Awareness of Genetic Counseling and Perceptions of its purpose: a survey of the Canadian public

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Abstract

Genetic counseling can result in better outcomes when clients understand what to expect, and at least theoretically, at some point in their lifespan, anyone could be referred for or benefit from genetic counseling. Thus, in order to identify (and ultimately address) issues around awareness of genetic counseling and perceptions of its purpose, we surveyed the Canadian general population. We acquired 1000 telephone numbers corresponding to a demographically representative sample of Canada from Survey Sampling International, and invited individuals to participate in a telephone-based survey. We administered a purpose-designed survey (in either French or English) comprising questions regarding: demographics, whether or not the individual had heard of genetic counseling, and 15 Likert scale-rated (strongly disagree – strongly agree) items about the possible purposes of genetic counseling. Responses to these 15 items were used to generate a total “knowledge score”. Of the 1000 numbers, n=372 could not be reached, and the survey was successfully administered to n=188 individuals (response rate 30%). Most respondents (n=129, 69%) had not heard of genetic counseling, and substantial proportions thought that genetic counseling aims to prevent genetic diseases and abnormalities, help couples have children with desirable characteristics, and help people to understand their ancestry. These data could be used to inform the strategy for development of future awareness efforts, and as a baseline from which to measure their effects.

Keywords

Public perception; Genetic counseling awareness; Genetic counseling; Genetic counselor

Introduction

In recognition of the importance of evidence-based practice, the genetic counseling profession has increasingly been focusing on assessing the outcomes of genetic counseling services. Genetic counseling aims to help people to “understand and adapt to the medical psychological and familial implications of genetic contributions to disease” (Resta et al, 2006) and is centered on promoting individual autonomy. Thus, some of the most

appropriate outcomes to measure are of a psychosocial nature (Bernhardt et al., 2000) and may include constructs such as anxiety (Albada et al., 2012b), empowerment (Bernhardt et al., 2000), satisfaction (Meiser et al., 2002) and well-being (Meiser et al., 2008) (for excellent reviews of validated measures that might reasonably be applied to the study of the outcomes of genetic counseling, see Kasparian et al. 2007; Payne et al. 2008)

Research shows that individuals who have a good understanding of what to expect from a genetic counseling session have better outcomes (Albada et al., 2012b; Pieterse et al., 2005a). Specifically, knowing what to expect from a genetic counseling session may lower anxiety (Hallowell et al., 1997) such that clients are more likely to participate actively in the session. When the client is less anxious, and able to be a more active participant in the session, rapport-building is facilitated, and the counselor may be better able to address the client's needs (Albada et al., 2012b; Pieterse et al. 2005b; 2012; Babul-Hirji et al., 2010). So, in order to promote optimal outcomes of genetic counseling, it is important to ensure that all prospective clients know what to expect from their appointment. Therefore, there is a need to explore the awareness of genetic counseling among prospective clients, as well as their perceptions of what genetic counseling might entail, as these data will provide a foundation for informing strategies to address gaps in awareness or misconceptions about its purpose.

However, to date, to the best of our knowledge, all North American studies that have looked at awareness of genetic counseling and perceptions of the purpose of genetic counseling have been conducted retrospectively in cohorts of individuals who have already received genetic counseling. These studies suggest that typically, those receiving genetic counseling do not know what to expect from their appointments (Bernhardt et al., 2000; Metcalfe et al., 2007). In one study for example, study participants indicated that the counseling aspect of the appointment was a pleasant surprise (Bernhardt et al., 2000). In another study, in the context of cancer genetic counseling, many participants expected that their family history would be assessed but were unsure of other aspects of the appointment, and almost 30% assumed that their role would be passive (Hallowell et al., 1997).

While retrospective studies certainly are of considerable utility, asking individuals to recall their pre-session expectations after having received genetic counseling is open to confounding influences. Furthermore, while surveying samples of individuals who have received genetic counseling has its benefits, ideally, it would be helpful to understand the perspectives of individuals who have not yet received genetic counseling. Given that, in theory, at some stage in their life, almost anyone could be referred for, or benefit from genetic counseling (individuals with any kind of common complex disorder - conditions that cumulatively affect a large proportion of the population –and their family members), it may be important to prospectively assess the awareness of genetic counseling and perceptions of what genetic counseling might entail within the general population. However, aside from the data from a single study conducted in Japan in the 1990s (Osawa et al., 1993), we were able to find no published data of this nature.

Thus, with the ultimate goal of generating data to inform efforts to ensure that prospective clients have accurate expectations of genetic counseling (and thus create circumstances that allow for optimal client outcomes), and to allow evaluation of the impact of future efforts to

increase public awareness of genetic counseling, we set out to survey a sample of the Canadian general population regarding: a) their awareness of genetic counseling, and b) their perceptions of what the purpose of genetic counseling might be.

Methods

We designed a prospective, cross-sectional, quantitative telephone interview-based survey of the Canadian general population. IRB approval for the study was obtained from the University of British Columbia (certificate number H11-01022).

The participants

One thousand phone numbers constituting a demographically representative sample of the Canadian population were purchased from Survey Sampling International (www.surveysampling.com) - a company that has a database of contact information of individuals who have agreed to participate in research. Individuals were eligible to participate if they were able to communicate in one of Canada's two official languages (English or French), and were 19 years of age. Each telephone number was called periodically throughout the study period (at different times of day and on different days of the week) for a maximum of 6 contact attempts, after which a potential participant was categorized as "could not be reached."

The Survey

We designed a survey to assess participants' awareness of genetic counseling, and their perceptions regarding its purpose. The demographic section comprised items relating to age, gender, education level, annual household income, self-described ethnicity and geographical location.

The survey was translated to French by a bilingual genetic counselor and back translated to English by a second, individual. The survey was piloted using a convenience sample of 12 individuals, and modifications, such as word changes to improve clarity, were made based on feedback received. The survey was administered for the study between October 2011 and March 2012, by a team of three English speaking team members, and two bilingual English/French team members.

Participants who expressed an interest in learning more about genetic counseling were provided with the web address for the Canadian Association of Genetic Counsellors (CAGC) (www.cagc-accg.ca/). Those who did not have Internet access or preferred written information were mailed a booklet provided by the National Society of Genetic Counselors (NSGC): Making Sense of Your Genes: A guide to Genetic Counseling.

Awareness of genetic counseling—To assess awareness of genetic counseling we asked two questions. First we asked: "Have you ever heard of the term genetic counseling?" Participants responses to this question were categorized according to how they had heard about it (specifically: participant had received genetic counseling, participant's friend or family member had received genetic counseling, participant had a friend or family member who was a genetic counselor, participant's healthcare professional had mentioned genetic

counseling, participant had heard of genetic counseling through their profession, in the media, in school, or during genetic counseling awareness week - these categories were not mutually exclusive). Second, to assess another aspect of awareness, we asked all participants who they thought would provide genetic counseling; participants were allowed to select as many as they liked from the following options: a family doctor, a specialized doctor, a psychologist, a health care provider trained specifically in genetic counseling, an obstetrician/gynaecologist, a nurse, a midwife.

Perceptions of the purpose of genetic counseling—Participants' perceptions of the purpose of genetic counseling were assessed through the completion of fifteen Likert scale-rated (strongly disagree – strongly agree) items (see Table 1), which were completed by all participants (regardless of whether or not they indicated that they had previously heard of genetic counseling). The 15 items, reflecting actual goals of genetic counseling, as well as some common misconceptions about its purpose, were developed collaboratively by the co-authors, informed by the previous work of others (Osawa et al., 1993, Wertz and Fletcher, 1988) and clinical experience. Feedback on these items was sought from genetic counseling colleagues prior to initial administration of the survey.

Data Analysis

In addition to applying descriptive statistics to summarize the data, we created a “knowledge score” for each participant based on their responses to the 15 items about the purpose of genetic counseling. This score was created by categorizing each item as true or false, and for items categorized as true, “strongly agree” was assigned a score of 5, and “strongly disagree” was assigned a score of 1. Items categorized as false were reverse coded. The true-false grading was established by consensus of the authors. The total “knowledge score” for each participant was derived by summing the scores of all 15 items; the total possible “knowledge score” range was 15 to 75. In exploratory analyses, t-tests and ANOVAs were used to investigate differences in knowledge scores between different groups (i.e. based on gender, education, geographic location, or whether or not they had heard of genetic counseling).

Results

A total of 188 surveys were completed with a response rate of 30% (of the 1000 phone numbers, 186 were not in service, 186 were unable to be reached and 440 declined participation). One hundred and fifty nine surveys (85%) were administered in English and 29 surveys (15%) were administered in French.

Demographics

Participants ranged in age from 19 to 78 (mean age = 50), detailed demographic data are reported in Table 2.

Awareness of genetic counseling

Overall, less than a third (n=57, 31%) of participants had heard of genetic counseling. Of these, half (n=28, 50%) had heard about genetic counseling in the media, 16% (n=9) had

heard about it through their own professional work in healthcare, 11% (n=6) had heard about it in school, 9% (n=5) had a friend or family member who had received genetic counseling, 7% (n=4) had been told about it by their doctor, 5% (n=3) had received genetic counseling themselves, and 5% (n=3) had a friend or family member who was a genetic counselor. One participant indicated that they had heard of genetic counseling through more than one source.

Most participants (n=113, 60%) felt that genetic counseling would be provided by “a healthcare provider trained specifically in genetic counseling”, but 47% (n=88) thought that it might be provided by a specialized doctor. Some participants felt that genetic counseling would be provided by an obstetrician or gynecologist (n=34, 18%), a psychologist (n=24, 13%), or a family doctor (n=23, 12%). Rarely did participants indicate that a nurse or a midwife would provide genetic counseling (n=6, 3% each). Those who had heard of genetic counseling were no more likely than those who had not to think that it would be provided by “a healthcare provider trained specifically in genetic counseling” ($\chi^2 = 0.828$, df = 1, $p=0.36$).

Perceptions of the purpose of genetic counseling

Nearly 90% of respondents identified that genetic counseling could provide genetic testing for people with family histories of genetic conditions (n=164, 87%), information and support to couples planning pregnancies that may be at risk for genetic conditions (n=164, 87%), and pregnant women whose babies may be at risk for a genetic condition (n= 162, 86%). Eighty percent (n=150) also identified that genetic counseling could help people understand their options for genetic testing. Approximately half of participants indicated that they thought a purpose of genetic counseling was to advise people about whether or not to have children (n= 86, 46%), or to help people understand their ancestry (n= 96, 51%). Three quarters of respondents (n= 141, 75%) indicated that they thought genetic counseling aimed to prevent genetic diseases or abnormalities. Full data for all fifteen items are shown in Table 1.

No respondents answered all items incorrectly (a score 30 or less), and few (n=7, 4%) answered the majority of items incorrectly (which would be reflected by a score of 30–45). The average “knowledge score” among participants was 53.8 (range 40 – 73), which represents a small majority of questions being answered correctly. The distribution of scores is shown in Figure 1. Those who had heard of genetic counseling (n = 57, 31%) had a significantly higher average knowledge score than those who had not (n = 127, 68%), (56.14 vs. 52.72, respectively; $p = <0.0001$). There were no significant differences in the mean knowledge scores based on province, education, language, annual household income or ethnicity. Females had higher knowledge scores than males (average score 54.46 vs. 52.59 respectively; $p=0.036$). Although no participants reported having heard about genetic counseling in the context of genetic counseling awareness week, this annual event occurred during the period that the study was ongoing (November 20–26, 2011). Thus, we conducted an exploratory analysis to compare knowledge scores of those who participated prior to November 20, 2011 (n=41, 22%) and after November 26, 2011 (n=147, 78%) this event. There was no significant difference in knowledge scores between these two groups ($p=.203$).

Discussion and Conclusion

This was the first North American study (of which we are aware) to empirically explore awareness and perceptions of genetic counseling among the general population. Similar to a 1993 Japanese study (Osawa et al., 1993), we found that the majority of respondents (69% here as compared to 62% in the Japanese study) had not heard of genetic counseling, and that when asked what kind of healthcare practitioner might provide genetic counseling, 40% did not include healthcare providers with specialty training in genetic counseling (i.e. genetic counselors) among the list of identified groups. This suggests that a sizable minority of our respondents thought of genetic counseling as an activity not associated with any particular specialized health profession.

These data become quite sobering when considered from a position that: a) values genetic counseling services for the important positive outcomes they can produce for clients (especially if we believe that there is likely to be a difference between genetic counseling as provided by genetic counselors, and that provided by other healthcare professionals without specialist training in this area), and b) accepts that at least in theory, anyone at some point in their lives could be eligible for genetic counseling. From this perspective, it would seem that the potential exists for there to be a huge gap in delivery of genetic counseling services (and therefore an associated gap in positive client outcomes) – essentially, those who are unaware of genetic counseling are unlikely to access it. Of the participants who had heard of genetic counseling, most had heard about it in the media – clearly, communicating with the media represents an opportunity that as a profession, we might exploit more fully to raise awareness about genetic counseling services and the profession as a whole.

With regard to participants' perceptions of the purpose of genetic counseling, a sizable proportion of participants also felt that a purpose of genetic counseling was to prevent inheritable disease and abnormalities, advising couples regarding whether to have children, and helping couples children with desirable characteristics. Taken together these data suggest that at least a proportion of the population considers genetic counseling to be based on eugenic-type values. This could be considered surprising, because although genetic counseling can trace its roots back to the eugenics programs of the first half of the 20th century, Sheldon Reed, who coined the term, actually defined genetic counseling as "...a kind of genetic social work without eugenic connotations" (Reed, 1975, p. 335). The modern day profession was founded on the concept of "non-directiveness", and more recently has moved towards articulating the fundamental principle of this more clearly - that in genetic counseling, promoting patient autonomy is of paramount importance. At a very basic level, this perspective can be interpreted as being the counterpoint to a eugenic approach (Weil, 2003).

A relatively common perception of the purpose of genetic counseling that emerged from participants in the current study, was the perception that genetic counseling can be applied to help people to understand their ancestry. It is possible that this perception is related to widespread interest in genealogy, and is a response to recognition of the fact that information from genetic testing (which is firmly associated with genetic counseling in the perceptions of the general population) can be used to reveal information about ones ancestry.

Indeed, a recent study examining users' motivations to purchase direct-to-consumer genome-wide testing, found that genealogy was a main motivating factor (Su et al, 2011).

When we looked at "knowledge" scores of participants, we found that on average, a small excess of responses were categorized as correct. Taken together, participants' perceptions of the purpose of genetic counseling indicate that there are some areas of misconception (particularly relating to perceptions that genetic counseling involves prevention of inheritable diseases, and helping couples to have children with desirable characteristics) that are ripe for redress that could be tackled through awareness and marketing campaigns.

Limitations

We recognize that among the broader genetic counseling community, there may be some scope for debate regarding the categorization of the statements we used in this study. In particular, we categorized the statement related to the purpose of genetic counselling being the "prevention of genetic diseases or abnormalities" as "false", and this perhaps warrants particular attention. In general, an important purpose of genetic counseling is to support clients' autonomous decision making. While in the prenatal context, a downstream consequence of these autonomous decisions may be that some clients choose not to have a fetus with a genetic condition, this outcome is neither the purpose nor the intent nor the objective of genetic counseling - we do not aim to persuade or advise clients to make this choice. Further, although a goal of genetic counseling in the context of cancer may be to increase screening, or encourage women to consider prophylactic surgery, strictly speaking *preventing* breast or ovarian cancer is not entirely possible (even among those who have had prophylactic mastectomy, recurrence of breast cancer can occur). Thus, even in this context, the purpose of genetic counseling cannot be to prevent genetic disease (although importantly, we may facilitate early detection of cancer, or reduce the risk of cancer). It could be argued that some support for our categorization of statements as true or false was afforded by the finding that those who indicated that they had heard of genetic counseling had significantly higher "knowledge" scores than those who had not.

Further, approximately 1/3 of our awareness questions pertained to prenatal and preconception genetic counseling. It is possible that repetition of this topic could have resulted in participants assuming that items related to pregnancy were more likely to be correct. However, it is worthy of note that the most strongly agreed-with statement was unrelated to pregnancy, and that two of the pregnancy-related statements were among those that were least strongly agreed with.

We cannot extrapolate from our findings to draw firm conclusions regarding awareness and perceptions of genetic counseling among the whole Canadian population (although the 1000 numbers supplied by the company reflected a demographically representative sample, we had a large proportion of non-responders, women - for example - were over represented among participants, and we did not recruit any participants from the Yukon, Nunavut, or Northwest Territories - regions which, combined account for 0.3% of the Canadian population). However, our data suggest that there is room to improve the public understanding of the purpose of genetic counseling in Canada, and there is much to potentially be gained by such improvements.

Conclusion

Ultimately, the concept of genetic counseling is founded (at least in part) on the idea that it can result in positive psychosocial outcomes for clients. Data suggest that improved psychosocial outcomes after genetic counseling are related to clients feeling that they know what to expect from their appointment (Albada et al., 2012b, Albada et al., 2012a, Joseph et al., 2010, Brown et al., 1999). Studies have shown that individuals who have been referred for genetic counseling would have liked more information about what to expect prior to attending the appointment (Metcalf et al., 2007). Assuming that almost anyone could at some point in their lives potentially be eligible for genetic counseling, future research could address different strategies that could be adopted to improve the understanding of genetic counseling among potential clients (not just those who have already been referred) in order to promote optimal outcomes.

In a sample drawn from the Canadian general population, our data empirically demonstrate for the first time that there were substantial gaps among the general population in terms of awareness of genetic counseling, and in terms of perceptions of the purpose of the service. These findings suggest that there is a potential gap in delivery of genetic counseling services (and therefore an associated gap in positive client outcomes) due to simple lack of awareness of genetic counseling at the level of the general population. We propose that investing in developing, expanding, and evaluating the impact of awareness and marketing campaigns would be worthwhile – and would potentially allow opportunities for better outcomes for a greater number of individuals as a result of increased access to genetic counseling services. The data presented here could be used to inform the strategy for development of future awareness-raising efforts, and could also be used as a baseline to which future data, gathered after the implementation of awareness-raising interventions, could be compared.

Acknowledgments

This research was undertaken, in part, thanks to funding from the Canada Research Chairs program. The authors thank Anna Cantor, Dana Young and Sevil Rahnama for their help with administering the survey, Emmanuelle Souzeau for translation of the survey to French, the UBC Genetic Counseling program for funding, and NSGC for providing copies of the pamphlet “Making sense of your genes: A guide to genetic counseling”. JA was supported by the Michael Smith Foundation for Health Research, the Canadian Institutes of Health Research, and BC Mental Health and Addictions Services.

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Fig. 1.
Distribution of “knowledge” scores. The frequency of each score is indicated on the y axis and the “knowledge” score attained is presented on the x-axis

Table 1

Participants' responses to questions about the purpose of genetic counseling listed in order of degree of concurrence with our classification of whether the statement was true or false, from lowest concurrence (most misconception) to highest concurrence. Patterned shading indicates disagreement (checkered=strongly disagree, stripes=disagree), white = neither agree nor disagree, and solid colours indicate agreement (grey=agree, black=strongly agree).

Statement	<p>Participant response summary</p> <p>Participant response summary</p> <p>Strongly Disagree Neither agree nor disagree Strongly Agree</p>	Statement Classification (True or False)
A purpose of genetic counseling is to prevent genetic diseases or abnormalities		False
A purpose of genetic counseling is to help people understand their ancestry		False

Statement	<p>Participant response summary</p> <p>Participant response summary</p> <p>Disagree</p> <p>Agree</p> <p>Strongly Disagree</p> <p>Neither agree nor disagree</p> <p>Strongly Agree</p>	Statement Classification (True or False)
A purpose of genetic counseling is to advise people about whether to have children		False
A purpose of genetic counseling is to provide information and support to all couples planning a pregnancy		False
A purpose of genetic counseling is to provide information and support to all pregnant woman		False

Statement	<p>Participant response summary</p> <p>Participant response summary</p> <p>Disagree</p> <p>Agree</p> <p>Strongly Disagree</p> <p>Neither agree nor disagree</p> <p>Strongly Agree</p>	Statement Classification (True or False)
A purpose of genetic counseling is to help couples have a child with desirable characteristics		False
A purpose of genetic counseling is to provide emotional support to anyone coping with a genetic condition		True
A purpose of genetic counseling is to provide information about how genetics contributes to health problems		True

Statement	<p>Participant response summary</p> <p>Participant response summary</p> <p>Disagree Agree</p> <p>Strongly Disagree Neither agree nor disagree Strongly Agree</p>	Statement Classification (True or False)
A purpose of genetic counseling is to provide an explanation of treatments for genetic conditions	<p>0% 50% 100%</p>	True
A purpose of genetic counseling is to provide information about the chances of your child having a genetic condition	<p>0% 50% 100%</p>	True
A purpose of genetic counseling is to help people understand their options for genetic testing	<p>0% 50% 100%</p>	True

Statement	<p>Participant response summary</p> <p>Participant response summary</p>	Statement Classification (True or False)
A purpose of genetic counseling is to provide referrals and resources for families with a genetic condition		True
A purpose of genetic counseling is to provide information and support to pregnant women whose babies may be at risk for a genetic condition		True
A purpose of genetic counseling is to provide information and support to couples planning a pregnancy which may be at risk for a genetic condition		True

Statement	<p>Participant response summary</p> <p>Participant response summary</p>	Statement Classification (True or False)
<p>A purpose of genetic counseling is to provide genetic testing to people with a family history of a genetic conditions</p>		<p>True</p>

Table 2

Participant sociodemographic characteristics

Characteristic		N (%)
Gender	Male	59 (31.7)
	Female	127 (68.3)
Education	Graduated High school	172 (91.5)
	Attended University	146 (77.7)
Ethnicity	Caucasian	144 (78.3)
	East Asian	6 (3.3)
	First Nations	3 (1.6)
	Black	5 (2.7)
	Mixed	22 (12.0)
	South Asian	4 (2.2)
Income	<\$20,000	17 (12.2)
	\$20,000–\$40,000	13 (9.4)
	\$40,000–\$60,000	23 (16.5)
	\$60,000–\$80,000	19 (13.7)
	\$80,000–\$100,000	19 (13.7)
	\$100,000–\$150,000	30 (21.6)
	\$150,000–\$200,000	12 (8.6)
	>\$200,000	6 (4.3)
Geographical Location	Alberta	24 (12.8)
	British Columbia	26 (13.8)
	Manitoba	7 (3.7)
	New Brunswick	2 (1.2)
	Newfoundland	5 (2.7)
	Nova Scotia	10 (5.3)
	Ontario	77 (41.0)
	Prince Edward Island	2 (1.1)
	Quebec	30 (16.0)
	Saskatchewan	5 (2.7)