

END OF LIFE IN CHILDREN NON MEDICAL DECISIONS IN A MEDICAL CASE

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Abstract

In this paper we are going to discuss about the end of life ... at the beginning of life, trying to analyze some of the main moral issue involved, by a clinical case. Our purpose is not to present a unique moral conduct but to show that the medical decision is backed-up by an ethical strength and, the same like in medicine, in bioethics there are several correct answers, depending on a particular perspective: the physicians', the patients', or the hosting institutions'. In a situation as complex as it is the one of a child at the end of life, when we discuss whether or not to use extraordinary resuscitation methods in order to prolong his/her life just until the mother comes to the hospital, the physician will make appeal to HIS right to consciousness. We will perform an ethical breakdown not by using the classical ethical theories but four arguments: the quality of life, life expectancy, futility, and sanctity of life.

Keywords: *end of life, quality of life, life expectancy, sanctity of life*

Those who consider that a child is just a „small adult” fall into a big illusion of a secular medicine. The child is a universe in miniature, and the physician who takes care of him adopts a professional role as well as a parental

one. However, many times medical knowledge does not solve the whole complexity of a case, given the multiple interference with social, legal and moral aspects. The highest ethical dilemmas in pediatric practice come from clinical

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situations that lead to "life and death" decisions or the decision with future long-term repercussions or with great impact both on the patient and his/her family and the physician and / or medical staff.

In Western societies, the parents are considered those entitled to make a decision. In Eastern societies, often family comes first, their decisions surpassing the actual decision of the patient (in our case the parents) (Gavrilovici, 2009). In transitional societies, where the transition from the paternalistic model dominated by the physician's authority and supremacy in any decision, to the liberal model, dominated by the sovereignty of the patient is very slow, being difficult to decide who is to bear the last word: the patient or the physician? In a transitional society (like the Romanian one), the values haven't been understood well, and the patients wish to express their autonomy but are reluctant to making decisions, still living under the myth of "Doctor, you know what is best for me", and physicians want to share responsibility for a decision with the patient, even if this is not always a consistent partner of debate on various medical options.

In the present study we refer to the end of life that comes to ... the beginning of life, trying to analyze some of the major moral issues based on a suggestive case. Our goal is to not provide a unique moral recommendation, but to show that the medical decision has a strong ethical backup and there may always be several solutions, depending on the physician's and patient's perspective, the hosting institution, etc. We are not going to perform an ethical deconstruction using the classical ethical theories and principles, but by making an appeal to four arguments: **quality of life, life**

expectancy, (f)utility, the sanctity of life.

While, traditionally, physicians and parents make most of the decisions on behalf of the children, the development of child autonomy has a major influence on the therapeutic decision. This is a challenge to physicians who must work with the child's family and other team members to determine what is the role and position of the child in the decision making process. A family oriented approach respects the complex nature of a parent – child relationship: it respects child dependency and vulnerability on one hand, and on the other, the development and stimulation of a child's ability to make competent decisions. But if the child is left in the care of his/her extended family, while the parents are working abroad, and the child is suffering from a lethal disease in terminal stage preceding death, life and death decisions become more difficult. The case below is illustrative in this respect.

Female patient, 10 years old, admitted in the pediatric oncology department, was diagnosed with end stage of liver cancer with extensive lung metastases. The girl was accompanied by an aunt, her mother being away, working in Italy. Her father - apparently does not exist in her life. We don't know anything about other relatives. At about 7 days after the last chemotherapy, the little girl began to feel very bad and she could only be fed by parenteral solutions, and she was in generalized pain. Blood tests were clearly modified, showing that any attempt to treat the tumor would have led to a reduced defense capacity of the body and, at the same time, to the enhancement of bleeding in different organs. At this stage she was treated by palliative means, focusing primarily on pain control and support of vital

functions. After three days, the little girl became confused, she could barely answer to sensitive stimulation, and became oxygen dependent. Both physicians and aunt understood and accepted that these were the last days of her life. However, her mother had not arrived from Italy to see her one more time, but she was on her way back home. She was intensively calling the medical staff, begging them to make all the efforts to prolong the life of her daughter so she could arrive at the hospital in order to say her good-bye and... to ask her forgiveness for having been away from her.

The risk of death from respiratory failure was very high, blood oxygen saturation decreasing progressively. The only way to prolong life for a short period was the oro-tracheal intubation and the administration of a supportive pharmacological treatment. The family reconciled with the idea of death and refused to prolong her life by extraordinary measures. They wanted a "short" prolongation, until her mother had reached the hospital.

Therefore, we contacted by phone the physician from the intensive care department in order to perform the intubation, while explaining the „non—medical” reasons for that request. The anesthetist accepted, but she draw the attention that this procedure was „for good”, and that she would not agree with any subsequent extubation that may allow the girl to die (the family wanted just a short-time intubation, to give time to the mother to come and, after that, to let her die). But, in this situation, thinking that intubation and supportive measures should be an extended ordeal, her aunt, who had become a second mother over the last years, requested no intubation. The girl died shortly after, before the arrival of her mother.

If any of the physicians would have requested an ethical opinion to clarify their own moral decision, there would have been two alternatives:

1. The child should have been intubated before the arrival of her mother, given the terrible suffering of a mother with a dying child, and her wish to be beside her daughter in the last moments of life. The contact with her child before death, a final farewell and forgiveness would ease the suffering of separation. Having no chances to survive, the prolongation of her suffering and that of her family did not justify the use of any extraordinary means for further maintenance of the vital support (i.e. after her mother arrival). In addition, we live in a society where the resources allocation becomes an important aspect in the ethical judgment. The extraordinary procedures of life maintenance must be a priority for those with high chances of survival, aiming at the improvement of their health condition and not to postponing death

2. The child should not have been intubated and then extubated on request, even if the disease is in terminal stage, with lethal prognostic and an irreversible progress towards death. It is against the natural laws, the sanctity of life and all medical codes of ethics.

Arguments invoked at the end of life: quality of life, life expectancy, (in)utility of treatment, the sanctity of life

Quality of life. The child presented above cannot take her own life and can not express any wish at the end of life, even if she would have had the legal right to do so. We do not say this to indirectly emphasize the potential benefit of adults' autonomy and their greater capacity to reason but to highlight a similar

argument for both adults and children, used in life end decisions: the quality of life. This is a new attribute raised by modern medicine. Seneca himself says: "It is not the life that brings the wellbeing, but the fact of living well. Therefore, the wise man lives as long as he need, and not as long as he can. He will always think in terms of quality, not quantity" (Seneca, 1958). Therefore Seneca believes that when a death involves pain and the other is simple and easy, why not pick up the easy one?

It is important to distinguish between the two meanings of "quality of life": the first one refers to personal satisfaction, meaning what an individual feels in terms of physical, mental and social comfort, and the second interpretation concerns the evaluation by an external observer (parent, family member, physician etc.), who considers the situation in terms of his/her personal values (Jonsen AR et al., 2006).

There is a tendency for physicians to define this argument in relation with clinical and laboratory data, which are actually the result of physical functions during normal daily activities. However, the physician tends to ignore the personal and social functions, the values attached to patients' quality of life. Thus, any discussion on quality of life, involves not only the biological body functions but also the patient's or the family's preferences. Therefore, provided that each case is a universe in one hand, we appreciate that the physician is not able to adequately assess his patient's quality of life (but only ... partly).

If we agree with that last statement, our case is edifying for the fact that this argument cannot be taken into consideration: the child is cared for by her aunt and not by her parents, but her aunt cannot and does not want to take a long term decision, but only a temporary

one, until the girl's mother comes back and takes full responsibility.

And if quality of life is a concept saturated either with subjectivity or lack of pragmatism, medical teams have raised a new argument, that of **life expectancy**. This is not a concept of moral nature, but its significance becomes ethical, if differences in life expectancy between individuals or groups of individuals constitute a determinant factor between choices that affect life in many ways (Small R., 2002). We have not considered this criterion when presenting this case because life expectancy of a young child actually means ... the entire life.

Life expectancy, in medical terms, is defined as an accumulation of information to be processed and properly understood. Thus, life expectancy differs depending not only on the disease per se, but also on sex, ethnicity, etc., which results in the transformation from a medical problem into a moral argument when used for allocation of resources: to whom should we give priority when recommending a particular medical treatment: to young patients, children or women because, basically, they have a higher life expectancy? It has been suggested even the fact that ... to allocate significant resources for elders despite youth, is like "giving money still to the rich, not to the poor" (Kappel K, 1992). Thus, "life expectancy" is converted into an economic argument, when in fact the problem is to respect ethical principles of justice and equity.

Obviously, each of us would like an estimate on how much we are going to live, and such information has implications in certain life decisions. On the other hand, we don't believe that many of us would like to know exactly when we are going to die. Faced with sincerity and disarmed in front of it, we

can say that what we would like to know is in fact our chances of living longer, and, if possible ... in good health. This is the paradox of "life expectancy".

Naturally, we regard death as a tragedy, perhaps the greatest of all. In addition we all have the intuition that the death of a young person generates greater suffering than one of an adult or elderly person. However, a premature death involves a greater loss (at least in terms of ... „potential time“, if not also for associated values), which is translated by the fact that a lower life expectancy is associated with a disaster ... greater. On the other hand, everyone agrees that the life of a person (whoever might he/she be) is as valuable as it is the life of any other person, and this suggests that ... the misfortune of a death could have the same implications for everyone. This implicitly creates a tension between these two arguments.

In conclusion, life expectancy argument might become weak enough when life reaches the end...at the beginning of life, and the rest of one's life is in fact the entire life. We cannot say that the value of life at its beginning is greater than in the end, even if, at least intuitively, the society is more impressed by children's death than of elders. We believe however that this term (life expectancy) does not mean anything more than strictly medical information, with a statistic impact but with no moral content when we have to decide over stopping, extending or strictly treating a disease that might affect our life.

It still remains in question the **(f)utility** argument for the use of extraordinary rescue means for treatment or life prolongation (when it seems that life is at its end). To describe or talk about what is **useful** or **useless** in medical care provided at the end of life is as difficult and fuzzy as in defining ...

justice. There is a very individual perception of what is good, meaning...important or valuable. „Useful“ is something without which our lives would be greatly impaired and things would be walking away from the default path. One can define (f)utility as a probabilistic concept, being difficult enough to assess it accurately. In medicine, useful and useless are attributes strongly shaped by patients' personality, by their desire to live and the values attached to life.

We usually appreciate „the useful“ in relation to objects or actions, but never related to values. An object can be useful or useless, according to its need to be immediately used. Thus, utility is defined in relation to a necessity (or need), even an addiction. Generally, an action is considered futile if it brings no benefits at all. For example, walking is very good for a good health, to most of us. But to those unable to perform this action (either due to a disability, or because of age), this action is meaningless. But if we link all these to our biological life, none of the above definitions presents solid arguments that can be taken into account in decisions regarding life saving, maintenance or prolongation.

The concepts described above (the quality of life, the life expectancy or futility) may contrast with the **sanctity of life** argument. Being guided by Holy Scripture, the thesaurus that transmits the divine revelation, we get to the conclusion that life is the form of existence in which God is expressed as a reality: "In Him was life and the life was the light of men (John 1:4). Creating him, God gave man the opportunity to choose what is best for him, by appealing to reason and sensitivity. The intention was to create the human being according to His image and likeness. But beware: His image does not mean His body

image, but to the spiritual, intellectual and moral aspects, and „likeness” refers to what people may become by practicing the teachings of God, the aspirations and purposes that He send. The church is a traditionally conservative institution, which may justify or reject a human act by making an appeal to a particular dogmas, or spiritual model of the Holy Fathers (Gavrilovici C., 2007). Life, as a gift from God is sacred, but God allowed man to decide upon the acceptance of the sanctity of life, and thus to praise or not this gift.

The sanctity of life in general, and religious beliefs in particular may take advantage over any medical proofs that might clearly demonstrate the futility of a medical treatment. If in adult patients with end-stage incurable disease, the decision of withholding or withdrawing treatment is accepted both morally and legally, in children at the end of their life, the moral aspect weighs more, its sanctity shadowing any notion of futility of medical treatment.

In conclusion, we consider that in a situation as complex as the one presented in this article, namely a child who reaches the end of life, where the question is whether to apply or not extraordinary resuscitation measures to prolong the life only until the family comes at the hospital, the physician will make appeal to HIS right to consciousness. There is no evidence based medical justification according to which such treatment would have any chance of success. On the other hand, to treat the patient as a whole, thus including his family and aspirations, can overpass the most thorough decision strictly based on medical and biological grounds. The role of the ethical “deconstruction” presented by us is NOT to make a recommendation to medical staff that might face similar cases, but to make an invitation to introspection, to confrontation to our „Self” and personal values, because one can help the other only when he/she acknowledges his/her role in life.

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