INSTITUT BORJA DE BIOETICA , 3 DIRECTOR

QUESTIONS ANSWERED:

Question 1

ANSWER:

We consider that human life is not a supreme good, but is based on other values that can be reached with it and make it possible to give it a meaning. This reflection concerns intrauterine life as well as situations at the edges of life. Related to intrauterine life, we must be aware that the aim of any pregnancy is, in principle, the birth of a child who, if no unexpected events or accidents occur, will be able to survive, breathe, feed, drink...When this possibility cannot be contemplated because the fetus will die in the uterus or will not survive outside the uterus, and we are sure of it, to what extent can we say that we are attempting the dignity of the person if the mother does not feel able to continue pregnancy and ask for help?. Let us consider the case of anencephaly, and cases of malformations incompatible with extrauterine life (renal agenesis; extreme pulmonary hypoplasia, limb body wall complex etc) for which there is no possible treatment. A different case is represented by fetuses with a severe pathological condition resulting in a life with limitations, but who will be able to breath, feed themselves, relate to others and perform voluntary acts and who can love, in spite of their physical or intellectual deficits. Some palliative treatments may sometimes exist, but there are not curative treatments. Actually, when such a prenatal diagnosis is made, most parents request pregnancy discontinuation based on the abortion act. Many of these parents are for the defense of life, and face with great anxiety the prospect of having a child with deficits or limitations that will require long, painful treatments, and will hardly live the life we consider normal. They sincerely believe that this suffering is excessive, and really think that the best for the child is not to be born. When defects or malformations are diagnosed, the decision of aborting a fetus with a disease perceived as intolerable often follows...The function of medicine is to cure, relieve and care, and must have the greatest respect for human life and for the dignity of all human beings. The function of medicine is not to suppress human beings, and is incompatible with aggressive or intolerant attitudes. Nevertheless, our function is not to condemn parents or people in difficult or painful situations, but to participate at all levels to create and promote the adequate social conditions to provide a truly human life to people with difficulties. Only under these conditions the ethical problems of pregnancy discontinuations may be approached to the best interest of the fetus and his/her parents. When there is a possibility to correct successfully some abnormality before birth should be intended, with the parents duly informed and with their consent. When possible we should try to correct abnormalities before birth, when the clinical condition of a fetus poses such a threat to its viability that later intervention would be unsuccessful. As example we can consider the introduction of shunts to bypass obstructions, or trying to correct a congenital diaphragmatic hernia when a university pediatric hospital has the means (manpower and trained pediatric surgeons to do it). Of course there are circumstances when we must override the wishes of the pregnant woman (such as unreasonable

demands due to ignorance or superstitions, or asking for miracles).

Question 2

ANSWER:

When the baby is extremely premature. When the baby has acquired brain damage and is considered to be likely to have severe disabilities later in life. When the baby has congenital abnormalities incompatible with acquisition of self conscience and lack of any kind of communication possibilities. We are quite reluctant to establish a clear universal rule saying "Never". The fact is where do we place the burden of the proof. In cases like the above mentioned when parents and doctors agree with some decision we must considered whether both parties could be right or both parties could be wrong or even in-between: right conclusion for wrong reasons. We prefer always dialogue with the parents rather than going to the courts. Sometimes it is unavoidable to accept going to the courts.

Question 3

ANSWER:

We do believe that most of our pediatricians will act according the solutions a) b) in the same order, although given the case we have to take the decision c) or even d). Dealing with fetuses we consider that they must be treated as if they were persons. Quite often the distinction of acting or omitting to act do not show any intrinsic moral difference although omitting to act shows more difficulties from the emotional point of view. We consider that at this stage the more relevant and difficult questions move around the quality of life issues, although the three basic issues in neonatological ethics are focused on the following problems. 1. What is the child's best interest? 2. Who has the power or right to make this decision? 3. What are the appropriate methods for solving conflicts? 1.1. What is the child's best interest. (The best argument). There is not doubt that the child's best interest ins to recover his/her health in order to be able to grow up and develop enjoying a healthy life. However, in neonatology dramatic conflicts often arise between vital and spiritual values. This has been expressively summarized in American literature although, it must be said, with a clearness that is only apparent. The formula is "sanctity of life vs. Quality of life". Sanctity of life refers to the belief that human life is an absolute value that must be defended at any cost and that no effort should be spared to save it. This doctrine is also known as vitalism. Quality of life, as the opposite position to the above, in its most extreme form, refers to the doctrine that allows treatment to be discontinued and even to actively cause death when any lesion or malformation which might become unbearable for the parents (or the care team) exists. The position of a vast majority of pediatricians and the catholic tradition have always maintained that human life is a basic, essential value, but that a certain quality of life is also necessary if it is to be obligatorily preserved. In other words, the duty to preserve human life is not imperative in particularly distressing conditions. In order to focus difficult cases we rely on the following general criteria: 1. Since the essential and intrinsic possession of a person, and the prior condition for enjoyment of all other

possessions, is his/her life, not only may it not be subordinated to any other possession, but as far as it is concerned, every person must have acknowledged equal rights to those of the rest of mankind. 2. Declaration of the dignity of all human beings, regardless of any abnormalities, handicaps that limit their autonomy or social deprival they might suffer. People with malformations, and therefore ill, disabled, or mentally retarded, must not be considered an undue burden for society, but members of the human community, beings who suffer and who, more than any others, need our support and demonstrations of respect, which will help them to believe in their value as human beings (P. Verspieren). 3. Of course, life is sacred, but the quality of life is also important: that is, the possibility of living it with meaning, as a human being. 4. Not all treatments that prolong biological life are humanely beneficial for the patient as a person. The individual is not under the obligation to accept disproportionate procedures to preserve life: reasonable belief in success, level of human quality (from the patient's viewpoint) of the life preserved, survival time, inconvenience (patients' own and that of their families) which the treatment will involve, cost of the intervention. 5. Treatments for prolonging life must be considered to be in the child's best interest (benefit), provided that the probable potential benefit is reasonably greater than the suffering entailed by the treatment. With these principles in mind, we can derive some theoretical and practical conclusions for more immediate application in everyday pediatric clinical practice: 1. Usually, the child's best interest will require treatment to preserve life. This is obvious when the result of the treatment will be the survival of the child with no handicap, or only minor ones, but it is also applicable when there is a chronic physical or a mental handicap. 2. The most important exceptions to the duty provide treatment or life supporting or maintenance techniques are: a) Irreversible progression of the disease towards imminent or early death. b) Treatment that is clearly ineffectual or harmful. c) Cases in which life expectation is definitely short despite the treatment and abstention from the latter allows greater care and comfort for the child than the treatment. d) Treatment which imposes excessive suffering and discomfort on the child which are significantly greater than any benefits that might be obtained. When making this decision in the last case, we must remember: a) The reason for not starting or for discontinuing a therapy lies in the fact itself of the discomfort it might cause and not in the painful nature of a congenital malformation or handicap, which already existed before the treatment and could be taken into account before beginning the treatment, if the result reasonably expected with same was minimal. b) The benefits offered by treatment must never be underestimated. The differences between a normal and a severely handicapped child do not affect the essential basic right whereby they should both receive ordinary care.

Question 4

ANSWER:

We fully agree with the concept of quality of life that you give in the consultation paper: The term "quality of life" will mean different things to each of us. In the context of a

medical condition, it usually refers to the overall effects of a combination of factors, including health and the presence of symptoms, and reflects a person's ability to function physically, psychologically and socially. The term can include subjective feelings of well-being, fulfillment or satisfaction resulting from factors beyond the specific impairment. Somebody with a disability but who is otherwise healthy might be expected to report a good quality of life, whereas someone with a troublesome and painful chronic disease that restricts what they are able to do would likely report that their quality of life is poor. We must stress that to be loved by parents and family is the most important thing in the life of every human being. We do believe that religious and spiritual influences can show Jano's faces. We believe that religious approaches in the line of any fundamentalism ends up in intolerance, lack of dialogue and violence and we consider such influences very negative, but we have to deal with them with a charitable spirit trying to correct as much as possible extremism through dialogue. There is not doubt that mass media influence decisions. The main problem is how to keep the freedom of individuals through education. The most important socially issue is poverty and how to implement a real social justice and peace all over the world.

Question 5

ANSWER:

Who is best placed to judge the quality of life for a child? Usually it is the parents who have the greatest right to decide what is in the best interest of their child. However, it is not the function of doctors to obey the decisions of parents if they consider them to be mistaken where the best interest of the child is concerned. When families as well as professionals are involved without reaching a consensus, then we consider imperative the advice of the institutional ethics committee of the pediatric hospital. In this committee should be medical doctors, (pediatricians, obstetricians, neonatologist, pediatric nurses, social workers, and psychologist). They should reach a clear position, not necessary uniform position. They should be able to explain clearly the situation to the parents, and all together should reach a reasonable conclusion. The courts should be the last resort. Decision making. We shall proceed to summarize some problems facing the main decision-making agents in neonatology treatments: the parents or legal guardians and the doctors and care team. Let us see first how relations are established between all these people who are presumably acting in t he child's best interest (table 1). We have described the possible attitudes in parents and doctors when deciding whether or not to administer treatment to a severely ill neonate, in the opinion of an ideal observer who analyzes the problem from outside. This is obviously a theoretical scheme, but it allows the different aspects of the problem to be considered and analyzed. objectifiable conflict will arise when the opinion of parents and doctors differs. According to the scheme suggested, a mistaken situation along the same lines by both parts would only create a possible conflict with regard to a third opinion of both health professionals and family members. The conflict would not arise and the behaviour would be unacceptable. It must be remembered that occurrence of this conflict also depends on social-cultural factors, since the attitude to the doctor-parent relationship is

not the same in Israel, Germany or the United States. It is very important to remember t his today, when the migratory currents establish pluricultural societies, thus requiring greater educational receptiveness and creativity.

Question 6

ANSWER:

We consider the need to value cost opportunity in order to set priorities in the distribution of resources, and it is against common sense the expenses to save a extremely premature baby without a rational hope to survive without severe disabilities or to try to increase at a very high cost the average survival of very premature babies with AIDS. The real problem relates on who is going to take responsibility for such decisions, since is unfair to leave the issue in the hands of the general practitioner or the pediatrician in the emergency room. Such politics should be at the highest level of health care policies, checking with the general feeling of people, well informed through mass education. Generally speaking the highest cost can be political cost, since such a measures are difficult to understand by the general population, managed by unwise advertising highly emotional.

Question 7

ANSWER:

Given the fact that we don't have comparable scale in the neonatal period at the same level that we have for adults, our answer is a bols answer, stressing only the need to check case by case.

Question 8

ANSWER:

We think so, bus this guidance should be enforceable for professionals and parents should be clearly informed about them. We think that this will be a very wise measure. A consensus among scientific community and public health authorities should be reached to set up a minimum age below which resuscitation normally would not be permitted.

Question 9

ANSWER:

We consider that enforceable guidelines, reached by consensus, will be better than a new legislation.