Some ethical issues raised by personalized nutrition

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Four principles in biomedical ethics

Ethics is the systematic reflection on the moral aspects of life and its conflicts. The theory of Beauchamp and Childress has become one of the most influential ethical guidelines in medicine and the application of biotechnology. They suggest four principles: respect for autonomy, nonmaleficence, beneficence, and justice.

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. *Nonmaleficence* means to strive not to harm a person who is dependent upon your actions. *Beneficence* means to strive to increase happiness and well-being. *Justice* means to strive for a fair distribution of limited resources. In ethically complicated situations, these principles have to be balanced against each other [1].

Health and welfare

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” [2]. There is good reason to question whether health in this sense can be achieved except in rare circumstances. Nordenfelt suggests a more cautious

definition. He understands health as a person’s ability in normal circumstances to realize his vital goals. Vital goals are the goals that are necessary and together sufficient for minimal happiness. 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. A person with unrealistic expectations may be less healthy than another person with more limited abilities but another understanding of vital goals [3].

What is welfare? Sumner offers a careful and systematic study of this problem. He rejects 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. Welfare, or authentic happiness, is connected to a life that is experienced as rewarding or fulfilling as a whole. Consequently, according to Sumner, an individual’s well-being is grounded in his or her attitudinal point of view on the world [4].

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. This may be observed as a general strong focus on health in modern living. Many persons give large attention to healthy living, by means such as physical exercise, healthy food, and by different kinds of health control.

In general this is a good thing. However, focus on the quest for health may sometimes be a health problem in

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itself. The understanding of health and well-being, based upon the analyses of Nordenfelt and Sumner, offers an understanding of the problems involved. There are tendencies in modern society to identify well-being with external rather than subjective circumstances, to identify well-being with health, and 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 well-being.

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 well-being, and not only an instrument for health. 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 National Food Administration 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 detailed advices for pregnant and breast-feeding women have received much attention [http://www.slv.se/templates/SLV_Page.aspx?id=12212]. 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. 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.

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. 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. In spite of expectations, consumers proved to be very reluctant. A recent study shows that

attitudes towards genetic engineering depend on the application area. Consumers have rather negative attitudes towards genetically modified food, which is perceived as not being healthy [5]. In another study Sjöberg investigates risk perception in relation to acceptance of gene technology. According to his report, reactions to gene technology are quite diverse. Public considers genetically modified food to be dangerous, useless, and morally questionable. 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. The conclusion is that the public seems to evaluate new technologies according to usefulness as well as risk [6].

Genetic testing for personalized nutrition

Targeted individual health advice can induce strong motivation [7, 8]. In theory personalized nutritional advice based on genetic data should help to fine-tune the prevention of nutrition associated diseases. In the current situation, however, it is unknown whether this will work in practice [9]. 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. Whether nutritional genomics may lead to changes in population-wide health advice seems to be an open question [10]. Whenever dietary advices are made on whole populations, care must be taken to avoid stigmatisation and marginalization.

Social and economic factors seem to be much more important than genetics in explaining diseases [11], as well as in the treatment of diseases [12]. Based upon the principles of beneficence as well as justice, there is reason to favour general strategies for improved nutrition, 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.

A number of genetic disorders can be detected by different kinds of phenotypic analysis and can in some cases be effectively retarded by dietary intervention. However, in monogenic disorders knowledge of the phenotype is usually sufficient for the dietary intervention. In complex polygenetic diseases such as diabetes and hypertension, the predictive value of a single genotype is small compared with that of the family history or other known risk factors. An advantage of genetic analysis is that it may offer earlier detection of disease [13]. The recommendation that can be made from an ethical point of view in this situation is to use phenotypic analyses whenever these are adequate.

However, when a genetic test can have a clear advantage, such as an earlier or more precise diagnosis, this should be preferred.

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. For persons concerned in this way, a well-founded genetic test may be beneficial. Cases such as these are easy to justify from an ethical point of view and are probably the most beneficial prospects for personalized nutrition.

In the case of genetic tests, there is reason to look carefully at the intimate and predictive character of the information received. 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. Because of this, a restriction is called for. The information offered should be clearly beneficial.

Should healthy people without identified risks, who ask for genetic tests, be offered opportunistic screening? The attitude in medical care is in general reluctant: The right to genetic information should be based on the values that can be achieved [14, 15]. In 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 well-being 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 these 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 [16]. 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. My recommendation is that 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.

How to handle genetic counselling?

Medical counselling is regarded to be sensitive and personal, deserving careful treatment. It is considered to be a task for medical doctors and groups of other persons with a

special training, and professional standards have been set up to handle this sensitive task.

A number of documents discuss the handling of such counselling and the ethical concerns involved and recommend that relevant genetic testing be considered an integral part of health service production [17–19]. 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. Many critics point out 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. 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” [20]. This problem may be solved in the future with increased knowledge as well as quality control, but the integrity and well-being of the consumers who take the tests may still be at stake. Even with counselling, and 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” [21].

The Council of Europe Working Party on Human Genetics 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 [22].

Based upon care for autonomy and well-being, the following preliminary ethical comments can 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 fabricated for personalized nutrition

Nutritional genomics has created hopes that gene-based nutrition planning can 1 day play a significant role in preventing chronic disease. It is inevitable that industry will have interest to use this knowledge for commercial purposes. Commercialisation is also the prevailing way for new technology to reach the public. Food industry can assist persons with specific nutritional needs. However, 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. 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. 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. Such a development may diminish the health of those concerned. Instead directions should be found for using knowledge achieved by nutritional genomics in such a way that the welfare of those in need can be increased.

The urgent matter for the application of knowledge from nutritional genomics is to make responsible choices for the future, choices that can be expected to respect the autonomy of those in need and support their well-being. 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.

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