COMMITTEE II
The Value of Human Life

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Discussant Paper on Helga Kuhse's Paper

HARD CHOICES: ETHICAL QUESTIONS RAISED BY THE BIRTH OF HANDICAPPED INFANTS

by

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[I] INTRODUCTION

The recent progress in biomedical technology made it possible for us to save many lives from various diseases. On the other hand, however, this progress has raised a new problem that a seriously ill patient can be kept alive by these advanced technologies even if their brain does not function as a human being anymore.

In the area of obstetrics or perinatology, we often encounter simillar problems in clinical practices. Dr. Kuhse raised ethical question related to the birth of handicapped infants, and proposed answers to some of them. I would like to present a typical case which we experienced recently, and discuss on several points raised by Dr. Kuhse.

[II] WHAT ADD THE SPECIFIC VALUE TO HUMAN LIFE?

Prior to the discussion on the treatment of seriously ill patients, we need to clarify our understanding of human lives. Dr. Kuhse rejected the sanctity-of-life views and took the quality-of-life view. He concluded with several examples that the value of human life does not depend on life itself but on the quality of life. I fundamentally agree with this conclusion, but I would like to add my own opinion on human life which, I think, is consisted of living and dying.

Seikoh Hirata, one of the highest theologian of Zen sect, explains his understanding of human life in his article entitled "KATSUJIN-ZEN" in Japanese, that means, "Zen as a practical ethics to live a true human life". He advises us to practice controlling the four most fundamental emotions, joy, anger, sadness and pleasure, to live a truely joyful life, because these emotions are the essences of 84,000 worldly desires characteristic to human being, and cause us all sufferings which prevent us from calm life and death. The important thing in Zen-Buddism is not a physical life and death but a quality of life and death. The background of this view is the understanding that all the living things must die and that one can find liberation from this predicament not by denying death but only by confronting it. From this point of view, he deneys a life sustaining treatment which brings about nothing worthy to the patient with nonfunctioning brain, but he rather accepts a death with dignity, passive euthanasia. Though this

understanding of human life is similler to the quality of life view, which was mentioned by Dr. Kuhse before, it include how human being should end its life which is inevitable to all living beings.

[III] DOES FETUS OR NEWBORN INFANT HAVE SAME VALUE AS ADULT?

To my understanting, Dr. Kahse concluded that newborn infants are not the same person because we have no conscious links with our infancy and infants cannot look forward to the time when they would be older children. Of course it may not be incorrect that there is no mental continuity between an infant and child. However, it is an undenyable fact that a child or an adult cannot exist as a person unless he experiences his infancy irrespective to its consciousness. This may be explained by "cause and effect" theory in Buddhism. Dr. Pinit Ratanakal, Mahidol University, Thailand explains the law of cause and effect as follows. (ref. "The Buddhist Concept of Life, Suffering and Death and Their Meaning for Heath Policy" in Bioethics, Pinit Ratanakal, pp.305, 1986)

> The law of cause and effect is thus expressed: "when this exists, that exists, when this arises, that arises, when this is not, that is not, when this ceases, that ceases." This is interpreted as meaning that all that exists is the result of antecedent causes. Each "event" or "happening" acts as the cause or the necessary condition for the arising of the following event, which then provokes or causes another event. Thus, as used in Buddhism, the relation between causes and effect is only that of the earlier to the later phase of a single process.
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> Through his deeds each person weaves his own web of

life. It is therefore in the power of each individual either to remain in the endless cycle or to escape from it. For in this cycle he is both cause and effect, the entire act or deed on the one hand, and, on the other hand, the consequence of the act. As an effect of his past deeds he is the product of the past. But as a cause he is a field of possibilities; he has the ability to gradually free himself from the past and to become whatever he wants to be.

Memory or will which is characteristic to human being is formed or affected predominantly by its experiences of stimuli from external environment. Simillarly, infants or even fetuses can respond to external stimuli and can memorize them although their capacity is still small, and they do not have ordinary means to express their will. For example, newborn infants remember the aortic sound of their mother to which they were used in utero and stop crying when they hear this sound even after birth. Another example which proves the brain of infant is already functioning, is the clinical treatment of brain-dameged infants. Most of the neurological function of brain-damaged infant can be recovered by physical therapy if it starts at the early stages of newborn. These facts indicate us that the brain of infant is already functioning and contributes to the formation of personality as a human being. If we admit that the value of human life does not depend on the quantity but on the quality of life, in other words, the recipients of Nobel Prize and ordinary persons have the same value as human beings, then we must accept

that infants with normally functioning brain or potential to develop are of the same value as adults. However, here raised a new difficult question, that is; What is the standard of normal function of the brain?. The assessment of brain function of infant is difficult, even more in cases of fetuses. Although we might tentatively borrow the medical standard of brain death for an adult patient, the establishment of medical and biological standard for the assessment of brain function of a newborn infant is urgent.

Another new problem is raised : This point of view on the value of the newborn infant contradicts to widely accepted concept on the allowance of artificial termination of pregnancy earlier than 24 weeks of gestation. This problem must be discussed together with the questions whose interest should be taken into account and who has the right of decision.

[IV] WHOSE INTEREST SHOULD BE TAKEN INTO ACCOUNT?

In the discussion of this question, Dr. Kuhse raised the view point from handicapped family and the "interests" of the next-coming sibling of handicapped infant. Recently, we have experienced a typical case of handicapped family.

The first baby of this couple was a premature baby and became severe cerebral palsy. His parents must take all the care of his daily life. The second baby was born at 35 weeks of gestation with approximate birthweight of 2.2kg. Soon after delivery, he was transferred to neonatal intensive care unit and taken care of there. His respiratory and neurological functions were normal, and discharged few weeks later. However, soon after discharge he was revealed to be a DiGeorge Syndrome, a syndrome caused by disturbance of T-lymph system and characterized by no defense mechanism to infection. Thereafter, he was kept in clean room for two years and the couple had to take care of "two handicapped infants". In the meantime, she became pregnant again, but the couple did not have enough ability both emotionally and financially to decide to have one more baby, and they chose the artificial termination of pregnancy according to the Eugenic Protection Law which gives an implicit permission of artificial abortion by socioeconomical reasons. After this decision, pediatrician proposed them a possible treatment of the second baby,

transplantation of thymus from aborted third fetus to the second baby with DiGeorge Syndrome. The couple accepted this proposal and the thymus of the aborted fetus at 12 weeks of gestation was transplanted to the second baby. The thymus implanted successfully and the DiGeorge baby discharged several months later.

In this case, the interests of handicapped family were taken into account rather than those of the third fetus, which might have a potential to become a normal infant if everything goes well. This family was releaved in a certain sense at the expense of third fetus, but an unforgetable memory of abortion remained. The couple could not say any words but just nod in tears when they were told that the transplantation was performed successfully.

It is quite easy for us to say that all lives are of same value, but who can share and releave the actual suffering and pain of this couple, doctors, members of ethical committee, court, or theologians? Doctors can only offer the information on the situation and the expected results of the treatment. The ethical committee and court can only guide not to abuse the medical technology according to the social consensus. Theologians can only offer the philosophical backbone of the decision. None of these people are affected by the results of the decision. In the cases of adults, we can confirm their "living will" before they become terminally ill, but infants or fetuses cannot express their own will even if they have such a will. Therefore, the

decision must be made under the consideration of the interests and will of the competent parents, the only persons who can share the suffering of infant and take the responsibility of all results of the treatment. However, it is of course that such a decision should be within the consensus of the society.

[V] HOW THE INFANT SHOULD DIE?

The last and unresolved question is : How the infant should die? Dr. Kuhse pointed out that severelly ill or handicapped infants should not be allowed to die, but should be helped to die in certain circumstances. This question contains same factor as the question : How the ternimally ill adults should die, active euthanasia or passive euthanasia ? The answer to such a kind of question may differ between societies, because it totally depends on the understanding of human life and death. Next I will introduce you the result of the poll on euthanasia in Japan performed by the third largest newspaper, "Mainichi Newspaper" in 1982. The question was following:

> "When you become terminal stage of an incurable disease, such as end stage of cancer, which causes great suffering, what kind of therapy do you choose?"
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> 13% chose the treatment which emphasizes life-sustaining regardless of great pain. 84% chose the treatment which emphsizes not life-sustaining but pain releaf to die a calm death with dignity.

84% of YES to euthanasia in Japan is rather higher than in western countries. This may be related to Japanese understanding of death; We must concur death by accepting it, because we never can be free from death. Ignorance of death causes fear of death, fear of death raises desire to free from death. But this desire

never can be attained because death and life are inseparable and complementary each other. Unsatisfied desire causes great suffering in daily life, and amplifies fear of death. The only way to break through this vicious circle is to accept death as it is. Reverend Tairyu Furukawa wrote in his article "Can death be releaved?": To live is to die. People are eager to learn to live a better life but not to die the best death. Therefore, they are caught by a great fear and suffering when they confront actual deaths. From this view point, patients at end stage of disease are closest to religious awakening and are able to obtain thick and deep life by understanding death, although their life time left is short. The most important is not the length of life but the quality of both life and death.

84% of YES indicates that 4 out of 5 Japanese understand and accept the death as mentioned above. However, this does not necessarily mean that the most Japanese basically accept euthanasis even in the cases of infant. The discussion on this kind of question has just started in Japan. It may take some time until the social consensus is established. But I propose that parents' will should be taken into account to the decision of treatment, because the living will of an infant cannot be detected. It is important to distinguish relief of fear by the help dying a calm death from mere shortening of duration of pain and suffer by killing.

In conclusion, we accept passive euthanasia which helps an infant to die a death with dignity but not active euthanasia which aims only to releave pain by shortening of life physically.