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Public Views on Genetics and Genetic Testing: A Survey of the General Public in Belgium

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Aims: To explore the views of the Belgian public on various topics surrounding genetics and genetic testing (GT).
Materials and Methods: A written questionnaire was administered to visitors of the annual cartoon festival in Knokke-Heist, Belgium, during the summer of 2014. The main theme of the festival was challenges and progress in human genetics and it was attended by more than 100,000 visitors.
Results: The survey was completed by 1182 respondents, resulting in a demographically diverse sample with a mean age of 48.5 years. Our respondents expressed moderate interest in predictive GT, with 39.1% willing to learn about their predisposition to diseases through GT and 49.5% indicating interest in getting tested exclusively for treatable/preventable diseases. We observed higher interest in GT for reproductive purposes, such as preconception screening for recessive disorders (53.8%) and prenatal GT (60.7%). A substantial minority (46.4%) of the respondents were worried that GT could further stigmatize people with disabilities, while 39.7% believed that carrier screening for recessive diseases would lead to an inferior image of people affected by them.
Conclusion: Paying due attention to the attitudes, beliefs, and concerns of the general public is important to ensure ethically sound and socially acceptable implementation of new genetic technologies.

Keywords: attitudes, survey, genetic testing, questionnaire

Introduction

Over the past two decades, the field of medical genetics has seen transformative developments, such as the completion of the human genome project and the emergence of next-generation sequencing technologies (Collins and McKusick, 2001; Margulies *et al.*, 2005; Koboldt *et al.*, 2013). These important milestones have significantly accelerated research into human genetics, elucidating the genetic basis of many medical conditions.

Improvements in our understanding of medical genetics have opened up new avenues for using genetic testing (GT), beyond traditional clinical diagnostic purposes. Some of these recent applications of GT include presymptomatic/predictive testing of healthy individuals for susceptibility to develop a disease later in life, pharmacogenomic and nutrigenomic GT aimed at optimizing medical treatment and diet, respectively, based on one's genetic makeup (National Institutes of Health, 2010; Collins *et al.*, 2014). Moreover, recent developments in human genetics have revolutionized GT for reproductive purposes, such as through carrier screening for monogenic recessive disorders, where individuals or couples can now be tested for the carrier status of hundreds of recessive conditions that may affect their children (Srinivasan *et al.*, 2010; Martin *et al.*, 2015; Nazareth *et al.*, 2015; Silver *et al.*, 2016).

On an individual level, GT may hold both medical and psychological benefits, such as increasing sense of control over one's life and, where possible, allowing deciding on various preventive measures (Houfek *et al.*, 2015). For example, individuals may choose to modify their lifestyles (e.g., adopt a healthy diet and regular exercise in the presence of an increased risk for heart disease or diabetes; O'Daniel, 2010), undergo preventive medical procedures (e.g., prophylactic mastectomy in women at risk of developing breast cancer; Di Prospero *et al.*, 2001), or alter future reproductive plans (in the context of carrier screening; Nazareth *et al.*, 2015). From a public health perspective, GT is appealing due to its potential to foster prevention-based medicine, thus minimizing costs associated with medical treatments and improving the overall health of the population (Zimmern and Khoury, 2012).

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Some of the disadvantages of GT include psychological distress associated with the procedure, potential harm due to unnecessary medical interventions where tests results are inaccurate (Botoseneanu *et al.*, 2011), and the possibility of discrimination against individuals with particular genetic predispositions (Wauters and Van Hoyweghen, 2016).

Given the potential benefits and harms of GT, it is important to investigate the acceptability of this technology among healthcare users, such as the members of the general public (Etchegary *et al.*, 2013).

Recent literature reviews have identified a large number of empirical studies on attitudes toward GT (Haga *et al.*, 2013; Sweeny *et al.*, 2014). Most of these studies focus on GT for specific medical conditions or particular demographic groups. In contrast, only a handful of studies have surveyed members of the public on GT more broadly. Additionally, results of previous attitudinal studies cannot necessarily be readily applied to any particular context for two reasons. First, the public's views on GT tend to evolve over time (Henneman *et al.*, 2013). Second, populations in different countries may hold diverging views and beliefs about GT due to differences between healthcare systems and varying exposure to critical debates on GT (Miettinen and Väliverronen, 1999).

The present study was conducted with the goal to explore the attitudes of the Belgian general public toward various aspects of medical GT.

Materials and Methods

Survey instrument

A Likert-scale written questionnaire (Norman, 2010) was developed to gauge the public's views on various topics related to GT, including interest in different types of GT; preferences among potential providers of GT; and future expectations and concerns regarding GT. The questionnaire was written in Dutch and administered in person by one of four master's students carrying out the fieldwork (C.B., R.P., D.V., and S.S.), who guided respondents throughout the survey, introduced the topics covered, and provided additional information or clarifications where necessary.

This study was approved by the Social and Societal Ethics Committee of the University of Leuven.

Participants

Convenience sampling was used to select participants for this study. Respondents were recruited from 100,000 visitors to the 2014 annual cartoon festival, part of which included an exhibition on cartoons and human genetics as well as cartoons from Press Cartoon Belgium and Europe and an open contest held in Knokke-Heist (Belgium). Inclusion criteria were fluency in Dutch and being aged 18 or older. Minors aged 16 or older were also included, provided they were accompanied by an adult family member and actively expressed interest in participation. Respondents were approached by one of the students with a request to participate in the survey. Recruitment and data collection continued throughout the festival, from July 13 to September 14, 2014.

Data analyses

Statistical analyses were performed using two nonparametric tests: Mann–Whitney U test and Kruskal–Wallis test (Fagerland and Sandvik, 2009; McDonald, 2009). The Mann–Whitney U test was employed for the dichotomous demographic variable *gender* to compare differences in attitudes between male and female respondents. The Kruskal–Wallis test was applied to the variables *level of education*, *age*, and *extent of religious involvement*.

To ensure meaningful comparison across groups, we divided *age* into three categories, resulting in groups of similar size. The groups were conventionally labeled younger (born after 1972), intermediate (born during the period 1956–1972), and older (born during the period 1927–1955). Similarly, with respect to the *level of education*, respondents were divided into three groups: academic degree (academic bachelor and higher), professional bachelor (vocational education), and primary education (no degree at a higher education institution). Finally, the *extent of religious involvement* was recoded into a new variable where those who identified as active and somewhat active were treated as the same group ($n = 373$), also resulting in three groups (active or somewhat active, passive, and none/inapplicable).

p-Values of 0.05, 0.01, and 0.001 were used for distinguishing between different levels of statistical significance. Where the Kruskal–Wallis test identified a statistical significance, a series of Mann–Whitney tests were carried out to additionally gauge differences between the groups. Two statements, where the number of respondents selecting a particular response was below 5, were excluded from the analyses. Statistical analyses were performed using SPSS 23.0.

Results

Sample

Overall, 1202 respondents were surveyed during the festival. Twenty questionnaires were excluded either because they were incomplete or the respondents' accompanying person(s) had strongly interfered with the interview process, resulting in 1182 valid responses. Nonresponse rate was not documented as this was a convenience sample.

Demographic characteristics

Respondents' characteristics are presented in Table 1. The average age of the participants was 48.5 years (range 16–87 years) and females comprised 52.5% of the respondents. Approximately two-thirds (70.7%) of our participants had a religious affiliation, 93.4% of whom identified as Roman Catholic. Less than one-third (31.6%) of the respondents described themselves as actively (9.1%) or somewhat actively (22.5%) religious, 47.6% rated their extent of religious involvement as passive, and the rest (20.8%) identified as nonreligious. Regarding education, more than one-third (34.8%) of the respondents held an academic degree from a university, 32.1% had obtained a professional bachelor's diploma, and 33.1% had not followed education at a higher education institution.

Attitudes toward GT

Respondents' attitudes toward GT are presented in Table 2. The majority of participants (64.6%) agreed or strongly agreed that they were curious about their predisposition to diseases, while 39.1% were willing to take a predictive genetic test to learn this information. However, approximately half (49.5%) of the respondents stated they would take such a test only if it provided predictive information about treatable or preventable disorders. Older age was associated with lower interest in

Table 1. Sociodemographic Characteristics of the Study Participants

Demographic characteristics	*Observed frequency* N *(%)*
Age	
Younger (Born during the period 1973–1998)	399 (33.8)
Intermediate (Born during the period 1956–1972)	395 (33.4)
Older (Born during the period 1927–1955)	388 (32.8)
Mean (SD)	48.5 (16.8)
Range	16–87
Gender	
Male	562 (47.5)
Female	620 (52.5)
Religious denomination	
Protestant	20 (1.7)
Roman Catholic	781 (66.1)
Other	346 (29.3)
None	35 (3.0)
Extent of religious involvement	
Active or somewhat active[a]	373 (31.6)
Passive	563 (47.6)
None/inapplicable	246 (20.8)
Highest level of education completed	
Academic degree	411 (34.8)
Professional bachelor's degree	379 (32.1)
Primary education[b]	392 (33.1)

[a]Includes self-identified religiously active ($n=107$) and somewhat active ($n=266$) respondents.
[b]Includes primary school ($n=6$); lower level of secondary school ($n=63$); and high school ($n=323$).
SD, standard deviation.

one's predisposition to diseases and predictive testing. Older participants were also more likely to prefer predictive testing solely for preventable/treatable disorders than those in both the intermediate and the younger age groups (Supplementary Data; Supplementary Data are available online at www.liebertpub.com/gtmb).

The majority of respondents (60.7%) indicated that they would consider having their unborn child tested for genetic diseases during pregnancy. More religious and younger respondents were the least likely to agree with this statement (Supplementary Data). Fewer respondents (25.9%) were in favor of having their newborns tested for disorders that manifest in adulthood. Male gender, young age, and lower education were associated with greater acceptance of having one's newborn tested for adult-onset conditions (Supplementary Data).

A minority of respondents (23.7%) were afraid that the results of genetic tests may fall in the wrong hands. This concern was less prominent among the female and the younger group (Supplementary Data). Additionally, 46.4% of the respondents were worried that due to GT, society would become less accepting of people with disabilities, with religiosity and age being statistically significant variables.

Preferences among potential providers of GT

Respondents' preferences among the different settings for providing GT are described in Table 3. Approximately three-quarters of the respondents agreed or strongly agreed that genetic tests should only be performed following a doctor's prescription. Older respondents and females were more likely to agree with this statement (Supplementary Data). A higher proportion of respondents (84.5%) were of the opinion that genetic tests should be performed exclusively in the hospital, with female and older respondents being more likely to agree (Supplementary Data). Furthermore, the vast majority of respondents (95.5%) believed that genetic tests should not be sold through the internet, and 74.8% were against selling of genetic tests by a pharmacist.

Attitudes toward carrier screening

The last section of the questionnaire included statements about carrier screening for recessive disorders. Respondents' answers to these questions are presented in Table 4. Most participants (63.9%) agreed that all couples planning a pregnancy should be offered the possibility to have carrier testing. However, fewer (53.8%) expressed willingness to take a carrier test themselves. A large majority of our respondents (96.4%) believed that people should be free to choose whether to take a carrier screening test. Only 12.5% agreed that refusing a carrier screening test is irresponsible of prospective parents, with 67.8% disagreeing and 19.6% having no opinion.

Most respondents (71.4%) agreed that carrier screening will lead to higher anxiety among future parents, with female respondents being more likely to agree (Supplementary Data). Less than 1/3 of respondents (30.5%) were of the opinion that carrier screening is an excessive interference of medicine in pregnancy. Females were more likely to agree with this statement, while younger respondents tended to disagree the most (Supplementary Data). A higher proportion of respondents (39.7%) agreed that carrier screening for specific diseases will lead to an inferior image of people with these disorders.

Discussion

To our knowledge, this is the first exploration of attitudes of the general public in Belgium toward genetics and GT. Our study sample of 1182 individuals was representative of the Belgian population in terms of age and gender.

While nearly two-thirds of our study participants were curious about their genetic predisposition to diseases, the proportion of those interested in taking predictive GT was somewhat lower (39.1% for general predictive GT and 49.5% for GT for treatable/preventable disorders). This could be due to barriers to GT, which may include the cost of the test (Cherkas *et al.*, 2010), time required for the procedure and follow-up (Foster *et al.*, 2004), and for some individuals, concerns about potential misuse of test results (Suther and Kiros, 2009). Additionally, as we did not ask the respondents to assume a perfectly accurate test, it is possible that for some of them, obtaining results of a predictive genetic test did not equate to receiving reliable information about their predisposition to diseases. In earlier studies, interest in predictive GT has been shown to increase as the accuracy of the test approaches 100% (Condit, 2010).

Our findings also confirm the observation reported by others that members of the general public express higher interest in GT for preventable or curable disorders, as opposed to predictive GT either generally or for incurable

Table 2. Attitudes Toward Predictive Genetic Testing

Statement	*Strongly disagree*	*Disagree*	*Nether agree nor disagree*	*Agree*	*Strongly agree*	*Influencing factors (*p-*value)*
	N *(%)*					
I am curious about my genetic predisposition to diseases	49 (4.1)	205 (17.3)	164 (13.9)	551 (46.6)	213 (18.0)	Age (<0.01)
I would take a genetic profiling test to learn whether I am at risk of developing diseases	94 (7.9)	375 (31.7)	251 (21.2)	348 (29.4)	114 (9.6)	Age (<0.05) Education (<0.01)
I would get tested only for disorders that are considered treatable or preventable	60 (5.1)	331 (28.0)	206 (17.4)	454 (38.4)	131 (11.1)	Age (<0.001) Education (<0.001) Religiosity (<0.05)
During my or my partner's pregnancy, I would have my unborn child tested for all serious genetic diseases, even though such tests are typically performed with a view on pregnancy termination	88 (7.4)	243 (20.6)	133 (11.2)	431 (36.5)	287 (24.3)	Age (<0.05) Religiosity (<0.05)
I would consider having my newborn child genetically tested to learn which diseases they may develop in adulthood	189 (16.0)	464 (39.3)	223 (18.9)	229 (19.4)	77 (6.5)	Age (<0.001) Gender (<0.001) Education (<0.01)
I am afraid that the results of a genetic test may fall into the wrong hands	179 (15.1)	498 (42.1)	225 (19.0)	190 (16.1)	90 (7.6)	Age (<0.01) Gender (<0.05) Religiosity (<0.05)
I am worried that due to genetic testing, disabled people will be less accepted in our society	63 (5.3)	346 (29.3)	224 (18.9)	431 (36.5)	118 (10.0)	Age (<0.001) Religiosity (<0.05)

genetic conditions (Shaw and Bassi, 2001; Singer *et al.*, 2004; Makeeva *et al.*, 2010; Botoseneanu *et al.*, 2011; Vermeulen *et al.*, 2014).

Of all genetic tests discussed in the questionnaire, our respondents expressed the greatest interest in reproductive GT, with ~61% stating they would take a prenatal genetic test for all serious diseases with a view of possible termination of pregnancy and ~54% indicating interest in preconception carrier screening for recessive disorders. Of note, younger (aged 41 or below) individuals in our study were significantly less likely to be interested in prenatal GT compared with both intermediate and older age groups. Although we did not ask our respondents about their future reproductive plans, it is reasonable to assume that prenatal GT was of the greatest personal relevance to those in the younger age group. Therefore, the lowest interest in prenatal GT among this group may suggest that respondents in our study were more likely to be approving of the general availability of this test than willing to personally use it. This appears to be consistent with earlier empirical studies, in which support for the general availability of reproductive genetic tests was usually higher than respondents' intention to use the test (Condit, 2010).

In the context of carrier screening for recessive disorders, we observed that despite high interest in this test (~54%) and even greater support for making it available to all couples planning pregnancy (64%), approximately two-thirds of the

Table 3. Preferences Among Potential Providers of Genetic Testing

Statement	*Strongly disagree*	*Disagree*	*Nether agree nor disagree*	*Agree*	*Strongly agree*	*Influencing factors (*p-*value)*
	N *(%)*					
Genetic tests may only be performed on doctor's prescription	35 (3.0)	146 (12.3)	105 (8.9)	540 (45.7)	356 (30.1)	Age (<0.001) Gender (<0.05) Religiosity (<0.05)
Genetic tests may only be performed in the hospital	11 (0.9)	82 (6.9)	90 (7.6)	552 (46.7)	447 (37.8)	Age (<0.001) Gender (<0.05)
Genetic tests may be sold through the Internet	829 (70.1)	300 (25.4)	29 (2.4)	20 (1.7)	4 (0.3)	
Genetic tests may be sold by a pharmacist	483 (40.9)	401 (33.9)	142 (12.0)	136 (11.5)	20 (1.7)	Age (<0.001) Gender (<0.01) Education (<0.05)

Table 4. Attitudes Toward Preconception Carrier Screening

Statement	*Strongly disagree*	*Disagree*	*Nether agree nor disagree*	*Agree*	*Strongly agree*	*Influencing factors* (p-*value*)
	N *(%)*					
All couples planning a pregnancy should have a possibility to have a carrier test	36 (3.0)	245 (20.7)	145 (12.3)	554 (46.9)	202 (17.1)	Age (<0.001) Education (<0.001)
I would (together with my partner) have a carrier screening test	66 (5.6)	308 (26.1)	172 (14.5)	492 (41.6)	144 (12.2)	Age (<0.01) Education (<0.01)
Carrier testing will lead to higher anxiety among people who want to become pregnant	21 (1.8)	170 (14.4)	147 (12.4)	617 (52.2)	227 (19.2)	Gender (<0.01)
Carrier testing is an excessive interference in pregnancy resulting from the medicalization of the world	84 (7.1)	441 (37.3)	296 (25.0)	284 (24.0)	77 (6.5)	Age (<0.01) Education (<0.05) Gender (<0.05)
Carrier testing for some diseases may lead to an inferior image of people affected with these diseases	61 (5.2)	372 (31.5)	280 (23.7)	396 (33.5)	73 (6.2)	Age (<0.001)
Everyone should be able to decide whether or not to undergo carrier testing	4 (0.3)	13 (1.1)	25 (2.1)	435 (36.8)	705 (59.6)	
It is irresponsible for prospective parents to refuse carrier testing	276 (23.3)	526 (44.5)	232 (19.6)	105 (8.9)	43 (3.6)	Age (<0.001) Education (<0.001)

respondents (67.8%) felt it was not irresponsible for prospective parents to refuse a carrier screening offer. One explanation for these findings could be that the decisions surrounding reproduction are considered intensely personal (Wilfond and Goddard, 2015) and given the implications of carrier screening for future reproductive choices, some respondents may have felt that the decision whether to participate in carrier screening is best left to the couples themselves.

Among the different types of genetic tests, we observed the lowest interest in having one's newborn child tested for diseases manifesting in adulthood. This is in contrast to the findings of two US-based studies reporting that most members of the general public prefer to receive all predictive genetic information about their youngest children, regardless of whether it is immediately relevant to the child's health (Goldenberg *et al.*, 2014; Dodson *et al.*, 2015). This difference may partly be attributed to the wording we used in the statement, which implied the distant and currently uncertain nature of medical benefits arising from such testing. Because of this, some respondents may have felt unsure as to whether performing a predictive GT during the newborn period for adult-onset disorders would be in the best interest of a child.

Our study also enquired about respondents' preferences among potential providers of GT. We observed a strong support for hospital-based GT performed exclusively with a doctor's prescription. Correspondingly, our respondents were against genetic tests being sold either by commercial providers over the internet or by a pharmacist. These results are similar to those reported in a survey of the Dutch public, where two-thirds of the respondents supported limiting GT to the hospital setting and <10% favored commercial GT through the internet or a pharmacist (Vermeulen *et al.*, 2014).

One explanation for this may lie in the organization of healthcare services in Belgium and the Netherlands. In both countries, health insurance is universal and covers medical procedures deemed to be of clinical utility. Therefore, provision of genetic tests through established healthcare channels in these countries may enhance the sense of security for many individuals who may view this as an important precondition for accepting the test.

Our respondents voiced several concerns about potential negative implications of GT technologies. Nearly one-quarter (24%) of them indicated they were worried that genetic test results may fall into the wrong hands. This is similar to the findings of a survey carried out in the United States in 2000, where $\sim$25% of a large multiethnic population agreed that information from genetic tests is likely to be misused (Suther and Kiros, 2009).

Furthermore, a substantial minority of our respondents were worried about the possible negative impact of GT on disabled people, with 46% agreeing that due to GT, the society would grow less tolerant toward people with disabilities, while 40% believed that carrier screening for recessive disorders may devalue the lives of people affected with them. These results are comparable with the findings of the study by Henneman *et al.* (2013), in which 38% of the respondents agreed that there will be a dichotomy in our society: people with a good and people with a bad genetic predisposition.

Existence of such concerns clearly indicates a need for adequate policy and regulatory supervision of the implementation of GT technologies to safeguard against potential harms emanating from such developments. Of particular importance is ensuring that growing availability of reproductive GT bears no discriminatory messages against patients currently living with these disorders. To this end, it is essential that reproductive genetic tests, including carrier screening for recessive disorders, serve as a means for allowing prospective parents to make informed reproductive decisions, rather than as public health

instruments aimed at preventing the birth of children affected with genetic disorders, since this may be interpreted as a negative value judgment about life with a disability (Janssens *et al.*, 2015).

Finally, 71% of our respondents believed that carrier screening will lead to greater anxiety among would-be parents, and 31% considered carrier screening as excessive interference of medicine in pregnancy. These concerns are not new in the literature with respect to carrier screening and they have been seen as potential adverse psychosocial consequences of this technology (Verweij, 2008; Mosconi *et al.*, 2014). It cannot be overemphasized that before deciding whether to take a carrier screening test, prospective parents should have access to high-quality information and, if required, face-to-face genetic counseling. This will help prospective parents weigh the advantages and disadvantages associated with carrier screening and make fully informed decisions in line with their personal values.

Limitations

The main limitation of our study is that we employed convenience sampling to recruit respondents and the setting in which the study took place may have had an impact on its outcomes. In particular, most exhibits at the cartoon festival depicted key topics in human genetics in entertaining and amusing ways, which may have positively influenced some of our respondents' attitudes toward genetics and GT. Therefore, despite a large and demographically diverse sample, the opinions of our study participants may not be fully representative of the Flemish or Belgian populations.

Conclusion

Respondents in our study expressed high interest in reproductive GT, such as prenatal testing and carrier screening for recessive disorders, whereas there was less interest in testing one's newborn child for predisposition to adult-onset diseases. We also observed that willingness to take a predictive genetic test for oneself was greater if testing was limited to treatable or preventable disorders. These findings suggest that the success with which different types of GT can be implemented is likely to vary as not all genetic tests will generate the same level of interest in the population. Therefore, it is important that the introduction of any new genetic test in the healthcare setting is preceded by careful assessment of the interest in and acceptability of the test among potential users.

Additionally, individuals' preferences among different forms of GT may help inform the development of guidelines and policies for the return of results by large-scale population biobanks. This is because biobanks may derive large amounts of health-related information from genomic data, which could be of varying interest to its participants.

According to a large majority of our respondents, genetic tests should be performed in a hospital with a doctor's permission, while commercial offers of genetic tests, either over the internet or through a pharmacist, are not permissible. Strong negative attitudes toward commercial GT offers may indicate that many members of the general public in Belgium are unlikely to pursue GT services outside the hospital setting. This highlights the need for rapid implementation of new genetic tests that have high clinical value into medical practice to provide the population with access to beneficial health-related interventions.

A substantial minority of our respondents were concerned that GT would stigmatize disabled people by fostering their image as individuals with undesirable genetic traits, while some were worried about potential misuse of test results. Since implementation of genetic tests is still in its infancy, at present, the validity of these concerns may be difficult to judge. Nevertheless, policymakers and regulators should be attentive to the concerns held by the general public and remain vigilant for potential societal harms emanating from new GT technologies. Additionally, continuous public education on genetics and routine provision of genetic counseling services to individuals undergoing GT have the potential to address some of the concerns associated with GT as well as dispel any misconceptions that members of the general public may hold regarding genetics and genetic tests.

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Author Disclosure Statement

No competing financial interests exist.

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