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OBSAH / CONTENTS

■ Pôvodné práce/Original Articles	1
- Euthanasia: Some Moral Aspects/Eutanázia: niektoré morálne aspekty <i>H. Watt</i>	1
- The Psychodynamics of Counseling Parents of Infants with Down's Syndrome <i>R. Peuschel</i>	5
■ Retrospektíva/Retrospective	9
* Medzinárodné sympóziu o medicínskej etike/International Symposium on Medical Ethics, Bratislava, 29. - 30. 5. 1992	
- The Euthanasia Debate/Debata o eutanázii <i>D. Callahan</i>	9
- Euthanasia in the Netherlands/Eutanázia v Holandsku <i>H. Jochemsen</i>	12
- Eutanázia v poňatí práva v ČSFR/Euthanasia from the Point of View of the Law in CSFR <i>V. Keseg</i>	14
- Úvaha o eutanázii/Reasoning about Euthanasia <i>M. Fritzmann</i>	15
■ Krátke správy/Short reports	16
- Morálne triedy v škole, morálne deti: prístup konštruktivismu/Moral Classes in School, Moral Children: the Approach of Constructivism <i>M. Glasová</i>	16
- Starostlivosť o rizikové rodiny vo Veľkej Británii/The Care of Families under Risk in Great Britain <i>M. Glasová</i>	17
■ Oznamy redakcie/News from the Editor	19
■ Obsah ročníka 1995/Contents of the Volume 1995	19
■ Objednávka časopisu/Subscription Form	20

PÔVODNÉ PRÁCE / ORIGINAL ARTICLES

EUTHANASIA: SOME MORAL ASPECTS

Helene Watt

The Linacre Centre for Health Care Ethics, London (England)

Abstract

Paper gives an overview of arguments concerning voluntary and non-voluntary euthanasia put forward in connection with debate on the Report of the Selected Committee on Medical Ethics of the British House of Lords, which has taken place since the document's submission (February 1994). *Key words: voluntary and non-voluntary euthanasia, competent and non-competent patients, value of life, obligations of a doctor, rights of patients*

In February 1994, a Report was brought out by the British House of Lords' Select Committee on Medical Ethics, which was set up to examine questions relating to euthanasia and its legalization. Before I move on to a general discussion of the topic of euthanasia, I would like to make a few comments about this Report, as it raises a number of questions which need to be dealt with in the more general discussion.

The Report was widely welcomed by pro-lifers as taking a stand against euthanasia. Due to known or suspected euthanasiast views on the part of various members of the Select Committee, it had been thought by many that the Report would be found to favour euthanasia. For this reason, the Report's condemnation of what it describes as euthanasia came to many as a relief. However, the fact that the Report was unanimous, despite the very different moral standpoints of Select Committee members, raises questions both about the range of issues dealt with by the Report and about the meaning of its recommendations. It is only because certain issues were not dealt with or resolved, and certain statements were understood in different ways by Select Committee members, that an unanimous Report of this kind was able to be produced [1].

Perhaps the most striking feature of the Report is the definition it gives of euthanasia as an intervention: 'a deliberate intervention undertaken with the express intention of ending a life to relieve intractable suffering'. In other words, it is only positive acts aimed at killing the patient which the Report describes as euthanasia, to the exclusion of deliberate omissions aimed at killing the patient. Whereas when it deals with positive acts the Report is rightly concerned with the intention of the agent - with whether or not he means to kill the patient - the Report fails to address the question of omitting to act with the same intention as is present in active euthanasia: the intention of killing the patient. This failure to recognize the possibility of euthanasia by omission is particularly unfortunate in view of the Law Lords' judgement on the case of Tony Bland in February 1993, to the

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effect that deliberately to terminate a patient's life by a planned series of omissions is a lawful, and sometimes obligatory, part of carrying out a 'duty of care' for that patient.

It is true that, on the subject of 'advance directives' made by a patient, the Select Committee Report says that these must not contain requests for any unlawful intervention or omission. However, the Report does not discuss the case of an advance directive made with suicidal intent. Moreover, in dealing with the treatment of competent patients, the Report goes so far as to declare its 'strong endorsement' of the right of the patient to decline treatment for any reason whatsoever. In short, while the Report does make some valuable recommendations - for example, on the subject of palliative care - it fails to address the question of intention in the context of omission which is central to an understanding of what is involved in euthanasia.

To return to definitions: a definition of euthanasia confined to positive acts - that is, to 'active' euthanasia - is seriously inadequate. This is because the aim of a doctor, rather than the means he takes to bring this aim about, is what places his decision within some general class of acts - whether 'euthanasia', 'curative treatment' or 'palliative care'. If the doctor's aim is to shorten the patient's life, there is morally speaking no difference (if we leave aside the question of which will cause more suffering) between killing by means of an intervention and killing by means of an omission. It is euthanasia if the doctor kills the patient by giving him or her a lethal injection, and it is also euthanasia if he omits to feed or treat that patient, providing his intention is to bring about death by one means or another.

If the doctor's intention is not to bring about death, but to do, or refrain from doing, something else, his action may or may not be reasonable in the circumstances, but it is not euthanasia. If, for example, a doctor gives morphine to relieve pain in a terminal patient this course of action will sometimes have the side-effect of shortening the patient's life. Providing the doctor's sole intention is to relieve pain, such treatment is not euthanasia, but rather palliative care. In the same way, if the doctor does not do something - for example, does not carry out some treatment - his omission is not euthanasia if the aim of the omission is not to shorten life.

The definition of euthanasia which I will use in this paper is taken from a Report produced in 1982 by the Linacre Centre for Health Care Ethics [2]. In this Report, there is said to be euthanasia if the death of someone is brought about on purpose in the course of his medical care, on the grounds that it would be better for him (or at least no harm) if he were dead. Euthanasia is, then, an act or omission chosen with the aim of ending someone's life, on the basis of a judgement that this life is not worth living.

It is worth repeating that euthanasia, on this definition, involves a judgment that the patient's life is not worth living: of no value, no 'net' value, all things considered, and/or a negative value. The point needs to be emphasized, because this kind of judgment is not always easy to detect in defences of voluntary euthanasia. Voluntary euthanasia is normally defended with reference to the patient's autonomy - his or her capacity and (it may be added) right to choose the time and cause of his or her death. However, supporters of voluntary euthanasia will generally require more than a simple request from the patient for euthanasia to be administered, in that the doctor in order to act on the patient's request will presumably first have to satisfy him or herself that the patient's life is indeed not worth living. For example, a pro-euthanasia doctor who believed that her patient did not understand his favourable prognosis would presumably feel obliged to refuse the patient's request for euthanasia. Voluntary euthanasia thus involves a situation in which the patient says "my life has no value", and someone else, such as the doctor, accepts this judgement and acts in such a way as to procure the patient's death.

Two further considerations emerge from the fact that

euthanasia requires the one performing it to judge that the life of the person killed is of no value. The first is that if the patient's life is of no value, or no "net" value, then it is hard to see why the practice of euthanasia should be confined to terminal cases. If the patient's life has no value it may surely be terminated, whether the patient is dying or not. The second consideration is that if the patient's life has no value, but the patient is unable to consent to euthanasia (being unconscious, or mentally handicapped, or senile, or simply too young), it is not clear that there is anything to stand in the way of our killing that patient, at least if the relatives give their consent. It is therefore not surprising that many supporters of voluntary euthanasia also support (whether openly or discreetly) non-voluntary euthanasia. For if death is either a benefit, or at least no harm, why should we deny it to those who cannot request it?

In fact some recognition of this theoretical step forward from judging some human lives to have no value can be seen in the practice of euthanasia in the country in which it is widely tolerated. Holland is often thought of as the home of voluntary euthanasia; however, there is no doubt as to the prevalence of non-voluntary euthanasia in Holland. The Rummelink Report published in 1991 referred to a survey on "medical decisions concerning the end of life" which had been made in the previous year: a survey which found that in 26,350 cases doctors had acted, or refrained from acting, either "partly with the purpose of shortening life" or with the "explicit purpose of shortening life" [3]. In 10,558 cases doctors had acted, or refrained from acting, with what was called the explicit purpose of shortening life, and of this last group 5,450 patients had been killed without their explicit request. It is interesting to note that when a few years ago a Dutch doctor was accused of carrying out non-voluntary euthanasia on patients in an old persons' home, his reported actions were defended by prominent members of the Dutch Medical Association and the Voluntary Euthanasia Society, one of whom claimed that if the doctor were sent to jail for killing his patients doctors all over the country would feel insecure. Clearly, if doctors in Holland have the explicit intention of killing 5,450 patients a year without their request, the doctors involved will want to feel that they can carry out their duties with legal immunity. They may already feel they can carry these out with moral immunity, since once death is seen as a benefit, or at least no harm, there would appear to be no reason in principle - or none relating to the patient - to deny it to those who cannot request it.

Of course, a similar position is accepted both in theory and in practice by growing numbers of doctors in this country. Not only is abortion now permitted up to birth on grounds of mental and physical handicap, but infants with mental and physical handicaps are sometimes deprived not only of basic medical treatment but of food, if the parents give their consent. Infants with mental or physical handicaps may be sedated so that they do not demand feeding, and given what is described as "nursing care" or "custodial management" until such time as they die. Parents will often be shocked and confused after the birth of a handicapped child, and in the absence of positive support may be disposed to accept what amounts to an offer of euthanasia. Doctors may believe euthanasia will benefit the parents whether or not it will benefit the child, who will, in many cases, have a handicap no more distressing than Down's Syndrome.

If the life of a patient, young or old, can have no value, or no 'net' value, there will be nothing in principle - or nothing relating to the patient - to stand in the way of killing, not for the sake of the patient, but for the sake of the patient's relatives. If the patient's relatives, or even the State, are seen as having an interest in the patient's death, there will be no recognition of the value of the patient's life to count against this presumed interest on the part of other people. Thus when Tony Bland's case was discussed by the media stress was laid not only on the supposed worthless-

ness of Tony Bland's existence in a Persistent Vegetative State, but on the suffering this caused his parents, and the desirability of putting an end to this suffering. While it is certainly true that to see one's son or daughter in a PVS can be a cause of real suffering, it is surely remarkable that the suffering of others should be used as an argument for ending the life of an innocent person. One might also question whether the experience of having been responsible for the death of their son has really been beneficial to Tony Bland's parents, as it was predicted that it would be.

In the case of serious mental handicap in particular, it is sometimes claimed not so much that the patient's life is not worth living, but that there is no life, or no "personal" life, in the case of the patient concerned. Thus Tony Bland's body was described by one of the judges of his case as a "shell" from which his soul had flown. This is despite the fact that Tony Bland's brainstem was functioning, that he was breathing spontaneously, his heart was beating, and so on. Clearly, the judge's view was that a person was a separate entity from a living human organism – a view which many philosophers (and others) reject as incompatible with our experience of ourselves and each other as bodily beings.

Those philosophers with dualist inclinations will sometimes distinguish between what they regard as 'personal' or 'human' life and 'mere biological' or 'vegetable' life. However, it can be argued that every human being has a single human life – not a vegetable life plus an animal life plus a personal life. Human life can be either healthy or unhealthy, but it is always the life of a human being. The human being, or person, who thinks and talks is the same human being who breathes, sleeps and is unconscious. And whether or not the most important part of the human being – the soul – survives our death, the death of the human being or person cannot be separated from the death of the living organism.

While it is sometimes claimed that a living patient is dead, or "dead as a person", it is perhaps more common to accept that the patient is still alive, but to argue that his or her life has no value. In other words, the lack of experience, or the presence of suffering and/or handicap, can deprive some human lives of any value at all. It is the short-term capacity for a certain kind of experience which gives value to the life. In defending such a view, a judgement must be made as to which capacity, and what degree of that capacity, is required for human status. If the capacity judged to be required is one which may exist in degrees in degrees, we must either ascribe higher and higher moral status to those with greater and greater capacities, or else we must draw an essentially arbitrary line by which we separate "human" from "not yet" or "no longer" human beings. In any case, after losing the relevant level of capacity, a life will be taken to have lost any value it once had. On such a view, there is no fundamental, intrinsic value to every human life. Rather, value and 'dignity' are features some human lives have, and others don't.

It must be recognized that this view is a radical departure from the traditional valuation of human life: radical both in itself and in its implications when it is used as the basis of law. Someone accused of killing another human being can say: "I admit I took a human life – but it was a life with no value". We should note that this is not the way in which, for example, killing in self-defence is rightly seen as justifiable. If I kill a person who is trying to kill me, this is quite compatible with my recognizing the value of the life of my aggressor, which I endanger only with reluctance on the grounds that he or she has deliberately chosen to endanger my own. To kill a person on the grounds that his or her life has no value is to demonstrate an attitude to human life not found elsewhere in justifiable homicide.

What, then, is the basis for rejecting killing on the grounds that life has no value? The basis is the fact that human beings are in possession of a fundamental human dignity which cannot be eliminated. They have this dignity in virtue of their nature – in virtue of the fact that they are human be-

ings, with the radical capacity of human beings to participate freely in the goods appropriate to human beings: goods such as life itself, knowledge, friendship, aesthetic experience, and so on. Clearly, not all human beings have the exercisable ability to participate freely in human goods other than life; however, all human beings have, by virtue of the fact that they are human beings, the radical capacity to participate freely in human goods other than life. A young human being acquires the ability to participate freely in further human goods by virtue of the radical capacity he or she possesses from conception. And a sick or damaged human being, who no longer has the exercisable ability to participate freely in human goods other than life nonetheless retains the radical capacity to participate in further human goods by virtue of his or her nature – that is to say, his or her possession of a rational human soul, or life-principle. Human beings therefore have inalienable dignity by virtue of their nature, such that it is always important that they participate in the goods appropriate to the kind of thing they are. Among these goods is the good of life: the good of human bodily existence. It is never something bad in itself, or a matter of indifference that a human being is alive; the lives of human beings have inalienable value.

The claim that human lives have inalienable value does not signify that human lives are equal in the good things they contain. There is no need to deny that some lives contain more of certain good things than others. Some lives are, for example, longer than others, and/or healthier, or more creative, or more altruistic. What the claim that human lives have inalienable value signifies is that beneath these variables there exists a fundamental value which is found in every stretch of human existence.

The word "value" is sometimes used to refer to whatever happens to be valued by a person. Here I am referring not to such "subjective" values but to real, objective values. I might value the pleasures of power and of causing pain to others, but these pleasures – unlike the values of life, knowledge and friendship – will do me no real, objective good. The existence of such objective human values as life, knowledge and friendship is something of which we are all aware: something so fundamental that we do not derive our awareness of these values from our awareness of anything else.

What is being claimed, then, is that there is an objective, fundamental value to any amount of any human life, which produces at least the prohibition of an intention to bring about death on the grounds that life has no value. What steps we must take (assuming we are not trying to kill the patient) to preserve the patient's life will depend on such variable factors as the patient's future health and life-expectancy. If the patient has just a few days or hours to live, I may not be obliged to do anything to prolong the patient's life, providing I at no stage have the intention of accelerating the patient's death, whether by act or by omission.

It is not a corollary of the value of every life that every life must be extended by every possible means. However valuable my life, I cannot demand a life-saving drug costing a million pounds an injection. Then again, I have no obligation to accept means of prolonging my life which are too burdensome for the benefits they bring in terms of life expectancy, or improvement of my condition. Once it has been determined that a patient has begun to die the benefits of any postponement of this by treatment must be carefully weighed against the burdens the treatment in question may impose. There is no lack of respect in providing terminal patients with palliative care, rather than burdening them with treatment which in their case will not be sufficiently effective.

If a patient is in the terminal phase of dying there will be cases in which even feeding may be withdrawn, either because food can no longer be assimilated by the patient, or because feeding is too burdensome for the slight prolongation of life it may achieve. If a patient is not in the terminal phase of dying, feeding, whether by spoon, by straw or by tube, will

always, or almost always [4], be "ordinary", or obligatory care.

There has been much debate as to whether tube feeding may be withdrawn not only from patients close to death, but from patients in a persistent vegetative state. It is sometimes argued that if a respirator may be withdrawn from a PVS patient, so too may tube feeding. There is, however, an important difference between ventilation and tube feeding, in that providing oxygen for other human beings forms no part of our normal care for others (at least after the prenatal period). In contrast, providing food for those who cannot feed themselves, due either to immaturity or to disease, does form, from time to time, a part of our normal pattern of care. Tube feeding is a simple extension of this normal pattern of care. For this reason tube feeding is less likely to become an optional means of support than is artificial ventilation. And whereas some methods of feeding bypass more functions than others and are therefore more 'artificial' than others (for example, intravenous as opposed to tube feeding bypasses not only manual feeding but also digestion) we should remember that spoon-feeding a person who has broken both his arms bypasses one failed bodily function - the ability to feed oneself manually. The fact that spoon-feeding bypasses this function does not make spoon-feeding burdensome care, much less high technology medicine.

Tube feeding also bypasses a failed "manual feeding function" and sometimes a failed swallowing function. (The patient may be able to swallow but fed by tube for the convenience of the hospital). Even where tube feeding does bypass a failed swallowing function, as well as a failed manual feeding function, this does not mean that pouring food down a tube become at this point burdensome care and/or high-technology medicine. Tube feeding of those who cannot feed themselves is basic nursing care (and is often given at home).

The refusal by a competent patient both of treatment and of basic nursing care is often discussed in terms of a need to respect the patient's autonomy. When we talk about autonomy, it is important to remember the point of autonomy, or the faculty of making rational choices, which is that we are able to make choices which promote our own well-being and the well-being of others. A patient who neglects to take reasonable care of his health is making bad use of his autonomy. However, since he is the primary person responsible for promoting his well-being, the doctor may have to limit him or herself, as long as the patient is competent, to attempts to persuade the patient to accept either treatment, or basic care and feeding. In failing to override the patient's refusal, the doctor is not guilty of euthanasia, providing the doctor does not co-operate with the patient in the sense that he or she aims at the patient's death.

In the case of a patient who is now incompetent there is no autonomy to consider, and care and treatment should not be withheld solely on the grounds that the patient requested this when competent - for example, by means of a "living will". After all, the patient's reasons for requesting the withholding of treatment or care may have been suicidal, in which case the doctor's later omissions may constitute complicity in suicide. Moreover, it seems unreasonable to hold that while a patient is competent that patient may change his or her mind at any time, but that no change of plan, even in the patient's best interests, may be made by others after loss of competence.

The doctor may, of course, withhold treatment on the grounds that this treatment is, for example, too painful, or too expensive, for the benefits it will bring. There would be no objection to a doctor's using a living will as evidence that a patient would find a certain treatment particularly burdensome. Objections would arise if the doctor were to carry out blindly all instructions, however unreasonable - for example, to give the patient a lethal injection, or alternatively, to give the patient every form of treatment available, however burdensome or futile. Whether or not doctors are legally obliged to respect living wills and other advance directives,

there is a good case for saying that doctors have a moral obligation to treat an incompetent patient according to his or her best interests. While a competent patient has the primary responsibility for his or her own life and health, an incompetent patient should be treated not on the basis of what he or she is thought to have wanted in the past, but on the basis of good medicine. It is not good medicine to refuse basic care on the grounds that the patient - perhaps many years before - has asked that this be done. Nor is it good medicine to share the patient's earlier intention that his or life be deliberately ended, on the grounds that this life has no dignity.

To **conclude**: the opponent of euthanasia holds that all human life has dignity; that dignity (at least in one sense of the word) is not the kind of thing a human being can gain or lose. The dignity of the patient is acknowledged by the provision of medical treatment where this will be sufficiently beneficial, and palliative care when it will not. This dignity is not respected by the choice of euthanasia, which assumes that a person's bodily existence can have no dignity or value. The practice of euthanasia can be expected to have a deeply harmful effect on the character of doctors, and on their relationship even with those patients they do not yet consider eligible for euthanasia. In contrast, doctor-patient relations are protected by the doctor's recognition of the principle of respect for human life: a principle which forms the basis not only of traditional medical ethics, but of general human justice.

References

- [1] Gormally, L.: 'The House of Lords' Select Committee and the Legalization of Euthanasia'. *Cath. Med. Quarterly* (London), 45, 1994, 1, p. 5.
- [2] Republished with other material in: Gormally L. (Ed.): *Euthanasia, Clinical Practice and the Law*. The Linacre Centre, London, 1994. This paper (which was delivered to the LIFE national conference on 9/10/94) is intended largely as a summary of arguments set forward in this volume.
- [3] See *Euthanasia, Clinical Practice and the Law*, p. 219 - 240.
- [4] In the case of food shortage (for example, in disaster relief) where food cannot be given to all those who need it, it is reasonable to give the food to those who have a greater chance of survival.

H. Watt: Euthanasia: Some Moral Aspects/Eutanázia: niektoré morálne aspekty, ME&B, 2, 1995, 4, p. 1 - 5. Práca podáva prehľad argumentácie týkajúcej sa dobrovoľnej a nedobrovoľnej eutanázie, ktorá vyzerala v súvislosti s debatou po predložení Správy Zvláštného výboru pre medicínsku etiku kreovaného Britskou snemovňou lordov o legislatívnej problematike eutanázie. *Kľúčové slová: dobrovoľná a nedobrovoľná eutanázia, kompetentný a nekompetentný pacient, hodnota života, povinnosti lekára, práva pacientov.*

Address for correspondence: Dr. Helene Watt, The Linacre Centre for Health Care Ethics, 60 Grove End Rd., London NW8 9NH, England

THE PSYCHODYNAMICS OF COUNSELING PARENTS OF INFANTS WITH DOWN'S SYNDROME

S. M. Pueschel

Child Development Center, Department of Pediatrics, Rhode Island Hospital, Brown University School of Medicine, Providence, Rhode Island (USA)

Abstract

Paper deals with psychodynamical and ethical aspects of counseling parents of infants with Down's syndrome. The conceptual framework of this paper is based upon experiences obtained during a longitudinal study of developmental parameters in young children with Down's syndrome enrolled in a program of comprehensive care and stimulation at the Developmental Evaluation Clinic of Children's Hospital Medical Center, Boston. (Abstr. ed.)

Key words: Down's syndrome, parents counseling, psychodynamics and ethics.

Professionals working with mentally handicapped children face the ever-present problem of how best to counsel parents. In particular, the physician encounters a dilemma after he has made the diagnosis of Down's syndrome in a newborn baby. There is no completely satisfactory way to tell parents that their child has Down's syndrome. The most difficult task of informing parents of the diagnosis demands tact, wisdom, compassion, and truthfulness. The physician's ability to communicate his message in a sympathetic and supportive manner is a vital influence on the parents' attitude and subsequent adjustment.

Although the physician also might experience feelings of sadness and disappointment, he must attempt to provide assistance, counsel, and comfort and thus help the parents in their acute distress (1).

Since in most instances the physician is the first person consulted, he is in a unique position to establish a professional relationship with the parents, meeting their anxieties with considered attention relative to the immediate situation and also to effective long planning. Commonly the physician is looked upon as an authoritarian figure and consequently a dependent relationship evolves.

Learning that their newborn is a child with Down's syndrome is an utmost traumatic experience for parents. A joyously awaited event is transformed into one of catastrophe with its inherent profound psychological threats. Nine months and more of hopes are shattered in seconds. The fear of failure, often a normal part of psychic anticipation of parenthood, here turns into reality. During this **initial period of shock** disturbance of personality integration and cognitive dysfunction become apparent and regular defense mechanisms often prove ineffective. Acute anxiety, disbelief and desperation are usually observed during these first days and parents are beset with fantasies and fears. Later, **grief, mourning and intense guilt feelings** prevail and parents search within themselves for nonexistent answers "How did it happen?", "What have I done?", "Why has it happened to me?", "Why?". A gradually developing awareness of the 'los', feelings of sadness and helplessness take over. Other emotional responses are feeling of inadequacy and shame, those of retribution and punishment, as well as self-pity and self-protective aggressiveness (2). Occasionally, rejection of the child and death wishes are expressed and, not infrequently, anger towards the physician is displayed. While some physicians may be blunt and unsympathetic in their counseling, the parents' anger is more often generated by the "bad news" and might not be aimed directly at the physician who may only serve as a scapegoat.

Garrand and Richmond described the **psychological adaptation** in such a crisis situation to progress in **three stages**: First one observes the *initial emotional desorganization*. This is followed by the process of *reintegration*, when psychological defenses become increasingly mobilized. Later, during *mature adaptation*, parents can face most of the realities then with a minimum of continued stress (3). This simplified concept - with time being a most important factor - holds true in most instances. On occasion parents do not progress to the stage of mature adaptation; but because of preexistent psychopathology they absorb and utilize the child and his problem in their own neurotic processes.

Although there are common patterns, each parent lives through and adapts to this crisis in modified ways. Attitudes are influenced by the individual parents' strength, emotional stability, maturity, and by their previous life experiences. Furthermore, cultural, educational, religious and philosophical differences affect the observed emotional responses. The extent of the preoccupation with their own feelings also determines the parents' behavior symptomatic of stress situations and their relationship with the immediate environment (4).

The physician should be aware of the general **needs and reactions of parents** as well as the uniqueness of the particu-

lar situation with which he is confronted. To respond appropriately to the parents' emotions, it is helpful for the physician to have a basic understanding of the processes of adaptation, the symbolism of behavior in stress and an insight into the application of defense mechanisms. Reports from the literature on crises theory describe the individual's vulnerability and accessibility to the influence of persons in the immediate environment (5, 6). Rapoport emphasizes three aspects leading to a **resolution of the crisis** (5): 1. Correct cognitive perception of the circumstances; 2. Management of disordered affect through appropriate verbalization and awareness of feelings; 3. Development of patterns of seeking and using help.

In order to **plan** for the **counseling** situation **effectively**, the following **questions** should be considered: *When and where should parents be informed? Who should talk first with them? How should they be told? What terminology should be used? What kind of recommendations should be made?*

It is generally accepted that when parents are to assume responsibility for making decisions they have a right to all available **information** about their offspring. Consequently, as soon as a definite diagnosis has been made, the parents should be notified. This principle is supported by other investigations exploring this question (7, 8, 9). As Drillien and Wilkinson reported, a full explanation given early, with support thereafter, appears to facilitate the mother's acceptance of and adjustment to her child's handicap (8). Carr's work yielded similar impressions in that parents who were given the basic information soon after the birth of their child with Down's syndrome in an honest and sympathetic manner tended to be more satisfied (9).

Other authors have claimed, however, that telling the parents "before they have become attached to the child" may not only prevent the formation of a close bond but also precipitate early and permanent rejection (10). Key is of the opinion that nothing is gained by making the diagnosis known to the parents immediately after the birth of their child (11). Yet, a **delay in informing** the parents may well lead to misunderstandings and undermine their trust and confidence in the guiding physician. If parents learn about their baby's condition from inappropriate sources, or in a distorted or incomplete fashion, the doctor-parent relationship is in jeopardy. On occasion a definite diagnosis cannot be made soon after birth, but parents should then be informed of the involved suspicion. A prompt chromosomal analysis should provide an answer within 4-5 days by present techniques.

The parents should have an opportunity to see the child prior to being informed, otherwise they are frequently afraid to look for fear that the child's appearance may be markedly deviant and that he might have grotesque features. Should the parents show apprehension in viewing their baby and express fear of becoming involved with the child, it is advisable to explore the nature of their fears since often unrealistic fantasies regarding the diagnosis might exist.

The circumstances surrounding the **first meeting with the parents** should be thoughtfully arranged to allow privacy and adequate time for discussion. It would seem most appropriate that both parents be present during the first session as they can offer support to one another. Some physicians prefer to inform the father initially (12). Others let the mother know of the diagnosis while still in the delivery room. Preferably, one should avoid that one parent has to bear the stressful load alone or even be responsible for informing the spouse.

In the present study parents frequently commented that, unfortunately, their **obstetrician** did not participate in counseling them, since they had considered their relationship with him as important. One mother stated bluntly "my baby suffered the first rejection at the hands of the obstetrician." A prima gravida mother may have had no previous contact with the pediatrician, yet a trust relationship with the obstetrician has been established during the prenatal period.

A coordinated effort in the initial counseling session by both specialists would be advisable.

In stressing the **physician's role** in the process of counseling, he is by no means the only professional engaged in such activities. Olshansky stated "Some physicians may not even do a very good job in telling parents what has to be told." (2) Although the physician will be looked upon as the primary source of information, he should consider utilizing the assistance of a **social worker** who is likely to be better trained in counseling parents and has more insight into family dynamics. The social worker has a greater knowledge of available resources and will be better equipped to pursue careful exploration directed toward an acceptable solution for the whole family. A team approach of social worker and physician should lead to a more positive interdisciplinary collaboration and will find ready acceptance by the parents.

It is also important that the **nursing staff** in the maternity hospital be supportive and display sensitivity by using appropriate terminology, supplying factual information, if needed, and facilitating contact with their child. One mother in this study talked favorably of the nurse who "let the baby stay with me longer and let my husband hold him".

There are others who might help a parent overcome the loneliness and isolation: the father and mother of an older child with Down's syndrome will be able to share their experiences in caring for such a child within the family and can give invaluable suggestions and practical information pertaining to many aspects of his development and management. Often these **resource parents** are apt to be more sensitive to the concerns of new parents. Offering them one family's experience in resolving such a crisis provides living proof to them that it is possible to 'survive' such a stress situation.

The **initial counseling session** might well be brief, without going into details, since the troubled parents ordinarily can assimilate only a few of the implications presented to them (13). During this first interview an intense emotional interchange occurs which disrupts logical thought processes and allows only a limited transfer of actual knowledge (14). Since hope, denial, and other defense mechanisms often help parents sustain emotionally during the period of their adjustments, the physician's discussion should be timed to coincide with the gradually increasing parental capacity to master additional realities. **Follow-up sessions** are mandatory in which a review of basic considerations is made, and more details are communicated. During subsequent meetings parents also can better articulate their feelings and formulate their questions more effectively.

The parents should be informed of the **meaning of the diagnosis**. It should be explained to them why the term Down's syndrome is preferred over the offending misnomer of "mongoloid, mongolism, and mongolian idiot", which might be more familiar to them but which conjures up unfortunate stereotypes. The term retardation also needs to be explained as this is frequently interpreted to mean that the child will be completely helpless. Physical characteristics and their relative frequency in Down's syndrome should be pointed out as well as the implications of additional congenital anomalies which may be present. The anticipated development of the child should be discussed, supplemented by making available illustrated reading materials. The parents should be advised that the motor function, mental development and language acquisition will be retarded, but that there is considerable individual variation and no definite prognostic statements about the future can be made. Evasive answers or provision of false hopes are no substitute for truthful empathetic guidance. Parents will not respect the counselor less because the answer to a given question is unknown.

One should emphasize that the child with Down's syndrome is an individual with characteristics apart from the "stereotype", that he is first and foremost a child. In presenting him as a human being with all the inherent rights the physician shows a genuine concern for the child for whom

he will be providing the same general care he is giving to other children and this endows the infant with **significance and worth**. In many ways his care will be like any other infant and he will have the capacity to be affectionate and socially responsive. Some parents in this study mentioned that "there is happiness in the family with a child with Down's syndrome", which, however, is difficult for parents to conceptualize during the initial period of adjustment when "there are no smiles." Then parents are in need of sympathetic endorsement of their human and parental competence. The critical role of parenthood should be stressed, the chance for an infant to be nurtured and loved by caring parents, as well as the evolving needs of the child with Down's syndrome as he matures and his basic human rights, should be pointed out (15).

Many professionals find it difficult to **see positives** in the child with Down's syndrome and become apprehensive if parents verbalize positive feelings and describe assets. They attempt to deal with this by overemphasizing negatives. In many situations this seems to be based on the professional's own biases and personal value judgements. Some physicians also might fear that the parents do not fully recognize the extent of their child's limitations. Yet, in order to care for any child parents do need hope and encouragement to see positive aspects to which they can relate in order to overcome fears and anxieties. The physician should attempt to identify and mobilize strengths which the parents reveal in their efforts to adapt.

After the chromosomal analysis has been performed, the results should be explained in simple terms and, accordingly, **genetic counseling** should be offered. Information should be provided in regard to the risk involved in future pregnancies, and the availability of amniocentesis should be discussed. Questions relating to the cause are inevitably raised. It is important to point out that neither mother nor father can be considered to have been at fault. Overpowering guilt feelings can, on occasion, be destructive to future family life or may lead to a disturbed parent-child relationship. Furthermore, it the physician's obligation to tell the parents that there is no cure or effective treatment available at this point time. They should be warned about false claims of unconventional treatment approaches. It should be emphasized that professional support and appropriate education will be forthcoming and should be of benefit to the child and his family.

The **impact upon family life** in general and the positive as well as negative effects on the siblings will also enter into the discussion. Parents may wish to protect their other children by not talking to them of the misfortune, feeling that this will effect their social status and future of their other children. Parents should be encouraged to inform them, since even very young children are sensitive to their parents's distress. Their fears might be far greater than realized by parents and exceed the existing reality. While talking of the birth of their child is a painful experience, since it acknowledges that their child is 'abnormal', lack of openness can lead to further isolation of parents and promote unrealistic concerns. Talking about this event to their children, relatives and close friends often relieves distress, provides mutual support, and allows for comfort from people with whom the parents have close relationships. In doing so they are, however, required to cope with attitudes and feelings of relatives and friends, sometimes even before they have come to grips with their own feelings. Parents should be made aware of possible **resources available** in the community and that there is a parents' association for retarded children.

Giving the parents a diagnosis cannot be an end in itself. Unless it leads to appropriate **future planning**, guidance and **support**, it will have failed in its main objective of securing realistic goals and an accepted place in the family for the child with Down's syndrome. Here, the physician plays a significant role in his continuing care of the child, focusing on deve-

lopmental aspects as well as realistic adjustment of the family.

Some physicians might introduce the thought of **residential placement** of the child. Usually the parents are shocked by this suggestion. On other occasions parents themselves might ask for information in this regard, in search of alternatives. Some might welcome the physician's suggestion for institutionalization as an opportunity 'to escape'. Parents, however, should know that an unqualified dictum for institutionalization will have profound and long-lasting implications for both the child and the family. The child living in a residential facility cannot be expected to achieve and develop as well as his counterpart in the home (16, 17, 18).

Less than in the past, today some physicians still recommend placement of the child with Down's syndrome without being informed of the availability, quality and cost, not to speak of the detrimental forces acting upon the developing organism. The advocates of early institutionalization often bring into the discussion as their objective the prevention of attachment of the mother to the child, ignoring the fact that there has already been 9 months of hope and attachment to the unborn child. Other unsupported reasons for the recommendations of residential placement include that there is profound retardation in the child, that he will never do anything. Some physicians might want to protect the parents, assuming that parents who do not see or touch the baby will be less involved. It can also be noted that unrealistic teaching in many medical schools decades ago which stressed that an institution is the best place for a child with Down's syndrome, might be in part responsible for the observed negative feelings of some older professionals toward retarded children. Other arguments point to the child with Down's syndrome as a destructive force in family life, in particular as a detrimental influence on the brothers' and sisters' future. There are indications, however, that siblings of retarded children who have been institutionalized at birth are often preoccupied with unrealistic concepts of what the absent child might be like and they may be fearful that their parents may plan a similar fate for them if they do not meet their expectations.

These views concerning institutionalization of children with Down's syndrome show little insight into the complex situation surrounding the birth of such a child. From the psychological point of view one might say that in many instances institutionalization obliterates a situation that professionals consider unbearable. Few opportunities for placement are actually available since most public facilities refuse admission of infants with Down's syndrome.

Unless there exists a relevant and serious medical, social and/or psychological condition, children with Down's syndrome should be nurtured in a home environment. Should the child care and involved stress create an unfavourable atmosphere for further progress in the home and for family integration, other alternatives such as foster home placement should be explored. Yet, this suggestion might be threatening to some parents as it may imply that someone else is willing to undertake a task which they do not dare.

It is the professional's obligation to inform the parents and to assist them in arriving at an acceptable realistic solution; it should never be the decision of the professional alone to place a child and he should never so influence the parents that they feel no other choice than sending the child to a residential facility. The physician only can offer guidance and factual information. He cannot be a substitute parent and he cannot accomplish the adaptation and achieve the solution of parental conflict which must derive from the parents who themselves must come to terms with reality and their own feelings. He may offer alternative suggestions in an attempt to broaden the parents' perspective and problem-solving repertoire, but he should encourage the parents to independent decision making. Whatever solution they finally reach after careful consideration of the multiplicity of issues at hand, this then deserves the thoug-

htful support of the involved professional personnel.

Since institutionalization can be viewed as an irrational recommendation and often is not available, what then should the physician offer to the parents? The "take-the-baby-home-and-love-him" concept, most often practiced today is not aiding the parents who would like to know what they can do to help their child. Because appropriate community resources often being unavailable for infant and small children, continuing professional support being scarce, and placement of the child undesirable, there exists an apparent vacuum in the provision of services for the family with a young child with Down's syndrome. Parents are in need of professional guidance in relation to training techniques and the recognition of developmental readiness. Well instructed parents are able to provide appropriate stimulation and can constructively engage in the teaching of the basic skills of daily living (19). Hence, contributing to the development of the child's potentialities, parents experience a sense of satisfaction which fulfills their own needs while at the same time they respond to the child's needs. Unfortunately there are only a few programs for children with Down's syndrome in the country where comprehensive care is provided, including stimulation programs, education for parents, medical and full supportive follow-up. Such community-based programs are urgently needed.

Peuschel, R.: The psychodynamics of counseling parents of infants with Down's syndrome. ME&B, Vol. 2, 1995, No. 4, p. 5 - 8. Práca sa zaoberá psychodynamickými a etickými aspektmi poradenstva rodičov detí s Downovým syndrómom. Koncepcná osnova príspevku je založená na skúsenostiach získaných počas dlhodobého longitudinálneho sledovania vývinových parametrov u malých detí s Downovým syndrómom zahrnutých do programu komplexnej starostlivosti a stimulácie na Oddelení vyhodnocovania psychodynamického vývinu Detskej nemocnice v Bostone. (Abstr. red.) *Kľúčové slová:* Downov syndróm, poradenstvo rodičom, psychodynamika a etika.

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The conceptual framework of this paper is based upon experiences obtained during a longitudinal study of developmental parameters in young children with Down's syndrome enrolled in a program of comprehensive care and stimulation at the Developmental Evaluation Clinic of Children's Hospital Medical Center, Boston. Basic information was gathered during individual interviews with more than 200 parents of newborn Down's syndrome children, from discussions in group meetings, and from responses of 340 questionnaires which had been sent to parents of older children with Down's syndrome pertaining to circumstances at the birth of their child.

Address for correspondence: Prof. S. M. Pueschel M.D., Ph.D., M.P.H., Child Development Center, Department of Pediatrics, Rhode Island Hospital, Brown University School of Medicine, Providence, Rhode Island, USA

Medzinárodné sympóziu o medicínskej etike/International Symposium on Medical Ethics, Bratislava, 29. – 30. 5. 1992

*V máji 1992 sa uskutočnilo v Bratislave v priestoroch Kongresového centra "Istropolis" významné podujatie s medzinárodnou účasťou - Medzinárodné sympóziu o medicínskej etike/International Symposium on Medical Ethics. Organizátorom sympózia, ktoré sa konalo pri príležitosti Svetového Pro-Life kongresu (World Pro-Life Congress, Bratislava, May 28 - 31, 1992), bol Ústav medicínskej etiky a bioetiky IVZ a LFUK v Bratislave. Sympóziu prinieslo rad zaujímavých pohľadov na viaceré konkrétne etické problémy súčasnej medicíny a zdravotníckej starostlivosti, mnohé v podaní významných osobností slovenskej a českej medicíny a bioetiky, i viacerých hostí zo zahraničia. Pokračujeme v postupnom uverejňovaní dostupných textov jednotlivých odborných príspevkov prezentovaných na sympóziu v tejto novej rubrike nášho časopisu. Veríme, že týmto spôsobom aspoň čiastočne splatíme dlh voči autorom prednášok a aktívnym účastníkom sympózia, ako aj voči našej lekárskej a zdravotníckej verejnosti.**

THE EUTHANASIA DEBATE

D. Callahan

The euthanasia debate is not just another moral debate, once in a long list of arguments in our pluralistic society. It is profoundly emblematic of three important turning points in Western thought. The first is that of the legitimate conditions under which one person can kill another. The acceptance of voluntary active euthanasia would morally sanction what can only be called "consenting adult killing". By that term I mean the killing of one person by another in the name of their mutual right to be killer and killed if they freely agree to play those roles. This turn flies in the face of a long-standing effort to limit the circumstances under which one person can take the life of another, from efforts to control the free flow of guns and arms, to abolish capital punishment, and to more tightly control warfare. Euthanasia would add a whole new category of killing to a society that already has too many excuses to indulge itself in that way.

The second turning point lies in the meaning and limits of self-determination. The acceptance of euthanasia would sanction a view of autonomy holding that individuals may, in the name of their own private, idiosyncratic view of the good life, call upon others, including such institutions as medicine, to help them pursue that life, even at the risk of harm to the common good. This works against the idea that the meaning and scope of our own right to lead our own lives must be conditioned by, and be compatible with, the good of the community, which is more than an aggregate of self-directing individuals.

The third turning point is to be claim being made upon medicine: it should be prepared to make its skills available to individuals to help them achieve their private vision of the good life. This puts medicine in the business of promoting

* Engl.: *The International Symposium on Medical Ethics (May 29 - 30, 1992) was held at the Bratislava Congress Centre "Istropolis" on the occasion of the World Pro-Life Congress, Bratislava 1992 (May 28 - 31, 1992). The organizer of the Symposium was The Institute of Medical Ethics & Bioethics of the Postgraduate Medical School and the Medical Faculty of Comenius University, Bratislava. The papers presented at the Symposium brought in a number of interesting views on many aspects of important ethical problems of contemporary medicine and health care. Several outstanding personalities of Slovak and Czech medicine and bioethics, as well as distinguished guests from abroad lectured in the Symposium, attended by about 500 participants. We continue in publishing of the available texts of papers presented at the Symposium in this new heading of our journal (started since ME&B 3/1995).*

the individualistic pursuit of general human happiness and well-being. It would overturn the traditional belief that medicine should limit its domain to promoting and preserving human health, redirecting it instead to the relief of that suffering which stems from life itself, not merely from a sick body.

I believe that, at each of these three turning points, proponents of euthanasia push us in the wrong direction. Arguments in favor of euthanasia fall into four general categories, which I will take up in turn: (1) the moral claim of individual self-determination and well-being; (2) the moral irrelevance of the difference between killing and allowing to die; (3) the supposed paucity of evidence to show likely harmful consequences of legalized euthanasia; and (4) the compatibility of euthanasia and medical practice.

Self-Determination

Central to most arguments for euthanasia is the principle of self-determination. People are presumed to have an interest in deciding for themselves, according to their own beliefs about what makes life good, how they will conduct their lives. That is an important value, but the question in the euthanasia context is. What does it mean and how far should it extend? If it were a question of suicide, where a person takes her own life without assistance from another, that principle might be pertinent, at least for debate. But euthanasia is not that limited a matter. The self-determination in that case can only be effected by the moral and physical assistance of another. Euthanasia is thus no longer a matter only of self-determination, but of a mutual, social decision between two people, the one to be killed and the other to do the killing.

How are we to make the moral move from my right of self-determination to some doctor's right to kill me—from *my* right to *his* right? Where does the doctor's moral warrant to kill come from? Ought doctors to be able to kill anyone they want as long as permission is given by competent persons? Is our right to life just like a piece of property, to be given away or alienated if the price (happiness, relief of suffering) is right? And then to be destroyed with our permission once alienated?

In answer to all those questions, I will say this: I have yet to hear a plausible argument why it should be permissible for us to put this kind of power in the hands of another, whether a doctor or anyone else. The idea that we can waive our right to life, and then give to another the power to take that life, requires a justification yet to be provided by anyone.

Slavery was long ago outlawed on the ground that one person should not have the right to own another, even with the other's permission. Why? Because it is a fundamental moral wrong for one person to give over his life and fate to another, whatever the good consequences, and no less a wrong for another person to have that kind of total, final power. Like slavery, dueling was long ago banned on similar grounds: even free, competent individuals should not have the power to kill each other, whatever their motives, whatever the circumstances. Consenting adult killing, like consenting adult slavery or degradation, is a strange route to human dignity.

There is another problem as well. If doctors, once sanctioned to carry out euthanasia, are to be themselves responsible moral agents—not simply hired hands with lethal injections at the ready—then they must have their own *independent* moral grounds to kill those who request such services. What do I mean? As those who favor euthanasia are quick to point out, some people want it because their life has become so burdensome it no longer seems worth living.

The doctor will have a difficulty at this point. The degree and intensity to which people suffer from their diseases and their dying, and whether they find life more of a burden than a benefit, has very little directly to do with the nature or extent of their actual physical condition. Three people can have the same condition, but only one will find the suffering unbearable. People suffer, but suffering is as much

a function of the values of individuals as it is of the physical causes of that suffering. Inevitably in that circumstance, the doctor will in effect be treating the patient's values. To be responsible, the doctor would have to share those values. The doctor would have to decide, on her own, whether the patient's life was "no longer worth living."

But how could a doctor possibly know that or make such a judgment? Just because the patient said so? I raise this question because, while in Holland at the euthanasia conference reported by Maurice de Wachter elsewhere in this issue, the doctors present agreed that there is no objective way of measuring or judging the claims of patients that their suffering is unbearable. And if it is difficult to measure suffering, how much more difficult to determine the value of a patient's statement that her life is not worth living?

However one might want to answer such questions, the very need to ask them, to inquire into the physician's responsibility and grounds for medical and moral judgment, points out the social nature of the decision. Euthanasia is not a private matter of self-determination. It is an act that requires two people to make it possible, and a complicit society to make it acceptable.

Killing and Allowing to Die

Against common opinion, the argument is sometimes made that there is no moral difference between stopping life-sustaining treatment and more active forms of killing, such as lethal injection. Instead I would contend that the notion that there is no morally significant difference between omission and commission is just wrong. Consider in its broad implications what the eradication of the distinction implies: that death from disease has been banished, leaving only the actions of physicians in terminating treatment as the cause of death. Biology, which used to bring about death, has apparently been displaced by human agency. Doctors have finally, I suppose, thus genuinely become gods, now doing what nature and the deities once did.

What is the mistake here? It lies in confusing causality and culpability, and in failing to note the way in which human societies have overlaid natural causes with moral rules and interpretations. Causality (by which I mean the direct physical causes of death) and culpability (by which I mean our attribution of moral responsibility to human actions) are confused under three circumstances.

They are confused, first, when the action of a physician in stopping treatment of a patient with an underlying lethal disease is construed as *causing* death. On the contrary, the physician's omission can only bring about death on the condition that the patient's disease will kill him in the absence of treatment. We may hold the physician morally responsible for the death, if we have morally judged such actions wrongful omissions. But it confuses reality and moral judgment to see an omitted action as having the same causal status as one that directly kills. A lethal injection will kill both a healthy person and a sick person. A physician's omitted treatment will have no effect on a healthy person. Turn off the machine on me, a healthy person, and nothing will happen. It will only, in contrast, bring the life of a sick person to an end because of an underlying fatal disease.

Causality and culpability are confused, second, when we fail to note that judgments of moral responsibility and culpability are human constructs. By that I mean that we human beings, after moral reflection, have decided to call some actions right or wrong, and to devise moral rules to deal with them. When physicians could do nothing to stop death, they were not held responsible for it. When, with medical progress, they began to have some power over death – but only its timing and circumstances, not its ultimate inevitability – moral rules were devised to set forth their obligations. Natural causes of death were not thereby banished. They were, instead, overlaid with a medical ethics designed to determine moral culpability in deploying medical power.

To confuse the judgments of this ethics with the physical causes of death – which is the connotation of the word *kill* – is to confuse nature and human action. People will, one way or another, die of some disease; death will have dominion over all of us. To say that a doctor "kills" a patient by allowing this to happen should only be understood as a moral judgment about the licitness of his omission, nothing more. We can, as a fashion of speech only, talk about a doctor killing a patient by omitting treatment he should have provided. It is a fashion of speech precisely because it is the underlying disease that brings death when treatment is omitted; that is its cause, not the physician's omission. It is a misuse of the word killing to use it when a doctor stops a treatment he believes will no longer benefit the patient – when, that is, he steps aside to allow an eventually inevitable death to occur now rather than later. The only deaths that human beings invented are those that come from direct killing – when, with a lethal injection, we both cause death and are morally responsible for it. In the case of omissions, we do not cause death even if we may be judged morally responsible for it.

This difference between causality and culpability also helps us see why a doctor who has omitted a treatment he should have provided has "killed" that patient while another doctor – performing precisely the same act of omission on another patient in different circumstances – does not kill her, but only allows her to die. The difference is that we have come, by moral convention and conviction, to classify unauthorized or illegitimate omissions as acts of "killing". We call them "killing" in the expanded sense of the term: a culpable action that permits the real cause of death, the underlying disease, to proceed to its lethal conclusion. By contrast, the doctor who, at the patient's request, omits or terminates unwanted treatment does not kill at all. Her underlying disease, not his action, is the physical cause of death; and we have agreed to consider actions of that kind to be morally licit. He thus can truly be said to have "allowed" her to die.

If we fail to maintain the distinction between killing and allowing to die, moreover, there are some disturbing possibilities. The first would be to confirm many physicians in their already too-powerful belief that, when patients die or when physicians stop treatment because of the futility of continuing it, they are somehow both morally and physically responsible for the deaths that follow. That notion needs to be abolished, not strengthened. It needlessly and wrongly burdens the physician, to whom should not be attributed the powers of the gods. The second possibility would be that, in every case where a doctor judges medical treatment no longer effective in prolonging life, a quick and direct killing of the patient would be seen as the next, most reasonable step, on grounds of both humaneness and economics. I do not see how that logic could easily be rejected.

Calculating the Consequences

When concern about the adverse social consequences of permitting euthanasia are raised, its advocates tend to dismiss them as unfounded and overly speculative. On the contrary, recent data about the Dutch experience suggests that such concerns are right on target. From my own discussions in Holland, and from the articles on that subject in this issue and elsewhere, I believe we can now fully see most of the *likely* consequences of legal euthanasia.

Three consequences seem almost certain, in this or any other country: the inevitability of some abuse of the law; the difficulty of precisely writing, and then enforcing, the law; and the inherent slipperiness of the moral reasons for legalizing euthanasia in the first place.

Why is abuse inevitable? One reason is that almost all laws on delicate, controversial matters are to some extent abused. This happens because not everyone will agree with the law as written and will bend it, or ignore it, if they can get away with it. From explicit admissions to me by Dutch proponents of euthanasia, and from the corroborating information provided

by the Rummelink Report and the outside studies of Carlos Gomez and John Keown, I am convinced that in the Netherlands there are a substantial number of cases of nonvoluntary euthanasia, that is, euthanasia undertaken without the explicit permission of the person being killed. The other reason abuse is inevitable is that the law is likely to have a low enforcement priority in the criminal justice system. Like other laws of similar status, unless there is an unrelenting and harsh willingness to pursue abuse, violations will ordinarily be tolerated. The worst thing to me about my experience in Holland was the casual, seemingly indifferent attitude toward abuse. I think that would happen everywhere.

Why would it be hard to precisely write, and then enforce, the law? The Dutch speak about the requirement of "unbearable" suffering, but admit that such a term is just about indefinable, a highly subjective matter admitting of no objective standards. A requirement for outside opinion is nice, but it is easy to find complaisant colleagues. A requirement that a medical condition be "terminal" will run aground on the notorious difficulties of knowing when an illness is actually terminal.

Apart from those technical problems there is a more profound worry. I see no way, even in principle, to write or enforce a meaningful law that can guarantee effective procedural safeguards. The reason is obvious yet almost always overlooked. The euthanasia transaction will ordinarily take place within the boundaries of the private and confidential doctor-patient relationship. No one can possibly know what takes place in that context unless the doctor chooses to reveal it. In Holland, less than 10 percent of the physicians report their acts of euthanasia and do so with almost complete legal impunity. There is no reason why the situation should be any better elsewhere. Doctors will have their own reasons for keeping euthanasia secret, and some patients will have no less a motive for wanting it concealed.

I would mention, finally, that the moral logic of the motives for euthanasia contain within them the ingredients of abuse. The two standard motives for euthanasia and assisted suicide are said to be our right of self-determination, and our claim upon the mercy of others, especially doctors, to relieve our suffering. These two motives are typically spliced together and presented as a single justification. Yet if they are considered independently—and there is no inherent reason why they must be linked—they reveal serious problems. It is said that a competent, adult person should have a right to euthanasia for the relief of suffering. But why must the person be suffering? Does not that stipulation already compromise the principle of self-determination? How can self-determination have any limits? Whatever the person's motives may be, why are they not sufficient?

Consider next the person who is suffering but not competent, who is perhaps demented or mentally retarded. The standard argument would deny euthanasia to that person. But why? If a person is suffering but not competent, then it would seem grossly unfair to deny relief solely on the grounds of incompetence. Are the incompetent less entitled to relief from suffering than the competent? Will it only be affluent, middle-class people, mentally fit and savvy about working the medical system, who can qualify? Do the incompetent suffer less because of their incompetence?

Considered from these angles, there are no good moral reasons to limit euthanasia once the principle of taking life for that purpose has been legitimated. If we really believe in self-determination, then any competent person should have a right to be killed by a doctor for any reason that suits him. If we believe in the relief of suffering, then it seems cruel and capricious to deny it to the incompetent. There is, in short, no reasonable or logical stopping point once the turn has been made down the road to euthanasia, which could soon turn into a convenient and commodious expressway.

Euthanasia and Medical Practice

A fourth kind of argument one often hears both in the Netherlands and in this country is that euthanasia and assisted suicide are perfectly compatible with the aims of medicine. I would note at the very outset that a physician who participates in another person's suicide already abuses medicine. Apart from depression (the main statistical cause of suicide), people commit suicide because they find life empty, oppressive, or meaningless. Their judgment is a judgment about the value of continued life, not only about health (even if they are sick). Are doctors now to be given the right to make judgments about the kinds of life worth living and to give their blessing to suicide for those they judge wanting? What conceivable competence, technical or moral, could doctors claim to play such a role? Are we to medicalize suicide, turning judgments about its worth and value into one more clinical issue? Yes, those are rhetorical questions.

Yet they bring us to the core of the problem of euthanasia and medicine. The great temptation of modern medicine, not always resisted, is to move beyond the promotion and preservation of health into the boundless realm of general human happiness and well-being. The root problem of illness and mortality is both medical and philosophical or religious. "Why must I die?" can be asked as a technical, biological question or as a question about the meaning of life. When medicine tries to respond to the latter, which it is always under pressure to do, it moves beyond its proper role.

It is not medicine's place to lift from us the burden of that suffering which turns on the meaning we assign to the decay of the body and its eventual death. It is not medicine's place to determine when lives are not worth living or when the burden of life is too great to be borne. Doctors have no conceivable way of evaluating such claims on the part of patients, and they should have no right to act in response to them. Medicine should try to relieve human suffering, but only that suffering which is brought on by illness and dying as biological phenomena, not that suffering which comes from anguish or despair at the human condition.

Doctors ought to relieve those forms of suffering that medically accompany serious illness and the threat of death. They should relieve pain, do what they can to allay anxiety and uncertainty, and be a comforting presence. As sensitive human beings, doctors should be prepared to respond to patients who ask why they must die, or die in pain. But here the doctor and the patient are at the same level. The doctor may have no better an answer to those old questions than anyone else; and certainly no special insight from his training as a physician. It would be terrible for physicians to forget this, and to think that in a swift, lethal injection, medicine has found its own answer to the riddle of life. It would be a false answer, given by the wrong people. It would be no less a false answer for patients. They should neither ask medicine to put its own vocation at risk to serve their private interests, nor think that answer to suffering is to be killed by another. The problem is precisely that, too often in human history, killing has seemed the quick, efficient way to put aside that which burdens us. It rarely helps, and too often simply adds to one evil still another. That is what I believe euthanasia would accomplish. It is self-determination run amok.

A: Prof. D. Callahan, director, The Hastings Center, 255 Elm Road, Briarcliff Manor, NY 10510, USA

EUTHANASIA IN THE NETHERLANDS

H. Jochemsen

The discussion in the Netherlands about some form of legalisation of euthanasia in the Netherlands has been going on for several years now. Two proposals to change legislation have been presented, but neither one has been accepted in Parliament. During the formation of the present government it was agreed that the practice of life-terminating action in health care would be investigated before a new proposal for law would be presented in Parliament. This investigation has been performed by a State Committee chaired by Prof. J. Remmelink, Attorney-General at the Supreme Court. The results are presented in a report published 10 September 1991. The main quantitative data from this report are presented in the Table 1.

Both the committee and the Underminister of Health Care concluded from these figures that in the Netherlands there is a "civilised practice of euthanasia". They pointed out that while 9000 people ask for euthanasia only 2300 get it. Some concern was expressed about the 1000 cases of unrequested termination of life. But on the basis of the answers of the responsible physicians, it was concluded that the life-terminating actions in these cases should be interpreted as help in dying.

Civilised practice?

We do not think that these results give any reason for optimism with respect to the practice of euthanasia in the Netherlands. We will just make a few observations with our main criticism.

1. In the course of the debate in The Netherlands euthanasia has been defined as the active killing of a patient at his or her request by a physician, traditionally called voluntary euthanasia. The main argument in favour of the acceptance of euthanasia, was the respect for the autonomy of the patient as it manifests itself in a free request for euthanasia. These data however indicate that the free request in practice is not the decisive reason for physicians to perform euthanasia. Of the 9000 people who asked for euthanasia 'only' 2300 get it. On the other hand, 1000 people who have not asked their physician to terminate their lives, actually have their lives terminated.

2. The conclusion of the committee that in these 1000 cases one should speak of 'care-in-dying', is not convincing. For if this had been the case, then the physicians who reported these 1000 cases would have mentioned them under the heading of intensification of pain and symptom treatment with the explicit aim to hasten death. But in those 1000 cases apparently they distinguished their action from intensification of pain treatment. Furthermore, about a quarter of the patients was competent to a certain extent, but the physician had nevertheless not discussed with the patient the possibility of terminating the patient's life. The figures also show that about 20% of those patients had a life expectancy longer than 1-4 weeks, and that 8% had a life expectancy of more than one month.

3. It is unclear how the intensification of pain and symptom treatment and the forgoing of life-saving medical treatment with the implicit or explicit aim to hasten the death of the patient should be interpreted. In about 30% of these cases the attending physician indicated that this decision implicated a shortening of life by more than one week. Intensification of pain- and symptom treatment and forgoing medical treatment can be good medical practice, even when this may imply a certain shortening of life. The important question is whether the physician choose for proportional pain- and symptom treatment and whether or not he initiated proportional life-sustaining treatment. However, the questions in the inquiry focussed on the intention of the physician, not on the proportionality of his medical treat-

ment. Therefore, it is unclear whether, and if so in how many cases of these two groups of patients, the physician actually provided disproportional medical treatment aiming at the shortening of the patient's life. The figures of the life-expectancy of those patients at least suggests that in a considerable percentage the latter has been the case. Furthermore it should be noted that in 20-30% cases in which pain treatment was intensified and or life-supporting treatment was forgone, with the implicit of explicit intention to hasten death, the physician had not consulted the - fully competent - patient. Here again we see that in medical practice the autonomy principle is not the decisive factor in the decisions of the physician. Therefore, this principle cannot constitute a solid basis for the acceptance and legalisation of euthanasia.

4. The results also indicate that 65-75% of the physicians after performing euthanasia falsely certify as death by natural causes, even though the risk to be persecuted if one has observed the requirements for careful medical practice is almost zero. This shows that the physicians are very reluctant to have their life-terminating actions controlled by justice and that it is unknown whether in the large majority of cases of life-terminating actions the requirements for careful medical practice are observed.

Proposal for legalisation

The proposal of the present Cabinet (Lubbers III) for a legal regulation of the euthanasia issue very much leans upon the report of the Remmelink Committee in the unjustified optimistic interpretation of the committee itself. With its present proposal the cabinet wants to maintain the government's responsibility for the effective protection of human life, but at the same time wants to consider the wish of patients to die in dignity and to shorten unbearable suffering. These two values can be reconciled by the opening that the Dutch Supreme Court has given in accepting the possibility that the physician who has committed euthanasia can, in cases of objectively established emergency, rightfully appeal to a 'state of necessity' or mental force majeure. This reasoning makes it necessary that justice will be able to test the physician's acts with regards to life-terminating actions and that these actions remain punishable. Therefore, the cabinet proposes to give an already existing reporting procedure a basis in law. This procedure entails that a doctor who has terminated a patient's life, must inform the coroner who inspects the body externally and takes from the attending physician a report containing the relevant data (history, the patient's request, possible alternatives, consultation with a second physician, intervention etc.). This report, together with the evaluation of the coroner, is given to the public prosecutor who then must judge whether the intervention was contrary to the Penal Law and its interpretation in jurisprudence.

We want to give our criticism of this proposal in a few observations.

1. This regulation is justified by referring to:

- a) the acceptance of euthanasia in medical ethics and in jurisprudence,
- b) the acceptable practice of life-terminating actions in medical practice.

However:

- internationally seen euthanasia is not accepted in medical ethics but remains a highly controversial issue,
- the so-called acceptability of euthanasia practice in The Netherlands is defended with a misinterpretation of the data of the Remmelink report, as argued above.

2. It is so that Dutch Penal Law provides the possibility of appealing to 'a state of necessity' when a punishable act has been committed (Art. 40, Penal Law). However, by definition this state of necessity can be described in general terms only. In each particular case it is up to the judge to determine whether appeal is justified or not. However, in the case of euthanasia it is clear that in jurisprudence the require-

ments for careful medical practice function as a description of a situation in which the physicians appeal to 'necessity' will be accepted. So, in fact, this article about necessity is used to systematically overrule the unambiguous article in Penal Law that forbids euthanasia (ar. 293). Combined with the fact that the physician who reports the life-terminating action and describes the circumstances under which it has been performed, is the attending physician himself, this leads to the conclusion that it is unlikely that the cabinet's proposal will maintain an effective protection of human life.

3. In the light of the results of the committee R Emmelink the cabinet's proposal must be considered inadequate in its description of the life-terminating actions that must be reported by the physician. The actions that must be reported are euthanasia, aid-in-suicide and life-terminating actions without a request. Euthanasia is defined as: the intentional termination of the life of a patient at his request by a physician. On the other hand, in agreement with the committee R Emmelink and others the proposal describes certain actions of physician that should not be considered as euthanasia. It concerns: a) not beginning or stopping a treatment at the request of the patient, b) forgoing a treatment that is medically useless, c) pain- and symptom treatment with, as a possible side-effect, a hastening of death.

It remains unclear how the intensification of pain-treatment and forgoing treatments with the explicit aim to shorten life must be considered. Should they be reckoned to the just mentioned actions that are not euthanasia, or as forms of euthanasia? The cabinet's proposal does not give an answer to this question. Therefore, it is not clear whether these actions should be reported. However, in practice the difference between these actions and euthanasia seems to be unclear. It must be assumed, therefore, that in practice physicians will perform very few life-terminating actions which they themselves will classify as euthanasia and therefore will report. Most life-terminating actions, even if it concerns the intentional shortening of the life of a patient, will remain invisible for justice. This supports our conclusion drawn in our former observation.

4. At one point the cabinet's proposal moves away from the position of the committee R Emmelink. As indicated above this committee interpretes the 1000 reported cases of the termination of the life of a patient without a request, as aid-in-dying and therefore as part of normal medical practice. The cabinet does not agree with this position. It stresses the necessity of control of these life-terminating actions. Therefore, the intentional termination of the life of a patient without the patient's request must be reported in the same way as euthanasia. The unrequested killing of a patient by the physician is not (yet) be accepted in jurisprudence and therefore every case of such and action should be brought before court, to give the judge the opportunity to give his opinion.

In itself we appreciate that the cabinet does not take over the view of the committee R Emmelink with respect to the unrequested killing of a patient. However, by including these actions in the regulation procedure of euthanasia the cabinet at least suggests that these two kinds of actions can morally and juridically be put at the same level. In its proposal the cabinet clearly leaves open the possibility that the intentional termination of the life of a patient without a request, and in practice this will often concern incompetent patients, will be accepted in jurisprudence just the same way as euthanasia is. It should be noticed in this context that the euthanasia is accepted in jurisprudence with referral to the acceptance of it by the medical profession and that this profession meanwhile has also accepted the termination of the life of incompetent patients under certain circumstances. It is not unlikely therefore that jurisprudence will accept these actions as well, with referral to the necessity article. Here again the Government fails to provide effective protection of human life, but leaves the decision about the life of certain groups of pa-

tients far too much in the hands of the medical profession.

During the debate in Parliament about this proposal (april 1992) this apparent equalisation of requested and unrequested life-terminating actions, was the point criticized mostly, also by those parties who favour the legalisation of requested euthanasia. On the other hand it must be admitted that the cabinet's proposal is more true to medical practice in which the request often is not the decisive factor for the physician to terminate the life of a patient.

In conclusion: considering the findings published by the committee R Emmelink and by others - that the majority of life-terminating actions remain unnotified and invisible for justice, - that there is a broad range of actions of physicians that very possibly include the intentional killing of patients, but that are not reported and not controlled, it must be feared that a practice of terminating patient's lives has already run out of control and that the present proposal of the cabinet will just consolidate this practice. With this state of affairs, that has risen because of the policy of prosecution of the Government during the last decennium, no effective protection of the lives of patients can be provided any longer by the government. (This is not to suggest that the lives of all patients are in risk in The Netherlands.) It should be added that it will be hard to change this situation. Any attempt to realise this should work at least at the following points: a) improve the quality and the possibilities of palliative care, b) try to bring about a change in the predominant ethical position in health care with respect to the respectability and protectability of every human being, c) execute a careful, adequate and strict policy of investigation and, if necessary, of prosecution of every case in which it is suspected that an intentional disproportional life-terminating medical action has taken place.

Table 1.: The main quantitative data from the report of the committee "Onderzoek medische praktijk inzake euthanasie" (Investigation of medical practice with regards to euthanasia)

Death cases in The Netherlands	129.000 (100)
Requests for euthanasia (termination of life at request of the patient)	9.000 (7)
Euthanasia applied	2.300 (1,8)
Aid in suicide	400 (0,3)
Life-termination without a request	1.000 (0,8)
Intensification of pain-and symptom treatment; of these:	22.500
- 6% with the explicit aim to hasten death	1.350 (1)
- 30% also with the aim to hasten death	6.750 (5,2)
- 64% at least taking into account the probability that death would be hastened	14.400 (11,3)
Not starting or stopping a treatment (including tube-feeding)	
- at the request of the patient	5.800 (4,5)
- without a request of the patient	22.500 (17,5)
Of the later group:	
- 16% with the explicit aim to hasten death	3.600 (2,8)
- 14% also with the aim to hasten death	4.275 (3,3)
- 65% at least taking into account the probability that death could be hastened	14.625 (11,4)

(All figures are valid for a period of a year. Between brackets is given the percentage of the total number of death cases.)

A: Prof. Dr. H. Jochemsen, Centrum voor medische ethiek, Prof. Dr. G. A. Lindeboom Instituut, Oude Kerkweg 100, Postbus 224, 6710 BE Ede, The Netherlands

Ťažký údel pre lekára je prítomnosť pri neodvratiteľnom, pomalom umieraní chorého, najmä keď predlžovanie života je spojené s útrapami. Rozvoj medicíny priniesol prostriedky, ktoré umožňujú predlžovanie života, ale nie vždy bez utrpenia. V prípadoch predlžovania života v útrapách, vzniká dilema z pohľadu na život chorého – byť ešte, a či už ďalej nebyť? Preto s takou nástojčivosťou sa už desaťročia vyslovujú úvahy medicínske, filozofické a právne, ktoré majú v ponímaní eutanázie význam de lege ferenda, lebo väčšina právnych poriadkov nemá pre eutanáziu právnu úpravu. Otázky súvisiace s eutanáziou sa bezprostredne dotýkajú lekárskej praxe a preto sú v sústredenom profesionálnom záujme lekárskeho kruhu. Svojou podstatou sú to otázky právne, v ktorých sa prirodzene nachádzajú aj názory filozofické a v nich najmä etické. Preto zámer sledovania v tomto príspevku je právna problematika eutanázie.

Stanoviská a názory vyjadrované na eutanáziu sú rozporné. Tie, čo za určitých okolností pripúšťajú upustenie od život udržujúcich prostriedkov v terminálnom štádiu choroby alebo pripúšťajú miernenie bolesti chorého s beznádejnou prognózou na život s použitím bolestlmiacich dávok vedúcich k skráteniu života chorého, často argumentujú s právom človeka na smrť. Týmto však nemožno argumentovať, lebo objektívne právo neobsahuje právo na smrť, ani nemôže obsahovať. Právo chráni záujem jednotlivca a spoločnosti tým, že vymedzuje subjektívne oprávnenia a právne povinnosti. Predmetom právnej ochrany sú najmä základné ľudské práva a slobody, politické, hospodárske, sociálne a kultúrne práva. Najdôležitejším je právo každého na život, ktorý je najvyššia hodnota pre človeka. Proti životu stojí smrť ako poznaná biologická nevyhnutnosť. Smrť ako zápor života nie je hodnotou, tak ako zápor osobnej slobody – nesloboda, ľudskej dôstojnosti – nedôstojnosť, občianskej rovnosti – nerovnosť, atď... preto ani koncepcia ľudských práv, ktoré sú predmetom Všeobecnej deklarácie, medzinárodných paktov a právnych poriadkov do subjektívnych práv nezahrňujú právo na život protirečivú smrť ako ľudské právo na ňu. S protirečivosťou ponímania smrti ako subjektívneho práva na ňu, súvisí aj právne neprijateľné ponímanie samovraždy ako práva na ňu, obsahom subjektívneho práva nemôže byť ani poškodenie vlastného tela alebo zdravia, tak často hlásané ako právo disponovať sám sebou. Keďže nie je na to právo, tak samovražda, resp. pokus samovraždy, poškodenie vlastného tela alebo zdravia sú protiprávne, i keď nie sú sankcionované, pokiaľ poškodenie seba samého nesleduje nepôsobilosť na plnenie právnej povinnosti.

Pre právne úvahy o eutanázii nie sú premisou "právo na smrť", ani "právo na samovraždu" nielen preto, že nie sú na to oprávnenia, ale je nezmyselné o nich uvažovať aj preto, že v obsahu pojmu eutanázia je skrátenie života konaním inej osoby, teda ide o domáhanie práva pre toho, kto úmyselne chorému skráti život, inak povedané – usmrť ho. V snáhach o legalizáciu prípustnosti eutanázie je v úvahách diferencovanosť a to – usmrtienie na žiadosť chorého a bez žiadosti, aktívnej eutanázie od pasívnej. Žiadosť chorého na skrátenie života právne je vlastne privolením na konanie toho, kto to má urobiť. Zásadne je takéto privolenie právne neprijateľné. Všeobecne neplatí "nulla iniuria est, quae in volentem fiat", a teda nemôže sa vylučovať protiprávnosť privolenia. Účinok privolenia vylučujúci protiprávnosť sa viaže len na také privolenie, ktoré je založené na oprávnení povoľujúceho. Ako už bolo skôr uvedené právo na život je protirečivé ponímanie zbavenie vlastného života ako práva, čoho dôsledkom je, že niet ani oprávnenia na to, aby človek mohol dať súhlas inému na zbavenie jeho života. K tomuto základnému a právne rozhodnému stanovisku k privoleniu sa pridružuje problém právnej relevancie prejavu vôle chorého nachádzajúceho sa v úpornej bolesti alebo v stave blížiacemu sa k agónii.

Nie je potrebné tu širšie zdôvodňovať, že človek v takýchto stavoch sa už neovláda, jeho psychika je narušená, právne vyjadrené je to nepríčetnosť. Prejav vôle teda nemôže byť právne relevantný. Podľa toho, či ide o činnosť, či nečinnosť, hovorí sa o eutanázii aktívnej alebo pasívnej. Jedna i druhá je konanie subjektu úmyselne zamerané na cieľ – zbavenie života nevyliciteľne chorého, nachádzajúceho sa v utrpení. V zdôvodňovaní prípustnosti eutanázie sa používajú aj argumenty hlásajúce, že vyhovieť žiadosti chorého nie je usmrtienie ale poskytnutie pomoci pri umieraní, že deontologické pravidlá požadujú od lekára, aby nepredlžoval život chorého v utrpení, ale ho ukončil, čo nemá byť, či nemôže byť hodnotené ako protiprávne konanie, lebo v tom nie je nebezpečnosť pre spoločnosť, skrátenie života v takýchto prípadoch nie je v rozpore s medicínskou etikou ani právom, je to humanitná úloha medicínskej starostlivosti, a pod..

Deontologické pravidlá, aby mohli mať svoje uplatnenie, nesmú odporovať právu, a etické názory, či pravidlá viac alebo menej v spoločnosti uznávané, majú svoj záväzný dosah len v tej časti, ktorú recipuje právo. Právo chrániac život ľudskej bytosti súčasne zakazuje zbaviť ju života. Úmyselné zbavenie života iného človeka, vyjadrované či už ako skrátenie života, pomoc zomrieť alebo inak, vždy je usmrtením so skutkovými znakmi trestného činu vraždy. Výsledok je jeden – usmrtienie. To, čím sa často dôvodí, že je rozdiel medzi vraždou z nenávisti, pre získanie majetkového prospechu, a medzi usmrtením z utrpnosti nevyliciteľne chorého, nie je rozdiel skutkový, usmrtienie ako dosiahnutý výsledok konajúceho subjektu je objektívne rovnaký, rozdiel je len v motíve, ktorý je subjektívnou stránkou páchatelovej činnosti. Motív má vplyv na stupeň nebezpečnosti činu pre spoločnosť. Nebezpečnosť činu je určovaná najmä významom chráneného záujmu a ďalšími zákonom určenými prostriedkami, ale motív nevylučuje nebezpečnosť činu, pôsobí len na jej stupeň. Dôvodenie rozdielnosťou pohnútky na usmrtienie z utrpnosti od inej pohnútky na usmrtienie so záverom, že pohnútky pre eutanáziu robí z nej čin bez nebezpečnosti pre spoločnosť je právne neprijateľná. Z toho, že eutanázia má skutkové znaky činu nebezpečného pre spoločnosť je žiaduce sa ešte zaoberať podmienkami pre zodpovednosť za takýto čin. Ak konajúci subjekt dosiahne výsledok – usmrtienie – kauzálny nexus je daný, ak tento výsledok nemá súvislosť s inou príčinou. Je hrubou chybou dôvodiť tým, že výsledok – smrť neodvratne by musela nastať z pôvodnej príčiny – chorobného stavu. Pôsobenie príčiny vedúcej k smrti z chorobného stavu sa nedovršilo vo výsledku, lebo zasiahla druhá príčina – eutanázia, ktorá spôsobila tento výsledok priamo a bezprostredne, teda príčinná súvislosť dosiahnutého výsledku – smrti – je v rozvinutí príčinnej reťaze súvisiacich javov v eutanázii.

Konanie v príčinnej súvislosti so smrťou je čin nebezpečný pre spoločnosť, preto právo ho zakazuje – nikoho nemožno zbaviť života. Eutanázia ako správanie zbavujúce život človeka nachádzajúceho sa v útrapách je tak v rozpore s objektívnym právom – je to protiprávne ľudské správanie. Pri eutanázii sú tak naplnené objektívne zodpovednostné kategórie, príčinná súvislosť a protiprávnosť. Keďže ide o protiprávnosť represívne sankcionovanú niet zodpovednosti bez zavinenia, ktoré ako subjektívnu zodpovednostnú kategóriu prichodí tu tiež rozobrať. Pre usmrtienie, čím, ako už bolo povedané, je aj eutanázia, je potrebné úmyselné zavinenie. Ak konajúci subjekt chcel spôsobom uvedeným v zákone porušiť alebo ohroziť záujem chránený zákonom, t.j. chcel výsledok – smrť, je úmysel priamy ako forma zavinenia, ktorá je v aktívnej eutanázii. V pasívnej eutanázii konajúci subjekt omisívne koná tak, že spôsobí porušenie právom chráneného záujmu, v danom prípade smrť, zavinenie a to úmyslom priamym, lebo tento protiprávny výsledok v objektívnom poznaní konajúceho subjektu nemá alternatívu, omisívne konanie príčinnosťne vedie len k smrti, teda chce tanto výsledok, ktorý je ako jedine možný aj dosiahnutý.

Záver: Proti legalizácii eutanázie stoja zásadné právne prekážky. Eutanázia, ako ľudské správanie úmyselne zbavu-

júce života chorého nachádzajúceho sa v útrapách, máň všetky skutkové znaky usmrtenia ako činu nebezpečného pre spoločnosť, ktorý v jeho podstate nemožno právne diferencovať od trestného činu vraždy. Motív pre eutanáziu môže mať význam len pre stupeň nebezpečnosti činu pre spoločnosť, ale usmrtenie sa nemôže stať právom. Právo na život nemožno meniť a suspendovať, bola by to dekadencia a dehumanizácia priečiaca sa ľudskému chápaniu. Priznať právo na rozhodovanie o ďalšom živote chorého je nepredstaviteľné aj čo do dôsledkov, ku ktorým by to viedlo.

A: JUDr. V. Keseg, Subkatedra zdravotníckeho práva IVZ, Limbová 12, 833 03 Bratislava

ÚVAHA O EUTANÁZII

M. Fritzmann

Etymologický význam slova eutanázia (eu-dobrá, thanatos-smrť, boh smrti) znamená dobrú smrť. Počas obdobia ľudských dejín sa postupne vyvinul ideál "spoluumierania" završenia života v rodine, v kruhu svojich najbližších milovaných a milujúcich. Najlepšia príhoda na dobrú smrť je práva cnostným životom. Preto sa Sokrates nezachvel, keď mu bola podaná čaša s jedom, lebo hlas svedomia "jeho daimonion" mu bol posvätný a hodnotou nadovšetko. Už v staroveku bola dobre známa určitá ambivalentnosť lieku, z ktorého, ak sa zneužije, stáva sa jed. Preto už Hippokrates vo svojej prísahe zakotvil zákaz podania lieku v inom úmysle, ako je liečebný, a to aj vtedy, ak by sa sám pacient domáhal podania smrteľného prostriedku.

Duchovný aspekt eutanázie ako dobrej smrti neskôr rozvinulo kresťanstvo vo forme očistenia duše ako prípravy na pokojnú smrť. Medicínsky pokrok vytvoril na hranici života a smrti mnohé situácie, ktoré predtým neboli mysliteľné. Dobré je známy napr. apalický syndrom, kedy medicínskou technikou sa dá udržať funkcia dýchania alebo aj krvného obehu pri ireverzibilne odumretej mozgovej kôre. Proces umierania je manipulovaný. Dá sa v niektorých prípadoch spomaliť až zastaviť, alebo naopak urýchliť úmyselným prípadne neúmyselným navodením smrti. Vznikli tým mnohé špecifické medicínske, etické, právne a deontologické problémy na hranici života a smrti.

Život i umieranie prebieha na trojjedinej úrovni somato-psycho-sociálnej. Obvykle umieranie na rovine sociálnej a psychickej začalo oveľa skôr, než sa dostavila agónia. Vážne chorý pacient bol chorobou vytrhnutý z pracovného kolektívu a ďalších spoločenských a rodinných kontaktov, kde mal svoje postavenie i poslanie. Často sa ocitá v izolácii anonymného nemocničného prostredia, pre ktoré je vlastná mašineria diagnosticko-terapeutických algoritmov a pacient-človek už existuje len ako prípad, diagnóza alebo choroba. Na sociálnej smrti má svoj podiel aj ľahostajnosť príbuzných, známych a spolupracovníkov, ktorí nechcú byť konfrontovaní s utrpením a umieraním, lebo nemajú tieto otázky poriešené, a preto reagujú únikom. Človek postihnutý závažným ochorením obvykle reaguje kaskádou psychických stavov. Tieto sú do značnej miery uniformné a pacient ich individuálne dotvára pečatou svojej osoby. Sokratovská vyrovnanosť je aj dnes vzácnosťou. Výslednou fázou psychického boja pacienta môže byť nielen zmierenie sa so situáciou, ale aj rezignácia, prípadne nezmierenie-vzbura pacienta. Všetky tieto situácie nezvládnutej bolesti vo forme strachu, úzkosti, depresie, beznádeje až zúfalstva predstavujú psychickú smrť pacienta. Psychosociálne mŕtvy pacient si často nepraje žiť ani fyzicky. Túto dešperátnu situáciu sa môže snažiť riešiť inakdeviatne únikom vo forme suicídia alebo eutanázie.

Eutanázia aktívna alebo priama vo forme aktívneho usmrtenia pacienta pod zámenkou bezcennosti života umierajúceho alebo skrátenia múk umierania, je mimo diskusie lekárskej etiky, morálky i práva. V tejto podobe naplňa skutkovú podstatu trestného činu úmyselného usmrtenia člove-

ka-vraždy. Neobstojí ani alibi súhlasu prípadne požiadanie samotného pacienta o eutanáziu. Náš právny poriadok zaručuje občanovi právo rozhodovať o vlastnej integrite. Vylučuje však konanie, ktoré je nezlučiteľné so spoločensky uznanými hodnotami, ktorými je aj zdravie a život občanov. Náš právny systém neuznáva právo dispozície nad vlastným životom, resp. právo na "vlastnú smrť".

Preto neakceptuje ani testamentárne právo na "vlastnú smrť", ktorého sa dožadujú určití občania. V praxi sa občas stretávame so žiadosťou pacienta o "milosrdnú injekciu alebo pilulku". Určite by boli tieto žiadosti častejšie, keby táto zvrátená možnosť bola reálna. Som však toho názoru, že väčšina týchto žiadostí o "milosrdnú injekciu" má demonštratívny podtón. Vychádza pritom z analógie, že pacient, ktorý chce skutočne spáchať suicídium, väčšinou o tom nehovorí otvorene. Tieto situácie by však mali byť pre nás varovaním, že pacient zlyháva v psychickej kompenzácií a vyžaduje si väčšiu starostlivosť. Eutanázia sa dá uskutočniť aj nepriamo-pasívne úmyselným odmietnutím prospešnej liečby. Predstavuje potom liečebný postup *non lege artis* a tiež je trestná. Z morálneho aspektu je istý rozdiel v tom, 1/ či sa eutanázia deje aktívne alebo pasívne, 2/ či sa ukončuje život druhého alebo vlastný život (suicídium), 3/ či sa deje bez súhlasu alebo so súhlasom osoby, na ktorú sa vzťahuje.

Nemožno hovoriť o eutanázii tam, kde sa nepoužijú všetky - aj keď dostupné - liečebné postupy, ktorými by sa nedosiahlo predĺženie života, ale len predĺženie umierania. Keď už neodvolateľne začal proces umierania, ďalšie liečebné výkony by prakticky len nerozumne predlžovali utrpenie. Nepoužitie liečebných opatrení vo fáze ireverzibilného umierania potom neznamená zabitie, resp. postup *non lege artis*, ale len odstránenie umelých prekážok procesu smrti. Uzákonenie "práva" na eutanáziu by pochovalo étos zdravotníckeho stavu a ohrozilo by nutnú dôveru pacientov k lekárom. Bola by to akási výzva, aby táto skupina ľudí (pacienti) uvážila, či nemá požiadať o "službu" eutanázie. Tým by sa posilnil už aj tak nebezpečný trend obklopiť týchto ľudí sociálnou smrťou. Ak by sa eutanázia stala zákonne garantovaným právom, rozpadlo by sa lekárstvo - rovnako ako u legalizovaných potravín - na dva špecificky protichodné smery. Z nich jeden by životu slúžil a ochraňoval by ho i v najťažších chvíľach, druhý by bol ochotný na požiadanie zabíjať. Náš právny poriadok by mal ochraňovať život rovnako počas celej jeho existencie. Najviac ochrany si vyžadujú 'najsľabšie' obdobia života, t.j. život na svojom začiatku a konci.

Dovolávanie sa práva na "vlastnú smrť" je motivované strachom pred bolesťou, utrpením a predlžovaním múk prípadným použitím medicínskej techniky. Je skôr emočným odporom ako rozumovou úvahou. Podľa Häringa prianie eutanázie nie je skutočným rozhodnutím pre vlastnú smrť, ale zúfalým výkrikom po väčšej pozornosti a účinnej pomoci.

Zdravotnícky pracovník, ktorý nemá vyriešenú otázku smrti, sa veľmi nerád konfrontuje s umieraním. Zákonite reaguje únikom. Nemôže s pacientom nadviazať pravdivý a láskavý vzťah. Tendencia o minimálny kontakt s pacientom vedie k zdecimovaniu starostlivosti. S pacientom sa zaobchádza ako so "živou mŕtvou", s ktorou sa iba manipuluje podľa našich potrieb. Neosobný, chladný vzťah zdravotníkov prehlbuje sociálnu izoláciu a sociálnu smrť. Nie vždy je to len nezrelosť a nechota zdravotníkov. V behu našich pracovných povinností nám často zostáva len málo času k precíznej práci, k nadviazaniu hlbokého vzťahu medzi lekárom a pacientom. Vytvorili sme si mnohé normy pre medicínske výkony, ale zabudli sme primerane znormovať výkony ducha. Vieme, že variabilita je tu najväčšia, ale napriek tomu v dostupnej literatúre som našiel len jedno jediné doporučenie. Podľa neho ošetrojúci lekár by mal byť denne 1 hodinu v kontakte s ťažko chorým pacientom. Nie zriedka sme svedkami tzv. medicínskej smrti, kedy lekár zaklinácou formulou "už sa nedá nič robiť", píše bodku za akoukoľvek medicínskou starostlivosťou. Opúšťa pacienta vtedy, keď ho tento najviac potrebuje. Lekár má dve neodmysliteľné po-

MORÁLNE TRIEDY V ŠKOLE, MORÁLNE DETI: PRÍSTUP KONŠTRUKTIVIZMU

Mária Glasová

Katedra psychológie a patopsychológie Pedagogickej fakulty Univerzity Komenského v Bratislave

V októbri tohto roku sme v rámci spoločného projektu Pedagogickej fakulty Univerzity Komenského v Bratislave a Schindlerovho College of Education University of Northern Iowa (názov projektu: "Orava Project – A Slovak Republic/University of Northern Iowa Collaborative National Education Restructuration Program") sledovali uplatňovanie **pedagogického konštruktivismu** v praxi tamojších základných škôl. Je to prístup inšpirovaný psychologickou teóriou Jeana Piageta a prácou ženevskej psychologičkej školy. Rozvíja sa v Spojených štátoch od 60. rokov ako výrazný protipól tradičného direktívneho pedagogického prístupu, ktorý má korene v asociatívnom a americkom behaviorizme.

Konštruktivistický pedagóg *vníma žiaka* ako aktívny organizmus, *ako autonómneho činiteľa vlastného rozvoja*. Snaží sa prispôbiť pedagogický prístup vývinovej úrovni poznania konkrétneho žiaka. Neregistruje mechanicky jeho chyby, ale pátra po ich pôvode v spôsobe rozmyšľania, hľadá "logické" zdroje omylov. Pedagogická prax vychádza z toho, čo žiak už zvládol a vytvára zodpovedajúce podmienky a podnety v prostredí stimulujúce ďalší proces poznania, ktoré však závisí od vlastnej aktivity a záujmu žiaka. *Cieľom* tu teda nie je "vybavenie vedomosťami", ale *podporenie rozvoja vyššej kvality myslenia a morálneho usudzovania*. Záujem a osobné zaangažovanie žiaka ho vedie k aktívnemu hľadaniu zmyslu toho, čo vníma a zažíva, sám teda konštruje svoje vlastné poznanie (DeVries, Kohlberg [1]).

Dôležitým je tu potom hľadanie takých spôsobov výchovy a vzdelávania, ktoré by reálne reflektovali spomínanú kognitívnu úroveň žiaka. Tento prístup, vychádzajúc z potreby vzbudiť aktuálny záujem žiaka, bohato využíva hru, tvorivé experimentovanie a spoluprácu, čo sa však neuskutočňuje živelné, ale je plánovité a starostlivo štrukturované. Podľa Piageta porozumieť znamená vlastne objaviť, vynájsť (ako uvádza vo svojej knihe z roku 1948/1973: "To understand is to invent", cit. podľa DeVries a Kohlberg [1]). Konštruktivistický pedagógovia *smierajú* vo svojej práci *k formovaniu mysle a rozvíjaniu poznávania* u žiakov, namiesto toho, aby ju jednoducho zaplnili hotovými poznatkami. Tieto myšlienky sa *osobitne uplatňujú v prístupe k etickej výchove* (De Vries a Zan [2]).

Vo vzťahu k etickej výchove všeobecne prevláda tradičný názor, že deti by mali zažiť autoritu, aby vedeli neskôr existovať v širšej spoločnosti. Tento náhľad sa však dostáva do rozporu so základnou myšlienkou slobody v rámci spravodlivého spoločenského systému. Konformita, podriadenosť voči autorite, nie je pravou socializáciou v slobodnej spoločnosti, ale skôr pripomína socializáciu pre väzenskú atmosféru. Aj v mnohých školách, žiaľ, vládne ovzdušie podobné totalitnej spoločnosti (sloboda je tu potlačovaná a neexistuje reálna možnosť dožadovať sa práva u autority, práva spolupodhodovať, odmeny sú viazané na poslušnosť voči autorite, o trestoch sa rozhoduje byrokraticky, niekedy aj za minimálny priestupok proti pravidlám...). Čo je potom *socio-morálna atmosféra triedy z pohľadu konštruktivismu*?

Konštruktivistická socio-morálna atmosféra je atmosférou komunity, vzájomného spoločenstva, danou vyšším stupňom socio-morálneho rozvoja žiakov (De Vries, Zan, [2]). Učitelia uznávajú právo žiakov na ich vlastné city a názory. Nezneužívajú zbytočne svoju moc, autoritu používajú

vinnosti voči pacientovi. Úloha liečiteľa automaticky vyplýva z povolania lekára. Druhou, nie menej dôležitou úlohou, je poslanie lekára byť pacientovi oporou a sprievodcom v období umierania. Občas sa objavujú nemorálne hlasy ľudí, včítane zdravotníkov, o bezcennosti života trpiacich pacientov. Táto skupina samozvaných sudcov si uzurpuje právo vynášať ortiel o tom, že život týchto ťažko chorých pacientov nemá zmysel. Nemáme morálne právo posudzovať hodnotu života druhých, aj keď je to život akokoľvek veľmi postihnutý. Lekár musí mať na pamäti ešte jednu dôležitú skutočnosť. Je ňou súbor adaptačných mechanizmov, ktorými sa organizmus sám chráni pred utrpením počas umierania. Terminálne u vážnych ochorení dochádza k milosrdnému útlmu-letargii CNS. Svoj význam majú aj endogénne opioidy (endorfiny, enkefalíny) secerované v CNS, ktoré majú silný analgetický a euforizujúci účinok, ako to poznáme po exogénnom podaní opiátov. Sú secerované v stresových situáciách, ku ktorým patrí aj umieranie. Hovoríme tiež o "prirodzenej eutanázii". Každý nedomyšlený liečebný výkon by mohol nepriaznivo vplyvať na priebeh umierania a navodiť zlé umieranie (dystanáziu, kakotanáziu).

Právo zomierajúceho na pravdu a lásku

Dôvera a pravdivosť medzi lekárom a pacientom je základom pre úspešnú liečbu i pre dôstojné sprevádzanie nemocného v poslednej fáze života. Veľa prác sa zaoberalo otázkou informovanosti pacienta o jeho smrteľnej chorobe. Hoci nie je k dispozícii jednoduchý návod na túto zložitú otázku, tiež možno využiť jej ideálne riešenie. Nie každý je schopný prijať pravdu o sebe a to nielen o smrteľnom ochorení. Pravda potom pôsobí ako najväčšie "násillie". Toho, kto však je schopný pravdu prijať, aj keď je ako ťažká, pravda oslobodzuje. Ak má byť pacientovi povedaná pravda o smrteľnej chorobe, predpokladá to hlboký vzťah dôvery a najvyššiu schopnosť vcítenia. Plnú pravdu môže povedať len ten, kto má rád. Vtedy sa dialóg stáva rituálom v tajomnej 13. komnate pravdy a lásky. Vstup do 13.komnaty však predpokladá prejsť spolu s pacientom tých predošlých 12, počínajúc somatickými ťažkosťami, cez jeho psychické problémy, determinovanie výchovou, rodinou, spoločnosťou až po danosti ducha. Teda všetkým tým, čo môžeme zhrnúť pod pojem perignóza. Život v pravde neexistuje bez lásky. Pravá láska na jednej strane vyžaduje hlbokú pravdivosť, na druhej strane vie trpezlivo čakať a vycítiť, kedy je pacient pripravený, aby vnútorne prijal ďalší dúšok pravdy. Život je postupné odkrývanie pravdy a lásky, a to platí najmä pre obdobie umierania. V terminálnom období je pacient emotívne mimoriadne otvorený pre empatickú prítomnosť lekára, iných zdravotníkov i svojich príbuzných. Je veľmi vnímavý na verbálne i metakomunikačné signály. Byť oporou a sprievodcom umierajúceho je profesionálnou a morálnou povinnosťou lekára. Vyžaduje to osobnú zrelosť lekára, ktorý dokáže pochopiť podstatu dokonania aj pre vlastný život. Lekár má nielen konštatovať exitus, ale má byť pri umierajúcom pacientovi. (Je to tiež podľa a nás platnej vyhlášky o liečebno-preventívnej starostlivosti.)

Pôvodný význam pojmu eutanázia ako vysoko humánnej starostlivosti o zomierajúcich bol neskôr zhanobený medicínsky, eticky i právne neprijateľnými formami eutanázie. Je tendencia tento pojem rezervovať len pre tieto negatívne formy eutanázie. Preto niektorí autori zaviedli pojem benemortázia, ktorý by bol renesanciou pozitívnej formy eutanázie, ako výrazu maximálnej medicínskej, ľudskej i duchovnej starostlivosti o umierajúcich. Moja prednáška sa chýli ku koncu. Nechcel som ňou nič definitívne vyriešiť, ale len čosi naznačiť. S otázkou zmyslu života a smrti nemožno byť raz navždy hotový. Toto je naša prvoradá a veľkolepá úloha zadaná nám na celý život. Smrť môže mať definitívne vyriešenú len ten, kto ňou dokázal statočne prejsť, a teda už nie je medzi nami. Nechcel som ani lekársku obec deklarovať a rozdeliť ju na dokonalých a nedokonalých. Nikto z nás nie je v týchto otázkach beznádejný prípad. Budem rád, ak si všetci aspoň čiastočne uznáme svoju nedokonalosť, ktorá bude pre nás výzvou do ďalšej práce na sebe a v prospech pacientov. Aby pravda a láska víťazila aj vo vzťahoch k našim pacientom i k nám samým.

A: MUDr. M. Fritzmann, CSc., Interné oddelenie NsP, 958 01 Partizánske

rozumne a citlivo. Takto umožňujú deťom, aby postupne zo seba budovali osobnosti s vlastným presvedčením, ktoré však nehľadajú len na svoj vlastný názor, ale rešpektujú aj druhých vo vzájomnom dialógu.

Keď potom hovoríme o **morálnych deťoch**, nemáme na mysli deti, ktoré majú v úcte pravidlá kvôli autorite alebo pre získanie výhod. Poslušnosť, motivovaná strachom z trestu alebo z túžby po odmene, ktorá nepramení z vnútorných pohnútok, alebo poslušnosť plynúca z obdivu a náklonnosti, nemusí byť primeraným motívom pre morálne správanie a nestačí pre plný rozvoj osobnej morálky. Žiaci by mali postupne rozpoznať, že *morálne princípy nie sú arbitrárnymi pravidlami, ale sú zakorenené v univerzálnom ideáli* (ktorý by bolo možné zhrnúť v zlatom pravidle: "Čiň druhým to, čo chceš, aby činili druhí tebe."). Morálne deti chápu "dušu" pravidla, nie sú vo svojom správaní povrchné prosociálne. Keď učíme žiaka len určitým spôsobom správania, ignorujeme uňho citový zážitok potreby správať sa morálne. Je morálne, že dieťa pomáha druhému (len) preto, aby získalo pochvalu učiteľa? Konštruktivistický pedagóg neodmeňuje vonkajšie správanie, ale vyzdvihuje, keď dieťa vykonalo niečo, čo bolo príjemné pre druhých, alebo im prospelo. Je tiež dôležité, aby sa dieťa naučilo uvedomovať perspektívu, pohľad toho druhého. To je prvý krok k vzájomnej tolerancii a úprimnosti vo vzťahoch.

Takýto prístup k etickej výchove však vyžaduje stálu premenu a osobnostný rast učiteľa. Tradičný učiteľ sa musí oslobodiť od niektorých svojich prístupov a budovať u seba **nové pedagogické stratégie**. De Vries, Kohlberg [1] ich zhrňujú v nasledovných podstatných bodoch zmeny: 1) *od inštrukcie ku konštrukcii* - učiteľ sa nemá natoľko sústreďovať na spôsob inštrukcie a obsah, ktorý sprostredkuje, ale na rozmyšľanie, "konštrukciu dieťaťa", možnosti jeho rozvoja a formovania, 2) *od posilňovania k záujmu* - pedagóg nez dôrazňuje posilnenia v procese učenia detí pasívne odpovedajúcich na vonkajšie podnety (odmeny a tresty), ale sústreďuje sa na motiváciu v učení prostredníctvom záujmu dieťaťa, 3) *od poslušnosti k autonómii* (alebo *od donucovania k spolupráci*) - kde sa dieťa neorientuje na učiteľa ako jediný zdroj informácií a pravidiel správania, ale je autonómnu, sebaregulujúcou bytosťou, sústreďuje sa na vlastné konanie a vzájomné vzťahy s druhými ako hlavný zdroj poznania a dôvod správania.

Učiteľove vzťahy k deťom podstatne ovplyvňujú socio-morálnu atmosféru triedy ako celku. Konštruktivistický pedagóg sa snaží 1) o *spoluprácu s deťmi* tým, že podľa možnosti minimalizuje vlastnú autoritu, rešpektuje rovnocenné postavenie detí v ich právach a zodpovednosti, 2) podporuje *spoluprácu medzi deťmi* tým, že u nich rozvíja emočnú rovnováhu a zdolávacie mechanizmy, buduje vzájomné porozumenie a pomáha rozlišovať morálne hodnoty (tamtiež).

V konštruktivistickej triede nevládne direktívne vydobyté ticho, ale je to živý organizmus, kde je stály pracovný ruch a v rámci voľných spoločenských vzťahov sa prirodzene vyskytujú *konflikty*. Deti sa v nich snažia orientovať a aktívne ich riešiť, ak je to potrebné, aj s pomocou dospelých autority. De Vries, Zan [2] uvádzajú **17 praktických princípov riešenia konfliktných situácií** pri práci s deťmi predškolského a mladšieho školského veku:

- 1) zostaň pokojný a ovládaj svoje reakcie,
- 2) uvedom si, že konflikt patrí deťom,
- 3) dôveruj v schopnosť detí vyriešiť si svoje konflikty,
- 4) preber zodpovednosť za fyzickú bezpečnosť detí,
- 5) používaj neverbálne metódy na upokojenie,
- 6) rozlišuj, akceptuj, zhodnoť odlišné názory a prežívanie konfliktu deťmi,
- 7) pomôž pomenovať deťom ich city, vysloviť potreby vo vzájomnom počúvaní,
- 8) formuluj, vyjasni problém,
- 9) umožni navrhnuť riešenia,
- 10) ponúkni riešenia, keď deti nenavrhnú svoje vlastné,
- 11) vyzdvihni hodnotu spoločnej dohody, ale dovoľ ju aj odmietnuť,

- 12) rozvíjaj u detí neosobné formy riešenia polemík, keď je riešenie arbitrárne,
- 13) nenaliehaj na vyriešenie konfliktu, ak medzitým ň ochladol záujem,
- 14) pomáhaj pri uvedomovaní si osobnej zodpovednosti v konfliktnej situácii,
- 15) ponúkni možnosti primeranej náhrady vzniknutej ujmy,
- 16) podporuj nápravu vzájomných vzťahov, neved však deti k neúprimnosti,
- 17) ved deti k samostatnému riešeniu konfliktov.

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A: PhDr. M. Glasová, Katedra psychológie a patopsychológie PdFUK, Račianska 59, 813 34 Bratislava

STAROSTLIVOSŤ O RIZIKOVÉ RODINY VO VEĽKEJ BRITÁNII

Mária Glasová

Katedra psychológie a patopsychológie Pedagogickej fakulty Univerzity Komenského v Bratislave

Prvá detská psychologická klinika vo Veľkej Británii, založená v roku 1927, ktorá sa nachádza vo východnej časti Londýna (Tower Hamlets Health District, do ktorého spadá aj známe "Icicle of Dogs") dnes nesie meno svojho zakladateľa, doktora Emanuela Millera - **Emanuel Miller Centre for Families and Children**. Ako vidieť už z jej názvu, poskytuje v súčasnosti rovnocenne svoje poradenské, diagnostické a terapeutické služby nielen samostatne detskej klientele, ale aj detskému pacientovi a jeho rodine ako neoddeliteľnému celku. Do centra prichádzajú rodiny a deti s pomerne širokou paletou problémov, ktoré sú často prítomné ako problémy detí znepokojujúce rodičov a pracovníkov iných inštitúcií. Bežne sa u detí vyskytujú také problémy, ako je enuréza, poruchy spánku, poruchy nálad a afektov, separačné ťažkosti, rušivé správanie, psychosomatické poruchy; u adolescentov môžu byť prítomné osobitne antisociálne aktivity, krádeže, vdychovanie prchavých, resp. abúzy iných látok, problémy v sexuálnej oblasti, túlanie a úteky z domu; ale vyskytujú sa aj prídružené psychologické a vážnejšie psychopatologické problémy u postihnutých detí ai.

Pracovníci centra - dvaja psychiatri, jeden klinický psychológ, jeden detský psychoterapeut a traja sociálni pracovníci s vysokoškolským vzdelaním v odbore psychiatrie - zabezpečujú komplexnú diagnostiku a terapeutickú intervenciu, poskytujú tiež konzultačné služby iným inštitúciám (školiace a doškoľovacie pracovisko pre medicov, lekárov, psychológov a sociálnych pracovníkov).

Práca s klientom začína úvodným interview s celou rodinou, vychádzajúc z princípu, že *každý jednotlivý problém (dieťaťa) v skutočnosti ovplyvňuje a vzťahuje sa na rodinu ako celok*, i jej životný štýl. Súhrnné vyšetrenie a ďalší plán intervencie závisí od viacerých faktorov - ako je charakter vlastného problému, postoje klienta ale i rodinných príslušníkov, zapojenie iných zariadení a odborníkov. Konečným cieľom intervencie, kde sa kombinuje individuálna s rodinnou, prípadne skupinovú terapiou, je navodiť zmenu v správaní, resp. prežívaní klienta a rodiny ako systému.

Multidisciplinárny tím centra intenzívne spolupracuje v rámci osobitných týždenných kazuistických workshopov, kde sa spoločne riešia komplikované prípady. Prakticky sa tu vytvára priestor pre pozitívne stretnutie aj tzv. protichodných terapeutických prístupov (odlišné zameranie psychoterapeutického výcviku jednotlivých odborníkov), keďže prvoradým je vždy aktuálne riešenie problému klienta, a nie polemika o najlepšom, prestížnom spôsobe intervencie.

Rodinnú terapiu vedie vždy dvojica terapeutov a môžu sa jej tiež zúčastniť aj ďalší odborníci, resp. školenci („one-way screen“). V praxi sme zaznamenali dôsledné dodržiavanie etických princípov, keď kolegovia sledujúci terapiu prerušili interview, aby sa nezabudlo informovať rodinu o prítomnosti pozorovateľov. Terapeutický kolektív centra priebežne sleduje efektívnosť tzv. „**brief solution workshopu**“, tj. terapeutických sedení s vybranými rodinami, s použitím „brief solution“ terapie (De Shazer [1]). Jedná sa o psychoterapeutický prístup, ktorý sa sústreďuje na to konanie a prežívanie klienta, keď príznaky problému boli nižšej intenzity, alebo sa nevyskytovali (Čo robil klient, keď sa cítil lepšie?). Primárnym je hľadanie riešení pri minimálnej sústredenosti na problémy, pre terapeutickú intervenciu je charakteristická tzv. „solution talk“: otázky podľa možnosti zamerané na prítomnosť a budúcnosť, do minulosti orientované výnimočne, viažúce sa na predošlé „lepšie obdobia“, na čas bez prítomnosti problému. Otázky a intervencie sú formulované v pravdepodobnostnej rovine, ide o hľadanie „výnimiek“ a podporu pozitívnych rezerv u klienta (George, Iveson a Ratner [2]).

Osobitná pozornosť sa venuje rodine s postihnutým. Starostlivosť a služby rodine tvoria kompaktný, detailne prepracovaný a presne fungujúci systém, kde je dobre prepojená zdravotnícka, školská, sociálna, až po komunálnu úroveň služieb ([3], [4]).

Uvedené výstižne dokumentujú **Hlavné princípy rozvoja a riadenia služieb pre rodiny s deťmi so zvláštnymi potrebami**, z ktorých vychádza rozsiahly londýnsky projekt multidisciplinárneho charakteru - „Under Five Project“ - zameraný na včasnú podporu rodín s deťmi so zvláštnymi potrebami (Cameron a Sturge-Moore [5]):

1. Hlavným záujmom služieb by malo byť, aby vychádzali nielen zo zdravotných a výchovných potrieb dieťaťa, ale komplexne z potrieb detí a ich rodín ako celku.

2. Maximálna vážnosť by sa mala prikladať všetkým členom rodiny ako tým, ktorí majú najdôležitejšiu úlohu v pomoci dieťaťu so zvláštnymi potrebami. Malo by sa s nimi zaobchádzať zdvorilo, dôstojne, čestne a s porozumením.

3. Každý profesionál by mal v práci s rodičmi vystupovať v partnerskom, a nie povýšeneckom, paternalistickom vzťahu.

4. Tie zdroje a schopnosti, ktoré rodina vlastní, by sa vždy mali podporovať a ďalej rozvíjať, a nikdy nie potláčať. Malo by sa vynaložiť všetko úsilie preto, aby sa podporila jej sebadôvera a kompetencia.

5. Každý profesionál by mal pozorne načúvať rodine a formulovať závery na základe podrobného rozhovoru s rodinou, dávajúc takto priestor pre jej individualitu, potreby, hodnoty, sily, názory a skúsenosti.

6. Rodičia by mali mať vždy plný prístup k informáciám, kedykoľvek ich potrebujú, aby ich mohli podľa potreby použiť.

7. U profesionálov pracujúcich v tejto oblasti sa vyžaduje explicitný psycho-sociálny výcvik hlavných psychologických a komunikačných zručností.

8. Vzájomným vzťahom medzi organizáciou služieb a rodinou by sa mala venovať plná pozornosť. Mala by zahŕňať určenie konkrétnej osoby buď z dobrovoľných alebo štatutárnych služieb, ktorá by mohla, ak je to po-

trebné, úzko spolupracovať s rodinou pri pravidelnom poskytovaní psychologickej, sociálnej alebo inej podpory.

9. Podpora a pomoc by sa mala poskytnúť okamžite, akonáhle sa ukáže podozrenie, alebo sa stanoví diagnóza u dieťaťa vyžadujúceho zvláštne potreby. Ak je to pre rodinu prijateľné, mala by následne nepretržite pokračovať.

10. Starostlivosť by mala posilňovať široká reťaz dobrovoľných a štatutárnych ponúk rodine dostupných služieb, ktoré by pomáhali naplňovať jej psychologické, výchovno-vzdelávacie, medicínske, praktické i materiálne potreby. Všetky ponuky by mali mať zodpovedajúcu publicitu, zabezpečenie zdrojov, organizáciu a koordináciu.

11. Služby by mali byť organizované na živej multidisciplinárnej báze a nemali by dominovať len predstavy jednej alebo dvoch profesií, ale mali by zahŕňať zastúpenie rodičov na všetkých úrovniach plánovania, organizácie a rozhodovania. Medzi dobrovoľnými a štatutárnymi službami by mala existovať spolupráca, pričom ich rola by mala byť jasná a vzájomne sa dopĺňajúca.

12. Každý obvod by mal vypracovať podrobný politický materiál, vymedzujúci ciele služieb, ich zabezpečenie a organizáciu, s určením pravidelného sledovania a hodnotenia toho, do akej miery sa uvedené ciele dosahujú. Tento informačný materiál by sa mal pravidelne aktualizovať.

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(Ďalšia literatúra u autorky.)

A: PhDr. M. Glasová, Katedra psychológie a patopsychológie PdFUK, Račianska 59, 813 34 Bratislava

I will maintain by all the means in my power the honour and the noble traditions of the medical profession;

I will not permit considerations of religion, nationality, race, party politics or social standing to intervene between my duty and my patient;

I will maintain the utmost respect for human life from the time of conception; even under threat, I will not use my medical knowledge contrary to the laws of humanity.

World Medical association - Declaration of Geneva

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SÚHRNNÝ OBSAH 2. ROČNÍKA ME&B

CUMMULATED CONTENTS OF ME&B, VOL. 2

No. 1

■ Od redakcie/Editorial	1
■ Plánované podujatia/Forthcoming Events	3
■ Oznamy redakcie/News from the Editor	3
■ Pôvodné práce/Original Articles	4
- The Dutch Regulation of Euthanasia/Holandská legislatíva o eutanázii <i>W. J. Eijk</i>	4
- Prenatal Diagnosis of Fetuses with Genetic and Chromosome Disorders: The Pros and Cons of Abortion/Prenatálna diagnostika plodov s genetickými alebo chromozomálnymi poruchami: argumenty pre a proti umelému potratu <i>S. M. Poeschel and M. Šustrová</i>	9
- Pokusy na zvieratách z hľadiska filozofie a etiky/Animal Experimentation from the View of Philosophy and Ethics <i>P. Munzar</i>	11
- Takzvaná sexuálna svoboda a rodina/So-called Sexual Liberty and Family <i>T. Lajkep</i>	13
■ Objednávka časopisu/Subscription Form	15

No. 2

■ Pôvodné práce/Original Articles	1
- The Ethical Debate in Bioethics: Contribution of Personalism/Etická debata v bioetike: príspevok personalizmu <i>L. Palazzani</i>	1
■ Výuka medicínskej etiky/Teaching of Medical Ethics	5
Patient as a Person/Pacient ako osoba <i>M. Nemčeková</i>	5
■ Materiály z kurzov ÚMEB/Materials from the Courses of IMEB (International Course on Medical Ethics: "Ethics of the Family Health and Care", Institute of Medical Ethics and Bioethics, Bratislava (Slovakia), September 2-4, 1994)	6

- Parenthood and Clinical Genetics/Rodičovstvo a klinická genetika <i>H. Watt</i>	6
- Dying Person in the Family: Problems and Conditions for a Real Accompanying/Umierajúci v rodine: problémy a podmienky skutočnej spoluúčasti <i>R. Pegoraro</i>	8
- What Can Palliative Care Offer?/Čo môže poskytnúť paliatívna starostlivosť? <i>I. Finlay</i>	11
- Why hospices oppose euthanasia/Prečo hospice odpovoria eutanázii <i>I. Finlay</i>	12
■ Oznamy redakcie/News from the Editor	13
■ Pokyny pre autorov/Instructions for Authors	14
■ Objednávka časopisu/Subscription Form	15

No. 3

■ Pôvodné práce/Original Articles	1
- Medical Ethics and Care of the Dying/Medicínska etika a starostlivosť o zomierajúceho pacienta <i>M. Petrini</i>	1
■ Retrospektíva/Retrospective	6
* Medzinárodné sympóziu o medicínskej etike/International Symposium on Medical Ethics, Bratislava, 29. - 30. 5. 1992	
- The Significance and Scope of Contemporary Bioethics/Význam a rozsah súčasnej bioetiky <i>D. Callahan</i>	6
- Etika v každodennej praxi lekára/Ethics in an Everyday's Practice of a Physician <i>A. Bajan</i>	8
- Práva pacientov v našich podmienkach/Rights of Patients in Our Conditions <i>S. Bezáčková, L. Šoltés</i>	9
- Práva hospitalizovaného dieťaťa/Rights of a Hospitalized Child <i>L. Šoltés</i>	10
- Medicínska etika - morálny kódex alebo aj zmena vzťahu k človeku? /Medical Ethics - Moral Code or Also a Change of the Relationship to the Man <i>M. Nemčeková, A. Hanzlíková</i>	11
- Etické problémy v dialyzačnej liečbe/Ethical Problems in Dialysis <i>A. Kováč</i>	12
- Porucha rastu u detí - bioetický problém/Growth Retardation in Children - Bioethical Problem <i>E. Mathéová, M. Pašková</i>	13
■ Plánované podujatia/Forthcoming Events	14
■ Oznamy redakcie/News from the Editor	14
■ Objednávka časopisu/Subscription Form	15

No. 4

■ Pôvodné práce/Original Articles	1
- Euthanasia: Some Moral Aspects/Eutanázia: niektoré morálne aspekty <i>H. Watt</i>	1
- The Psychodynamics of Counseling Parents of Infants with Down's Syndrome <i>R. Poeschel</i>	5
■ Retrospektíva/Retrospective	9
* Medzinárodné sympóziu o medicínskej etike/International Symposium on Medical Ethics, Bratislava, 29. - 30. 5. 1992	
- The Euthanasia Debate/Debata o eutanázii <i>D. Callahan</i>	9
- Euthanasia in the Netherlands/Eutanázia v Holandsku <i>H. Jochemsen</i>	12
- Eutanázia v poňatí práva v ČSFR/Euthanasia from the Point of View of the Law in CSFR <i>V. Keseg</i>	14
- Úvaha o eutanázii/Reasoning about Euthanasia <i>M. Fritzmann</i>	15
■ Krátke správy/Short reports	16
- Morálne triedy v škole, morálne deti: prístup konštruktivismu/Moral Classes in School, Moral Children: the Approach of Constructivism <i>M. Glasová</i>	16
- Starostlivosť o rizikové rodiny vo Veľkej Británii/The Care of Families under Risk in Great Britain <i>M. Glasová</i>	17
■ Oznamy redakcie/News from the Editor	19
■ Obsah ročníka 1995/Contents of the Volume 1995	19
■ Objednávka časopisu/Subscription Form	20

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