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Support Seeking or Familial Obligation: An Investigation of Motives for Disclosing Genetic Test Results

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Abstract

Genetic test results reveal not only personal information about a person's likelihood of certain medical conditions but also information about their genetic relatives (Annas, Glantz, & Roche, 1995). Given the familial nature of genetic information, one's obligation to protect family members may be a motive for disclosing genetic test results, but this claim has not been methodically tested. Existing models of disclosure decision-making presume self-interested motives, such as seeking social support, instead of other-interested motives, like familial obligation. This study investigated young adults' ($N = 173$) motives to share a genetic-based health condition, alpha-1 antitrypsin deficiency, after reading a hypothetical vignette. Results show that social support and familial obligation were both reported as motives for disclosure. In fact, some participants reported familial obligation as their primary motivator for disclosure. Finally, stronger familial obligation predicted increased likelihood of disclosing hypothetical genetic test results. Implications of these results were discussed in reference to theories of disclosure decision-making models and the practice of genetic disclosures.

Keywords

disclosure; decision-making; familial obligation; genetics; motives

Prior to the Human Genome Project's completion in 2003, people could not know whether they had genetic mutations associated with a genetic-based health condition until symptoms actually appeared (Mclean, 1998). Since the project's completion, genetic tests have become increasingly, widely available; used for both predictive and diagnostic purposes; and applied in personalized medicine (Burke & Zimmern, 2004; Evans, Skrzynia, & Burke, 2001; Guttmacher, Porteous, McInerny, 2007). Genetic tests can confirm suspected diagnoses, predict the likelihood of future illnesses, detect the presence of carrier states in unaffected individuals (whose children may be at risk), and predict responses to therapy (genome.gov, 2013). Therefore, a person's decision to disclose his or her genetic information to a family member is a powerful one, with potentially life-altering implications (Klitzman, 2009).

Genetic information reveals personal information about a person's likelihood of certain medical conditions and also information about their genetic relatives (Annas, Glantz, & Roche, 1995). One's obligation to protect family members may be a motive for disclosing genetic test results, but this claim has not been tested. This study investigated whether

familial obligation is a salient motivation for genetic disclosures, and whether it predicts disclosure likelihood; therefore, extending existing models of disclosure decision-making that presume self-interested motives, such as seeking social support, instead of other-interested motives, like familial obligation. Such research is important, because people motivated by familial obligation more than social support may share different kinds of information when they make their disclosures.

Disclosing Health Information

Drawing from Greene, Derlega, and Matthews (2006), self-disclosure is the voluntary, intentional, deliberate decision to reveal, verbally and/or nonverbally within an interpersonal, dyadic encounter. The voluntary, intentional, deliberate decision to disclose is also the basis for why current models assume disclosures to be goal-driven (Chaudoir & Fisher, 2010; Greene et al., 2006; Omarzu, 2000). Therefore, how disclosure messages are presented is an important feature of self-disclosure; it allows people to achieve their goal (Greene et al., 2006). Goals include managing uncertainty (Afifi & Weiner, 2004; Greene, 2009) and attaining social benefits via social support (e.g., self-expression, self-clarification; Altman & Taylor, 1973; Derlega & Chaiken, 1977; Derlega & Grzelak, 1979; Jones & Archer, 1976).

The discloser, in these models, is described as an autonomous decision-maker, thoughtfully weighing the pros and cons of each treatment decision (d'Agincourt-Canning, 2006) and weighing risks and rewards of disclosure (e.g., Greene et al., 2006; Petronio, 2002). Grounded in social exchange and interdependence theories (Kelley, 1979), many disclosure decision-making models posit that people make disclosure decisions based on the subjective value of self-disclosure (Derlega, Winstead, Mathews, & Braitman, 2008). These theories consider self-oriented rewards to be catharsis, self-clarification, and instrumental support, whereas costs of disclosing are rejection, shame and embarrassment (Derlega & Grzelak, 1979; Derlega, Metts, Petronio, & Margulis, 1993).

Patients may also have more other-focused concerns about disclosure. For example, patients have expressed concerns such as causing family members harm by delivering difficult information (e.g., stigmatization and insurance discrimination; Forrest et al, 2003; Ormondroyd et al., 2007) or feelings of guilt associated with passing genetic diseases (d'Agincourt-Canning, 2001; Forrest et al., 2003; James, Hadley, Holtzman, & Winkelstein, 2006). There has also been documented fear of causing tension within the family regarding decision making (e.g., family planning, financial; James, et al., 2006).

Disclosing Genetic Information

Disclosing genetic test results is associated with many of the same outcomes of general health disclosures, but scholars (e.g., Hallowell et al., 2003) argue that the familial nature of genetic information does distinguish it from other types of medical information. This distinguishing quality of genetic information, therefore, may lead genetic self-disclosures to be associated with different goals than other health information self-disclosures and additional concerns regarding individual and familial rights and obligations. In order to

explore the motives driving genetic self-disclosure, for the purpose of this study, the definition of self-disclosure has been narrowed to the voluntary, intentional, deliberate decision to reveal, verbally and/or nonverbally within an interpersonal, dyadic encounter, genetic test results to a blood relative who does not know about the information.

Family Considerations of Genetic Tests and Disclosure

The manner in which genetic conditions are inherited has social and psychological consequences for both the discloser and related family members (James et al., 2006). Knowledge of genetic risk can impact the individual's psyche, relationships, and family identity (McConkie-Rosell & DeVellis, 2000; Rolland & Williams, 2005). Communication literature on disclosure indicates that people weigh the potential risks and rewards of disclosure (Magsamen-Conrad, 2012) and their right to privacy to decide what information to share and with whom (Petronio & Martin, 1986; Petronio, 2002). Although people may feel obligated to share genetic information with relatives, the discloser is under no legal obligation to disclose. Bioethics literature (Doukas & Berg, 2001; Dupras & Ravitsky, 2013; Gilbar, 2007; Laurie, 2002; Parker & Lucassen, 2004) has considered the tensions between the patients' rights to privacy and confidentiality versus family members' rights to receive information that is clinically relevant to them. For genetic disclosures, then, disclosers may be compelled by a sense of responsibility or duty to disclose genetic test results with relatives (d'Agincourt-Canning, 2001; McGivern et al., 2004; Ormondroyd et al., 2007).

Multiple Motivations Involved in Genetic Disclosures

The decision to share genetic knowledge is influenced by how people consider the benefits and burdens of potentially intervening in their own health and that of others (Williams & Schutte, 1997). Studies on health disclosure (not including genetic self-disclosure) have identified several motivations for disclosure and nondisclosure, which have been organized into self-, other-, relationship-focused and situational-environmental categories (Derlega, Winstead, & Folk-Barron, 2000; Derlega et al., 2008).

Self-focused reasons for disclosure are related to tangible and psychological benefits of disclosure for the discloser, including catharsis, help/support, and self-clarification. This category is similar to the motivation assumed in many disclosure decision-making models founded on social exchange and interdependence theories. An example would be disclosing genetic test results in order to access emotional or tangible help in coping with the condition. *Other-focused motives* are centered on how sharing information creates benefits or risks to others (Derlega et al., 2000; 2008). In the genetic context, other-focused motives might be based on a "duty to inform" a relative because it is the right thing to do. A person's moral compass guides their decision to disclose their genetic information to a blood-related relative due to relevant risk and/or family planning implications. *Relationship-focused reasons* for disclosure concern the benefits for the relationship between discloser and target recipient, such as increased intimacy or similarity (Derlega et al., 2000). A relationship-focused reason for genetic disclosure would be to foster a bond with a relative based on a shared genetic vulnerability to a genetic condition. Relationship-focused reasons are important, but this study focuses only on the self- and other-oriented reasons.

Some disclosers may be motivated by concerns for the other (Afifi & Steuber, 2009; Greene et al., 2003, 2006). People who carry genetic mutations may feel the need to inform relatives of the test results, because the genetic status of one person has biological, psychological and relational implications for his or her family members as well (Dancyger, Smith, Jacobs, Wallace, & Michie, 2010). They may also feel a duty to inform relatives of the availability of screening and predictive genetic testing so that family members can act responsibly in relation to their genetic risk (Etchegary et al., 2009). A person's felt moral obligation to their at-risk family members is a reason reported for genetic testing in the first place (Hallowell et al., 2005). Thus, the concept of duty to disclose genetic test results to relatives may appear in the form of *familial obligation* (Arribas-Ayllon, Sarangi, & Clarke, 2008).

Family Obligation

Familial obligation is the responsibility family members feel to warn and protect each other from effects of genetic mutations (Forrest, Delatycki, Skene, & Aitken, 2007; Nuffield Council on Bioethics, 1993; Nycum, Avard, & Knoppers, 2009). Genetic information, then, is personal and familial (Nycum et al., 2009). Indeed, in a review of ethical and clinical guidelines and policies that address the communication of genetic information to families, a majority of the published guidelines stated that genetic information is relevant to both the person receiving it and their family members (Forrest et al., 2007). One guideline stated that nondisclosure of genetic information to family members is viewed as "morally condemnable" (National Consultative Ethics Committee for Health and Life Sciences, 2003). And, more recently, the American Society of Human Genetics and Genetic Alliance sponsored, in partnership with a local Washington D.C. television station, the Talk Health History Campaign (TalkHealthHistory.org, 2009) as a family health history public service announcement to increase awareness about the importance of sharing family health history information.

Genetic Case: Alpha-1 Antitrypsin Deficiency

The disclosure decision-making process and the motives guiding it were explored with a specific genetic-based condition: Alpha-1 antitrypsin deficiency (AATD). AATD is a hereditary condition that occurs when there is a severe lack of alpha-1 antitrypsin protein in the blood. This deficiency can lead to serious liver damage that can cause cirrhosis in people of all ages and lung disease in adults. AATD is one of the most common (American Thoracic Society, 2003), potentially lethal heredity disorders (Colp, Pappas, Moran, & Lieberman, 1993) but is, unfortunately, under-recognized (Stoller et al., 2005). This is partly because AATD-related symptoms mimic other conditions such as asthma, leading frequently to a five- to eight-year gap between onset of symptoms and diagnosis (Stoller et al., 2005). The prognosis for AATD is highly variable: some carriers show symptoms and others dominant for the deficiency experience no symptoms (Wienke, 2012). This contributes to the uncertainty associated with this disorder.

Definitive AATD diagnosis requires a blood test to determine the alpha-1 antitrypsin levels in the blood (Alpha-1 Foundation, 2006). Early diagnosis allows patients more time to prepare for the manifestation of symptoms, receive counseling for healthier lifestyles, and

gain access to relevant treatments (e.g., augmentation therapy). It can also facilitate detection of AATD in other relatives before symptoms arise (Campos, Wanner, Zhang, & Sandhaus, 2005). This would allow relatives to become aware of their own health risks and to make decisions to, for example, avoid toxins and air pollutants, which are known to exacerbate AATD (Alpha-1 Foundation, 2006; American Thoracic Society, 2003) or other decisions that could maintain or improve their health (Alpha-1 Foundation, 2010). Therefore, it is important to empower patients to get tested and disclose their results with relatives (Alpha-1 Foundation, 2006).

However, there is risk associated with disclosing AATD to others. The National Human Genome Research Institute Director, Dr. Francis Collins (2000), testified that, “The misuse of genetic information has the potential to be a very serious problem, both in terms of people’s access to employment and health insurance and the continued ability to undertake important genetic research.” Such discrimination has been documented for those with AATD, such as Terri Seargent (Jones, 2001). Although policies exist to safeguard against discrimination, genetic discrimination can take on many forms, including indirect, implicit and subtle, which can make it difficult to document or prove (Klitzman, 2010). Beliefs about genetic stigma in regards to the control one has over the condition can be held against people diagnosed with AATD (Smith, Wienke, & Baker, 2013) as well. A similar phenomenon has been observed in studies examining family disclosure and mental illness stigma, in which family members attribute the manifestation of the mental illness to personality flaws or situational factors (Kreisman & Joy, 1974). For example, the disclosure of bipolar disorder, which is an illness that runs in families, to family members, was met with negative affective responses (e.g., worry, anxiety, discomfort) and stigmatizing behaviors such as labeling and “special treatment,” among other responses (Bauer, 2011).

The Present Study

The goals of this study were to identify whether social support and familial obligation were motives for disclosing genetic test results to relatives, and whether one type of motivation was more predictive of disclosure than another. This study focuses on young adults (18–26), who are an under-researched sample for genetic disclosure studies (Smith, Greenberg, & Parrott, 2014), but are old enough to undergo genetic testing, receive results, and make subsequent decisions (Feero, Guttmacher, & Collins, 2008). More compelling, young adults are able to make autonomous decisions about their health but may still heavily rely on their family for support and advice. As such, self-oriented motivations (e.g., social support) and other-oriented motivations (e.g., family obligation) may be particularly salient. While the general hypothesis is that stronger motivations to disclose predict greater likelihood of disclosure, this study provides insight into which motivations matter.

Methods

Participants

A total of 173 undergraduate participants were recruited from a multiple-section, required course at a large, eastern university. Participants were required to be at least 18 years of age to participate. Of these participants, 89 (51%) identified as female, 83 (48%) as male, and 1

(1%) unidentified. Participants on average were 20 years old (*Mode*=20, *SD*=1.13, *Minimum* = 18, *Maximum* = 23 or older) and held a junior class standing (51%). Participants self-identified as Caucasian (84%), Asian (10%), African-American (4%), and American Indian or Alaskan (2%); a few participants self-identified as Hispanic (6%). Most participants reported that they were not adopted (98%), and had at least one sibling (92%). Participants lived in different social environments, including living alone (8%), with other students (83%), other roommates that were not students (2%), with parents/relatives/guardians (5%) or with a spouse/significant other (2%).

Procedures

A university's institutional review board approved the study. After providing consent online, participants were presented with a survey that opened with a hypothetical scenario. Participants were asked to imagine that they had recently been diagnosed with a genetic condition called alpha-1 antitrypsin deficiency (AATD) and provided a simple fact sheet on the condition. A genetic counselor reviewed both items to ensure medical accuracy. Participants were also asked to judge the scenario and fact sheet for credibility.

After reading the scenario and fact sheet, participants were prompted to specify one blood-related family member (relation and first name only) to possibly disclose to and evaluate their disclosure likelihood (Greene et al., 2012) and breadth of disclosure (Greenberg & Smith, 2013). Participants were then asked to indicate how much certain specified reasons (Derlega et al., 2000) motivated their decision to disclose. Questions on demographics, family, previous experience with genetics, and previous knowledge of AATD were included at the end of survey.

Measures

Likelihood of disclosure—Four items (adapted from Greene et al., 2012) were used to measure the likelihood of disclosing (e.g., *I'm likely to tell him/her about my diagnosis in 24 hours after learning about my test results*). The response options were *strongly disagree*, *disagree*, *neutral*, *agree* and *strongly agree*, which were later coded for analysis (1 = *strongly disagree* to 5 = *strongly agree*). The confirmatory factor analysis (CFA) for a single-latent-variable model showed reasonable goodness-of-fit: *CFI* = .97, *SRMR* = .03, *RMSEA* = .14 (90% CI, .06, .24). The items were averaged (Cronbach's α= .81, *M* = 4.36, *SD* = 0.64, *Skewness* = −0.59, *Kurtosis* = −0.76); higher scores indicate higher likelihood.

Social support motivation—Five items (based on Derlega et al., 2000) were used to measure how much social support would influence their decision to disclose the genetic test results to the blood relative (e.g., *My family member would give me the comfort I need*). The response options were *not at all, a little, somewhat, strongly,* and *definitely*, which were later coded for analysis (1 = *not at all* to 5 = *definitely*). The CFA for a single-latent-variable model produced these goodness-of-fit indices: *CFI* = .99, *SRMR* = .02, *RMSEA* = .07 (90% CI, .00, .14). The items were averaged (Cronbach's α= .91, *M* = 4.34, *SD* = 0.70, *Skewness* = −0.94, *Kurtosis* = 0.45); higher scores indicated stronger motivation.

Familial obligation motivation—Five items (based on Derlega et al., 2000) were used to measure how much familial obligation would influence their decision to disclose the genetic test results to the blood relative (e.g., *If there is a chance that my family member might have the genetic mutation I want them to find out*). The response options were *not at all, a little, somewhat, strongly,* and *definitely*, which were later coded for analysis (1 = *not at all* to 5 = *definitely*). The CFA for a single-latent-variable model produced these goodness-of-fit indices: *CFI* = .92, *SRMR* = .07, *RMSEA* = .17 (90% CI, .12, .23). The items were averaged (Cronbach's α= .80, *M* = 4.17, *SD* = 0.71, *Skewness* = −0.56, *Kurtosis* = −0.39); higher scores indicated stronger motivation.

Primary motive—In addition, participants were also asked to identify their primary reason for disclosure. Participants were asked to choose only one primary motive from the following list: *to attain support or help in managing your diagnosis, a duty to inform and/or protect blood-related family members, a desire to educate other of your diagnosis, to vent or share feelings of distress, the family member would find out anyway, it seemed like the right thing to do,* and *the family member is available to me.*

Breadth of disclosure—Nine items (adapted from Greenberg & Smith, 2013) were used to measure the amount of information, or breadth, that would be shared about the genetic test results and the AATD diagnosis with the specified relative (e.g., *I would tell him/her that other blood relatives could have these abnormal genes that lead to AATD*). The response options were *not at all, a little, somewhat, strongly,* and *definitely*, which were later coded for analysis (1 = *not at all* to 5 = *definitely*). The CFA for a single-latent-variable model produced these goodness-of-fit indices: *CFI* = .94, *SRMR* = .07, *RMSEA* = .08 (90% CI, .06, .12). The items were averaged (Cronbach's α= .92, *M* = 4.25, *SD* = 0.65, *Skewness* = −0.38, *Kurtosis* = −0.93); higher scores indicated greater breadth of disclosure.

Results

Descriptive Statistics

When asked if the following blood-related relatives were alive and known, participants reported the resulting: mother (99%), father (98%), brother (59%), sister (59%), aunt (92%), uncle (94%), female cousin (93%), and/or male cousin (93%). Then, when prompted to choose one of these relatives as the recipient of the hypothetical disclosure, about half of the participants chose their mother (54%); the other half of the sample selected their father (20%), brother (11%), sister (10%), cousin (3%), aunt (1%), or uncle (1%). There was a gender difference in the selected relative, X^2 (6, 166) = 17.59, $p<.05$, *Phi* = .32: more female (67%) than male participants (40%) selected their mother. More male participants (27%) than female participants (14%) selected their father. The same percentage of male and female participants selected their sister (10%); more male (17%) than female participants (6%) selected their brother.

A minority of participants were familiar with genetics due to taking a course in college (32%) or through genetic testing (6.9% had personally been tested, 18.5% had a relative undergo testing). Not surprisingly, only 7 individuals (4%) had previously heard of AATD.

Motives to Disclose

Primary motivation—The results for primary motivation appear in Table 1. The most popular reason was to attain social support. The second and third most popular reasons related to duty and the ethical choice. These results answered the overall research question: both social support and duty are reported as primary reasons for disclosure.

Primary motivations did not differ by participants' gender, X^2 (6, 166) = 10.83, *ns*, *Phi* = .25, or age, $F(6, 165) = 0.86$, *ns*, $R^2 = .03$. Participants who selected their mothers differed in their primary disclosure motivation from those who selected other relatives, X^2 (6, 166) = 20.02, $p<.05$, *Phi* = .34. The most frequent motivation reported by those disclosing to their mothers was social support (55%), followed by a duty to inform (30%), right thing to do (8%), to vent feelings (3%), to educate about the diagnoses (2%) or because she would find out anyway (2%). In contrast, those disclosing to other relatives reported primary motivations of social support (31%), duty (28%) and right thing to do (21%), followed by availability (4%), desire to educate (2%), and finding out anyway (1%).

Motivation scales—Participants, on average, reported that familial obligation was a strong motivation to disclose genetic test results to their selected blood relative ($M = 4.17$, $SD = 0.71$). Social support, on average, was also reported as a strong motivation guiding the disclosure decision ($M = 4.34$, $SD = 0.70$). One-sample *t*-tests show that both averages are above the mid-point of the scale (3), $t(172) = 21.65$, $p<.05$ and $t(172) = 25.31$, $p<.05$ for familial obligation and social support, respectively. These results also showed that both social support and duty were strong motivations involved in participants' decision to disclose.

The level of familial obligation was tested to assess whether it differed by participants' demographics. Familial obligation differed by gender, $t(170) = 2.14$, $p<.05$; female participants reported stronger familial obligation ($M = 4.28$, $SD = 0.71$) than male participants ($M = 4.05$, $SD = 0.70$). The strength of familial obligation was not related to age, $t(172) = -.001$, *ns*. Familial obligation was a stronger motivator for those selecting to disclose results to their mothers ($M = 4.30$, $SD = 0.64$) than other relatives ($M = 4.07$, $SD = 0.70$), $t(170) = 2.15$, $p<.05$.

These differences replicated for the strength of social supportive motives. Social support differed by gender, $t(170) = 4.47$, $p<.05$: female participants were more motivated by social support ($M = 4.56$, $SD = 0.59$) than male participants ($M = 4.11$, $SD = 0.73$). The strength of social support as a motivator was not related to age, $t(172) = .10$, *ns*. Social support was a stronger motivator for those selecting to disclose results to their mothers ($M = 4.51$, $SD = 0.62$) in comparison to other relatives ($M = 4.15$, $SD = 0.74$), $t(171) = 3.58$, $p<.05$.

Motivations and Likelihood of Disclosure

Zero-order correlations between social-support motives, familial-obligation motives and likelihood of disclosure were estimated (see Table 2). The results showed that a greater likelihood of disclosure was positively correlated with stronger familial obligation and with social support. Notably, the two motives were also strongly correlated.

Comparison tests—To assess whether a relatively stronger familial obligation or social support motive predicted likelihood of disclosure, a motive discrepancy score was created, in which participants' familial obligation scores were subtracted from their social support scores ($M = 0.17$, $SD = 0.59$). The correlation between disclosure likelihood and preferential motive was not statistically significant, $r(172) = .13$, *ns*. These findings suggest that the relative strength of familial obligation and social support motives were not related to greater likelihood of disclosure.

An ANCOVA was conducted with likelihood of disclosure as the dependent variable, disclosing to mothers as the independent variable, and age and strength of familial obligation as covariates. The model was statistically significant, $F(3\ 168) = 17.29$, $p<.05$, $R^2 = .24$. There were statistically significant effects for familial obligation, $F(1,168) = 39.43$, $p<.05$, $\eta^2 = .19$, and for disclosing to mothers, $F(1,168) = 4.56$, $p<.05$, $\eta^2 = .03$, but not for age, $F(1,168) = 2.13$, *ns*, $\eta^2 = .01$. The likelihood of disclosure was positively related to stronger familial obligation (unstandardized $\beta = 0.38$, $SE = 0.06$) and selecting to disclose to their mothers (M=4.44, $SD = 0.57$) instead of other relatives ($M = 4.17$, $SD = 0.65$).

Breadth of Disclosure

Participants were asked the likelihood of sharing particular kinds of content if they decided to disclose the genetic test results to their selected blood relative. Ten types of content were explored to assess whether they represented latent classes of disclosure based on the types of content shared. Latent class analysis (LCA) is used to empirically test whether people fall into mutually exclusive and exhaustive subgroups (Lanza, Collins, Lemmon, & Shafer, 2007). Conceptually, LCA is similar to other latent variable models such as factor models, in that it attempts to capture latent constructs from measurable variables. LCA is used when the latent construct is categorical (Collins & Lanza, 2010). PROC LCA (Lanza et al., 2007) requires categorical observed variables to measure the categorical latent variable. It provides two kinds of parameters: the likelihood of providing a particular response to a measured variable conditional on the set of classes, and the likelihood of membership in a latent class. LCA also provides goodness-of-fit indicators for models, which are used to determine the best number of classes (e.g., a three-class or four-class model). Proc LCA (Lanza et al., 2007) was used to calculate fit indices for two- to seven- class models using 500 sets of random starting values for each test (see Table 3 for fit indices). The four-class model was selected because it had the lowest Akaike's information criterion (AIC) scores (Collins & Lanza, 2010). LCA generates two parameters to characterize these underlying classes of health states (see Table 4). The first is the likelihood of membership in a class; the second is the likelihood of reporting that they intended to share particular content in their disclosure.

Respondents in the largest group (58%), labeled Full Disclosers, indicated that they were likely to disclose all disclosure breadth items: short- and long-term diagnosis information, including the probability of developing the condition and/or a symptom. The second largest group (20%), labeled Certainty Avoiders, indicated that they were likely to disclose all disclosure breadth items except those items pertaining to probability. They were, however, likely to share statements that described the possibility of developing AATD-related symptoms or specific conditions. Respondents in the Present-Focused Disclosers class

(14%) indicated that they would share only the disclosure breadth items relating to the present or immediate future, regardless of the language or probabilities used and whom the diagnosis information pertained to. Respondents in the Minimalist class (8%) indicated that they were likely to disclose only to their specified blood relative, and indicated that they would not share any disclosure breadth items.

Covariate analysis—A covariate analysis tested whether reporting a relatively stronger social support motive (vs. familial obligation) for the disclosure (the discrepancy score) and selecting one's mother as the disclosure recipient predicted membership in the disclosure-breadth classes, using Full Disclosers as the reference class. Both variables were statistically significant (see Table 5). Those who selected mothers for the disclosure had lower odds of being in any of the limited breadth classes in comparison to the Full Discloser class. Those motivated by social support more than familial obligation had over twice the odds of being in the Minimalist and Certainty Avoider classes, but lower odds of being in the Present-Focused Disclosers class, in comparison to the Full Discloser class.

Discussion

The goal of this study was to explore the motives driving disclosure of one's genetic test results. The results showed that familial obligation was reported as a primary motivator for the hypothetical disclosure of AATD to a blood relative. In addition, familial obligation predicted the likelihood of disclosing hypothetical genetic test results.

Familial Obligation as Motivation to Disclose

There is ongoing debate about who holds the right to share information about a genetic test between at-risk relatives. Who owns the genetic information and the ethical and moral obligations related to revealing or concealing information are central to the debate and could impact the health of relatives. Research Question 1 examined whether other types of motivation besides social support, namely familial obligation, did exist and were present in participants' decision to disclose. The data revealed that familial obligation exists as a motivation and was the second most common answer participants choose as their primary motivation.

Negotiating rights and obligations—Familial obligation has been examined in relation to disclosure decision making and secret revealing, but its prominence as a motivator for disclosure, in this study, may be a result of the context and the special nature of genetic information. Since genetic test results can have an overpowering and direct effect on both the person receiving them and their blood-related relative(s), the person cannot just consider their self when deciding whether to self-disclose or not. People can learn how to address health problems from their family (Gilotti, 2003) based on the rules the family has established on what is appropriate and inappropriate to share when a health crisis occurs (Petronio, 2002). Little is known, however, of how families' health disclosure rules apply when it is genetic information needed to be disclosed. Petronio's Communication Privacy Management (CPM) theory (2002) translates well in this context and could offer insight into how a person considers the rights and obligations that come with privately owning genetic

information and the collective privacy boundary that is established when genetic test results become co-owned with a family member (Petronio, 2010).

The process of disclosure decision making—The genetic disclosure decision-making process, while narrow in scope, is complicated and involves multiple factors. Disclosure models (e.g., Cycle of Concealment Model, Afifi & Steuber, 2010; Disclosure Decision-Making Model, Greene, 2009; Revelation Risk Model, Afifi & Steuber, 2009) identify specific factors that influence the assessment of coming to a disclosure decision. For instance, the Revelation Risk Model (RRM) (Afifi & Steuber, 2009) acknowledges that people may reveal a secret if they feel the target recipient needs to know or has a right to the information. Revealing this information may be considered risky, invoking judgment and discrimination, but concealment could be guilt-inducing and lead to rumination (see Wegner, Sneider, Carter, & White, 1987). Although self-oriented reasons (i.e. attainment of help and support) continue to play a predominant role in disclosure of genetic test results, the fact that reasons for disclosure may vary in specificity, from broadly relevant to circumstantially specific (Goldsmith, Miller & Caughlin, 2008) coupled with the existence of other motives begs for further exploration both in this health context and others (e.g., infectious, chronic).

Motivated Young Adults

As previously explained, the results indicate that there is more than one reason for disclosure of genetic test results. This strong motivation to disclose may be due to the hypothetical nature of the study; it may reflect how young adults have been socialized to think about genetic testing and its disclosure; or it may reflect generalized, sociological changing in sharing (e.g., through social media) and salience of reasons to share. However, it is important to note that results indicate that the reported reasons for disclosure are not mutually exclusive.

Characteristics of disclosure—Possibly as a function of young adulthood, the majority of the sample (74%) chose either their mother or father to potentially disclose to. Interestingly, familial obligation was the greater motive for disclosure when participants chose either parent. This result bolsters those found by Derlega & Winstead (2001) in which people reported telling family members of their HIV-positive status because of a sense of duty or loyalty (see also Greene et al., 2003). In regards to home life, familial obligation was not the greater motive for disclosing only among the subsample that reported living with a husband/wife/significant other/domestic partner. Again, this may be a function of young adulthood. It could also be that the concept of family and feelings of responsibility shift when a person is beginning their own family. The want for social support from relatives, instead of feelings of obligation, may increase as the young adult begins a life with a significant other.

In reference to demographics, analyses indicated that all races (i.e., American Indian or Alaskan, Asian, and White) except Black or African American identified familial obligation as a greater motive for disclosure to a genetic relative than social support. Those who identified as Hispanic indicated familial obligation as a greater motive for disclosure as well. The results did show gender effects: females reported being more motivated by a sense of

familial obligation than their male counterparts. Previous research shows that females are more likely to discuss genetic disease risk than men (Wilson et al., 2004) and are more likely to initiate disclosure and engage in open communication about genetic disease risk (Chivers Seymour, Addington-Hall, Lucassen, & Foster, 2010; d'Agincourt-Canning, 2001; Forrest et al., 2005;).

Young Adults' Disclosure Breadth Profiles

The LCA on breadth of disclosure further supports the notion that young adults are motivated to disclose their genetic test results. The results showed that a four-class model fit the data well, with four categories representing the spectrum of disclosure breadth.

The Minimalists indicated a likelihood to disclose their genetic tests results to a specific relative, but disagreed with all disclosure breadth statements. This class may be a function of the relative chosen earlier in the survey. As the covariate analysis indicated, Minimalists were more motivated to disclose for social support but less likely to select their mothers as the disclosure recipient when compared to the Full Discloser class. The lack of sharing might be attributed to protecting others and/or themselves (e.g., Goldsmith, 2009), in hopes of preserving the social support offered. Similarly, fears of genetic discrimination and stigma may prevent a detailed disclosure in hopes that providing less information will diminish the discloser's and recipient's risk of experiencing negative repercussions of disclosure. Previous research found similar results such that people who were really afraid of the consequences of revealing their secret were more likely to conceal the secret or "strategically" disclose (Afifi & Olson, 2005; Afifi, Olson, & Armstong, 2005; Afifi & Steuber, 2009). Being denied access to health insurance, employment, education, and loans (Clayton, 2003; Murray & Livny, 1995; Wertz & Fletcher, 1991) are among the common fears of disclosing genetic test results. In any case, this profile described a minority of the sample; young adults are motivated to disclose, and the majority are willing to share more than the minimum amount of information.

Present-Focused Disclosers, unlike Minimalists, are willing to disclose more than just their genetic test results, but do have firm limits on their breadth of disclosure. When the genetic information refers to the potential future development of a condition and/or symptom, Present-Focused Disclosers indicated that they would not disclose such information to their specified relative. The focus of their disclosure is geared to what the discloser and the target recipient can do now or what they may immediately experience. Perhaps this limited disclosure breadth is a function of Present-Focused Disclosers' motivation for disclosing. The covariate analysis showed that members of this class are more likely to disclose out of familial obligation and less likely to disclose for social support when compared to Full Disclosers. Feeling obligated to disclose may emphasize the need to share only what is relevant and what can be done immediately to prevent AATD-related symptoms or protect others from the effects of AATD.

Certainty Avoiders were willing to share more than Present-Focused Disclosers but were not willing to share statements that had to do with probability (e.g., "I probably don't have asthma"; "He/she probably has AATD"). They were, however, willing to disclose statements relating to the possibility of developing a condition or symptom. It may be that the word

"probably" conveys too much certainty. Certainty Avoiders may only feel comfortable sharing "just the facts" or those statements that cannot be disputed in hopes of not causing undue concern or fear, especially as related to AATD (e.g., uncertainty regarding the diagnostic process; Sandhaus, 2010; and variability in prognosis; Wienke, 2012). Since Certainty Avoiders are more than twice as likely to be motivated to disclose due to want of social support than Full Disclosers, it could be that the certainty of probability statements was perceived to be too tedious or too threatening to incite support, and sharing would feel more like an obligatory task. This finding is somewhat consistent with Checton and Greene (2012) and Omarzu's (2000) argument that as the personal utility of the disclosure reward increases (e.g., obtaining support), the greater the breadth of disclosure.

The Full Disclosers, which was the majority of the sample, agreed with all of the disclosure breadth statements. This group may operate under the notion that knowledge is power. For instance, people have reported feeling able to accomplish their goals of helping oneself and other relatives take action (d'Agincourt-Canning, 2001). Therefore, sharing the full range of information related to their genetic test results allows both the discloser and recipient to be prepared and makes it more likely that the discloser will receive social support from the recipient. This argument corresponds with the reasoning behind Greene's (2009) disclosure decision-making model (DD-MM), that people are more likely to disclose when a diagnosis is perceived to be relevant to others, especially if the diagnosis can be passed to others, and that people disclose health information to acquire social support. These results are also consistent with those of the covariate analysis, which showed that Minimalists and Certainty Avoiders were twice as likely as Full Disclosers to be motivated to disclose for social support, and Present-Focused Disclosers were less likely. Representing more than half of the sample, it makes sense that the Full Discloser class is comprised of young adults motivated to disclose for both social support and out of a familial obligation.

Limitations

Although we hope that this study's findings are indicative of the motives reported by any person with a genetic condition, we cannot test generalizability within the present study. The genetic context is complex, and the evaluation of both information regarding test results and information about the recipient may make it impossible to generalize across genetic conditions. Furthermore, these data were collected in one state in the northeastern United States, which makes it unclear whether results would generalize to other areas or countries or represent the variance in cultures' emphasis on familial obligation in the family unit.

The study also required participants to elaborate on a hypothetical scenario in which they were tested and diagnosed with AATD. Participants were not actually burdened with Alpha-1 or the decision to disclose to a genetic relative and, consequently, may not respond the same way to the measures as someone who is faced with the reality of being diagnosed with a genetic condition. In addition, this was a cross-sectional study. Disclosure within relationships is an ongoing dyadic process (Greene, 2009). Future research should prospectively study disclosures to better capture the disclosure process and to improve causal inferences between motivations and disclosure.

Future Research

Studying disclosure is essential for understanding how health information is managed in terms of illness and relationships. The disclosure processes model (DPM; Chaudoir & Fisher, 2010) offers a framework from which to examine when and why self-disclosure may be beneficial and the DD-MM (Greene, 2009) specifically focuses on the disclosure of health information, but neither model has been applied to the genetic context. Research shows that people learn of their risk for a genetic condition through previous generations' experience with the condition (Parrot, Miller-Day, Peters, & Dillard, 2010; Peterson, 2005), but research on the intergenerational genetic disclosure decision-making process from the young adult perspective is scant. This study attempted to examine both: the young adult's genetic disclosure decision-making process about disclosing to a blood relative. However, our understanding of how social support and/or familial obligation influence the disclosure decision-making process is limited. Future research could recruit young adults that have tested positive for a genetic mutation, such as AATD, and examine their decision-making process.

Similarly, this study only examines the disclosure process of young adults. However, many individuals are diagnosed with a genetic mutation at other life stages. The diagnosis experience, motivation to disclose, and the decision-making process can be very difficult for a young adult just establishing themselves and their independence, versus an older adult that is more established in their career and has a family of their own. The functions of self-disclosure may vary depending upon the discloser's gender and stage in lifespan (Parker & Parrott, 1995). Future research should investigate how people of different age groups are motivated to disclose.

Finally, the literature discussed in this study highlights several elements that may affect self-disclosure that have not all been methodically tested using a disclosure model such as the DPM (Chaudoir & Fisher, 2010). People's sense of personal responsibility, genetic beliefs, family orientation and communication patterns, and cultural values could inform profiles of motivation and likelihood to disclose genetic information. It is possible that any or all of these variables are cofounders that, if measured, could be better labeled as moderators or mediators. Future theory extension and development should investigate the intertwining nature of family communication environment, information management, and ethical ownership of information, especially in reference to health information.

Implications

There is literature on disclosure spanning a number of stigmatized conditions, including abuse, mental illness, HIV/AIDS, and sexual orientation, that examine the causes and courses of disclosure and its implications on people's well-being (e.g., Chaudoir & Fisher, 2010), but there is a dearth of theory-guided literature investigating the process of communicating genetic information. Many people are managing genetic conditions such as AATD and are making habitual disclosure decisions about sharing information regarding their condition. This study opens the door for scholars to expand their investigation beyond what individual, family, and disease-related factors influence genetic self-disclosure and

suggests that theoretical guidance is needed to explore the process that ties a person's goals, considerations, and outcomes together.

Results of the current study also have several implications for the study of communicating about genetic risk. A potential focus for future research might be the narrative approach to communicating personal and familial genetic risk to understand how narratives change based on motivation, privacy management, relational closeness, familial communication patterns, or uncertainty related to genetics. There is a growing body of research examining genetic testing from the viewpoint of the person being tested (Polzer, Mercer, & Goel, 2002), but the focus has not been on the person's active construction of meaning given to their genetic test results and genetic risk.

Conclusions

If individuals understood the motivations behind disclosure and specific communication habits (perhaps through genetic counseling appointments), they may use this information to improve communication with family members about genetic risk based on the goals of their disclosure. For example, if a person chooses to disclose to their parent for social support, the disclosure may contain more storytelling with emotional elements, to elicit support or catharsis. Motivating families to negotiate rules about revealing and concealing private information (Petronio, 2002) may help increase genetic disclosure.

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Table 1

Primary Motivation to Disclose ($N = 173$)

Variable	Frequency
To attain support or help in managing your diagnosis	44%
A duty to inform and/or protect blood-related family members	29%
It seemed like the right thing to do	14%
To vent or share feelings of distress	7%
A desire to educate other of your diagnosis	2%
The family member would find out anyways	2%
The family member is available to me	2%

Table 2

Correlations among Reason for Disclosure and Likelihood of Disclosure ($N = 173$)

	M	*SD*	1.	2.
1. Social support motive	4.34	0.70	--	
2. Familial obligation motive	4.17	0.71	.65*	--
3. Likelihood of disclosure	4.36	0.64	.59*	.47*

$p < .05$ level

Table 3

Comparison of Latent Class Models

Number of classes	G^2	AIC	BIC	*df*
2	309.06	351.06	417.28	1002
3	254.83	318.83	419.74	991
4	**214.30**	**300.30**	**435.89**	**980**
5	197.82	305.82	476.10	969
6	183.40	313.40	518.36	958
7	169.55	321.55	561.20	947

Note. Boldface type indicates the selected model. AIC = Akaike's Information Criterion; BIC = Bayesian Information Criterion; *df* = degrees of freedom.

Table 4

Item-Response Probabilities for Four-Class Model Given Latent Class Membership

	Minimalists	Present-Focused Disclosers	Certainty Avoiders	Full Disclosers
	8%	14%	20%	58%
I probably don't have asthma.	.00	**.68**	.22	**.69**
My genes predispose me to have AATD	.14	**.85**	**.64**	**1.00**
Other blood relatives could have these abnormal genes that lead to AATD	.00	**.81**	**.86**	**1.00**
I'm getting new treatments for my breathing issues.	.06	**.82**	**.75**	**.99**
I need to see a specialist.	.34	**.61**	**.80**	**.98**
I would tell him/her to get tested for AATD.	.35	**.70**	**.72**	**1.00**
He/she probably has AATD.	.34	.15	.48	**.65**
I may develop lung disease.	.14	.00	**.97**	**1.00**
I may develop liver damage.	.14	.18	**1.00**	**.99**
I may develop certain chronic conditions due to my genetic predisposition to AATD.	.14	.48	**.94**	**.99**

Note. Percentages reflect the number of participants likely to be in each profile. Cells contain the likelihood of *agreeing* with the concept. Likelihoods over 50% have been bolded.

Table 5

Covariate Analysis with Full Breadth as the Referent Class

	Minimum		Avoid long term info		All but Asthma		LL^2
	OR	***B***	***OR***	***B***	***OR***	***B***	LL^2
Motivated by social support > familial obligation	2.04	0.48	0.48	0.72	2.39	0.87	9.25*
Selected mothers for disclosure	0.22	0.33	0.33	−1.54	0.67	−0.40	9.85*

*$p < .05$