Published in final edited form as:
Am J Med Genet B Neuropsychiatr Genet. 2008 April 5; 147(3): 320–325. doi:10.1002/ajmg.b.30600.

Perceptions of Discrimination Among Persons who Have Undergone Predictive Testing for Huntington's Disease

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Abstract

Potential discrimination from genetic testing may undermine technological advances for health care. Researching long-term consequences of testing for genetic conditions that may lead to discrimination is a public health priority. The consequences of genetic discrimination generate social, health, and economic burdens for society by diminishing opportunities for at-risk individuals in a range of contexts. The current study objective was to investigate perceptions of genetic stigmatization and discrimination among persons who completed predictive testing for Huntington's disease (HD). Using semi-structured interviews and computerized qualitative analysis, the perceptions of 15 presymptomatic persons with a positive gene test predicting HD were examined with regard to differential treatment following testing. The sample comprised 11 women, 4 men, mostly married (73%), aged between 22 and 62 years, average education of 14.6 years (SD ± 2.57) , and residing in urban, rural and suburban settings of eight U.S. States. Participants reported consequences following disclosure of genetic test results in three areas: employment, insurance, and social relationships. Although most employed participants (90%) revealed their test results to their employers, nearly all reported they would not disclose this information to future employers. Most (87%) participants disclosed test results to their physician, but a similar majority (83%) did not tell their genetic status to insurers. Most participants (87%) disclosed test results to family and peers; patterns of disclosure varied widely. Give bottom line here.

Introduction

Huntington's disease (HD) is an autosomal dominant progressive neurological condition, which leads to impairments in cognition, emotion, and motor control. The symptoms

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generally appear in individuals between the ages of 30 and 50, but juvenile HD and late symptom onset also occur. Research is progressing rapidly, but currently there is no cure.

Since the identification of the HD expanded allele on *IT15*, genetic testing can identify those who will develop HD before their symptoms are noticeable (Gusella JF & MacDonald ME, 1993). In the absence of a cure, the decision to be tested is controversial. There are important legal, financial and personal considerations regardless of whether the testing outcome results in positive or negative results (Cox SM, 2003; Smith JA et al., 2002). For these reasons, genetic counseling is recommended for individuals seeking predictive testing for HD (Botkin JR et al., 1996; Huggins et al., 1992; Kessler S et al., 1992; Teltscher et al., 1981). Several studies describe individual reasoning *for* and *against* testing. Relief from uncertainty and assistance with reproductive planning were considered among the most important factors associated with those who test, while fear of results and insurance discrimination were factors associated with those not testing (Cadori AM & Brandt J, 1994).

Researchers investigating the long-term impact of genetic testing have focused on participant reports of relief and regret themes following test results (Williams JK et al., 2000; Wahlin et al., 1997). Other studies have examined the psychosocial aspects of testing for HD by using questionnaires and psychiatric rating scales to identify emotional responses to genetic test results. Results from these studies suggest that testing positive for the gene expansion may lead to psychological distress but not major psychiatric impairment (Decruyenaere et al., 1996; Wiggins et al., 1992; DudokdeWit et al., 1998). In one study, an individual's positive gene test, the presence of symptoms, a history of psychiatric illness, and unemployment status were factors associated with the occurrence of a serious adverse event, although research findings suggest that the frequency of serious risks (e.g., suicide attempts) is fairly low (0.97%; Almqvist E et al., 1999).

There is increasing attention toward the prejudice and discrimination concerns surrounding the disclosure of genetic test results (Lapham VL et al., 1996; Lynch HT et al., 1997; Lerman C et al., 1996; Hall MA & Rich SS, 2000). Genetic discrimination refers to a bias directed against an individual or family, because of real or perceived deleterious genetic status (Billings PR et al., 1992; Treloar et al., 2004). Stigmatization occurs when individuals are treated differently in social situations and informal activities because of their genetic status (Geller et al., 1996). Genetic discrimination may generate significant social, health, and economic burdens for society by diminishing opportunities for genetically at-risk individuals in a range of contexts (e.g., insurance and employment) (Harper PS et al., 2004; Bird SJ, 1989; Engelking C, 1995; Barondes SH, 1998). While the complexities surrounding genetic discrimination are receiving growing recognition, there is a need for more empirical data documenting the nature and extent of the bias. The number of people coping with knowledge of future onset of a genetic illness is broadening as more genes that are associated with disease risk are identified through predictive methods (Khoury M et al., 2004; cite Hall, Apse, Peterson here). Consequently, understanding the ethical, legal, and social implications of "living at genetic risk" is critical. The purpose of this research was to identify perceptions about discrimination in persons who have received predictive testing for HD. The objective was to develop and test a qualitative approach that identifies concerns of genetic discrimination among those who tested positive for HD.

Methods

Participants

The project focused on healthy individuals who are aware of their future likelihood to develop HD. After the University of Iowa's Institutional Review Board (IRB) approved the protocol, eligible participants were invited to participate in the study. All interviewees were

recruited from an HD Research Registry, which is a list of individuals who have consented to receive information about HD research opportunities. It was estimated that between 15–20 participants would be needed to attain saturation of content for commonly practiced qualitative methods in exploratory research. A letter of invitation, and consent form were mailed to 17 randomly selected individuals from 54 eligible registry participants. Fifteen individuals responded, and completed a 30–60 minute interview by telephone. Participant's ages ranged from 22 to 62. The sample comprised 11 women and 4 men, all of who tested positive for the HD gene expansion. Most participants were married (73%), years of education ranged from 13 to 19, and participants were employed in diverse professions (e.g., attorney, fitness trainer, teacher, and construction worker). Participants lived in eight U.S. States and resided in urban and rural settings; however, most lived in Midwest suburban communities. Eight married participants had children and 3 did not. Among single participants, one individual had children and was previously married. Most participants (80%) were insured, and they maintained health coverage through their employment or spouse's policy. Five participants were unemployed and two of the unemployed individuals were seeking work. Four of five unemployed participants had current health insurance coverage that was either put into place prior to their genetic testing or through their spouse's policy. One employed participant and one unemployed participant (13%) did not maintain any type of insurance policy, and one participant received medical benefits through the Department of Veterans Affairs health system.

Instrument Development

A semi-structured interview was used to qualitatively examine perceptions of being treated differently following predictive testing. The interview guide (see Table 1) was developed for this study and was based on information from previous research and literature on the concerns of persons who are at-risk for HD (Otlowski MF et al., 2002; Williams JK et al., 1999). The interview questions were designed by the research team to elicit perceptions of discrimination, defined as being treated differently, after predictive testing. The interview guide had eleven scripted questions and several probing statements that prompted detailed responses. Four pilot interviews were conducted in a non-target sample to validate whether the questions asked during the interview had the same meaning to the participant as to the research team. Participants in the pilot interview were asked to state if the questions allowed them to respond without reservation. If the interview question was unclear, limiting, or had a different meaning to the participant than to the research team, the interviewer asked the participant to suggest words that may help improve the question.

Data Analysis

Semi-structured interviews were recorded onto audiotapes and subsequently transcribed. The printed transcription was verified with the audiotape interview by the interviewer. Responses were coded using methods described in qualitative research literature (Edwards A & Talbot R, 1999; Hoskins CK, 1998; Munhall PL, 2001; Knafl KA & Webster DC, 1988). Codes were derived through impressionistic analysis of whole transcripts and through the assignment of topical codes. Qualrus (i.e., a computer-assisted text analysis software program) was used to enhance coding, sorting, and categorizing of transcript data. The research team monitored the quality of the data throughout the project. Participants were asked to report experiences following genetic status disclosure in three areas: *employment, insurance, and social*. These themes were determined apriori and were anticipated as they follow the topics derived from previous studies. A content analysis approach was used to analyze the interview transcripts, which consisted of identifying descriptive data categories and emerging themes within and across coding categories. For example, *insurance discrimination* was a prominent concern for most participants and, within this category, concerns were often linked with anxiety about the confidentiality of genetic information,

access to medical records, and an insurer's right to deny coverage based on genetic records. Other themes emerging from data analysis included altered senses of identity, issues of autonomy and changes in life planning. The research team reviewed the transcripts for the appropriateness with which the interview script captured a representative sample of behaviors and content domain about which inferences were made. Two members of the research team independently coded the interviews and another expert who was not part of the data coding team audited the analysis for accuracy. Data was sorted by topic, and the research team conducted a second series of analyses through comparison with the literature and original transcripts. Qualitative data were numerically presented to more fully describe and interpret experiences in this group. Although there is debate over the use of numbers in presenting qualitative research, displaying information numerically reveals patterns with greater clarity (Wise C et al., 1992; Pope C et al., 2000). Numerically presented data gauge the magnitude of the concerns reported by participants. The 'frequency' and 'severity' of concerns cited within the interview text were evaluated to deliver meaningful interpretations of the data. The participant narratives balance the 'counting of experiences' and tell the more significant story.

Results

Employment

Although the majority (90%) of employed participants initially had a low level of concern about employment discrimination and revealed their test results to their employers, eight of out nine who disclosed reported that they would not disclose this information when looking for new work. For nearly all participants, test results affected their decisions to pursue career advancement or to seek new employment. Participants described a sense of "feeling stuck" in their current position because of their gene test results due to uncertainty about being hired, receiving benefits, providing a long-term commitment, and/or passing performance evaluations. One participant described her concern about the possibility of being passed up for promotion by saying, "*I don't want [supervisors at work] to know and think 'god, why should I waste my time on her*.'" Two individuals cited specific discrimination experiences related to employment. One experience related to job termination ("*for talking about predictive testing at the workplace*"), and the other involved being denied employment. The participant reported that it was after advancing to a third and final round of interviewing before disclosing his/her genetic status and that he/she was subsequently denied employment: "*nobody said anything directly about the Huntington's but they said other things about why they didn't hire me*."

Insurance

Concerns regarding insurance discrimination were initially high as shown by results that the majority of insured participants (83%) did not disclose their test results to insurers. Two participants submitted an insurance claim for their predictive testing and indicated that their test results had been disclosed to their insurance carrier. Both claims were reimbursed and no differential treatment was reported. Several participants reported paying out of pocket for predictive testing. One participant was tested through a Veterans Affairs hospital and another was receiving Title XIX benefits at the time of testing. Three participants (21%) supplied false data during the testing process. One of these participants stated that an insurance claim was submitted by their physician who "*didn't put my name on anything; it was a fake number,*" and two participants said they used a false identity during the testing process. One participant described experiencing increased concern after learning the test results: "*I'm even more cautious now about it, if there's not an absolute reason that some information needs to be handed out, then I don't give it*." The concerns surrounding the disclosure of test results to insurance carriers included losing one's policy or being denied

coverage for disease related medical expenses. Two participants expressed concern about their eligibility to enroll in a long-term care insurance plan. Participants who kept information from insurers said they worried about losing their policy due to test results. Nearly every insured participant (eleven of twelve) expressed concern about future insurability as a result of learning his or her test results. Close to half of the insured sample (42%) expressed concern over the legality of withholding information from insurers, and all of these individuals indicated worry about their ability to cover future medical expenses. There were no reports of concrete insurance discrimination.

Relationships

Based on the frequency and magnitude of participant comments, the social impact of genetic testing was the most dominant concern. Patterns of disclosure to family and peers varied; some reported being cautious and others said they were open to sharing their results. Most participants (87%) openly disclosed the test results within their families and social network, and two participants reported having revealed their genetic status in a public forum (e.g., newspaper and TV). These publicly disclosing participants described feeling responsible to advocate and support HD causes. Two of the study participants withheld their testing experience from certain family members, while selectively sharing the test results with other family members who they believed to be more supportive. Although twelve participants openly shared test results with friends, two participants reported sharing information only with certain friends, and another participant said that he/she did not reveal the results to any friends.

All participants reported differential treatment within family relationships after sharing their test results. Nearly all participants (93%) endorsed at least one negative impact on family relationships whereas one participant noted an improvement in his/her relationships, particularly the spousal relationship, after predictive testing. Participants noted a greater sensitivity and appreciation for time with loved ones, increases in spousal stress or support and family differences in approaching financial management.

Additional social consequences were reported. These included finding it difficult to convey health information while dating, concern for the implications of a positive test result to other at-risk family members, increased concern about reproductive decisions, and an increase in depression and greater anxiety over their children's and grandchildren's lives. After disclosing his/her risk status to a fiancée, one participant shared this statement: "*[the person] broke up with me, and I think it's for the best, because I don't want to be with someone who can't handle that; if I am honest I will find someone to love*." Nearly half the sample expressed concern that others might monitor their behavior to identify disease symptoms. For example, one participant said that during arguments her husband would accuse that her "HD behavior was kicking in". Three individuals reported distress about scrutinizing their own behavior for symptoms of HD. The timing surrounding symptom onset of manifest disease concerned most participants.

Some participants experienced increased support and sensed more deeply connected relationships. A mother described sharing positive and healthy accounts of her condition with her children, "the more knowledge the better; they need to know this so they can understand my experience." Although only two participants reported feeling no regret about having tested, over half of the respondents described a newfound appreciation for things they had taken for granted in the past. Participants cited diverse motivations for testing. Reasons cited for testing included "*needing to know*" and using genetic test results to influence future plans about school, employment, and childbearing.

Discussion

All types of discrimination were reported as significant concerns to persons who had undergone predictive testing and were found to have a positive gene expansion for HD. Level of initial concern was highest for insurance discrimination, followed by social discrimination and then employment discrimination. Actual (concrete or specific) discrimination experiences were only reported for employment and social discrimination, however, suggesting that participant' concerns were not always supported by concrete experiences. Nearly all participants reported that they would disclose genetic information differently if there were a "next time around".

Our data is consistent with previous research suggesting that fears and concerns about discrimination might be discrepant with the actual experiences of high-risk participants (Peterson, et al., 2002). Although nearly all participants reported high levels of concern about discrimination, only four relayed specific instances of employment discrimination (n=2) or social stigmatization (n=2). Perceptions of genetic discrimination clearly impacted behaviors, however, as several participants paid out of pocket for predictive testing, used an alias, or asked for test results to be excluded from their medical record. These findings are consistent with the literature (Apse et al., 2004) and extended to new areas of potential discrimination (employment and social). It is striking to note that one third of the study sample was unemployed, larger than is expected in a healthy population. We cannot determine from the current study, however, whether this high unemployment rate reflects actual discrimination or behavior change secondary to fear and concern of possible discrimination. One study suggests that the low numbers of persons pursuing genetic information, even when preventive intervention is available, is because of discrimination fears (Hall et al., 2005). Future studies may explore the relationship between employment outcomes and discrimination concerns.

Our findings also suggest that discrimination fears have differential impact on specific discrimination outcomes depending upon life stage. That is, although every study participant had some concern about differential treatment in the areas of employment, health insurance, and social relations, the strength of concern varied with life circumstance. All but one participant endorsed a fear of disclosing their genetic status in at least one of these dimensions. Upon further questioning it was determined that less concerned participants reported having initial concern about disclosing the test results but currently worry less since he/she is nearing retirement or applying for disability benefits. All responses characterized a careful process of 'weighing outcomes' in making the decision to reveal health information.

Findings suggest that a primary contributor to discrimination concern is lack of knowledge. For example, 83% did not disclose their test results to insurers due to their understanding that medical history could allow them the right to deny coverage. Less that 13% of these same participants, however, withheld this information from their physician. Participants were unsure about an insurer's access to their medical records. The results illustrate that perceived consequences are important factors in disclosure decisions. Patient attitudes and knowledge about health care policy should be explored to study relationships between perceived discrimination threat and genetic privacy legislation. It is important to note that all of the participants in this study had already undergone predictive genetic testing, yet significant knowledge gaps remained about discrimination. These findings may guide predictive testing guidelines to include a more structured didactic component where HIPPA (spell out and cite here) and state discrimination laws are reviewed.

The most surprising finding of this study was the high significance given to social stigma and discrimination. Studies documenting potential distress on family systems suggest that

predictive testing has a ripple effect of the families and friends of test participants (Bailey DB et al., 2003; Williams et al., 2000; Tibben A et al., 1990). The manner in which participants interpreted their testing experiences influenced their partnerships, family planning, self-image and identity within the family. Negative social outcomes concerned this population profoundly, and were cited as more distressing than insurance and employment concerns. Future research should explore fears of social stigmatization, quality-loss in valued relationships, and missed social and family opportunities to fully understand the impact of predictive testing in these dimensions. Attitudes about conveying health information, the implications of test results to other at-risk family members, and reproductive issues should be longitudinally studied to elucidate the impact of genetic testing on family systems. Future measurement tools may seek to assess the stressors, strategies for stress management, and nature of social support in persons at genetic risk.

There are some limitations of the research worthy of mention. This population cannot be fully generalized to other populations with specific genetic risks since the HD gene mutations are fully penetrant, a situation not found in most other predictive testing situations at this time. Findings in a small sample are limited and do not account for the experiences of all persons at risk for genetic disease. Furthermore, there may be notable differences in the concerns and perceptions of individuals who were willing to participate in this type of research. Surveying a larger sample about these issues may allow for a comparison of subgroups, such as comparing persons in different health care and legislative systems. From there, the conclusions drawn may achieve a more universal understanding.

Discoveries emerging from the Human Genome Project promise to improve the identification of disease-risk, facilitate earlier diagnosis, and develop new, safer, and more specific drugs for the treatment and prevention of diseases (Collins FS et al., 2003; Gebbie K et al., 2001; Guttmacher AE & Collins FS, 2002). Findings from this study suggest that concerns about discrimination and stigmatization are paramount in advancing health care advances into the community. Discrimination concerns remain high in a sample of persons who have undergone genetic testing for HD, and specific discrimination reports are available. Much work remains to identify discrimination hindrances that may help genetic counselors, legislators, policy makers, and the medical communities address the translation of the human genome project more broadly and effectively.

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Table 1

Interview Questions:RESPOND-HD Pilot in PREDICT-HD

Differential Treatment	To get us started, please tell me how you have been since your predictive testing results.
	Please tell me about any experiences you have had where you felt treated differently because you had the HD predictive testing.
Employment	Are you employed right now?
	What are your experiences regarding being treated differently and your employment?
	What do you believe would happen if your employer knew of your HD test results?
	If you were deciding to look for a new employer, would your test results impact this decision?
Insurance	What are your experiences in obtaining or keeping insurance after you learned of your HD test results?
	What do you believe would happen if your insurance company knew of your genetic test results?
Social	Please describe any occasions where you felt you were treated differently by your family because you had genetic testing for Huntington's disease.
	Please describe any occasions where you felt you were treated differently by your neighbors because you had genetic testing for Huntington's disease.
	Please describe any occasions where you felt you were treated differently by your friends because you had genetic testing for Huntington's disease.
	Please describe any occasions where you felt you were treated differently by others not yet mentioned because you had genetic testing for Huntington's disease.