Patients, evidence and genes: an exploration of GPs’ perspectives on gene-based personalized nutrition advice

Laura Bouwman, Hedwig te Molder and Gerrit Hiddink


Background. Nutrigenomics science examines the response of individuals to food compounds using post-genomics technology. It is expected that in the future, personalized nutrition advice can be provided based on information about genetic make-up.

Objectives. Gene-based personalized nutrition advice emerges at the junction of different disciplines and technologies and may directly influence people’s lives. Therefore, public concern is to be expected. Because GPs are gatekeepers of health care, their involvement in early stages of the development process is desirable.

Method. In 2006, 15 GPs were interviewed to collect their perceived barriers and opportunities towards involvement in gene-based nutrition advice. The interviews were qualitatively analysed with use of Atlas.ti, a qualitative analysis programme.

Results. The participants held a mostly critical view towards such personalized nutrition advice. They argued that findings of nutritional studies lacked robustness, were not based on patients’ needs and were often equivocal. And that a patient central perspective urges them to question consequences for patients. Participants argued that GPs should be involved in selecting and monitoring patients in nutrigenomics studies.

Conclusions. Early involvement of GPs in the development process is needed to allow for the integration of their practical, social and ethical considerations in the technical and scientific agendas. However, the background of their critical attitude towards nutrigenomics-based personalized nutrition, and nutrition advice more generally, has to be explored further. To facilitate a joint learning process and to improve socio-technical decision making with respect to this innovation, initiatives that allow different stakeholders to exchange their perspectives should be organized.

Keywords. Behavioural sciences, genetics, health promotion, nutrition, qualitative research.

Introduction

Diet-related diseases are increasing. Although this is a complex issue, one could safely say that a considerable part of this increase is due to unhealthy eating behaviour. This growing rate has further encouraged calls for innovative approaches that motivate people to eat healthfully (World Health Organization and Ministry of Health). Personalization of nutrition advice is often proposed as one of the most promising approaches. Recent reviews of health intervention methods and research on the effect of personalization show that advice targeted to an individual’s physical parameters, lifestyle and environmental situation is more effective in influencing their health behaviour than general information.

Such personalized nutrition advice is not the domain of dieticians only. Rapid developments in interactive computer technology applications such as the Internet allow for interventions that provide a large number of people with access to personalized advice at relatively low cost. Computer-assisted devices are used to collect data about someone’s current dietary intake, lifestyle, socio-economic situation and indicators of diet-related risk such as body mass index and blood cholesterol. Also, rating scales or questionnaires are used to measure behavioural variables, for instance attitudes and perceived self-efficacy towards healthy...
eating. Such interventions have induced changes in smoking, diet and physical activity. In a recent review, Kroese et al. concluded that the evidence for the effectiveness of computer-tailored interventions is quite strong and most consistent for reducing dietary fat. In this article, we will emphasize an innovation that is expected to add a new dimension to personalized nutrition advice: knowledge about the interaction between nutrients or food components and the genome (see Box 1 for an example of such advice). These diet–gene interactions comprise the impact of nutrients or food components on gene expression (nutrigenomics) and the impact of genetic variations on the response to nutrients or food components (nutrigenetics). Nutrigenomics studies the relationship of what we eat and how our genes, proteins and metabolism function to affect our long-term health. The aim of nutrigenomics studies is to achieve so-called ‘personalized nutrition’: recommendations of food and/or supplements based on a person’s entire genetic profile. This genetic profile can be assessed through genetic testing at birth or later in life. Nutrigenomics is expected to influence prevention and treatment of diet-related illnesses. ‘Nutrigenetics’ studies single gene—single food components where possession of a particular genotype may confer a disadvantage that can be addressed through dietary modification. Nutrigenetics may allow individualized recommendations of specific foods or supplements based on a person’s genotype. This genotype can be assessed through genetic testing.

### Box 1 Innovative nutrition advice

A patient with a family history of early death from heart attack comes to the dietician’s office to obtain nutrition and lifestyle advice. As well as making dietary and lifestyle recommendations, she also scans their electronic genome card. From this information, she develops a selection of targeted recommendations for diet and exercise, and drug regimens depending on their preferred lifestyle. Is this entertaining fiction or a glimpse into the future of personal nutrition advice? And what about general practitioners’ perspective towards such innovative developments?

**Involvement of GPs**

There are several important issues to consider in both nutrigenetics and nutrigenomics that are relevant to GPs. Up to now, the complexity of researching diet–gene interactions has limited the translation of research findings into practical applications of personalized nutrition advice. However, even without scientific consensus about the validity of the tests, companies already offer DNA tests that indicate someone’s vulnerability, for instance type II diabetes, osteoporosis or heart disease. In their recent report, the US Government Accountability Office concludes that ‘such tests mislead consumers by making predictions that are medically unproven and so ambiguous that they do not provide meaningful information to consumers’. Because most companies offer these tests through the Internet, some tests are even available without the advice of health professionals, so it is likely that GPs will be confronted with patients’ questions. Additionally, people have been confronted with an increasing amount of attention to the developments in gene-based nutrition advice in the popular press since 2004. A recent market survey showed that 42% of US consumers had heard or read about using individual genetic information in the context of nutrition and diet-related recommendations. Also the percentage of consumers that believe family history plays a moderate to great role in maintaining or improving health increased from 85% in 1998 to 90% in 2005, indicating a growing awareness of the interaction between food, genes and health. Little of such awareness research has been performed in Europe. However, among a community sample of British adults, 80% expressed interest in being tested for genetic susceptibility to heart disease.

The next issue is that the inclusion of genetic knowledge in nutrition advice has ethical and social implications that may directly influence people’s lives and thereby GPs practices. Görman applies the four-principles theory for biomedical ethics constructed by Beauchamp and Childress for this particular innovation. He states that the principle of autonomy raises questions about individual rights and integrity when a personalized nutrition application is used. Such usage should also contribute to a good life in line with the values of each person, to assure beneficence, avoid or minimize harm and be fairly distributed among populations (justice).

Studies show that consumers consider GPs as gatekeepers of health; therefore, they are expected to become important actors who implement and/or communicate about personalized nutrition based on genetic information on the basis of their profession. Their specific role in providing genetic information was highlighted in a US consumer survey that showed that 80% of the respondents vested confidence in their GPs for guidance through the stages of the DNA testing process.

The above issues support the necessity of early involvement of GPs in the innovation process. Their involvement is not so much to smoothen the introduction of the technology as to improve socio-technical decision making more generally. Within science and technology studies, the assumption that innovation is a linear process in which scientists invent, businesses apply and consumer buy, has been replaced by the notion of innovation as a co-evolutionary product of science, technology and society (for example).
Different forms of stakeholder participation have received considerable attention as important ways to bring a wider range of social and ethical issues into technological decision making and to turn co-evolution into a more reflexive process.

Although uncertainties can complicate discussions about practical relevance in such an early stage of the innovation process, postponing involvement might leave no room for dealing with questions such as ‘is this the way we want to go with nutrition advice in GPs practices?’ This dilemma is known in literature as the Collingridge dilemma: ‘in order to minimize any negative impacts of a technology, it is in theory most effective to influence the technology early on in the development process; once a technology has been designed, there is little left for stakeholders in society to do except either approve or reject it’.

However, although the need for an interdisciplinary approach, in which science, health professions and industry exchange expertise and opinions, is emphasized in publications in health promotion science and technology, and nutrigenomics, high early failure rates of such collaborative efforts suggest that a better understanding is needed about the way such efforts do or do not work. According to health promotion literature, a shared problem and goal to effectively address challenges such as unhealthy eating, the existence of a shared social responsibility to make this happen and the recognition of mutual dependency are preconditions for working together. From the literature, it is also apparent that those preconditions are often challenged by the variety of views that participants bring to the table.

A first challenge to involvement of GPs, in the literature, is the lack of attention that is paid to nutrition and to genetics in their education. A study among US medical school graduate students found that over half of the respondents rated the time devoted to nutrition as inadequate. Farrel concludes that the same applies to Canada. In a recent longitudinal study, Visser et al. found that, although Dutch GPs were more interested in the impact of nutrition on health compared to 1992, the participants provided less nutrition counselling in their practices. According to the participants, this was mainly due to of patient’s lack of motivation to change dietary habits and doctors lack of time.

With respect to genetics, studies among medical genetic trainees in several European countries showed that non-genetics specialist physicians lacked awareness of genetic features, made few referrals for genetic counselling and had little awareness of benefits and harms to family members.

We are not aware of any study that aimed to explore the barriers and opportunities perceived by GPs towards nutrition advice based on genetic knowledge. We report here the findings of our study about the arguments GPs use to evaluate such health advice. The study aimed to explore the issues that facilitate or hinder the involvement of GPs in an early stage of the development process of innovative, personalized nutrition advice.

This study was part of a larger study that explored the views of health professionals towards innovative diet and health advice, initiated by members of The European Nutrigenomics Organization, NuGO. This European-funded Network of Excellence aims to develop and integrate genomic technologies for the benefit of European nutritional science and to facilitate applications of these technologies in nutritional research worldwide.

Method

Interview guideline and interviewers

We used semi-structured in-depth interviews that combine a structured guideline with the opportunity to ask additional questions. The interview guideline was developed based on literature research on innovations and involvement in innovation processes and the findings of our previous study about this topic.

In Table 1, the key topics of the interviews are shown. Firstly, the respondents were asked for their awareness of and perceptions about (dis)advantages and complexity of the innovation, compatibility with health-care practice and social-ethical issues. Secondly, participants were specifically asked for their perspectives towards scientific evidence of nutrition advice and towards the needs of their patients. These topics were shown to be important in our previous study, in which we found that Dutch stakeholders in health care, education, social science, industry, the media and health insurance treated uncertainties in scientific evidence and the needs of their patients as barriers towards involvement in innovative personalized nutrition advice. Lastly, the respondents were

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<tr>
<th>Table 1</th>
<th>Guideline GPs interviews</th>
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</thead>
<tbody>
<tr>
<td>Nutrigenomic-based personalized nutrition advice</td>
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<td>Nutrition advice based on genetic information</td>
<td>-Awareness</td>
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<td>-Relative (dis)advantages: scientific evidence</td>
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<td>-Compatibility with health-care system</td>
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<td>-Complexity of use in practice—patients needs</td>
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<tr>
<td>-Social-ethical issues—patient needs</td>
<td></td>
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<tr>
<td>Collaborative efforts</td>
<td>-Experience with collaborative efforts</td>
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<td>-Personal and collective goals of collaborative efforts: own role</td>
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<td>-Other participants who have to be involved: others role</td>
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asked for their perspective towards involvement in the development process of innovative personalized nutrition advice, with specific attention to their own and other potential members’ roles.

The interviews were performed by two interviewers: the first author, who is a social scientist with education in nutrition science and an experienced interviewer, and a nutrition scientist with education and experience in interviewing.

**Data collection and transcription**

In August 2006, the European conference of the World Organization of National Colleges, Academies and Academic Associations of General Practitioners (WONCA) provided the opportunity to interview GPs from diverse countries. The conference did not have a theme that was related to nutrition, although this topic was addressed in a small number of sessions. Before the conference, three GPs with specific roles in initiatives to stimulate nutrition advice in general practice were asked for their participation. They all agreed. Also, five GPs with a leading position in the WONCA were selected, of which three agreed to participate. We aimed to recruit another 10 GPs during the conference from countries in which (future) collaborating partners of the European Nutrigenomics Organization operate. However, many GPs refused to participate, due to expected language problems or out of disinterest in the topic. Eleven GPs who worked in Denmark, Ireland (2), The Netherlands, Slovenia, Spain (2), Sweden, Switzerland and Australia (2) participated. The interview with one of the Spanish GPs was not finished because of language problems and therefore not used in the analysis.

Each interview lasted about 1 hour and was recorded with a digital voice recorder.

**Analysis**

The interviews were fully transcribed and analysed with use of Atlas.ti, as software package for qualitative analysis. The qualitative analysis involved a process of selecting and coding text fragments according to the research question: ‘What barriers and opportunities do GPs perceive with respect to the development process of gene-based nutrition advice?’

**Results**

**General results**

Although the term genomics was known by most respondents, only one participant had heard of nutrigenomics and nutrigenetics. He perceived the innovation as relevant to nutritionists and the industry but not to general practice. The other participants based their perception of the innovation on the explanation provided by the interviewers.

The main topic of the interviews was about the use of genetic knowledge in nutrition advice. However, we found that participants often related their arguments about this topic to barriers and opportunities of nutritional research as such. Despite the natural limitations of research into (perspectives about) future situations, these arguments are relevant because gene-based advice will be embedded in and start from current practices in nutrition advice more generally. The participants held a mostly critical view towards both. Nevertheless, some participants argued that GPs should become more involved in nutritional studies.

With respect to this specific analysis, we did not find substantial differences between the participants who were involved in stimulating nutrition advice, WONCA leaders and the other GPs. This finding suggests that participants argued mainly from the perspective of being a GP working in general practice, other roles seemed to have been of secondary importance. Differences in arguments were also to be expected, due to the different nationalities, and therefore cultural backgrounds of the participants, however, such differences were not found.

In the following section, we present the participants’ arguments about personalized nutrition advice in general practice. The barriers related to the status of scientific evidence about the relation between nutrition and health and the consequences for their patients. The opportunities related to the GPs expertise about their patients. Table 2 provides a summary of the arguments.

**Barriers towards GPs’ involvement: factors that relate to evidence**

All participants, except one, contested the results of most nutritional studies. Three different arguments were found.

**Examples of arguments**

**Awareness**

- Little knowledge about nutritional genomics

**Evidence**

- Different populations in studies and practice
- Nutrition is more about common sense than about research
- Nutritional studies do not meet criteria for biomedical (drugs) research

**Patients**

- GPs hold a more holistic perspective towards their patient’s health than only their ‘genes’
- Results create unnecessary patient anxiety
- Patients do not ask for nutrition advice themselves

**Opportunities**

- GPs can select and monitor patients for research studies
- GPs can provide nutrition advice on a regular, repetitive basis
1. Results of nutritional studies often lack relevance for general practice because they are not based on the needs of patients in general practice; research often studies hospital patients, illustrated by Extract 1.

**Extract 1.**

If you look at cardiology and you see a patient with heart disease and you look at prevalence of a certain gene in a hospital, this prevalence will be much bigger than the prevalence in general practice. So the advice based on this evidence to a general practitioner would be much stricter, much more aggressive treatment than could be useful [I-02].

2. Nutrition is more about using common sense than about findings of research studies, as illustrated with Extract 2.

**Extract 2.**

But I think all we can do is what one of the other lecturers [RE: during conference] stated that really use our education and our long years of experience in general practice, our feel for our patients and you know it comes down to a lot of common sense and just good practical advice [I-5].

3. Nutritional studies often do not meet the criteria of biomedical (drugs health) research, illustrated by Extract 3.

**Extract 3.**

In principle when you have randomized controlled trials and meta-analysis such kind of reviews you are right to put evidence into practice [1 line omitted] Especially for lifestyle advices it is difficult to find good evidence on that, so that is why many people [RE: general practitioners] are reluctant to put such evidence into practice because they think that this evidence is not very good and is not robust enough compared to other evidence that comes from clinical trials with drugs and so on [I-01].

### Barriers towards GPs involvement: factors with respect to patients

The participants all mentioned barriers relating to different sorts of concerns about their patients that were related to three topics.

1. A DNA test does not provide insight in other influences on health such as social-economic circumstances; GPs have to consider those influences because they have a more holistic view towards their patients. Extracts 4 and 5 illustrate this type of argument.

**Extract 4.**

That’s the thing with any kind of innovation, like you know going into genes, people are, you know, it’s very biological and I guess people [Re: GP] try to be more holistic than that [I-06].

**Extract 5.**

I change because I have a person in front of me. I haven’t an organ, a gene, I have a person, the culture, the tradition [I-3].

2. If study results are based on populations in hospitals or people with serious illnesses, such advice could be picked up wrongly or create unneeded anxiety, illustrated with Extract 6 in which the participants argues about nutrigenomics studies.

**Extract 6.**

I think it is a combination of exciting, because there is huge potential in better understanding how to improve health. But it is also scary because of the ethical issues that will come with it. [1 line omitted]. I have been very interested in prevention for a long time, in labelling people and the negative impact, the potentially negative impact of saying to somebody, well your blood sugar is slightly elevated. So you are a diabetic and the negative impact of doing that. So that makes me very worried about testing somebody’s genetics and saying well you know you are at risk for a change of the breast, this, that or the other thing [I-9].

3. Respondents argued that results of nutritional studies are not useful for their practice because patients do not ask for nutrition advice themselves.

### Facilitating GPs’ involvement: factors that relate to patients

In reaction to questions about involvement of GPs in the development process, participants presented arguments that could facilitate such involvement. The arguments related to their expertise about patients. As experts on the subject of their patients health status and needs, GPs could contribute to the nutritional studies by selecting and monitoring patients, illustrated by Extracts 7 and 8.

**Extract 7.**

We can get the right persons who can benefit from the research, we see so many people, we can get the right persons [I-15].

**Extract 8.**

General practitioners have a very important role in research, you know to identify people having
a potential interest for research or people that fulfill certain criteria or people are a potential risk in developing chronic illness. General practitioners are very good messengers, very good agents in identifying those people. And, at the same time, in researching, the general practitioners are potentially important in following patients and describing clearly the so-called natural causes of disease which provide valid information to researchers from other disciplines [I-10].

Some participants argued that GPs could also provide nutrition ‘advice’ in practice because their special relation with patients allows for the provision of regular, recurrent advice.

Discussion and Conclusion

Early involvement of GPs in the development process of gene-based nutrition advice is needed to allow for the integration of their practical, social and ethical considerations in the technical and scientific agendas. However, factors underlying their current, critical views towards gene-based nutrition advice, and nutrition advice more in general, should be further explored. Initiatives that create opportunities for GPs to exchange their perspectives with other stakeholders should be undertaken. The different sorts of barriers and chances that GPs perceive and the possible implications of these perceptions for their (non-)involvement in the innovative development process could be addressed here.

The findings of this study need to be interpreted in the context of the limited number of participants and the fact that they attended an international conference. However, we believe that our findings reflect issues that have to be taken into consideration when the involvement of GPs in development processes of innovations in nutritional research is pursued. But such collaborative efforts can only be successful if all potential participants acknowledge that their involvement is relevant for successful integration of the innovation (which should not be equated with straightforward acceptance of the technology). Previous research of Bouwman and te Molder on this topic showed that Dutch stakeholders in health care and education, health insurance, social science, food industry and the media did not treat early involvement as an opportunity to co-shape the innovation. They rather drew upon uncertainties in scientific knowledge, the ‘wants’ and ‘needs’ of consumers and fixed roles and responsibilities to account for a wait-and-see policy concerning innovations in personalized nutrition advice. 31

It seems obvious to us that GPs, as gatekeepers of health and experts about their patient health status, should become involved in an early stage of the development process of gene-based nutrition advice. Not so much as to arrange for GPs to provide the nutritional advice, but to exchange perspectives about social, ethical and practical consequences for patients and practices, and the implications these insights could and should have for the development of this health innovation.

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References


