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ETHICS & MEDICINE

An International Christian Perspective on Bioethics

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From the Editor

DEATH ON THE AGENDA

The coincidence of two recent developments in the United States should give us all pause for thought. First there was the Washington State referendum on a proposal which would have created the first euthanasia jurisdiction in the modern world. Despite widespread expectations of victory, the proposal was defeated—narrowly. We may expect a yet more vigorous campaign next time round, in this attempt to force open the door to active euthanasia. A few weeks later came the implementation of a federal (i.e., U.S.-wide) act requiring hospitals receiving government funding to ask every patient, on admission, whether he or she has a living will. Lest *Ethics and Medicine* readers labour under the misapprehension that this latter move is motivated by a desire to gather public opinion information, or perhaps, to scare already scared people by officially endorsing their conviction that in hospital death is never far away, it may do both these things but its motive is at root one of money. Living wills have the effect of saving it: they tend to cut out treatments which would otherwise be given, especially in a medical culture—like that of the United States—where fear of litigation and the profit motive may combine to ensure what a more restrained medical tradition would withhold. And, of course, if the politics of living wills is the politics of cost containment, it is also and equally the best ploy so far of the euthanasia lobby. The living will is their creature, and a clever one too. In the increasingly pluralistic environment of post-Hippocratic medicine, the arguments are strong that advance directives are but the complement of informed consent. They allow the patient to give consent ahead of time to whatever treatment regime he or she prefers. And what could be wrong with that?

Yet they themselves also help advance the move into post-consensus medicine. In a situation—like that in the United States—where consensus has already broken down in terminal care a good case can be made for taking steps to ensure that you get the kind of treatment you would wish to get. There is a much better argument for granting durable power of attorney to relatives or friends than a blank cheque to whomever will be the final interpreter of a living will. In more conservative and, still, consensus-minded Europe the balance of argument is still against encouraging any further step into an atomised medical culture. Yet whatever our tactics for ourselves and for our society—it needs to be said, again and again, that the idea of privatised medical values, of a culture driven by individual moral agendas, is a mere flight of fancy. Informed consent is a worthwhile element in ethical and legal medical understanding, but it is far less significant than the purveyors of medical pluralism would like us to believe—than, indeed, their vision requires them to believe in order to remain intact. That is to say, the vision of a pluralistic medical culture, with each of us his or her own Hippocrates, the author of our own private codes of medical values, is a vision driven by necessity. The rejection of the Hippocratic consensus in the name of a consensus-denying pluralism *requires* the model of autonomy/informed consent; it has nowhere else to go. That road is not—cannot be—blocked because it is the only way ahead. The fact that this model is not only attractive but necessary leads—surprise, surprise—to an energetic neglect of its problems. Yet those problems are insuperable. And, *since* they are insuperable, the only alternative to the past consensus of Hippocratism is some new, post-Hippocratic, pattern of values which will either be candidly embraced by the community as the basis of its medical culture or, failing that, covertly imposed in the name of autonomy by those who have power to do so.

That is what lies behind the debate about death. In the repudiation of consensus Hippocratism and the move to private pieces of paper in its place we are stepping out of the light of beneficent, humane, patient-centred medicine into the shadowlands of power-play. In the politics of death the patient becomes also the victim.

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MEDICAL GENETICS: ITS PRESUPPOSITIONS, POSSIBILITIES AND PROBLEMS

1. INTRODUCTION

Medical genetics is one of the areas of medicine that in recent years has received much attention, both in the scientific literature and in the mass media. This interest primarily concerns the constant progress in the biomedical field and the inherent ethical and social problems, whether they be implicit or explicit. The extensive research programmes aimed at the mapping and sequencing of the human genome (the entire genetic endowment of an organism) reflect both the technical and scientific progress that has been made and symbolize the possibilities and promises of modern medical genetics.

Genome mapping is the physical location on the chromosomes of pieces of genetic information (locus). Activities in this area started as early as the beginning of the 1900s and by 1990 over 6,500 of those loci had been established. About 2,000 of these are genes, of whose function something is known.[1]

Sequencing is the word used for activities that lead to the elucidation of the particular sequence of the nucleotides, the units that in a linear arrangement make up DNA, the molecule that contains the hereditary information.[2] The total sequence of the human DNA has been called the 'grail of human genetics'.[3] In the USA as well as in Japan and the EC, specific programmes for mapping and sequencing the human genome have been started.[4,5] The aims of this 'big science' project are both theoretical, *i.e.*, increased insight in what is called human evolution and in the organization and structure of the human hereditary information, and practical, *i.e.*, new methods for the practice of medicine.

For the practice of medicine, mapping and sequencing the human DNA will provide increasing possibilities for diagnosing genetic diseases and disorders as well as for therapeutic interventions. Some of these will be elaborated in section 4 of this chapter.

Diverse and increasing possibilities to intervene in the lives of human beings do not necessarily require special attention. Medicine has always dealt with intervention in human life. It is believed, however, that modern medical genetics presents particular problems for at least the following reasons:

- the genetic material is closely connected with *who* we are and *how* we are; in human DNA we deal with the physical foundation not just for human life in general but for human individuality. Therefore, the techniques of the 'new genetics' are providing us with new power to manipulate human life at its most basic level.
- because of the far-reaching and radical character of the interventions that are already with us or will be available in the future, it is imaginable that they will be used not only for preventive, diagnostic and therapeutic purposes but also for reconstructive or even for eugenic purposes; in addition such interventions may serve financial interests, for instance of insurance companies.

It is interesting to note that both those who favour further application of modern gene technology in medicine and those who warn against the dangers in general tend to believe that the genes not only play an important, if not decisive role in the determination of individual identity, but also that gene manipulation will allow the manipulation of specific traits of an individual and therefore of his or her identity.

The increase in knowledge and the possibilities of intervention by medical genetics imply a corresponding responsibility to use these new options in a morally correct way. This, of course, applies for every new medical technique and treatment. However, to be able to define a morally correct way of using a new technique more than only a factual and an ethical analysis of its possible applications is needed. Science and technology are human activities and as such they embody a certain way of looking at the world and life, including its ethical implications. Furthermore, the practice of scientific research at any given moment also reflects and represents social and economic interests. This is also true for medical genetics. This raises two sets of questions: (1) What is the implicit and possibly hidden philosophical character of these new developments in (medical) genetics? In other words, what are their presuppositions? What does this

mean for their ethical evaluation? (2) What are the main present or future applications of those new techniques and what major ethical problems do they pose?

In this paper an attempt will be made to address these questions. Sections 2 and 3 deal with the first set of questions, while in section 4 some of the main applications and their entailing ethical problems are discussed. It will be attempted to do so from a Christian perspective. This treatise is meant as a contribution to further discussion and thinking.

2. Presuppositions of medical genetics

2.1 Modern science

Medical genetics, like medicine in general, is based primarily on the principles and results of natural sciences. Before discussing the predominant paradigm of medical genetics it is helpful to try to define the presuppositions that underlie natural science in general. Modern science is characterized by a specific way of investigating the reality in which we live. The scientific methodology can essentially be characterized with one keyword: abstraction. Generally this goes together with reduction of reality, objectivation of what is investigated, quantification of what is observed, the establishment of causal relations between observations and the formulation of models and theories.[6] The meaning of these words show some overlap. The most central notion of the scientific method, however, is abstraction.[7,8]

In science this abstraction has at least two different forms.[8] In the first place the *generalization*: not considering the concrete unique individual but considering the object under study as a representative of a class or a group; *e.g.* in studying the body of man. Here, man is a generalization. In real life there are only unique, human beings. The second form of abstraction is not considering the object, *e.g.* the human body, as a whole, but studying only certain characteristics of it or only particular relationships within the body, or of the body, with other entities. These characteristics and relationships are as much as possible expressed in number and measure. This leads to a *deterministic* view of man.

These abstractions imply a reduction of the real 'thing', or individual creature under study to an impersonal object (objectivation), taken out of the context in which it naturally or normally is situated. As a consequence, only what can be perceived by the senses, directly or indirectly, is taken into consideration. With respect to man this results in a dualism of body (that can be observed) and mind or soul.

The presentation of the scientific methodology may seem rather evident. It has been pointed out, however, that science in antiquity (*e.g.* that of the ancient Greeks) was different. It took as its starting point the 'naive' experiences that were obtained through the encounters with reality. But the starting point of modern science is no longer an unprogrammed wonder about the phenomena in the world, but the scientific query of man and the leading (mathematical) theories[9] and increasingly economic interests. The question concerning the origin of all things is transformed into a question about the material causes; reflections on the essence and meaning of things are replaced by querying their function and usage.[10] The new approach can be called the *instrumental rationality* of modern science.

2.2 Modern medicine

This approach also characterizes modern medicine. For main-stream modern medicine the explanatory strategy can be expressed with the words reductionism, dualism and determinism.[11] As a consequence of this methodology basic sciences like physics, biochemistry and molecular biology are considered the basis for the applied sciences that make up medicine: anatomy, physiology, pathology etc. The central presupposition of medicine is 'that all disease is physiology gone astray'.[12] Some authors[13] have argued that in medicine the dualism of modern science manifests itself in three forms: the mind-body dualism (the so-called Cartesian image of man[14]), the body-environment, and the individual-population dualisms. Most scientific abstractions leave out the mind (one can also say, the soul), the environment and social relations of the individual patient. The body is studied as a separate entity, the 'machine' being the leading model. In this model, disease is a deviation in the body's structure or processes that in principle can be localized and treated on a material basis.

It has been argued that the abhorrent experiments carried out by physicians in the German concentration camps were the ultimate consequence of a medicine that wanted to understand itself as nothing but natural science.

It is clear that this approach has been very successful in elucidating the functioning of the human body and in discovering causes of many diseases at the material level. This has resulted in many possibilities for therapeutic or palliative interventions. This has been and continues to be of great benefit to many people.

Nevertheless, it is important to look critically at the predominant medical model and at its role in medical practice (as is also done by many people working in medicine, cf. section 3). For it is one thing to use a certain methodology to study reality, to set up models of certain phenomena and to have specific questions answered in a way that allows some intervention; it is quite another thing to consider these abstract models as true representations of reality itself, omitting the notion that the models are an abstraction of reality. Then reality itself is seen and experienced and treated more and more as though it really were as the models that represent it. This over-estimation of abstract theories and models is dangerous. Gabriel Marcel has called such losing sight of the limitations of abstraction the abstract mentality, which 'inevitably degenerates everything she touches'.[15] It has been argued that the abhorrent experiments carried out by physicians in the German concentration camps were the ultimate consequence of a medicine that wanted

to understand itself as nothing but natural science.[16] Although the Nazi atrocities took place in a very specific and unique historical context, the danger of the abstract mentality in today's medicine is not fictitious. It was not without reason that over twenty five years ago also the Dutch physician G. A. Lindeboom warned that medicine should not be understood as the teaching of diseases and their treatment but as the science of patient care. Only then, Lindeboom asserted, can ethics be an integral part of medical science.[16]

Quite recently a philosopher has argued similarly, though reasoning along completely different lines, that the objectivation, that dominates the physician-patient relationship is itself a form of power or control over the patient. This leads to practices that treat persons as abstractions. Medical ethics will not be able to humanize medicine without restructuring medical practice.[17] The author rightly points to the constant danger in modern medicine of treating persons as abstractions. Not because physicians are any worse than other people, but because they have been educated to study the human body with the aid of abstract models.[17] In practice it appears to be easy to forget the limitations of the models when dealing with actual people. (Though, evidently, the danger to treat patients as objects is much more acute in some specialisms, *e.g.* transplantation surgery, than in others, e.g. general practice.)

There are still two more reasons why the abstract mentality is a real danger in medicine and, through it, in health care. First, the abstract models of medicine do not only influence physicians in the way they tend to see their patients. Scientific theories and models are communicated in popularized forms to society at large. But lay people generally have even less understanding than scientists as to the relative and limited character of those theories; thus they are often seen as 'established truth'. This means that science provides a frame-work through which people interpret and experience themselves and the world.[18] For example, the theories of Copernicus, Darwin and Freud, to mention just a few, have profoundly influenced the self-understanding of people in Western culture, and, therefore, the way they behave. With respect to medicine this means that to a certain extent people understand their disorder or disease in terms of the medical model (a certain organ is not functioning properly). This makes it even more tempting for the physician to relate to the patient according to scientific abstractions. Another consequence is that people tend to feel very dependent on medicine and, although they may criticize physicians or hospitals, expect from medicine an instant solution for whatever health problem they may have.

The above manifests a more general tendency in our society, namely that science and technology are looked upon as *the* instruments to solve all problems.[19] In defence of this statement two witnesses can be quoted. The philosopher Carl Friedrich von Weizsäcker said: 'Faith in science plays the role of the dominating religion of our time'.[20]

Karl Jaspers, philosopher and physician wrote: 'The loss of transcendent reality has increased the earthly will for happiness to the absolute. All difficulties should be eliminated through technical measures, on the basis of science'.[21] (This in spite of criticism that in more recent years has been addressed at science and technology and in spite of the fact that there are anti-science minorities in Western countries.)

This brings us to the second reason why in medicine (but certainly not only there) the danger of the abstract mentality is real. Modern science and technology are strongly motivated by a pursuit for power; power to control our circumstances, our lives and our societies.[22,23] But this striving for power and through it, for security, has at the same time facilitated the overestimation of the scientific method and thus favoured the instrumental rationality of science in society. This rationality asks for the functionality and the usefulness of things, but as a further consequence also of persons.[24] This thinking is penetrating the practice of medicine, and by no means least, that of medical genetics as well.

2.3 *Reasons for the interest in genetics*

Medical genetics is a relatively new specialism, combining parts of pediatrics and anthropogenetics. Before discussing the predominating model in this specialism it is useful to outline a few reasons why medical genetics has been receiving increasing emphasis during these last decades.

a. The benefits of public health policies, of better hygiene, sufficient nutrition, prevention and medical care have led to a substantial decrease in diseases with a primarily external cause (deficiency of some nutrient, natural hazards like parasites, bacteria, viruses). As a consequence, the relative contribution of genetic causes to all causes of diseases has increased significantly, particularly in Western countries.

   In the Netherlands in 1985 about one-third of the mortality during the first year of life was due to congenital disorders.[25] About one-half of admissions to hospitals of children under the age of 15, are due to inherited disease.[26]

b. The diseases currently prevailing in the Western countries that account for a large percentage of medical consultations, admissions to hospitals and caring insitutions, and mortality, are chronic and degenerative diseases such as mental illnesses, cancer, cardiovasclar diseases, arthritis, or chronic aspecific respiratory diseases.

   It is becoming increasingly evident that these diseases often have a hereditary component; *i.e.*, the risk of acquiring such a disease is related to one's genetic endowment.[27]

c. Another, less obvious, reason is that since the origin of modern genetics (second half of the 1800s), geneticists have shown interest in the genetic component of personality traits and behavioural patterns. Although the extreme claims of sociobiology during the mid-seventies were untenable and have been severely criticized,[28] the endeavour to explain behaviour on the basis of biology, and especially of genetics, continues.[29] In this context it is worthwhile to mention an interesting observation of Th. Dobzhansky.[30] He asserts that when in society the opportunities of everybody to receive education become more equal and when at the same time social mobility increases and one's socio-economic position depends increasingly on capacities and merits (meritocracy), then the socio-economic

position of people will be determined increasingly by their genetic endownment. All other things being equal, the differences in capacities between individuals, that in an open meritocracy will determine their position, will correlate strongly with genetic differences.[30] Though, of course, social transmission of status and opportunities still play an important role, it can be observed that Western societies are moving towards an open meritocracy. This may well be a factor for the interest in genetics.

d. A last reason for this interest is that the predominant thinking in genetics, as will be described hereafter, fits in nicely with the medical model and with the pursuit of control over life which, as we have seen, is a leading motive of science and technology (cf. section 1.2).

If a person is largely determined by his genes then the most direct way to control life and to prevent or cure disease can be obtained by intervention at the level of the genes.

2.4 Medical Genetics

In genetics the 'medical model' finds a particular expression in the so-called central dogma of molecular genetics.[31] This states that the hereditary information is stored in DNA in the form of a code, and that this information is expressed by two sequential processes: transcription into RNA and then translation into specific proteins, that are essential for the expression of the individual traits (see fig. 1).

replication DNA RNA protein traits.

Fig. 1. The central dogma of molecular genetics.

In other words, the genetic information encoded in DNA determines the phenotypic traits of an organism through the direction of the synthesis of proteins. The flow of information occurs in one direction: from DNA via RNA and proteins to traits. A gene is defined as a unit of heredity containing the information for one protein.

It will be understood that this model implies a rather deterministic view of man. The genes determine how the individual will be, or at least how that individual can be.

It will be understood that this model implies a rather deterministic view of man. The genes determine how the individual will be, or at least how that individual can be. The environment influences the extent to which certain traits will be expressed, but not the character of the traits themselves as fixed entities.[32] This model clearly invites to study the genes and gene defects as the most fundamental causes of disease. By a few quotations it will be illustrated how this view under a rationale for research in human molecular genetics.

– In a brochure announcing the newly established Center for Molecular and Genetic Medicine at Stanford University, USA, it is stated that the 'new medicine' is based on 'the present belief that almost all human diseases are, in some way, genetically determined, and that given precise understanding of the structure, organization, and the regulatory processes of genes, many diseases can be prevented or cured'.[33]

– The chairman of the Ciba Symposium that took place in June 1989, G. J. V. Nossal, said in his introductory speech: 'DNA is iconic for the new biology, a biology that seeks to explain phenomena not just at the level of the whole organism or particular tissue, though clearly embracing these frames of reference; but also at the level of the cell, of the individual protein molecule with its near-magical powers as molecular machine, and of the informational molecules which control cellular functioning—DNA and RNA'.[34]

– At this same symposium Sydney Brenner, a leading scientist involved in the mapping and sequencing of the human genome, expresses his view on genetics as follows: 'Genetics investigates the plan of the organism. This plan is embodied in a collection of genes that is handed down in the germ-line to specify the construction of the organism'. And, at the end of his lecture: 'The manifesto—if not the programme—of molecular genetics must remain the computation of organisms from their DNA sequences. Understanding the language of genes remains the major scientific objective of all genetic research'.[35]

2.5 Paradigm shifts in clinical medicine

Two recent pleas for shifts in clinical medicine demonstrate a major emphasis on genetics in health care. P. A. Baird observes that the main burden for health care is caused nowadays by chronic and degenerative diseases that not only have external causes but also an internal genetic background (cf. point b under 2.3). Today's medicine is treating these diseases mainly symptomatically. 'We need a shift from concern with manifestations to a concern with cause in health care'.[36]

First, the major genes that predispose people for such a common disease should be identified. This would allow the identification of people at risk, which would give the opportunity to prevent expression of the disease, *e.g.*, by changes in life-style or by some causal therapy.

Against the background of the fact that medical genetics in practice very often regards child-bearing concerns, E. T. Juengst suggests that 'geneticists can help their patients most effectively by shifting their clinical goals from enhancing the patients' somatic health to enhancing their reproductive health: *i.e.*, towards helping them to achieve their reproductive goals'.[37]

This thought is clearly in line with the increasing impact of genetic diseases (cf. point *a* under 2.3). At the same time it is evident that indeed a real shift in the clinical setting is proposed here. Its seriousness is nevertheless concealed by speaking of 'reproductive goals of the patient' that is attended by the genetic counsellor. But this clearly involves other human beings that are not yet conceived, or are in a prenatal stage. We will discuss this point in section 4.

3. CRITICISM AND ALTERNATIVE

3.1 A criticism of the predominant paradigm in medical genetics

The central dogma of molecular genetics is a simple model for the biophysical and biochemical relationship that exists between a particular nucleotide sequence of some stretch of DNA and the structure of a particular protein. The structure of a protein determines its function(s), given the right circumstances. This knowledge of the fundamental role of DNA in the process of protein synthesis has thus far produced the most positive practical application of gene technology. In combination with techniques to manipulate specific DNA sequences (recombinant-DNA techniques) it is now possible to have important human proteins, like insulin and interfon, produced by bacteria in sufficient supply at a reasonable price. But this is done with micro-organisms, cultivated in special growth media, that are forced by specific manipulations to synthesize such a protein. The relationship between a specific protein and the expression of a trait of an organism under normal conditions is mostly unknown, even for micro-organisms, let alone for man. An undisputed expert like Francois Jacob has formulated this as follows:[38] '. . . during the development of the embryo, the world is no longer merely linear. The one-dimensional sequence of bases in the genes determines in some way the production of two-dimensional tissues and organs that give the organism its shape, its properties, and . . . its four-dimensional behaviour. How this occurs is a mystery'. The genetic formation does not give a plan or a description of the entire organism; DNA sequences do not *direct* the synthesis of proteins. They contain the necessary information for the structure of proteins, but at what moment during development, under what conditions a specific protein is synthesized, and how much and in what cells of a higher organism, is partly determined by regulatory DNA sequences, but also by many environmental factors and by stimuli that cells in a higher organism exert upon one another. This is already evident from the fact that the whole process of protein synthesis is dependent upon various proteins, of which some are involved in very specific interactions with DNA and RNA.[39] It is obvious that the regulation of gene expression is influenced decisively by external stimuli that can moderate the activities of certain enzymes.[40]

In fact it is only within a living cell that DNA can be of any use at all. In the world of living organisms not DNA but the living cell has the primacy. The genes are not active, directing units of information, but rather constitute a passive essential precondition for the survival of the living cell or the living organism. This is already clear from the fact that every cell of, for example, the human body contains the complete genetic information of the individual, while in each cell only a small proportion of the genes is expressed, dependent on the place and the function of that particular cell within the body.

Also from a more theoretical point of view the total interdependence of DNA and the totality of the biochemical and biophysical reactions that are coordinated in time and in space within a living cell in an extremely intricate way, can be argued. Speaking of the genetic code or of the genetic message, as geneticists do, in itself presupposes that there is someone or something that can read and interpret the code of the message. The word 'message' implies that there is a meaning to be interpreted. The really astonishing thing about the genetic information, and of the living organism, is that the DNA sequence contains a message for the organism, because the organism contains the 'mechanism' that can translate the DNA sequence into meaningful activities. The meaning of the DNA sequence is not generated by the mechanism; this mechanism presupposes the meaning of a genetic message. Nor has the DNA generated the translation mechanism. This is impossible, since for the expression of this meaning the DNA precisely needs that mechanism. So, the genetic message cannot give a sufficient explanation of the development of the organism; the genetic code as a meaningful message itself needs an explanation, both a final and a causal.[41,42]

It is interesting to note that some biologists, being aware of the meaning of the genetic message for the organism, speak of the 'spirit of living matter', and of 'intelligence which is inherent in the dissymetrical structure of the macromolecule', and of 'unconscious intelligence'.[43] This 'inherent intelligence' has no satisfactory immanent explanation. In a Christian understanding of reality, the Creator is seen as its origin.[44]

Considering the fact that the meaning of the DNA sequences is related to the role they play in the living organism, whereby this role cannot be derived directly from the sequence, it is asserted that the elucidation of the DNA sequences and of biochemical processes is of relatively little value for understanding the organism as organism.[42,45] The biologist Portmann has argued that the study of the gene sequences and of biochemical and biophysical processes that take place in the living organism has produced much useful information for those who want to intervene and control the processes of nature. However, to get an understanding of the organism as a whole, one should take a completely different perspective. It should be realised, then, that a living organism has the quality of 'inwardness'; they are always centres of activity, autonomously acting beings that relate actively to their environment.[46] If this is true for animals and plants, the more so for human beings.

In medical genetics it appears that the major interest concerns the sequences and expression of genes. Such knowledge certainly constitutes a form of power and implies certain possibilities of control. But it contributes little to the understanding of man as a human being. However, when the abstractions of molecular genetics acquire a more important role in the relationship between a physician and a patient, it will, unintentionally and possibly unconsciously, lead to a form of violence to man.[47]

3.2 An alternative view

Genetic information is an essential precondition for biological life. The genetic information in itself neither describes nor determines the life of the organism as a whole. That genetic information is essential is most clearly seen by a negative approach. A defect in the genetic information can be related to or can cause a more or less serious disorder in the organism. The genetic information provides the boundary conditions that lead the development of the organism along the lines that are characteristic for the species. The genetic material can be

seen as the embodiment of the specific character of the organism as a separate individual entity yet belonging to a certain species, at the level of the molecules and the molecular interactions. We shall call this specific character of the organism as an entity, its *identity*. This first level can be studied by biophysics and biochemistry. This level is essential but not all-determining. There are other levels of organization that come into play. Based upon the first level, there is the level of organic life, of the living organism as an entity. At this level one could also consider the immunological defense in higher animals and in man as an expression of the identity of the individual organism. In animals and man there is a third level, the sensitive level, qualified by the role of the senses and by a form of consciousness that is dependent on the presence and the activities of a central nervous system (CNS). At this level the identity of the individual is manifested in the consciousness which is intimately with the CNS.

Each of these levels is governed by its own laws and regulations. Each level also provides boundary conditions for the level above it, at the same time leaving open many possibilities of developments that are, as it were, encompassed by the next level. Although the processes at a certain level are governed by the laws that are operative at that level, they are qualified by the higher level. For instance, as discussed earlier, the gene expression in the sense of protein synthesis obeys the laws of physics and chemistry, but the process as a whole is integrated in and governed by the cell as a living unity. In the same way the activities of a living cell in a higher organism are governed by the individual organism as a whole.

(Before continuing, it should be underlined that in reality these four levels do not constitute separate entities. They, in turn, are human abstractions meant to give more insight in reality. In real life these different levels are completely intertwined, forming the integrated unity that each organism is.)

In man, on top of the three levels mentioned before, a fourth level can be distinguished that can be indicated as the level of mental and spiritual life. This fourth level concerns the acts a human being can realize in life (including of course, social life). At this level the spiritual life can be seen as the expression of the identity of the individual. Since the life of an individual together with all the activities at the various levels that life entails, are ultimately qualified by the highest level, as explained above, the life of a human being is ultimately spiritually qualified at all its levels. The different conceptual levels or aspects that can be distinguished in a human being, form an integrated unity and totality in the individual human being. Influences can be exerted both 'bottom-up' and 'top-down'. There certainly are genetic and physiological influences on, for example, mental processes. But on the other hand the body's processes can be influenced by the self-experience of the person and the meaning the person gives to these experiences. Relatively new research demonstrates that personality characteristics and emotional distress factors influence the onset of certain diseases, as well as the healing process. These results also indicate that brain cells, neuropeptides, and immune cells are all influenced by experience. In other words, it is becoming clear that there are very specific correlations between: a) man's bodily experienced meanings and b) conditions or states of the 'medical body' as it figures in the clinical practice of medicine.[11,48,49]

These and earlier mentioned insights give reasons to critically evaluate the usual distinction that is made between acquired and genetic diseases. We will briefly mention these reasons.

a. When there is an epidemic of an infectious disease some people catch the disease, while others do not. This depends not only on environmental differences but also on differences in resistance, to which hereditary immunological as well as psychological factors will contribute.
b. Among people that have a so-called genetic disease, there is a considerable variation in the way and the measure in which the disease manifests itself. Some interesting examples of this, with respect to diseases of the blood, are given by Konotey-Ahulu.[50] There certainly are genetic defects that, while allowing a certain variation in the manifestation of the disease, in all or virtually all cases lead to a serious disease. But the concept of the role of the genetic information in the organism, as indicated above, gives reasons to interpret these cases not as typical demonstrations of the prevailing model for gene expression and the role of genes in the functioning of the body, but rather as exceptional cases with relatively few variables.
c. Most and maybe all of the common diseases have some genetic component; *e.g.*, some people are genetically more disposed than others to acquire such a disease. Here the interplay between hereditary factors and environmental factors is of importance. When a person is genetically predisposed to acquire a certain disease he has a higher than average probability to get that disease than another member of that population.

   Probabilities, however, do not allow definite statements about individuals. When differences in susceptibility to a disease are contributed partly to genetic factors and partly to environmental factors, in fact the person as an individual is left out. The same happens when differences between people in a certain population with respect to a particular trait, *e.g.*, intelligence, are explained by genetic and environmental factors. Then, too, the person as an agent that actively influences his own personality characteristics, is not taken into account. In fact, human traits and characteristics are seen as determined by nature and nurture. In the light of the intimate relationship between genetic endowment, environmental influences and mental and psychological characteristics, as briefly indicated above, such a presentation of man clearly must be seen as a reduced picture.

Based on the reasoning above, we may conclude that the identity of man does not reside in his genetic endowment only, nor in the natural and social environment, nor exclusively in his brain consciousness. The identity of man is ultimately spiritually qualified (*i.e.*, by his basic beliefs or religious conviction), but it is expressed in different ways at the different levels (see above). Now, what is it that gives us the experience of identity of ourselves and of each individual human being, in spite of the variation and the constant changes? The experience of identity throughout life is based *on the constancy and*

continuity in time of the structuredness *of the individual in the various levels*, as described above.[51,52]

It is important to realize the difference between changes that respect identity and changes that violate or manipulate identity, even to the extent of bringing about a different identity, that is, another person. A change in identity experience can be induced by a serious disease, for this can influence the way in which a person experiences himself as well as the way in which he relates to other people. Similarly, a change in identity experience can be brought about by a medical intervention that cures a person from a disease or disorder. A clear example of this is the prescription of psycho-pharmaca to people with psychological disorders. But in spite of the changes brought about by such intervention we realize that we deal with the same identity before and after the intervention.

Now, in the context of our subject two important questions come to mind, to be elaborated in the sections 4.2 and 4.3. 1) When is a change *in* identity experience so radical and so fundamental, that it should be considered as a violation or manipulation *of* identity?
2) How should different forms of genetic modification be evaluated in this context? Can it be used to induce a beneficial change in identity or does any genetic modification always cause an unacceptable change of identity?

4. Ethical problems in some areas of medical genetics

In this section ethical problems will be discussed that are related to three areas in medical genetics, namely prenatal diagnosis, somatic cell genetic modification, and germline genetic modification.

4.1 Prenatal diagnosis

Prenatal diagnosis is associated with several ethical problems for which a wealth of literature exists. We do not presume to give an overview of all problems or of the main literature on these issues; just one or two of the main ethical issues will be discussed that we consider to be central themes in this area.

The term 'prenatal diagnosis' refers to techniques that enable the diagnosis of certain congenital diseases in the human embryo or fetus. These congenital diseases can be hereditary, can have a hereditary component, or can be acquired. Two well-known examples are the Down's syndrome (trisomy 21) which can be hereditary but is mostly non-hereditary, and neural tube defects in which hereditary factors play a role. When prenatally a disorder is diagnosed, parents almost always decide to have an abortion.[53] So, the life of an unborn child is terminated on the basis of the results of a medical test, indicating that the child has a disorder that will manifest itself, sooner or later in life, in a serious disease. This decision to terminate unborn life is the central ethical problem.

An ethical evaluation of some human action requires, on the basis of factual analysis, an ethical evaluation of the action itself, of the motives of those who carry out the action, and of its consequences.

4.1.1 Ethical evaluation of prenatal diagnosis and selective abortion

A very central issue in this problem is the status of the human embryo or fetus. As we have concluded in section 3.2, in man the different aspects or levels that can be distinguished form essentially a unity. Man's total existence is qualified by the highest, the spiritual aspect (cf. section 3.2), which means to be created by God to live in a personal and spiritual relationship with Him. This remains to be his destiny, independent of the question whether he will accomplish this destiny or not. Since man is a unity, it should be assumed that every individual is spiritually qualified from the very beginning of his bodily existence. As a consequence, from conception onwards, man deserves the same protection as every human being already born. For that reason abortion is in essence to be condemned. Only in very exceptional circumstances abortion might be the lesser of two evils. Prenatal diagnosis, however, if combined with selective abortion cannot be defended with reference to such extreme, exceptional cases, because:

- During genetic counselling a woman may be offered the option of trying to get pregnant, to undergo prenatal diagnosis and then to have an abortion in case the fetus has a particular disorder. For this situation there exists no extreme exceptional reason for abortion, since the woman willingly and wittingly sought the situation in which she would decide about an abortion.
- Prenatal diagnosis is also performed when there is an increased risk for a disorder that, although it may cause a severe burden, cannot generally be considered extremely serious, e.g. some hemoglobinopathies, which are due to abnormal hemoglobines.[50]

Furthermore, there is a risk of fetal loss associated with the techniques of prenatal diagnosis of 0.5 to 1.5% for the experienced clinics.[54,55] This risk should not be taken without a good reason.

Therefore, in our opinion, prenatal diagnosis in principle should only be carried out when a medical problem is suspected for which therapeutic measures can be taken. However, most people in health care and in our societies do not share this viewpoint. Abortion is legalized in most Western countries and prenatal diagnosis associated with the possibility of selective abortion is widely practised. So we have to continue the discussion by trying to show that there are serious ethical objections against this present practice, also if one in principle accepts abortion as a free choice of the woman.

4.1.2 An ethical evaluation of the motives behind prenatal diagnosis and selective abortion

The generally accepted overall motivation for medicine, namely the prevention, healing and/or alleviation of diseases and suffering, is also valid for medical genetics.[56,57] At the same time, the most important principle of genetic counselling is the non-directiveness. The counselling intends to enable people to make informed decisions in agreement with their own values and view of life. The non-directiveness of the counsellor and the freedom of the client especially concerns the decisions regarding procreation.[58] So it is asserted by some geneticists and ethicists that the aim of genetic counselling should not be to reduce the number of births of handicapped children. Genetic counselling should not be considered as a form of preventive medicine, but should aid people in their attempts to avoid suffering, in agreement with their own norms and values.[57,59,60] This

well describes, I think, the general attitude of the genetic counsellors in The Netherlands. In one of the discussions during the Ciba Foundation Symposium that took place in 1989, one of the participants made an interesting statement on prenatal diagnosis, that also shows that this is seen as an instrument to avoid suffering. This biologist said:[61] 'It is clear that the greatest triumph in the study of human genetics has been prenatal diagnosis. It affects human lives much more than anything geneticists can do or are likely to be able to do for quite a while. . . . Therefore, the greatest threat to our ability to make contributions to human welfare is the opposition to abortion . . .'. It is clear that this position focuses on the need felt by the people who come for genetic counselling, to which the respect for the life of the unborn child is subordinated. So, the avoidance of suffering that is aimed at in seeking prenatal diagnosis, primarily refers to the prospective parents instead of the still unborn child.

However, the prospect of causing sorrow and suffering to other people is a very shaky argument for killing an innocent human being, especially if it is unborn.

When it concerns a very serious genetic disorder like Tay Sachs and the Lesch-Nyhan Syndrome, the suffering of a child with such a disease will certainly also play in such considerations. But in many instances there is no reason to suppose that the child with a disorder will suffer more than a 'normal' child (think of Down's syndrome). The ethical defence for selective abortion in these cases is that the burden of having a handicapped child is heavier than the parents think they can probably bear. It is true that having a child with a handicap can be a heavy burden involving much sorrow and concern and sometimes tensions within the family. However, the prospect of causing sorrow and suffering to other people is a very shaky argument for killing an innocent human being, especially if it is unborn. People can willingly or unwillingly bring about much suffering to other people in many ways. It would, however, be disastrous if in society this would be accepted as a valid reason to terminate the life of such people. Because of important legal and social differences between born and unborn human beings, the acceptance of the killing of unborn handicapped children does not *necessarily* lead to the acceptance of the killing of other human beings who may also bring about serious suffering and sorrow to other people or who will suffer themselves, such as handicapped newborn babies, demented elderly, or people with severe psychiatric disorders. Whether the first will ever become a precedent for the latter depends on other factors in society as well. We return to this point later on.

Another important problem that needs further consideration is the question whether prenatal diagnosis can be seen as a form of preventive medicine. Some people who justify selective abortion in certain circumstances, reject the argument of prevention of the births of handicapped children.[59,60,62] They realize that this would imply a value judgement about the lives of handicapped people; they find this ethically undesirable.[63] But the rejection of prevention as an aim for prenatal diagnosis is certainly not general, neither among the health care professionals, nor in society in general. We shall give a few examples.

In 1971, at a symposium on biomedical progress and human values, a Canadian professor in medical genetics states: 'People are making uninformed decisions that act dysgenically. Perhaps it would be a good idea to think about how people could learn to make informed decisions that would act eugenically'.[64]

Results of a survey among genetic counsellors indicate that quite a number of them consider prevention clearly secondary to informing the counsellee, but not unimportant. There was no consensus among them about the question whether a goal of genetic counselling is to improve health and vigour of the population. This means that at least some of the counsellors consider this a valid goal.[57] Although genetic counsellors in The Netherlands would not defend prevention as an explicit goal of genetic counselling, a well-known geneticist, in a publication, clearly connects genetic counselling and selective abortion with the prevention of the birth of handicapped children.[65]

In a letter published in *The Lancet*, the author, apparently related to the Clinical Genetics Unit in Birmingham, writes that 'surely one aim of clinical genetics is to reduce the burden of handicapping genetic disease in the community?'[66]

In 1987 the Department of Health Welfare and Cultural Affairs of the Dutch Government published a report entitled: 'Prevention of Congenital Disorders'.[67] In this report, selective abortion was called a form of 'secondary prevention'. Furthermore, the report uses some expression that even had an eugenic flavour; *e.g.*, when it spoke of 'responsible parenthood', or 'optimalization of reproductive behaviour', meaning with both expressions in fact reducing the risk of having a handicapped child, if possible prevented with the use of prenatal diagnosis and subsequent selective abortion. There was much protest against this government report, in parliament as well as from ethicists and geneticists, and especially from organizations of handicapped persons and of parents of mentally handicapped people. They apparently felt that the idea of prevention implies a value judgement about their own and their children's lives. The Minister who was responsible for this report later declared that these were just unlucky formulations; that he did not want to give any judgement whatsoever about the lives of handicapped persons. It seems he was sincere, but where did those thoughts and words come from in the first place?

In 1988, in the EC a research programme was submitted under the title: 'Predictive medicine. Analysis of the human genome'.[68] In this programme a very deterministic view of man was presented in writing: '. . . the genetic material that contains the instructions for the description of every human being'. These ideas we criticized earlier (section 3.1). But the objective of the programme also had an eugenic flavour: '. . . predictive medicine is aiming at . . . if necessary, the prevention of the transmission of

genetically weak elements to the next generation'.

The European Parliament heavily criticized the research project. It was rewritten and procedures were added for an ethical, legal and social evaluation of the results of this research, before they would be published and applied in practice. The revised program has now been approved.

These examples clearly show that there is a tendency in our society to use medical, and in particular genetic technology, as an instrument to reduce the number of people born with handicaps. Basically everybody would agree that the more we can prevent handicaps occurring or can cure them, so much the better. But in practice it seems to be very difficult to distinguish this endeavour from trying to prevent (unborn) handicapped people being born at all. An important question in this context is whether this attempt will not provoke a negative attitude in society towards persons with a handicap.

In a Swiss inquiry into the motivation of women who request a prenatal diagnosis on the basis of age indication, the attitude towards these modern technologies is formulated as follows: 'Qualitatively new is that medicine, armed with the necessary technology sees it as desirable to eliminate genetically 'damaged' embryos. Routinely and still packaged in the medical terminology of 'prevention', the systematic discriminatory selection of life is being pursued: judgement about what 'kind' of embryo is 'worth' or 'not worth' being carried to full term is becoming socially acceptable. The act of elimination itself is being institutionalized'.[69]

This inquiry also indicated that many women had the prenatal diagnosis performed because it was presented by their physician as a routine-examination, because of social pressure from other people like the partner, friends, *etc.*, because of a more generally felt social pressure to do anything to prevent the birth of handicapped child, or because of the conviction that the birth of a handicapped child would disturb their future life. As the Swiss publication stated: 'by means of emphasizing their unconsious fears . . . women are easily manipulated and are therefore seduced into using prenatal diagnosis'.[70]

Similar results were obtained by the American sociologist Katz-Rothmann.[71] The ideal of the healthy, ever-young and well-looking, productive individual that is so predominant in our society, forms without doubt part of the background of the attitude of those women towards the choice of prenatal diagnosis. It is very unlikely that this ideal of society and this way of looking at medical technology does not play a role in the counselling process. Although the genetic counsellors are anxious to be non-directive, it should be recognized that their manner of presenting the same set of facts may vary greatly[72] and that, therefore, the decision to have an abortion of a fetus with a relatively mild disorder (*e.g.*, XYY) is often 'greatly influenced by the attitude of the clinician who informs the couple of the chromosome result'.[73]

Results of inquiries among genetic counsellors in the USA indicate that, even when there was no specific recognized indication,[74,75] in general they strongly favour the use of prenatal diagnosis, supposedly with a view towards selective abortion, if 'necessary'. This attitude is likely to 'colour' their counselling and influence the counsellee.

It is doubtful whether a similar survey among genetic counsellors in The Netherlands would give the same results, but it can also be doubted whether in *this* respect the differences between these two countries are large enough to prevent a development in The Netherlands towards the situation in the USA.

In Western societies science and technology are widely used as instruments to control life and to attain the desired life-style (see section 2.2). This implies that in the medical context the relationship between health care professionals and patients are easily 'coloured' by the abstractions that are embodied in words like fetus, embryo gene defect, quality of life. With the use of these abstractions an evaluation is made of the desirability of the lives of the unborn children. The enormous heterogeneity in the manifestation of a particular genetic defect is not considered to be important. One wants to have as little risk as possible. Now, of course, one should realise that the sufferings that genetic or congenital disorders may entail are not at all abstract, but very real. However, if on the basis of an evaluation of the desirability of the life of an unborn child, it is decided to kill it, then this child is completely identified with the suffering it would undergo itself or would bring about for other people. Then, essentially, the person who is concerned is lost sight of. Then a principal goal of medicine, namely to prevent or alleviate the suffering of people is distorted into terminating the lives of people who suffer or cause suffering. This, in fact, is a perversion of medicine. For that reason the motivation for prenatal diagnosis is ethically at least very disputable.

In the last part of this ethical evaluation of prenatal diagnosis the possible long-term consequences will be considered.

4.1.3 *An ethical evaluation of the consequences of the practice of prenatal diagnosis*

As argued above, the impact of prenatal diagnosis on society far exceeds the influence it has on women who had an abortion because of the disorder of their unborn child. As it was formulated in the previously mentioned Swiss publication: 'The act of elimination itself is being institutionalized'. It is our conviction that the motivations and the ideological background behind this practice cannot but influence all other relationships in society and especially in health care. The danger that it will lead to a more negative attitude towards the handicapped and elderly people in our society is very real. The German ethicist Eibach, at a symposium organized by the Prof. Lindeboom Institute a few years ago, said: 'When a concept of health and quality of life will become dominant in which there is no place for suffering, then the intolerance in society towards people who are weak and ill will increase. A pressure to be healthy and to eliminate socially unwanted lives will arise, as the genetic testing in combination with the prenatal diagnosis demonstrates. This attitude considers it as irresponsible not to ask for a genetic test and to take the risk of the birth of a handicapped child. The aim of this examination is, finally, to prevent the birth of ill and socially unwanted children. This objective is already felt by handicapped people who understand it as a threat for their right to life. They are afraid that the progress in the possibilities of genetic diagnosis will increase the intolerance in society towards the handicapped'.[76] In the context of the dis-

cussion about the objectives of gene technology Eibach puts forward the idea that a definition of health should contain the notion of the capacity to endure suffering and to demonstrate compassion with those who suffer.[77] I think it is a valuable thought, although it is not easy to see the practical implications of it.

The endeavour to prevent any form of suffering, in combination with the high appreciation of patient autonomy, could in the future lead to selective abortion of unborn children with relatively mild disorders or with an increased risk of acquiring later in life a more common disease that is related to a genetic component. The findings of Wert and collaborators indicate that in several countries a significant proportion of the genetic counsellors was willing to collaborate on sex selection for no medical reason.[58] From their results they further conclude that in the USA and Canada a much larger percentage of geneticists was willing to perform prenatal diagnosis for sex selection than 17 and 15 years ago, respectively. In The Netherlands the Centres for Genetic Counselling clearly reject prenatal diagnosis for sex selection only. However, if the ethical attitude behind the present practice does not change, there is a real danger that in the future prenatal diagnosis will be performed on demand for any disorder that can be diagnosed. This danger will become even more real when new techniques are introduced that are less invasive and less burdensome for pregnant women. Three techniques can be mentioned in particular. First, it appears to be possible to isolate fetal cells from the mother's blood during pregnancy and use these cells for genetic tests.[78] This is, of course, much less burdensome than an amniocentesis or a chorion villi biopsy.

Another technique that is being developed is the preimplantation diagnosis. This has already enabled to diagnose the sex of human embryos before implantation, as well as a gene defect underlying cystic fybrosis.[79,80] Only embryos that do not have the gene defect that is related to an increased risk will be transferred into the uterus. However, this technique will become popular only if the success rate of the *in vitro* fertilization + embryo transfer technique will increase.

A third development in prenatal diagnosis is the possibility to screen pregnancies in which there is a high risk that the unborn child has Down's syndrome or a neural tube defect, by analyzing the concentration of three different substances and an enzyme in the maternal blood.[81] Only those women who according to these tests have a very high risk of having a child with one of those two disorders, will then have to undergo an amniocentesis. This development will bring the acceptance of screening of all pregnant women much nearer.

In the light of the possibility of having unborn children tested and aborted for any disorder that people might find unacceptable, however mild or even trivial it may be, some ethicists have proposed that the possibility of prenatal diagnosis should be limited.[82] Until now, however, there are no indications that in the practice of health care these suggestions are taken seriously.

This leads to a last possible consequence of the present practice of prenatal diagnosis and selective abortion. This has been eloquently pointed out by B. Katz-Rothmann. She emphasizes that the possibility of selective abortion is changing the character of motherhood. She writes: 'Selective abortion means also selective acceptance, a fundamental challenge to the social institution of motherhood. Selective abortion, selective acceptance, selective motherhood—a denial of the myth of the all-giving, all-accepting mother. With birth control and abortion women were able to choose not to bear children, not to be mothers. But with selective abortion we ask mothers to decide just what kind of child they choose to mother'.[83] The author also points out that new possibilities of choice after some time exclude other possibilities: '. . . the ability to control the quality of our children may ultimately cost us the right not to control that quality'.[84]

If these developments come to pass the humanity of human relationships in society and the solidarity with handicapped people or people at risk for a serious disease, will be undermined.[85]

Summing up the ethical evaluation of prenatal diagnosis in combination with selective abortion, I come to the following conclusions.

1. For those who recognize that the human embryo as a human being deserves full protection, abortion, also of an unborn child with a disorder, is principally ethically rejectable. However, those who hold this position, should not fail to recognize that sometimes children with a handicap or disorder and often their parents will have to endure much suffering. Therefore, the ethical rejection of selective abortion should go together with a promotion of as much support for these children and their parents as society can possibly offer.
2. Those who take the position that the human fetus before birth deserves only a relative protection, will ethically justify selective abortion at least when it concerns serious disorders. However, I think that the 'ethos' behind the present practice of prenatal diagnosis and selective abortion, and the consequences that present developments may have for society at large, should bring those who hold this position to recognize the need to limit the possibility of selective abortion to disorders of a certain degree of severity. By some of them this is recognized already.
3. The present practice of prenatal diagnosis and selective abortion is a manifestation of the ethos of our society as a whole. Therefore, with regard to a strategy for activities by Christians, I think it is neither correct nor useful to blame exclusively the professionals and the patients who are involved. We are all to be blamed. We should rather dispute the predominant view of life and of man, and morality in our society, and at the same time promote adequate care for all people who need it.

4.2 Somatic cell genetic modification

In order to come to an ethical evaluation of genetic modification of somatic cells we will consider again the modification process itself, the motivations of the people involved, and the consequences it may have.

4.2.1 Ethical evaluation of genetic modification of somatic cells

Somatic cell genetic modification concerns certain cells removed from an individual and the subsequent implantation of these genetically modified cells into the same individual. When it concerns the repair of a genetic defect of the individual, one can speak of gene therapy. This can be done by either adding a piece of DNA containing the

correct genetic information present in the target cells in a defect form, or by replacing the incorrect genetic information by the correct one.[86] Recently important progress was made in this field. In 1990 the first clinical experiments started in the United States; the year after more experiments were started.[87] In 1991 a research group in The Netherlands asked permission to start clinical experiments with somatic cell gene therapy for a particular genetic disorder that almost completely eliminates the immunological defence (ADA).[88] Recently, a new technique was developed, called gene therapeutics,[89] which involves the direct delivery of purified genes *in vivo*. Especially, though not exclusively atemporal expression of such genes has been observed in muscle tissue. This technique clearly holds promise for the treatment of certain genetic diseases.

We have seen before that the specific genetic information of the individual can be seen as an expression of the identity of the individual at the level of the biochemical substances that compose the body. Therefore, the genetic information that the DNA entails is clearly related with the identity of man. However, this does not so much concern matter, *i.e.*, the molecules that contain the genetic information, but rather the information, the 'message' it entails. When by this treatment a defect in the information in the relevant cells is corrected and a patient is cured from a serious disease, this will be associated with some change in the experienced identity of that person. However, as in the case of other therapeutic medical interventions, this change is beneficial. One cannot speak of an arbitrary or violent change of identity. So, when a certain error or defect in the genetic information that is related with a disease, can be corrected in a safe way by the addition of a piece of DNA containing the correct information, this is in itself ethically acceptable.

The body of a human being is not just an object, a vehicle that can be manipulated arbitrarily, the human body is the manifestation of a person in the visible world.

However, it is imaginable that in the future this technique can be used not only to cure specific diseases, but also to enhance desired traits in certain human individuals.[90] This concern has become more acute since recent experiments indicate that by this technique it is possible to enhance the production of certain proteins in cells, giving them specific characteristics, after which these cells can be reintroduced into the person from which they were removed. On the one hand this finding opens the way to treat certain diseases that are not related to a specific genetic defect, *e.g.*, forms of cancer, but on the other hand it may provide opportunities to 'improve' on people.[87] This, however, could imply a way of manipulating the identity of an individual involved, against which we have at least three objections:

a. What should be considered an improvement is always arbitrary, at least to a certain extent. But the body of a human being is not just an object, a vehicle that can be manipulated arbitrarily, the human body is the manifestation of a person in the visible world. The body does not belong to the individual himself, but the human being in his total existence belongs to God. So, any manipulation that does not restore a definable defect, but that intends to mold a human being into a model that was conceived by a human mind, should be rejected as being in conflict with the dignity of man as a personal creature of God.
b. The freedom of a person in his relation to other persons is very much related to his being a unique individual, not designed or 'made' by others. The unique individual identity is very much related to what we called before the *expressions of identity* at the various levels, namely of the genes, of the bodily integrity, of the consciousness and of the spiritual life. Therefore, manipulating people arbitrarily on each one of these levels is violating a person's personal freedom[91] (cf. brainwashing, or imposing a religion with violence, which constitute similar violations at other levels).
c. A third objection concerns the consequences of such a development. We will deal with this in the next section.

4.2.2 Ethical evaluation of the objectives and consequences of somatic cell genetic modification

Somatic cell gene therapy in principle can be seen as a new form of treatment that is in accordance with the accepted goal of medicine, *i.e.*, trying to cure the ill and, therefore, as a positive contribution to medicine. Of course, the first clinical applications have to observe the usual rules for new medical treatments; so one has to deal with questions such as: are the risks foreseeable and acceptable?, which patients will first receive the experimental treatment?, *etc.* These issues can be complicated in themselves, but that does not alter the ethical acceptability of the technique itself when applied with medical objectives.

However, the application of somatic cell genetic modification with the objective to 'improve' on healthy human beings, in our opinion is ethically rejectable. Not only on the basis of the Christian view of man as indicated in the previous paragraph, but also because this is not proper medicine. Medicine should be applied to heal people and alleviate suffering, but not to transform people. If it would become possible and permitted to use genetic techniques to enhance desired qualities, this would further in society the mentality of quality control that is already introduced into society by genetic diagnostic possibilities. So, the previously described unfavourable tendency in society that is very much related to prenatal diagnosis, would be fostered by such an application of somatic cell genetic modification. This would be ethically unacceptable and socially unwanted.

Now, making a distinction between healing and transforming or improving as objective of somatic cell genetic modification, presupposes that in practice this distinction can be made. We realize that in this respect there are significant problems. What then, should be considered a disease or a disorder, and what the 'normal phenotypical variation within the human species'? We realize that a

concept of health, and therefore of disease, is to a certain extent culturally determined. Furthermore, some precedents of a type of medicine, that in a way transforms people, already exist. Think of elective cosmetic surgery (not the same as plastic surgery to restore injuries) and the use of hormones by athletes and the ethically even more difficult issue of the 'reconstruction' of transsexuals. Should these activities form part of a socially financed medical practice? In the context of this paper we cannot further deal with this issue. It nevertheless leads us to the conclusion that, since the first clinical experiments with somatic cell gene therapy have just started, it is becoming increasingly urgent that the scientists and physicians involved, together with ethicists and jurists and perhaps other professionals, draft a set of regulations and agreements as to which applications of somatic cell genetic modification are permitted and which are not.

4.3 An ethical evaluation of germ-line genetic modification

Since with respect to germ-line genetic modification the technique itself, the objectives of its use, and its short and long-term consequences are very much interwoven we will try to evaluate this (medical) technology by making a number of observations in which the technique itself, its objectives and consequences will be considered together.

1. The principal difference between somatic cell and germ-line genetic modification is that the latter implies the introduction of a genetic modification into the germ-line, which means that the modification will be transmitted from one generation to the next. Another important, more practical difference is that with somatic cell genetic modification, the modification—whether it is an addition to or an exchange of genetic information—is introduced into cells in which only a small proportion of the genetic information is being used. The germ-line genetic modification on the other hand, brings about the modification in cells in which practically all the genetic information of the individual will have to be activated and used at some stage of the development of the individual. This not only means that the risk of causing a defect by the genetic modification is much larger than with somatic cells, but also that the risk cannot be foreseen, since it is not known at what time and for what purposes certain parts of the total genetic information will be activated in the developmental process. This is at least the case as long as the total sequence and organization of the human genetic information remains unknown.

On the grounds discussed in sections 3.1 and 3.2 we think that especially in this early stage of the zygote and of the very early embryo, the model of the genes as material and informational units is deceiving. The mutual regulatory influences between different parts of the total genetic information, as well as the environmental influences on these relationships, render the complete genetic information into one dynamic totality interwoven into the living organism as a whole. This makes the replacement or the introduction of 'genes' also conceptually a very complex issue.

2. Purely theoretically we would say that if it would be possible to totally safely exchange a segment of DNA with a defined genetic defect related to a serious disease, with a DNA segment containing the correct genetic information, from an ethical point of view this could be evaluated positively. We say so, to make clear that we do *not* believe in the sanctity of the human DNA as matter, but in the sanctity of human life and, therefore, of the individual's total genetic information in as far as it is a precondition for its life. Just as the principle of sanctity of human life does not entail that we should not intervene in the life of a human being in order to heal a disorder or a disease, neither does it imply that in itself the human genetic information would be untouchable.

However, this is a purely theoretical statement, since such a technique as germ-line genetic modification cannot be evaluated by just considering certain applications that theoretically might become possible in the future and that might be appreciated positively in themselves. So, we will now try to give a brief evaluation of germ-line genetic modification.

3. Any clinical application of germ-line genetic modification needs to be preceded by many experiments with embryos in order to develop a safe performance of the technique. Since we believe that the human embryo deserves full protection from conception onwards, the development of the germ-line genetic modification in man is ethically not permitted. This argument is also valid if one tries to genetically modify the gametes, since the only way to control whether the modification has really succeeded is by using the modified gametes for fertilization and subsequent examination of the embryo.

4. Germ-line genetic modification would not only involve unknown risks, but unforeseeable risks, at least as long as the complete sequence and organization of the human genome has not been elucidated and understood, which may well be practically impossible (cf. point 2). This is not only true for the embryo during the early stages of development, but also for children that eventually would be born after a successful intervention in the embryo. The developments of the human zygote and the role of the genetic information in it are so complex, that in fact the consequences cannot be foreseen for any direct genetic modification. 'We can manipulate DNA at will, but we cannot manipulate organisms at will'.[91] The only way to establish a safe performance is just doing it and see what happens. But this way of dealing with human beings is ethicallly rejectable.[93]

5. For those who accept embryo selection after pre-implantation diagnosis, germ-line genetic modification to cure specific genetic disorders is practically unnecessary. Only in very rare cases has a couple one hundred percent risk that an embryo from their gametes will have a genetic disorder. This means that in almost all cases it may become possible by pre-implantation diagnosis to select and transfer to the uterus only those embryos that do not have the defect for which they possess an increased risk. The pre-implantation diagnosis would in any case be necessary before the genetic modification would be applied.[94]

So, if the development of germ-line genetic modification in man is defended, we should seriously consider the underlying motives and objectives. We suspect that these motives would incline towards improving or introducing certain desired traits in humans. Reasons to reject such applications are given earlier in the sections 4.2.1 and 4.2.2. Those arguments apply here *a fortiori* since the intervention would not only concern the individual that is treated, but also his possible progeny. It would in fact

be a matter of eugenics. Especially in the light of the ethos of our Western societies and of science and technology, we think that such a power to model man according to our own image would be extremely negative for the humane character of our societies.[95] It is certainly not without reason that of the experts participating in the Ciba Foundation Symposium in 1989, some were defending a total prohibition of germ-line genetic modification, while others were pleading for an embargo of at least a couple of decades.[96] It is not exactly clear whether some of the participants would rather leave the question open for the moment. The fact that there is much on-going research on germ-line genetic modification with animals and that the first preliminary results are coming in, should keep us alert with respect to this kind of research with human embryos.

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This paper was read at the conference on The Christian State in Bioethics in Edinburgh, Scotland, during August 1991. The conference papers will appear in book form at a later date.

BOOK REVIEWS

'If we can keep a severed head alive.'
Chet Fleming
Polimyn Press, 1988, £12.95

Fact, fantasy and fiction are all to be found in this book. It may alarm you by its speculations as to '. . . what will happen to the world over the next twenty, fifty or a hundred years if scientists and doctors create a way to keep a severed head alive for months or even years?' (XII) Or you may feel that the whole thing is just a hoax—a suspicion that arises particularly in those sections that deal with the experiments to keep the head of an ape alive by an extraordinary system of pumps, oxygenators and added nutrients: the author having taken out a U.S. patent (No. 4,666, 425) for such a device.

—'Is this serious? Is this thing real, or a hoax?—as the blurb on the cover puts it. On balance the author is probably genuine in addressing this question—he freely admits that he uses speculation as well as fact, along with a fair amount of surmise and comes to no definite conclusions.

The opening chapters deal with the various techniques available for perfusing isolated animal and human heads. These are presented in outline—but without supporting scientific references. Assessment of the validity of these experiments is

also made difficult because proven facts are frequently not clearly differentiated from speculation and the author's personal views are often mingled with quotations from other writers. This is particularly noticeable in chapter 3, describing his own US patent.

The rest of the first half the book consists of a rambling disconnected series of chapters with a mixture of fact, fiction and speculation which are hard to disentangle.

The legal aspects of 'discorporation' are considered with the conclusion that there is no adequate legal precedent or safeguards, at least in the USA, for such experiments. It is also pointed out that the press is unlikely to take much interest until there is something controversial to report, i.e. until something goes wrong or a human head is actually used in such experiments.

The second half discusses the ethical aspects and a Christian perspective is presented to a limited extent. In this respect on the most interesting chapters is 'The two commandments'—referring to the great commandment of Christ to love God with 'all your heart, soul and strength and your neighbour as yourself' in which he seems to argue that keeping a head alive would be morally acceptable if carried out by Christians for a high moral purposes. But how this could be guaranteed he does not say.

The ethics of technological and scientific research are considered including one chapter on 'Controlling dangerous technology' and one on 'Stimulating beneficial technology.' As with other parts of the book the problem is to assess the validity of the author's views when speculative theories are given the same validity as acknowledged facts. For example the totally unproven idea that the AIDS virus might be spread by insects is given the same weight as the existence of acid rain.

Although the questions raised by this book are very disquieting if taken seriously, it is refreshing to encounter straightforward speculation, of the Jules Verne type, on the results of applied technology in contrast to the all too real imminent consequences of 200,000 abortions a year and current human embryo experiments, which are increasingly accepted by our society. We are now so used to the idea of abortions that the public reads about them with equanimity but the idea of keeping a human head alive would be repugnant to many—which shows how an activity that is rejected by one generation may be accepted by another, just as slavery was acceptable until the conscience of the country was awakened to its evils.

Anyone who has read *That Hideous Strength* by C. S. Lewis will be struck by the similarity of subject matter and would not be in any doubt that it is pure fiction, with a very powerful message. Chett Fleming, on the other hand, weakens his argument by not either using fiction or limiting himself to a strictly scientific basis for his arguments. Despite having many reservations about this book, I have a faint suspicion that it might just represent a valid prophetic voice of warning of what may be part of the shape of things to come.

Dr P. K. Buxton

Euthanasia: Should We Kill the Dying?
Brian Pollard MB, BS, DA, FFA, RACS
Little Hills Press Pty.Ltd. 000pp., paperback, UK £5.95. Aust. $12.95
ISBN 0 949773 921

This important and timely book about terminal care bears the hallmark of many years experience. Its author, Dr Pollard, a firm opponent of euthanasia, worked for thirty years as an anaesthetist before he took up the challenge of heading the palliative care unit at Concord Hospital, Sydney. He explains calmly and clearly why improved palliative care is the only way forward in terminal care and, conversely, why euthanasia is the wrong remedy for the dying; a poor alternative to the aggressive use of technology in the care of them; and a dangerous answer to escalating health care costs.

Where caring rather than curing is the object, control of physical symptoms, especially pain, is of prime importance for the patient. Only if he is made reasonably comfortable, writes Dr Pollard, is it possible for the patient to attend to the things he wishes and needs to do. The other two cornerstones of palliative care, in his view, are empathic emotional support and tactful communication. Thus, 'deception whether by giving wrong information or by withholding needed information should play no part in the doctor's dealings with the patient at this time, though that is not the same as telling the full truth or telling the truth in an insensitive way'. Also, in the care of those with advanced terminal illness it is especially important that doctors and nurses work as a team. Indeed, the closest members of the family should also be involved as much as possible. This is not only for the sake of the dying patient, explains Dr Pollard, but because it might help his relatives later when they grieve his death.

If the standards of palliative care were raised, there would be no reason, according to Dr Pollard, for anyone to consider euthanasia as a way out of suffering. Calling for better medical education in the treatment of suffering, psychological and physical, he especially emphasises that in order to counter the demand for legalisation of euthanasia we need to establish criteria of 'appropriate treatment' when cure is no longer possible. That is to say, those working in palliative care must know when treatment is useless or too burdensome and, hence, ought to be discontinued so as not to prolong the act of dying. Secondly, they should understand when 'not to commence treatment which it is judged will not benefit the patient'. Thirdly, they must learn under what circumstances to use 'vigorous measures to control severe distress . . . even though they may possibly shorten life'. And, above all, they must realise that what distinguishes these measures: properly employed in the care of the dying from measures amounting to euthanasia is their intended effect. That is to say, they are not means to euthanasia when 'they are not done with the intention of killing'.

In Dr Pollard's view, the call for euthanasia has gained ground only because people have not understood what is entailed by good palliative care or, for that matter, by euthanasia. The advocates of euthanasia have propagated a distrust of high technology medicine, with the consequence that many people today fear that their lives might be 'needlessly and inappropriately prolonged'. But good palliative care, Dr Pollard assures us, entails nothing of the sort.

Dr Pollard is scornful of the claim that voluntary euthanasia should be legalised in order to recognise everyone's 'right to die'. As he curtly points out, while 'there is a right to life and there is a right to life with dignity while one is dying', there is no such thing as the 'right to die'. This is because a right is 'a claim we have on others to do something or to refrain from doing something for us'. What those who claim a right to die are really claiming, he writes, are 'the right of some to be killed on request in certain circumstances, and the right of others to respond to that request by killing them'.

Moreover, Dr Pollard is quite certain that if voluntary euthanasia were legalised that would constitute a fateful step down a most slippery slope. He warns us that once it was accepted practice to kill on grounds of distress, it would be hard to restrict euthanasia to those who have requested it. Furthermore, to legalise euthanasia in societies with ageing populations and, hence, increasing health care costs is, he believes, to create temptations.

This book deserves to be widely read. The subject matter is a pressing one which concerns us all. And the fact that the author's moral convictions are reinforced by his vast clinical experience makes the book especially valuable.

Agneta Sutton

Itinéraires Bioethiques or the Path of Bioethics
Edouard Boné
In the Series: Catalyses
Ciaco, Brussels, 1990, 203pp., paperback.
ISBN 2 87085 234 7

Itinéraires Bioethiques (The Paths of Bioethics) by Edouard Boné SJ, Professor Emeritus, l'Universite Catholique de Louvain, is a fascinating work of reflection and contemporary history. This is hardly surprising since Bone is one of the most prominent protagonists in the field. He has played an important role in establishing the Bioethics Centre at the Catholic University of Louvain and indeed in shaping the awareness not only in Belgium but also in France of this new area of thought. He was also for many years Secretary to the European Association of Centres of Medical Ethics and is still playing an important role in bioethics within the International Federation of Catholic Universities.

The author begins by outlining how, over the last twenty years, the interdisciplinary field of study we now call 'bioethics' (or, often, focusing more narrowly, 'medical ethics') has gradually developed in response to concerns about twentieth century bio-medical discoveries and technologies and the ways in which they might affect man. On the author's account, bioethics is effectively a normative study centring on the dignity of the human person. But because we live in a pluralist society, he sees the task of the bioethicist more as a search for dialogue with others with a view to establishing common ground in diversity than as study in search for hard and fast rules. He is well disposed to international declarations of basic human rights, which he regards as reflecting a generally shared core morality, but he realizes that such declarations cannot provide a detailed universally acceptable code of practical rules. He defines himself as belonging to a Louvain tradition in which philosophy reflects upon the advances made by the sciences; it elicits their meaning with reference to the Christian ethical heritage but does not seek to impose from the outside a set of fixed and irrevocable rules.

The central part of the book consists of a critical survey of the main areas of discussion in bioethics. Thus, to mention some, there are chapters on assisted conception, gene therapy, transplantation, AIDS, experimentation on man, euthanasia, prenatal diagnosis and handicapped newborn. There is also a chapter on the question of legal regulation at national and international level. The author here restates his own non-legalistic approach and makes it clear that he is sceptical of codes providing precise specifications of what can or cannot be done in medicine and biology—especially if these codes are viewed as immutable.

The chapters in the third and final part of the book are about the view of man inherent in the Christian tradition and the influence of that tradition on Western thinking—not least in the field of bioethics. Discussing the roles of the individual conscience and that of the magisterium within the Catholic Church, he speaks of varying degrees of authority of magisterial pronouncements depending on their status as papal encyclicals, declarations by the Sacred Congregation for the Doctrine of the Faith, papal addresses or episcopal statements. Referring to the Catholic community, he speaks of the convergence of conscience and magisterial thought as an ideal to be aimed at but sometimes hard to achieve. And he points to a general awakening of conscience and ethical thinking as we approach the end of this century.

This is a both informed and readable account of where bioethics—especially Continetal bioethics—stands today and of how it arrived there. It can be recommended to anyone who reads French and is at all interested in this subject.

ANNOUNCEMENTS

Conferences, recent and forthcoming

World Pro-Life Congress
Bratislava 1992
'Pro Life Perspective Challenge for Humanity'.
May 28–31 1992, Bratislavia, Slovakia.
Registrations to Congress Secretariat, Ministry of Health SR, Spitalska 6, 81305 Bratislava, Slovakia CSFR

'Bioethics in a Changing World'
Cambridge, England, 9–14 August 1992
Details from International Bioethics Institute, 1721 Mar West, Tiburon, CA 94920, 1932 USA

'Can you really hear me: Communication within the context of palliative care.'
26 June 1992 in London
Details from Mrs. P. Bennett, Norfolk Wing Study Center, St. Joseph's Hospice, Mare Street, London E8 4SA.

Toronto '92: Third International Conference on Health Law and Ethics
19–23 July 1992 in Toronto
Details from American Society of Law and Medicine, 765 Commonwealth Avenue, 16th Floor, Boston, MA 02215 USA.

Values and Ethics

Loyola University of Chicago and Loyola University Press have scheduled publication of Volumes IV through VII in their joint *Values and Ethics Series*. For 1992–93 our publication schedule includes works on: the narrative theology of St Teresa of Avila; abortion based on prenatal diagnosis; antinomies of social theory; and the burdens of distributive justice.

Interested authors in humanities, history, philosophy, theology, law, education, political science, sociology, medicine and the helping professions, etc. should send letters of inquiry, CV, an outline of the manuscript, Table of Contents, etc. to:

Dr. Rosanne Perez-Woods, Chairperson
Editorial Board, Values and Ethics Series
Loyola University of Chicago Medical Center
2160 South First Avenue, Bldg. 131–N
Maywood, Illinois 60153

Canadian Bioethics Report

The **Canadian Bioethics Report** out to undergo a major transformation. Beginning in July 1992, it will be published as an insert in *Humane Medicine*, an internationally recognized quarterly journal devoted to humanistic studies in medicine and health care. The purpose of the *Report* will remain the same: to provide information on significant bioethics activities in Canada. The readership will be expanded to include the 45,000 Canadian Medical Association members and individual subscribers in many countries who currently receive *Humane Medicine*.

The founding editor of the *Report*, John R. Williams, will continue to be responsible for its content. All inquiries should be directed to:

John R. Williams, Ph.D., Director
Canadian Medical Association,
Department of Ethics and Legal Affairs
1867 Alta Vista Drive
Ottawa, ON
K1G 3Y6
CANADA
(613–731–9331–Fax: 613–731–9013)

As a result of these changes, the first number of the *Report* in 1992 will be in the July issue of *Humane Medicine*. Recipients of this letter will be sent a copy of this issue, along with information about how to continue receiving the journal.

Support for the first four issues (1991) of the *Report* and for its predecessor, *Synapse: A Canadian News Service for Biomedical Ethics*, from the Center for Bioethics, Clinical Research Institute of Montreal, is gratefully acknowledged.

HIV/AIDS Awareness

The Oxford Regional Health Authority has identified the need to appoint a freelance consultant to develop network and training programmes in conjunction with local churches on the Church's role in the prevention of HIV and in caring for people with HIV (Oxon/Berks/Bucks/ Northants). I would be interested to hear from anyone who has been involved in a similar venture in other parts of the country.

I would welcome the insights of those who have been touched by this issue. In developing existing and new regional networks I will be liaising with national bodies. I can be contacted through Oxford Regional Health Authority, Old Road, Headington, Oxford, OX3 4LF. Tessa Sowerby

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