Perception, Experience, and Response to Genetic Discrimination in Huntington's Disease: The Australian Results of the International RESPOND-HD Study

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Aims: This study examines elements of genetic discrimination among an at-risk, clinically undiagnosed Huntington's disease (HD) population. **Methods:** Sixty at-risk individuals, either positive or negative for the HD genetic mutation, completed a survey regarding their experiences of genetic discrimination, adverse and unfair treatment, and knowledge about existing laws and policies surrounding genetic discrimination. **Results:** Sixty eight percent of participants reported feeling "Great benefit" from knowing their genetic test results. Reported benefits of knowledge included planning for the future, making decisions, and many individuals found meaning in active participation in the HD community and in advocating for themselves or families at risk for HD. Many individuals found personal meaning and a sense of community from knowledge of this information and from the ability to participate in research. Despite these positive feelings toward gene testing, results demonstrated that 33% of participants perceived experiences of genetic discrimination, which occurred repeatedly and caused great self-reported distress. Significantly, more gene-positive respondents reported experiencing incidents of genetic discrimination, compared to gene-negative respondents. At least 58 separate incidents of discrimination were reported, the number of incidents ranged from 1 to 10, with 45% of individuals (9/20 respondents) indicating more than one event. Of the most significant events of discrimination, 58% were related to insurance, 21% to employment, 16% to transactions of daily life, and 5% to relationships. **Conclusion:** Results contribute toward validation of empirical data regarding genetic discrimination.

Introduction

GENETIC DISCRIMINATION is defined as differential treatment, denial of rights, privileges or opportunities or other adverse treatment, based solely on genetic information, including a family history (Gostin, 1991). Discrimination can also happen to individuals who have a genetic diagnosis, but who are asymptomatic or who will never become significantly impaired (Billings *et al.*, 1992). Many investigations into the concerns about genetic discrimination have been published (Motulsky, 1974; Kenen and Schmidt, 1978; Alper *et al.*, 1994; Lapham *et al.*, 1996; Low *et al.*, 1998; Hall and Rich, 2000; Geller, 2002; Harmon, 2008). The 5-year (2002–2005) Australian Genetic Discrimination Project (Barlow-Stewart and Keays, 2001; Otlowski *et al.*, 2002; Taylor *et al.*, 2007) reports cases of genetic discrimination against healthy people, with

most related to insurance and employment domains, informal and social contexts, and within health services. Those having neurodegenerative conditions were more likely to report discrimination or social stigma across multiple domains (Taylor *et al.*, 2008). Half the participants in an Australian bowel cancer study withdrew participation when told that the required genetic testing could impact life insurance access (Keogh *et al.*, 2009).

Huntington's disease (HD) is a neurodegenerative disorder with progressive psychiatric, cognitive, and motor symptoms. Currently, no treatments are available to delay the onset of disease. It is inherited via an autosomal dominant fashion with almost 100% penetrance (Myers *et al.*, 1998). Direct gene mutation detection methods (via blood test) have been available since 1993, leading to highly accurate predictive testing with a sensitivity and specificity of almost 100%

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(Meiser and Dunn, 2000), and confirmation of a disease mutation may occur years before any symptoms appear. HD gene testing measures the number of expanded CAG trinucleotide repeats in exon 1 in the HD gene. If there are too many repeats, the test result and individual are gene-positive and will eventually develop HD symptoms. However, a positive test result provides little information regarding age of onset, rate of progression, or symptom severity. If the repeat size is found to be in the normal range (usually less than 35 repeats), then the individual is considered gene-negative, and is not at risk for developing HD.

Studies have found that discrimination concerns are high in the HD community. A genetically untested woman was refused employment due to a family history of HD (Harper *et al.*, 2004), and individuals at risk of HD have been refused or asked to withdraw child adoption applications (Billings *et al.*, 1992). Bombard and colleagues (2009) found that 40% had concerns about genetic discrimination in 233 asymptomatic genetically tested and untested people at risk for HD in Canada. A study of 1001 at risk for HD individuals in North America revealed that their greatest concern was losing health insurance, and 41.6% reported paying out of their pocket for testing or other medical services to conceal their genetic risk from their insurer/employer (Oster *et al.*, 2008). Concerns about employment, health insurance, and social relationships in people at risk for HD were reflected in the pilot study and preliminary interviews as a part of the current research (Penziner *et al.*, 2008).

As a result of the gains in HD research, the scope for genetic testing is now extended to include predictive testing for monogenic and multifactorial diseases, and impacts upon personal risk reduction—with far-reaching effects—from families to large sections of the ostensibly healthy population (Goh and Chiu, 2011). The quantification and verification of the relationships between genetic discrimination and the domains of insurance, employment, and social relationships is much needed (Treloar *et al.*, 2004).

Materials and Methods

Participants and recruitment

All 99 PREDICT-HD (Paulsen *et al.*, 2006) participants at our site were invited to participate. Sixty-three individuals consented. Surveys were completed and returned by 60 of these 63 participants for a response rate of 61% overall (two surveys returned blank, one survey not returned due to participant finding it stressful). All participants had undergone predictive DNA testing examining the CAG trinucleotide repeat in exon 1 of the Huntington gene. The PREDICT study assesses asymptomatic participants. This ensures the measurement of genetic discrimination based on purely genetic traits rather than disability-based discrimination due to disease. However, as the PREDICT-HD study is longitudinal (now in its 10th year of recruitment at our center) some participants may have been closer to active manifestations of disease than others. Table 1 shows participant demographics. The Institutional Review Board approval was obtained.

The RESPOND-HD survey is a self-administered questionnaire designed for this study. The study used a cross-sectional, descriptive, mixed-method survey design with closed- and open-ended response formats addressing multiple

TABLE 1. PARTICIPANT DEMOGRAPHICS

	χ^2 <i>p</i> -value	n (%)
		60
Gender		
Female	0.020^a	39 (65)
Male		21 (35)
Education		
Some primary or secondary education	0.107	14 (23.3)
Completed secondary school		7 (11.7)
Some community college or technical school		4 (6.7)
Completed community college or technical school		7 (11.7)
Some university or teacher's college		8 (13.3)
Completed university or teacher's college		3 (5.0)
Postgrad Education or Degree		9 (15.0)
State of residence		
Victoria	0.000^a	25 (41.7)
South Australia		20 (33.3)
Queensland		6 (10.0)
Tasmania		6 (10.0)
New South Wales		2 (3.3)
Western Australia		1 (1.7)
Gene status		
Gene-positive	0.121	36 (60.0)
Gene-Negative		24 (40.0)
Age		
Mean (SD)		44.6 (12.4)
Range		19–68 years

^aBold values are significant at the 0.05 level.

topics, including perceptions of genetic discrimination, employment, insurance, and legal issues. The measure used the terms “differential treatment,” “treated unfairly,” and “discrimination” throughout the survey in an attempt to minimize response bias (Treloar *et al.*, 2004). Experiences were not limited to situations governed by laws, regulations, or policies, but also included those that may result in prejudice, loss of privileges, and personal hardships. Full description of development, validation, and analysis is reported elsewhere (Erwin *et al.*, 2010). This study forms part of The International-RESPOND-HD study: Erwin *et al.* (2010) report combined results across three countries (USA, Canada, and Australia), and Williams and colleagues (2010a, b) report combined qualitative narrative findings from all countries.

Results

Genetic testing

Seventy percent of respondents reported that they strongly agreed that it was important to find out their genetic status, with strong agreement that knowing can provide a greater sense of personal control (58%), and help plan one's future (68%), including the decision to procreate (47%). 68% reported feeling “Great benefit” from knowing their test results. However, there were strong concerns about family members

coping with the results (48%), about insurance (30%), employment (20%), and being treated differently (27%). 17% were strongly concerned about privacy of results. No participant was strongly concerned that the test is not useful as there is no cure for HD. See Table 2.

Genetic discrimination. Thirty-three percent of all respondents ($n=20$) reported experiencing genetic discrimination. Significantly, more gene-positive respondents ($n=17$) reported experiencing incidents of discrimination, compared to 3 gene-negative respondents ($\chi^2(3)=8.78, p=0.032$). At least 58 separate incidents of discrimination were reported by these 20 individuals. The number of incidents ranged from 1 to 10, with 45% of individuals (9/20 respondents) indicating more than one event (Table 3). The most significant incident of reported discrimination occurred in the domain of insurance (58%), followed by employment (21%), transactions of daily life (16%), and then relationships (5%). When asked how much distress the incident caused, 55% (11/20 respondents) reported experiencing "a lot of distress", 25% reported moderate distress, 10% reported very little distress, none reported no distress.

Insurance discrimination. Seventeen percent of all respondents ($n=10$) had been refused insurance coverage, 20% offered coverage, but at a higher premium ($n=12$), 7% offered limited coverage ($n=4$), 5% offered a limited term for the coverage ($n=3$), and 2% had their coverage cancelled ($n=1$). The greatest area of concern was that almost 17% had been denied life insurance, compared to lower incidences for health insurance (8%–12%), long-term care insurance (7%), disability insurance (8%), and auto insurance (1 person). One respondent had been denied a disability claim. 11% of respondents had avoided applying for insurance because they did not want to disclose their gene status, and 13% have given up before applying for insurance because they believed they would not be covered due their gene status. Three people (5%) kept their family history and test results out of their medical

files. Three people (5%) concealed their family history of HD and their genetic test results from their insurance company. Three people bought more insurance than they would have otherwise and six people made multiple applications for insurance, in case they were denied coverage.

A total of 3 (5%) individuals reported that they had been asked to take a HD genetic test by an insurance broker, agent, or company. One respondent reported that they had asked for a genetic test for HD to be done anonymously so that their insurance agent or company could not find out the results. Three respondents (5% of the sample) reported that they postponed having their genetic test so that they could get insurance first. No one reported that they paid for services out of pocket, or had their testing done in another state or country, so that their insurance company could not find out their results.

Social discrimination. Results revealed that 33% of respondents have been watched for symptoms by family members due to their genetic test results. Nine respondents reported that people had made negative comments to them due to their genetic testing. Twelve individuals reported that people changed how they talk to them as a result of genetic testing.

Employment discrimination. Only one respondent reported that they had been denied a promotion because of test results. One other person reported that they were denied a job due to their genetic testing. Two people reported that they believed they were placed under surveillance at work due to genetic testing. However, when discrimination in employment occurs, it is perceived as a significant experience, with 21% of respondents reporting their employment discrimination as their most significant incident of discrimination.

Education discrimination. Two respondents reported that they had been discouraged from continuing their education because of genetic testing, and an additional three individuals

TABLE 2. RESPONDENTS' OPINIONS ABOUT GENETIC TESTING % (N)

	<i>Strongly disagree</i>	<i>Somewhat disagree</i>	<i>Neutral</i>	<i>Somewhat Agree</i>	<i>Strongly agree</i>
Important to find out I carry the gene for HD.	0	5.0 (3)	5.0 (3)	18.3 (11)	70.0 (42)
Knowing can provide a greater sense of personal control.	0	1.7 (1)	8.3 (5)	30.0 (18)	58.3 (35)
Knowing can help me plan for the future.	1.7 (1)	1.7 (1)	3.3 (2)	23.3 (14)	68.3 (41)
Concerned about my family coping with the results.	0	1.7 (1)	11.7 (7)	36.7 (22)	48.3 (29)
Concerned that my test results will not be kept private.	58.3 (23)	11.7 (7)	21.7 (13)	10.0 (6)	16.7 (10)
Concerned about insurance.	13.3 (8)	10.0 (6)	20.0 (12)	25.0 (15)	30.0 (18)
Concerned that knowing my gene status will affect my employment.	15 (9)	16.7 (10)	21.7 (13)	23.3 (14)	20.0 (12)
Concerned that others will treat me differently if they know I have the gene that causes HD.	10 (6)	15.0 (9)	23.3 (14)	23.3 (14)	26.7 (16)
Concerned that the test is not useful because there is no cure for HD.	55 (33)	21.7 (13)	13.3 (8)	8.3 (5)	0
Helps me make decisions about having children.	6.7 (4)	5.0 (3)	21.7 (13)	18.3 (11)	46.7 (28)

HD, Huntington's disease.

TABLE 3. PERCENTAGE OF POSITIVE RESPONSES TO SPECIFIC AREAS OF PERCEIVED GENETIC DISCRIMINATION
(BASED ON GENETIC TESTING, OUT OF ALL 60 RESPONDENTS)

	% (n) Total (both gene-positive and -negative)	Number of responses from gene-positive participants	Number of responses from gene-negative participants
Employment			
I have been fired from a job.	0	0	0
I have been denied a promotion.	1.7 (1)	1	0
I have been denied a job.	1.7 (1)	1	0
I have been placed under surveillance at work.	3.3 (2)	2	0
Total		4	0
Education			
I have been discouraged from continuing my education.	3.3 (2)	2	0
Transactions of daily life			
I have been denied housing.	0	0	0
I have been denied a bank loan.	0	0	0
I have been denied custody or access to my children.	0	0	0
Insurance			
I have been denied health insurance.	8.3 (5)	4	1
I have been denied life insurance.	16.7 (10)	9	1
I have been denied long-term care insurance.	6.7 (4)	4	0
I have been denied disability insurance.	8.3 (5)	5	0
I have been denied auto insurance.	1.7 (1)	1	0
I have been denied a disability claim.	1.7 (1)	1	0
I have bought more insurance than I would have otherwise.	5.0 (3)	3	0
I have made multiple applications for insurance, in case I was denied coverage.	8.3 (5)	4	1
I have avoided applying for insurance because I didn't want to disclose my status.	15.0 (9)	9	0
I have given up before applying for insurance because I believed I would not be covered due to my gene status.	20 (12)	12	0
I have been advised not to apply for insurance because of my gene status.	5 (3)	3	0
I have concealed my test results from my insurance company.	5 (3)	2	1
I have kept my test results out of my medical files.	5 (3)	1	2
I have been refused insurance coverage.	16.7 (10)	9	1
I have been offered coverage, but at a higher premium.	20 (12)	7	5
I have been offered limited coverage.	6.7 (4)	3	1
I have been offered a limited return for the coverage.	5.0 (3)	1	2
I have had my coverage canceled.	1.7 (1)	1	0
I have been denied a claim because of my FH or GT results.	1.7 (1)	1	0
Total		80	15
Relationships			
I have been watched for symptoms by family members.	33.3 (20)	18	2
People have made negative comments to me.	15.0 (9)	9	0
People have changed how they talk to me.	20 (12)	12	0
Total		39	2

reporting that the same had occurred due to their family history of HD. There were no reports of an education incident being the most significant incident of genetic discrimination.

Other discrimination. Similar to the findings of Taylor and colleagues (2008), issues arose where healthcare providers offered inappropriate and unwanted advice. Two individuals reported that their most significant event was related to healthcare providers (being told not to have children). One individual was denied the opportunity to donate blood. 16% of the respondents experiencing discrimination reported this kind of discrimination as their most significant. No respon-

dents reported feeling that they had been denied housing, a bank loan, or access to children.

Legal issues

Of the 20 people who described specific incidents of genetic discrimination, 11 reported that they questioned or challenged the unfair treatment (58%). Only nine (15%) placed a complaint when they felt that they were treated unfairly. One person (1.7%) challenged an insurer's access to, or use of, genetic information on legal grounds (court case relating to a car accident). None had, or knew anyone who had challenged an employer's access to, or use of, genetic information on legal

or policy grounds, or filed a lawsuit because of genetic discrimination. Only 10 respondents (16.7%) knew where they could complain if they felt discriminated against. There was very poor knowledge of local legislation related to genetic discrimination—76.7% of respondents reported no knowledge of any laws preventing employers from accessing genetic information about an employee, and 73.3% of respondents had no knowledge of laws preventing employers from using genetic information in an unfair or discriminatory way. Knowledge of legislation relating to insurance was worse, with 86.7% of all respondents not knowing if there were local laws preventing health insurance companies from accessing or requiring genetic information about an insured person. 88.3% did not know of any laws preventing insurers from requiring the release of genetic test information on an application. 90% of respondents did not know of any laws preventing insurers from using genetic information to deny them insurance.

Discussion

Insurance

Under Australia's government-mandated system, public health insurance is financed by direct salary contribution to Medicare (proportional to income). Private health insurance is only subject to age. The greatest area of concern in this study was life insurance (including death cover, trauma, and income protection, and long-term care insurance). This type of insurance is risk-rated, with premiums determined by individual risk factors, such as age, health history, health status, occupation, serum cholesterol, alcohol and tobacco use, and now genetic information is simply an additional factor to be evaluated in the underwriting actuarial process (Pokorski, 1994). Another option in Australia is group insurance via employers or superannuation funds. These are automatically approved up to a certain level (usually a limited amount) without revealing personal and health information. Superannuation policies can also include a component of life insurance income protection, but, again, tend to insure for less than private policies.

Australian insurance contracts are governed by the legal doctrine of *uberrima fides* (utmost good faith). All parties must make full declaration of all relevant facts so the contract accurately reflects the risk being taken. Thus, people applying for insurance, changing policies, or switching insurers must disclose whether they have had genetic testing (and the results). Products sold by general insurers, such as travel and cover for sickness and accidents, require annual renewal, and any new information relevant to the risk must be disclosed. If a policyholder conceals a test, then the policy may be deemed invalid and the insurer refuse to pay a claim. However, life insurance policies are guaranteed renewable in Australia—once cover is obtained legitimately it cannot be cancelled nor does the policyholder need to provide any new health information. Some people secure insurance before undergoing testing (thus, there is nothing to disclose) although known family history still needs disclosure.

Insurer access to genetic information in Britain was limited under a 2001 moratorium (applies to life, critical illness, and income protection insurance). Above predetermined policy levels, applications only need to tell insurers the results of those predictive genetic tests that an independent government committee has approved as relevant to insurance companies—so far, HD is the only condition listed, for life

insurance. In the USA, the Genetic Nondiscrimination Act 2008 (GINA) states that health insurers cannot deny coverage or charge higher premiums on the basis of genetic test results. However, GINA does not cover life insurance, disability insurance, or long-term care insurance. In Australia, the Disability Discrimination Act 1992 acknowledges the commercial nature of life insurance, and insurers are currently able to discriminate between people on the basis of their health status and future health risks when making underwriting decisions (but are required to demonstrate rationality in such decision making using sound actuarial or statistical data). This act was amended in 2009 to cover genetic predispositions to disability, but the definition of a disability is far narrower than the range of genetic conditions that expose people to discrimination. The Australian Financial Services Council (FSC) stated that of the 455,000 insurance applications received annually, about 400 were from people who had genetic tests, and only 8 cases (2%) had been declined on the basis of genetic testing alone (2005 data from Smith, 2009). Members of FSC are not permitted to ask an individual to have a genetic test, or indirectly coerce people to have a test (e.g., by offering the inducement of a lower premium). Written consent is required for the insurer to access genetic test results and the results cannot be used in the applications of relatives. Privacy laws also bar a health insurer from sharing information with an allied life insurance business.

Employment

In Australia, there is no linkage between employment and health insurance. Most issues relating to genetic testing relate to the appropriate use of genetic information in the workplace, particularly, in relation to occupational health and safety issues (for example, using genetic information to identify those susceptible to workplace hazards, those who pose a risk to themselves and others in the future, and also to monitor health over time). Economic factors also exist to limit payouts in the case of workplace injury or liability. Currently, most Australian employers are not using genetic testing to monitor present or future employees, but this is largely due to the limited accessibility and excessive cost. The low number of respondents in the present study reporting perceived discrimination in employment, compared to the more common occurrence in the USA, may arguably be due to the fact that in the USA employers are usually also responsible for health insurance (Erwin *et al.*, 2010).

Knowledge of legal avenues

Current results revealed a concerning lack of knowledge of formal legal rights, and very poor knowledge of legislation that prevents employers or health insurers from accessing and using their genetic information. Questioning or challenging of the perceived unfair treatment tended to be within organizations, such as a complaint to the manager at an insurance agency, and not through the legal system. This study revealed very poor knowledge of local legislation that prevents employers or health insurers from accessing and using genetic information. Formal legal protections are not useful in preventing genetic discrimination if the individuals affected are not aware of their legal rights. Researchers have already noted the complexity of making complaints or seeking redress within the Australian legal system (Otlowski *et al.*, 2007). In Australia, there are federal and state-based agencies for complaints. The federal Australian Human

Rights Commission (AHRC) leads the implementation of the Disability Discrimination Act 1992 (Commonwealth) under the Australian Human Rights Commission Act 1986 (Commonwealth). There are also state-based agencies, operating state-based legislation.

Limitations

Data were based on self-report, raising accuracy issues, particularly, in a condition where self-awareness may be decreased (Duff *et al.*, 2010). HD also affects families over several generations; this frame of reference may influence perceptions of emotional experiences, thus affecting discrimination reports (Tibben, 2009). However, people may make important decisions based on these perceptions (Williams *et al.*, 2010a), thus feelings of discrimination hold validity in how they affect lives. The survey reported on a range of behaviors within genetic discrimination and, thus, reported a broad overlap of these experiences with those also associated with stigma in the literature, resulting in difficulty distinguishing the effects of stigma from those of discrimination. There are limitations of the sample, which was homogenous for genetically tested individuals, mostly from two Australian states who were participants in the PREDICT-HD study. This is not a representative sample and conclusions are thus limited.

Implications

Results contribute toward validation of empirical data regarding genetic discrimination. Knowledge of frequency of discrimination may inform public policy in addition to private decision making (Williams *et al.*, 2010b), particularly as the prevalence of genetic testing is likely to increase. The results of this study, and the perceptions, experiences, and responses of these individuals are helpful in increasing understanding how we may move forward as individuals and a society where genetic information will be more accessible and fairly used for the purposes of healthcare, life planning, or personal interest. Concern about genetic testing and the risk of discrimination can result in individuals refusing testing and limiting their options to take advantage of available interventions that might lower the morbidity and mortality associated with genetic disorders. Discrimination fears can also prevent individuals from research participation, thus delaying treatments and potential cures. As more illnesses with a substantial (and testable) genetic component are revealed, there is an increasing need for education, knowledge, and tolerance for having genetic risk, as well as resources to ameliorate genetic discrimination, including more awareness of obligations and rights relating to genetic discrimination. The results of this study suggest that there is a pressing need for increased education, intervention strategies, and support programs, particularly in the arena of insurance. Continuing education of insurance workers, and clear application forms and information about the insurance issues relating to genetic tests will be helpful in making the process transparent and understandable.

Acknowledgments

The authors acknowledge the HD community who participated in the project. The study was supported by the National Human Genome Institute Grant No. R01 HG003330, J.S. Paul-

sen, Principal Investigator, and also by a grant from the Legal Services Board, Victoria, Anita Goh, Principal Investigator. We also acknowledge Joy Preston and Professor Nicola Lautenschlager, Head of Academic Unit for Psychiatry of Old Age, Department of Psychiatry, The University of Melbourne.

Author Disclosure Statement

All authors declare no conflict of interests. No competing financial interests exist for any of the authors.

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