Nutrigenetic testing for personalized nutrition – an evaluation of public perceptions, attitudes and concerns in a population of French Canadians

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Abstract

Background/aims: This study aimed to evaluate attitudes, perceptions and concerns about nutrigenetic testing for personalized nutrition in the general population of the province of Quebec, in Canada.

Methods: A total of 1425 individuals from the province of Quebec fully completed a 37-question online survey on nutrigenetics and were included in analyses. Chi-square tests were used to test for associations between categorical variables.

Results: The majority of participants (93.3%) considered dietitians as the best professionals to give personalized dietary advice based on nutrigenetic testing. The main reported advantage for nutrigenetic testing was “health” (23.5%), followed by “disease prevention” (22.2%). Among disadvantages, “no disadvantage” (24.4%), followed by “diet restriction” (12.9%) were mostly reported. The two major concerns raised were the accessibility to genetic testing by telemarketing companies and spammers (51.8%), and solicitation by companies using the personal genetic data to sell products (48.6%).

Conclusions: French Canadians generally have a positive attitude towards nutrigenetics and find many benefits to its use. They rose up possible confidentiality issues associated with the management or property of genetic test results. However education about confidentiality issues is still considerably needed. These findings overall suggest that the population is interested by a more extensive use of nutrigenetics in health management.
Introduction

Nutrigenetics and nutrigenomics explore the interactions between food and genes, and how these interactions can influence one’s health and risk to develop chronic nutrition-related diseases [1-3]. Despite that the science of nutrigenetics/nutrigenomics has greatly evolved since its emergence in the late 90’s, and has now sufficiently progressed to bring a wide variety of genetic tests to predict the individual response to nutrients and/or nutritional interventions, nutrigenetic technologies have still rarely been used in health care practice [4-6]. Besides their recent commercialization by companies specialized in nutrigenetic tests, sometimes in collaboration with registered dietitians, a very small proportion of registered dietitians actually use nutrigenetics in their practice to provide personalized nutritional recommendations to their patients, and often do not consider themselves sufficiently trained to adequately use it [4,5]. Despite the infrequent use of nutrigenetic testing by registered dietitians, many companies offer genetic tests directly to consumers, thus making the technology very accessible, and the genetic testing market as a whole has been steadily increasing in recent years [6,7].

Nutrigenetic technologies appear to be well accepted in European and North-American countries, including Canada [8-11]. Nielsen et al. studied public perceptions of personalized nutrition based on genetic testing among Canadians and observed that participants’ interest in nutrigenetics increased when participants received dietary advice based on their genetic profile in comparison with participants who received dietary advice without genetic information [12,13]. Attitudes of Canadian consumers towards nutrigenomics
were also studied by Morin et al. in focus groups in five Canadian cities, namely Halifax, Montreal, Toronto, Edmonton, and Vancouver, and concluded that consumers perceived benefits of nutrigenomics outweighed the risks [14].

However, cultural differences between populations might affect the way people perceive nutrigenetics. Hence, our research group recently surveyed a population of French Canadians living in the province of Quebec to assess their current knowledge and level of interest in nutrigenetics. In order to bridge the substantial gap between research and clinical practice regarding nutrigenetics, and to facilitate its integration in professional practice, attitudes, beliefs, perceptions and fears of consumers towards nutrigenetics must be comprehensively assessed. We therefore aimed, in the present study, to draw a global portrait of the current situation of nutrigenetics in Quebec by evaluating apprehensions, perceptions and attitudes of nutrigenetic testing for personalized nutrition of the population of Quebecers.
Methods

Recruitment

A total of 2238 individuals aged of 18 years old or older living in the province of Quebec, in Canada, were recruited via Facebook and the Laval University list of employees and students and surveyed from March 10, 2015 to April 28, 2015. Participants had to have access to a computer with an Internet connection and to be able to answer the questionnaire written in French. To reduce the risk that someone completes the survey more than once, the IP address of the computer used to complete the survey was checked. A total of 1535 individuals completed the survey, from which 110 were thereafter excluded for missing information. A total of 1425 participants, including 252 men and 1173 women were kept for statistical analysis. The Ethics Committee on Research Involving Human Subjects of Laval University approved this project.

Questionnaire development

SurveyMonkey Gold with enhanced security (http://www.surveymonkey.com), an online survey development cloud-based software, was used to build the questionnaire. Twenty unrelated individuals pre-tested the questionnaire to estimate the necessary time to complete it, to verify the clarity of the questions and to evaluate the relevance of the proposed answers. The survey comprised a total of 37 questions. Thirty-three of them were closed-ended and four were open-ended. Most of the closed-ended questions were multichotomic with one or multiple possible answers, so that the respondent could choose more than one answer.
A brief definition of nutrigenetics was given at the beginning of the survey. A total of 14 questions for quota sampling were found at the beginning (ex. citizenship, age, etc.), and at the end of the questionnaire (ex. personal and familial health history, gender, ethnicity, etc.). Questions about citizenship, province/territory and age were discriminatory to ensure that respondents were Canadian citizens living in the province of Quebec, and were 18 years old or older. Seven items evaluated perceptions, attitudes and concerns of participants, which were used to address the objective of the present study. Five items evaluated genetic literacy and knowledge of participants on nutrigenetics, six evaluated participants’ interest and willingness to undergo nutrigenetic testing, and five evaluated intentions to follow dietary advice based on genetic testing. These last 16 items were mainly addressed in another paper by our research group [15].

Statistical analysis.

Results were exported from SurveyMonkey into Microsoft Excel (Microsoft, Redmonds, CA, USA) to be converted into calculation sheets, before being imported into SAS, v9.4 (SAS Institute, Cary, NC, USA). In open-ended questions, common themes were identified using NVivo software v10.2.0. Results were analyzed as categorical variables. Chi-square tests were used to test for associations between categorical variables. Statistical significance was set at p<0.05.
Results

Study population

Characteristics of subjects are presented in Table 1. Participants had a mean age of 38.3 ± 14.9 years. A proportion of 49.4% of participants had completed undergraduate or graduate university studies, and 14.6% had a college degree. A total of 25.2% of participants had an annual household income equal or superior to $100 000/year. The vast majority were Caucasians (96.7%) and were not familiar with the term “nutrigenetics” (82.7%). Five participants had already undergone genetic testing.

Preference for Health Care Professional

When asked to which health care professional(s) should be referred an individual wishing to receive nutritional recommendations adapted to his genetic profile, 93.3% of participants identified registered dietitian as a good choice. Doctor/family physicians were identified by 39.7% of participants, followed by geneticists (39.2%) and genetic counsellors (28.6%). Naturopaths, nurses and pharmacists were identified by 11.9%, 10.3% and 8.2% of participants, respectively.

Perceived Advantages and Disadvantages of Nutrigenetic Testing

Table 2 shows the principal advantages and disadvantages given by study participants from receiving personalized dietary advices based on genetic makeup. Briefly, when asked about the perceived advantages of receiving DNA-based dietary advice, “health” was the most frequently reported theme (23.5%), followed by “disease prevention” (22.2%), “personalized dietary advice based on genetic makeup” (22.0%), “improving diet” (9.1%), “food classified as being good or bad” (7.7%), “weight control” (6.9%), and
“feeling better” (5.4%). Additionally, 24.4% of respondents perceived no disadvantage for receiving DNA-based dietary advice. The item “diet-related restrictions” was the most frequently mentioned disadvantage (12.9%) followed by “worry/fear/anxiety” (8.1%), “the loss of pleasurable eating practices” (5.5%), and “the risk to develop food obsession” (5.0%).

A proportion of 90.7% (n=1292) of participants reported to be ready to follow a personalized diet based on the results of a nutrigenetic test, as reported in a previous paper [15]. The remaining 9.3% (n=133) were questioned about the reasons for not being inclined to follow personalized dietary advice based on genetic makeup.

Restrictions associated with the diet (25.6%) (e.g. “I do not like having restrictions.”), the fact that they do not want to follow any diet (12.8%) (e.g. “I do not like diets […] Having a food structure bores me and I will not follow a diet for the rest of my life.”), that they already have a suitable diet (9.8%) (e.g. “I already have a balanced diet”), the pleasure of eating (10.5%) (e.g. “It could take away the pleasure of eating.”), the absence of health problems and illness (8.3%) (e.g. “I do not have any particular disease. I do not think I need to follow a special diet.”), the complexity to follow a diet based on DNA dietary advice (6.8%) (e.g. “It must be complicated to eat in restaurants.”), the personal food preferences (6.0%) (e.g. “The fear of having to cut my favourite food. I am very picky on the food side, so it would be difficult for me to go on a diet.”), and the negative impact of diet on psychological aspects such as self-control and guilt (6.0%) (e.g. “I do not want to have to personally control what I think […] Knowing my genetic profile would make me feel guilty if I do not follow the nutritional recommendations, and I would know
that I have a direct effect on my health. I just do not want to know.”) were among the answers most often quoted by the participants in qualitative analyses (data not shown).

General Concerns about Nutrigenetic Testing

As shown in Figure 1, the accessibility to personal genetic data by telemarketing companies and spammers, and the solicitation by companies using personal genetic data to sell products/supplements adapted to the genetic profile of individuals being tested were the two main concerns (51.8% and 48.6%, respectively; % of study participants that answered, “Very concerned”). Participants were generally not concerned about the scientific advancement in the field of nutrigenetics, the destruction of their DNA samples by the genetic testing company once results are reported to the customer, and the accessibility to personal genetic data by the genetic testing company. The price and the high cost of the technology were not among the major concerns with regard to the limits most commonly reported. A proportion of 55.8% of participants were ready to pay less than $100 CAD, 22.46% of the participants were ready to pay between $100-199 CAD, and 4.6% were ready to pay between $200-299 CAD to obtain DNA-based dietary advice. In an ordinal model for multinomial data adjusted for sex, annual income was significantly associated with willingness to pay for DNA-based personalized nutrition (p<0.0001), where individuals with an income ≥$80 000/year were more likely to be willing to pay $200 or more (p≤0.015) for nutrigenetic testing.

When asked if they would share their nutrigenetic test results, 82.0% declared that they will share them with their life partner, but only 51.4% intended to share the results with their children. With regard to other relatives, most people were ready to share their results with parents or with their brothers and sisters (68.4% and 68.1%, respectively).
Percentages were higher with health care providers; 87.3% of participants intended to share their nutrigenetic test results with a family physician and 88.1% with a registered dietitian.
Discussion

This survey aimed to assess public perceptions and general concerns regarding nutrigenetic testing for personalized nutrition in a population of French Canadians from the province of Quebec, in Canada. In this study, advantages and disadvantages of nutrigenetic testing were documented as well.

Study Population

The study sample was mainly composed of Caucasian women, often presenting high socioeconomic status and level of education. The majority was under 40 years of age, and all were French Canadians living in the province of Quebec. Because of the homogeneity of the study sample, generalizability of the results could be limited. Part of this homogeneity can be explained by the recruitment methods. Participants were partly recruited via the Laval University list of employees and students, explaining high levels of education, and it is likely that more women returned the questionnaire than men.

Preference for Health Care Professional

Almost all participants preferred dietitians for providing DNA-based personalized dietary advice. This observation is rather consistent with other studies on the subject. In a Canadian study by Nielsen DE et al., 56% of participants answered “registered dietitian” when asked which health care professional, including registered dietitians, medical doctors, registered nurses, naturopaths or other, they felt would offer them the best personalized nutrition recommendation [12]. Similarly to the present study, medical doctor was reported as the second-best source (27%) for personalized nutrition recommendation [12]. However, in that study, health care professionals were not
perceived as being the best source for personal genetic information [12]. A total of 47% of participants reported “university research lab” as the best source, followed by “health care professional” (41%), and finally “direct-to-consumer genetic testing company” (12%) [12]. Conversely, Poínhos R et al. documented, in a large survey of 9381 individuals across nine European countries, that family doctors/general practitioners were deemed the best service providers for personalized nutrition in all countries except in Poland, where registered dietitians were preferred [16]. Family doctors were also the most trusted providers for personalized nutrition information in all nine countries studied [16]. In Norway and Poland, trust in registered dietitians for providing personalized nutrition information did not significantly differ from family doctors [16]. It should be mentioned that, in France and Germany, the minimum level of training to become a registered dietitian requires less than a bachelor’s degree unlike in Canada, the United States and several other European countries [17]. These differences in educational levels may partly explain the discordances of public opinions between different countries and studies. These observations demonstrate that registered dietitians and physicians are generally well trusted for giving personalized nutritional recommendations from genetic testing, including in Quebec. Nonetheless, this high level of trust from the public towards family doctors is rather surprising considering that dietitians receive much more nutritional training during undergraduate studies than family doctors, and actually have a much higher level of expertise in nutritional counselling [18-21].

Perceived Advantages and Disadvantages of Nutrigenetic Testing

Health benefits were reportedly the most frequent perceived advantage in the present study. Consistently, our group previously observed that participants with personal and/or
familial health issues history were more willing to undergo a genetic testing [15]. These  
results are consistent with the work of Rankin et al., who showed that “health benefits”  
was positively associated with attitude towards and intention to adopt personalized  
nutrition [22]. In the same study, they demonstrated that attitude towards and intention to  
adopt personalized nutrition were positively influenced by several other determinants of  
food choice, including “weight control”, “ethical concern” and “mood” [22]. Unexpectedly,  
“weight control” was among the less reported advantages for receiving personalized  
dietary advice in the present study. Similar findings were reported in a study by Morin et  
al., in which participants indicated, among others, “better diet, disease prevention and  
overall healthier habits” as benefits of nutrigenomics testing [14]. Participants generally  
deemed that benefits of nutrigenomics outweighed risks, as opposed to health care  
professionals, who had a more conservative thinking [14].

General Concerns about Nutrigenetic Testing

Morin et al., also reported several risks perceived by the public regarding nutrigenomic  
testing. Insufficient scientific evidence to support nutrigenomics testing, misinterpretation  
of the results by the public, psychological risks, confidentiality aspects, and high costs  
were raised [14]. Rankin et al. reported “price” as negatively associated with attitude  
towards and intention to adopt personalized nutrition [22]. In the present study, most of  
participants would pay less than $100 for dietary recommendations based on their  
genetic profile. These results show that, in this population, price also appears to be a  
limiting factor. A substantial proportion of participants had a high socio-economic status.  
Considering that annual income was significantly associated with willingness to pay for  
personalized dietary recommendations based on genetic profile, price would probably
have constituted an even more important barrier to genetic testing and personalized nutrition if the survey was conducted in a population with lower incomes. Fisher et al. reported that about 30% of participants, particularly men with high incomes, would be willing to pay more for personalized dietary advice than non-personalized dietary advice [23]. Participants were, on average, willing to pay 150% of the standard price for non-personalized nutrition advice [23]. Henneman et al. showed that men were more prone to genetic testing as well [24]. In the present study, willingness to pay for DNA-based personalized nutrition was not different between men and women.

Accessibility to genetic information was reported as an important preoccupation in some cases. Similar concerns were widely reported in other studies. It was documented that privacy risk was an important determinant of consumers’ intention to use recommendation systems to obtain personalized nutrition advice [25]. Apprehensions about genetic risk profiling were reported in about half of participants (all physicians) of a recent study by Haga et al., where 50% of participants expressed concerns about health insurance discrimination and 43% about confidentiality regarding genetic testing [26]. Authors also found with participants from the public that agreed or strongly agreed with the possibility that results of genetic tests could affect their capacity to get health insurance (51.3%) or a job (15.7%) [27]. In other studies, employment and insurance taking were matters of concerns for participants as well [9,27-29]. These observations clearly demonstrate a certain public’s awareness of the ethical issue of confidentiality.

However, the majority of participants were comfortable with sharing nutrigenetics information within the family. Similarly, it was previously observed that almost half of participants (49%) of a study believed that the information from genetic tests belongs to
the whole family [30]. In a survey by Haga et al., 89.7% of participants agreed or
strongly agreed with the share of results of their genetic test with their family members,
and only 22.7% agreed or strongly agreed that the family does not need to know the
results [27]. Similar findings were reported in another study, in which almost every
participant considered that genetic information was familial, not merely individual [31].
Interestingly, Heaton TG et al. observed that individuals are more willing to give away
personal information from genetic testing to an at-risk relative of a disease when the
disease is preventable (mostly) and serious [32]. Authors state that information about
genetic testing is very dependent on disease characteristics [32]. Moreover, Nielsen et
al. reported that participants who received personalized dietary advice based on
participants’ genotype shared more their information with a family member compared to
the control group (dietary recommendations with no genetic information) [12].
Participants were also little concerned by the accessibility and destruction of DNA
samples by the genetic testing company, and the regulation of the industry of genetic
testing. There is currently very little legislation surrounding the provision of evidence-
based nutrition information and nutrigenetic testing, and customers may not be aware of
it [33,34]. Also, there are still some debates on the strength of scientific evidence
supporting the marketing of nutrigenetics and its use in health care practice [33,35].
Conclusion

Overall, the present study showed that individuals perceive many advantages from nutrigenetic testing, mainly for health, and are comfortable with the disclosure of genetic information with relatives. They, however, remain generally aware of the potential privacy issues of nutrigenetic testing, although they do not seem to fully understand the risks associated with ownership of personal genetic information. These findings further support that the population is generally optimistic regarding the use of nutrigenetics in health care practice via registered dietitians.
Declarations and special requirements

Investigations Involving Human Subjects

Written informed consent was obtained from all subjects for the publication of this report. The Ethics Committee on Research Involving Human Subjects of Laval University approved this project (2014-292 / 24-02-2015). Authors’ signatures:

Statement for Authors Submitting Original Research or Case Reports

The enclosed manuscript “Nutrigenetic testing for personalized nutrition – an evaluation of public perceptions, attitudes and concerns in a population of French Canadians” has been approved by me as well as by the responsible authorities at the institute where the work has been carried out. I certify that none of the material in this manuscript has been published previously in any form and that none of this material is currently under consideration for publication elsewhere. This includes symposia and proceedings of meetings and preliminary publications of any kind except an abstract of 400 words or less. Authors’ signatures:
Declarations

Competing interests

Authors have no conflict of interest to declare.

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Authors’s contributions and acknowledgements

BVM and HC wrote the paper and performed statistical analysis; JR, VG, SD and MCV designed research; BVM and MCV have primary responsibility for final content.

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## Table 1. Characteristics of participants

|                           | Men*   | Women*  | Total*   |
|---------------------------|--------|---------|----------|
| **Gender**                | 252 (17.7) | 1173 (82.3) | 1425 (100.0) |
| **Age (years)****         |        |         |          |
| 18-29                     | 60 (23.9) | 477 (40.7) | 537 (37.7) |
| 30-39                     | 34 (13.6) | 283 (24.1) | 317 (22.3) |
| 40-49                     | 47 (18.7) | 150 (12.8) | 197 (13.8) |
| 50-59                     | 52 (20.7) | 143 (12.2) | 195 (13.7) |
| 60 and up                 | 58 (23.1) | 120 (10.2) | 178 (12.5) |
| **Matrimonial status**    |        |         |          |
| Single (including divorced, separated and widowed) | 89 (6.3) | 506 (30.0) | 595 (41.8) |
| Married or Common law     | 162 (11.4) | 651 (45.7) | 813 (57.1) |
| No answer                 | 1 (0.07) | 16 (1.1) | 17 (1.2) |
| **Ethnicity**             |        |         |          |
| Caucasian                 | 244 (96.8) | 1134 (96.7) | 1378 (96.7) |
| Others                    | 8 (3.2) | 39 (3.3) | 47 (3.3) |
| **Level of education**    |        |         |          |
| High School               |        |         |          |
| Not completed             | 3 (0.2) | 12 (0.8) | 15 (1.1) |
| Completed                 | 2 (0.1) | 25 (1.8) | 27 (1.9) |
| Vocational training       | 11 (0.8) | 63 (4.4) | 74 (5.2) |
| College                   |        |         |          |
| Not completed             | 6 (0.4) | 43 (3.0) | 49 (3.4) |
| Completed                 | 29 (2.0) | 179 (12.6) | 208 (14.6) |
| University                |        |         |          |
| Not completed             | 46 (3.2) | 302 (21.2) | 348 (24.4) |
| Completed                 | 155 (10.9) | 549 (38.5) | 704 (49.4) |
| **Annual household income ($ CAD/year)** |        |         |          |
| ≤ 39 999                  | 35 (13.9) | 243 (20.7) | 278 (19.5) |
| 40 000 - 59 999           | 26 (10.3) | 185 (15.8) | 211 (14.8) |
| 60 000 - 79 999           | 33 (13.1) | 140 (11.9) | 173 (12.1) |
| 80 000 - 99 999           | 30 (11.9) | 168 (14.3) | 198 (13.9) |
| 100 000 and up            | 96 (38.1) | 263 (22.4) | 359 (25.2) |
| No answer                 | 32 (12.7) | 174 (14.8) | 206 (14.5) |
| **Geographical distribution** |        |         |          |
| Quebec City               | 187 (74.2) | 594 (50.6) | 781 (54.8) |
| Montreal                  | 7 (2.3) | 66 (5.6) | 73 (5.1) |
| Elsewhere in the province of Quebec | 58 (23.0) | 513 (43.7) | 571 (40.1) |
*Number (%).

**One participant had missing data for age.
Table 2. Perceived advantages and disadvantages for nutrigenetic testing

| Advantages                                      | %*  |
|------------------------------------------------|-----|
| Health                                         | 23.5|
| Disease prevention                              | 22.2|
| Personalized dietary advices based on genetic makeup | 22.0|
| Improving diet                                  | 9.1 |
| Dichotomy between good and bad food             | 7.7 |
| Weight control                                  | 6.9 |
| Feeling better                                  | 5.4 |
| To understand the impact of food on health      | 4.1 |
| Awareness of current health status              | 3.8 |
| Awareness of own situation                      | 3.5 |
| Having better results (glycaemic controls, physical activity, weight loss, etc.) | 3.0 |
| Motivation                                      | 1.4 |
| Allergies/Intolerances                          | 1.3 |
| Avoiding bad behaviours that could increase the risk | 1.1 |
| Better digestive health                         | 1.1 |
| Promote personalized healthy lifestyle habits    | 1.1 |
| Informed decision                               | 1.1 |
| Reliable source of information                  | 0.8 |
| Self-confidence                                 | 0.8 |
| Does not know                                   | 0.8 |

| Disadvantages                                   | %*  |
|------------------------------------------------|-----|
| No disadvantage                                | 24.4|
| Diet restrictions                              | 12.9|
| Worry/Fear/Anxiety                             | 8.1 |
| Loss of pleasure of eating                     | 5.5 |
| To develop food obsession                      | 5.0 |
| No knowledge about potential disadvantages      | 4.8 |
| Changes in food habits                         | 4.7 |
| Food intake complexity                         | 3.9 |
| Costs                                           | 3.9 |
| Awareness of current health status              | 3.8 |
| To only rely on the nutrigenetic test results   | 3.8 |
| Guilt                                           | 3.2 |
| The diet does not necessary apply to all people or family members | 2.9 |
| Unestablished relevance of dietary advices based on genetic makeup | 2.0 |
| The predictive value of nutrigenetic testing is unknown | 1.9 |
| Difficulty/Inability to follow the dietary advices | 1.6 |
| Higher risks of nutritional deficiencies        | 1.6 |
| Feeling obligated                               | 1.6 |
| Population misunderstanding                    | 1.5 |
| Insurability                                    | 1.4 |

Data are from qualitative analyses. Common themes were identified using NVivo software v10.2.0.

*Percentage of participants who reported this advantage and/or disadvantage
Figure 1. Level of concern in regard to principal limits commonly reported in the field of nutrigenetics.
