Short Report

Adoption and the communication of genetic risk: experiences in Huntington disease


Adoption can present significant challenges when seeking or communicating genetic risk information. Adoption agencies can use genetic information to determine the eligibility of prospective adoptive parents and to establish a child’s suitability for adoption. We describe experiences and implications of communicating genetic risk for Huntington disease (HD) in the context of adoption. A secondary analysis was employed using data collected from a cross-sectional survey (n = 233) and two qualitative studies on the psychosocial effects of predictive testing for HD. We demonstrate several ethical and practical challenges in the search for and communication of genetic information for adoptees and their birth relatives. We also found that concern for adoption discrimination was reported by 13.7% of survey respondents (n = 32). Concerns were higher among tested respondents than those who had not been tested (n = 29 vs n = 3, p = 0.010). However, more respondents were concerned about being discriminated based on their family history (FHx) vs their genetic test results (GTR) (concern based on FHx: n = 18 vs based on GTR: n = 1 vs based on both: n = 10). These findings contribute to the limited empirical literature by offering evidence on the experiences and implications of communicating genetic risk information in the context of adoption with reference to HD.

Conflict of interest

Nothing to declare.

The aim of this article is to describe experiences of communicating genetic risk for Huntington disease (HD) in the context of adoption in Canada. HD was the first adult-onset disorder for which a predictive test was available and thus likely one of the first circumstances in which communicating genetic risk information in adoption may have been required (4–6). HD is an incurable, inherited neurodegenerative disease characterized by cognitive, psychiatric and movement disturbances, which begin in adulthood and progress until death (7). It follows an autosomal dominant inheritance pattern and is caused by ≥36 CAG
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Trinucleotide repeats in the \textit{HTT} gene (8). Individuals with 27–35 repeats have an intermediate allele (IA) and will not develop HD themselves but due to repeat expansion, children may develop HD, particularly if a father passes on the allele.

Pre-adoptive practice

Soon after predictive testing (PT) for HD became available, genetic testing clinics began to receive requests to test at-risk minors. These requests came from both parents of at-risk minors as well as third parties, such as adoption agencies (4–6, 9). Genetic professionals advocated against PT of children, including those placed for adoption, on the grounds that testing for a currently untreatable adult-onset disorder should be the voluntary and informed choice of the individual. There were fears that a mutation-positive result could subject the child to negative emotional effects or genetic discrimination (GD) by educators, insurers, and employers or differential treatment within the family (5, 6). Therefore, recommendations against the use of genetic testing of minors have been incorporated into several practice guidelines (10–13), and have extended to guidelines for PT of children in adoption (9, 13, 14).

Genetic discrimination and adoption

While practice guidelines have generally advocated against the use of genetic information to determine a minor’s suitability for adoption (9–12, 14), genetic information has been used to evaluate the suitability of prospective adoptive parents. Published case reports have illustrated several issues surrounding alleged GD against individuals at-risk of genetic disease who apply to adopt a child. They described prospective parents who, having a 50% risk of developing HD, decided to pursue adoption and had their applications reportedly rejected by adoption agencies because of their family history (FHx) of HD (15, 16). Therefore, recommendations against the use of genetic testing of minors have been incorporated into several practice guidelines (10–13), and have extended to guidelines for PT of children in adoption (9, 13, 14).

Communication of genetic risk after adoption

After an adoption has been finalized, relatives may wish to seek or share health information, which may continue to emerge throughout the life of the adopted child and their birth relatives. This may create potential barriers to obtaining or communicating accurate and timely genetic information. Studies of family communication of genetic information rarely address adoption (20, 21), and published accounts of post-adoptive communication of genetic information have been limited (22, 23). Moreover, there is a scarcity of empirical research on the prevalence of concern about adoption discrimination among individuals and families with genetic illnesses. The objective of this article is to describe case reports and survey data related to the use and implications of genetic information in adoption among individuals at-risk for HD.

Methods

Methodology, measures, and participants

The study employed a secondary analysis of data collected from three larger Canadian studies: a cross-sectional survey and qualitative study on GD in HD and another qualitative study, which explored the process of PT when an IA for HD is identified. The participants of these three studies were mutually exclusive: 233 from the GD survey, 55 from the qualitative GD study (24, 25), and 33 from the qualitative IA study.

The qualitative studies involved in-depth, open-ended interviews. Both studies utilized Grounded Theory (26), where the constant comparative method was used (27). Data related to adoption from the two qualitative studies are presented as three case reports.

The reports of concern about GD in adoption are derived from the survey study, which examined the prevalence and contexts of perceived GD among 83 respondents found to carry the HD mutation (HD+), 84 without the HD mutation (HD−) and 66 who chose not to test (NT). Respondents were asked questions about whether they had ever worried about themselves or their family members being treated unfairly in 23 different settings, including an adoption agency, due to their FHx or GTR. Study methods are described in detail elsewhere (18). The relevant research ethics boards granted approval for these studies.
Concern about unfair treatment of:

(a) Self only<sup>a</sup>  
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<tr>
<th></th>
<th>Total</th>
<th>Not tested</th>
<th>Tested&lt;sup&gt;3&lt;/sup&gt;</th>
<th>Mutation-negative</th>
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<td>12</td>
<td>1</td>
<td>11</td>
<td>6</td>
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<td>%</td>
<td>5.2</td>
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(b) Family only  
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(c) Self and family  
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<th>Not tested</th>
<th>Tested&lt;sup&gt;3&lt;/sup&gt;</th>
<th>Mutation-negative</th>
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<td>n</td>
<td>14</td>
<td>1</td>
<td>13</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>%</td>
<td>6.0</td>
<td>1.5</td>
<td>7.8</td>
<td>6.0</td>
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Total concern (self and/or family)<sup>c,d,e,f</sup>  
| n  | 32    | 3          | 29                | 14                | 15                |
| %  | 13.7  | 4.5        | 17.4              | 16.7              | 18.1              |

Total sample  
| n  | 233   | 66         | 167               | 84                | 83                |

<sup>a</sup>(a) Self only, (b) family only, and (c) self and family are mutually exclusive categories.

<sup>b</sup>Percentage of the total sample in each category (total, not tested, tested, mutation-negative, mutation-positive).

<sup>c</sup>Total of (a) self only, (b) family only, and (c) self and family.

<sup>d</sup>Total not tested vs. total tested:  \( p = 0.010 \) (‘Total tested’ is the sum of the mutation-negative and mutation-positive categories).

<sup>e</sup>Total not tested vs. total mutation-negative:  \( p = 0.020 \).

<sup>f</sup>Total not tested vs. total mutation-positive:  \( p = 0.012 \).

<sup>g</sup>Having ever had concern was attributed solely to having a family history of HD by 12 (86%) of the mutation-negative respondents and 6 (40%) of the mutation-positive respondents. The rest of the tested respondents reported that they had ever had concern due to both their family history and their genetic test result. Only one respondent (mutation-positive) attributed their concern solely to their genetic test result. (N.B. Concern due to genetic test result may have occurred prior to having the test or as a result of the test).

Results

Reported concern about discrimination by an adoption agency

The sociodemographic characteristics of the respondents have been described elsewhere (18). Of the 233 respondents to the survey, 32 respondents (13.7%) reported that they had ever been concerned about unfair treatment by an adoption agency towards themselves or members of their family. Concern for adoption discrimination among those who were tested was significantly higher those who were not tested (HD + n = 15 vs. NT n = 3,  \( p = 0.012 \); HD − n = 14 vs. NT n = 3,  \( p = 0.020 \)) (Table 1). There was no difference, in concern, in the tested group depending on the results of PT. When exploring respondents’ attributions of concern for adoption discrimination against themselves and/or their family members, we found that more respondents were concerned about discrimination based on their FHx vs. their GTR (concern based on FHx:  \( n = 18 \) vs. based on GTR:  \( n = 1 \) vs. based on both:  \( n = 10 \)).

Case reports

Case #1: adoption denial due to genetic risk for HD

Ms. B. and her partner applied to adopt a child in the late 1970s and were subsequently approved. While waiting for their adopted child, Ms. B.’s mother was diagnosed with HD.

A social worker working with Ms. B.’s family reportedly told her that it was necessary to disclose the newly discovered FHx of HD and that she was at 50% risk to the adoption agency. This social worker allegedly threatened to disclose this information to the agency unless Ms. B. did so herself.

After disclosing her new risk status for HD, Ms. B. 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.”

Ms. B. 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. Ms. B. elected not to pursue PT at the time nor did she report having symptoms of HD. It was not until recently that she underwent PT and was found not to carry the HD mutation.

Case #2: adoption and the search for genetic risk information

In her early 20s, Ms. E began searching for her biological family to learn about her family’s medical history for reproductive planning. At the
time of Ms. E’s adoption, the provincial policy was to provide only non-identifying information about biological parents to the adoptive family.

It took Ms. E almost 10 years to locate her birth family because of regulation surrounding her sealed adoption records. Reflecting on this long journey, Ms. E wished for a better way to exchange important medical information between adoptees and their biological family: “There's secrecy around [adoption], there’s not really a mechanism to receive information. [My biological parents] also wished that they had a way to communicate [to me] that Huntington’s was a disease that ran in the family”.

Access to medical information was of particular importance for Ms. E and her biological family given that at the time of her adoption her birth family was unaware of HD. Ms. E’s adoption agency acted as an intermediary and obtained her birth family’s permission to provide her with identifying information for contact. Soon after she made contact with her biological family, Ms. E learned of the newly discovered FHx of HD and her own risk to develop the disease. Ms. E pursued PT and will not develop HD. Having learned her biological family’s medical history and her HD gene status, Ms. E indicated that she would have her own children in the future. Ms. E and her birth family do not have regular contact.

Case #3: communication of genetic risk by adoption intermediaries

At 17 years of age, Ms. V made the choice to place her son for adoption. During that time, Alberta provincial legislation mandated all adoption records to be sealed. Decades later, Ms. V’s sister was diagnosed with HD. In dealing with the news of her sister’s diagnosis and the genetic risk implications for herself, Ms. V decided to pursue PT. During this process, Ms. V thought of the son she placed for adoption and resolved to locate him after she received her test results.

Ms. V received an IA test result. Ms. V contacted the adoption agency to locate her biological son and inform him of his risk for having an IA for HD. It was during this communication process that Ms. V recalled a barrier; the adoption agency reportedly did not list HD as a disease for which they would assist birth families in locating their biological children: “Huntington’s wasn’t on the list as information that would qualify them contacting somebody . . . I said ‘it is a genetic disease; it’s not something that I got or caught. I just want him to know [his FHx]’.” It was not until Ms. V requested her genetic clinic to send a letter to the adoption agency explaining HD and its genetic implications that they agreed to assist her in contacting her son.

After receiving a gene-negative predictive test result, Ms. V’s son contacted Ms. V and they have since established a long-term relationship. Ms. V’s recalled her son’s concerns about the manner in which the adoption agency informed him of this genetic health information. She reported that the agency did so by telephone while he was driving his vehicle. Allegedly, the meaning of Ms. V’s predictive test result was misinterpreted; “They just told [my son] right then, ‘your birth mother has Huntington’s and you’re at-risk . . .’ which is obviously not the case and has completely different ramifications”.

Discussion

Genetic information can facilitate the prevention, treatment or early diagnosis of genetic illnesses and can inform reproductive decision-making. Yet for individuals who have been adopted, this information may be missing, incomplete, or not readily accessible (23). We demonstrate both ethical and practical challenges in the search for and communication of genetic information for adoptees and their birth relatives. We also illuminate the concern and experience surrounding GD in the context of adoption. These findings contribute to the limited empirical literature by offering evidence related to the experiences and implications of communicating genetic risk information in adoption.

Both Ms. E and Ms. V’s case reports indicate that information about the presence of a genetic illness in the family often comes to light years after the initial adoption placement. At the time of these adoptions, neither birth family was aware of HD and its implications for the future health of the adopted child. This trend is likely to continue given the increasing number of adult-onset genetic conditions for which genetic testing is available (28). Genetic counsellors are in a position to inform their clients about the main channels available to convey genetic health information between adoptees and their biological families. Depending on the client’s jurisdiction, these may include: passive registries, confidential intermediary systems, or open adoption records (2).

On the basis of Ms. E’s lengthy search, clients could be counseled to initiate contact with post-adoption information channels early because it may take years to find relatives. Genetic providers can warn adoptees that the ability to obtain genetic information depends on the willingness of their birth families to provide both consent
and up-to-date medical information (2). Moreover, genetic professionals could also inform birth families of the opportunity to file updated genetic information with the appropriate post-adoption information channels for the benefit of adoptees that may be at-risk. Ultimately, it is important for clients to have realistic expectations about the scope, accuracy and timeliness of the genetic information they may obtain.

Ms. V’s experience demonstrates that misinterpretation of genetic information can occur during the communication process. Genetic professionals may facilitate appropriate post-adoption communication of genetic risks by supplying written information that clearly describes the condition and its associated genetic risks. Given the complex nature of genetics and its consequences for families, it would help to reduce the potential for misunderstanding if genetic professionals remain available for consultation with the jurisdictional authorities on what information to communicate and the best method for doing so. Genetic professionals are aware of several strategies to utilize when communicating genetic information within families (29). The application of these strategies could be beneficial when jurisdictional authorities communicate genetic information to adoptees. In addition, contact information for local medical genetic support should also be provided so that adoption agencies can refer adoptees for further consultation.

Ms. B’s case report of adoption denial based on her genetic risk substantiates at-risk individuals’ fear that they will not be eligible to adopt a child. In fact, the survey findings support the existence of concern about adoption discrimination in this community, as approximately 14% of individuals at-risk expressed concern for adoption discrimination for themselves and their family. Among this group, 11% (n = 26) reported concern for adoption discrimination for themselves. Interestingly, in comparison to the actual experience of GD, 1% (n = 3) of the same sample reported experiencing GD themselves (18). Therefore, it is possible that the concern for adoption discrimination may exceed its actual occurrence, as it is possible that those who are concerned may avoid applying for an adoption entirely.

Although concern for adoption discrimination appears to be higher among those who were genetically tested than those who were not, most individuals were concerned about the potential for discrimination by an adoption agency based on their FHx. This finding is consistent with previous reports that have indicated that the FHx is the main reason for and predictor of GD among individuals at-risk for HD (18, 30). Moreover, the importance of the FHx in discrimination is further reflected in Ms. B’s experience, in addition to the two published case reports where adoption agencies rejected prospective parents’ applications because of their 50% chance of developing HD (15). Ultimately, these lines of evidence support the notion that any efforts developed to protect individuals from adoption discrimination need to include the FHx, as it has and continues to be a major hurdle for individuals at-risk for HD.

While many industrialized countries have established protections against GD, most of these protections focus on insurance and employment domains and do not extend to protect individuals from GD by adoption agencies (31). Genetic professionals may be able to help mitigate the realities of GD in adoption for their clients. Counselors could encourage clients to find adoption agencies where HD families have had success in the past, and select which agency they first approach with caution, because if they are deemed unsuitable once this then may extend to other adoption agencies. However, effectively addressing these issues likely extend beyond the realm of genetic counseling, requiring a range of approaches including: greater community awareness among a broader range of health professionals and social services, legal protections and non-discriminatory policies.

A few limitations should be considered. The original studies from which this data derived were not designed to collect information on the impact of genetic risk communication in adoption, which is a limitation in secondary analysis (32). Participants in the qualitative studies were not specifically recruited for, or asked about, their adoption experiences. Therefore, we cannot draw conclusions about whether these findings represent the full spectrum of implications that arise as a consequence of disclosure of genetic information in adoption. Another limitation was the small sample sizes, which do not permit demographic or group comparisons. Moreover, accounts also are based on situations that occurred in the past and rely on self-reports.

In conclusion, this study contributes new insights to the limited empirical evidence about the communication of genetic information in the context of adoption and demonstrates both ethical and practical challenges for adoptees and their birth relatives. With the increasing availability of genetic testing and the trend towards sharing of information between birth families and adoptees, formal studies are required to investigate GD and the communication of genetic risk. If such studies confirm the existence of ethical and practical challenges, guidelines should be developed for the appropriate
use and communication of genetic information in the context of adoption. These guidelines should reflect the interests of all stakeholders, including adoptees, birth families, genetic professionals, and the relevant adoption authorities.

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References