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Abstract

This study compares gender differences in attitudes towards prenatal testing, testing in minors, Huntington testing and the creation of designer babies and identifies how risk of genetic disease is perceived by both genders. A questionnaire was developed to explore attitudes towards different types of genetic testing, interpreting risk of genetic disease and concerns relating to genetic testing. A total of 140 people (45 males and 95 females) responded. Respondents, 65 of which were parents, included a wide range of ages and professions. Fourteen percent more females than males thought that it was **highly likely** ($p=0.025$) the way they lived their life would be affected if they knew they were going to develop Huntington disease (HD) and fourteen percent more men thought it was **likely** ($p=0.025$) that they would alter their child's genes to benefit their personal preferences and lifestyle compared females. Both genders appeared unsure when interpreting numerical representations of risks, different responses were given when interpreting risk perception between ratios and percentages of equal value. Women appeared to be more concerned about the use of genetic test information, particularly about providing information to insurance companies. The study highlights important differences between genders, which may have an impact on health professional's interaction with both male and female clients.

Introduction

Genetic testing is used to establish the carrier status of a client. The way in which the information is provided prior to the test in addition to how the results are related to the patient and their family is important. It is recognised in the genetics competency standard statements for nurses and midwives that there will be difference in perspectives towards genetics due to ethnicity, culture and religion; these ought to be recognised throughout health care practice (Report to the Department of Health NHS Genetics Team 2003). In North American graduate programs, 97% of graduating genetic counsellors are women (Schoonveld et al. 2007); the vast majority of counsellors being women may affect the approach taken by the counsellor towards same sex and opposite sex patients. Data generated from a questionnaire-based study by Pirzadeh et al. (2007) indicated differences in personal values between people of different genders that may affect counselling practice.

Previous studies in a Finnish population showed that women have a more negative attitude towards genetic tests compared to men, (Toiviainen et al. 2003; Aula et al. 1996). There have been many studies that have specifically explored women's attitudes towards several areas of genetic testing; including carrier testing and cancer susceptibility testing (Ryan et al. 2003; Durfy et al. 1999; Lerman et al. 1994), but little is known of men's attitudes. A study by Miesfeldt et

al. (2000) did identify that 72% ($n=326$) of male respondents had an understanding of inherited risk and 89% indicated they would undergo hereditary prostate cancer testing if available. The study aims to identify a greater depth of men's attitudes. In a 2003 study, women were less likely than men to want personal genetic testing although people of different genders did not differ statistically when deciding on genetic decisions about possible children (Harman 2003). However in earlier studies, carrier tests (cystic fibrosis) and predispositional tests (neurofibromatosis type 2, familial adenomatous polyposis, von Hippel-Lindau disease) were more likely to be undertaken by women than men (Bekker et al. 1993 and Evans et al. 1997). A study in 2004 found that women report higher levels of stress and tend to report more chronic health problems and had lower levels of self-rated health (Denton et al. 2004). Higher stress levels and a greater level of perceived health problems could be a factor in influencing the decision to undergo a genetic test. It will be interesting to identify the reasons behind decisions regarding personal genetic testing, if there appear to be any.

This study aims to investigate some of the differences in risk perception between people of specific gender, including level of risk and the presentation of risk. It may be likely that the perception of risk varies between genders; this may be reflected in a client's understanding of the presented risk. Individual life situations and

personality characteristics may also play a role in risk perception. Numeracy has been linked to understanding the benefit of mammogram screening. Aggarwal et al. (2007) found that adequate numeracy was associated with an increased knowledge about breast cancer screening; however numeracy did not affect mammography screening rates; numeracy affects informed decision making. The 'conventional attitude theory' assumes that attitude is involved in risk perception and is a function of beliefs and values (Fishbein et al. 1975; Sjöberg 2000). Alternative theories state that risk perception is due to risk sensitivity, with some people viewing all risks as equal (Sjöberg 2000). When describing the practice of genetic counselling, Harper (2001) makes clear that both odds and percentages can be used to describe risk depending on the patient's preference. It has been shown that the understanding of numeracy is not linked to intelligence; numerical ability does affect judgements and decisions (Peters et al. 2006). It will be important to identify the way people perceive risk, which numerical representation is best understood and how this can be linked to understanding genetic risk.

This area of research was deemed novel and innervating at the start of the study. The specific area of gender differences towards genetic testing and genetic risk had not previously been widely studied in the UK. It was believed that it would be interesting to identify some of the differences in attitudes between males and females towards genetic testing that would allow a greater awareness of how information may need to be communicated to different genders, including specific areas of genetic testing. The area of research was also deemed to be extendable, as information gained on public perceptions towards genetic testing to identify differences between men and women's attitudes from this study could be built upon.

A questionnaire-based approach was used and included questions around scenarios including topics such as prenatal testing, testing in minors, specific disease testing and designer babies. Questions also focused on genetic risk and risk interpretation as well as respondents concerns surrounding genetic testing.

The aims of the project were as follows:

- To explore how males and females view genetic testing and what types of genetic testing they would be prepared to participate in.
- To provide an insight into the variability with which males and females may view

and perceive risk when risk is provided as both percentage and ratio and in relation to a range of diseases.

- To highlight any concerns held by respondents regarding the future uses of DNA and whether these views differ between males and females.

This paper is part of a wider study into attitudes towards genetic testing and focuses only on gender differences in attitudes towards genetic testing.

Materials and Methods

The study design was mainly quantitative with some aspects of qualitative input, it was a cross-sectional study with a non-experimental design. Questionnaires were distributed to known contacts amongst a convenience sample. Of the 140 respondents, 32.14% (n= 45) were males and 67.86% (n=95) were female. The sample had a mean age bracket of 25-34. 46.43% (n=65) of respondents were parents.

The questionnaire was distributed without any intentional bias towards religion, health, financial status or geographic location. The respondents were not asked about geographic location or profession. Twenty trial subjects were used to pilot the questionnaire and to enable appropriate improvements to be implemented. From the final sample 140 responses were received between October 2007 and December 2007 and no reminders were needed. Ethics for the project came under Swansea Universities' undergraduate program. This study was part of an undergraduate project within a BSC (hons) degree.

Questionnaire Design

The questionnaire was designed with the help of project supervisors and a qualified genetic counsellor, no previous questionnaires were consulted. The questionnaire comprised three sections measuring attitudes and responses to scenarios surrounding genetic testing and risk perception. Section one included scenarios inviting the respondents to make a connection with real life situations they may find themselves in. The four scenarios dealt with different areas within genetic testing. Subjects were asked to rate their responses in a four point 'Likert' like scale with an additional option for unsure.

- Scenario One: Prenatal testing following amniocentesis to evaluate how subjects might respond to the offer of genetic testing which could potentially lead to the decision to terminate a pregnancy.

- Scenario Two: Respondents considered whether they thought there were benefits to testing minors and whether they would want to find out the cystic fibrosis carrier status of their own child.
- Scenario Three: Pre-symptomatic testing for Huntington disease (HD). The respondents were informed that HD is a fatal hereditary disease that destroys neurons in areas of the brain involved in emotion, intellect and movement. Someone with HD has a 50% chance of passing the condition on to their children. Respondents were asked to consider if they would want to be tested for this condition and if a positive test would affect the way they lived their lives.
- Scenario Four: A real life situation involving a woman who intentionally created a deaf child using a friend's sperm (Savalescu 2002). Previous research identified that 2% of deaf participants would prefer to have deaf children (Middleton et al. 2001). Subjects were asked to decide whether they would want to select their own unborn child's genes.

Section two analysed risk perception and different mathematical representations of risk. Equal percentage and ratio risks were used in different questions to test whether subjects perceived ratios differently from percentages. Respondents were presented with a range of diseases varying in risk and clinical severity. The response to risk was either *high* or *low*. Examples of the questions in section two are as follows:

You are informed that your child has a 60% risk of having Down syndrome. Do you think this is a high or low risk?

High Low

You are informed that your child has a 60% risk of having colour blindness. Do you think this is a high or low risk?

High Low

You are informed that your child has a 3 in 5 risk of having Down syndrome. Do you think this is a high or low risk?

High Low

Section three identified respondents concerns regarding the use of genetic tests. Questions explored how the involvement of insurance companies and the storage of DNA

could affect their decision to undergo a genetic test.

In sections one and three, respondents were asked to explain their decisions and to describe how they felt about the scenario. Sociodemographic data included gender, age (in ranges), parental status and employment. Respondents were asked two closed questions at the start of the questionnaire regarding whether they agreed with human genetic testing and if they would participate in such tests.

Statistical analysis

Variables for each question were cross-tabulated between genders. The χ^2 (Chi-Squared) test and the Fishers exact tests were used. The software SPSS for Windows was used for all data analysis, with a p value of <0.05 being considered significant. A Log-linear test was conducted when comparing the answers to two questions along with a specific variable. This test is based on the ANOVA test and highlights an explicit dependence between the variables in the table. The natural log of the expected results were calculated and compared to the sum of the parameters (Hanson et al. 2000).

Results

The results presented are those questions where a significant difference was found between genders.

Section One: Scenario Two - Child Testing
Gender differences concerning the benefit of a cystic fibrosis carrier test for a 10 year old child (Appendix A, Section One, Question 4b). Respondents were asked if they thought a genetic carrier test for cystic fibrosis in a ten year old child was beneficial. A greater number of females than males gave a negative response to this question. (1) Interestingly 33.7% of all respondents were

Gender	Question Responses (%)					
	Strongly Agree	Agree	Disagree	Strongly Disagree	Unsure	Not completed
Male	6.6	42.2	26.6	4.4	20.0	0.0
Female	11.6	23.2	30.5	17.9	13.7	3.2

Table 1. Gender responses concerning carrier testing for cystic fibrosis for a 10 year old child (Appendix A, Section One, Question 4b). ($p = 0.050$, $\chi^2 = 9.390$, degrees of freedom (df) = 4).

unsure about carrier testing in a 10 year old. This was the highest response for unsure out of all question responses.

A female respondent commented “*that the status of the child being a carrier will only affect the child in adulthood and therefore it should be their decision to undergo the test*”. However one male respondent believed that “*a parent has the right to such information*”.

Section One: Scenario Three - Presymptomatic Testing

Gender differences concerning the effects on respondents lives if told they would develop Huntington disease (Appendix A, Section One, Question 5b).

Respondents were asked ‘if you knew you would eventually develop Huntington disease (HD), would this affect the way you live your life’? Women tended to think that it was **highly likely** or **likely** that their lives would be affected with the knowledge that they would develop HD. (Table 2)

Gender	Question Responses (%)				
	Highly Likely	Likely	Unlikely	Highly Unlikely	Unsure
Male	37.7	35.6	15.6	8.9	2.2
Female	51.6	35.8	8.4	0.0	4.2

Table 2. Gender responses’ concerning the effects on respondent’s lives if told they would develop Huntington disease (Appendix A, Section One, Question 5b). ($p = 0.025, \chi^2 = 11.426, df = 4$).

One female respondent who answered **highly likely** thought that “*knowing that you had HD would have a significant influence on life choice and decisions although it would make you question previous knowledge and live a self fulfilling prophecy*”. Another woman commented that this particular question made her change her view on genetic testing from “*I don’t agree with genetic testing, to being unsure*”. A male respondent who answered **unlikely** commented that “*the only reason I would want to know is to avoid passing it onto the next generation*”. A male who answered **likely** said he “*would want to get his insurance sorted out and live everyday as if it was his last*”.

Section One: Scenario Four - Case Study

Gender differences relating to whether respondents would want to alter their unborn child’s genes (Appendix A, Section One, Question 6c).

Respondents were given the real life case study concerning a deaf female in the USA creating a

deaf child using a deaf friend’s sperm (Savalescu, 2002). In this study participants were asked if they would want to alter their unborn child’s genes to benefit their personal preferences and lifestyle. (Table 3)

Gender	Question Responses (%)					
	Highly Likely	Likely	Unlikely	Highly Unlikely	Unsure	Not completed
Male	2.2	15.6	15.6	64.4	2.2	0.0
Female	6.3	2.1	9.5	75.8	3.2	3.2

Table 3. Gender responses concerning whether respondents would want to alter their unborn child’s genes (Appendix A, Section One, Question 6c). ($p = 0.025, \chi^2 = 11.087, df = 4$).

A male respondent who answered **likely** commented that “*a parent wants the best for their child and I don’t see any issues with natural selection to make a child more advantaged*”. A woman who answered **highly likely** responded that “*I would want to alter my child’s genes to benefit the child*”, whereas a woman who answered **highly unlikely** stated that “*genetic technology is being misused to create ‘designer babies’*”.

Section Two: Risk Perception

Gender differences in the risk perception of having a child who has a 60% risk of having Down syndrome (Appendix A, Section Two, Question 1).

Respondents were informed that their child has a 60% risk of having Down syndrome and asked whether they thought this was a high or low risk. All women considered the 60% risk that their child would have Down’s Syndrome as **high**. (Table 4)

Gender	Question Responses (%)	
	High risk	Low risk
Male	93.3	6.7
Female	100.0	0.0

Table 4. Gender risk perception responses to a 60% risk of having a Down syndrome child (Appendix A, Section Two, Question 1). ($p = 0.032, \chi^2 = 6.472, df = 1$).

Section Two: Numerical Representations of Disease

Percentage Differences in Risk Perception of Cystic Fibrosis between Genders when Risk is presented in Different Statistical Forms (Appendix A, Section two, Questions 2 and 8).

Gender differences were compared in the perception of risk when different numerical

representations were given for the same disease. Men and women were asked 'You discover that you are 25% likely to have cystic fibrosis. Do you think this is a high or low risk?' (2) and 'You discover that you have a 1 in 4 chance of having cystic fibrosis. Do you think this is a high or low risk?' (8) The log-linear test was used to analysis the data. (Table 5)

Gender	Question Responses (%)		
	Statistical Representation	High risk	Low risk
Male	Percentage	53.3	46.7
	Ratio	62.2	37.8
Female	Percentage	67.4	32.6
	Ratio	74.7	25.3

Table 5. Gender risk responses when a risk of cystic fibrosis is presented in different numerical form. ($P = 0.053$, $\chi^2 = 3.726$, $df = 1$).

Section Three: Insurance Concerns
Gender differences concerning the decision to undergo a genetic test knowing that the results would be sent to insurance companies (Appendix A, Section Three, Question 2).

Respondents were asked, 'if you knew that your results of a genetic test were going to be sent to your insurance company, would that affect your decision to undergo a genetic test?' The majority of respondents believed that information being sent to their insurance companies would influence their decision to take a genetic test. (Table 6)

Gender	Question Responses (%)					
	Highly Likely	Likely	Unlikely	Highly Unlikely	Unsure	Not completed
Male	48.9	28.9	17.8	2.2	2.2	0.0
Female	42.1	40.0	4.2	3.2	8.4	2.1

Table 6. Gender responses concerning the decision to undergo a genetic test knowing that the results would be sent to insurance companies (Appendix A, Section Three, Question 2). ($p = 0.048$, $\chi^2 = 9.741$, $df = 4$).

A woman who responded *likely* to the question commented that "test results should not be used for business profit" and she had a concern "it could lead to prejudice".

A male who answered *highly likely* said that it would affect his decision to undergo a genetic test because "it would disadvantage him or his family", whereas a male who answered *unlikely* had "no problem" with information going to his insurance company.

Discussion and Conclusion

This study identifies potential differences between genders relating to genetic testing, and has identified that men and women hold different views and values on certain issues. Gender differences were not significant in many question responses, this is important as it highlights areas of genetic testing where men and women think alike. However the significant differences observed relates to specific issues within genetic testing such as child testing. It was found in 1996 by unspecified non-governmental women's groups and feminist health researchers that access to health services and treatment by the health care authority differed in quality between genders (Gijsbers van Wijk et al. 1996). This could have a direct affect on responses between men and women as prior experiences of health care could influence their future decisions and decisions for their children.

In this study more females were against genetic carrier testing on children (48.4% of female compared with 31.0% of males answered disagree or strongly disagree). Borry et al. (2007) found that gender did not affect opinions about child genetic testing, including recessive, x-linked and carrier testing, however this study focused only on clinical geneticists. This is an area that needs careful consideration by both genders when considering carrier testing.

Interestingly 32.2% of parents stated that it was *Highly Unlikely* that they would undergo an Amniocentesis test with the knowledge of a 1% risk of miscarriage as opposed to 50.7% of non parents that answered *Likely*. Parental views and risk interpretation needs to be considered by healthcare professionals when undertaking genetic testing, including prenatal testing such as amniocentesis.

Another aspect of this study looked at whether gender influenced attitudes towards presymptomatic testing. The majority of women in this study believed that the way they lived their life would be affected if they knew they would eventually develop HD, however there was a mixture of responses from males. For some, the knowledge that they might develop this incurable disease can end uncertainty, for others this may cause anxiety as they wait for the disease to appear (Meiser and Dunn 2000). McPherson (2006) found that whilst some people find the test outcome useful for reproductive decision making and life-planning, for others, HD testing has led to suicide, depression, lack of commitment in relationships and job discrimination. Furthermore,

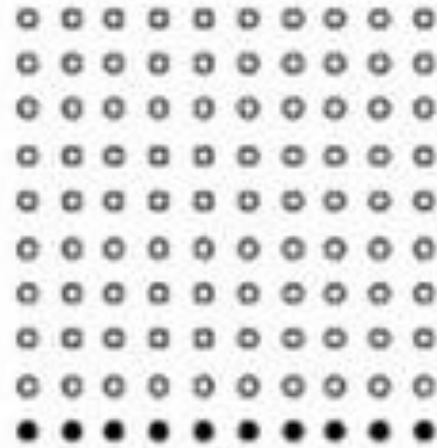
a study completed by Van der Steenstraten et al. (1994) found that non-participants of HD testing believed that the quality of their lives would decrease if the test had an unfavourable outcome compared to those who choose to take the test. However this result was not significant between genders. Based on research by Creighton et al. (2003) and Tassicker et al. (2009) the genetic testing uptake for HD by those offered a test following genetic counselling was 15-20% in Canada and 13-15.4% in Victoria, Australia respectively.

Harper's 2001 suggestion of using more than one approach for the communication of risk is supported by this study, and should be considered by all healthcare professionals including doctors, nurses and midwives. A study which looked at cancer risk communication between patients and physicians noted that a subject's perceived risk varied greatly between different numerical versions of risk (Gurmankin et al. 2004). A study by Abramsky and Fletcher (2002), looking at the interpretation of information, found that 90% of respondents (n=581) were worried by genetic jargon and 92% of respondents (n=581) found risk expressed as a ratio was more worrying than when it was presented as a percentage. However these results were not affected by the gender of the respondents (Abramsky and Fletcher 2002). Although in this study men appear less confident with numerical representations of risks, they gave different responses when presented with ratios and percentages of the same risk. Although not significant, a higher percentage of women gave different responses in a similar question (Section 2, Qu's 3 and 9). Together this data supports that healthcare workers need to use more than one method of communicating risk to all patients, especially to those who find it difficult to relate to different numerical representations. One example is the use of icon arrays which have improved the accuracy of understanding medical risk especially amongst the elderly and people with low numeracy skills (Galesic et al. 2009). One option could be for healthcare professionals to use icon arrays (Fig 1.) more frequently when communicating risk to clients.

In this study, genders were found to differ in their risk perception of Down syndrome. All female respondents believed a 60% risk of Down syndrome was high. Finucane et al. (2000) found that males judge risk lower than women, which is supported by the current study. Gustafson (1998) documented that differences in risk perception between genders arise due to gender structures, reflected in beliefs and practice.

A USA study (Lapham et al. 1996) identified 25% of respondents with a genetic disorder were refused life insurance and 22% were refused health insurance. In the UK there is a current agreement with the Association of British

Without screening



With screening

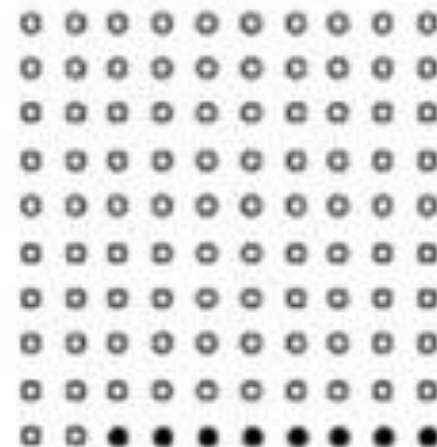


Fig 1. Icon Array – Black circles show people who will die of cancer – with and without screening (Galesic et al, 2009).

Insurers stating that genetic information cannot be used to calculate life insurance policies except those over £500,000 or critical illness policies over £300,000 (Mayor 2001; HM Government 2005). In this study, it was identified that clients, particularly females, may need to be informed of these insurance policies when they are considering genetic testing. d'Agincourt-Canning and Baird (2006) found that women felt obligated to share genetic information after a positive test even if

they were not comfortable sharing it, which could be linked to the findings of this study where female respondents were unsure about undergoing a genetic test knowing that this information might be shared. In general, the lack of assurance surrounding genetic testing and insurance reinforces Skirton and Patch's (2002) belief that 'dialog needs to continue between the involved parties to ensure that the potential limitations of genetic advances are fully discussed'.

Different genders have various views and values surrounding child testing, impact of tests on insurance and specific disease testing. Risk communication and statistical understanding can be variable between the genders and should be taken into account on an individual basis by healthcare professionals. Both genders were found to misunderstand risk representation, especially men. Icon arrays and awareness by healthcare professionals of this misunderstanding will be of benefit to patients. Females need to be strongly assured of insurance policies surrounding genetic testing, however this should be extended to males in individual situations. Healthcare professionals need to be aware of the differences between genders in their ideas surrounding degenerative disease testing, such as HD.

In the future this research could be extended to include patients undergoing or having undergone genetic testing. It would be beneficial to ascertain the attitudes of the above respondents towards genetic testing and what factors influenced their decision. It could also be of interest to obtain an understanding of the baseline genetic knowledge of participants.

This study could be extended by the use of a random sample instead of a convenience sample to provide a greater statistical representation of attitudes towards genetic testing. Using a convenience sample meant that most of the respondents were professionals and had a fairly high level of education, this could have affected the range of responses received. It is not known if any respondents in this study were at genetic risk, therefore they may not have truly thought about the issues in depth and been able to apply them to their own life. This study could be further developed if separate sample groups are approached for investigating risk perception. One group could be asked the ratio risk questions and the other the percentage risk questions. This approach would produce a greater difference in risk understanding and interpretation between males and females. An increased number of variables such as nationality, religion, education and health status could be used and compared in

an extended study to enhance the overall area of findings. This initial study has identified a number of interesting points that warrant discussion and further investigation in a larger sample size.

When seeing clients, healthcare professionals need to be aware of the gender differences in perceived effects of a disease on an individual's life, risk perception, understanding numerical risk and concerns surrounding insurance. It will be important to continue to gain public perspectives on genetic testing as such testing becomes more widely available. The advancement of direct to consumer testing will be an important future research initiative for other health care professionals who may become involved in offering testing. The issues of consent, confidentiality and consumer education will need to be explored in relation to public attitudes as "there isn't much regulation of these new services and we may be getting information that causes more harm than good" Professor Christopher Hood, 2009 (Nuffield Council on Bioethics 2009).

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