

Ethical Approach to a Child with an Inborn Developmental Defect and to Its Parents

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Abstract: Fundamental principles of ethics, which form our ethical views, may, in this area, be confronted with conflicts and dilemmas. The crucial principle is to act always to the benefit of the child and in favour of its parents and the whole family. The Helsinki Declaration of Human Rights expressly emphasizes the rights of the child to the detriment of the society. Regarding the attitude of the parents ethical problems do not arise at the moment of birth of their child. They are the result of their lives, of relations within their families and of their system of values. Therefore it is not a surprise to find that each child is born into specific conditions. The unique quality of each human life is determined not only by genetic, but also by so called epigenetic influences. A handicapped child is born into some specific environment, materially and mentally prepared or unprepared. There exists a whole range of problems which enter the process of confrontation with the new reality in the case of the birth of an afflicted child and the solution of these problems requires time. The paediatrician needs the support and cooperation from other specialists: consultants, social workers, spiritual and ethical advisers, etc. The possible shortage of stimuli (insufficient quality and quantity) could lead to the development of secondary frustrations in the child and in the attending staff, which leads to further errors in the care of the afflicted. Social problems and answers to the questions are determined by such notions as quality and dignity of human life. To come to terms with the situation means first of all to take a stand against claims that an afflicted child is a burden to the family and society, that it has a lower quality of life or that principles of eugenics should be taken into consideration in making decisions. The paper discusses possible ethical attitudes and solutions in detail.

Zusammenfassung: *Ethischer Umgang mit einem Kind mit angeborener Fehlbildung und mit dessen Eltern.* Fundamentale Prinzipien der Ethik, die unsere ethischen Ansichten bestimmen, können in diesem Bereich der angeborenen Behinderungen mit Konflikten und Zwiespältigkeiten konfrontiert sein. Das grundlegende Prinzip ist, gemäß dem Wohl des Kindes zu handeln und gemäß dem, was für die Eltern und die ganze Familie gut ist. In der Menschenrechtserklärung von Helsinki werden ausdrücklich die Rechte

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des Kindes gegenüber der Gesellschaft betont. Was die Einstellung der Eltern betrifft, tauchten ethische Probleme nicht erst bei der Geburt eines Kindes auf. Sie ergeben sich auf ihrem Leben, aus den Beziehungen mit ihren Familien und ihren Wertsystemen. Darum überrascht es nicht, daß jedes Kind in ganz spezifische Bedingungen hineingeboren wird. Die einmalige Qualität jeden menschlichen Lebens wird nicht nur durch genetische Einflüsse bestimmt, sondern ebenso durch die sogenannten epigenetischen Einflüsse. Ein behindertes Kind wird, vorbereitet oder unvorbereitet, in ganz spezifische materielle und psychische Gegebenheiten hineingeboren. Es gibt eine ganze Reihe von Problemen bei dem Prozeß der Konfrontation mit der neuen Realität der Geburt eines behinderten Kindes, und die Lösung dieser Probleme erfordert Zeit. Der Kinderarzt braucht die Unterstützung anderer Spezialisten und die Zusammenarbeit mit Beratern, Sozialarbeitern, spirituellen und ethischen Ratgebern usw. Ein möglicher Mangel an Anregungen (qualitativ und quantitativ) kann zur Entwicklung sekundärer Frustrationen bei dem Kind und bei den unterstützenden Personen führen, was zu weiteren Irrtümern in der Versorgung des behinderten Kindes führen kann. Soziale Probleme und mögliche Antworten betreffen die Qualität und Würde des menschlichen Lebens. Um die Situation bewältigen zu können, ist zu allererst wichtig, das behinderte Kind nicht als Last für die Familie und Gesellschaft zu sehen, sein Leben nicht als von minderer Qualität zu betrachten oder an eugenische Maßnahmen zu denken. Dieser Beitrag diskutiert Einzelheiten möglicher ethischer Einstellungen und Lösungen.

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The goal of neonatal and postnatal care is to produce a child who has the best opportunity for social and intellectual development. In the perinatal period there are three common groups of diagnoses in which medical and ethical decisions are most difficult:

- 1) infants with severe perinatal asphyxia,
- 2) extremely low birth weight infants,
- 3) infants with severe congenital defects (including infants with severe inborn errors of metabolism).

The birth of a child with an inborn developmental defect poses for the paediatrician numerous diagnostic, therapeutic, psychological, social and ethical problems. Fundamental principles of ethics, which form our ethical views, may, in this area, be confronted with conflicts and dilemmas. The crucial principle is to act always to the benefit of the child and in favour of its parents and the whole family. (Nelson 1978). A special issue is represented by women where prenatal diagnostics was performed and foetal anomalies (and future congenital malformations) have been detected. Partial-birth abortion performed under the guise of reducing suffering, threatens the best interests of the mother, the family and the infant. An alternative for parents faced with the decision to terminate their pregnancy is (in some countries) perinatal hospice. Perinatal hospice recognizes the value of bringing these infants to term by treating them as human beings conceived with a tangible and non-repeatable future. This alternative is preferred because of post-termination psychological distress and because moral (not only religious) philosophy emphasizes the dignity and worth of each fetus. This opinion is held not only by those in the Judeo-Christian tradition, but also Muslims and numer-

ous other non-religious people. Perinatal hospice can support parents through their grief when their infant dies and maximizes the opportunity for authentic mourning. (Colhoun, Reitman and Hoeldtke 1997).

In the early postnatal period it is first of all the parents who have to cope with the new situation and form their attitudes, which are primarily based on ethical norms and values. It seems that maternal ethnocultural background and philosophical principles may have a more profound influence on medical/ethical decision-making than specific personal life experiences with perinatal problems. (Hammerman, Kornbluth, Lavie, Zadka, Aboulafia and Eidelman 1997). In departments of neonatology and current neonatal intensive care units it is inevitable that ethical decisions on such neonates with a poor or questionable prognosis will have to be made. In some countries (also in Japan) most families are not asked to make the final decision and the ethical committees are not actively involved in such discussion. Staff of the neonatal intensive care unit make the decision after plenary discussion. (Nishida and Sakamoto 1992).

It has to be stated, however, that the attitudes of the parents to their newborn child are not born suddenly with the birth of the child. These attitudes are the result of their lives, of relations within their families and of their system of values. Therefore it is not a surprise to find that each child is born into specific conditions even in similar families. The unique and never-to-be-repeated quality of each human life is determined by genetic, but also epigenetic influences. (Strohman 1993). A handicapped child is born into some specific environment, materially and mentally prepared or unprepared. Everyone who has worked in a neonatal department has experienced the trauma and dismay of the mother on learning that there is something wrong with her child. This first shock is commensurate to how serious and manifest the defect is and how the mother is able to understand the impact of this defect on the child's life, on her life as mother and on the life of the family and that of other relatives. This dismay may be the worse if the mother has undergone routine prenatal diagnostics and has been falsely reassured about a trouble free pregnancy and auspicious expectations and if the physician and other staff have not found time to advise the future mother of the limitations given by sensitivity, specificity and predictability of methods of prenatal diagnostics. Routine (non-specifically ad personam oriented), perfunctory activity on the part of the staff can, due to the lack of time, lead to this shock.

The pediatrician needs the support and cooperation from other specialists. This cooperation is especially demanding in the case of genetically determined pathological states and includes not only a diagnostical examination of the individual, but also of his or her parents and relatives (at an appropriate time). (Scriver ChR, Beudet AL, Sly WS, Valle D, 1995; Hyaneck 1991). These examinations have to be offered, provided and sent to genetic consultations. It is our aim to win the family toust for cooperation even in future potentially difficult periods. Unfortunately, most recommendations and guidelines concentrate predominantly on the specific and theoretical aspect of diagnostics or on the probable character of the result of the examination, leaving the ethical aspect in the background. It is not possible to enumerate all other factors which enter into this process of confrontation with a new reality and which will invariably have impact on the family's life. The family will have to be helped in reorganizing their system of values, modifying their daily

routine and plans for the future. Otherwise there is no end to the questions of why, and why it had to be our child and our family, i.e., some kind of analysis of the causes of the disaster. It all takes time.

In the first place it is important that the parents accept the defect of their child as a fact and that they, in cooperation with a team of experts reasonably evaluate its current condition and its developmental prospects and include these into an optimum program of medical and rehabilitation care, where they should act as protagonists. The parents should be assisted in accepting the fact of life and facing the situation bravely. The change of the term “maternal-infant bonding” to currently using term “parent-infant bonding” reflects recognition of the role of fathers in the parenting of neonates.

It has to be emphasized that the primary shock of the revelation may lead to the situation where the children are endangered by an insufficient quality and quantity of stimuli from the environment, which could lead to the development of secondary frustrations. The child’s affliction may cause tension and stress in the family and substantially raise the demands on the parents, who may turn anxious and sensitive into a lack of interest or lack of understanding from the environment. Sometimes the parents refuse to accept both the child and the assistance, (i.e., they refuse to accept the new reality). This can result in problems and errors in the child’s upbringing. In this respect, upbringing can be

- overanxious
- unduly protective
- spoiling
- perfectionistic or, contrarily,
- resignationistic and
- renouncing the afflicted child.

The pediatrician may have to intervene in the developmental process of the child at an appropriate time. The art of choosing the appropriate time for an intervention is based on his or her experience and knowledge of the afflicted child’s family. The intervention must neither take place too early, nor too late. Although so-called critical developmental periods, as they are known from experiments on animals, cannot be automatically applied to human physiology (ontogenesis) and pathogenesis, gradual and often step-like involvement of enzyme systems and adjusting their lifetime activities as well as adjusting the neurohormonal control mechanisms is a time-limited activity. An opportunity wasted is very difficult to make up for. Sometimes the parents spend a lot of energy and financial resources, simply because of a lack of clear, well-thought-out guidances from the specialist and a team of various experts (e.g., psychologist, rehabilitationist, special pedagogue, social worker, etc.) and all this is due to the lack of, or loss of, mutual trust because of insufficient interest or insufficient or faulty vertical – but mainly horizontal communication. An early examination and detection of a malfunction or defect of sensory organs (mainly sight and hearing) are of paramount importance for the further strategy of developmental rehabilitation, in which the mother will play the main role.

A trauma caused by the affliction affecting the child’s metabolism or organs may lead to slackening of attention and underestimation of the need of proper

and optimal nutrition and thus to further potential damage to the already afflicted newborn. (Avery and Fletcher 1987).

It is a well-known fact that the brain develops until the fourth year of life. One of the things to be borne in mind is the danger of nutritional stress. (Burt 1990). A human brain is extremely sensitive to energy supply and the structure of fatty acids received, as it consumes up to two thirds of the entire energy intake. The mass of the brain doubles in the first year of life. (Nelson 1978). We have now much more information about the structure and formation of cell membranes, maturation of the brain, the eye, peripheral nerves and the immune system, in dependence from omega-3 fatty acids (Bracco and Deckelbaum 1990). Our knowledge of the significance of antioxidants has increased. The new information has emphasized the importance the breast-feeding and proper nutrition not only be emphasized in the perinatal and postnatal periods, and there is more and more talk about the extraordinary importance of proper nutrition for the future mother mainly in the last trimester of pregnancy (Hansen 1994).

The mother herself needs motivation, instruction in rehabilitation, and guidance and support in all her demanding functions. She will undoubtedly hear a lot of advice, like placing the child as soon as possible in an institution and not binding herself and the whole family to the afflicted child and not sacrificing her private and social life. It is unacceptable from the point of view of ethics, if it is the physician who robs the afflicted child of the mother's and parental love, of the love of its relatives, of the feeling of security and safety, the trust and self-confidence so important for the individual and the society. It is certainly appalling, if it is the physician, who exerts pressure on the family to abandon a child. It will not be possible for all the families to accept an afflicted child permanently, however, the physician must always be at the side of the ailing, the weak, the helpless or the undesired. It is his or her professional duty and the ethical mission of the medical profession.

It may not be useless to emphasize the well-known experience that a timely diagnosis and a prompt therapeutic and rehabilitational intervention have significantly greater chances of success than a later one, when:

- 1) the child has already undergone some development
- 2) his or her defect is processed and built-in into the anatomical and functional equipment of the organism
- 3) his or her defect has been incorporated into the psycho- and the personality structure.

On the other hand the fact is sometimes pointed to that time, good will, determination, energy exerted by the the parents, and the team of therapists are precious and must not be wasted, especially where there is no hope of success and should be applied where the patient can be helped. This opinion can be argued against, as unacceptable from the point of view of ethics. On what grounds is anyone authorized to evaluate the need of therapy and rehabilitation and to turn them down as unrealistic? (Horak 1994). At a time when health service is working in a crisis regime according to a system of allocations resulting from the transformation process in the health service and the medical insurance system, such pressures from without or from within exist and represent a professional

and an ethical problem. From the specialist's point of view it is a principal question: to treat or not to treat. Many national societies of neonatology and perinatal medicine have worked out guidelines, so called codices, which specify states that need not be treated. The Dutch neonatologists' codex is widely known.

One of the principal questions is how the afflicted child itself feels about its affliction. The parents of afflicted children are mostly convinced that their child is in great distress. This notion may be true, but not exclusively. These children live their lives with the joys and sorrows typical for the period of life which to us, adults, seems to be the happiest. The anxieties and disillusionments of the adult are often remote to the child's mind. Even if it could be argued against, we should come to the conclusion that the parents and the attending staff should not express their negative or emphatic feelings towards the child in the form of "sympathy" and project on the child their own pessimism and negative thinking and depressive moods. Pessimism and depressive moods are a serious obstacle in the development of the child's personality and a serious impediment to any effort to improve. This is applicable also in the cases where clinical experience and statistical figures indicate a shorter life expectancy.

One of the most important tasks of the rehabilitation of children with an inborn speech impediment is the effort for support of development of speech. (Fitzhardinge 1987). A human being becomes a human being when it learns to speak. Speech is the main connecting element and the most important vehicle for communication in social relations. What we mean by "speech" is the spoken and written language, accompanied by facial expressions and gesticulation. This so-called nonverbal communication (achieved by facial expressions, intensity and tone of voice, gestures, etc.) is of extreme importance as we learn from experiences gained in children's nursing homes. Speech is in its nature an auditory reflex, which evolved from the ability of listening. This could lead to the conclusion that the sense of hearing is the main gateway towards human intellect and development of the mind. To be able to speak, a human being must first be able to listen. Without hearing there is no speech. A child that cannot hear its mother's voice and heartbeat in prenatal and especially postnatal periods is significantly deprived in its emotional development. Predictably, much attention is paid to early diagnostics of auditory defects in the earliest days of the newborn child's life. On the other hand, children afflicted with some other inborn and perinatally acquired defects need equally, or even more, stimuli from the auditory analyzer. We know that there are children who cannot speak and hear (e.g., a result of various inborn metabolic diseases, congenital malformations, neurologic disorders, infection and also for social or educational reasons). We consider an early diagnostics of defects of speech formation, therapy and rehabilitation very important so that we do not concentrate only on the rehabilitation of motoric defects and treatment of metabolic disorders, while neglecting at the same time support of development of speech.

The same applies to eye and sight disorders. Life for a child with an inborn defect of sight is difficult not only due to the impairment itself, but also due to faulty education in the earliest periods of life. We have to bear in mind that a blind child can otherwise be completely healthy. The lack of sight has to be compensated by compensatory senses, namely hearing, touch, smell and taste. (Friendly

1987). The child gets to know the world by sounds which have to be distinguished. It is, however, afraid of space and its world is limited and it suffers from a lack of stimuli. Although the child learns how to pronounce and use words, it is often not familiar with their content and this makes its thinking inconcrete. The names gain concreteness when the child can touch the objects. The development of speech in blind children should be given great attention, with emphasis on the hand and its motion and skin analyzer and receptors. The child uses touch to get acquainted with the space, shape, size, distances and their change.

In this paper we could only mention the most important problems children with inborn defects have to face. We feel it important to point to the ethical component of the physician's work. He or she must understand the whole complexity of problems these children, their parents and families live with in order to be able to contribute to their rehabilitation. For various reasons the former society isolated these children in groups of similarly afflicted. They lived in the confinement of their institutions (often in adapted old buildings) cut off from contacts and communication with other people and everyday life. Today we want to integrate them with the healthy children and we are learning to be aware of their needs and help them find their place in life. This is where the paediatrician's role is irreplaceable as he or she jointly decides the future of these children. At the same time it is necessary to give more support to the family of such child and help create favourable conditions for the development of the child's personality and substitute the incessant "why's" by "how's". If the aim is clearer, it is easier to find the ways to achieve it.

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