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Discrimination and stigmatization in work organizations: A multiple level framework for research on genetic testing

Lizabeth A. Barclay and Karen S. Markel

ABSTRACT

In this article, we examine how genetic testing may be the basis of a new form of exclusion in organizations. Testing reveals the genetic composition of an individual and can identify genetically linked conditions. Discrimination, related to genetic composition, may occur through either the stigmatization or categorization of individuals or groups based on genetic test results. The potential impact of genetic testing and the associated discriminatory processes on both employees and organizations is outlined. This research discusses individual (stigmatization, perceived discrimination, and symptom timing and visibility), organizational (actual discrimination, genetic testing use and accommodation) and environmental (regulatory agencies, genetic testing laboratories, insurance providers and genetic advocacy groups) factors that impact genetic testing. Lastly, we propose research questions linked to these factors to guide future organizational study.

KEYWORDS

discrimination ■ genetic testing ■ human resource management
■ organizational behavior

Genetic mapping is the ability to document an individual's genetic composition. Genetic variations may be found in any person, and can transcend membership in groups that have been discriminated against historically. Because of the completion of the human genome sequence, genetic testing is

likely to become more prevalent. After a brief introduction on the background of genetic testing, this article discusses the implications of testing as it relates to possible discrimination within organizations. Using a multilevel framework, we outline the factors important to the understanding of genetic testing and propose directions for future research.

The Human Genome Project

The Human Genome Project (HGP) was 'the international, collaborative research program whose goal was the complete mapping and understanding of all the genes of human beings' (National Human Genome Research Institute, 2005). The term genome refers to all genes of a species taken together (National Human Genome Research Institute, 2005). Scientists have indicated that the human genome can be considered a blueprint for cell building (National Human Genome Research Institute, 2005). By completing the human genome, specific gene locations can be mapped or identified. Because the sequence has been completed, scientists are now extending their research to work to identify, treat and eradicate certain diseases (Human Genome Project Information, 2003). For example, current research is focusing on the identification of genes related to asthma, diabetes, cancer and heart disease through the use of the haplotype map or HapMap (National Institute of Health, 2005). HapMaps detail blocks of genetic material that are inherited together as a package. Individuals from worldwide population groups have provided DNA samples to generate the HapMap data.

While no one would disagree with the benefits of increased medical knowledge, there is a growing body of literature that debates the use of information gained through genetic testing. This literature provides the groundwork for our proposed research agenda on genetic testing issues related to organizations. Authors have suggested outcomes of the project that are directly relevant to Organizational Behavior and Human Resource Management. Brock (1994) states, 'the HGP will eventually enable us to understand human motivational and character traits as having important genetic determinants' (p. 26). The focus on the identification of genes could lead to a reductionism approach. If society believes that employee characteristics and attendant behavior can be reduced to genetic causes, the ways individuals are selected, trained or evaluated could radically change without input from those in our field. Suzuki and Knudtson (1989) characterize this approach as society's 'impatience for easy answers to difficult questions' (p. 156). In addition, attribution of behavior to genetic composition ignores the complexities of the interaction of genetic inheritance and the environment.

Because genetic testing could influence organizational processes and individual employees, its use has the potential to create a multitude of adverse outcomes for both the firm and its constituents.

The stigmatization process

In his seminal work on stigmatization, Goffman (1963) relates stigma to 'virtual' social identity or an individual's imputed character. He refers to stigma as 'an attribute that is deeply discrediting' (p. 3). A stigma can either be immediately evident or it may be discovered. If immediately evident, the individual's social identity could be discredited by those who see it. If the attribute could be uncovered, the individual may live in fear of being discredited and hence take steps to modify his or her identity to escape notice. This dynamic is illustrated by the following genetic examples. Huntington's disease is a degenerative neurological disease that does not manifest its symptoms until middle age and leads to early death (Kenen & Schmidt, 1978). This condition may not be evident to others while it is in its latent form. Therefore, how could it be stigmatizing? The condition may still be stigmatizing for the carrier if they are reticent to engage in activities such as having children or making future plans because of fear of disease onset. A number of authors (e.g. Butchvarov, 1994; Cates, 1994) have discussed how knowledge of one's genetic make-up can have an impact on self-image. If one discovers, that they belong to the group of Huntington's carriers, the resulting change in self-image could invoke self-stigmatization. Self-stigmatization relates to how one perceives oneself (Reilly, 1978), and can affect the interpretation of communication cues from others. Hence stigmatization, as opposed to discrimination, can occur without others imposing constraints on one's opportunities. Conversely, Billings et al. (1992) report that a couple in which one person carried the Huntington's gene decided not to have biological children because of the risk of passing on the disease. They tried to adopt a child. The couple would not have attempted to adopt a child if they had not self-stigmatized. Additionally, there may be individuals who self-stigmatize who would not even consider adoption.

Jones et al. (1984) extend Goffman's work by applying the concept of stigma to social relationships. The mark of stigmatization affects the interactions between marked and unmarked individuals. The term marked is used to represent deviance from a norm. Huntington's carriers may be marked as they deviate from the genetic norm (i.e. most people do not carry the gene). With Huntington's, the mark can include visible physical symptoms related to the disease, as well as having passed a genetically linked disease to a future

generation. Both of these situations could affect the social relationships of Huntington's carriers as illustrated above. Additionally, as the disease progresses, affected individuals may be unable to interact with others, and couples who are known to possess the Huntington's gene are likely to be pressured to not have children.

Link and Phelan (2001) state that stigma is a result of the co-occurrence of labeling (mark), stereotyping, separation, status loss and discrimination. They would argue that it is not simply being a Huntington's carrier that would stigmatize an individual. Only if that condition accompanied some type of actual discrimination would stigmatization occur. Billings et al. (1992) report that the couple discussed earlier had their application for adoption rejected because the adoption agency was concerned that one of the parents had a 50–50 chance of developing the disease about the age of 50. The agency felt that this would disadvantage the adopted child since a parent could become disabled before the child reached adulthood. The potential parents, in this case, could have felt discriminated against because there is no guarantee that parents without Huntington's will survive until their children are adults. Using Crocker's (1999) claim that stigmatization has a situational component, this couple did not feel disadvantaged until they experienced discrimination. The adoption agency decision provided the context.

Based on the work of these authors, we believe that stigmatization involves an attribute or state that can lead to feelings of devaluation. These feelings can lead to self-imposed limitations in choice and life direction. In addition, if the attribute or state is visible, as opposed to hidden, the individual may be not only stigmatized by others through labeling, but may experience discriminatory treatment.

Social science researchers have considered stigmatization in relation to disability (Stone & Colella, 1996) and race (Evans, 2003). However, organizational researchers have neither investigated stigmatization nor discrimination based on genetics. According to Billings et al. (1992), genetic discrimination is 'discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the "normal" genome of the individual' (p. 477). In order to understand genetic discrimination, its tie to stigmatization and self-concept, and why this is of growing importance to organizations, it is first important to discuss how genetic discrimination is not another form of disability discrimination.

Genetic inequity: A special case of disability discrimination?

Asch (1996) states that, 'people who carry genes for disabilities or illnesses, and people who themselves are affected by those conditions, are likely to

experience employment problems that the civil-rights laws are not designed to solve' (p. 159). Other authors (Gostin, 1991; Hubbard & Henifin, 1985; Natowicz et al., 1992; Nelkin & Lindee, 1995; Nelkin & Tancredi, 1994) have also become increasingly concerned that advances in genetic testing techniques will lead to discriminatory employment practices.

Legislators around the globe have understood that genetic discrimination is a unique form of discrimination. For example, in the United States, The Genetic Information Nondiscrimination Act of 2007 specifically bars insurance companies from denying coverage or raising insurance premiums and prevents employers from making employment decisions based on genetic information in the private sector. Executive Order 13145 passed in 2000 grants these same protections for federal government employees. Genetic discrimination was not covered under other laws that protect from discrimination (e.g. disability, minority group).

Canada is experiencing a gap in legislation to prohibit genetic discrimination. The Canadian Charter of Rights and Freedoms does not specifically include genetic variations, but only the traditionally protected classes of race, national or ethnic origin, color, religion, sex, age or mental or physical disability as groups entitled to rights of equality.

Genetic discrimination has also been addressed in many documents produced within the European Union. The European Union's Charter of Fundamental Rights prohibits discrimination based on those with 'genetic features,' as well as sex, race, color, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation. In 2004, The European Commission's Research Directorate-General invited a group of experts from various backgrounds to discuss and provide recommendations on the ethical, legal, and social implications of genetic testing. This group was clear in its report regarding the issues of discrimination in the 11th recommendation in their report that specifically details how data derived from genetic sources should not be used in ways that discriminate in employment and insurance (McNally et al., 2004). However, the Charter is non-binding for member states, and the research report merely provides recommendations. States would not necessarily be liable for adherence in a court.

Australia has been actively trying to address the ethical, legal and social implications of the knowledge gathered from the Human Genome Project. The Australian Health Ethics Committee conducted a two-year inquiry on these issues and reported that genetic health information should and is likely to be treated in the same manner as other health information collected either for employment purposes or other common uses (ALRC 96, 2003). However, there is still no specific Australian legislation to address this issue.

Lastly, the German government has produced draft legislation that would allow employers to carry out genetic tests on people applying for jobs. This could potentially be used to identify hereditary genetic disorders through genetic screening (Burgermeister, 2004a).

To understand how genetic discrimination could occur, it is important to understand how genetic testing might be implemented. Organizations can employ two forms of genetic testing procedures. The first type of testing, genetic monitoring, involves testing an at-risk group of current employees for genetic changes that occur because of workplace exposure to chemicals or radiation. Monitoring is designed to find actual harm (Diamond, 1983). Employees working in a nuclear power facility may be monitored to determine whether genetic changes are occurring. Organizations may have a legal obligation to conduct such tests to prevent individuals from being harmed on-the-job.

In the second type of testing, genetic screening, individuals, regardless of job, could be tested to identify variations from the 'normal' human genotype. That is, the genetic test is not related to a specific job process; all applicants or employees could be screened. This information, even with limited dissemination, could lead to subtle discrimination. An individual diagnosed with a condition may find that they are excluded from important work or career-related information or opportunities. The individual would not be told that their condition was precluding advancement or training. Slowly the person would be put at a competitive disadvantage. Both screening and monitoring could influence the prevalence of stigmatization and discrimination of employees with certain genetic conditions. The possession of particular genetic alleles could reflect on how an employee is perceived by others, or even themselves.

In addition, the growth of the genetic testing industry for the public, may lead individuals to 'self-test' (Bowen et al., 2005; Lueck, 2005). This testing may result in non-disclosure on the part of job applicants, and may lead to individuals attempting to hide aspects of their identity. Fear that genetic testing could become a new method of differentiating employees for a variety of organizational processes could be driving part of the self-test industry. Suzuki and Knudtson (1989) even suggest that genetic testing itself could result in a caste system where the genetically stigmatized become unemployable.

There has been international debate by ethicists, legal scholars, medical professionals, and politicians that argues the appropriate use of genetic tests (e.g. Burgermeister, 2004a, 2004b; MacDonald & Williams-Jones, 2002; McNally et al., 2004; Staley, 2003). Based on this debate, it appears that genetic discrimination differs from other forms of disability discrimination

for several reasons. First, unlike attributes linked to disability (e.g. sight, hearing, mobility), the genetic attribute may not be readily visible or immediate. Second, current legislation does not clearly protect individuals from discrimination based on genetic information. Lastly, genetic information has an impact, not just on the individual employee or applicant, but their family as well. That is, genetic tests tell us about a constellation of individuals who share genetic information. This could influence the health insurance, and personal medical care of individuals not associated with the organization or individual requesting the genetic test.

Some authors (Begley, 2004; Nowlan, 2000) claim that genetic discrimination is overstated. These authors do not speak to the organizational concerns that will be discussed in this article. Their primary focus is on the blatant denial of insurance and/or employment. The issues surrounding genetic testing are important for academicians to understand and explore. The stigmatization and discrimination processes are the foundations of the individual experience of genetic mapping; however, this experience overlaps with employee roles. Our research centers on how the employee role is impacted by the implementation and (mis)use of genetic testing. We discuss factors at multiple levels that are relevant to understanding this phenomenon as well as detail research questions for scholars interested in examining these issues.

Factors involved in genetic testing

Table 1 presents factors to be considered when examining the impact of genetic testing as well as their related research areas. We first discuss the factors by level. This categorization then leads into a discussion of the various research areas, also classified by level. Although we categorize these factors by level of analysis, we do not assume independence across levels, rather factors in one level clearly may influence factors in another level.

Individual

The first level of organizational genetic testing factors concerns the individual. Applicants and employees may perceive that the organization treats them differently based on genetic conditions. These perceptions can have an impact on both the individual's attitudes and behaviors in that organization. In addition, the genetic condition may be differentially visible to others and lead to differential treatment. Individual factors include stigmatization, discrimination, and visibility and timing.

Table I Impact of genetic testing across multiple levels

	<i>Individual</i>	<i>Organizational</i>	<i>Environmental</i>
Factors involved	<ul style="list-style-type: none"> • Stigmatization • Perceived discrimination • Symptom timing and visibility 	<ul style="list-style-type: none"> • Actual discrimination • Genetic testing use • Accommodation 	<ul style="list-style-type: none"> • Regulatory agencies • Genetic testing laboratories • Insurance providers • Genetic advocacy groups • Organized labor
Research areas	<ul style="list-style-type: none"> • Job search behavior • Work affect 	<ul style="list-style-type: none"> • Risk management • Human Resource Management • Safety • Culture 	<ul style="list-style-type: none"> • Legal • Ethics • Social movements

Stigmatization

Every individual's genetic composition is unique. Unless a genetic disease is already manifest, an individual's genetic condition is invisible. Thus, genetic testing reveals previously undetected conditions. Hubbard and Henifin (1985) indicate that publicity aimed at preventing the spread of genetically linked diseases itself is 'an extreme form of stigmatization' (p. 241). Pressure to be tested by an organization exposes individuals to possible stigmatization. For example, if screening indicates that an employee cannot work near certain materials based on their genetic predisposition, they may have to be accommodated through reassignment. This reassignment can stigmatize an individual through the labeling process.

Extending this line of thought to another genetic condition, Michael Bérubé states that, 'The more people who think the condition [Down syndrome] is grounds for termination of pregnancy, the more likely it will be that you'll wind up with a society that doesn't welcome those people once they're here' (Harmon, 2005: 1). This argument could be extended to other conditions that are able to be detected through genetic testing in the future. Therefore, society may not only exert pressures that isolate or stigmatize individuals with a variety of genetic conditions, but put pressures on individuals to undergo testing to avoid medical and accommodation costs associated with completing a pregnancy that has been identified as having a genetic risk. This is another area where societal debate is likely to occur and generate controversy from those engaged in the social movement

surrounding genetic testing described later in this research. These decisions and debate will affect the relationships among individuals, their families and organizations. The increased ability to predict the future onset of genetic disease through the HGP ‘. . . will be that people who feel healthy and as yet suffer no functional impairment will increasingly be labeled as unhealthy or diseased’ (Brock, 1994: 29), and this labeling as indicated earlier can result in feelings of stigmatization.

Perceived discrimination

How genetic tests are administered, or used in the employment relationship, can influence whether applicants or employees perceive discrimination. We have previously presented examples of discrimination related to genetic condition. In addition, when an individual is not at risk for developing a genetic disease (i.e. they are heterozygote because they possess only one gene for a particular disease rather than the two that are necessary to actually develop the disease), they can still be marked or labeled as being a member of a genetic group. Thus, they may perceive their options within the organization as being limited. Billings et al. (1992) provide an example of such employment discrimination. A person who was classified as ‘unaffected carrier status [heterozygote]’ (p. 478) for Gaucher Disease, a metabolic disorder, was denied a job since he was ‘a “carrier, like sickle cell”’ (p. 478). Hence, the language of science itself can become a mark of stigmatization that leads to perceived discrimination. While the label ‘carrier’ has a specific biological definition, the societal connotation conjures images of isolation and quarantine. Job applicants have not disclosed chronic illnesses because they believed that they would be screened out of a job because the employer would perceive higher costs associated with such a hire. These applicants believed that the employer would find other ‘reasons’ not to hire them (Lublin, 2004).

The belief that being diagnosed as a member of a genetic disease group would invoke discrimination is not an unreasonable assumption. Individuals who have a family history of Huntington’s experience social pressure to be tested to determine whether they are carriers of the disease. For example, a young teacher in Germany was denied employment for failing to undergo a test of her genes. When school authorities learned that the applicant’s family had a record of Huntington’s disease, they wanted to find out whether she could also develop the illness. A court ruled in the woman’s favor that the test should not be included as part of the employment screening process (Hessler, 2005).

Symptom timing and visibility

Genetic tests will be able to determine if an individual is predisposed for a specific disease, however, the ability to predict if, and when, an employee will develop symptoms remains unclear. Murry et al. (2001) indicate that all individuals have genetic markers; however, not all result in disease. Even if specific gene markers are identified, the interaction effect of genes also needs to be considered. For example, the presence of two genetic components might result in another condition.

Clinical variability must also be considered (Billings et al., 1992). Individuals who possess a gene for a disease will not demonstrate the same level of impairment. Billings et al. (1992) discuss several cases of individuals with Charcot-Marie-Tooth, a neurodegenerative disease. In one case, an individual was denied employment (after a job offer) because she had the disease even though her symptoms were not noticeable. In another case, the individual was denied automobile insurance even though he had a stellar driving record. Murry et al. (2001) state that penalizing an individual for a marker that might not actually result in a disease poses a 'significant ethical issue' (p. 372). The question arises as to whether an individual should be differentially treated within the work relationship because of a condition that would not be detected if it were not for genetic testing.

Organizational

Just as genetic testing can impact individual employees, testing can also have an effect on the organization. Organizational factors to be considered include actual discrimination in selection and placement, the decision to use genetic testing, and accommodation of employees based on genetic screening.

Actual discrimination

Liability may take many forms for the organization. Genetic tests could be linked to protected class status. For example, in the United States, certain groups (e.g. racial, ethnic, age) are protected under the law against discriminatory practices. Any type of organizational decision (e.g. screening, work responsibilities, promotion) based on genetic test results that link to protected status could open the door to legal problems. In addition, depending on future legislative developments, organizations may have a legal liability to handle genetic test results using a specific protocol. However, there does not appear to be any progress in developing protocols for either individual refusal for genetic tests or handling this personal information, within the organizations,

from any of the likely government agencies, for example, occupational health and safety organizations.

Genetic testing use

As mentioned earlier, unlike some other forms of discrimination within organizations, genetic discrimination is a factor to both the employee and their family. Despite the fact that an employee is currently healthy, possessing a particular genetic allele may mark them in some way. Even if an employee is heterozygous for a genetic disease, the employee's children may manifest the disease if the other parent also contributes a disease-linked gene. Ethnic or gender discrimination in the work environment is generally not based on family relationships. Nicholson (2000) purports 'since genes are inherited and found not only in an individual but also in blood relatives, a genetic test involves many people and could invade the privacy of them all' (p. 3). A regular medical exam for an employee would not involve the collection of medical data from family members. Hence, with genetics, the testing transcends immediate organizational relationships. Organizations considering genetic testing would have to factor the role of family genetics into this decision-making.

Additionally, organizations considering the use of genetic testing would have to determine whether they needed to use a monitoring or a screening protocol. Like other types of medical testing, these protocols influence employee attitudes and behaviors. For example, if an organization routinely monitors employees for hazardous materials exposure (e.g. nuclear plant workers), workers might adopt certain attitudes or beliefs about the role of these tests within the context of their employment. If the tests reveal certain harmful levels of toxins, employees may be removed or reassigned positions, a direct consequence of the monitoring process.

Accommodation

In some cases organizations may have to reassign employees to different work environments based either on genetic monitoring or because of the actual or possible on-set of genetically related disabilities. However, recent research by Baldrige and Veiga (2006) suggests that unsupportive organizational cultures can develop when employees seek accommodation help. This change in culture could be related to both co-workers' beliefs that they are at risk in a possibly hazardous environment as well as the management of the organization feeling imposed on to rearrange work. Co-workers might also begin to stigmatize these individuals for this reassignment based

on genetic information and begin to exclude them from 'fitting' in to the workplace.

Environmental

The use of genetic testing could affect the organization's interaction with its environmental stakeholders, such as regulatory agencies, genetic testing laboratories, insurance providers, genetic advocacy groups, and labor unions. The interaction of the organization and these stakeholders may lead to policy decisions related to the implementation of genetic testing.

Regulatory agencies

Articles in legal journals continue to discuss possible litigation related to genetic discrimination and how it might be positioned within the current legal frameworks. There is also discussion, described earlier, about the role national governments need to take in passing legislation to deal with the factors and issues surrounding genetic testing (e.g. discrimination and privacy concerns).

In the realm of public policy, there seems to be interest in investigating how genetic discrimination is different from, or similar to, other forms of discrimination. The US Equal Employment Opportunity Commission (EEOC) regulators report that individuals are protected against employment discrimination if it is due to the perception that they are predisposed to become ill. However, they also note that this policy position is still to be tested in court (Reynolds, 1997). Someone experiencing genetic discrimination may be unsure as to how or if they have legal protections against this disadvantage. Also, organizations concerned about the regulation of genetic testing will encounter a similarly ambiguous legal environment.

Genetic testing laboratories

As genetic research progresses, organizations will need to assess the accuracy of genetic tests (Diamond, 1983). In the 1980s, the reliability and validity of such tests was debated. The 1983 United States Office of Technology Assessment (United States Congress, Office of Technology Assessment, 1983) report stated that none of the tests reviewed met their standards for use in an occupational setting. The US Task Force on Genetic Testing explored the state of genetic testing in 1995 (Holtzman, 1999) and found that there were still problems with the safety and effectiveness of genetic testing at that time within the US. With the completion of the HGP, genetic testing will become

more accurate, and hence lead to increased testing in a variety of environments. Organizations will have to proactively seek information about test validity either through their own education efforts or outsourcing this expertise.

Insurance providers

The HGP has opened debate in the area of risk management (Peters, 1998; Pokorski, 1997; Steinberg, 2000). This debate has focused on the ability of insurance underwriters to accurately assess risk on the basis of medical data that includes genetic information. These underwriters suggest that all insured, regardless of genetic background, will have to pay higher premiums if genetic information is not considered. That is, significant data would not be entered into risk equation and would underestimate insurance costs. In the United Kingdom, the insurance industry purports that even if the result of a genetic test indicates that you are at a higher risk for getting a disease it is only relevant to life and some health insurance (not motor, household or private medical insurance). There is no implication that one's application will be denied based on one's genetic make-up, each case will be judged on its merits. There is no protection against insurance discrimination in the United Kingdom (The Association of British Insurers, 2007). What is interesting to note in the United Kingdom is that there are guidelines as to when an individual must disclose the results of genetic testing. For example, these guidelines relate to the amount of life insurance under review.

Genetic advocacy groups

There are already a number of advocacy groups based on genetics that are actively posting information related to genetic testing. The US Cystic Fibrosis Foundation does not endorse prenatal testing (Harmon, 2005). The Huntington's Disease Society of America has an advocacy link on their website (HDSA, 2004) that states they have goal to educate others about genetic discrimination. However, the Huntington's disease association of Australia's website does not have any information about advocacy; this organization seems to be centered on the daily concerns of managing the disease for the individual and their family while providing a clearinghouse on the latest medical research. This is likely because Australia has its own advocacy groups focused on the issues of disability rights (e.g. Disability Rights Victoria, Genetic Support Network Victoria). As testing becomes more common, organizations may find themselves dealing with either genetic- or disease-centered advocacy groups.

Organized labor

Depending on the industry, regulatory agencies may support or even mandate the use of genetic testing to protect workers from harm related to adverse work conditions. At the same time, organized labor is likely to object to an organization's use of genetic testing to either recruit or allocate work for its membership. Trade unions are beginning to understand that genetic testing is an issue to be proactive about in the future. For example, the International Association of Machinists and Aerospace workers included a session on Genetic Testing in the Workplace at their meeting last summer (International Association of Machinists and Aerospace Workers, 2007). Future collective bargaining agreements may outline what tests can be used for specific organizational purposes. For example, will it be more acceptable to use genetic monitoring in hazardous work environments (e.g. nuclear plants) than in relatively safe environments (e.g. clerical employees). The European Trade Union Confederation¹ has already called for a ban on the use of genetic testing in the workplace for all employees (Trades Union Congress, 2003).

Research questions related to genetic testing in organizations

The previous section clearly details the impact genetic testing can have on multiple levels of analysis. This section will outline how scholars can examine these issues through suggested research questions at each level. The research questions are grouped into categories traditionally found in organizational research in the hope that frameworks currently used in research in these areas can guide efforts on the genetic factors identified in the previous section. These research questions are only a starting point. As genetic testing related to organizations becomes more prevalent, additional questions should surface.

Individual

Individuals play a key component not only in how they are affected by genetic testing, but also as it relates to their own organizational behavior. Initial work on individual level research can focus in two main areas. These areas include job search behavior and work affect.

Job search behavior

As more individuals undergo genetic screening as part of the employment application process, one's genetic background may add elements to job

search behavior. Without legal mandate, organizations may begin to require the disclosure of this information if they can deem it relevant for the position. Individuals seeking employment will have to decide whether to both disclose genetic information to potential employers and/or undergo screening tests. In addition, because genetic conditions have a family link, will employers now require a detailed family genetic history as part of the screening process? Scholars will have to investigate the job search behavior of individuals as it relates to the role of genetic screening and genetic information disclosure in order to better understand how these issues may play a role in the employment process. Perceived discriminatory practices may have an impact on search behavior.

- 1a. Will applicants with genetic conditions be predisposed to underreport those conditions in employment screening?
- 1b. Will there be a reputation effect for organizations that genetically screen? In other words, will these organizations be regarded as less desirable employers by potential applicants regardless of personal genetic condition?

Work affect

Individuals have a variety of work-related reactions to their employment experience. They may feel positively or negatively satisfied, committed or involved, with regard to their employment experiences. Work affect is widely studied. For example, organizational commitment is commonly examined due to its relationship to a variety of job behaviors such as performance, citizenship, and withdrawal. For the sake of brevity, this article will focus on commitment as an example of how work affect relates to genetic testing. Research has identified different forms of commitment: affective, continuance and normative commitment (Heffner & Rentsch, 2001; Meyer et al., 1989, 2002). Affective commitment involves emotional attachment to the organization, continuance commitment involves the perceived cost of withdrawing from the organization (commitment to the organization because an individual *has to*), and normative commitment involves perceived obligation to the organization. Having a genetic disease, may affect the form of an individual's commitment. Supporting this line of thought, Mellor et al. (2001) indicate that having many non-work obligations is related to continuance commitment (feeling of being 'trapped' at an organization). Therefore, in countries which tie medical care to employment, employees may be bound to an employer to keep insurance coverage.

- 2a. In countries that tie medical care to employment, will employees have higher levels of continuance commitment (tied to employer based on their provision of health care benefits) if they are genetically 'marked' than if they are not?

Shifts in commitment could be related to employee perceptions of the existing psychological contract. Dabos and Rousseau (2004) suggest that a degree of reciprocity exists in such contracts. The degree to which the organization is perceived as shifting or 'violating' such a contract by instituting genetic testing could also result in a shift to continuance commitment. Conversely, if genetic testing is perceived as being conducted for the well-being of employees, there could be a shift to a more emotional form of attachment, affective commitment.

- 2b. Will individuals with diagnosed genetic markers possess different levels of commitment than individuals without diagnosed markers?
- 2c. Will the form of commitment vary by diagnosed versus non-diagnosed status?
- 2d. Will the perception of reason for testing differentially shift individuals into continuance and affective commitment?
- 2e. How does the perceived genetic discrimination of an individual relate to their work affect?

Organizational

Organizational level research related to genetic testing is focused in a variety of areas. These include risk management, human resource management, safety and culture. Although the organization interacts with the environment in several of these areas, the research focus in this section deals with processes within the organization.

Risk management

The use of genetic information within the field of underwriting presents an opportunity for decision-making researchers. If legislation is passed that prohibits the use of genetic information in the area of underwriting and risk management, research determining the impact of this decision could be studied. A survey of geneticists concerning the use of genetic information by insurance companies indicated a strong consensus for limited or no access without permission of the individual who had been tested (Wertz & Fletcher, 1989). Stone (1996) indicates that adverse selection will occur unless the

industry itself has access to this medical information. That is, an individual who has been diagnosed with a genetic condition would seek additional insurance at a higher participation rate than individuals without genetic conditions. However, this actual decision-making process has not been studied. At the organizational level, an understanding of the new context of risk management (especially in the insurance industry) is important to consider if genetic testing becomes a part of the medical diagnostic landscape.

- 3a. If genetic testing is provided as a health care benefit option, will employees use this benefit or pay for testing out-of-pocket for self-initiated testing to avoid organizational access to medical information?

Risk managers may have to manage the genetic testing process as part of liability management. An additional responsibility for these managers may also include determining the organizational protocol to handle the results of genetic testing, whether part of the employment or health care process (Markel & Barclay, 2007b).

- 3b. How will insurance providers change decision strategies in risk management as the number of clearly identified and testable genetic markers increases?

Human Resource Management

Traditionally, Human Resource Management has been engaged in the recruitment, selection, and evaluation of employees. Organizations have already begun to use genetic testing as part of their screening process. When organizations use any method to separate groups of individuals to qualify for an organizational reward, whether it is getting a job, a new assignment, or access to training programs, issues of diversity and potential discrimination arise. The use of genetic screening is likely to be a diversity management issue because many genetic conditions appear to have protected class links (e.g. race, gender). As Nicholson (2000) indicates, 'current regulations do not allow testing based on racial origin, but, for many genes, the results of the tests may help define race' (p. 3). For example, US employers cannot ask applicants for information on their racial background. If these same individuals are genetically tested, their racial backgrounds will be discovered. Organizations and their Human Resource Management programs will have to defend the use of genetic testing especially if protected classes are increasingly screened out of certain jobs as a result (Markel & Barclay, 2007a). Flynn (2000) suggests that employers 'become proactive' and clearly explain

the reasons why they use genetic testing to alleviate concerns about the improper use of such technology.

- 4a. Will genetic testing for conditions with no protected class links be more widely implemented in screening and monitoring programs than those that do link?
- 4b. How will protected class status impact the use of genetic testing, in general?

As previously mentioned, the visibility and controllability of genetic markers may affect employee-supervisor interaction. Stone and Colella (1996) suggest that when employees suffer from disabilities beyond their control, supervisors may act leniently toward them. For example, does an employee with sickle cell receive differential treatment from supervisors and does this treatment vary by visibility, controllability, or severity of impairment? This differential treatment can impact the career trajectories through potential bias in the performance review process.

- 4c. Does the reassignment of job responsibilities due to genetic markers impact supervisor treatment of these individuals?
- 4d. Will this treatment vary by degree of impact in change of work responsibilities?

Safety

Diamond (1983) has expressed concerns about how genetic screening might affect the safety of the work environment. She suggests that by being able to identify the 'hypersensitive' employees in hazardous environments, organizations may be tempted to relocate employees rather than change the environment. Using the example of carpal tunnel syndrome, an employer could modify the work environment to reduce repetitive stress. Diamond's (1983) concern is that those predisposed to the condition would be screened out and transferred to another work area to reduce their risk, while other individuals would remain in the unchanged environment. These less sensitive employees could still develop carpal tunnel. On one level, organizations may consider whether to transfer employees or redesign the work by assessing the total cost and benefits to both the employees and organization. However, as seen in the Ford Motor Company Pinto decision (Gioia, 1992), the salience of cues to make such a decision is often not clear. Gioia (1992) describes the script schema he used when making recall decisions for Ford. In the Pinto case, his

response to cues led to executive dismissal of the reports that revealed problems with the Pinto gas tanks. In the case of job redesign, perceptual processes and risk projections could interfere with such analysis. Organizations may have to examine the cost–benefit analysis of employee transfer versus work redesign as well as consider the cues leading to such an analysis.

All organizations typically have an obligation to provide employees with working conditions free from hazards that may cause illness, injury or death as regulated by governmental agencies designed to monitor occupational safety. Safety includes protecting workers from undue harm; this includes providing conditions that will not cause genetic mutations. Women have already experienced work segregation because of their ability to bear children. Workers, fearful of exposure to adverse conditions that may cause genetic mutations, may avoid employment in these organizations.

- 5a. Will employees labeled as ‘non-sensitive’ in a hazardous environment demand the safety accommodations provided to ‘sensitive’ employees?
- 5b. What cues help or hinder a cost/benefit analysis of employee transfer versus work redesign?

Culture

Organizational culture provides individuals with an identity as well as shaping their behavior by helping them make sense of their surroundings (Smircich, 1983). The nature and specificity of an organization’s culture could clearly impact how its members make sense of their organizational genetic testing experiences. Trice and Beyer’s (1993) work focuses both within the organization and on the interaction of an organization and its environment. They state that an organization can have a distinctive umbrella culture; however, at the same time subcultures can exist. Genetic mapping may now delineate subcultures that have often been drawn along boundaries of race, gender, and age. Organizational culture contains the espoused norms and beliefs and therefore has a great impact on employee experiences. In order to understand how the culture may impact the use of genetic testing, future research should gather information on the values and norms that evolve through the use of this technology.

- 6a. What types of organizational cultures will be supportive of employees with markers for genetic disease?
- 6b. How will the organizational subcultures change because of genetic testing?

Environmental

Organizations considering or using genetic testing exist in a changing environment. There are expectations that the legal environment will continue to evolve. Additionally because genetic testing is a sensitive issue, there will be increasing debate related to the ethical use of genetic testing in society. Lastly, scholars need to examine a new social movement arising internationally centered on the individual's right to genetic privacy.

Legal

There are many legal areas that remain unresolved and ambiguous where genetic testing is concerned. Jones (2001) indicates that legal issues with regard to genetics center on privacy and discrimination. Progress in examining the legal issues relevant to the use and dissemination of genetic mapping is likely to be left to judicial and legislative work. As issues are resolved in the court system, precedent will be set. As with many other areas of organizational life, the handling of genetic information is likely to be imposed through legislation. Governments may also provide an incentive for organizations to offer genetic testing (e.g. tax incentives), especially if the results minimize health care costs through prevention of debilitating symptoms. Research is needed to assess the degree to which legal actions result in changes to organizational policies and procedures.

- 7a. How does public policy change organizational policies related to medical testing?
- 7b. How is genetic information handled within organizations as compared to other medical information?

Ethics

The research in this area centers on how individuals with genetic differences are or should be treated by society (or organizations as representatives of society). An interesting example of health care delivery in the US illustrates this issue. Billings et al. (1992) received information from a physician about a family with a child who was diagnosed with cystic fibrosis. This family was provided insurance through a Health Maintenance Organization (HMO).² Prenatal testing for a second child determined that the fetus had the disease. The doctor reported that the HMO considered withdrawal of coverage for both the pregnancy and future pediatric care. When threatened with legal action, the HMO changed its position. Similarly, Harmon (2005) reports that

'some bioethicists envision a dystopia where parents who choose to forgo genetic testing are shunned, or their children denied insurance' (p. 1). Ethicists grapple with the similar issues such as of the genetic screening of embryos to avoid gender-associated diseases (e.g. hemophilia).

There are even ethical concerns on how genetic information should be communicated. Wyld et al. (1992) report that Huntington's patients have a high suicide rate because the disease is so debilitating and its onset consistently occurs in middle age. Murry et al. (2001) believe that employers 'must consider the psychological impact on the employee and the employee's family and provide the necessary support mechanisms that mitigate any adverse psychological impact' (p. 373). Murry et al. (2001) outline five guiding principles to adhere to in screening programs. These include: autonomy (or voluntary testing), privacy (no information to third parties), justice (what must be done to preserve a diverse gene pool), equity (access to information, resources), and quality (oversight and ethical review). We are unaware of any research that has empirically investigated the degree to which these principles are followed.

- 8a. What support systems are implemented by organizations using genetic testing protocols?
- 8b. Do organizations with Employee Assistance Programs (EAPs)³ communicate more effectively with their employees than organizations without these programs?

Social movements

Many of the environmental constituents discussed earlier are taking steps to promote what they perceive as fair and accurate programs surrounding genetic testing. For example, trade unions are beginning to include genetic testing as a discussion topic at their national forums. Disease advocacy organizations are increasing attention on the potential (mis)use of this information in employment and insurance decisions. There is a growing concern internationally that society, as a whole, needs to be mindful of the knowledge obtained through the Human Genome Project and the resulting stream of genetic tests. For example, the Council for Responsible Genetics publishes a genetic bill of rights that includes a statement on freedom from genetic discrimination and the right to privacy concerning an individual's own genetic composition (Board of Directors of Council for Responsible Genetics, 2000). This organization fosters public debate about the social, ethical and environmental implications of genetic technologies. Researchers need to examine how this social movement might exert pressure not only on

individual behavior toward genetic testing, but the stance that organization's adopt and the legal context in which we operate.

- 9a. As the social movement surrounding genetic technologies becomes more visible, what is the impact on individual, organizational and legal behavior?

Methodological considerations

There is clearly no defined body of research dedicated to the issues of genetic testing in organizations. Much of the research is either anecdotal or the result of judicial work. However, before making recommendations about how to conduct needed research a few uncertainties must be discussed.

Research related to genetic testing involves acquiring data that are highly sensitive and personal. This information could seriously alter an individual's (or their family's) life by revealing them as a carrier of a potentially chronic or terminal condition. Hence acquiring data may be problematic. Depending on future legislation and judicial decisions, one possible source of nonspecific data on the prevalence and use of genetic testing may be through government sources. Another possible source of information may be private genetic testing centers. Researchers may be able to gather subjects using such facilities with informed consent. Because of these options, organizational researchers may wish to partner with others in order to conduct the research. For example, working with advocacy organizations may also permit collection of both individual and group level data in a more systematic manner. Similarly, partnering with labor organizations, insurance organizations and other environmental stakeholders may also provide data to address supraorganizational questions.

One way to overcome some of the other privacy challenges in our proposed research area is to conduct initial research in a laboratory setting. For example, risk assessment decision-making could be examined using a policy capturing approach. Additionally, while we are hesitant to use research focused on 'paper people,' some of the basic studies concerning the evaluation and treatment of individuals could be done with controlled descriptions of situations with systematic varying of genetic condition, onset of symptoms, etc. Experimental research that examines the job seeking behavior of potential applicants with genetic conditions in relation to various organizational characteristics would be a good starting point.

More extensive quantitative and qualitative methods could be employed to explore these questions. Individuals that have taken a genetic

test could be surveyed about both the intent to use the information, longitudinal organizational issues (e.g. career progress, health care benefit eligibility), and even resulting illness/condition. Organizations could be surveyed concerning their decisions to use genetic testing. While several older surveys of this nature have occurred (e.g. US Congress, Office of Technology Assessment, 1983), newer efforts could add dimensions discussed in this article. Differences in approaches could be examined both within an industry as well as among different industries.

Qualitative data could supplement this information and gather more information on subjective experiences that may not be captured through the survey research. For example, researchers could conduct case studies to examine the underlying processes organizations use to decide what strategy, work redesign or employee transfer to adopt in relation to their safety management practices. Lastly, Bonham et al. (2005) indicate that research in this area must be both well designed and effectively communicated because misrepresentation of the information can result in stigmatization.

The only example of research specifically targeted toward the experience of genetic discrimination has been conducted in Australia. Researchers conducted a large longitudinal study on the legal and social context of genetic discrimination. Researchers used survey, interviews, and archival data to examine the role of individuals, insurers, and the legal system in the discrimination experiences of individuals and/or their relatives who are assumed, or known, to have genetic predispositions to specific conditions, disorders or diseases (Genetic Discrimination Project, 2007).

Conclusion

We have discussed issues central to genetic testing as well as proposing the relevant factors and research questions that can serve as a starting point for scholars in this area. Answering these questions will be challenging. Because this research will use often-private medical information, access to data needed to conduct the research may not be forthcoming. Research designs that can be used may result in generalization concerns. However, the area of genetic testing as it relates to employees and organizations is too important to ignore despite these methodological concerns. Unless organizational researchers are informed and actively working on the questions we pose in this article, the field runs the risk of letting others address issues central to our discipline.

Organizations are beginning to collect related types of information from their employees. The Chrysler Group (US) recently announced a new

initiative that offers 18,000 salaried workers discounts on their health insurance for next year if they submit to an illness-detecting blood test (Norris, 2005).⁴ These workers must have their blood pressure checked and be tested for diabetes and high cholesterol to earn a discount on their health care premiums. Workers can earn an additional discount for completing a lifestyle questionnaire. It is unclear what the next step in employee testing may be or how that information can be used. This example of employee screening reinforces the timeliness of our inquiry.

Some organizations are responding to employee fears concerning the use of genetic information in the workplace. IBM has recently announced in a memo to all employees that the company was revising its policies to prevent the use of genetic information in making personnel decisions, therefore removing the potential for employment discrimination from genetic information (Barrett, 2005). This illustrates how some organizations are taking their own initiatives in regards to the use of genetic information. How these initiatives relate to other aspects of organizational function, such as insurance costs and risk management, remains to be seen.

On a theoretical note, we have employed the use of stigmatization theory to provide the mechanism whereby the unique discrimination from genetic testing may operate. As described earlier the stigmatization and discrimination process may influence the individual's experience of genetic testing either in or out of the employment context. Regardless of the testing context, these individuals carry that information into their employment roles. This research discusses that connection through the relevant factors that exist at the individual, organizational and environmental level. The research questions can be used to both examine the stigmatization and discrimination process as well as the belief that genetic testing discrimination operates differently than other conditions of employment discrimination that have been previously examined. The legal arena is already handling this area of regulation and judicial precedent differently.

This research has been the first attempt to synthesize the current research on genetic testing as it pertains to organizational issues. We have extended the use of the existing theory on traditional employment discrimination to a new area. Together, the theoretical grounding and suggested empirical propositions provide a path for future research.

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Notes

- 1 The European Trade Union Confederation, together with the other European social partners, works with all the EU institutions in developing employment, social and macroeconomic policy.
- 2 An HMO manages an individual's entire medical care delivery. Through the use of a primary physician, all approvals for additional care (e.g. specialists, second opinion, testing) must be granted from the managed care provider.
- 3 Employee Assistance Programs are found in organizations in the United States. They are programs designed to assist employees in providing confidential help in managing their mental health or stress. Often they include mental health services, assistance with securing child or elder care services, and stress management.
- 4 In the US, health insurance coverage is typically tied to the employment relationship. Many employers offer some type of health care insurance for their full-time employees (and families).

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