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WRITTEN TESTIMONY TO THE STANDING SENATE COMMITTEE ON HUMAN RIGHTS REGARDING BILL S-201, AN ACT TO PROHIBIT AND PREVENT GENETIC DISCRIMINATION

Submitted by:

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Introduction

I welcome the opportunity to present this written testimony to the Standing Committee on Human Rights regarding Bill S-201, *An Act to prohibit and prevent genetic discrimination.*

Scientist's Background

I am a genomics health services researcher and Scientist at the Li Ka Shing Knowledge Institute of St. Michael's Hospital. I am an Assistant Professor at the University of Toronto in the Institute of Health Policy Management and Evaluation. My research focuses on evaluating the adoption of new genomic technologies in clinical practice. I also conduct public and patient engagement research to advance health technology assessment and health service delivery. I am active in numerous international policy advisory committees; my research informs policy development in this area.

I am internationally recognized for my expertise in genetic discrimination. From the first empirical study on genetic discrimination in Canada[1], to my leadership in clinical practice guidelines on genetic discrimination[2], and an International review of the evidence and policy on genetic discrimination[3], I have pioneered research on this subject.

Genetic Discrimination Study

Genetic discrimination - the differential treatment of an individual based on genetic information - represents an important social risk associated with genetic testing. The extent and impact of genetic discrimination has been the subject of much public concern and policy attention. Indeed, following 12 years of lobbying, the federal Genetic Information Non-discrimination Act (GINA) was enacted in 2008. While the passage of GINA has heralded a new era for precision medicine in the U.S., public concern and policy inertia still linger in Canada, as empirical evidence for its existence remains scant.

Recognizing the limited policy protections and empirical evidence in Canada, I conducted a national study on the nature and extent of genetic discrimination. I was inspired to do this research after witnessing the difficulties individuals undergoing genetic testing for Huntington disease (HD) had with securing insurance and maintaining their employment.

This was the first national study on genetic discrimination and was published in the British Medical Journal[1]. This study therefore made a significant contribution to our understanding of genetic discrimination in Canada.

Overview of the Survey Results

The study's population included asymptomatic individuals at risk for HD, some who had undergone genetic testing, and some who had not; hence, it was able to examine the differential impact of genetic testing versus family history on the extent of discrimination.

The study provided, for the first time, evidence that genetic discrimination was prevalent, as 86% of the population sampled feared discrimination against themselves and their children, not just by insurers and employers but also by friends and family[4]. A further 40% reported experiences of discrimination, especially when buying insurance and in family, social and other situations[1]. Importantly, these experiences and concern resulted in high levels of psychological distress[4].

I shared these survey results with the committee during my oral testimony at an earlier Hearing on this Bill (http://www.parl.gc.ca/content/sen/committee/412/RIDR/11EV-51620-e.HTM). While these survey results provide a snapshot of the nature and extent of the problem, it is only through hearing the patients' stories, does one appreciate the depth and impacts of genetic discrimination.

I appreciate the opportunity to provide written testimony on Bill S-201 and to draw the attention of the Committee to the patient stories of genetic discrimination that I documented during interviews I conducted with patients across the country[5-7]. These narratives illustrate the impacts of genetic discrimination on individuals and their families on a day-to-day level. Importantly, these stories include the domains of insurance and employment, but also span to areas such as adoption, custody and access cases in the courts, in order to highlight additional settings in which genetic discrimination can manifest.

Patient narratives

The following are excerpts and case examples across several domains that emerged from the interviews to illustrate the many faces of genetic discrimination. Pseudonyms have been used to protect the identity of the participants.

Insurance

Many participants described experiences where their genetic tests resulted in insurance denials and being imposed increased insurance premiums. Others spoke of requests to undergo genetic testing to qualify for insurance. Brad described his experience of the latter:

> *"Before I actually got the [genetic] test results I was looking into getting insurance and had a couple of very bizarre exchanges with insurance brokers. One guy said "well … we don't know what your [genetic test] results are so I don't know how easy it would be to obtain insurance from us. You know you are a risk in a sense because you know you directly don't have it and your mother doesn't have it but because it's in the family, you know there is a risk". And then he said …the most bizarre thing,*

> *"there is testing that they can do and perhaps you know you should look into that first."*

Being requested or required to take a genetic test is unethical given the gravity and impact of the decision to undergo genetic testing, and thus ought to be free of third-party coercion. Indeed, this principle of free and informed decision making about a genetic test is enshrined in clinical practice guidelines[2] and by the Canadian Life and Health Insurance Association's code of conduct[8]. The above example provides evidence that insurers do not necessarily follow this code of conduct and that regulatory oversight and laws are required.

Some participants were very concerned about the chance that insurance companies discover their genetic test results if they applied for insurance in the future. Rachel said:

> *"What concerns me if an insurance company says that they want to look through the medical records and they find this [genetic test result], are they now going to say: 'No, we're not going to cover you'? I don't want anything on my medical file that says that's a positive result because I believe that insurance companies would treat me differently knowing that even though I'm not symptomatic."*

Kerry described wide-ranging consequences of insurance discrimination on herself and family:

> *"I'd thought about insurance and I knew…that I would be at risk, that my job would be at risk that my ability to get insurance would be at risk which would, in my view, would put my family at risk if I couldn't be insured and that was a horrible, horrible feeling just knowing that, because you're treated, you're treated differently if you have this [HD mutation]."*

Kerry interpreted insurance discrimination as *'horrible negative treatment, having something taken away based on a birth defect.'*

Participants likened genetic discrimination to other types of discrimination based on ethnicity or religion, which were similarly '*unethical*.' Patrick, for example, explained why his genetic discrimination experiences were a '*definite Charter [of Rights and Freedoms] issue*:'

> *"From a legislative point of view, discrimination based on genetic testing…is no different than discriminating against somebody who's a visible minority or [has] a handicap, you know, because right now you can't, under the charter [of Rights and Freedoms], you can't discriminate against people because of a disability, right? So do I have a disability? Right now, today, no, but I'm being discriminated against."*

Employment

Many participants believed that their genetic results were directly related to unsuccessful bids to obtain a job or promotion, imposition of an unwanted early retirement and increased surveillance by their employers. For example, Michelle, a health-care professional, felt

singled out because of her genetic test results when her supervisor requested access to her medical files so that her employer could *'monitor'* her for symptoms *'faster, easier than taking [her] word for it.'* Although Michelle refused this request, she felt that this experience amounted to *'prejudice'* and caused her to feel *'shafted'*.

Many also described feeling vulnerable due to the potential for employment discrimination. Rachel's sentiments of employment insecurity were typical:

> *"Any mistakes that I make or anything might be blamed on that or you know might be 'Oh well, you know, it's because she's got that gene'... I think it could be used as a you know as a reason or an excuse to not promote me further if an opportunity like that were to arise, you know, and worrying, you know well, 'Is it safe to give that job to her because you know, you know she might not be all there?"*

These feelings of insecurity caused many to employ various strategies. Wesley, a married father and corporate executive, described his fear of genetic discrimination at work and his decision to keep his genetic test results private:

> *"I struggled a lot...I thought about if, you know, taking on a new role, taking on a new job which I've just recently done, is not something I should do, it's not something I should tell somebody about, you know, should I tell somebody that I have this condition that in five years time might affect me and all of that and I said, you know what: 'no'."*

Many participants spoke of avoiding changes in employment or insurance arrangements in order to avoid the potential loss of insurance benefits or inability to obtain a job. Paul recalled feeling vulnerable if he would change jobs:

> *"There was never any chance then of changing [jobs] because I felt if I went to another employer that to give them that information, there's a lot of issues over… [and] I wasn't willing to take a chance at a secure job."*

Legal proceedings

Participants also described experiences of genetic discrimination in legal proceedings. For example, Jane recalled an unexpected encounter where her genetic test results were *"used against"* her by her ex-partner as a threat to pursue custody of their daughter. At the time of our interview, Jane was a 35-year old single mother. Several years before our interview she tested positive for the HD mutation but was clinically confirmed as asymptomatic (based on eligibility requirements of the study[5,6]). Jane described the time when she tried to pursue child support from her former husband. Upon being served, her ex-husband's lawyer countered with a threat: to use Jane's genetic test result to seek full custody of their child. Jane recounted:

> *"It was a threat on-when he got served with papers, that's what they came back at us with-was …that perhaps (named child) remaining in my full care custody might be*

threatened by the fact that if her mother wasn't going to be able to care for her so maybe she shouldn't grow up with mother."

Jane did not pursue the case further in fear of losing her child, emphasizing that it was *"a million times scary"*.

Adoption

While adoption cases did not frequently emerge in the interviews, Barbara's case provides a shocking example. Barbara and her partner applied to adopt a child and were subsequently approved. While waiting for their adopted child, Barbara's mother was diagnosed with HD. A social worker working with Barbara's family reportedly told her that it was necessary to disclose the newly discovered family history, and that she was at 50% risk of the disease, to the adoption agency. This social worker allegedly threatened to disclose this information to the agency unless Barbara did so herself. After disclosing her new risk status for HD, Barbara reported that the adoption agency told them that they were no longer considered a '*viable'* couple to adopt a healthy baby and were only eligible to adopt a special needs child:

"We had already been approved and were waiting to adopt when my mother was diagnosed with HD. All of a sudden, [we were] no longer considered a viable couple. [We were] told [we] could adopt a special needs child but not a healthy baby. To me this says it didn't matter what type of home a special needs child went to."

Barbara and her partner at the time did not file a complaint, nor did they seek any recourse because of a lack of information about where to complain. She also remarked that the experience caused her considerable psychological distress. Barbara elected not to pursue genetic testing at the time nor did she report having symptoms of HD. It was not until several years later that she underwent genetic testing and was found not to carry the HD mutation.

Summary and implications

This research presents objective evidence that: genetic discrimination exists in Canada; it is a prevalent phenomenon that occurs in many domains; and has long-lasting impacts, including significant psychological distress.

These patient stories highlight the subtleties and breadth of genetic discrimination, which can span insurance and employment to adoption and legal proceedings. These narratives illustrate the wide-ranging ramifications of genetic discrimination, which create psychological, economic and health care challenges for patients and their families. Importantly, genetic discrimination significantly affects patients' health outcomes and participation as equal members in our Canadian society.

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Accelerating advances in genomic science are providing unprecedented opportunities to use genetic information to facilitate the prevention, treatment or early diagnosis of many diseases. However, genetic discrimination remains a fundamental barrier to accessing genetic testing that prevents individuals from seeking optimized health care. Increasingly patients are being deterred from taking genetic tests because of fears that an unfavourable result will lead to difficulties with insurance[5,6,9-12]. Arguably, such fear creates barriers to accessing medically or psychologically important information that can guide prophylactic management strategies or life decisions. In addition, the fear of genetic discrimination also prevents patients from participating in research, which can stifle Canada's scientific advances in genomic medicine. Indeed, the concern about insurance discrimination is pervasive and has prevented some individuals from participating in genetic testing and genetic research[12-14]. If people refuse to participate in genetic research programmes because of concerns about insurance and employment discrimination, it can negatively impact public health and advances in medicine.

Taken together, Bill S-201 would provide comprehensive protection for Canadians, which would prevent discriminatory experiences, allay patients' fears, encourage their participation in genomics research, and most importantly, empower patients and their families to take preventative measures to reduce their risks for future diseases. Genetic fairness is a fundamental right, which can empower patients to live healthy, productive and meaningful lives, while also ensuring Canada remains on the cutting-edge of genomics research.

I thank the Committee in advance for considering this landmark Bill and for an opportunity to reflect on its importance. I have no doubt that the Bill, once approved, will make an important contribution towards addressing a pressing need for genetic fairness in Canada.

Respectfully submitted,

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