

COMMITTEE II
The Value of Human Life

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Discussant Paper on Helga Kuhse's Paper

**ON DEVELOPMENT OF PERSONALITY WITH RESPECT TO
HARD CHOICES: ETHICAL QUESTIONS BY THE
BIRTH OF HANDICAPPED CHILDREN**

by

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Progress of modern medicine brought about treatments the application of which to seriously ill or handicapped infants can make extant ethical principles and legal regulations questionable. Babies who earlier would have died are now kept for rather long alive but often with alarming cruel methods or under severely handicapped conditions caused sometimes by the treatment proper. Is it right to keep such infants alive or would not be better for them to die smoothly? This is the problem investigated by the authors. However, how can one decide the above question and who should be justified to do it? The authors with sharp arguments and without any concession to hypocrisy reach to their conclusion by which in such cases the parents should decide whether their baby will be treated or put to death. The authors show that such ideas as the sanctity of life or equal worth of all human lives which gave enough guidance in the past must now be revised. This is demonstrated on highly instructive and moving examples and on lengthy legal disputes provoked by the obscurity of the mentioned ideas. Ethical contradictions arise as in taking reference to the sanctity of life or to the equal worth of all human lives the really relevant concept of personality is only implied. The progress of medicine requires that with regard to certain decisions personality should be indicated at explicitly. However, personality, if scrutinized, appears to be an entity endowed with the quality of life, making the individual self-aware, purposeful being who identifies with what happened to him in the past and has hopes and plans for the future. The thus characterized personality is though inseparable from the physical life of the individual, but does not coincide with it. "The infant and

the child or adult are - the authors say - physically the same organisms, but the child is a person, in the full sense of the term, and a newborn infant is not." This matters if the rightness of decision is pondered about the survival of a newborn infant by the use of agonizing treatments stamped even by doctors to barbaric. If there is a personality, its value is and in own decision will be reckoned with if sufferings must be endured for example by surgery. As infants can not made such decisions, some speak about their best interests based on their potential. However, the authors clearly show that personality can not be substituted with potential. If one's best interests are pondered, also those of others should be taken into consideration who are connected with him. If a severely handicapped infant is kept alive, his whole family will be affected with a great burden and even those siblings interests afflicted who are only planned to ^{be} born in the future. Therefore moral decision about life or death ^{of} ~~regarding~~ severely handicapped infants must not be made by anybody else than their parents. The parents are expected to get the necessary advise based on relevant informations from the doctors and they should give them help in execution of their decision too.

This has been the essence of the authors' presentation. Now it seems inevitable to ask whether their idea about personality can be accepted as true. Is a newborn infant really a being without personality at all? Theologians using of course another meta-language never could settle their long debates about the date of ~~pres~~ence of soul or spirit or personhood in the human body or even in the fertilized ovum. The authors' thesis is by all means supported by the triunism theory of the neurophysiologist J.M.R. Delgado saying about the mind that it is not present in the newborn infant's brain function, but gradually develops under the influence

of the specific human environment. The entity named as mind is easily identifiable with that termed by the authors as person. All the same, if no personality is present in the newborn infant and it is going to develop only later, by what effect is it created and how, that is the question. Interestingly, both questions could be answered by studies made of certain severely handicapped children.

Let us, then, concentrate upon a particular subgroup of severely handicapped infants which by all means is the greatest one. While the authors choose^{as} their highly instructive examples deformities together with their frightful surgical corrections, now cases of cerebral palsy will be brought up. This restriction does not diminish the importance of the question as C.P. infants themselves make a scourge of humanity. Their number as the authors hint at is the more increasing the more premature infants are kept alive. It is judged that about so many C.P. cases live as cancer patients. Cancer is generally recognized as a problem of great importance for the mankind. However cancer mostly hits the old and does not lasts long, while C.P. begins after birth and is a burden for decades not alone upon the patient himself, but on his family and the society as well.

By expert opinion 25 percent of all C.P. cases are hopeless and not to be treated. Such infants without special efforts can remaine alive growing up to adults of sheer passive existence. The further 50 percent of all C.P. cases are suggested to get medical treatment and receive accordingly in the most developed countries some forms of physiotherapy and often orthopedic surgery as well. It is expected for all that about these patients that they remain bodily and mentally crippled.

At the same time the state of the overwhelming majority of a great number often very severe C.P. cases treated in the Petó

Institute (Budapest, Hungary) with Pető's "conductive education"¹ method changed for the better radically. The same method can be applied to C.P. infants too, but only by his own mother and with marvelous results in a rather short period. The mother needs only to be aided with some instruction from time to time and she will be able to change without any torture her severely handicapped C.P. baby into a joyful and healthy child with all hopes to become a normal adult. Consequently the authors seem mistakenly included, if without specification, into the group of severely handicapped infants about whom a life or death decision is pondered, the C.P. babies. This is though not their fault. They cannot but accept the general opinion ruling nearly everywhere about these children. But it would be available the solution for almost the whole world problem of C.P. Only the concerned mothers should obtain the pertinent instructions and follow them².

This also means that the authors were not enough cautious in their consideration about the expectable informations given by the physicians to the parents of handicapped infants asking advise. It seems that the authors in their investigation were so much influenced by the progress of medicine that they forgot the strength of obstruction against acceptance of new discoveries.

However, C.P. was mentioned here from quite another reason. By long studies of Pető's method it has been found³ how personality of each baby is generated. The baby's personality appears and is going to develop in "cooperative educational two-way relationship" between him and his mother. The mother not only solves her baby's emerging problems or plays with him, but also elicits his cooperations involuntarily already by the newborn infant. The baby's cooperations serve as directions for her to promote his farther cooperations. She thus educates him to cooperate ever more better

with her and by this way he gradually learns selfsufficiency, purposefulness and through mastering the mother tongue consciousness. So begins the personality development of each baby. It is, then, a process of inductive maternal psychogenesis or better anthropogenesis. In C.P. infants this process of anthropogenesis is fully or partly hampered as the child's innate ability for cooperation is impaired by his brain damage. Hence primarily the mother does not receive from her baby those directions by which she secondarily teaches him to improve his cooperations, therefore his personality is not going to develop at all or adequately. If the mother will be instructed how to elicit her baby's cooperations and how to recognize and follow his initially weak directions, the baby will more and more well cooperate and his personality becomes in a time normal. Secondarily he also learns to compensate the C.P. symptoms and the C.P. infant in a year or two changes to a healthy, joyful child.

The statement of the authors about the newborn infant having no personality could thus be proven as true. Also they may be credited with indication to personality as bearer of quality of life. However, the question of personality development is of far greater consequence than that of the handicapped children. Human species consists of members born with a brain which at first has only physiological functions. These under lifelong intercerebral influences, in anthropogen cooperations, transform into human biological functions of personality. By this way absolute values are produced for the species which is by the individual sensed as quality of life. Still human biological values can not only be created and accumulated, but also wasted. Therefore in societies a regulation by ethical norms has been necessarily generated accordingly.

Footnotes

1. Maria Hari and Karoly Akos, Conductive Education, in Hungarian, Budapest, 1971, in Japanese, Osaka, 1979, 1981, in English, London, 1987
2. Karoly Akos and Magda Akos, How the Baby Afflicted with Motor Disorder ("Cerebral Palsy") Can be Cured by Its Mother? MS.
3. Karoly Akos and Magda Akos, The Sense of Human Life, Inter-relationship Psychology. MS.