“To perpetuate blindness!”: attitudes of UK patients with inherited retinal disease towards genetic testing

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Abstract Availability and accuracy of genetic testing in ophthalmology has increased yet the benefits are unclear especially for those conditions where cure or treatments are limited. To explore attitudes to and patients’ understanding of possible advantages and disadvantages of genetic testing for inherited retinal disease, we undertook focus groups in three West Yorkshire towns in the UK. Most of our participants had retinitis pigmentosa and one of the focus groups consisted of participants from (British) Asian ethnic background. Here, we report only those attitudes which were common in all three focus groups. Some of the attitudes have already been reported in the literature. Novel findings include attitudes held towards informed choice and life planning, particularly among more severely affected participants. For example, participants appreciated that genetic testing increases informed choice and enables life planning, but these understandings tended to be in a specific sense: informed choice whether to have children and family planning in order to prevent illness recurrence. We conclude that even though these patients are not a homogeneous group, their attitudes tend to be underpinned by deep anxiety of passing their visual impairment onto their children. In this respect, they differ importantly from a small minority of the deaf who would prefer to have children with hearing loss, and from the more general population who do not believe that blindness is a “severe” enough disability to warrant avoiding having children.

Keywords Attitudes · Genetic testing · Inherited retinal disease · Patients’ perspectives · Qualitative research

Introduction

Inherited retinal disorders are a common cause of visual disability in all age groups. The most common among them, retinitis pigmentosa (RP), describes a group of retinal illnesses characterised by night vision difficulties, and peripheral visual field loss with pigment deposition in the retina. The condition usually affects both eyes equally and ranges in severity from no visual disturbance at all in some families to blindness at birth in others (Boughman and Caldwell 1982). RP can be an autosomal recessive, autosomal dominant or x-linked condition and despite different inheritance patterns, their vision mostly becomes significantly reduced at a later age in life. Those affected therefore usually undergo a prolonged asymptomatic or mildly symptomatic period, or might believe that their reduced vision is of non-genetic origin. During this period, those affected by inherited retinal disease might decide to have a family without realising that they and their children might be affected, or the degree of being affected cannot be clearly known. This has important consequences as for many inherited retinal disorders there are currently no available treatments.

Although inherited retinal disease is genetically heterogeneous, considerable progress has been made in identifying the genetic basis of disease. With the progress of molecular genetics increasingly more detailed, genotypes of these conditions are being identified, better predictive testing is becoming available and a more accurate estimation of future vision is possible (Pradhan et al. 2009). This has been followed by the start of gene therapy trials in animal models of human retinal degeneration and the early results of gene therapy for RPE65-mediated disease are encouraging (Simonelli et al. 2010; Le Meur et al. 2007; Hauswirth et al. 2008; Bainbridge et al. 2008). Stem cell

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therapy has also shown promise in animal models and clinical trials of stem cell therapy for inherited retinal disease are imminent (Tucker et al. 2011; Wong et al. 2011).

Medical professionals and those affected point out advantages offered by genetic tests for late on-set conditions with no treatments or cure, arguing that it gives those affected greater control over their lives and especially reproductive choices (Decruyenaere et al. 1993). Nevertheless, predictive genetic testing for late on-set conditions with no treatment or cure is subject to controversy. Parallels to inherited retinal disease can be drawn with Huntingdon disease (Mezer 2007), a paradigmatic condition for understanding attitudes towards such predictive tests (Decruyenaere et al. 1993; Taylor 2004). Research on this neurological disease points out that a significant proportion of those potentially affected refuse knowing whether they or their children carry a defective gene (Decruyenaere et al. 1993) but might feel morally obliged to undergo testing since the technology is available (Taylor 2004). Once known, distressing knowledge of one's genetic status cannot be taken back (Decruyenaere et al. 1993; Taylor 2004).

Some researchers on inherited retinal disorders argue that there might be little point for expensive and time-consuming testing in a situation when there is no treatment or cure available (Boughman and Caldwell 1982). Others point out that the same genetic configurations can result in substantially different phenotypes, and some of those affected will never fully develop RP despite their genetic diagnosis. In such cases, making genetic testing and counselling available to those who might never fully develop RP might cause unnecessary distress (Varajanant et al. 2008). Genetic tests are often difficult to interpret and this can again cause considerable anxiety and distress (Webster 2003; Boughman and Caldwell 1982).

Because of increasing availability and accuracy of genetic testing and since it might be difficult to strike a balance between advantages and disadvantages of genetic testing, it is therefore of the utmost importance to explore attitudes to and patients' understanding of possible advantages and disadvantages of genetic testing for inherited retinal disorders. So far, only a handful of studies have been conducted and none of them has been a qualitative in-depth exploration. Mezer's (2007) questionnaire study detected favourable attitudes towards predictive testing for RP, and the study of Furu et al. (1993) in this patient population established that two thirds of their respondents were in favour of genetic testing even though only one fifth would opt for abortion if the foetus was affected. To our knowledge, in line with overall lack of studies exploring the views of those who are affected by disabilities and/or genetic conditions in general (Raz 2005), there have been no studies on attitudes to genetic testing from the points of views of those affected by eye diseases in general, or those by retinal disease in particular, even though Taylor (2004) points out that lay and medical attitudes often differ considerably. The aims of the current study were

therefore to shed more light and fill the gap in existing knowledge; thus we conducted an inductive qualitative study in three focus groups among those affected with inherited retinal diseases, living in three different West Yorkshire towns in the UK, on their attitudes toward genetic testing.

Materials and methods

The data for this study was collected with the help of focus groups because this method enables observation of the constructions, expressions, defences, and modifications of particular attitudes (Wilkinson 2004) in a group context which most closely resembles real-life situations. In line with the explorative scope of the study, we decided to conduct three focus groups. Two focus groups were conducted among white British participants. One focus group consisted of participants of (British) Asian origin for whom genetic testing might be important in their marital and reproductive decisions (El-Hazmi 2006) and who might be marginally more affected by autosomal recessive genetic conditions due to a proportion of consanguineous marriages. As our participant population was mostly affected by the same condition (RP) and were of relatively homogeneous ethnic, religious and geographic origin, we decided to conduct one focus group in each of three West Yorkshire towns.

After obtaining ethical approval from University of Leeds, we used our pre-existing contacts with members of relevant local charities, and those at local centres for the visually impaired in the three towns to introduce our study to potential participants and help in recruitment. We sent participant information sheets, consent forms, and our contact details to the RP group leaders to be disseminated to those potentially interested in participation. In this way, those interested in participation were able to obtain more information about the study. Leaders of the groups and potential participants suggested dates (instead of their regular meetings) for conducting a focus group, and only those interested to participate were invited to come. Our sampling strategy was therefore opportunistic and driven by convenience (Silverstein et al. 2006; Onwuegbuzie and Leech 2005). All participants had been told by their ophthalmologist that their condition was genetic, and some reported receiving genetic counselling, but it was not possible to sample systematically on this basis. Before starting a particular focused discussion, we again allowed for time to give yet another opportunity to the potential participants to ask any remaining questions.

After obtaining signed consent forms from all the participants, we conducted focus groups which lasted approximately 60–100 min. All three focus groups were conducted and observed by the same researchers (BP and MM, respectively) following the same topic guide. The participants were invited to talk about their understandings of genetic diseases and genetic tests; advantages and disadvantages of genetic testing; about the ways they manage genetic risk and how and to whom

they disclose it, and the ways in which their condition impacts on their daily lives. The discussions were digitally audio-recorded. The recordings were later transcribed verbatim by the researcher and managed with the assistance of NVivo8.

We analysed the data using a thematic approach (Hoffe and Yardley 2004; Boyatzis 1998) which is commonly used in this type of research (Kasparian et al. 2006; Douglas et al. 2009). Analysis was undertaken using constant comparison and contrastive approach to identify common themes. To ensure consistency, two researchers read for the emerging themes independently, coded the data, and compared codes and coded themes. Looking for negative cases further refined the understanding and relationships between and within the themes. Findings were discussed and agreed by everybody in the research team.

Results

Sample characteristics

Three focus groups consisting of five people per group were conducted in three West Yorkshire cities (Table 1). Two groups consisted of participants of only white British origin and even though four of them indicated that they were of white, but not British origin, this should most probably be ascribed to their reduced vision—they circled the first item on the demographic sheet which they believed applied to them (white) and did not proceed to the next item (white British). However, in the focus group discussions nobody indicated that they were of white, but non-British origin. One group was conducted among ethnic minority participants of (British) Asian origin. Most of the participants were Christians or Muslims. A vast majority of participants had RP (including one participant who had RP as a symptom of another genetic disease), one participant had macular dystrophy (loss of central vision due to damage of retina), two had unclear diagnosis and one was included as he was enthusiastic to participate even though this person suffered from congenital cataracts (clouding of eye lens). Participants were predominantly male, married and considered themselves as severely visually impaired. The participants in our sample were atypical since they were relatively well educated as more than half had GCSE levels or more, but most were retired and no longer in active employment. The age range of participants was between 32 and 68 years.

Common themes

Data analysis identified several attitudes, both positive and negative, which were common to all three groups despite their socio-demographic differences. In all the following excerpts, we use pseudonyms for the participants and all discussions are continuous.

Table 1 Participants' characteristics

Diagnosis	Retinitis pigmentosa	11
	Macular dystrophy	1
	Unclear	2
	Congenital cataracts	1
Gender	Male	10
	Female	5
Marital status	Single	5
	Married	6
	Divorced/separated	3
	Widowed	1
Sight status	Sight impaired	4
	Severely sight impaired	11
Educational level	Secondary	7
	College/diploma	5
	University	1
	Postgraduate degree	2
Occupation	Skilled manual	1
	Clerical	2
	Professional	4
	Retired	7
	Unable to work	1
Religion	Christian	9
	Muslim	4
	No religious beliefs	1
	Other: agnostic	1
Ethnic origin	White	4
	White British	6
	Asian	2
	Asian British	3
Age range	32–68	
Average age	52.53	

Being that type of person

In all three focus groups, the participants agreed that some people just want to know their diagnosis and what they are facing. Such people will always want a diagnostic or predictive testing regardless of potential cure, anticipated distress or bleak diagnosis. Illustrative statements:

Barry: I'd myself, I'd... yeah, I'd have always wanted to know (his genetic diagnosis), even from the early start, I'd have wanted to know...

Karen: My brother's just like that. He's like, yeah... He'd want to know. He wants to get everything, like you say... not hiding the life under carpet, but he wants to be sorted...

(Focus group 2).

Genetic connection is confusing if there are no other affected family members

Only a few participants knew their inheritance patterns while some were not even certain that their condition was inherited because they pointed out that they had no other affected relatives. Even though the participants were clear that RP is a genetic condition, they were still uncertain how predictive or diagnostic testing would benefit them or their children because they were unclear what the genetic connection was. Such a view might be due to the lack of adequate genetic counseling, but it is also congruent with the argument of Richards (1993) who contends that when lay understanding of genetics (of recessive conditions) is at odds with a scientific one, lay understanding has a central role.

Keith: What's confusing here as well is that people like Judy and Margaret is family related (their RP) whereas they told me back that myself and Judy, we are without... there is no link. It's just... We are an odd leap in there. There is no one in my background—going as back as we could—with this condition. No one in the future got to... I'm a middle child... there is no... (...) My brother and my sister, their kids, no problems.
(Focus group 1).

In both British groups, some could not determine a genetic connection because there were not enough family members, or information on their eyesight to establish it. The following excerpt which mentions both “bad eyesight” and “night blindness” however demonstrates that the participants were generally able to differentiate between impaired eyesight which could be attributed to older age or a condition, other than genetic disease, and symptoms which very likely resulted from their genetic condition:

Barry: The problem I have because my mum's parents... they were dead when my mum was young, they were dead when my mum went to school, so I have no history of my grandparents how they were like. My mum's father was a big businessman and that. I have no history of their medical health. My mum had no eyesight problems. On my father's side, I don't know. You know, I've said this before. His father and his brothers had bad eyesight, night blindness, so I have and my granddad did. So, I'm presuming that my dad had been a carrier because my dad had no problems with his eyesight. And my mum's completely clear.
(Focus group 1).

However, in the discussion within the British Asian group, one of the participants pointed out that diagnostic testing was

beneficial because it could persuade the relatives that the condition is indeed genetic:

Aisha: I... I'd share with my family (genetic diagnosis) because I know in the past when we've had conversation it might be genetic, it's like, no, it can't be because, you know, three out of five (children) are fine, it's just two, it can't be, it's just one of those things, you know... to have something concrete, to say, look it is, they might take more notice.
(Focus group 3).

Treatment options and cure

The decision of whether to undergo a genetic test for diagnostic or predictive reasons was strongly related to whether there was a treatment or cure available. For example, talking about the reasons for genetic testing, two participants commented:

Iqbal: I think it's also how you can treat... the certain disorder. To find a cure for it. And... if... if somebody does have it, there're means and ways of curing that disease, overcoming that disease.
Imran: Yeah, I think that's... pretty much it, isn't it. It's going to be two things, obviously...
(Focus group 3).

A negative opinion going against genetic testing, i.e. that there might not be any point in genetic testing since nothing can be done, was a flipside of the positive opinion that genetic testing, both predictive and diagnostic, is valuable if a treatment or cure is available. This negative opinion was also shared by all three groups. In one particular focus group, we also detected misunderstanding of genetic testing as some of the participants considered electroretinography (ERG), examination of electrical responses of the different types of cell in the retina, as an integral part of the genetic test:

Margaret: I'll tell you something, years back when I was diagnosed along with my daughter, they already had two children and one was only a baby, and the other one would be... about two. We went through an ERG. There was no shadow of a doubt that both had RP... We went to see a registrar and he said he wanted the children tested. But we already knew from speaking to a geneticist that there was no cure. Now, those two babies had just had the tests and they're not pleasant, having electrodes attached while sitting still. And my daughter made that choice at that moment at time, she said no. She didn't want them do it on the children.
(Focus group 1).

Having informed choice

Participants in all three groups noted the importance of having informed choice as a significant advantage provided by genetic testing.

Judy: And it comes down to choice. I mean, if you're a young couple and you think, you want a family I think you should be given that choice

Margaret: But I found the hardest thing when I was first diagnosed... there were no decisions for me to make (whether to have children or not as she had already had (grand)children). My daughter already had her children and that was the hardest thing to bear... the hardest thing to bear, to know that my daughter was also being diagnosed at the same time. And perhaps that my grandchildren might have it. And now I know my grandchildren have it. And that was harder than talking about it myself. You know.

Others agreeing.

Margaret: I had 6 months of hell, anger, despair (after being diagnosed)... It's an awful feeling that I hadn't got that choice. I think yes, genetic testing and research and everything that goes with it is so important. That we're informed.

(Focus group 1).

Life planning

All three groups agreed on the importance of genetic diagnosis for planning the future with impaired or no eyesight and three participants offered practical examples of planning. One wished that he had known his diagnosis earlier so his wife could learn to drive, and another one stated that he would not have become a professional driver with his diagnosis, had he known his prospects.

A participant in the British Asian focus group gave another example of actual planning:

Imran: I suppose in a way, what I've done is I try to do whatever I've kind of desired to want to do in case... my sight... did go. And I was able to do it, do those things with sight. Not to say that I couldn't do them without sight but I wanted to do them whilst I still had sight.

(Focus group 3).

However, the same participant found the question of how to plan for disability ultimately ridiculous:

Imran: I don't think you can PLAN (sarcastically) for your sight getting worse.

Abdul Ghafoor: Not really, no ...

(Focus group 3).

Thus, in all three groups, only three participants could explain how they planned for their future disability and one of them recognised that it is ultimately impossible. There is therefore an apparent disparity between declarations and practical solutions to address future disability. An explanation for this gap was offered by one of the participants in the (British) Asian focus group in which it was evident that planning was understood in a very specific sense, as family planning:

Ibrahim: When we said planning, I thought we're thinking of long-term planning. Particularly around genetic testing, I mean, I was thinking around, particularly the time I mentioned, when you have issues are you going to have children, whether they'll be affected. That's where I was at really when you asked that question. And... I said... those are the questions that crop up. And those are the questions that you sort of respond to. And those are issues that you try and deal with and respond to. And you try and think about and you think, ok, I've got a genetic condition, do I really want children with the same mine condition?

(Focus group 3).

Prevention of occurrence

As previous excerpts indicate, the idea of having informed choice tended to be understood in the specific sense of having informed choice when deciding whether to have children, or making informed choice in family planning. This theme is closely related to the attitude, shared by all three groups, that genetic testing offers a possibility of prevention of occurrence. In all three groups, they understood prevention only in one sense, prevention of having potentially affected children. Here, Grace uses genetic counselling and diagnosis as synonyms when discussing the potential of genetic testing for prevention of occurrence in the future generations:

Grace: I think the thing... that... I'm hoping with genetic... counselling or whatever is it... we'll get better understanding of what's possible and what isn't. And also... perhaps... a way... of preventing... other people having the same difficulties... like... in my case, I wasn't aware that I could pass it on... to my children. Ehm... if people had that... ehm... if we could actually... prevent it from being... occurring in the next generation we could stop it from happening.

(Focus group 2).

In the cases where participants chose not to have children to prevent occurrence in future generations, contraceptive means were used. However, it is very important to note that not all individual participants avoided having children because of their condition. In fact, some participants had

children despite wanting genetic testing and finding out their diagnosis. The reasons offered were disability not being “bad” enough, good quality of life and support they enjoyed and individual (or partner’s) wish to have children. Nevertheless, in her focus group, Grace was the only one who appeared to be severely visually impaired as she came with her guide dog and with assistance. Also, there was a substantial number of participants in all three groups who experienced their disability as so impairing as not to want to pass it onto their children. One of the focus groups spontaneously started comparing blind with deaf communities:

Judy: And how’s ... I mean, I know we’re talking about the blind community now, but in a DEAF (person’s own emphasis) community, some deaf couples are actually disappointed when they have an able bodied ... child.

William: I believe that’s right.

Paul: I think the majority are.

Judy: Yes. Because then ...

Margaret: Do they?

Judy: Oh, yes! It’s well known down at the deaf centre. So some of them would choose to have a deaf baby! (with an incredulous voice)

Moderator: Actually, a few years ago a couple chose to have a deaf baby.

Margaret: Can’t understand that!

Judy: I’ve never heard of anybody in our blind community talk like that.

Paul: To perpetuate blindness! I don’t know anybody in the blind community who’d want to do that.

(Focus group 1)

Discussion

The participants of three focus groups, conducted in three West Yorkshire towns in UK expressed a number of common attitudes towards genetic testing which cross ethnic and religious boundaries. The participants believed some people will always opt for predictive and/or diagnostic testing just because of the type of person they were—one who always wanted to know where they stood. This opinion has also been encountered elsewhere (Taylor 2004). This is in line with studies arguing that affected individuals opt for genetic testing for reasons of knowledge and certainty (which is an integral part of their perceived personal control) (Berkenstadt et al. 1999; McAllister et al. 2011a, b; Payne et al. 2007). The flipside of this opinion was that some people might prefer not to know. An explanation for this is offered by Richards (1993) who argues that some people might not want to know their genetic status because as long as they are not definitely diagnosed as affected, they can continue to hope that they do

not have affected gene. There was also uncertainty about the appropriateness of genetic testing as some participants, particularly those in the group of British Asians, wondered whether their condition is genetic since none of their relatives in their living memory had it. In such cases, both diagnostic, predictive genetic testing and genetic counselling might be welcome to ascertain that the condition is congenital and not acquired.

The participants in all three groups expressed opinions that if there was treatment and cure available, those (potentially) affected might much more readily opt for genetic testing. But if nothing can be done, genetic testing might be irrelevant. In this respect, our study is in agreement with Mezer’s (2007) but as some other studies—including ours (Mezer and Wygnanski-Jaffe 2009; Bong et al. 2010) offer additional dimension of understanding. Many of the participants in our study believed that diagnostic and/or predictive testing is valuable even in the absence of treatment or cure because the affected could creatively imagine ways of how it could lead to potential treatments and cure, or make these available quicker. Our research therefore suggests that individuals might often opt for genetic testing even when there is no treatment or cure. It has already been argued that altruism is an important motivating factor for participation in genetic research (Basson et al. 2007). Our findings indicate that this may also apply to genetic testing more broadly.

We also detected several attitudes towards genetic testing which have never been reported in this patient population. At first glance, our participants echoed those affected by Huntington’s disease who appreciated genetic tests as a ground for their decisions about planning their future (Taylor 2004; Decruyenaere et al. 2007). However, when asked for practical examples of planning for visual disability, our participants could recall only a very limited number of practical examples, and found such a notion “ridiculous”. One way in which our study differed from those conducted among patients potentially affected by Huntington’s disease concerned the level of abstraction required of participants; we requested specific examples of planning, whereas others might have only asked for theoretical possibilities. Similarly, the participants appreciated the possibility of informed choice offered by genetic testing, but they comprehended this concept in a very specific sense, as making informed choices whether to have potentially affected children. Indeed, closely related was the opinion that the most important advantage of genetic testing was prevention of occurrence by not having children. Such an opinion was also found among those affected by Huntington’s disease (Decruyenaere et al. 2007).

This narrow focus of interpretation seems to be underpinned by a deep anxiety of many affected with inherited retinal diseases to pass their disability onto their children. It is important to note that not everybody shared this deep preoccupation. In one of the focus groups, several participants mentioned that they did not feel disabled to the degree to try

to avoid having children. The degree to which the individuals are affected might therefore importantly influence the attitudes to genetic testing and readiness to have children. Furthermore, some participants expressed the opinion that their good quality of life and tolerant and supportive social environment did not warrant avoiding having children, whereas in another group, an occasionally intolerant environment was mentioned as an important negative, but not a decisive consideration. This attitude is therefore, to a degree, in line with the arguments of disability rights campaigners who contend that negative life experiences and problems of the disabled are of social rather than biological nature (Morris 1996; Ward 2002).

Our research offers several new insights into attitudes towards genetic testing for inherited retinal diseases. Our findings may resolve the apparent paradox encountered by Mezer (2007; Mezer and Wygnanski-Jaffe 2009), the majority of whose participants were in favour of prenatal testing for their children yet did not contemplate termination of potentially affected foetuses. Our research points out that the implicit assumption about having a prenatal test in order to terminate pregnancy if the foetus is affected, implied in several other studies (Mezer et al. 2007; Furu et al. 1993; Mezer and Wygnanski-Jaffe 2009) might be spurious. This is because many participants in our study were in favour of genetic testing but were against the termination of affected pregnancies. As most of our participants were aware that their condition was most probably genetic, those who did not want to pass it onto their children preferred less radical measures, such as (permanent) contraception rather than opt for termination of pregnancy.

The preference for not having children in order to stop occurrence of inherited retinal conditions is in line with Huntington's disease paradigm on late on-set diseases with no treatment and cure—those affected with this genetic condition also did not want to perpetuate it by having children (Mezer et al. 2007). However, our research importantly points out that this is only applicable for a part of this patient population. Opinions of those with a lower level of experienced disability differed in regards to whether one should avoid having children in order to avoid occurrence. Those in this participant population who (still) do not experience difficulties with their disability and enjoy a high level of societal support might differ importantly in their attitudes to genetic testing.

Their attitudes remain in stark contrast with a small minority of people with congenital hearing impairments (Martinez et al. 2003) who might be opposed to genetic testing because they do not see deafness as a disability to be eradicated but as something that situates them in their own culture with its own language, customs, practices and beliefs (Arnos et al. 1991). The attitudes of those affected by inherited retinal disease are also in stark contrast with those of the general population—white and Pakistani women who have recently had a healthy

child—a vast majority of who did not find blindness “serious” enough to justify termination of pregnancy (Hewison et al. 2007). In contrast, most of our participants were concerned about passing their visual disability onto their offspring, and opted for not having any children by using (permanent) contraception. Our findings therefore point out that the attitudes held by this patient population are very complex. More detailed research is needed to investigate which attitudes can be explained by several already existing theoretical models on attitudes to genetic testing and counselling and which attitudes require new theoretical perspectives.

Limitations of the study

This exploratory study was based on three focus groups, and as such, can only identify some issues experienced by those affected by inherited eye diseases rather than give definite answers. The participants with RP are over-represented in our sample. Furthermore, as the participants were recruited with help of local RP societies, they are a specific category of patients—they are active members who are relatively well informed and proactive when addressing their condition. Further studies conducted on a greater number of participants and more general profile of this patient population are therefore necessary to draw more general conclusions.

An important aspect of such future studies should be the patterns of inheritance. In our study, several participants mentioned that they did not have children because the odds of having an affected child were too high, but said they might have taken the risk had it been lower. The age of when people get diagnosed—whether they are still young enough to consider having a family or in middle age when they have already made their reproductive choices, and whether they already have a potential partner to have children with and partner's vision status, all influence how people think about genetic testing. Our participants had not undergone a genetic test and therefore might be considered to have discussed the issues around testing from a theoretical and abstract position. Their responses may have been very different had they actually experienced the genetic test. Finally, another factor which should be taken into consideration in future studies, is the outcome of the voluntary moratorium, accepted by the insurance companies in UK, on considering genetic diagnoses in calculating insurance premiums. Once the genetic diagnoses become an important parameter for determining insurance premiums, the attitudes of those affected might also change considerably.

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