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# Concerns about Genetic Discrimination after Regulation: A Qualitative Study of the Situation Regarding BRCA and Huntington's Disease in Belgium

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**Abstract:** Although there is no unequivocal evidence of genetic discrimination (GD), and despite laws that prohibit it, individuals confronted with genetic diseases still seem to be concerned. The aim of this study was to gain in-depth understanding of experiences and concerns in relation to possible genetic discrimination. This article presents an analysis of semi-structured interviews with 42 individuals who had or were at risk of breast and ovarian cancer (BRCA) or Huntington's disease (HD) in Belgium. Even after regulation, individuals at risk of BRCA and HD express concerns about possible genetic discrimination. These concerns relate to direct forms of GD, for instance those related to insurance and employment. Individuals were often unclear about and wary of legislation. Importantly, concerns were also expressed as to more subtle and indirect forms of GD, e.g., in social relations, where individuals fear being treated 'differently' and unfairly. Our study demonstrates how these concerns emerge at particular moments in life and how levels and forms of concern are influenced by the specific genetic disorder. Worries concerning these more subtle forms of genetic discrimination are more difficult to protect by law. Current legislative efforts do not appear to be effective in alleviating concerns about genetic discrimination. These regulations seem to be unclear, some participants are unsure about their effectiveness and they do not succeed in incorporating all forms of genetic discrimination. Particularly challenging is how to address indirect forms of genetic discrimination.

**Keywords:** genetic discrimination; concerns; BRCA; Huntington's disease; living with genetic risk; stigma; regulation; qualitative research; Europe

## 1. Introduction

Genetic discrimination, defined as 'discrimination directed against an individual or family based solely on an apparent or perceived genetic variation from the "normal" human genotype' (Billings et al. 1992; Natowicz et al. 1992) has been one of the main ELSI issues addressed in the Human Genome Project. An often cited example of genetic discrimination is that insurance companies refuse to insure individuals at risk<sup>1</sup> of a genetic disease. Since the 1990s, several Western countries have reacted to fears of genetic discrimination by enacting legislation aiming

<sup>1</sup> For this article, the use of 'individuals at risk of a certain genetic disorder' refers to individuals who have not undertaken genetic testing for a particular genetic disorder and are at risk because of their family history of disease, as well as individuals who have received a positive genetic test result. If it is necessary to point to a difference between these two groups, it will be explicitly mentioned.

to prohibit genetic discrimination in various contexts, mostly in relation to insurance and employment (Otlowski et al. 2012; Van Hoyweghen 2014; De Paor 2017). These regulations vary between specific national contexts<sup>2</sup>, but overall two legal–political principles can be identified (Lemke 2013; Van Hoyweghen 2014). The first principle focuses on ‘genetic privacy’, or the idea that individuals should control their own genetic information and that this information can only be passed on with explicit consent. The second regulatory principle is a ‘non-discrimination approach’ which focusses on preventing the use of genetic information. In addition to national legislation, international bodies have also produced soft law (e.g., The Universal Declaration on the Human Genome and Human Rights; The International Declaration on Human Genetic Data; European Convention on Human Rights and Biomedicine of the European Council) (De Paor 2017). Although international regulations are not binding, they do set the stage for nation states.

Research on genetic discrimination in life insurance has shown little unequivocal evidence for genetic discrimination (Joly et al. 2013). In addition, it is argued that complaints about genetic discrimination often prove to be exaggerated (Nowlan 2002; Wertz 2002; Nowlan 2003), and what is described as evidence is often merely anecdotal (Anderlik and Rothstein 2001; Nowlan 2002). However, notwithstanding the lack of evidence of genetic discrimination, and despite the regulatory efforts to prohibit genetic discrimination, a recent systematic literature review has shown that considerable levels of concern about genetic discrimination are still present (Wauters and Van Hoyweghen 2016). Only few studies have provided in-depth understanding of concerns relating to genetic discrimination (Bombard et al. 2008; Klitzman 2010; Geelen et al. 2012; Lemke 2013). These studies have shown how concerns about genetic discrimination may have severe consequences, such as not undergoing genetic testing. Furthermore, they have provided some insight into the backgrounds to these worries. Concerns about genetic discrimination seem to be influenced by the specific genetic disorder of which participants are at risk. For example, it has been suggested that a lack of treatment options as well as stigma surrounding the disease increase concerns about discrimination. The systematic review has also shown how the current body of studies tends to focus on concerns relating to direct forms of genetic discrimination by organizational actors, such as insurers or employers. This form of genetic discrimination entails all discrimination that confront individuals with direct disadvantages, such as not being hired because of a positive genetic test result. By exclusively focusing on (concerns for) direct genetic discrimination, research and discussions on genetic discrimination have disregarded more spontaneous and indirect forms of discrimination such as stigmatization or prejudices in for example social relationships. Indirect genetic discrimination is discrimination that is often very subtle and difficult to prove but that reduces chances and opportunities to individuals with a positive genetic test result or a family history of genetic illness (Lemke 2009).

The aim of this article is to gain an in-depth understanding of concerns and fears of genetic discrimination relating to two genetic disorders in Belgium: Hereditary breast and ovarian cancer (BRCA) and Huntington’s disease (HD). Belgium was one of the first countries to enact legislation prohibiting genetic discrimination in the insurance context (Law on terrestrial insurance contracts of 1992). To study concerns about genetic discrimination, we have looked at everyday life experiences of individuals with or at risk of BRCA and Huntington’s disease. Drawing on findings from in-depth semi-structured interviews, this article contributes to the current understanding of concerns about genetic discrimination by discussing the contexts in which participants express concern about genetic discrimination as well as seeking to understand how these concerns persist despite regulation.

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<sup>2</sup> For example, in the life insurance context six different approaches have been identified: (1) Fair limits approach; (2) human rights approach; (3) prohibitive approach; (4) moratorium approach; (5) rational discrimination approach; (6) status quo (Joly et al. 2010).

## 2. Materials and Methods

As indicated in the systematic literature review ([Wauters and Van Hoyweghen 2016](#)) as well as in [Klitzman \(2010\)](#) study on experiences and concerns of genetic discrimination, disease characteristics (prevalence, treatability and associated stigma) may influence experiences of, as well as concerns to, genetic discrimination. For this reason, we have selected two genetic disorders (hereditary breast and ovarian cancer, more specifically BRCA, and Huntington's disease) that differ significantly in terms of the level of disease risk that is associated with being a mutation carrier, the kind of symptoms, the availability of preventive measures and treatment options, as well as societal awareness on the disease. A mutation in one of the BRCA genes indicates a highly increased risk of various cancers, primarily breast, ovarian and prostate cancer ([Armstrong et al. 2003](#))<sup>3</sup>. Several preventive options exist when a person is found to have a mutation in a BRCA1 or BRCA2 gene (e.g., a preventive mastectomy or oophorectomy), and different treatments are available for the cancer itself. Huntington's disease (HD) is a severe degenerative neurological disease ([Maxted et al. 2014](#)). A mutation in the Huntington's gene will lead to illness. The average age of onset is 30–50 years old ([Kessler 1993](#)). No preventive or treatment options are available, except for some measures that can temporarily suppress or reduce certain symptoms. Both genetic disorders have an autosomal dominant pattern of inheritance which means that each child of a mutation carrier also has a 1 in 2 risk of carrying the mutation.

The interviews were semi-structured and addressed comparable topics for all participants, but were open enough to go into depth. In research on genetic discrimination it is important to ask about different experiences, attitudes and visions regarding genetics (positive, negative as well as neutral experiences) ([Treloar et al. 2004](#)), as well as about the strategies that individuals at risk use to cope with negative treatment ([Lemke 2009](#)). Our topic list consisted of themes that addressed questions on: participants' characteristics (e.g., family situation, education, job), living with/awareness of a family history of a genetic disorder, the process of (not) agreeing to genetic testing, coping with the test result, social implications of the test result, genetic responsibilities and communicating about genetic risk. We also asked specific questions on experiences and concerns of genetic discrimination, stigmatization and prejudice. [Bombard et al. \(2008\)](#) indicated in their study on genetic discrimination that using the term 'discrimination' might create bias. They suggest to talk about 'differential treatment' so participants would not be directed to rather negative perceptions. We have followed this methodological approach. Indicative questions were: What went through your mind after getting a positive genetic test result? Did you have any concerns? What do you consider to be an advantage of knowing that you carry this mutation? What do you consider to be a disadvantage of knowing that you carry this mutation?

For both diseases, we aimed to recruit individuals via purposeful sampling, more specifically aiming to have a varied sample ([Savin-Baden and Major 2013](#)), considering the following characteristics: gender, age, family situation, stage of the testing process (not tested, tested a while ago, tested very recently) as well as whether the participant was asymptomatic or symptomatic. Interviewees were recruited through patient group membership (BRCA.be and the 'Huntington Liga'). The major benefit of this recruitment strategy is the larger variation among members: patient group members may be asymptomatic or symptomatic as well as being at different stages of the testing process, whereas in genetic centers, potential participants are merely at the same stage of the testing process ([Lemke 2013](#)). Furthermore, individuals recruited in genetic centers might be confronted with a clinical point of view and have at least already considered the option of genetic testing. A potential disadvantage of recruitment through patient group is self-selection or recruiting exclusively or merely 'engaged individuals'. However, patient groups come in various forms and can have different objectives and

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<sup>3</sup> Female BRCA mutation carriers have a 50 to 80% risk of breast cancer and a 10 to 40% risk of ovarian cancer. Men with a positive test result for BRCA1 or BRCA2 also have a higher chance of getting cancer in the future, but the risks are less significant ([Shiovitz and Korde 2015](#)).

members (Epstein 2008). It is important to note that in Belgium, these patient groups are called ‘self-help groups’, with the specific aim of providing social support to members and improve the living situation of individuals with a shared problem or disease (Gielen et al. 2012). These ‘self-help groups’ differ in their objectives from ‘patient groups’ where the latter are more directed to lobbying and thus can be expected to have more ‘engaged individuals’ (Rabeharisoa and Callon 2002). In self-help groups, like BRCA.be and the Huntington Liga, however, individuals gather around the same disease for psychosocial support, thus representing a broader variation of individuals. With the help of these patient groups we have aimed at recruiting a varied group of individuals. A written invitation was distributed at the yearly BRCA congress in 2015, through publication in the patient group’s journal, announcement on the Facebook page and/or mailing newsletter of the patient group). We have drafted the invitation letter with great caution to not influence participant’s view nor to exclusively attract individuals with concerns or experiences of genetic discrimination by introducing our study as ‘the lived experiences of being at risk for cancer or Huntington’s disease’, while mentioning that part of the interview would deal with the views on genetic discrimination.

Each participant contacted the interviewer (first author) on his/her own initiative, and the interviews were conducted in person (by the first author) at a time and place chosen by the respondent. In this way we could ensure that interviewees could speak freely. Furthermore, we have repeatedly ensured participants that interviews would be anonymized. The interviews lasted between 20 minutes and three hours and were conducted in two stages (stage 1: BRCA 28 interviews November 2015–April 2016; stage 2: HD 14 interviews November 2016–March 2017). In addition, the interviewer wrote field notes to capture potential important information. The interviews were recorded digitally and then transcribed verbatim. For the data analysis we draw on aspects of Charmaz’ grounded theory approach (Charmaz 2006). We started the analysis after having conducted a few interviews which enabled us to constantly adjust the topic list and select participants according to the first findings. Through memo writing ideas that came up during the analyses process were captured. The interviews were inductively coded by the first author and the latter coding phases were performed by both authors. The first open coding phase resulted in several interesting insights, such as the stigma that was present in families with Huntington’s disease or the concerns regarding reimbursement of breast reconstructions expressed by BRCA participants. In the next coding phases themes, categories and patterns were further refined in the story lines, by iteratively comparing and reviewing the data (Bernard and Ryan 2010; Savin-Baden and Major 2013). Throughout the analyses we have been looking at relevant theories and frameworks from studies on living with genetic risk in general and more specifically genetic discrimination. The process of analysis was facilitated by using Nvivo<sup>4</sup>.

Table 1 provides an overview of characteristics of participants. Firstly, for BRCA, we have conducted semi-structured interviews with 24 women and four men. Eight of them have (had) cancer. Twenty-seven participants underwent genetic testing for BRCA1 or BRCA2 and the testing turned out to be positive for 26 of them and negative for one participant. Secondly, the HD group consisted of 11 women and three men. Ten out of 14 participants chose to do a genetic test. Nine of these ten HD participants tested positive while one individual did not have a mutation in the Huntington’s gene. Two individuals who participated in our study were diagnosed with HD. They were in the first stages of the disease but one of them had speech difficulties and wanted his wife next to him during the interview. As indicated before, we aimed at recruiting a varied group of participants but it appeared very challenging to have equality on all characteristics. For example, for BRCA we had only one individual who did not undergo genetic testing. In addition, with regard to gender, we see that gender equality could not be reached which is in line with similar research on genetic discrimination (Bombard et al. 2008; Erwin et al. 2010). This might be related to our recruitment process, since research has shown that

<sup>4</sup> All participants signed a written informed consent. A few days after the interview, the first author contacted the participants again to respond to any additional questions or concerns. All interviews were anonymised. The study was approved by the Social-Medical Ethical Commission (SMEC) of the KU Leuven (File number G-2015 09 350).

women often appear to be more engaged in genetic testing (Kenen et al. 2004; Richards 1998) and in addition more likely to join a patient group than men (Treloar et al. 2004).

**Table 1.** Characteristics of participants.

	BRCA1/2	HD	Total
<b>Gender</b>			
Female	24	11	35
Male	4	3	7
<b>Symptom status</b>			
Symptomatic	8	2	10
Asymptomatic	20	12	32
<b>Tested</b>			
Yes	27	10	37
No	1	4	5
<b>Test status</b>			
Positive	26	9	35
Negative	1	1	2
Indeterminate	1	4	5

### 3. Results

In general, participants expressed considerable levels of concern regarding genetic discrimination. Participants worried about genetic discrimination in at least one context, such as being worried that an employer would not hire him or her because of a mutation in a BRCA gene or the Huntington's gene. However, often they mentioned several contexts in which they believed that their genetic information might turn out to be disadvantageous. The levels of concerns and the impact it had on daily lives varied. While some participants considered their concern for genetic discrimination to be a marginal element in their daily struggling with BRCA or HD, others' lives were dominated by the concern. For example, an HD participant explained that he did not undergo genetic testing because he was too worried about not being able to conclude an insurance contract or having to pay a severely increased premium. The result section is divided in two parts.

In the first part we discuss how participants deal with Belgian regulation on genetic discrimination. The majority of BRCA and the minority of HD participants were aware of Belgium's regulatory efforts. However, participants were still concerned to become the victim of genetic discrimination. Thus, the question arises why these concerns still persisted. In the first section, we will discuss in detail participants' concerns of direct forms of genetic discrimination by organizational actors since legislation tend to focus on direct forms of genetic discrimination by institutional actors (e.g., insurers, employers, adoption agencies) (Lemke 2013; Wauters and Van Hoyweghen 2016).

In the second part of this article, we will discuss more subtle and indirect forms of genetic discrimination for which participants were worried, e.g., in more informal social contexts. Until now few research has dealt with these concerns. Indirect forms of genetic discrimination might be rather difficult to protect in legislation and therefore come with specific challenges. We will pay special attention to these indirect forms of genetic discrimination. However, and importantly, our findings show that the widely used distinction between direct and indirect genetic discrimination is rather arbitrary.

#### *3.1. Dealing with Regulations Prohibiting Genetic Discrimination: Concerns of Direct Forms of Genetic Discrimination by Organisational Actors*

Belgium was one of the first countries to enact a law prohibiting the use of genetic information in the context of insurance, namely the 'Law on terrestrial insurance contracts of 1992' (changed in

2014 to ‘Law on Insurance’)<sup>5</sup>. With this law, Belgium has adopted a prohibitive approach to the use of genetic information in the insurance context, but protection is only provided for individuals who are asymptomatic. For genetic discrimination in the context of employment or in social relations, the general Belgian anti-discrimination legislation of 2007 includes genetic information as one of the criteria on the basis of which citizens should not be discriminated against.<sup>6</sup>

Some participants, especially those at risk of HD, did not know that Belgium takes a prohibitive approach to the use of genetic information in insurance. Melany’s father has HD, so she therefore knows that she has a 1 in 2 chance of also carrying a mutation in the Huntington gene. However, she has decided that, at least at this point in her life, she does not want to be genetically tested to find out whether or not she will get HD. When talking about insurance, Melany made it clear that she did not know whether or not she had to disclose to the insurance company that she is at risk of HD, in other words she was not aware of the legal ban.

*I didn’t inform them [insurance companies]. Well actually I haven’t had to purchase insurance since I’ve known about it [her father’s diagnosis of HD and related to this her own chance of being a mutation carrier] so my insurance hasn’t changed. But I won’t tell them because I wouldn’t want to put myself at a disadvantage. [ . . . ]*

Researcher: and if you have to purchase a new insurance policy, what would you do?

*I’ve no idea. That’s a good question. I’ve absolutely no idea what I should do. Would it be possible to conceal it?*

Melany [40, HD, not tested, asymptomatic]

It might seem obvious that informing these participants about Belgium’s effort in protecting them against genetic discrimination might reduce or even take away potential concerns. However, our findings show that several of our BRCA and HD participants still expressed concerns about genetic discrimination. One of these participants is Lilian, a 53-year-old woman who found out that she carries a mutation in the BRCA2 gene after having breast cancer. At the beginning of the interview Lilian recalls that when the geneticist informed her about the positive genetic test result for BRCA2, he also mentioned that she does not have to disclose this information to insurance companies.

Researcher: imagine that you want or need a new insurance policy, would you inform the insurance company about being a BRCA mutation carrier?

*I think I would not mention it, but I’m afraid that’s not right.*

Lilian [53, BRCA2, tested, positive, symptomatic]

Thus, notwithstanding the geneticist’s advice not to disclose this specific genetic information, Lilian feels that it would not be right to keep it a secret. Lilian is unsure about what she has to do when she wants to purchase a new insurance contract and, finally, despite knowing about the legal ban, she is still concerned.

Ashley is 24 years old and recently found out about BRCA at a point in her life at which she still had to take out insurance. Her father, who worked for a bank, advised her to conclude an insurance contract as soon as possible so that she would not become sick before being insured. Ashley followed his advice.

<sup>5</sup> Article 58 and article 61 are of relevance in the context of genetic discrimination. Article 58 of the Law on Insurance states that genetic information should not be disclosed by the insured person. Article 61 includes that medical investigations, which may be necessary to obtain an insurance contract, can only be based on the previous history of a current health status of an individual, and not on genetic research to determine future health status

<sup>6</sup> Wet ter bestrijding van bepaalde vormen van discriminatie. 10 May 2007.



*So I got a medical questionnaire with questions like ‘have you been in hospital lately?’ ‘do you have grandparents who ... (hesitates)?’ Yes, I have a grandmother who got cancer at the age of 78. But that doesn’t seem to be very uncommon. It won’t give rise to any suspicions so I don’t think that I would have to pay a higher premium because of that. So that’s why it was a good moment to go for insurance. I wouldn’t have to lie on this form. So imagine you had all these checks [regular examinations or check-ups to make sure that she does not have cancer] and you have to declare it on this form and they say to you ‘well, your premium has now doubled’. That sucks.*

Ashley [23, BRCA2, tested, positive, asymptomatic]

These questions about family history and regular check-ups make Ashley confused. She knows that insurance companies are not allowed to ask for or use genetic information, but the abovementioned questions do seem to reveal information that could be categorized as ‘genetic’. Ashley felt not assured by the legislation anymore. Another participant, John, is 62 years old and tested positive for BRCA1 and has similar suspicions as Ashley.

*Insurers can’t know about it [genetic information]. Well, they can’t know about it, but I think that there’s an uncontrollable area between not being allowed to know anything and knowing.*

John [62, BRCA1, tested, positive, asymptomatic]

John’s concern regarding genetic discrimination in insurance, despite knowing that insurers are not allowed to have and use this information, are grounded in his job experiences of the past as a banker. These experiences resulted in certain negative assumptions about insurers, such as that insurers cannot be trusted. In addition, John is not confident in the effectiveness of the law since he has witnessed a lack of decent inspection of insurance practices. Thus, he believes that insurers might still use the information.

Ellie, who is 31 years old and has tested positive for HD, knows about the legal ban in the insurance context because she has been informed about it by the social service of the ‘Huntington Liga’.

*I’ve heard others talk about problems with loans and stuff. People say ‘you’ll have less chance of being accepted or you have to pay a higher premium.’ But then they said, the people from the Huntington Liga said ‘well no, that’s not true. As long as you’re not ill and the doctor ... ’ (hesitates) Well, people are sometimes confused about this. There’s a huge difference between a positive genetic test and being ill. Not everyone knows that there’s a difference. [ ... ] But I think you have to be a very strong and confident person not to be deceived by insurers because their questions are often tricky questions.*

Ellie [31, HD, tested, positive, asymptomatic]

Thus, Ellie also experiences difficulties and uncertainties in what she would have to declare to insurers and how it might be wrong to keep this information from insurers. In addition, she has seen how others in the same situation also express confusion. More specifically, the difference between being symptomatic and asymptomatic does not seem to be clear. In principle, the Belgian law only protects asymptomatic individuals. This means that once symptoms occur, an insurance company is allowed to take that medical information into account. This ambiguity between genetic discrimination and discrimination on the grounds of disease or handicap has been an issue in the genetic discrimination debate (Lemke 2013). Ellie’s quote shows how individuals at risk of or with HD also struggle with this. In addition, Ellie herself is confused about the possibility of being asked what she calls ‘tricky questions’. These tricky questions seem to be asking indirectly for genetic information. So despite being aware that there is a legal ban on genetic discrimination in insurance, she remains concerned.

BRCA mutation carriers who wished to have a mastectomy and breast reconstruction had very specific problems with the Belgian legal ban. After undergoing genetic testing, Jenny knows she carries a mutation in the BRCA1 gene. To reduce her chances of getting breast cancer, Jenny decided to have a mastectomy followed by breast reconstruction. To obtain approval for reimbursement of this surgery Jenny informed the insurance company about her plans. After receiving her genetic

information, the insurance company replied that they were not allowed to use genetic information, and consequently Jenny should not have informed them. However, their response did not satisfy her.

*Then I thought 'so this means I should in fact lie about it so as not to jeopardize my loan or insurance?' In fact they oblige you to lie about it [the genetic information] because 'they can't use it anyway.' And still you get questions like 'do you have any health issues?', 'have you had any surgery in the last five years?' in their medical questionnaires. Of course I had surgery in the last five years. Then they ask: 'Why?' What should I write then? 'Preventive mastectomies?' and then they say 'we won't take the genetic information into account.'? (astonished) That surgery tells them something about it [having an increased chance of breast cancer]. Then I think to myself 'they will take this into account.' You're not telling me that they will simply ignore that.*

Jenny [41, BRCA1, tested, positive, asymptomatic]

At first Jenny wanted to inform the insurance company about the BRCA mutation. By taking preventive measures, she believes that future costs for them (related to having breast cancer) will be avoided. Jenny thought that if insurance companies realized that by reimbursing her current surgery they will be able to decrease her overall costs, they would be happy to pay the cost of preventive actions. It came as a surprise to Jenny that they cannot use that information, and because of their reactions she now even feels obliged to lie about being a BRCA mutation carrier. Furthermore, Jenny is frustrated and confused because the insurance company still asks questions that might reveal genetic information. Thus, in the end, she remains concerned about genetic discrimination in relation to insurance.

Our study demonstrates that some participants were not aware of the legal ban, but the majority did know that insurance companies cannot discriminate on the grounds of genetic information. However, participants were confused about this law and ultimately, despite the Belgian legal ban, participants still expressed concerns regarding genetic discrimination. This is in line with other studies (Allain et al. 2012; Geelen et al. 2012; Klitzman 2010; Parkman et al. 2015).

### 3.2. Concerns about More Subtle and Indirect Forms of Genetic Discrimination

Our findings show that, in addition to concerns about direct forms of genetic discrimination by organizational actors (e.g., in the insurance and employment context), our participants also worry about more indirect forms of genetic discrimination. For Lizzy, who is a 28-year-old HD mutation carrier, being able to build a career is essential. She believes that while she is still healthy she has to make as much money as possible, so that she is in a secure financial position for the period when she has HD.

*I won't talk about my genetic risk if not doing so will prevent my career from being affected negatively.*

Researcher: In what way do you think it could affect your career?

*I think if (hesitates) I don't think they'll invest in me as much. If I (hesitates) if I tell them 'ok well, my use-by date is in so many years' they would be like 'well, why would I invest in you when I know you're not going to be able to work beyond this time when this other person . . . ' You know, we're both at this level. 'Your potential working life is so long and if this other person's is longer then we will just invest in this person.' Basically (hesitates) that's my concern.*

Lizzy [28; HD, tested, positive, asymptomatic]

Lizzy will not inform her employer about her positive genetic test result for HD because she is concerned that it might reduce her career opportunities. Like Lizzy, other participants worry that because of their genetic predisposition, their employers will not 'invest in them' as much as they would have done if they did not have this genetic predisposition. As such, some employees fear that they will not be able to obtain a secure position in the company, that they will not be eligible for promotion or that employers will not invest in additional training or education. Where genetic discrimination in



the employment context is usually defined as ‘direct discrimination’, the concerns that are expressed here by our participants are related to more subtle forms of genetic discrimination in the employment context (Lemke 2009).

A specific concern that was mentioned by some participants at risk of HD was that employers or co-workers might not trust them in the same way as they did before. Chantal took a genetic test for HD and it turned out to be positive. It has been very hard for her to cope with the idea that she will get HD. Since she might become very emotional she decided to inform colleagues about her genetic mutation so that if she felt sad they would know why. However, afterwards she regrets telling her colleagues, as she explains a little later in the interview:

*So before I informed people at work [about the HD mutation] I always used to be responsible for signing certain forms for the company. And then suddenly, after talking about HD, someone else was asked to do this instead of me. I was like ‘oh no! Would this have anything to do with my Huntington risk?’*

Chantal [45, HD, tested, positive, asymptomatic]

The fact that a colleague suddenly had to take over that specific task made Chantal suspicious that her co-workers or employers did not trust her with the same responsibilities as they did before. It is hard to prove that her positive genetic test is the reason why Chantal may no longer carry out this particular task. However, Chantal recalls it as being very painful to realize that people at work do not trust her as they did before she was open about her HD mutation, or at least she feels like something has changed after informing people at work. Thus, at first she did not worry about genetic discrimination, but because of this particular experience at work, she did begin to have concerns.

The worry felt by participants such as Chantal about trust issues or loss of responsibilities may be due to certain specific characteristics of HD. In addition to severe physical symptoms such as involuntary choreic movements, individuals with HD may have various psychiatric symptoms, such as short temper, periods of depression or memory loss. In general, greater stigma is attached to psychiatric symptoms, even if these are not associated with a genetic disorder (Klitzman 2010). Valerie, whose genetic test for HD turned out to be positive, saw how her father suffered from mental problems due to HD, such as being ‘revolting, difficult and short-tempered’ and how it resulted in problems at work. This makes her concerned for herself, which is why she is very careful with revealing that she has an HD mutation. In the interview Valerie talks about her experiences when they found out her father’s diagnosis of HD.

*We [the family] were like ‘oh ok, it’s Huntington. Well, that’s why my father reacts so strangely. Or why he reacted so strangely at work. That’s why his colleagues . . . ’ (hesitates) The employees who worked under my father still respected him but his direct colleagues, they (hesitates) well they actually bullied my father and eventually side-lined him. [ . . . ] So that’s why I don’t talk about it either. If you say that your father has HD then they might immediately think ‘oh! She might have it too.’ Or people might look it up. And that’s difficult because, well I don’t want people to look at me like ‘could she already have it [HD]?’ And you don’t want that of course.*

Valerie [34, HD, tested, positive, asymptomatic]

Seeing how the disease had an impact on her father, as well as how it affected others’ behavior toward her father, makes Valerie sad and concerned for herself and how her father’s genetic disease could affect her, so she decides to ‘conceal’ it from others. Another participant who was at risk of HD also referred to the experience of being part of an HD family. Until Danielle was genetically tested for HD she had been very cautious with information about her family risk. A few years before the interview took place, Danielle found out that her genetic test was negative. However, in the interview she reflects on the period in which she had not been genetically tested, so in which she had, as far as she knew, a 50% chance of becoming sick.

*Before I was genetically tested I actually always avoided talking about the disease. I've always wanted to live a normal life. At work no one knew. I wanted to live a normal life. I didn't tell my children either. It took me a long time to finally talk with them about it. [ . . . ] It was hard enough to carry this burden [knowing about the genetic disorder and the associated risk for herself and her relatives] with the people who knew about it. I didn't want others to feel sorry for me. I didn't want that label. I didn't want to see that unhealthy curiosity that people have. I felt that people might label me, 'oh! Really? I'm so sorry' (hesitates). I immediately felt that they would think 'that disease runs in families, your family is worth less'. That's how it felt for me.*

Danielle [58, HD, tested, negative]

Because she is part of a family with HD, Danielle could refer to several incidents in which she saw stigma attached to sick family members, and this seemed to influence her concerns as well as her choice to deal very cautiously with her personal genetic information. One example of the stigma she experienced is this:

*My aunt once gave a party for her 50th wedding anniversary. She contacted me to say that my brother [who had HD] was actually not welcome at the party because she did not want other guests to see him (hesitates). My cousin told me 'If he [Danielle's brother] is at the party, I won't come because I don't want to see him. I don't want to see someone ill at the party.'*

These experiences took their toll on Danielle. Until she had undergone genetic testing she kept quiet about being at risk of HD, even to her children who were also at risk. She was also concerned about the impact on her relationship, and gave her partner an opportunity to leave her when her father was diagnosed with HD.

*I was convinced that it [the news that her father had HD and she consequently was also at risk] would have a huge impact on my relationship. I was convinced that I would be labelled, 'you'd better choose someone else because you know the future which awaits you'.*

As the above accounts demonstrate, participants express concerns about genetic discrimination in the context of social relationships. Valerie, the women with a positive genetic test for HD, is worried that her friends would see her differently.

*Once I've become sick, people will look at me as 'that sick person'. That's very hard (cries). I'm not particularly concerned about issues like insurance or work but (hesitates) more 'how will friends look at me?' 'how will they approach me once I'm sick?' I once met a guy with HD and I didn't really notice anything but still, I don't want that. I'm afraid to be seen that way. But I do it myself to others too. I feel sorry. And I don't want to feel that others would feel sorry for me (cries). So I waited very long to talk to my friends about it.*

Valerie [34, HD, tested, positive, asymptomatic]

Valerie worries about a form of genetic discrimination that might only appear when she becomes symptomatic. However, even now when she is not yet ill, this concern meant that she kept the result of the genetic test secret from her friends. She worried that the information that she would become sick in the future, even if she does not know when or how severe the disease will be, might already make a difference in how her friends interact with her. These worries about being looked at differently or labeled are particularly strong among participants at risk of HD or with the Huntington's gene.

Another concern about a relatively indirect form of genetic discrimination has been expressed by Lizzy, a young participant who has tested positive for HD. She decided for herself that she would love to have children, but because she does not want them to be at risk of HD she will opt

for Pre-Implementation Diagnosis (PGD)<sup>7</sup>. Despite being very happy about the possibility of PGD, Lizzy worries that friends might disapprove of that choice.

Researcher: How would others react if you opted for PGD?

*My best friend who has known the illness since I was young is very strongly Catholic. So she would be totally against abortion and totally against all that stuff. If she knew all about the procedure [what it entails to have PGD in combination with IVF] she might not be very (hesitates) in favor.*

Lizzy [28; HD, tested, positive, asymptomatic]

Participants at risk of HD have mentioned worries about several forms of indirect genetic discrimination. BRCA mutation carriers, however, were less concerned about genetic discrimination in general, and the nature of their concerns was also different from those mentioned by participants at risk of HD. At the time of the interview, Nora, a 38-year-old woman who tested positive for BRCA2, did not have any symptoms of cancer. However, Nora worries that people might label her.

*That's [genetic discrimination by insurers] not the only thing I worry about. From a social viewpoint, I hope that people will not look at me as if I'm the next cancer case.*

Nora [38, BRCA2, tested, positive, asymptomatic]

Nora refuses to be put in that box because she is not yet sick. Her concern about being looked at or labelled as 'the next cancer case' hurts Nora because she is doing everything she can to prevent cancer from happening. This specific possibility of taking preventive actions seems to come with another concern about genetic discrimination. Sophia is a 26-year-old woman who recently found out that she has a mutation in the BRCA2 gene. She is currently employed, but she worries about her work for the future.

*I would never tell my bosses about it [being a BRCA2 mutation carrier]. It's none of their business.*

Researcher: Why not?

*Because, it might not be an advantage for me if they knew. [ . . . ] Other employees have time off work as well, for example for burnout, having a baby or breaking an arm. Most of this time off is unplanned. And I think that just because I know now that I might be absent for a while, doesn't mean that I have to put myself in a situation like 'hi, I'm the weak employee here.' I even think that the preventive surgery will not mean that much time off work. Only if I'm diagnosed with cancer, then I might be unable to work for a long time. [ . . . ] Not all employers might make an issue out of this but I just would not tell my bosses. If they had to choose between two equally qualified persons, then, in my head, they would probably choose the person without medical problems.*

Sophia [26, BRCA2, tested, positive, asymptomatic]

Sophia fears that the fact that preventive surgery will cause her to be absent from work might cause her to be seen as 'a weak employee'. She even compares this with other people's sick leave. BRCA mutation carriers are what [Timmermans and Buchbinder \(2010\)](#) define as 'patients-in-waiting'. A positive test result for BRCA puts participants in a strange position, somewhere between 'being healthy' and 'being sick', especially if they take preventive measures. That makes their concerns different from concerns expressed by HD participants about being labelled or about being looked at that. No preventive options are available to individuals at risk for HD, so these participants know they will eventually become sick. The HD concerns were mostly due the specific characteristics of HD, and

<sup>7</sup> In combination with In-Vitro Fertilization, this technology enables couples to select embryos without a mutation in the HD or BRCA genes ([Wu et al. 2014](#)).

particularly the mental issues that are involved, rather than fear of being absent due to sick leave, as in the BRCA case.

Until now we have shown which concerns are expressed and which differences could be found between the two genetic disorders. Another aspect that seems to have an impact on worries about genetic discrimination is the 'stage of life'. Jenny, a BRCA1 mutation carrier, did not expect the issue to have an impact on her current love relationship. She has been married for a long time and she was convinced that her husband would not leave her because of this. However, Jenny did have a very particular concern regarding relationships, namely the potential relationships of her not-yet-adult children, who might also carry a mutation in the BRCA1 gene.

*My husband and I have already been through a lot so I knew he would be able to tackle this issue with me. He wouldn't make an issue out of it. But nowadays, a lot of young people don't know what it [having a BRCA mutation] actually is and I think that when you're not able to explain it [what it means to be a BRCA mutation carrier] (hesitates) I think a lot of them [potential partners for her children] would turn around and say 'oh no, I don't want this love relationship, I'll look for another girl.' They still have the chance, they are still free, they are still young, so why wouldn't they?*

Jenny [41, BRCA1, tested, positive, asymptomatic]

Jenny's concern highlights an important finding of our study. Concerns about genetic discrimination surface at particular moments in life: when having to search for a new job, when applying for a new insurance contract and when single and looking for a relationship. These events can occur at every point in life, but young people, such as Jenny's daughter, often still have to navigate all or at least several of these choices and events, while her mother only became aware of her genetic risk at a point in life when her relationship, work and insurance situation were stable.

Melany was not genetically tested for HD, but because of her family history she knows she has a 50% chance of carrying the mutation. When her father was diagnosed with HD, Melany had already, for years, been in a love relationship with the same man.

*I think that being at risk of HD might have an impact on love relationships. (hesitates) But I think it depends on when you tell your partner. When you're settled and you've built a relationship, then you have I guess what we [she and her partner] had, 'we'll see what happens and we'll go on with our lives.' But if you keep it from your partner he might get angry. However, if you tell him at the beginning of a relationship I think it might play a role in whether or not the relationship succeeds. And that's not blaming the partner. It's not that simple [to be in a relationship with someone at risk of HD]. A partner needs to be very strong to be with someone who might get HD.*

Melany [40, HD, not tested, asymptomatic]

Melany did not experience any changes in her relationship. Like Jenny, Melany thinks that this is due to the fact that she has a stable relationship. However, this might be different for individuals at the start of a relationship. Melany believes that at that point, the news of being at risk of HD might be a reason not to get involved. This shows that concerns about genetic discrimination may be stronger or emerge at certain points in life: such as when a person is single and looking for a love relationship. Thus, next to worries about direct discrimination by organizational actors, participants are also concerned about rather indirect genetic discrimination, such as being looked at differently by friends. It is important to take the latter worries into account in the debate on genetic discrimination.

#### 4. Discussion and Conclusions

This study aimed to gain in-depth understanding of concerns and fears of genetic discrimination relating to two genetic disorders in Belgium: hereditary breast and ovarian cancer (BRCA) and Huntington's disease (HD). Our findings demonstrate that, despite the Belgian legislation to prohibit the use of genetic information in insurance, participants still express concerns about genetic

discrimination. Some participants were not aware of this legislation. In these cases, we could suppose that concerns persisted because of this lack of awareness. However, of those participants who were aware of the legislation, the majority of them still remained concerned. These concerns were expressed both by BRCA mutation carriers as well as individuals at risk of HD. Participants are unsure about the exception in the law, on not communicating genetic information. Some felt as if it was not ‘logical’ to keep this specific information ‘secret’ from organizational actors, e.g., insurance companies. Others remained worried about genetic discrimination because they had a stereotype negative idea of insurance companies as an institution that cannot be trusted. Furthermore, some participants referred to insurers asking ‘tricky questions’ about medical check-ups and family history that might still reveal genetic information. In the case of BRCA, participants were also confused because they often wish to have a mastectomy followed by a breast reconstruction and be reimbursed for this latter treatment. However, they are not supposed to give the information on BRCA to insurers, not even if this means that they might reduce their chances of getting cancer and consequently reduce their overall disease-related costs. Requiring participants and insurers ‘to lie’ or ‘to keep genetic information secret’ is considered troublesome and difficult: this results in persistent distrust and wariness about genetic discrimination.

Next, our study indicates that in addition to concerns regarding direct forms of genetic discrimination by organizational actors, more subtle forms of genetic discrimination are also an important cause for concern. These concerns for indirect forms of genetic discrimination relate to the way participants may be approached and treated by others, as for example in the context of their job activities. Our participants worry that they may not be given opportunities in their career, may not be ‘invested in’, may lose the trust of colleagues and bosses or be labelled. They are also concerned that they may not be chosen as a partner, may be looked at differently than before, may be left by their partner, or may face disapproval of the choices they make in relation to their genetic predisposition. Being concerned about indirect forms of genetic discrimination might have severe consequences. For example, the concern that friends might look differently at the individual at risk for a genetic disease might result in him or her not wanting to engage in social activities. Since these concerns are very subtle and hard to prove it might be challenging to find a way to alleviate them.

While BRCA as well as HD participants demonstrate considerable concerns of genetic discrimination, some differences in the nature of these concerns can be observed between these two disease types. First, BRCA mutation carriers are less concerned about direct and indirect forms of genetic discrimination than participants at risk of HD. BRCA mutation carriers believed that the preventive measures potentially available to them enabled them to reduce their risks to the level of ‘normal people’. HD mutation carriers do not have the option to take preventive measures. A positive genetic test only reveals that they will definitely get this severe genetic disorder. The definitive character of this genetic disorder is such that HD participants find it ‘logical’ that it might be a source of direct as well as indirect genetic discrimination. Most notably, HD is a very severe mental as well as physical disorder, which is an extra argument for HD participants to be concerned about genetic discrimination. Participants have witnessed the impact of HD on relatives, for example how the severe psychiatric symptoms have a serious stigma attached to them, and this seems to aggravate participants’ concerns. In contrast, BRCA participants do not recall much stigma and even by contrast, experience considerable societal understanding. Consequently, the majority of BRCA participants express less profound concerns. These findings are in line with a US study on experiences of and concerns about genetic discrimination ([Klitzman 2010](#)) within three disease groups (hereditary breast and ovarian cancer; Huntington’s disease and Alpha-1 antitrypsin). Disease symptoms, such as psychiatric problems, influence whether genetic discrimination and stigmatization occur as well as whether individuals at risk worry about such phenomena.

Another finding of our study is that concerns as to genetic discrimination surface at particular moments in life, i.e., when certain choices have to be made: starting a new relationship, having to find a (new) job, taking out insurance, having children etc. Participants who found out about their

genetic risk later in life often already had a steady relationship and children, had found a good job and taken out their insurance contracts. Younger participants still had to make these choices, and with each of the abovementioned choices, genetic information and consequently the possibility of genetic discrimination emerges. Older participants sometimes did not worry so much about it for themselves, but they feared that their children might become victims of genetic discrimination once they had to face genetics-related decisions. Therefore, parents dealt very cautiously with their personal genetic information so that they would not also reveal genetic information concerning their children.

These findings should be considered in light of limitations of our study. Our recruitment strategy, namely recruitment through patient groups, might be associated with limitations, such as a self-selected group of individuals (Lemke 2013), membership can be small (Lemke and Liebsch 2015) and members might be interested in the disease but not eligible for participation in our study, such as health professionals (Treloar et al. 2004). However, as we have shown in the methods section we have made several efforts to reduce biases. In addition, it is important to keep in mind that this study focused on two genetic diseases and that conclusions might be different for other genetic illnesses.

To conclude, in this article we have gained an in-depth understanding of concerns to genetic discrimination in relation to two genetic disorders in Belgium: Hereditary breast and ovarian cancer (BRCA) and Huntington's disease (HD). Even after the adoption of legislation prohibiting the use of genetic information, our participants were concerned about genetic discrimination. Until now, research focused on direct forms of genetic discrimination by organizational actors. Our study confirms that participants worry about for example not being able to conclude an insurance contract or losing a job because of the fact that they are at risk for a genetic illness. Our findings demonstrate how current legislation on direct genetic discrimination can be confusing and uncertain, and how, as a consequence, participants remain concerned about genetic discrimination. Next, we have shown that participants also worried about indirect genetic discrimination such as being looked at differently or not being trusted anymore. These indirect forms of genetic discrimination should be taken into account in discussions on genetic discrimination because they guide and limit the choices that people make and subsequently have important social consequences. This form of genetic discrimination is however often very subtle and consequently can be hard to prove.

These conclusions urge us to rethink societal efforts to address concerns about genetic discrimination. Policy makers could create additional specific laws on genetic discrimination to include subtler forms of genetic discrimination. However, addressing the concerns about indirect and subtle forms of genetic discrimination might be difficult. Other non-regulatory efforts, such as creating more societal awareness of or familiarity with a genetic disorder such as HD, might be more effective in alleviating concerns. Finally, more education and counselling about existing legislation through patient organization or genetic services might help to create awareness and a better understanding of existing legislation.

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