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ETHICAL ISSUES RAISED BY PERSONALIZED NUTRITION BASED ON GENETIC INFORMATION

Ulf Görman

Lund University, Department of Ethics, CTR, Allhelgona kyrkogata 8, SE-223 62 Lund, Sweden

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ABSTRACT: *Four principles are taken as basis for the ethical analysis: autonomy, nonmaleficence, beneficence, and justice. Health is understood as a limited aspect of wellbeing. Food is understood as an important aspect of wellbeing, not only an instrument for health. Modern society is characterized by a tendency to identify wellbeing with external rather than subjective circumstances, to identify wellbeing with health, and to create exaggerated health expectations. Based upon this understanding, aspects of personalized nutrition are discussed: genetic testing, counselling, and development of special dietary products. Today the predictive value of genetic tests for personal nutrition is limited, and experimental at best. Recommendations for the future: Personalized nutrition must be based on solid knowledge. Phenotypic analyses should be used when adequate. When a genetic test can have a clear advantage, this should be preferred. Opportunistic screening should only be used when clearly beneficial. Specially trained persons should collect information from genetic tests and carry through councelling on a personal basis. Marketing of genetic tests directly sold to the public should be discouraged. Development of special products for personalized nutrition may be necessary in some cases. However, this may also lead to a medicalization of diet.*

KEY WORDS: Ethics, Genetic test, Health, Nutritional genomics, Personalized nutrition, Wellbeing

Corresponding Author: Ulf Görman, Lund University, Department of Ethics, CTR, Allhelgona kyrkogata 8, SE-223 62 Lund, Sweden; Fax: +46 46 222 44 26; E-mail: Ulf.Gorman@teol.lu.se

INTRODUCTION

Subsequent to the mapping of the human genome new possibilities have opened for understanding the genetic background to diseases, not least for understanding the relation between genes, nutrition and health. This article discusses some ethical issues raised by the possible applications of knowledge from nutritional genomics for therapy or prevention of diseases. One influential idea in this respect is the prospect for tailor-made nutritional advice based on genetic tests – personalized nutrition.

In this article the concept *personalized nutrition* is used to cover the activity of adjusting personal dietary counselling and advice as well as adjustment of personal diet to information from genetic tests, combined with knowledge received from current and future development in nutritional genomics.

It should be noted that the concept of personalized nutrition is also used with other connotations. The British Food Ethics Council (2005) understands personalization in a wider sense, including the notion that people should take greater responsibility for their own health, in combination with government commitment to support healthier food and lifestyle choices.

Ethics is the systematic reflection on the moral aspects of life and its conflicts. This article will not be the place to develop a new and original theory in this respect. Instead I will rely on a few influential ideas developed by other scholars. These include understanding of the main ethical concerns in relation to health promotion and health care, as well as central concepts such as well-being and health.

FOUR PRINCIPLES IN BIOMEDICAL ETHICS

In ethics a large number of different normative theories have been proposed. The fact that they can lead to different conclusions and moral standpoints in difficult situations has induced extended discussions. One possibility that has been proposed is the construction of a holistic theory or combination theory, where several reasonable principles are introduced and balanced against each other.

An influential theory of this kind is the four-principles-theory constructed by Tom Beauchamp and James Childress (2001) in their well-known work "Principles of Biomedical Ethics". Their theory has become one of the most influential ethical guidelines in medicine and the application of biotechnology. Their ethics is a useful instrument for discussing and taking a balanced view of the possible applications of nutritional genomics for personal food advice. They suggest four principles to be used as ethical guidelines: respect for autonomy, nonmaleficence, beneficence, and justice. These principles are all considered as mandatory obligations for any person with power over or responsibility for someone else within biomedicine.

Autonomy means the understanding of every person as an independent agent with right to decide over himself or herself. Respect for autonomy means to acknowledge the right of the individual to make such decisions. Lack of respect involves attitudes or actions that ignore, insult or deny someone's right to autonomy. This principle is a negative duty – to abstain from making controlling limitations for others. And it is a positive duty – to treat others respectfully when giving information and promoting autonomous decision. Among else it means to respect the right to accept or decline information.

Nonmaleficence means to strive not to harm a person who is dependent upon your actions. Examples of such harm are limitations of freedom or opportunities, suffering, handicap, and death.

Beneficence means to strive to increase happiness and wellbeing, which includes the active prevention of suffering and evil. It is a duty to act for the benefit of others in this respect. This benefit may involve balancing of good and bad effects in order to achieve the optimal result. This means that an action that causes harm may be legitimate if its foreseeable benefit overrides its risk.

Justice means to strive for a fair distribution of limited resources.

An ethical theory like this, with several basic principles, makes it clear that ethically complicated situations are often characterized by conflicts between several values that are worth realizing and maintaining. Because of this it offers the opportunity for a careful discussion of the conflicts of values involved. For instance, respect for autonomy of one person may come in conflict with the wellbeing of others, or claim an unreasonable share of limited resources. In such cases the principles need to be balanced against each other by means of arguments: Which solution can realize all the principles as much as possible? Is there no better alternative? How to deviate from the principles as little as possible? How can negative effects most effectively be avoided? Which solution is fair to all those involved?

WHAT IS HEALTH?

According to the classical definition of World Health Organization, "[h]ealth is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1946). This is a far-reaching and ambitious understanding of health. There is good reason to question whether health in this sense can be achieved except in rare circumstances. However, it may surely be seen as an ideal to strive for, even if it can seldom or never be completely fulfilled.

In this interpretation the definition may function as an "ideal norm" as some ethicists would phrase it. An ideal norm is a norm that is used as a far-away goal, which is considered important to strive for but can never or seldom be achieved. Instead it is expected to function as vision and inspiration for action. An ideal norm may be effective in order to stimulate efforts, but it can also be too far-reaching and perhaps even misguided. It may produce too far-reaching expectations, and the inability to achieve its goals may lead to frustration.

Lennart Nordenfelt (1995) suggests a different and also more cautious definition. Nordenfelt argues for a holistic theory of health. In this theory the concepts of ability and disability are central and more important than the corresponding concepts of pain and suffering. He understands health as a person's ability in normal circumstances to realize his vital goals. He clearly distinguishes this understanding of health from the idea of complete health favoured in the WHO definition. The notion of a vital goal is tied to a minimal degree of happiness. Vital goals are the goals that are necessary and together sufficient for minimal happiness. In this understanding a person may have many goals whose fulfilment can contribute to happiness, although they do not belong to the vital goals of the agent. A capable person can fulfil goals well beyond his or her vital ones, but this ability, he says, does not add to his or her health.

Nordenfelt's interpretation of health has characteristic and interesting consequences. Criteria for health depend on a specific context. The standards for ability will depend on a particular society and, evidently, changes in values or circumstances in society may result in new and different standards for ability and a new understanding of health. As a consequence of this, increased expectations within a society may in fact diminish the perceived health, just as more realistic expectations concerning vital goals may increase health in the population. It is also in line with this understanding that a person may change his or her personal understanding of a minimal happiness. As a consequence of this, a person with unrealistic expectations may be less healthy than another person with more limited abilities but another understanding of vital goals. However, this is only true to some extent, as "many maladies strike in a basic and general way".

Two aspects of this analysis of health stand out as especially interesting and important. First, health is subjective rather than objective. This means that the health of a person depends on his or her perception of vital goals, as well as the perceived ability to fulfil these goals. And second, health is not the only or final desire in a person's life.

QUALITY OF LIFE AND THE VALUE OF HEALTH

It is widely acknowledged that health is perceived as an important value in human life. This is well supported by many studies, and recent investigations in Sweden even indicate that health is for many an important aspect of the meaning of life (Philipson and Uddenberg 1989; Löwendahl 2002). However, in line with the analysis made above, this has to be understood in a wider context.

According to a recent Eurobarometer survey, respondents felt that "being in good health" contributes most to their current quality of life. It was ranked among the top three items by three-quarters of the population in the EU member states, and by two thirds in the acceding and candidate countries. Health was followed by "sufficient income to meet my needs" and "having family members who are there when I need them". The conclusion drawn in the report is that "quality of life is obviously understood as a multi-dimensional concept depending on several components rather than just one particular ingredient of well-being" (Alber & Fahey 2004).

The results of this empirical investigation seem to fit well with the theoretical analysis of the concept of health made above.

WHAT IS A GOOD LIFE?

The classical view of a good life claims that it is connected to happiness. Further, according to the influential idea of hedonism, you reach happiness when you fulfil your wishes or desires. However, some afterthought makes this idea a little more complicated. An early hedonist was Epicurus, in the 3rd century before our time. He maintained that happiness is a result of fulfilling your desires. However, there is a problem. Often we cannot fulfil our desires, and then the result of our desires will instead be pain. If we can be confident that our future desires will be fulfilled, then we will reach tranquillity (ataraxia) which may be considered complete happiness. So, what most deeply threatens our happiness is anxiety about the future, including fear of death.

Against the background of this understanding, Epicurus realizes that there seem to be two very divergent ways to achieve happiness. One of these is to try to fulfil your desires. But there is also another way, i.e. to adjust or even eliminate your desires. This is the main strategy that Epicurus proposes. If you cannot fulfil the wishes you have, then you must adjust your wishes to what you can achieve. In this way the hedonistic argument of Epicurus leads to a certain amount of modesty, or even asceticism (Mitsis 1988).

The question that Epicurus faced seems to be an enduring aspect of the human condition. Wayne Sumner (1996) is a modern moral philosopher who offers a careful and systematic study of this problem.

What is welfare? Is it possible to find objective criteria for the welfare of an individual, or even for any person? Options that have been offered as objective criteria are, among else, the idea that welfare is the fulfilment of needs, or that it consists in the realization of objective human goals. Sumner's discussion is well worth following, but too extensive to be described in detail here. In sum, he rejects the objective theories, mainly based on the argument that a state of affairs is better for me only if it affects my experience. As a consequence of this, a person's happiness is a matter of his or her experience, the experience of the conditions of his or her personal life. Welfare, however, is not simply identified with happiness. Instead it is described as informed and autonomous endorsement of the conditions of one's life.

Such life satisfaction reaches beyond experiences of pleasure and pain. Instead welfare, or authentic happiness, is connected to a life that is experienced as rewarding or fulfilling as a whole. "When we accept that our lives cannot, must not, be painless, relatively brief episodes even of relatively intense pain need not greatly compromise our happiness", and he even claims that "there is no ground for the dogmatic claim that the ascetic life cannot be a happy one." Consequently, according to Sumner, an individual's wellbeing is grounded in his or her attitudinal point of view on the world.

THE UNHEALTHY QUEST FOR HEALTH

People in modern western societies have exceptional possibilities for a healthy living. Present society, as well as modern medicine, offers better opportunities than ever to avoid health risks and to cure, retard or mitigate diseases. However, this improved situation also implies larger hopes and expectations and subsequent actions. This may be observed as a general strong focus on health in modern living. Society makes large political and financial efforts for the benefit of health. Many persons give large attention to healthy living, by means such as physical exercise, healthy food, vitamin pills, and by different kinds of health control.

In general this is a good thing. Measures to improve health can certainly be expected to lead to valuable improvements. As a visual illustration of this, the total effect of all societal, medical and individual efforts, average lifetime in western societies has more than doubled since the middle of the 18th century, and is still increasing. However, there are also complications. Focus on the quest for health may sometimes be a health problem in itself. This focus may be emphasized by a number of sources: advices from society to the public, alarm reports in mass media, and marketing of the vision of health through commercial products. A number of critics of the current situation argue that this is the case.

Robert Crawford (1980) understood his own time as characterized by exaggerated attention to personal health – "elevating health to a super value, a metaphor for all that is good in life". By introducing the term *healthism* he wanted to point out a phenomenon that characterizes modern society: an ideology where maintaining health and avoiding illness have become the supreme human values. Greenhalgh and Wessely (2004) understand healthism as a modern cultural, mainly middle class, phenomenon, characterized by excessive health awareness and expectations. Some of its expressions are strong health-awareness, focus on lifestyle choices, use of food supplements, and concern about "unnatural" substances. Geoffrey Rose (1992) frankly states: "To be preoccupied with health is unhealthy." Ivan Illich (1976) described the modern strive for health as *medicalization*, a term defined by Conrad (1992) as a process where non-medical, social problems become defined in medical terms. Often, however, medicalization is given a wider application, indicating also the idea that natural events like child birth or stages in life as menopause are being understood as ailments or diseases (O'Grady). Michael Fitzpatrick (2001) argues that most disease screening and health promotion will probably not have any substantial positive effect on individual life. Typical advices are: alter diet, cut drinking, give up smoking, and increase exercise. His own advice, instead, is to treat the sick and leave the well alone.

Other critics, such as Petr Skrabanek (1994), identified the current situation as part of a state ideology of health that regulates the health behaviour of its citizens. A similar argument can be found in a recent report from the Food Ethics Council in UK. According to them, the government is actually reducing people's autonomy, because it assumes that consumers should see food primarily as a means to health. "This treats food like medicine and society like a hospital." (Food Ethics Council 2005)

Critical comments like these may be one-sided or exaggerated. However, they point at some characteristic aspects of the modern situation and at least a number of possible problems. Based upon the concepts of wellbeing and health discussed earlier in this article, these problems can now be described more precisely.

The understanding of health and good life that was based upon the analyses of Nordenfelt and Sumner, indicates a few important ideas:

- Wellbeing is subjective and not directly dependent on external factors.
- Health is only one of several aspects of wellbeing. Health is an important goal in human life, but not the only or final desire in a person's life.
- Health is to a large extent a subjective concept. Perceived health is dependent upon individual and societal standards of ability.

This also offers an understanding of the problems involved. There are tendencies in modern society:

- to identify wellbeing with external rather than subjective circumstances,
- to identify wellbeing with health,
- to create exaggerated health expectations.

When this is the case, a health orientation of life is at the peril of decreasing perceived health as well as limiting the realization of wellbeing.

FOOD, PERSONALIZED NUTRITION AND QUALITY OF LIFE

Food means much more than nutrition. Food is enjoyment as well as cultural and personal identity. A meal is a social event, an important manifestation of the relationship with others. This means that food is an important aspect of human happiness and wellbeing, and not only an instrument for health.

What role may personalized nutrition play in relation to this manifold role of food in human life? Hopes are that personalized nutrition can offer clear health benefits for those concerned, benefits that contribute to improved wellbeing. How can this be achieved? Will personalized nutrition contribute to a good life? Or will personalized nutrition instead limit the role of some or all food to medicine and transform eating to a lifelong medication?

An example from Sweden may offer an interesting illustration of the complexity of food in relation to health and health efforts. The Swedish National Food Administration (Livsmedelsverket) is a public authority with the task to control and secure food quality and food safety in Sweden. Among else, they issue food advices for the public. Their recent advices for pregnant and breast-feeding women have received much attention. See text box.

Swedish national food administration

Advice for women during pregnancy and breast-feeding
(http://www.slv.se/templates/SLV_Page.aspx?id=12212)

Eat every day:
Fruit and vegetables – at every meal
Carrots and other root vegetables
Potatoes, rice or pasta
Bread – preferably several times each day
Milk or cheese – preferably at breakfast or as light meal
Meat, chicken, fish
Eat four meals every day:
Breakfast, lunch, light meal, and dinner
Eat only small amounts of:
Cakes, sweets, candies, snacks etc.
You need extra iron:
Blood products, peas, whole grain bread
– to be consumed together with fruits and vegetables
You need extra calcium:
Milk and cheese
– or cabbage, green beans, shrimps, eggs and blackberries
You don't need extra vitamins:
– but if you are anxious about vitamins, you can take one multivitamin pill per day
Fish is good for you, but don't eat these fishes more than once a month:
Herring from the Baltic sea
Wild salmon and trout from lakes or from the Baltic sea
Avoid completely a number of fishes, including:
Fishes from lakes, eel, sword fish, fresh or frozen tuna, cod liver
Raw shellfish, raw marinated fish, smoked vacuum packed fish
Avoid eating:
liver dishes, raw meat,
soft dessert cheeses like Brie, Camembert, Vacherol and Livarot,
non-pasteurized milk,
more than 3 cups of coffee per day or 4-5 cups of tea
all so called "health products"
Don't smoke or drink alcohol during pregnancy

These food recommendations are certainly well meant. The advices are based upon detailed conclusions from a number of studies of larger and smaller health risks in relation to food. However, they have created discussion in mass media and anxiety among many of the women concerned. Many have perceived the advices as strong limitations in their choice of food. They are concerned about the health of their children when they buy food and prepare meals. Often the recommendations have created a feeling of insecurity rather than safety when it comes to the choice of food. Other women, however, have appreciated the advices as an instrument for avoiding health risks.

The example illustrates the complexity of a strict food advice when it comes to the different individuals who are to follow the guidelines. For some persons such advices will be gladly accepted as tools for the improvement of health. For others they will be considered as limitations, which can be accepted – for better or for worse. In some persons detailed advices like these will create anxiety and decreased wellbeing.

What will be the role of personalized nutrition in this respect? In a certain sense it is unavoidable that nutritional genomics will have consequences for dietary advice and for the food that is offered in the future. The human genome has been mapped. Its functions are being studied all over the world. As a result of this, the interplay between genes and diet in metabolism and its consequences for health will be better understood. It is not a question whether this knowledge will be used for practical purposes, but how. The urgent matter is to make responsible choices for the future, choices that can be expected to respect the autonomy of those involved and support their wellbeing. Care must be taken to find a way where health may be improved for those who need so, while avoiding an accentuation of the already existing tendency in our society to an unhealthy focus on health.

WHY DID GENETICALLY MODIFIED FOOD FAIL?

One aspect that needs some comments is the fact that personalized nutrition will be based on genetic information. It is a common understanding that such information is perceived as special, problematic, and perhaps even frightening for people in general. This is evident when it comes to the use of genetic modification. Parallels have been drawn between personalised nutrition and genetically modified food. Will personalised nutrition face the risk of being regarded as controversial in the same way as genetically modified food has been?

Genetically modified food was the result of an effort to apply genetic knowledge and gene technology for improvement of food. Great visions have been connected to genetically modified food, such as lower susceptibility to frost, better durability for storing, improved vitamin content, etc. Advantages such as these should make genetically modified food attractive to producers, in trade, and not least to consumers.

In spite of expectations, consumers proved to be very reluctant. Several studies indicate this. In a recent study, Maria Magnusson (2004) shows that attitudes towards genetic engineering appear to depend on the application area. Medical applications are more easily accepted than food and agricultural applications. Consumers have rather negative attitudes towards genetically modified food, which is perceived as not being healthy. Genetic modification of animals for food production is perceived more negative than genetic modification of plants.

In another study Lennart Sjöberg investigates risk perception in relation to acceptance of gene technology. According to his report, reactions to gene technology are quite diverse. Genetically modified food was rated as the worst of 18 technologies and highly replaceable. This should be compared to the fact that medical and forensic applications of gene technology were very well accepted.

Table 1. Public attitudes to two different applications of gene technology

Q 14 A. There are now scientific methods to change the genes of animals. They can be used in the food industry. What is your opinion, on the whole, of that technology and its applications? Is it in your view on the whole good?

To a large extent	6.1 %
To a certain extent	18.6 %
Doubtful	33.7 %
Hardly at all	12.4 %
Absolutely not	29.2 %

Q 21 A. Gene technology can be used by police in their work to find the perpetrator of a certain crime (DNA analysis). What is your opinion about the police using that technology? Is it in your view on the whole good?

To a large extent	86.9 %
To a certain extent	10.7 %
Doubtful	1.7 %
Hardly at all	0.4 %
Absolutely not	0.2 %

(Sjöberg, 2004)

The result indicates that public attitudes to the application of genetic knowledge are not a general attitude to genetics as such. Sjöberg's conclusion is that the public seems to evaluate new technologies according to usefulness as well as risk. Public considers genetically modified food to be dangerous, useless, and morally questionable.

Sjöberg criticises what he considers to be the received view of risk perception, stimulated by a seminal paper by Fischhoff et al (1978). The standpoint of Fischhoff is that public's risk perception is driven by emotional reactions (gut feelings) and ignorance, a standpoint, which is still influential (Loewenstein et al. 2001). In contrast to this view Sjöberg argues convincingly that instead of emotions and ignorance, important explanatory factors are ideological convictions, such as interfering with nature, moral value of technology, and trust in science. The perception of usefulness as well as risk should be seen as related to such convictions (Sjöberg 2004).

So, will personal nutrition based on genetic knowledge be more successful than genetically modified food? The answer to this question seems to depend on whether it will be perceived as beneficial. This understanding, in its turn, may to a large extent depend on how personalised nutrition is implemented. In the remaining part of this article, I will look at three aspects of this implementation: the collection of genetic information, counselling, and the possible creation of special food products related to personalized nutrition.

STRATEGIES FOR GENETIC TESTING ORIENTED TOWARDS PERSONALIZED NUTRITION

Several alternative strategies for genetic testing in combination with personalized nutrition advice may be discerned. I will focus on a few central questions.

Should nutritional advice be individually targeted or general?

Targeted individual health advice can induce strong motivation. In the Whitehall study by Rose et al. (1982), those whose examination had given evidence of exceptional risk received individual explanation, why they in particular would benefit from stopping smoking. More than 50 % of them stopped smoking compared to success rates of around 10 % from routinely given antismoking advice (Rose et al., 1982, Rose 1992).

Another example is phenylketonuria (PKU), a genetic disorder resulting in an inability to metabolize phenylalanine. Those concerned have to follow a strict diet through all life, low in phenylalanine, which means no meat, fish or dairy products, but addition of synthetic protein without phenylalanine (Levy 1999). With few exceptions they show very strong observance to these restraining dietary advices.* Examples like these indicate that well-founded and precise personal information may be very effective. However, there are also problems.

Personalized nutritional advice based on genetic data should in theory help to fine-tune the prevention of nutrition-associated diseases. In the current situation, however, Joost and Mathers (2005) make the following estimation concerning the prospects of this endeavour: "Whether it will work in practice, however, is unknown and will depend on the predictive precision of the genetic information, on the robustness of the gene-diet-disease relationship and on the acceptance of the concept by the public." If it will be a good strategy to use nutritional genomics for general dietary advice, depends among else on the frequency of specific alleles in the population. For instance, in ethnic groups where lactose intolerance is very high, such as individuals of Asian origin (95 %) or African Americans (79 %) (Sahi 1994), there is no reason to base the dietary advice to avoid fresh milk on individual genetic tests. Whether nutritional genomics may lead to changes in population-wide health advice seems to be an open question (Gibney and Gibney 2004). Whenever dietary advices are made on whole populations, care must be taken to avoid stigmatization and marginalization.

According to Rose (1992), social and economic factors are much more important than genetics in explaining diseases. A similar assessment is made by the Food Ethics Council (2005). They claim that many health problems can be better handled by political regulations such as regulation of marketing, measures to tackle poverty, and health-oriented reforms of agricultural subsidies.

Based upon the principles of beneficence as well as justice, there is reason to favour general strategies for improved nutrition, well-founded advice as well as political measures. Scholars in nutritional genomics should investigate the possibilities of drawing general nutritional conclusions from their studies. The investigation of such a strategy should be given attention, because it would help as many individuals as possible. However, general nutritional advice must also be given with great care and be based upon solid scientific evidence, as the autonomy of a large number of persons may be affected, and it may emphasize tendencies to healthism.

Individual nutritional advice that can be made in a precise way with clear health benefits for the individual should also be welcomed. There is reason to believe that the individuals concerned will be motivated to follow such advice, and that it may increase their wellbeing. Without clear health benefits, however, knowledge of genetic dispositions can result in low compliance to advice as well as loss of perceived health.

Phenotypic analyses of diseases, without personal genetic tests?

A number of genetic disorders can be detected by different kinds of phenotypic analysis, and in some cases, such as phenylketonuria, the corresponding disease can be effectively retarded by dietary intervention. However, "in the monogenic disorders, knowledge of the phenotype is usually sufficient for the dietary intervention", according to Joost and Mathers (2005). In complex polygenetic diseases such as diabetes and hypertension, they conclude, with reference to Song et al. (2004) and Colditz et al. (1995) that "the predictive value of a single genotype is small compared with that of the family history of a person or with that of other known risk factors." Because of this, they consider current attempts at dietary recommendations in such cases as experimental at best.

This situation may change as knowledge in nutritional genomics increases. A genetic analysis may be regarded as a more precise instrument for diagnosis of monogenetic diseases, but an advantage of a phenotypic analysis will be that it measures the actual expression of the disease. However, the understanding of the genetic basis for polygenetic disorders will increase, and genetic analysis may offer earlier detection of disease. "This is particularly important for diseases where the development of the pathology and its complications has long latency periods and is essentially irreversible, such as in type 2 diabetes and osteoporosis." (Joost and Mathers 2005)

The recommendation that can be made from an ethical point of view in this situation will be to use phenotypic analyses whenever these are adequate. They will involve less intervention for the involved patient, and they will have a more direct relation to the expression of the disease in question. When a genetic test can have a clear advantage, such as an earlier or more precise diagnosis, this should be preferred.

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* Björn Åkesson, personal communication.

Should genetic testing be limited to those with diseases or belonging to risk groups?

Genetic tests may be effectively used for confirmatory diagnosis of specific genetic disorders, as well as for predictive testing for asymptomatic individuals belonging to risk groups. This may apply to persons with health problems in the family, as well as persons belonging to a specific population with known genetic disorders. For persons concerned in this way, who are aware of belonging to a risk group, a well-founded genetic test may be beneficial, because it will be helpful for those involved to handle an already existing anxiety and take appropriate measures. Cases such as these are easy to justify from an ethical point of view, and perhaps they are the most beneficial illustrations of the prospects for personalized nutrition.

An example may illustrate how well a genetic test for hereditary diseases may be accepted in a population. East European (Ashkenazi) Jews are carriers of genes for Tay-Sachs disease, as well as a number of other genetic diseases, including cystic fibrosis, at a higher rate than a normal population. Since the early 1970s, the Jewish society has offered a Tay-Sachs screening programme, later extended to seven genetic diseases. The results of the tests are used as devices for reproductive choices and even choice of partner. The programme has been very well received by the population. It is carried through on a large scale and has resulted in a reduction of newborn babies with Tay-Sachs disease by 90 % (Wahrman 2002). Rose (1992), who favours population-wide approaches to health problems in general, points out a circumstance that may be important to take into account. In many cases the high-risk part of the population has only a small number of the incidents of a certain disease. "[I]t is common to find that the burden of ill health comes more from the many who are exposed to a low inconspicuous risk than from the few who face an obvious problem. This sets a limit to the effectiveness of an individual (high-risk) approach to prevention."

However, in the case of genetic tests there is reason to look very carefully at the intimate and predictive character of the information received. Because of this, a restriction is called for. Unsolicited genetic screening should not be accepted. A population-wide offer for genetic tests for personalized nutrition will influence attitudes to life and food, and there is a risk that it will spread the already existing unhealthy quest for health. For persons without any identified risk, the situation is complicated. In such cases a balance between beneficence and autonomy is needed. In general, a person should have the right to know, but also the right not to know. The information offered should be clearly beneficial for the individual. Because of this a genetic test of this kind is only justified, when a nutritional or other advice that can be offered as a result of the test is targeted and well founded.

Opportunistic genetic screening for healthy individuals?

Opportunistic screening refers to ad hoc tests offered by a medical doctor to a patient without symptoms, or a test made upon request from a person without symptoms or known risk factors. Opportunistic screening is controversial, but is often accepted in society when it can give predictive information on diseases that may involve a heavy burden for the person involved.

Should healthy people with no identified risks who ask to have genetic tests for different possible problems be offered that possibility? The attitude in medical care is in general reluctant. Juth (2005) argues that the right to genetic information should be based on the values that can be achieved by a pre-symptomatic test, and nothing else. Wertz et al. (2003) comment on this question: "Respect for freedom of choice does not mean that all technically possible services must be provided at the request of individuals and families, but only that services normally provided be provided equally, without regard to people's ethical views."

Are genetic tests good for the patient? This question presupposes that the person who receives a genetic test is already a patient. In many cases, however, the person who is offered or asks for a test is considered to be a healthy person, perhaps belonging to a risk group, but definitely not a patient. " [M]ost of those who attend [screening examinations] are seeking, not the discovery of hidden troubles, but rather a reassurance that they have no unusual problems." (Rose 1992)

In many, often most cases, the result of the test will be an alleviation of anxiety, but when the test is "positive", the person in question is turned into a patient, perhaps for the rest of his or her life. The future will be characterized by a consciousness of an actual, or possible infirmity. In this way the wellbeing of a person who considers himself or herself as normal, may not be supported, but instead decreased. To counterbalance this, the discovery of the disease must be able to offer clear health benefits, larger than the negative effects.

In the current situation, only very limited dietary advice can be given on the basis of genetic tests, and to a large extent on an experimental basis. This situation may change in the future. The principles of autonomy as well as beneficence need to be taken into account. It seems too early to estimate how they should be balanced against each other in such a possible future.

Recommendations: Opportunistic screening should only be used in cases when use of the test results can be clearly beneficial, i.e. when the nutritional advice is based on solid knowledge and has clear advantages. Genetic tests should be preceded by adequate information on the character of the test, on the information that can be collected, and on how this information can be used. Based on considerations on justice, opportunistic screening can be more easily accepted when the costs for the test fall upon the person involved, and it should be more restrictive in cases when others pay.

HOW TO HANDLE GENETIC COUNSELLING?

Medical counselling is regarded to be sensitive and personal, deserving careful treatment, and it is considered to be a task for medical doctors and groups of other persons with a special training. Genetic counselling is considered to be especially demanding, and professional standards have been set up to handle this sensitive task.

The so called Oviedo convention (1997) for the protection of human rights and biomedicine has been set up to be a new norm for all European countries. Article 12 comments on predictive genetic tests: "Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for a scientific research linked to health purposes, and subject to appropriate genetic counselling."

A number of documents discuss the handling of such counselling and the ethical concerns involved. The European Commission (2004) recommends that relevant genetic testing be considered an integral part of health service production. The application of genetic testing for non-medical reasons requires careful consideration. "[A] test should only be offered … when there is a sound medical reason to consider it." Genetic testing should "be accompanied by the provision of key information, and, where appropriate, by the offer of individualised counselling and medical advice". Similar standpoints are expressed in detail by Wertz et al. (2003) in their review of ethical issues in medical genetics for WHO, as well as by the Bioethics Advisory Committee in Singapore (2005).

The understanding that genetic tests should be followed by counselling within the healthcare system is well in line with the four ethical principles, especially autonomy, nonmaleficence and beneficence. Genetic counselling is needed to achieve sufficient information and appropriate support, and requires an emphatic manner in a face-to-face meeting wherever possible.

As genetic information becomes more easily available, this view has been challenged. An illustration of this is the fact that a number of commercial companies are setting up Internet sites where anyone is offered a genetic test, including a limited number of genes, followed by analysis and dietary recommendations by mail. How should this new situation be handled?

The European Commission (2004) comments on the current situation: "Genetic testing will soon become part of everyday healthcare systems, and patients and professionals will have to learn to make decisions on the need for a test as well as understanding its consequences." The document notes that genetic information is somehow different according to current public perception. This has to be acknowledged and addressed. However, "[t]he sentiment that genetic data are different from other medical information ('genetic exceptionalism') is inappropriate. Genetic information is part of the entire spectrum of all health information and does not represent a separate category as such. All medical data, including genetic data, must be afforded equally high standards of quality and confidentiality at all times." The upshot of their argument is that genetic exceptionalism is not needed in order to argue that genetic information should be handled with the same care as any medical information, and be subject to appropriate genetic counselling.

Will the use of genetic information for dietary advice create a special situation? Meijboom et al. (2004) discuss this question. They suggest that following a test the decision what to eat will be influenced by disease prevention reasons. This may evoke a correct feeling of having restrictions when it comes to choosing food. They emphasize the possibility of misinterpretation: No special dietary advice may be understood as implicating that a normal healthy diet is unnecessary – because "there are no bad genes involved".

Another problem is that the risks associated with specific genes are still poorly understood. The relation may be more direct between phenotypic variations and health problems than between genetic information and similar problems. Many critics point out – rightly or not – that dietary advices based on inconclusive knowledge may result in unnecessary restrictions in life style and doubtful health effects. Considerations like these indicate that dietary advice based upon genetic tests should be handled with at least as much care as genetic counselling in general.

This affects the question whether genetic tests should be sold to the public. Commercial companies will offer tests if there is a market of interested consumers. The quality of the products is important. "Companies that offer such genetic testing apply scientific information that is still inadequate to be used in the prediction of disease risks and in decisions on intervention strategies." (Joost and Mathers 2005) This problem may be solved in the future with increased knowledge as well as quality control. But the integrity and wellbeing of the consumers who take the tests may still be at stake. Will they be taken care of properly? Even with counselling, and perhaps much more without it, those involved may start worrying about their health. This may be a result of the mere focus on this kind of information, but still more so if the test gives results identified as health problems. However: " 'Sowing worries' might be an effective marketing strategy" (Meijboom et al 2004).

The Council of Europe Working Party on Human Genetics (2003) discusses the question of genetic tests sold to the public. Interestingly enough, they have not been able to come to an agreement on this point. Different alternatives are proposed, from the restrictive view that "Genetic tests shall not be directly sold to the public" to the liberal view: "Where the law permits direct sale of genetic tests to the public, there shall be adequate regulation, in particular to ensure proper information and understanding of the implications of the test the person concerned." The choice between these alternatives is left open. No conclusions are drawn, but readers are invited to give comments.

Today many health consumers are much better informed about medical questions than ever, a result of the level of education as well as the accessibility to information through Internet. An unknown number of individuals are happy to take any opportunity offered to know more about their health and find measures of improvement. In many cases, however, this may not be a demand based on need, but on a focus of interest on personal health. Probably, many consumers of commercial genetic tests for dietary advice can be found within this group. The regard for autonomy gives reason to adjust to this demand, but also reason for concern, when it comes to the reception of test results.

Based upon care for autonomy and wellbeing, the following preliminary ethical comments may be made: Information concerning results of genetic tests and counselling based upon such results should be made on a personal basis by specially trained persons, because of the sensitivity of the information as well as the possibility of misinformation. Marketing of genetic tests directly sold to the public should be discouraged. Whether this will lead to restrictions or prohibitions must be a matter for political decision.

PRODUCTS PRODUCED FOR PERSONALIZED NUTRITION

Nutritional genomics has created hopes that gene-based nutrition planning can one day play a significant role in preventing chronic disease. It is inevitable that industry will have interest to use this knowledge for commercial purposes. In general, this is not a bad thing. Commercialisation is the prevailing way for new technology to reach the public. Food industry can assist persons with specific nutritional needs. Industry will be a necessary "helping hand" in cases where the specific nutritional needs are difficult to meet through ordinary food. For instance, this is already the case with synthetic protein for PKU patients.

In the foreseeable future, the number of people who have received personalized nutritional advice based upon genetic tests will be fairly small. Because of this the market for a new generation of functional food, targeted for these individuals, will be limited. In this situation food industry may be interested in creating a larger market for each product by developing the product and marketing it in such a way that it is considered healthy not only for people with a specific genetic constitution, but also for others. Commercial marketing seems to have a tendency to apply specific products to a wider group of consumers than it was created for. This is an undesired development. It will trigger the already existing tendency to healthism. It will probably involve higher costs for those who choose to buy the products without clearly belonging to the group with this identified genetic problem.

A more difficult problem may be that this development will involve a medicalization of diet. Those involved will be encouraged to eat specially targeted salt instead of less salt, commercial sugar-free cakes instead of fruit, XX-adjusted frozen food instead of available natural food. There is no industrial market for helping people make healthy choices among existing natural products. A major concern when it comes to tailor-made diets is that normal healthy food may be overlooked. The Food Ethics Council (2005) comments on this: "Little money can be made by selling the fresh fruit and vegetables that form the mainstay of healthy eating advice." As a result of this, choice of food for those with specific genetic-nutritional needs may become directed and limited. Such a development may diminish the perceived heath of those concerned.

Instead direction should be found for using knowledge achieved by nutritional genomics in such a way that the welfare of those involved can be increased. Some relevant questions in this respect are: Is there enough scientific evidence for creating a special nutritional product? How can personalized-nutrition-products reach the correct target group? Will special products made for personalized nutrition make people believe that only some people need to hold a healthy diet or create unwarranted or exaggerated hopes and expectations? How can such a development be counteracted?

Society may have the capacity to handle questions such as these by means of political regulations. Governments can use political means to regulate not only general quality of food, but to make sure that food with alleged health effects is marketed to the correct target groups. The Food Ethics Council (2005) states: "The government needs to be a firmer advocate of the public's health interests."

THE MAIN ETHICAL CONCERNS FOR PERSONALIZED NUTRITION

Autonomy: The rights and integrity of each individual should be supported in connection with the use of personalized nutrition. Beneficence: Personalized nutrition should be used in order to contribute to a good life in line with the values of each person involved. Nonmaleficence: Personalized nutrition should be used so as to avoid or minimize harm. Justice: The benefits of personalized nutrition should be fairly distributed.

CONFLICT OF INTEREST DISCLOSURE

There is no conflict of interest to disclose.

REFERENCES

Alber, J. and Fahey, T. (2004) Perceptions of living conditions in an enlarged Europe. European Foundation for the Improvement of Living and Working Conditions, (Luxembourg: Office for official publications of the European communities).

Beauchamp, T.L. and Childress, J.F. (2001) Principles of biomedical ethics, 5th ed., (Oxford: Oxford University Press).

Bioethics Advisory committee, Singapore (2005) Genetic testing and genetic research. (Singapore). http://www.bioethics-singapore.org

Colditz, G.A., Willett, W.C., Rotnitzsky, A. and Manson, J.E. (1995) Weight gain as a risk factor for clinical diabetes mellitus in women. *Annals of Internal Medicine* **122**, 481–486.

Conrad, P. (1992) Medicalization and social control. *Annual Review of Sociology* **18**, 209–232.

Council of Europe Working party on Human Genetics (2003) Working document on the applications of genetics for health purposes, CDBI/INF. 3, Strasbourg. http://www.coe.int/T/E/Legal_affairs/Legal_co-operation/Bioethics/Activities/Human_genetics/INF(2003)3e_genetics_working_doc.asp

Crawford, R. (1980) Healthism and the medicalization of everyday life. *International Journal of Health Services* **10**, 365–388.

European Commission (2004) EUR 21120 – The 25 recommendations on the ethical, legal and social implications of genetic testing, (Luxembourg: Office for official publications of the European Communities). http://europa.eu.int/comm/research/conferences/2004/genetic/pdf/recommendations_en.pdf

Fischhoff, B., Slovic, P., Lichtenstein, S., Read, S. and Combs, B. (1978) How safe is safe enough? A psychometric study of attitudes towards technological risks and benefits. *Policy Sciences*, **9**, 127–152.

Fitzpatrick, M. (2001) The tyranny of health. Doctors and the regulation of lifestyle, (London: Routledge).

Food Ethics Council (2005) Getting personal: shifting responsibilities for dietary health, (Brighton: Food ethics council). http://foodethicscouncil.org/

Gibney, M.J. and Gibney, E.R. (2004) Diet, genes and disease: implications for nutrition policy. *Proceedings of the Nutrition Society* **63**, 491–500.

Greenhalgh, T. and Wessely, S. (2004) 'Health for me': a sociocultural analysis of healthism in the middle classes. *British Medical Bulletin* **69**, 197–213.

Illich, I. (1976) Medical Nemesis. The Expropriation of Health, (New York: Pantheon Books).

Joost, H.-G. and Mathers, J. (2005) Personalized nutrition: Status and perspectives, (Unpublished draft document).

Juth, N. (2005) Genetic information – Values and rights. The morality of presymptomatic testing, (Göteborg: Acta Universitatis Gothoburgensis).

Levy, H.L. (1999) Phenylketonuria: Old disease, new approach to treatment. *Proceedings of the National Academy of Sciences of the United States of America* **96**, 1811–1813.

Loewenstein, G. F., Weber, E. U., Hsee, C. K., and Welch, N. (2001). Risk as feelings. *Psychological Bulletin* **127**, 267–286.

Löwendahl, L. (2002) Med kroppen som instrument, (Stockholm: Almqvist & Wiksell International).

Magnusson, M. (2004) Consumer perception of organic and genetically modified foods. Health and environmental considerations, (Uppsala: Acta Universitatis Upsaliensis). http://www.diva-portal.org/diva/getDocument?urn_nbn_se_uu_diva-4218-1 fulltext.pdf

Meijboom, F.L.B., Verweij, M.F. and Brom, F.W.A. (2003) You eat what you are: moral dimensions of diets tailored to one's genes. *Journal of Agricultural and Environmental Ethics* **16**:557–568.

Mitsis, P. (1988) Epicurus' ethical theory. The pleasures of invulnerability, (Ithaca, Cornell University Press).

Nordenfelt, L. (1995) On the nature of health. An action-theoretic approach. 2nd ed., (Dordrecht, Boston, London: Kluwer).

O'Grady, K. The Medicalization of menopause. http://www.cwhn.ca/resources/menopause/

Oviedo Convention (1997) Convention for the protection of human beings and dignity of the human being with regard to the application of biology and medicine: Convention of human rights and biomedicine. (European treaty series 164.) http://conventions.coe.int/treaty/en/treaties/html/196.htm

Philipson, S.M., and Uddenberg, N. (eds.) (1989) Hälsa som livsmening, (Stockholm: Natur och Kultur).

Rose, G. (1992) The strategy of preventive medicine, (Oxford: Oxford University Press).

Rose, G., Hamilton, P.J.S., Colwell, L. and Shipley, M.J. (1982) A randomised controlled trial of anti-smoking advice: 10-year results. *Journal of Epidemiology and Community Health* **36**, 102–108.

Sahi, T. (1994) Genetics and epidemiology of adult-type hypolactasia. *Scandinavian Journal of Gastroenterology* **202** Supplement.7–20.

Sjöberg, L. (2004) Gene Technology in the eyes of the public and experts. Moral opinions, attitudes and risk perception, (SSE/EFI Working Paper Series in Business Administration No 2004:7) (Stockholm: Stockholm School of Economics). http://swoba.hhs.se/hastba/abs/hastba2004_007.htm

Skrabanek, P. (1994) The death of humane medicine and the rise of coercive healthism, (London: The social affairs unit).

Song, Y., Niu, T., Manson, J.E., Kwiatkowski, D.J. and Liu, S. (2004) Are variants in the CAPN10 gene related to risk of type 2 diabetes? A quantitative assessment of population and family-based association studies. *American Journal of Human Genetics* **74**, 208–22.

Sumner, L.W. (1996) Welfare, happiness, and ethics, (Oxford: Clarendon Press).

Wahrman, M.Z., (2002) Brave New Judaism. When science and scripture collide, (Hanover and London: Brandeis University Press).

Wertz, D.C., Fletcher, J.C. and Berg, K. (2003) Review of Ethical Issues in Medical Genetics. Report of consultants to WHO. World Health Organisation, Human genetics Programme. http://www.who.int/entity/genomics/publications/en/ethical_issuesin_medgenetics%20report.pdf

WHO (1946) Preamble to the Constitution of the World Health Organization, adopted by the International Health Conference, New York, 19–22 June, 1946. http://www.who.int/about/definition/en/