hesitant to turn from his pro-life role and become an agent of death. Physicians enter medicine with a pro-life bias - and this is good - and sometimes this makes it difficult for them to come to terms with the inevitability of death - and this is bad." 553/

381. There is a growing movement which asserts that there is a right to die as well as the right to live and that prolonged and excruciating medical interventions violate the former.

382. In 1972 the general conference of the United Methodist Church of the United States of America asserted the right of every person to die in dignity "without efforts to prolong terminal illnesses merely because the technology is available to do so". 554/ In January 1973, after a three-year study by its board of trustees and four consumer representatives, the American Hospital Association approved, as a national policy statement, a bill of rights in which it is stated that an adult patient with no prognosis for recovery has a right to die without medical therapy. 555/ A judge in Miami, United States of America, stated that a 72-year-old woman suffering from hemolytic anemia had the right to die with dignity and could refuse blood transfusions

551/ Cf. Jerry Lisker, "A matter of life and death", Sunday News (New York City), 8 July 1973, p. 80.

552/ Harry C. Meserve, "Dignity and death", Journal of Religion and Health, No. 3, July 1971, p. 205.

553/ Jonas B. Robitscher, "The right to die", The Hastings Center Report, No. 4, September 1972.

554/ New York Times, 27 April 1972.

555/ New York Times, 9 January 1973.

or surgery that would cause pain. 556/ In the case of a 60-year-old female patient facing surgery for possible breast cancer, another judge said in Northampton, United Kingdom, that "the constitutional right of privacy includes the right of a mature, competent adult to refuse to accept medical recommendations that may prolong one's life". 557/

383. It has become a common practice for people to express, in writing, the desire that they not be kept alive at any cost. The Euthanasia Educational Fund, founded in New York City in 1967, has answered demands for over 40,000 copies of what it calls a "living will", which states, in part:

"If the time comes when I can no longer take part in decisions for my own future ... and if there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial or heroic measures." 558/

384. In the light of advances in medicine it is felt by many to be not obligatory for the doctor to continue to use extraordinary means indefinitely in hopeless cases.

385. In an address on "The prolongation of life", Pope Pius XII said:

"Since these forms of treatment [resuscitation techniques] exceed the ordinary measures to which recourse should be had, it cannot be held obligatory to employ them and consequently to authorize the physician to use them." 559/

386. If a patient has a meaningful right to die, many claim that the doctor does not have a right to force a patient to live against his will or to prolong suffering unnecessarily. Heroic measures are then seen as appropriate only when they can result in a meaningful improvement, not a maintenance of a comatose or painwacked state, or when these heroic measures are what the patient desires. 560/ At the discussion of surgical ethics held in Warsaw in September 1966, Professor Witold Rudowski, Head of the Department of Surgery, Institute of Haematology, Warsaw, said:

"So long as there is hope of real recovery or of the restoration of a happy and comfortable life, the surgeon is right to preserve life by any method at his command, even if it is painful. ... if he goes on prolonging a life that can never again have purpose or meaning, the surgeon's activities become a cruelty. Especially if the patient with an incurable condition wants to die, it would be wrong to lengthen his distress by cytotoxic agents, blood transfusions or the administration of antibiotics. It is tragic to contemplate people whose minds are subconscious and sedated by drugs and whose bodies, invaded by cancer, are kept alive because of a rule. This is nothing but the prolongation of the act of dying ..." 561/

556/ Cf. Jonas B. Robitscher, op. cit., p. 12.

557/ New York Times, 8 June 1973.

558/ Cf. Paul Wilkies, "There are times when keeping someone alive may be crueler than death", Life, 14 January 1972.

559/ "Replies of Pope Pius XII to some important questions concerning 'reanimation'" in G. Wolstenholme and M. O'Connor, eds., op. cit., p. 228.

560/ Cf. Jonas B. Robitscher, op. cit., p. 13.

561/ News Bulletin, pp. 36-37.

At the same meeting, Professor J. Englebert Dunphy, Chairman, San Francisco Medical Centre, University of California, said: "Death is normal, it comes to all men and we should not fear it as much as we should fear, and studiously avoid, the prolongation of suffering. Our objective is to relieve suffering and pain, not to prolong a useless and intolerable existence." 562/ Mr. Gordon R. Taylor has written: "We must face the unpleasant fact that death protracted by such methods is usually visibly more painful than if the patient had been denied the treatment ..." 563/

387. Dr. G. B. Giertz has written:

"... when we have been able to establish that the end must soon come, then we should take this into account in our action. In this situation death is a natural phenomenon and should be allowed to run its course ... It must be regarded as a medical axiom that one should not be obliged in every situation to use all means to prolong life ..." 564/

At the Third World Congress on Medical Law, which took place in Ghent, Belgium, in August 1973, Jorge de Figueiredo Dias proposed the establishment of the following principles:

"... medical assistance towards death is undoubtedly lawful and perhaps even a legal obligation arising out of the doctor's duty to help and treat his patient, provided the giving of it does not shorten the natural term of the patient's life ...

"... the doctor is always entitled to refrain from intervention that will prolong the patient's life beyond its natural end (unless the patient or his representative expressly requests it), and even to furnish intervention which will ensure that it is not prolonged beyond that point (unless the patient or his representative expressly forbids it)." 565/

At the fourth Besançon colloquium on human rights in France, which took place in January 1974, L. Cotte, referring to the words of Pope Pius XII about the doctor's right not to use extraordinary means of reanimation, pointed out:

"The same attitude should be adopted towards patients suffering from a serious disease which is in an advanced stage, and a fortiori towards those in the state of agony, and even towards elderly persons whose infirmities are such that their hold on life is becoming increasingly tenuous. The doctor should carefully weigh not only medical considerations but also the psychological, family and social factors which distinguish each case and make it unamenable to a general rule." 566/

562/ Ibid., p. 43.

563/ Gordon R. Taylor, op. cit., p. 118.

564/ G. B. Giertz, "Ethical problems in Sweden", in G. Wolstenholme and M. O'Connor, eds., op. cit., pp. 144-145.

565/ Jorge de Figueiredo Dias, "De l'illégalité de l'euthanasie à la légalité de l'orthothanasie", paper prepared for the Third World Congress on Medical Law, Ghent, 19-23 August 1973, p. 4.

566/ L. Cotte, "Le droit à la mort", Besançon University, Fourth Besançon Colloquium, Human Rights in France, 17-19 January 1974, p. 26.

388. Besides humanitarian there are also economic and social aspects of the problem. Any dying patient whose life is unduly prolonged imposes serious costs on those immediately around him and, in many cases, on a larger, less clearly defined "society". "The prolongation of death", Gordon R. Taylor writes, "puts a massive strain on relatives. The patient's family not only suffer cruelly, but may have to pay as much as \$250 a day for the use of the equipment, in the absence of a national health service. There is also, in the present conditions of equipment shortage, a dilemma for the surgeon" - the expensive equipment may serve someone else who might live. 567/ Dr. Henry Beecher pointed out that "the hospital and society in general have a vested interest in terminating the appallingly costly and useless procedures in hopeless cases". The money spent to maintain unconscious and hopelessly damaged persons could be used to restore those who could be saved. 568/ Dr. Walter V. Sackett estimated that it would cost \$5 billion in Florida alone to allow "1500 individuals retarded to the point that they are bedridden, diapered, tube-fed and completely unaware, to live out artificial lives prolonged by the marvels of science. This money", he said, "could be better used on persons with illnesses that could be cured such as those that need kidney transplants."56

389. There are suggestions that age limits should be set for treating incurably ill or very elderly patients. "It may be", Professor Bruce said at the meeting in Warsaw in September 1966, "... that in salvage procedures like transplantation we should begin to think in terms of age limits of applicability. Is it justifiable to transplant a kidney or a liver to a woman crippled with pyelonephritis or cirrhosis at the age of sixty - or fifty?" 570/ At a congress of the Royal Society of Health, United Kingdom, Dr. Kenneth O. A. Vickery said: "The time has come for a minimum age to be agreed upon, beyond which medical and nursing staffs may be relieved of the prevailing obligation 'officially to keep alive' and confine their administrations to symptomatic relief and good nursing." He suggested that 80 be the minimum age beyond which doctors should halt the practice of "resuscitating the dying". 571/

390. It has been emphasized that the withholding of life-prolonging measures is an ethical decision and not a murder or a mercy killing which is legally and theologically unacceptable. Speaking at a Ciba Foundation symposium, Dr. Brock said:

"It has long been the accepted practice and philosophy in the medical profession that it is legitimate to withhold life-prolonging treatment from people whose life is ... no longer bearable ... We have always made a very sharp distinction in medical ethics, and I think it is a sharp legal distinction also, that there is a world of difference between withholding action which would prolong life, and taking action to terminate life." 572/

567/ Gordon R. Taylor, op. cit., p. 113.

568/ H. K. Beecher, "Definition of death: the individual's right to be let alone", in CIOMS, Eighth Round Table Conference, op. cit., p. 112.

569/ Cf. William F. Buckley, Jr., "The right to die", New York Post, 19 August 1972, p. 26.

570/ News Bulletin, p. 18.

571/ Cf. Jerry Lisker, op. cit., p. 80.

572/ Civilization and Science in Conflict or Collaboration? A Ciba Foundation Symposium (The Hague, 1972), p. 118.

Dr. Robitscher points out:

"I think we can differentiate between a decision to stop intravenous feeding in a comatose or terminal patient ... and more aggressive methods of terminating life, such as leaving death-producing drugs within the patient's reach ... Physicians cannot hasten patients into death except to the extent that medication sufficiently strong to relieve pain may depress respiratory function. Here the physician's aim is not to produce death but to relieve pain." 573/

Dr. Giertz emphasizes that:

"No step is taken with the object of killing the patient. We refrain from treatment because it does not serve any purpose, because it is not in the patient's interest. I cannot regard this as killing by medical means: death has already won, despite the fight we have put up, and we must accept the fact. Only the recognition of this limit can enable us to solve the problem that for many has made the thought of death an agonizing one - the fear of an artificial prolongation of life when it has already been bereft of all its potentialities." 574/

391. In respect of "the patient with a terminal illness who suffers great pain or disability and has formed a firm and irrevocable wish to die", the WHO reports: "It is a widely held opinion that in such a situation, although a physician may in no circumstances deliberately take the life of another, he should do what is in his power to ensure for his patient a painless and dignified death, even in the knowledge that the measures he adopts may slightly accelerate the extinction of life." 575-576/

392. As regards the question of who should decide on withholding life-prolonging measures, mention should be made of a report of the American Medical Association which says: "The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family." 577/ Dr. Walter Sackett proposed that the decision may be made by the patient only after he has been declared terminally ill by two licensed doctors. In the event that the patient is incapable mentally or physically of directing his own terminal neglect, the spouse would inherit the authority to do so. It has been maintained that the determination of the moment when life-prolonging measures should be stopped must not be left to the physician concerned alone, because he may have subjective judgements on the probability of recovery. Speaking at the Third World Congress on Medical Law, Dr. Philip H. Addison pointed out the necessity for the physician to have consultation with his colleagues in such cases. 578/ Jean Jonchères, referring to such cases, said at the Eighth CIOMS Round Table Conference: "Every doctor always has the right and the duty when confronted with a difficult case to ask a colleague's opinion." 579/

573/ Jonas B. Robitscher, op. cit., p. 13.

574/ G. B. Giertz, loc. cit., p. 145.

575-576/ E/CN.4/1173, p. 22.

577/ New York Post, 5 December 1973, p. 21.

578/ Cf. Philip H. Addison, "Voluntary euthanasia", paper prepared for the Third World Congress on Medical Law, Ghent, 19-23 August 1973, p. 7.

579/ Jean Jonchères, loc. cit., p. 123.

393. The views of most of the Governments which have supplied information imply that the application of intensive methods to incurably ill or very elderly patients should not be obligatory and that the matter usually depends to a great extent on the circumstances.

394. The Government of Argentina states:

"The terms 'incurable' and 'very elderly' are highly subjective, extremely unscientific and wide open to error, and so as things stand at present doctors and medical teams are not qualified to decide when intensive life-prolonging measures should be withheld; nevertheless, a comparison between the patient's present and foreseeable sufferings and the satisfaction which he and his family would derive from his life being prolonged in difficult circumstances may help a medical team to decide after mutual consultation whether intensive measures should be withdrawn." 580/

395. The Government of Romania considers that the duration of resuscitation procedures and the moment when they should be discontinued should be determined by a specialized commission. A single person, however competent, must not make such decisions. The principal guiding criteria in this respect could be established by special institutions.⁵⁸¹

396. The information from Luxembourg points out that this question is "to be decided in accordance with scientific criteria and moral principles". 582/

397. In the information from the Government of Norway the following considerations from Professor Enger's book Transplantasjoner ("Transplant Operations") are cited as representing the attitude of the medical profession in Norway to this question:

"The principal rule must be that the medical practitioner shall not attach an ultimate standard of value to the patient's existence as such, in a way entailing medical consequences. The prolongation of life by hours or days may be of great value to the conscious patient and his relatives. This must be the general guiding principle. On the other hand ... with ... a patient either unconscious or with greatly diminished mental capacity, who has suffered irreparable brain damage and who is being kept alive by artificial methods ... it may sometimes be medically and ethically justifiable to terminate the treatment. This applies even if the relevant measures enable life to be prolonged for hours, days or weeks. Humanitarian considerations are the most important in taking such a decision. By this I mean consideration for the patient's life and suffering and respect for his death. But there is also the consideration for the relatives who go through the experience of seeing those dear to them being destroyed by slow degrees. Finally, consideration for the social aspect of the question may be required.

"To concentrate certain types of resources (i.e. those represented by nursing care and the technical apparatus) around one single hopelessly sick individual might have unfortunate consequences for others who have more need of such measures. In order properly to fulfil his function in society, the medical practitioner is bound to take such considerations into account." 583/

580/ Information furnished by the Government of Argentina on 30 May 1974.

581/ Information furnished by the Government of Romania on 29 April 1974.

582/ Information furnished by the Government of Luxembourg on 16 March 1974.

583/ Information furnished by the Government of Norway on 15 April 1974.

398. The Government of Singapore states that "generally in such cases no such intensive methods are used. However, in certain cases it may be necessary". 584/

399. Touching upon the economic aspect of this problem, the Government of Sri Lanka points out that "this applies especially to developing countries where limited financial resources place constraints on keeping incurably ill or very elderly patients alive by expensive and intensive methods". 585/

400. In information furnished by the Government of Sweden it is stated:

"The termination of treatment is only considered justifiable when death is inevitable as the immediate result of the patient's condition and when his condition is such that treatment aimed at prolonging life has no effect other than a brief postponement of death. The question of how long such treatment should be continued or, in other words, if treatment should be discontinued in certain cases for humanitarian reasons because it only causes prolonged suffering for the patient, is very difficult to answer, and views on what is right in such a situation can vary." 586/

401. The information from the Government of the United Kingdom contains the following passages:

"There is no legislation in the United Kingdom related directly to this question, neither is the United Kingdom Government aware of any studies into the question of cessation of treatment of very elderly patients.

"A National Symposium (sponsored by the United Kingdom Government) on the 'Care of the dying' was held on 19 November 1972. ... Perhaps the most relevant paper from the conference was that presented by Professor Anderson in which he argues ... that 'We must plan each step in a therapy with care and humanity ... bearing in mind that age of death is a very secondary point and that quality of life is the important criteria'. Extending Professor Anderson's point it appears likely that pressure on resources together with the larger numbers of terminal cases in geriatric departments would keep down the use of intensive treatment methods for the very elderly.

"The decision to discontinue intensive methods of treatment in any patient, no matter how ill or elderly, must be made by the responsible clinician on the spot in relation to the patient concerned. There are difficulties in drawing up general rules to cope with this problem." 587/

402. A different view was expressed by the Governments of the Ukrainian SSR and the USSR. Information from the first points out that in the Ukrainian SSR "doctors continue to fight for that person's life until biological death occurs". 588/ Information from the USSR states: "In the USSR, irrespective of the patient's state of health and age, the doctor is obliged to apply the entire range of medical care to save the patient's life and improve his state of health. Soviet medicine is categorically opposed to euthanasia." 589/

584/ Information furnished by the Government of Singapore on 13 March 1974.

585/ Information furnished by the Government of Sri Lanka on 5 March 1974.

586/ Information furnished by the Government of Sweden on 12 March 1974.

587/ Information furnished by the Government of the United Kingdom on 8 August 1974.

588/ Information furnished by the Government of the Ukrainian SSR on 23 October 1974.

589/ Information furnished by the Government of the USSR on 25 July 1974.

5. The question whether there is a point beyond which surgical technology should not be applied, for the prolongation of life or the relief of symptoms, if the result is severely to handicap the patient

403. Progress in some areas of medicine has reached the stage where the application of advanced medical technology can permit the survival of a patient, or the relief of severe and dangerous psychotic symptoms, in cases which were formerly considered hopeless. But after the surgical intervention the patient sometimes remains severely handicapped or subject to a substantial personality change. In this connexion the questions asked are: Is the application of advanced medical technology in such circumstances justifiable? How much can one change a man and still leave him human? Is it better to leave patients with severe uncontrollable behaviour problems to their fate of probably permanent confinement or to use psychosurgery even though the technique cannot guarantee success and there is a chance of worsening their condition? Can a patient involuntarily confined in a State mental hospital give legal consent to brain surgery if his brain shows some physical abnormality that torments him or threatens the safety of others?

404. Speaking about resuscitative and supportive measures in efforts to save those who are severely injured, Professor Henry K. Beecher writes:

"Sometimes these efforts have only partial success so that the result is an individual whose heart continues to beat, but whose brain is irreversibly damaged. The resulting burden is great on the patient, who suffers a fate of permanent loss of intellect should he survive, on the family, on the hospital, and on those in need of hospital beds already occupied by these comatose patients." 590/

405. At the Eighth CIOMS Round Table Conference, Dr. Gellhorn said:

"In the past, the physician's ethic was to preserve the life of his patient at all costs ... As, however, technological means for the maintenance of respiration and circulatory function have become more sophisticated, the quality of living has been recognized as a necessary consideration in the preservation of life." 591/

406. Touching upon hemicorporectomy, the amputation of the lower half of the trunk and the legs, Professor Rudowsky raised the question "whether the surgeon is right to propose a procedure producing grave disability with no hope that the patient after hemicorporectomy will ever regain his activity as a useful citizen". 592/

407. Much debate has been provoked by the personality-changing operation called prefrontal lobotomy, consisting in the removal, destruction or disconnection of the frontal lobes, which has been applied to certain seriously disturbed and violent mental patients after psychiatric and drug therapies have failed. After the operation, the patients are less or no longer subject to anxieties, fears or symptoms of violence, but

590/ Henry K. Beecher, "Scarce resources and medical advancement", Ethical Aspects of Experimentation with Human Subjects, Daedalus, Spring 1969, pp. 291-292.

591/ Alfred Gellhorn, loc. cit., p. 249.

592/ News Bulletin, pp. 15, 36.

are reduced to a state considered by some to be incompatible with human dignity. They have been described as "buffoons", "clowns", ^{593/} "human vegetables" ^{594/} or "something barely human". ^{595/} "Some lobotomized patients", Lee Edson writes, "lost their 'creativity' and higher reasoning powers and became vegetable-like in their placidity". ^{596/} A Washington psychiatrist, Dr. Peter R. Breggin, says that the problem with such surgery is that "destruction of frontal lobe tissue is immediately reflected in a progressive loss of all those human functions related to the frontal lobes - insight, empathy, sensitivity, self awareness, judgement, emotional responsiveness and so on". ^{597/} The Minister of Public Health of the USSR in 1950 promulgated an Order prohibiting lobotomy in the treatment of neuropsychiatric conditions. ^{598/}

408. Even more controversial are certain other psychosurgical operations which represent the next step in brain surgery after prefrontal lobotomy. They consist in selective surgical removal, or destruction by other means, in the absence of evidence of organic cerebral disease, of a part of the brain, or the surgical interruption of nerve pathways between one part of the brain and another, with a view to changing the behaviour of mentally ill persons who do not respond to conventional forms of treatment. Destruction of brain tissue may in these cases be effected by mechanical cutting instruments, electrodes for inducing coagulation, injection of chemical agents, insertion of radioactive yttrium⁹⁰ seeds, ionizing radiations, ultrasonic beams, or cryotherapy. ^{599/} There are no reliable statistics on the number of such operations performed at present. The yearly total for the United States, for example, is somewhere between 100 and 1,000 and shows a tendency to grow. ^{600/}

409. Proponents of psychosurgery, while admitting that it cannot guarantee results and that there are many failures, claim that in carefully selected cases it offers the only hope for ameliorating some extreme disturbances in behaviour, such as uncontrollable violence, and enables some otherwise intractable patients to adapt to society or to become more manageable in institutions. They insist that more than three decades of clinical evidence and human case histories, not to mention extensive animal experimentation, have shown that psychosurgery, properly practised, brings beneficial behavioural changes. "Until we get a truly good non-destructive treatment, surgery is the only alternative for thousands of desperate patients for whom all other forms of therapy have failed", says Dr. Vernon Mark of the Boston City Hospital. ^{601/} Speaking in favour of psychosurgery

^{593/} Robert J. Trotter, "A clockwork orange in a California prison", Science News, 11 March 1972, p. 174.

^{594/} Lee Edson, "The psyche and the surgeon", New York Times, 30 September 1973.

^{595/} Isaak Azimov, The Intelligent Man's Guide to Science (New York, 1960), vol. II, p. 723.

^{596/} Lee Edson, loc. cit.

^{597/} Robert J. Trotter, loc. cit., p. 175.

^{598/} See International Digest of Health Legislation, 1952, vol. 4, p. 312.

^{599/} E/CN.4/1173, p. 25.

^{600/} Harold M. Schmeck Jr., "Criteria sought in brain surgery", New York Times, 1 April 1974.

^{601/} Cf. Lee Edson, loc. cit.

for extreme behavioural disorders, Dr. O. J. Andy, Chairman of the Department of Neurosurgery at the University of Mississippi at Jackson, stressed that the procedure was done on persons for whom all other forms of treatment were clearly hopeless. He described the typical psychosurgery patient as erratic, hyperactive, uncontrollably violent, given to attacks on others and unresponsive to psychiatric and psychological treatment. He said that psychosurgery could also be useful in brain damaged children and adolescents who exhibit that kind of behaviour. It would allow their developing brains to mature with as normal a reaction to the environment as possible. 602/

410. Dr. W. J. Nauta of the Massachusetts Institute of Technology emphasized that one of the problems in the debate on psychosurgery was a failure by some to appreciate the grim and tragic effects of some mental illnesses, which, he said, are themselves capable of destroying most of a person's humanity and all of his civil liberties. 603/ In favour of psychosurgery it has been said that "it's a happy compromise between capital punishment ... and keeping criminals incarcerated forever ..." 604/

411. At the Behaviour Control Conference sponsored by the Institute of Society, Ethics and the Life Sciences, United States of America, it was pointed out that psychosurgery operations should be the last resort after (1) psychotherapy, (2) drug therapy, (3) cooling of selected portions of the brain, (4) placement of control chemicals in selected portions of the brain, and (5) electrical stimulation. 605/

412. Dr. Gardner C. Quarton, Programme Director of the Neuro-sciences Research Programme of the Massachusetts Institute of Technology, has written:

"It is tempting to say that certain types of behaviour control that are novel, efficient, and easily identified - such as deliberate destructive brain surgery - violate the rights of the individual, particularly if they are performed against the wishes of that individual and are irreversible. But this is too easy a solution. Other types of behaviour control, such as confinement behind bars, are carried out against the will of the individual, and these may also have some irreversible effects. 606/

413. At the Eighth CIOMS Round Table Conference, H. Lansdell said:

"There are reports of patients whose unacceptable acts have been reduced in frequency or eliminated by psychosurgery. Despite reduction in IQ score, which may only be temporary, the new social competence - the personality change - can be a laudable result, perhaps even if life expectancy were reduced. Lowered intelligence or erratic behaviour can follow open-heart surgery. When surgery saves a life, or when the procedure is truly a 'last resort', long-lasting deficits may be more acceptable. The magnitude of the impairments and their duration have to be offset by benefits to the patient." 607/

602/ Cf. Harold M. Schmeck Jr., "Brain surgery to alter behaviour stirs a major medical debate", New York Times, 22 December 1973.

603/ Cf. "Research backed in psychosurgery", New York Times, 9 November 1973.

604/ "Changing the patient's personality", The Hastings Center Report, No. 6, December 1973, p. 13.

605/ "Manipulating the brain", The Hastings Center Report, No. 1, February 1972, p. 11.

606/ Gardner C. Quarton, "Controlling human behaviour and modifying personality", Toward the Year 2000: Work in Progress, Daedalus, Summer 1967, p. 852.

607/ H. Lansdell, "Psychosurgery: some ethical considerations", CIOMS, Eighth Round Table Conference, op. cit., p. 265.

414. Opponents of psychosurgery argue that it is an extreme and destructive attempt at controlling human behaviour involving at least partial death of the personality, an irreversible "mutilation", and assert that surgical manipulation of the brain for purely behavioural aberrations of unknown etiology must not be practised.

415. "Psychosurgery is a crime against humanity", says one of the most prominent opponents, Dr. Breggin, "a crime that cannot be condoned on medical, ethical, or legal grounds". Because it often leaves patients with flattened emotional responses and lessened intellectual capacity, he says, "psychosurgery in all its forms is a partial abortion of a living human being". Dr. Breggin calls psychosurgery "a little murder" because the brain is a unique organ, the seat of man's intellect, emotions, and personality. "It's illegal for me to help you kill yourself", he says, so it should be illegal to perform surgery that partially kills the self. Thus he considers it unethical to operate - except where the patient's life is threatened, as by a tumour, if the surgery lessens one's humanness. 608/ "At worst", states Dr. Breggin, psychosurgical operations "are irreversible damaging to the patient's self. At the very least they are blunting the patient's emotional responses". 609/ In his opinion, psychosurgeons commit an atrocity in destroying normal brain tissue because to "destroy normal brain tissue is to cause damage to the human personality ... You cannot possibly help someone by giving him a defect in his personality, and these operations - one and all - produced defects in the personality". 610/

416. Leaving aside operations for obvious brain damage, as is sometimes the case in epilepsy, Dr. Paul D. MacLean of the National Institute of Mental Health, of the United States of America believed the medical profession should call an end to psychosurgery. 611/ In performing a psychosurgical operation, Dr. Rollin points out, "you may be transferring somebody from life-long incarceration in a prison to life-long incarceration in a mental hospital, because of the damage that has been done". 612/ At the Eighth CIOMS Round Table Conference, H. Lansdell pointed out that:

"The procedures in contemporary psychosurgery are based on inadequate or limited research and they entail many hazards. Psychosurgery has unpredictable effects on a precious organ which, even when a locus of society's discontent, should rarely need a lesion instead of special care." 613/

417. A special three-judge panel in the United States of America in an unanimous opinion concerning psychosurgery, stated that it "is clearly experimental, poses substantial danger to research subjects, and carries substantial unknown risks". Among the risks listed were "the blunting of emotions", "the deadening of memory",

608/ Cf. Jim Hampton, "A curse or a blessing? Eerie brain surgery", The National Observer, 25 March 1972.

609/ Cf. Newsweek, 27 March 1972, p. 64.

610/ Cf. Robert J. Trotter, loc. cit., p. 175.

611/ Cf. Harold M. Schneck Jr., "Brain surgery to alter behaviour stirs a major medical debate", New York Times, 22 January 1973:

612/ "Changing the patient's personality", The Hastings Center Report, No. 6, December 1973, p. 13.

613/ H. Lansdell, loc. cit., p. 269.

"the reduction of affect /feeling/", and limitation of "the ability to generate new ideas". Further, the judges added, there is "no persuasive showing" that psychosurgery would have its intended beneficial effects. 614/

418. In view of this controversy, experts in neurology, psychiatry, law and ethics are trying to assess the true value and potential of psychosurgery and to define its proper role in the treatment of emotional and behavioural disorders. In the report of the National Institute of Mental Health, United States of America, it is recommended that psychosurgery be regarded as experimental and, therefore, should be done under only the most rigorously defined and controlled circumstances. "Special constraints that apply to any experimental therapeutic procedure are required", the report said, "and the procedure should be only undertaken in those circumstances where there is special competence and experience and in institutional environments where appropriate safeguards" are available. 615/ Defining these special circumstances, the report said that the operations should be done only in hospitals closely linked to scientific centres and that research records should be developed to ensure that maximum scientific information was obtained in each case. The report stressed that all reasonable alternative treatment should be tried before resort to psychosurgery. The Institute's recommendations also said a registry should be established to monitor psychosurgery practice and to provide continual information on the extent of the practice, the types of patients selected and the outcome of treatment. The registry should "have provisions for indicating intent to perform a psychosurgical procedure so that scientific and clinical experts in psychology, psychiatry and neurology have an opportunity to assess the patient's status prior to operation, as well as to study the short- and long-term effects of psychosurgical treatment". 616/

419. Psychosurgeons recognize that the techniques could be abused to control persons whose chief abnormality is a failure to observe the mores of society. Dr. Robert Neville of the Institute of Society, Ethics and the Life Sciences at Hastings-on-Hudson, New York, head of a task force designed to study the full social impact of psychosurgery, admitting that psychosurgery has potential for mischief, said: "It can be the cheapest and easiest treatment to adopt for controlling patients and therefore potentially dangerous especially because it can be used improperly to subdue aggressive dissidents on the theory that they're diseased." 617/

420. In this context authors urge strict control on the part of special boards and panels over psychosurgical operations. Thus, Dr. Vernon Mark suggested that "consumer advocacy" boards should have a say to protect patients who were poorly equipped to look after their own interests. In conjunction with Dr. David Allen, he was exploring "consumer advocacy", utilizing a group with religious, legal and community representatives in addition to physicians. 618/ "The practice of psychosurgery", H. Lansdell stated at the Eighth CIOMS Round Table Conference:

614/ William K. Stevens, "Psychosurgery curbed by court", New York Times, 11 July 1973.

615/ Cf. Harold M. Schmeck Jr., "Criteria sought in brain surgery", New York Times, 1 April 1974.

616/ Ibid.

617/ Cf. Lee Edson, loc. cit.

618/ Vernon H. Mark, "Brain surgery in aggressive epileptics", The Hastings Center Report, No. 1, February 1973, pp. 4-5.

"will need review panels for diagnoses, and for follow-up evaluations of safety and efficacy. This surgery of the brain needs special review because of the importance of the brain for meaningful existence. The panels should include non-medical personnel such as a biostatistician and a neuropsychologist. A civil-rights lawyer could also be a helpful member of such panels." 619/

Lawrence C. Kolb, a British psychiatrist, stated that:

"The credibility and renewed acceptance of any psychological procedure will be regained in this country only through agreement of the surgical speciality to accept ... prior review of propriety ... for such procedures by both professional peers ... as well as representatives of the non-medical public." 620/

421. The experimental character of psychosurgery calls forth the necessity, in case of its application, for informed and voluntary consent. In the above-mentioned opinion of the three-judge panel in the United States concerning psychosurgery it was emphasized that, given the unfavourable "risk-benefit ratio" and the "dangerous, intrusive, irreversible" effects of a psychosurgical operation, the question of patient's consent becomes much more important than, for example, "when they are going to remove an appendix". Considering the question of patient consent, the judges concluded that an involuntarily confined mental patient cannot really give his legitimate consent because he is living in "an inherently coercive atmosphere" that, through the pressures it imposes, deprives the patient of any real choice. 621/

422. In the above-mentioned report of the National Institute of Mental Health, dealing with psychosurgery, informed and voluntary consent was declared an absolute essential. For this reason the report ruled out psychosurgery on mental patients, inmates of prisons and persons under the legal age of consent. 622/ When the consenting organ - the brain - is either damaged or disordered so that the patient is mentally incompetent, usually close members of their families are the sources of consent. Dr. Mark believes that in such cases the patient and his family should have the assistance of an impartial, non-involved professional group to determine whether surgery or other forms of treatment should be undertaken. 623/

423. While the World Federation of Scientific Workers asserts that "medicine should prolong every human life and make it pleasant", the World Federation of Neurosurgical Societies considers that "the answer will depend mostly on the kind and the severeness of the symptoms and also on the chance for a radical therapy". 624/

424. The World Health Organization draws the following conclusion in respect of psychosurgery:

619/ H. Lansdell, loc. cit., p. 268.

620/ Cf. The Hastings Center Report, No. 1, February 1974, p. 16.

621/ Cf. William K. Stevens, loc. cit.

622/ Cf. Harold M. Schmeck Jr., "Criteria sought in brain surgery", New York Times, 1 April 1974.

623/ Vernon H. Mark, loc. cit., p. 4.

624/ Information furnished by the World Federation of Scientific Workers on 5 March 1974, and by the World Federation of Neurosurgical Societies on 16 January 1974.

"In view of the wide divergences of opinion that exist within the medical profession on the justification or otherwise for psychosurgery, the uncertainty of its results, and its lack of a firm theoretical basis, it seems that further study is necessary to evaluate such procedures." 625/

425. The majority of Governments which have expressed their views in connexion with this problem consider that the answer to the question depends on the prevailing circumstances.

426. The Government of Argentina states that the remarks made in connexion with the question of application of intensive methods to keep incurably ill or very elderly patients alive are applicable here (see para. 394), "since the difficulty in finding the answer to both problems stems from the fact that human knowledge is insufficient to provide accurate criteria for diagnoses or prognoses". 626/

427. The Government of Austria has pointed out:

"It should be noted that application of certain medical techniques may have a remedial effect but, at the same time, do harm to the patient. In applying techniques tending to entail such effects it is necessary to balance in the light of medical experience the remedial and harmful effects. The variety of possible cases is so wide that general comments can hardly be made." 627/

428. The Government of Luxembourg considers that the question under consideration is "to be decided by scientific criteria and the professional conscience of the practitioner". 628/

429. The Government of Norway emphasizes "the right and duty of the medical practitioner to form an opinion on the individual merits of the particular case". 629/

430. The Government of Romania is of the opinion that "the problem cannot be discussed in general terms. For each case the solution depends on the decisions of specialized commissions or the specialized superior centres". 630/

431. The Government of Singapore considers that "the principal duty of the doctor is to save lives and in every instance the doctor will adhere to that principle". 631/

432. The Government of Sri Lanka is of the opinion that "there is a point beyond which technology should not be applied if it is to severely handicap the patient". 632/

433. The Government of Sweden writes that the question "is very difficult to answer and that views on what is right in such a situation can vary". 633/

434. In the opinion of the Governments of the Ukrainian SSR and the USSR the question does not arise since the doctors should always fight for the patient's life and imprisonment of his state of health (see para. 402 above).

625/ E/CN.4/1173, p. 27

626/ Information furnished by the Government of Argentina on 30 May 1974.

627/ Information furnished by the Government of Austria on 21 November 1974.

628/ Information furnished by the Government of Luxembourg on 16 March 1974.

629/ Information furnished by the Government of Norway on 15 April 1974.

630/ Information furnished by the Government of Romania on 29 April 1974.

631/ Information furnished by the Government of Singapore on 13 March 1974.

632/ Information furnished by the Government of Sri Lanka on 5 March 1974.

633/ Information furnished by the Government of Sweden on 12 March 1974.

III. PRE-NATAL GENETIC DIAGNOSIS

1. The human rights implications of pre-natal genetic diagnosis

435. In the Secretary-General's preliminary report it was recalled that:

"By means of the surgical procedure called amniocentesis it is becoming increasingly possible to identify genetic defects in a foetus before birth. This being so, a trend has been foreseen towards the greater resort to abortion, in jurisdictions where this is legal, to avoid the birth of children who would suffer from mental retardation or other serious defects."

Certain human rights problems posed in that connexion were then stated. 634/

436. The World Health Organization has dealt with some problems connected with this procedure. 635/

437. This question will be dealt with further in document E/CN.4/1172/Add.3

IV. INCREASING USE OF TECHNICAL DEVICES IN MEDICINE

1. Measures necessary to safeguard the health, safety and life of patients who are exposed to electrical, electronic, mechanical and other technical devices during diagnostic or therapeutic procedures

438. Human rights problems arising from the use of electrical, electronic, mechanical and other technical devices during diagnostic or therapeutic procedures were referred to in the Secretary-General's preliminary report. 636/

439. These questions will be explored further in document E/CN.4/1172/Add.3.

634/ See E/CN.4/1028/Add.5, paras. 71-73.

635/ E/CN.4/1173, pp. 3, 8 and 14.

636/ See E/CN.4/1028/Add.2, para. 267, and E/CN.4/1028/Add.5, paras. 74-77.