Using the Theory of Motivated Information Management (TMIM) and Family Communication Patterns (FCP) to Understand Individual Decisions to Undergo Genetic Testing for Huntington’s Disease (HD)

A thesis submitted to the College of Communication and Information of Kent State University in partial fulfillment of the requirements for the degree of Master of Arts

by

Kaitlin R. Banduch

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Thesis written by

Kaitlin R. Banduch

B.A., Augustana College, 2011

M.A., Kent State University, 2014

Approved by

Rebecca J. Cline, Ph.D., Advisor

Paul Haridakis, Ph.D., Director, School of Communication Studies

Stanley T. Wearden, Ph.D., Dean, College of Communication and Information
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Chapter I

Introduction

Huntington’s disease (HD) is a rare genetic disease that attacks the nervous system, affecting both physical and psychological functioning (Walker, 2007). HD is a late onset disease. This means that symptoms do not occur until the individual is 30 to 50 years old (Kent, 2004). However, becoming aware of their HD status before the onset of the disease is important to at-risk individuals so they can begin to engage in secondary prevention measures that could slow the progression of the disease and increase longevity. Individuals can become aware of their HD status before the onset of symptoms via predictive genetic testing. The present study examined the decision-making process of individuals regarding whether to undergo predictive genetic testing, which would definitively diagnose their HD status.

Afifi and Wiener’s (2004) Theory of Motivated Information Management (TMIM) was used in conjunction with the conversation orientation dimension of Koerner and Fitzpatrick’s (2002a) Family Communication Patterns (FCP) framework to examine the decision-making process regarding genetic testing of individuals at risk for HD. The conversation orientation was chosen to provide potential insight into the family communication practices surrounding HD and related predictive genetic testing and to examine if these practices influenced the individual’s decision-making process. TMIM was used to examine the decision-making process explicitly regarding a chosen information management strategy (i.e., undergoing the predictive genetic test for HD). Also, the study combined TMIM and the conversation orientation from FCP in a unique way in an effort to examine the roles that individual and family communication have in individuals’ decision regarding genetic testing for HD.
Rationale

Predictive genetic testing allows individuals to better understand their risk for genetically-linked diseases. This testing has become widely used for individuals at risk for genetic abnormalities. Genetic testing involves one of three different scenarios: (a) assessing an individual’s pre-disposition for genetically-related diseases, such as breast cancer and diabetes, (b) determining if an individual has an autosomal recessive genetic disorder, such as sickle-cell anemia, or (c) determining if an individual has an autosomal dominant genetic disorder, such as Huntington’s disease (Walker, 2007).

The first scenario assesses pre-dispositions for genetically-related disease. Identified genetic abnormalities only signal an increased risk (or pre-disposition) to develop certain diseases. The tests do not diagnose the presence of a disease. The test detects genetic abnormalities that interact with other factors, such as environment and lifestyle, to increase the risk of developing the disease. Past communication research has focused on this type of genetic-risk assessment for numerous diseases, ranging from breast cancer to colon cancer (e.g., Ersig, Hadley, & Koehly, 2011; Katapodi, Munro, Pierce, & Williams, 2011).

In the second scenario, genetic testing is conducted to diagnose whether an individual has an autosomal recessive genetic disorder. In this scenario, the presence of genetic abnormalities indicates the presence of a disease (e.g., sickle cell anemia). Individuals who have an autosomal recessive genetic disorder have two mutated genes (one from mother and one from father). In other words, both parents must be genetic carriers of the disease (The Genetics Home Reference, 2012). The probability of inheritance is 25 percent if both parents are carriers of the disease. Some communication research has been done on this type of genetic testing, especially for pre/neonatal screening for cystic fibrosis (e.g., Dillard & Carson, 2005). Although Dillard and
Carson (2005) investigated only one example of autosomal recessive genetic diseases (i.e., cystic fibrosis), others include sickle-cell anemia and Tay Sachs disease.

Finally, in the third scenario, genetic tests are used to diagnose *autosomal dominant* genetic disorders. Disorders that are autosomal dominant require inheriting only *one* mutated gene (one from the mother or one from the father). The probability of inheritance is 50 percent if only *one* parent is a carrier of the disease (Sheth, Dugdale, & Zieve, 2011). Autosomal dominant genetic disorders are the least common type of genetic disorders. However, they have the highest chance of inheritance among the various types of genetic disorders. Examples of autosomal dominant disorders include Marfan syndrome, tuberous sclerosis, and Huntington’s disease. The study focuses on Huntington’s disease.

Huntington’s disease (HD), an autosomal dominant genetic disorder, is rare in the United States. HD is estimated to affect approximately 3 to 7 per 100,000 people in the United States; currently, more than 15,000 people are diagnosed with HD in the United States (National Institute of Neurological Disorders and Stroke, 2013). HD is a disease in which the brain and nerves degenerate at an abnormally fast rate. Symptoms include psychological changes, such as psychosis and depression, and movement changes, such as facial tics and the loss of fine motor skills, and even the onset of dementia in later stages of the disease (Kent, 2004). The lifespan of individuals with HD after the onset of symptoms is approximately 15 to 20 years due to the rapid progression of the disease and the high suicide rate associated with HD (Imarisio et al., 2008).

Genetic testing is important for individuals at risk for HD because the genetic test could trigger secondary prevention measures for those diagnosed. These measures would allow individuals with HD to begin earlier management of their disease in an effort to slow disease progression and extend individuals’ lifespan (Kent, 2004). Note that no cure exists for HD.
However, medications may help slow the degeneration of nerves and manage other related symptoms. Communication about the issues surrounding HD related to the diagnosis and management of the disease, at both the individual and family levels, may influence decisions related to the genetic testing.

Family communication processes are an important facet in the diagnosis and management of HD. Past communication research has focused on the individual’s decision-making process regarding whether to undergo HD testing (e.g., Smith, Michie, Stephenson, & Quarrel, 2002; Taylor, 2005). Research also has focused on the communication outcomes of HD predictive testing (i.e., Hagberg, Biu, & Winberg, 2011; Penziner et al., 2008). However, this author was unable to identify any research focusing on the role(s) that family communication plays in decisions to undergo predictive genetic testing for HD. Understanding family communication is important because HD’s very basis is a family matter—its presence is determined by familial genetics. Further, individuals with HD usually do not show signs of the disorder until their 30s or 40s in many cases, perhaps after they have started a family (Imarisio et al., 2008; Walker, 2007). Thus, family communication about the disease and related genetic testing for HD is important because the diagnosis of HD will have lasting effects on the individuals, the family, and related family communication processes.

The present study focused on individuals who have HD or who are at risk for developing HD (i.e., they have a parent with HD). The study included both individuals who have and individuals who have not undergone genetic testing, in an effort to better understand and differentiate their decision-making process and information management strategies. The study employed Koerner and Fitzpatrick’s (2002a) concept of family conversation orientation from
their framework of Family Communication Patterns (FCP) in conjunction with Afifi and Weiner’s (2002) Theory of Motivated Information Management (TMIM).

Koerner and Fitzpatrick (2002a) posit that two types of FCP commonly arise in families: *conversation orientation* and *conformity orientation*. *Conversation orientation* is related to the depth and breadth of conversation topics within the family. An open conversation orientation is characterized by high amounts of depth and breadth in the topics discussed; in contrast a closed conversation orientation is characterized by low amounts of depth and breadth in family conversations. *Conformity orientation*, which is not directly addressed in this study, is related to the amount of homogeneity, or "sameness," within the family conversations. High conformity orientation families tend to have similar attitudes and discourage differing opinions in discussions; in contrast low conformity orientation families tend to have differing attitudes and welcome a variety of opinions during conversations. Research has shown that these FCP orientations affect the way that family members engage in communication outside of the family as well as inside the family (see Schrodt, Witt, & Messersmith, 2008, for a review).

The present study posited that the *conversation orientation* may serve as a basis for understanding how individuals engage in the information management process discussed in TMIM (Afifi & Wiener, 2004). According to the FCP model, families with an open conversation orientation tend to have more in-depth discussions about a greater variety of topics, potentially including HD-related issues, compared to families with a closed conversation orientation, who tend to have less in-depth discussions about fewer topics (Koerner & Fitzpatrick, 2002a). TMIM posits that individuals use the information they garner from their interactions to manage and influence their own information regarding an issue (Afifi & Morse, 2009; Afifi & Wiener, 2004). In the present study, the family conversation orientation was
examined as an influence on individual decisions regarding the information management strategy of genetic testing for HD. According to TMIM, an individual goes through three phases when selecting an information management strategy: the *interpretation phase*, the *evaluation phase* and the *decision phase*. The present study posited that individuals deciding whether to undergo genetic testing for HD would move through these phases of the decision-making process. The family conversation orientation may influence how an individual progresses through each of these three phases and whether he or she ultimately chooses to engage in the information management behavior of undergoing predictive genetic testing for HD. Thus, the current study developed a conceptual model, and tested hypothesized relationships derived from that model, that combined the family conversation orientation and TMIM in a novel way in order to examine the influence of family communication on individuals' decision-making process related to genetic testing for HD.

Although using a combination of the family conversation orientation from FCP and TMIM to study the decision-making processes of individuals who have or who are at risk for developing HD is novel, both frameworks have been applied individually in other health contexts. FCP, and specifically the family conversation orientation, has been used in health communication research. Baxter, Bylund, Imes, and Scheive (2005) examined the influence of family communication on adolescents’ healthy lifestyle choices at college. Hay et al. (2009) used FCP to look at family discussions of a melanoma diagnosis. Past research used TMIM to explain various health-related information management strategies. For instance, Afifi et al. (2006) examined the organ donation decision-making process and Afifi and Weiner (2006) investigated sexual health disclosures in college-age couples. These past successful applications of FCP and TMIM to explain health-related communication practices provided a basis for
conceptualizing the present study. The study extended the application of the conversation orientation from FCP and TMIM in several ways: (a) by applying them in the unique context of HD, (b) by combining the concept of family conversation orientation and TMIM in an effort to understand how family communication influences an individual’s decision-making process, and (c) by exploring the communication processes within the family and individuals’ decision-making process specifically regarding whether to undergo predictive genetic testing.

Focus and Overview of the Study

The current study proposed a model that combined the conversation orientation dimension from the FCP framework and TMIM in a novel way to explore the influence of family communication surrounding HD-related issues on individuals’ decision-making process related to genetic testing for HD. The family conversation orientation dimension provided insight into the general family communication surrounding HD and related issues, such as genetic testing for HD (Koerner & Fitzpatrick, 2002a). TMIM was used in an effort to examine individuals’ decision-making process related to genetic testing for HD (Afifi & Weiner, 2004).

The Literature Review section discusses the conversation orientation dimension of FCP and TMIM and proposes a conceptual model that combines the two in an effort to understand the link between family communication and individuals’ decision-making process related to genetic testing for HD. A survey methodology was employed to test relationships suggested by this model and assess individuals’ experiences regarding family communication about HD-related issues and their decision-making process related to the genetic test for HD. The Method section provides an in-depth discussion of the participants, procedures, measures, and analyses used. Data collected were used to test hypotheses and answer the research question generated by the
proposed conceptual model. The Results section provides the outcomes of statistical analyses that were conducted.

The Discussion section focuses on the insights gained related to FCP’s usefulness for understanding the family communication environment surrounding HD-related issues and how TMIM provided limited insight into individuals’ decision-making process. Although the findings may have been limited by sample size, they signaled possible limitations of using the conversation orientation dimension of FCP to understand the family communication surrounding HD-related issues and TMIM to provide insight into the decision regarding genetic testing for HD. Results are discussed in terms of the possibility that other communication factors, beyond family communication, may be influential in this decision-making process, thus, highlighting the need for future research into this complex decision-making process. The limitations and successful applications of the conversation orientation of FCP and TMIM in the current context and the need for more research into this complex process also are considered further in the Discussion section. The following chapter provides an in-depth explanation of FCP and TMIM, and reviews past research that used FCP and TMIM and examined communication processes surrounding genetic testing, setting the basis for the current study.
Chapter II

Review of Literature

Theoretical Framework

To gain insight into the decision-making process of individuals regarding predictive genetic testing for Huntington’s disease (HD), two perspectives were employed. The conversation orientation dimension from Koerner and Fitzpatrick’s (2002a) Family Communication Patterns (FCP) model provides insight into family communication practices related to HD and associated genetic testing. FCP posits that individuals’ general communication practices are influenced by family communication practices. Thus, family communication surrounding HD may influence how individuals engage in the decision-making process regarding whether to undergo genetic testing. In turn, Afifi and Weiner’s (2004) Theory of Motivated Information Management (TMIM) was employed as a theoretical framework to understand individuals’ decision-making process related to engaging in the specific information management strategy of genetic testing for HD. This combination of frameworks had the potential to allow the individual decision-making process to be better understood by considering the influence of family communication.

Family Communication Patterns. Koerner and Fitzpatrick (2002a) argue that the family, and the communication that takes place within it, constitute a unique situation which functions at both the familial and individual levels. That is, the family’s expectations surrounding communication influence not only communication within the family, but also the individual family member’s expectations regarding interpersonal communication in general. Koerner and Fitzpatrick (2002a) theorize that two independent dimensions characterize the communication practices of families: the conversation orientation and the conformity
orientation. Each orientation influences different aspects of family communication (Koerner & Fitzpatrick, 2002a).

Koerner and Fitzpatrick (2002a) define the conversation orientation as “the degree to which families create a climate in which all family members are encouraged to participate in unrestrained interaction about a wide array of topics” (p. 85). Families who have a high conversation orientation are more likely to disclose to each other about more topics than families who have a low conversation orientation. Koerner and Fitzpatrick (2002a) define the conformity orientation as “the degree to which family communication stresses a climate of homogeneity of attitudes, values and beliefs” (p. 85). Families who have a high conformity orientation tend to emphasize “sameness” within the family; in contrast, families who have a low conformity orientation tend to welcome differing opinions. The conversation orientation is used to examine general family communication practices related to frequency of talk and the number of topics discussed. (The present study did not include the conformity orientation.)

The Family Communication Patterns (FCP) model has been used extensively to research different familial contexts. Schrodt, Witt, and Messersmith (2008) present a comprehensive review of the many applications of this model, ranging from a focus on basic disclosure within the family, to investigating how FCP influences individual communication behaviors outside of the family. The present study expanded upon past research concerning family influence on individual communication in two ways. First, the present specific context of the application of FCP, genetic testing, had not been examined previously. Specifically, the current study examined predictive genetic testing for HD. Second, the present study expanded research related to FCP by using the conversation orientation dimension as a framework to examine how family communication may influence individual information management strategies (i.e., genetic
testing) surrounding health issues. The information management process itself was examined using the Theory of Motivated Information Management (Afifi & Weiner, 2004).

**Theory of Motivated Information Management.** The Theory of Motivated Information Management (TMIM) posits that individuals attempt to manage their uncertainty surrounding a particular communication issue (such as an HD diagnosis) through the use of information management strategies (Afifi & Morse, 2009; Afifi & Weiner, 2004). TMIM posits that the decision to engage in information management strategies takes place in three stages: the interpretation phase, the evaluation phase, and the decision phase.

**The interpretation phase.** The interpretation phase of information management is characterized by the individual recognizing an uncertainty discrepancy and the related emotions that surround an important issue. TMIM assumes that the perceived importance of the issue to the individual activates the individual’s information management process (Afifi & Morse, 2009; Afifi & Weiner, 2004). An uncertainty discrepancy occurs when individuals become “aware of an important issue for which they desire more or less uncertainty than they have” (Afifi & Weiner, 2004, p. 174). When this discrepancy is sufficiently large, and elicits a high level of emotion, the individual is motivated to seek information (Afifi & Morse, 2009). Anxiety is commonly associated with uncertainty in past research using TMIM as a framework (see Afifi & Weiner, 2004 for a discussion). Thus, the present study used anxiety as its operationalization of the emotion related to the uncertainty discrepancy. Additionally, past research has found high levels of anxiety are commonly related to undergoing genetic testing (see Hamilton, Lobel, & Moyer, 2009 for a review).

The degree of emotion (i.e., anxiety) experienced is related to the individual’s investment in the uncertain situation (Afifi & Morse, 2009). For instance, individuals at risk for HD may be
experiencing the physical and psychological toll that the disease is taking on a loved one; this experience may elicit a high amount of emotion, specifically anxiety, around their own unknown status regarding HD and spur them to seek information by engaging in a decision-making process regarding genetic testing.

**The evaluation phase.** The second phase of information management, the *evaluation phase*, is characterized by *outcome expectancies* and *efficacy assessments*. Afifi and Weiner (2004) explain that the *outcome expectancies* take into account the individual’s perceived costs and benefits associated with an information management strategy. Thus, outcomes perceived to be high in cost and low in benefits likely are less attractive compared to outcomes perceived to be low in cost and high in benefits. As outcome expectancies are two-fold, related both to the process of enacting an information management strategy and to the potential outcome of that information management strategy (Afifi & Morse, 2009). Thus, both the act of information seeking and related outcomes are considered in the outcome expectancy. In the case of pre-symptomatic genetic testing for HD, the process assessment is related to the act of testing itself, while the outcome assessment is related to the potential results of the genetic test and the implications of these results for what the individual may need to do moving forward. Thus, individuals with positive outcome assessments (i.e., low costs and high benefits) may be more likely to undergo genetic testing for HD compared to individuals with negative outcome assessments (i.e., high costs and low benefits).

*Efficacy assessment* is the individual’s perception of his or her ability to successfully engage in the information management strategy, the genetic test for HD in this study (Afifi & Morse, 2009; Afifi & Weiner, 2004). This assessment is based on three components of efficacy: *coping, communication*, and *target efficacy*. *Coping efficacy* is related to the individual’s
perceived ability to emotionally and instrumentally manage the outcome assessment of the potential information management strategy (Afifi & Morse, 2008). For instance, individuals considering genetic testing for HD will assess if they will be able to cope with either a positive or negative result. As an individual’s coping efficacy increases, so does his or her perceived ability to engage in the chosen information management strategy. Thus, for predictive genetic testing for HD, the individual’s perceptions of his or her ability to manage the results of the genetic test are related to the probability of engaging in the information management strategy of undergoing the test.

Communication efficacy is related to the individual’s belief that he or she has the communication skills to enact the potential information management strategy (Afifi & Weiner, 2004). Thus, individuals who perceive themselves to have high communication efficacy concerning the situation are more likely to engage in information management strategies than are individuals who perceive themselves to have low communication efficacy. Applied to predictive genetic testing for HD, TMIM suggests that individuals who believe that they are able to engage effectively in enacting the genetic test will be more likely to engage in the information seeking strategy of undergoing the predictive genetic test.

Finally, target efficacy is the individual’s perception of the ability of the information source, or target, used in his or her information management strategy to provide useful information (Afifi & Morse, 2009). Individuals make judgments related to the target’s trustworthiness and expertise as a source of information; thus, they consider if the target is an honest and reliable source of information, as well as if the target is capable of providing accurate information (Afifi & Weiner, 2004). As the individual’s perception of target efficacy increases, so does the likelihood of the individual using that information source. In the present study, the
information source is the genetic test itself. Thus, TMIM suggests that if individuals believe that predictive genetic tests are trustworthy and accurate, they are more likely to engage in information seeking by having a predictive genetic test for HD.

**The decision phase.** The third stage of TMIM is the decision phase. In this phase, the information management strategy is chosen. Three possible decisions exist: *information seeking*, *information avoidance*, and *reassessment* (Afifi & Morse, 2009; Afifi & Weiner, 2004). Individuals who engage in *information seeking* actively seek information, information sources, and opinions related to the original communication issue. *Information avoidance* occurs when individuals actively or passively avoid information. In cases of *reassessment*, individuals return to the interpretation phase and reassess their uncertainty discrepancy and associated emotional responses.

All three decision outcomes are possible in the case of pre-symptomatic genetic testing for HD. Individuals who engage in *information seeking* strategies may seek information from their family about the genetic test, seek information from others diagnosed with HD, search the internet or read books to increase their knowledge about HD, or engage in a predictive genetic test to learn if they have HD. Individuals who engage in *information avoidance* strategies may deny their risk for HD, avoid information sources regarding HD, and choose not to undergo the genetic test for HD. Individuals who engage in *reassessment* strategies may resolve their uncertainty discrepancy through personal acceptance of or denial of their risk for HD. Also, these individuals may reconfigure emotions associated with their uncertainty, thereby lessening the need to resolve their emotions (e.g., reconfigure high anxiety to low anxiety). Thus, individuals who engage in *reassessment* do not undergo genetic testing; rather they resolve the
issue cognitively. The present study assessed decisions about genetic testing and, thus, did not differentiate *information avoidance* from *reassessment*.

The current study used the three phases of information management, posited by TMIM, to understand individuals’ decision-making process related to a particular potential information management strategy, genetic testing for HD, and used the conversation orientation (Koerner & Fitzpatrick, 2002a) to examine how family communication may influence this individual decision-making process. The following section reviews past research that used FCP and TMIM, as well as past research that examined communication processes surrounding genetic testing.

**Past Research: FCP, TMIM, and Genetic Testing**

Afifi and Weiner’s (2004) TMIM was applied as a framework to gain insight into how individuals at risk for HD engaged in decision-making regarding whether to undergo genetic testing for HD. FCP was used to better understand the influence of family communication about HD on this individual decision-making process (Koerner & Fitzpatrick, 2002a). This combination of approaches is appropriate in this study because genetic diseases, such as HD, are inherently a family-based communication issue, as they are passed down from parent to child (Walker, 2007). Past literature has identified multiple factors that may influence the individual decision-making process regarding genetic testing. These include: perceptions of risk and genetic testing, triggers, and outcomes related to their disease. Past research that used the FCP model has shown that family communication influences factors that individuals consider when engaging in health-related communication.

**FCP and health-related communication.** The Family Communication Patterns (FCP) model, including the family conversation orientation, has been used to examine various familial
communication contexts. Contexts examined include both basic disclosure within the family and how FCP influences individual communication behaviors outside of the family. Schrodt et al. (2008) present a comprehensive review of the many applications of this model. An area of this literature that is particularly relevant to the present study examines family communication concerning health-related topics.

Baxter et al. (2005) found that individuals from families with different FCP orientations made different health-related lifestyle choices. Families with a high conversation and low conformity orientations, which encourage communication and do not expect adherence to family values, produce individuals who are more willing to create their own rules for health behavior choices compared to individuals from families with a low conversation orientation. On the other hand, individuals from families that do not encourage communication and expect adherence to family values use family rules to guide their health behavior choices (Baxter et al., 2005). Thus, Baxter et al. (2005) showed that FCP influences individual behaviors outside of the family environment, particularly health-related behaviors.

The FCP model has been employed for explaining health-related communication. For example, Hay et al. (2009) examined the diagnosis of a family member with melanoma and related communication between the diagnosed individual and other family members. Hay et al. (2009) found that FCP not only influenced if the family member diagnosed with melanoma disclosed his or her diagnosis to the family, but also if he or she disclosed his or her diagnosis to others outside the family. As predicted by the model, families that encouraged communication (i.e., high conversation orientation) produced members who were more likely to disclose to both family members and to others outside of the family. The opposite was true for those families that did not encourage communication (i.e., low conversation orientation). These families
produced members who were less likely to disclose to both family members and to others outside of the family. These findings are important to note. If individuals are less likely to talk about their melanoma diagnosis, they may be less likely to talk with family members about getting screened for melanoma and also may be less likely to seek support from individuals within the family, as well as others outside the family (Hay et al., 2009). Results from this study illustrate how family communication practices can provide insight, through family expectations, into individuals’ management of their communication surrounding health crisis, both within and outside of the family. The influence that the conversation orientation from FCP, in particular, has on individual communication can be examined further by using TMIM to understand the individual decision-making process related to information management strategies in health contexts.

**TMIM and health-related communication.** Past research used TMIM to investigate how individuals seek health-related information. For example, Afifi and Weiner (2006) discerned that the way individuals engage in sexual health information seeking with sexual partners about sexual transmitted infections (STIs) affects the likelihood of engaging in safe sex (i.e., condom use). The motivations implicated by TMIM were important to the information management strategy of seeking information about a partner’s STI status. Consistent with TMIM, Afifi and Weiner (2006) reported that individuals who had a related uncertainty discrepancy (i.e., no knowledge, but wanted knowledge), and therefore experienced anxiety surrounding their partner’s STI status, were more likely to initiate information seeking behaviors than individuals who felt more certain and less anxious about their partner’s STI status.

However, Afifi and Weiner (2006) also noted that individuals who had the highest uncertainty discrepancies (i.e., they were very uncertain about their partner’s STI status and
wanted to know his or her status) were the least likely to initiate information seeking strategies. The authors suggest that the very high degrees of emotion that surrounded the issue may have prevented the individual from taking action because too much emotional risk related to potential negative outcomes as a result of information seeking (Afifi & Weiner, 2006). Results also indicated that individuals who had high efficacy assessments about discussing STI status with their partners were more likely to engage in STI information seeking, which supports the theory.

TMIM was useful in the health context of STIs by shedding light on how individuals engage in the interpretation phase, the evaluation phase, the decision phase, and even beyond that to the next step after a management strategy is chosen (i.e., initiation of sexual behaviors).

In addition to being applied to sexual health-related issues, TMIM has been used specifically to examine the influence of family communication surrounding the issue of organ donation. Afifi et al. (2006) examined how family communication about organ donation influences an individual’s decision regarding whether to become an organ donor. As in the previous study, efficacy assessments were found to be an important motivation for enacting information seeking behaviors. Higher efficacy assessments were associated with greater likelihood of engaging in information seeking behaviors, as well as health behaviors. Afifi et al. (2006) found that families that engaged in discussions that encouraged organ donation lead to more family members becoming potential organ donors, compared to families that engaged in discussions that did not encourage organ donation. This finding shows that family communication about a health issue can influence individuals’ behavior related to that health issue.

The influence of family communication on individual perceptions of health issues is particularly pertinent to the present study. Thus, my general hypothesis was that family
communication about HD ultimately influences an individual’s decision to engage in an information management strategy, specifically the strategy of undergoing pre-symptomatic genetic testing for HD. Although the findings of Afifi et al. (2006) and Afifi and Weiner (2006) discuss general factors that may influence individual information seeking behavior, specific factors, such as risk perceptions, also have been identified in the literature.

**Risk perceptions and uncertainty.** Individuals who are at risk for HD have a 50 percent chance of a positive genetic test, meaning they have a 50 percent chance of having the disease. This inheritance pattern is due to the autosomal dominant nature of the genes associated with HD (Imarisio et al., 2008). However, individual *perceptions of risk* may differ from this actual 50 percent chance, leading an individual to have a perception of increased or decreased personal risk for developing HD. This potential difference is important. Individual perceptions of personal risk regarding HD may be implicated in the interpretation phase of TMIM because they help to inform uncertainty (and the uncertainty discrepancy) surrounding this issue (Afifi & Weiner, 2004). Smith, Michie, Stephenson, and Quarrell (2002) found that the 50/50 chance for developing HD was a point of contention for individuals who were deciding to undergo genetic testing for HD. Individuals felt that these odds were “too nebulous” and wished to have “easier” odds to interpret (i.e., higher), such as 70/30 (i.e., were not equal; Smith et al., 2002).

Cypowyj et al. (2003) found that the uncertainty surrounding the odds of positive test results also were considered by individuals’ who were deciding whether to undergo genetic testing for BRCA1 and BRCA2, which are related to breast and ovarian cancer. They noted that as individuals’ risk-assessments increased in severity (i.e., they perceived greater risk), so did the trepidation surrounding their decision-making process regarding the genetic test. Thus, Cypowjy et al. (2003) and Smith et al. (2002) show how individual perceptions of risk are a factor.
considered when deciding whether to undergo genetic testing. These individual perceptions of risk may inform individuals’ uncertainty discrepancy related to genetic testing for HD, which is implicated in TMIM (Afifi & Weiner, 2004). This is because uncertainty discrepancy is an individualized assessment of the overall uncertainties related to the issue which the individual is managing through TMIM.

An individual’s perception of his or her own risk for developing a genetic disease, such as HD, may be informed through family communication (Ando, Iwamitsu, Takemura, Saito, & Takada, 2009; Holt, 2006). Ando et al. (2009) found that families with first-hand experience of genetic diseases were more knowledgeable about the effect that genes have on health, and their own risk related to genetics, compared to families with no first-hand experience. Thus, in the case of HD, families with a high conversation orientation could produce individual family members who are more knowledgeable about their own risk for HD, compared to families with a low conversation orientation.

Furthermore, Holt (2006) also found that family communication, specifically the openness or closedness of that communication, helps to create individual perceptions of risk. Children in families who openly discussed parent struggles with HD had more knowledge and understanding of HD, compared to children in families who did not discuss parent struggles with HD (Holt, 2006). Thus, families who have a member with HD who discusses his or her disease may have a greater understanding of genetics than families with a member who does not discuss his or her disease. These findings are consistent with the suppositions of FCP regarding conversation orientation. That is, increased family communication surrounding a health issue should result in increased understanding of that issue among family members (Koerner & Fitzpatrick, 2002a). Also, this potential increased understanding of the health issue may lead to
assessments of greater efficacy, which is considered in TMIM (Afifi & Weiner, 2004). Another factor found in past research that influences the decision-making process related to genetic testing is the individual perceptions of genetic testing, which can also be influenced by family communication.

**Perceptions of genetic testing.** A second factor that is implicated in the decision to undergo genetic testing is the perceptions of the genetic test itself. Perceptions of the genetic test may influence how an individual engages in the evaluation phase of TMIM, particularly the target efficacy assessment that considers how reliable and accurate the target (i.e., the genetic test for HD) is as an information source (Afifi & Morse, 2009; Afifi & Wiener, 2004). Ando et al. (2009) noted that individuals who had first-hand experience with genetic diseases had less negative appraisals of genetic tests compared to individuals who had no first-hand experience with genetic diseases. Specifically, individuals with first-hand experience were more trusting of genetic tests and related results compared to those with no first-hand experience. Chapman (2002) examined the communication of families with a history of HD and how referencing that history in family conversations influenced perceptions of genetic testing. In families who openly discussed the family history of HD and related genetic testing, the perceptions of genetic testing were more positive (i.e., more trusting of the results) compared to families who did not openly discuss the family history HD and related genetic testing (Chapman, 2002). This trend can be explained by FCP (Koerner & Fitzpatrick, 2002a), which argues that families who generally discuss more topics more often, create an open and trusting family communication environment. That family communication environment may create more open conversation and accept more opinions within the family, compared to families who generally discuss fewer topics less often.
The findings of Ando et al. (2009) and Chapman (2002) are important because, as Cypowyj et al. (2003) reported, positive perceptions of genetic tests lead to greater use of genetic testing. Again, these findings support the tenets of FCP which state that family communication influences how individual family members create their own assessments of communication events (Koerner & Fitzpatrick, 2002a). The potential implication of these findings is that family communication about the issue may lead to a more positive appraisal of genetic testing from HD, which may, in turn, lead to a greater chance of an individual family member undergoing the test. Another factor that may lead to a greater chance of an individual undergoing genetic testing is comprised of triggering communication events.

**Triggers to testing.** Afifi and Weiner (2004) argue that, in the evaluation phase of TMIM, individuals recognize an uncertainty discrepancy that they wish to address. A “trigger” may compel individuals to recognize an uncertainty discrepancy about their genetic health and then to decide whether to undergo genetic testing for HD. One such trigger commonly noted in the literature is family communication, both implicit and explicit, about the genetic disorder (Etchegary & Fowler, 2008; Etchegary, Miller, deLaat, Wilson, Carroll, & Cappeli, 2009; Smith et al., 2002).

The literature discusses implicit family communication as occurring in two different forms: nonverbal communication and via a sense of personal responsibility to family members. Implicit messages that are nonverbal are cited as the most commonly remembered and influential triggers regarding decisions to undergo genetic testing for HD (Smith et al., 2002). Examples of these nonverbal implicit triggers include a father’s loss of motor control due to the progression of HD and having had multiple family members die from HD (Smith et al., 2002; Taylor, 2005).
A second type of implicit communication trigger that is noted in the literature is a sense of personal responsibility to family members (Etchegary & Fowler, 2008; Etchegary et al., 2009). Individuals who have a strong sense of responsibility to family members may feel obligated to undergo genetic testing for HD in order to alert other family members to potential genetic risk. Although explicit family communication about responsibility may occur, personal responsibility is an internalized process that individuals develop through implicit family communication regarding risk for a genetic disease, such as HD (Etchegary & Fowler, 2008; Etchegary et al., 2009). Although implicit triggers play an important role in the decision processes regarding genetic testing for HD, explicit triggers also may be important.

Explicit verbal family communication may trigger individuals’ decisions related to health outcomes, such as genetic tests. Multiple studies note that family conversations signaled individuals to begin the process of deciding to undergo genetic testing for HD (Holt, 2006; Smith et al., 2009). FCP suggests that families with a higher communication orientation likely discuss the genetic test for HD more often than families with a lower communication orientation. In turn, these explicit conversations may function as triggers to engage in the decision-making process related to genetic testing (Koerner & Fitzpatrick, 2002a). The present study examined both the implicit and explicit communication triggers that occur in family interactions as potential influences on the individual decision-making process regarding undergoing predictive genetic testing for HD.

Living with the results. TMIM posits that personal efficacy is a factor that individuals consider in the evaluation phase when selecting an information management strategy. In TMIM, efficacy is related to individual perceptions of the ability to successfully engage in information management strategies, in this instance, a genetic test (Afifi & Morse, 2009; Afifi & Weiner,
2004). Included in an efficacy assessment is whether an individual that believes that he or she can cope with the outcomes of a particular information management strategy (Afifi & Morse, 2009). In the context of a positive test result for HD, individuals encounter difficult changes in numerous aspects of their lives, including the practical, emotional, social, and health-related aspects of their lives (Chapman, 2002; Etchegary, 2009; Hagberg, Bui, & Winnberg, 2011). These changes may represent an enormous shift in lifestyle with which individuals must cope on a daily basis (Chapman, 2002).

Once diagnosed with HD, which is a progressive neurological disorder that can rapidly affect a diagnosed individual mentally and physically, individuals will need to make changes in the practical aspects of their lives (Kent, 2004). Hagberg et al. (2011) noted that once diagnosed with HD, individuals commonly re-evaluate their career choices/paths. Some individuals may need to stop doing the more physical aspects of their careers (i.e., lifting heavy objects, driving), or may even have to give up their careers all together. On the other hand, some individuals noted that the diagnosis spurred them to go back to college or to pursue their dream career (Hagberg et al., 2011).

A second practical aspect to which individuals must adapt in light of an HD diagnosis is the need for engaging in new preventive behaviors. For instance, once diagnosed with HD, individuals are encouraged to begin an exercise regimen and a strict diet in an effort to slow the progression of HD symptoms (Etchegary, 2009).

A final practical change that may need to be addressed is whether to start having or to continue having children (Chapman, 2002). Because genetic testing can diagnose an individual with HD at any time in the lifespan, family planning may be affected by genetic test results. Many couples who have a partner with HD choose not to have any or not to have additional
children due to the 50 percent chance that their children will have HD (Hagberg et al., 2011). Pre-natal genetic testing, which is done on a fetus in-utero, also is a popular choice with these couples. This pre-natal genetic test can be done early enough to safely terminate a pregnancy if needed (Chapman, 2002). In addition to practical changes, emotional adaptations also may be needed.

New emotions may arise that need to be managed after a genetic test and resulting diagnosis with HD. Although the uncertainty of the individual’s HD status is now gone, other uncertainties and issues may arise due to the results of the genetic test. One emotional issue that may arise is regret over the having undergone the test. Hagberg et al. (2011) noted that, after the test, many individuals felt their lives were dramatically changed and that the changes were hard to accept. One participant noted that his genetic test and subsequent diagnosis with HD led him to feel as if his life was over and he regretted undergoing the test (Hagberg et al., 2011, p. 73). Emotional adaptations do not end once the diagnosis is accepted. Further emotional adjustments may be needed as the disease progresses (Chapman, 2002). Not only do individual processes such as practical and emotional adaptations take place after the diagnosis of HD, but social processes also may be affected.

Social relationships may change as a result of a positive genetic test for HD. Relationships may change for the better as individuals look for increased social support and others respond to that need. For instance, Hagberg et al. (2011) noted that some individuals felt that their family became closer and more supportive once they were diagnosed with HD, compared to before the diagnosis. However, these same relationships may deteriorate to reduce the emotional risks of both parties. Chapman (2002), Etchehary (2009), and Hagberg et al. (2011) all noted that individuals who were diagnosed with HD felt that their diagnosis had
changed some relationships in a negative way; anger, insecurity, and unfamiliarity all have been identified as negative influences on the social relationships of individuals with HD. Hagberg et al. (2011) even noted that some relationships ended due to these negative influences.

Finally, health-related aspects of life may change after a positive genetic test for HD. Chapman (2002) found that individuals who tested positively for HD faced questions of their own quality of life in light of their disease. That is, they questioned how well they would be able to function in day-to-day situations once symptoms began to arise. Hagberg et al. (2011) also found that after a diagnosis of HD, these individuals began to search for symptoms and prepare for the worst possible outcomes. Thus, many individuals become preoccupied with their disease after diagnosis. In addition, once diagnosed, individuals with HD are advised to undergo routine doctor’s appointments and physical therapy sessions, and to begin a drug regimen to help prolong their lifespan and increase their quality of life (Etchegary, 2009).

The ability to cope with changes in practical, emotional, social, and health aspects of life may be related to family communication that surrounds issues related to HD and the related genetic test. Open family communication, which is a characteristic of families with a high conversation orientation, compared to families with a low conversation orientation, may help individuals feel more efficacious to cope with these numerous changes. That is, because more discussion likely has occurred regarding coping behaviors related to the test results and the disease, individuals may feel better able to cope with a diagnosis of HD (Afifi & Weiner, 2004; Koerner & Fitzpatrick, 2002a).

An individual’s decision regarding whether to undergo genetic testing is difficult, with multiple factors to consider. These factors may include personal perceptions of risk and genetic testing, triggers to testing, and future implications of his or her potential disease status. These
factors influence the decision regarding whether to undergo genetic testing (Taylor, 2005). Although genetics, and genetically-linked diseases such as HD, are by definition a family-based issue, little research has examined family communication surrounding HD and individual decisions to undergo genetic testing.

**HD, Families, and TMIM**

This study posited that the family conversation orientation is a factor that may influence individuals’ decision-making process regarding information management, as explained by TMIM. Past research used TMIM to examine how family communication about a specific issue influences the information management process and outcome regarding a specific issue (Afifi et al., 2006). But research using TMIM had not previously examined the overall family communication practices that may be influential in information management processes. By integrating the family conversation orientation dimension of FCP and TMIM, the family communication surrounding HD was examined in conjunction with an individual’s decision to engage in a specific information management strategy (i.e., undergoing pre-symptomatic genetic testing). See Figure 1 for a conceptual model that integrates the family conversation orientation dimension of FCP and TMIM in predicting decision outcomes regarding genetic testing for HD.

The family conversation orientation may be implicated in the *interpretation phase* of TMIM because emotion surrounding the issue, and the individual’s evaluation of that emotion, may be influenced by family communication surrounding the issue (Afifi et al., 2006). According to FCP, families with relatively high conversation orientation tend to talk to each other relatively more about a relatively greater number of issues than families with a relatively low conversation orientation (Koener & Fitzpatrick, 2002a). Thus, families whose members
have HD should be relatively be more likely to talk about HD and related genetic testing. The study tested the following hypothesis:

H1: For individuals at risk for HD, family conversation orientation is positively associated with the amount of talk (i.e., information seeking) within the family about HD and related genetic testing.

Figure 1

Proposed Model for Predicting Genetic Testing for HD

TMIM states that an uncertainty discrepancy arises when individuals become “aware of an important issue for which they desire more or less uncertainty than they have” and that these uncertainty discrepancies arouse emotions (Affifi & Weiner, 2004, p. 174). Uncertainty discrepancies may be informed by personal perceptions of risk and perceptions of the genetic test itself. Past research has noted that both are important factors to individuals considering undergoing genetic testing (Cypowyj et al., 2003; Imarisio et al., 2008; Smith et al., 2002). Individuals’ perceptions of risk, as created in part by family communication, may inform their uncertainty discrepancies and thereby affect related emotions (Ando et al., 2009, Koerner & Fitzpatrick, 2002a). FCP suggests that families with a high conversation orientation are more likely to discuss, and explicitly and openly manage, their uncertainty surrounding HD compared
to families with a low conversation orientation (Koerner & Fitzpatrick, 2002a). Thus, the present study posed the following hypotheses:

H2: For individuals at risk for HD, the amount of talk within the family about HD and related genetic testing is negatively associated with uncertainty discrepancy surrounding their HD status.

H3: For individuals at risk for HD, the amount of talk within the family about HD and related genetic testing is negatively associated with emotional assessment of anxiety regarding their uncertainty discrepancy surrounding their HD status.

TMIM (Afifi & Weiner, 2004) posits that individuals’ perception of the emotions related to the issue implicated in the information management process influences their outcome expectancies and their assessments of efficacy. Afifi and Weiner (2004) argue that emotion motivates individuals to move from the interpretation phase to the evaluation phase. However, when emotion reaches a relatively high level, it may impede individuals’ information seeking behaviors (Afifi and Weiner, 2006). Thus, this study proposed the following hypothesis:

H4: Individuals’ anxiety is negatively associated with (a) their outcome expectancies, and (b) their overall assessment of efficacy.

In the context of individuals deciding whether to undergo genetic testing for HD, the evaluation phase of TMIM also may be influenced by the family conversation orientation. FCP posits that families with a high conversation orientation may be relatively more willing to discuss concerns of individual family members than families with a low conversation orientation (Koerner & Fitzpatrick, 2002a). Specifically, concerns related to HD and genetic testing may be considered when the individual creates his or her outcome expectancy and efficacy assessments, as implicated in TMIM (Afifi & Weiner, 2004). Family conversations may include discussions
of where and how to undergo genetic testing for HD, methods for coping with the genetic test results, adequate communication skills and techniques for effectively discussing HD with others, and the reliability of genetic testing for HD. Past research has shown that family communication about these issues is an important factor for individuals who are considering whether to undergo genetic testing (Chapman, 2002; Cypowyj et al., 2003). Thus, this study tested the following hypotheses:

H5: For individuals at risk for HD, the amount of talk within the family about HD and related genetic testing is positively associated with outcome expectancies.

H6: For individuals at risk for HD, the amount of talk within the family about HD and related genetic testing is positively associated with assessments of (a) overall efficacy, (b) coping efficacy, (c) communication efficacy, and (d) target efficacy.

TMIM (Afifi & Weiner, 2004) argues that outcome expectancies are related to individuals’ assessments of efficacy. The framework assumes that positive outcome expectancies may lead to higher assessments of overall efficacy, compared to negative outcome expectancies which may lead to lower assessments of overall efficacy. Thus, this study proposed the following hypothesis:

H7: Individuals’ outcome expectancies are positively associated with assessments of (a) overall efficacy, (b) coping efficacy, (c) communication efficacy, and (d) target efficacy.

TMIM states that an individual’s assessment of overall efficacy is considered when deciding to engage in an information management strategy (Afifi & Weiner, 2004). When the overall efficacy assessment is high (i.e., the individual believes he or she can successfully engage in the information management strategy), the likelihood of engaging in an information
management strategy is also high. Likewise, when the overall efficacy assessment is low (i.e.,
the individual does not believe that he or she can successfully engage in the information
management strategy), the likelihood of engaging in that strategy is low. Thus, the present study
hypothesized:

H8: Individuals’ assessments of overall efficacy differ for those who engage in an
information management strategy (i.e., undergo genetic testing for HD) compared to
those who do not.

For individuals who are deciding whether to undergo predictive genetic testing for HD,
theoretical tenets from FCP also may be implicated in the decision phase of TMIM. As argued,
family conversation orientation may affect the interpretation and evaluation stages of TMIM.
Further, the accumulation of any family discussions around HD may affect the interpretation and
evaluation phases, and is likely to manifest itself in the decision phase. That is, family
communication ultimately influences decisions regarding whether to undergo genetic testing for
HD. In the decision phase, the individual chooses an information management strategy. Thus,
the current study asked:

RQ1: Do individuals who undergo genetic testing for HD, compared to those who do not,
differ in their family conversation orientation?
Chapter III

Method

The methodology was designed to examine the influence of family communication on individual decisions to undergo predictive genetic testing for Huntington’s disease (HD). Participants were drawn from state chapters of the Huntington’s Disease Society of America (HDSA) and completed the survey. The survey included three sections: (a) demographic items, (b) a Family Communication Patterns (FCP) instrument, and (c) a Theory of Motivated Information Management (TMIM) instrument. Item analyses were conducted on each instrument to assess their internal validity and conceptual coherence. After data were collected, statistical analyses were conducted to assess demographic characteristics of the sample and to assess instrument reliability and to refine TMIM measures by examining the conceptual and empirical coherence and internal consistency of the proposed instruments.

Participants

Participants in this study were individuals who have HD or are at risk for developing HD (i.e., they have a parent who has been diagnosed with HD). Both tested and un-tested individuals were included in the sample. In order to avoid dependencies in the data, only one member per family was eligible to participate. Demographic information (e.g., age, race, sex, current HD status, and results of the predictive testing for HD) were collected to assess the characteristics of the sample.

A convenience sampling technique was used. Multiple state chapters of the HDSA agreed to distribute the survey instrument to individuals who are associated with their chapters of the HDSA. The state chapters that distributed the survey instrument included: Ohio, Pennsylvania, Illinois, Indiana, Wisconsin, Iowa, Michigan, Missouri, California, Texas, Oregon, Washington, Florida, and Colorado. The sample size was 30 participants.
Demographic characteristics of the sample. The demographic characteristics of the sample were assessed using descriptive statistics. A total of 30 people participated in this study. Twenty-five participants self-identified as female and five self-identified as male. The median age of the sample was 36 to 45 years old; the age range was from 18 to over 75. All but one participant identified as white; that participant self-identified as mixed-race. The median level of education noted by participants was a bachelor’s degree. Two participants (6.67%) had completed some or all of high school; 20 participants (66.67%) had completed some or all of a technical or bachelor’s degree; and eight participants (26.67%) had completed a graduate degree. The median income reported for the sample was $40,000 to $59,000. Three participants (10%) reported an income of at least $19,000; six participants (20%) reported an income between $20,000 and $40,000; 11 participants (36.67%) reported an income between $40,000 and $100,000; and 10 participants (33.33%) reported an income greater than $100,000.

Sixteen participants reported that they had undergone the genetic test for HD; 14 reported that they had not undergone the test. Ten participants reported that they had been diagnosed with HD; the remaining 20 participants reported that they were not diagnosed with the disease. Twenty-five participants reported that at least one immediate family member had been diagnosed with HD. Finally, 22 participants reported that at least one family member had undergone genetic testing for HD; the remaining eight reported that no immediate family members had undergone genetic testing.

Procedures

Two rounds of survey distribution were used in the current study. The initial survey distribution was small scale, focusing on three chapters of the HDSA in Ohio. Once it became apparent that this small scale distribution was not providing enough responses, a larger scale
approach was adopted. This second round of survey distribution used an online version of the original paper survey; this allowed multiple state chapters of the HDSA from around the United States to act as distributors of the survey. Both rounds of survey distribution received approval from the Institutional Review Board from Kent State University before they were implemented.

During the first round of distribution, the researcher sent paper copies of the survey instruments and written instructions to HDSA social workers in Ohio who acted as distributors. Participants were informed about the survey by social workers at HDSA social support groups. If participants expressed interest in completing the survey they were asked to contact their social worker in order to receive a survey. Participants then completed the survey and returned it to the researcher (n = 7).

Due to a low response rate from the initial round of distribution, an online version of the survey was created in order to expand the potential participant pool. The instructions and questionnaire in the online and paper versions were identical. The researcher contacted multiple state chapters of the HDSA, and sent the instructions and the link of the online version of the survey to HDSA social workers who agreed to distribute the online survey. Social workers in Pennsylvania, Illinois, Indiana, Wisconsin, Minnesota, Iowa, Michigan, Missouri, California, Texas, Oregon, Washington, Florida, and Colorado agreed to inform their chapter members (e.g., via chapter newsletters and Facebook pages). Individuals interested in participating in the survey contacted their HDSA social worker, who then sent the survey link to these potential participants. Data from the online version of the survey were collected in a secure database that only the researcher could access (n = 23). The data from the paper version and the online version of the surveys were compiled into one secure dataset for analysis (N = 30).
Measures

The questionnaire consisted of three sections: (a) an FCP instrument, and (c) a TMIM instrument and (c) demographic items. To avoid question order influencing results, the order of the FCP and TMIM instruments were counterbalanced. One half of questionnaires had the FCP instrument first and the TMIM instrument second; the other half had the TMIM instrument first and the FCP instrument second. The FCP instrument that was used in this study is Koerner and Fitzpatrick’s (2002b) Revised Family Communication Pattern Instrument. See Appendix A for the FCP instrument. The TMIM instruments were a version of the survey instrument used by Afifi et al. (2006), modified for the HD context. See Appendix B for the TMIM instruments. Demographic items included questions about age, sex, race, education level, and socio-economic status. Also included in the demographic section were questions about current HD status, immediate family members with HD, and the results of any predictive genetic testing for HD. See Appendix C for the demographic and HD status items. See Appendix D for the complete questionnaire and instructions in the format provided to the participants in both the paper and online versions of the survey.

To ensure that the scales used in data analysis for the current study were sufficiently reliable, scale development analyses were conducted. Item analyses were conducted to assess the internal consistency of both the FCP and TMIM instruments. Cronbach’s alphas were interpreted to assess the internal reliability of all scales. In conjunction with the results of the item analyses, each proposed scale was examined for conceptual coherence.

**Family conversation orientation instrument.** Ritchie and Fitzpatrick (1990) created the Revised Family Communication Pattern Instrument (RFCP) to measure how individual family members perceive their family communication patterns and practices. They argue that
these individual perceptions of family communication practices affect individual family members’ general communication practices. Koerner and Fitzpatrick (2002b) identify two independent dimensions of family communication: the conversation orientation and the conformity orientation. Both are measured by the RFCP. For the proposed study, only the conversation orientation dimension was used.

The conceptual definition of conversation orientation used by Ritchie and Fitzpatrick (1990) is “parental encouragement of conversation and the open exchange of ideas and feelings” (p. 525). This dimension was measured using a 15-item scale. Respondents rated each item on a rating scale, anchored by “1” for “strongly agree” and “7” for “strongly disagree.” Sample items included: “In our family we talk about our feelings and emotions,” and “In our family we often talk about topics like politics and religion where some persons disagree with others.” These items assess the degree to which family members discuss a variety of topics freely within the family (Koerner & Fitzpatrick, 2002a). Thus, families who have a high conversation orientation have a greater likelihood of discussing a greater number of topics and discussing them more freely than families who have a low conversation orientation. On the RFCP, individuals who have a low score on the conversation orientation perceive their family to have a high conversation orientation. Conversely, individuals who have a high score on the conversation orientation perceive their family to have a low conversation orientation.

The original formulation of the RFCP has a children’s version and a parents’ version, with slightly different wording to designate the child’s or the parent’s perspective (Ritchie & Fitzpatrick, 1990). In the present study, because there was no differentiation among family members (i.e., parents and children), the language was adapted to reflect family members in general. For example, “My parents tend to be open about their emotions” was modified to read
“My family members tend to be open about their emotions.” See Appendix A for the RFCP measure.

To ensure that the data collected from this RFCP survey instrument were valid and reliable, the psychometric properties of the Revised Family Communication Pattern Instrument (RFCP) were examined.

**Reliability.** Ritchie and Fitzpatrick (1990) reported acceptable internal reliability coefficients in the initial conceptual tests of the RFCP scale. The conversation orientation dimension had a Cronbach’s alpha of .84. The RFCP has been used extensively in research. For instance, Scott and Quick (2012) reported a Cronbach’s alpha of .94 for conversation orientation. Sillars, Koerner, and Fitzpatrick (2005) reported acceptable Cronbach’s alphas on the RFCP, ranging from .79 to .89.

**Validity.** Ritchie and Fitzpatrick (1990) discussed the concurrent validity of the RFCP. They compared the original FCP instrument to the RFCP and found that both instruments measured the same family communication patterns and practices. Ritchie and Fitzpatrick (1990) also argued that the revisions led to stronger construct validity for the RFCP because the new items better encompassed the conceptual definitions of the conversation and conformity orientations. Sillars et al. (2005) and Scott and Quick (2012) also reported good construct validity for the RFCP.

**TMIM instrument.** Afifi et al. (2006) created a series of scales to gauge how individuals engage in information seeking behaviors related to certain topics/situations. Their study investigated individual decisions related to becoming an organ donor. Similar instruments were adapted from the original measures to fit specific decision-making situations. For example, Afifi and Weiner (2006) and Fowler and Afifi (2011) examined decisions regarding sexual
health disclosures and decisions about elder care respectively. In the present study, the Afifi et al. (2006) instrument was adapted to fit the present context, individuals’ managing their uncertainty related to decisions regarding genetic testing for HD. The TMIM instrument in the study was comprised of questions designed to assess all six dimensions of TMIM. Participants responded to 45 items on 7-point rating scales, anchored on one end by “1” for “strongly agree” and on the other end by “7” for “strongly disagree.”

The following six dimensions of TMIM have been measured by a series of scales in past research: uncertainty discrepancy, anxiety, issue importance, outcome expectancy, efficacy (communication, coping, and target), and information seeking behavior (Afifi et al., 2006; Afifi & Weiner, 2006; Fowler & Afifi, 2011). The survey instrument used in this study assessed these six dimensions, which are based on the information-management phases included in the TMIM theoretical framework.

The first three scales in the current study are a part of the interpretation phase of TMIM (Afifi & Weiner, 2004): uncertainty discrepancy, emotion—specifically anxiety in the current study, and issue importance.

_Uncertainty discrepancy_ is defined conceptually by Afifi et al. (2006) as “a discrepancy between the amount of uncertainty [individuals have] about an important topic and the amount of uncertainty they desire” (p. 191). Items on the uncertainty discrepancy scale relate to the amount of uncertainty that the individual experiences about the amount of information he or she possesses about an issue (Afifi & Weiner, 2004). For example, items in past research included, “I want to know more than I currently know about my family’s opinion regarding my organ donation decision,” and “How certain are you about your parent’s preferences for their future care?” (Afifi et al., 2006; Fowler & Afifi, 2011). In the current study, questions that address
uncertainty discrepancy assessed the uncertainty discrepancy surrounding the individual’s HD status. For example, one item read, “I wanted to know my own Huntington’s disease status.” See Appendix B for the uncertainty discrepancy scale.

The second scale in the interpretation phase measures anxiety. Anxiety is conceptually defined as the emotion that is related to “individuals’ experience of a discrepancy between desired and actual levels of uncertainty” (Afifi & Weiner, 2004, p. 191). According to TMIM, this anxiety motivates individuals to move through the information management process. Anxiety, as it is measured in this scale, is associated with uncertainty discrepancy related to a specific issue (Afifi & Weiner, 2004). Questions in past research that measure anxiety include, “It makes me anxious to think about how little I know, compared to how much I want to know, about my family’s reaction to organ donation” (Afifi et al., 2006). For the current study, questions assessing anxiety were associated with predictive genetic testing for HD. They included: “It made me anxious to think about how little I knew about my own diagnosis for Huntington’s disease.” See Appendix B for the anxiety scale.

The third scale of the TMIM instrument assesses issue importance. Afifi et al. (2006) assume that issues that create an uncertainty discrepancy and related anxiety are personally important. Past research measuring issue importance included items such as, “It is important that I know my parent’s future care preferences” (Fowler & Afifi, 2011). In the current study, issue importance focused on the importance the individual attributes to knowing his or her HD status. Items included: “It is important to me to consider undergoing genetic testing for Huntington’s disease,” and “It was important to my family for me to consider undergoing genetic testing for Huntington’s disease.” See Appendix B for the issue importance scale.
The fourth and fifth scales of the proposed instrument are implicated in the evaluation phase of TMIM (Afifi & Weiner, 2004). Outcome expectancy is related to the cost/benefit analysis that the individual makes concerning the information seeking strategy. Afifi et al. (2006) conceptually defined outcome expectancy as the “expectations about the outcome behavior” (p. 192). TMIM assumes that as these expectations become more positive, individuals are more likely to engage in information seeking behaviors. Items measuring outcome expectancy in past research included, “There are a lot more benefits than there are problems associated with talking to my family about my organ donation decision,” and “Asking my parents what s/he thinks about this issue would produce a lot more negatives than positive” (Afifi et al., 2007; Fowler & Afifi, 2011). In the present study, the cost/benefit analysis considered in the outcome expectancy related to the genetic test for HD. Items included, “I assumed that knowing my diagnosis for Huntington’s disease, by having the genetic test, would be beneficial to me,” and “I thought that knowing my Huntington’s disease status would be more beneficial than harmful.” Higher scores on this scale indicated relatively greater benefits than costs. See Appendix B for the outcome expectancy scale.

The efficacy scale, related to the evaluation phase of TMIM, has three dimensions: communication efficacy, coping efficacy, and target efficacy (Afifi & Weiner, 2004). Communication efficacy is defined as “individuals’ perceptions that they can successfully enact a particular information-seeking strategy” (Afifi et al., 2006, p. 192). In previous studies, communication efficacy was measured using items such as, “I feel I have the ability to approach my partner to ask about her/his sexual health,” and “I know what I need to say to successfully discuss possible plans for my parent” (Afifi & Weiner, 2006; Fowler & Afifi, 2011). Items used to assess communication efficacy in the present study focused on the individual’s perceived
ability to communicate about predictive genetic testing for HD. Sample items included, “I knew that I would be able to discuss the results of my genetic test with my friends,” and “I knew that if I decided to undergo the genetic test for Huntington’s disease, I would be able to talk about the results with my family.”

Coping efficacy is an individual’s perception of how well he or she will be able to manage his or her information strategy (Afifi & Morse, 2008). Conceptually, coping efficacy considers “the emotional, instrumental, and other resources to manage the process- and results-based outcomes” (Afifi & Weiner, 2004, p. 178). Items previously used to assess coping efficacy included, “I feel I can manage discovering that my partner has an STI,” and “I’d be able to fully cope with my family opinions about my organ donation decision, whatever they may be” (Afifi et al., 2006; Afifi & Weiner, 2006). Items in the current study used to measure coping efficacy related to how the individual feels he or she can manage the results of the predictive genetic test for HD. For instance, items included, “I knew that I would have no problem with the results of the genetic test, whatever they were,” and “I was certain that I could handle the results of the genetic test for Huntington’s disease, whether they were positive or negative.”

Finally, target efficacy is comprised of two components: target ability and target honesty. Target ability is defined as “the assessment of whether the target has access to the sought-after information” (Afifi et al., 2006, p. 192). Target ability has been measured previously using items such as, “If we talked, my family would hide their true feeling about my organ donation decision,” and “I feel that my partner could provide be with information about her/his sexual health” (Afifi et al., 2006; Afifi & Weiner, 2006). In the current study, target ability related to the ability of the genetic test to provide a diagnosis of HD. Items used to assess target ability included, “I trusted the ability of the genetic test to provide an accurate diagnosis for
Huntington’s disease.” *Target honesty* “reflects confidence in the target’s willingness to provide all the information about the issue that is at his/her disposal” (Afifi et al., 2006, p. 192). Target honesty has been measured previously using items such as, “If we talked, my family would be upfront about what they think of my organ donation decision,” and “My parent would be forthcoming about sensitive issues that we would need to discuss about their possible future care” (Afifi et al., 2006; Fowler & Afifi, 2011). For the current study, items about target honesty included, “I knew that the genetic test would provide me with clear information about my Huntington’s disease status.” See Appendix B for the communication, coping, and target efficacy scales.

The sixth and final scale in the TMIM measure assesses *information seeking behavior*, which reflects the decision phase of TMIM (Afifi & Morse, 2009). Information seeking behavior relates to seeking information, avoiding information, or reassessing the situation. In past studies, items assessing information seeking behavior included: “How many questions have you asked your partner regarding his/her sexual health?” and “How many questions have you asked your parent regarding his/her preferences for care?” (Afifi & Weiner, 2006; Fowler & Afifi, 2011). Items used in the current study to assess information seeking behaviors are related to the information seeking done in family communication related to decision to undergo genetic testing for HD. Information seeking behaviors were assessed by items such as, “While I was deciding whether to undergo genetic testing, my family discussed Huntington’s disease often.” See Appendix B for the information seeking behavior scale.

To ensure that the data collected from the TMIM survey instrument were valid and reliable, the psychometric properties of past instruments were examined.
Reliability. Generally strong reliability coefficients have been reported for TMIM survey instruments used in previous studies. Table 1 shows the Cronbach’s alphas reported in three studies (Afifi et al., 2006; Afifi & Weiner, 2006; Fowler and Afifi, 2011). These reliabilities support the internal consistency of TMIM assessments. The present study relied on items that followed the format of items from prior studies in order to help ensure good reliabilities. See Table 1 for Cronbach’s alphas reported in previous studies assessing TMIM components.

Table 1

Cronbach’s Alphas (α) Reported in TMIM Studies

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<td>Coping Efficacy</td>
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<td>.73</td>
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<tr>
<td>Target Efficacy</td>
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<td>.71/.93</td>
<td>n/a</td>
</tr>
<tr>
<td>Information Seeking Behavior</td>
<td>.89</td>
<td>.94</td>
<td>.68</td>
</tr>
</tbody>
</table>

n/a = Cronbach’s alpha was not reported

Validity. Afifi et al. (2006), Afifi and Weiner (2006), and Fowler and Afifi (2006) all used the same conceptual definitions in developing the six scales in the TMIM instrument used in their respective studies. Using the same conceptual definitions of the six dimensions when
creating scales helps to ensure construct validity associated with TMIM instruments adapted to different contexts.

Afifi et al. (2006), Afifi and Weiner (2004) and Fowler and Afifi (2011) all discuss the predictive validity of the TMIM measure. When individuals had an uncertainty discrepancy and related emotions, as well as high outcome and efficacy assessments, they tended to engage in information-seeking behaviors (Afifi et al., 2006; Fowler & Afifi, 2011). Afifi and Weiner (2004) noted the predictive validity of the TMIM model in reporting that outcomes beyond the initial information-seeking behavior could be predicted. Their results support the predictive value of the process-model of TMIM, which suggests that individuals engage in interpretation and evaluation phases before deciding on an information seeking strategy, and thus, support the predictive validity of the set of TMIM measures.

Instrument Development

Item analyses were conducted to assess the coherence and internal consistency of the conversation orientation dimension of the Family Communication Patterns (FCP) instrument and Theory of Motivated Information Management (TMIM) instrument used in the current study. In order to confirm that each scale used for data analysis was sufficiently reliable, two criteria for scale development were considered. These criteria were: (a) the products of item analyses (i.e., Cronbach’s alpha and item-total correlations) and (b) the extent to which the items in the scale appeared to be conceptually coherent.

Family conversation orientation instrument. The 15-item subscale measuring the conversation orientation dimension of family communication was adapted from Ritchie and Fitzpatrick’s (1990) Revised Family Communication Pattern Instrument (RFCP). This subscale examined the general family communication patterns related to the frequency of talk and the
number of topics discussed. In the present study, the conversation orientation subscale produced high internal consistency (Cronbach’s $\alpha = .94$). Examination of the items revealed conceptual coherence, thus the all items in the conversation orientation scale were included in the subscale used for data analysis. See Appendix A for the conversation orientation instrument.

**TMIM instrument.** The TMIM instrument used in the present study was adapted from the survey instrument used in Afifi et al. (2006). This adapted TMIM instrument examined how individuals at risk for HD engaged in information seeking behaviors related to the decision to undergo genetic testing for HD. The TMIM instrument is comprised of six scales that reflect the specific phases in the decision-making process theorized by TMIM (Afifi & Weiner, 2004). These scales assessed: uncertainty discrepancy, anxiety, issue importance, outcome expectancy, efficacy—communication, coping, and target, and information seeking behavior. The originally proposed scales were modified for final data analysis based on the scale development criteria. See Appendix B for the originally proposed items and the items used for data analysis in each scale.

**Uncertainty discrepancy.** The five proposed uncertainty discrepancy items were designed to assess the amount of uncertainty that the individual experienced about the amount of information he or she possessed about the decision to undergo genetic testing for HD. The item analysis reveal that the proposed five-item scale had insufficient reliability for conducting analyses (Cronbach’s $\alpha = .42$). Upon further examination of the items in conjunction with the results of the item analyses, three items were deleted because they did not focus conceptually on the amount of uncertainty the individual experienced about the amount of information he or she possessed about the decision to undergo genetic testing. For example, “I wanted to know more than I did about Huntington’s disease itself” focused on disease-related knowledge rather than
the decision to undergo the genetic test for HD. The remaining two items correlated at a sufficiently high level for acceptable reliability \((r (28) = .70, p < .01; M = 2.47, SD = 1.82).\)

These items clearly related to the amount of uncertainty the individual experiences surrounding the amount of information he or she possesses about the decision regarding genetic testing for HD. See Appendix B for the final uncertainty discrepancy scale.

**Anxiety.** The seven items proposed to measure anxiety assessed the amount of anxiety that the individual had related to his or her assessment of the amount of information he or she possesses about the decision to undergo genetic testing for HD (i.e., uncertainty discrepancy). The item analysis revealed that a 5-item scale best met the criteria of conceptual coherence and reliability. Two items were deleted. The first deleted item related to family anxiety rather than individual anxiety (i.e., “My family was nervous that I did not know my Huntington’s disease status”). In the second deleted item, the locus of anxiety surrounded the individuals’ response to the outcome of the genetic test (i.e., how the person would react) rather than being related to his or her decision to undergo the test (i.e., “Not knowing how I might react to the results of the genetic test made me anxious”). The final anxiety subscale contained five items (Cronbach’s \(\alpha = .74\)). See Appendix B for the final scale.

**Issue importance.** The six items proposed to measure issue importance were designed to assess the importance the individual attributed to knowing his or her HD status through genetic testing. The proposed 6-item subscale produced sufficient reliability (Cronbach’s \(\alpha = .78\)). However, examination of the scale revealed that deleting two items would better ensure conceptual coherence. The deleted items related to participant family’s assessments of issue importance rather than participants’ assessments of issue importance (i.e., “It was important to my family for me to consider undergoing genetic testing for Huntington’s disease”). The final 4-
item *issue importance* scale produced acceptable reliability (Cronbach’s α = .74). See Appendix B for the final issue importance scale.

**Outcome expectancy.** The seven items proposed to measure *outcome expectancy* were designed to assess individuals’ cost/benefit analysis related to the genetic test for HD. The reliability analysis revealed that the proposed 7-item subscale produced acceptable reliability (Cronbach’s α = .83). However, after further examination of the scale, two items were deleted to ensure greater conceptual coherence. Specifically, “I expected that the results of the genetic test for HD would have too many drawbacks” was deleted because it did not explicitly relate to the cost/benefit analysis. The item “I expected that my family would have beneficial (i.e., helpful) reaction to me having the genetic test,” was deleted because it related to the *family’s* cost/benefit analysis rather than to the *individual’s* analysis. The resulting five-item scale to measure *outcome expectancy* produced high reliability (Cronbach’s α = .91). See Appendix B for the final outcome expectancy scale.

**Efficacy assessments.** A series of 17 items were proposed to measure total efficacy. The measure was comprised of three dimensions: *communication efficacy, coping efficacy,* and *target efficacy.*

The six items proposed to measure *communication efficacy* focused on the individual’s perceived ability to communicate about predictive genetic testing for HD. Results of the reliability analysis revealed that the proposed 6-item scale was not adequately reliable (Cronbach’s α = .62). Examination of the items revealed variation in the targets for the relevant communication. One item focused on *strangers,* two items on *friends,* and three on *family members.* Due to the focus of the present study on family communication the three items that focused on *family members* as the target for the relevant communication were retained. The
resulting 3-item communication efficacy scale had high internal consistency (Cronbach’s $\alpha = .93$).

The six items proposed to measure coping efficacy were designed to assess how well the individual believed he or she can manage the results of the predictive genetic test for HD. The reliability analysis revealed that the proposed 6-item scale had moderately strong reliability (Cronbach’s $\alpha = .81$). However, further examination of the scale indicated that two items focused on the family’s coping efficacy rather than the individual’s coping efficacy (i.e., “I believed that my family would help me cope with the results of the genetic test for HD, if I decided to get tested”). Those two items were deleted. The remaining four items related to the individual’s assessments of his or her coping efficacy and were retained. The resulting 4-item scale had greater conceptual coherence and produced high reliability (Cronbach’s $\alpha = .90$).

The five items proposed to measure target efficacy were designed to assess the perceived “ability” and “honesty” of the genetic test to provide a diagnosis of HD (Afifi et al., 2006). The reliability analysis indicated that the 5-item scale produced strong reliability (Cronbach’s $\alpha = .86$). Examination of the items revealed conceptual coherence, thus the complete proposed scale was used in the data analysis.

The total efficacy subscale was a sum of the items from the three dimensions of efficacy measured in the present study. Three items measuring communication efficacy, four items measuring coping efficacy, and the five items measuring target efficacy comprised the total efficacy subscale. This 12-item total efficacy scale produced strong reliability (Cronbach’s $\alpha = .80$). See Appendix B for the final communication, coping, and target efficacy scales.

**Information seeking behavior.** The four items proposed to measure information seeking behavior were designed to assess information seeking behaviors related to undergoing the
genetic test for HD. These items specifically assessed the amount of information seeking (i.e.,
the amount of talk) within the individual’s family about the decision to undergo genetic testing
for HD. This 4-item scale produced moderately strong reliability (Cronbach’s $\alpha = .81$).
Examination of the items revealed conceptual coherence; thus four proposed items were retained
and comprised the scale used in the data analysis.
Chapter IV

Results

The present exploratory study examined potential links between family communication and individual decision-making processes regarding genetic testing for individuals at risk for Huntington’s disease (HD). After the data were collected and entered into an SPSS file, statistical analyses were conducted to test the hypotheses and answer the proposed research question.

Hypotheses and Research Question Testing

Statistical analyses were conducted to test the hypotheses and answer the research question posed in the present study. The hypotheses and research question were derived from the proposed conceptual model. Two-tailed tests were used in all analyses. Alpha was set at .05. Pearson product-moment correlations were used to test the first seven hypotheses. The $r^2$ values were computed to determine the strength of the significant correlations (Cohen, 1988). Independent sample $t$-tests were conducted to test Hypothesis 8 and to answer the research question. The results of the Levene’s test were reviewed to test the assumption of equal variances, and the appropriate $t$-test results were reported. See Figure 2 for results of the statistical analyses that tested specific hypothesized relationships derived from the proposed conceptual model; see Table 2 for a correlation matrix of all variables examined the current study.

Hypothesis 1. Hypothesis 1 stated that for individuals at risk for HD, family conversation orientation is positively associated with the amount of talk (i.e., information seeking) within the family about HD and related genetic testing. The resulting Pearson product-moment correlation yielded a significant positive relationship ($r (28) = .75, p < .01$). This result
is a large effect size, explaining 56.25% of the variance (Cohen, 1988). Results indicated that individuals who rated their family as having a relatively open conversation orientation tended to report relatively higher amounts of talk (i.e., information seeking) within the family about HD and the related genetic testing. Thus, Hypothesis 1 received statistical support. See Table 2 for a correlation matrix with all significant relationships flagged.

**Figure 2**

Results of Statistical Testing of Relationships Suggested by the Proposed Model

Hypothesis 2. Hypothesis 2 posited that for individuals at risk for HD, the amount of talk within the family about HD and related genetic testing is negatively associated with uncertainty discrepancy surrounding their HD status. The Pearson product-moment correlation that examined this hypothesis was not statistically significant \( r(28) = .04, p = .82 \). Thus, Hypothesis 2 was not statistically supported.

Hypothesis 3. Hypothesis 3 stated that for individuals at risk for HD, the amount of talk within the family about HD and related genetic testing is negatively associated with the emotional assessment of anxiety regarding their uncertainty discrepancy surrounding their HD
status. The Pearson product-moment correlation that tested this hypothesis was not statistically significant \((r(28) = .03, p = .88)\). Thus, Hypothesis 3 was not statistically supported.

**Hypothesis 4.** Hypothesis 4 stated that for individuals at risk for HD, anxiety is negatively associated with (a) their outcome expectancies; and (b) their overall assessment of efficacy. The Pearson product-moment correlation that tested the relationship between anxiety and outcome expectancies yielded non-significant results \((r(28) = -.15, p = .44)\). The Pearson product-moment correlation that tested the relationship between anxiety and overall assessments of efficacy also yielded non-significant results \((r(28) = -.18, p = .34)\). Thus, Hypothesis 4a and Hypothesis 4b were not statistically supported.

**Hypothesis 5.** Hypothesis 5 posited that for individuals at risk for HD, the amount of talk within the family about HD and related genetic testing is positively associated with outcome expectancies. The Pearson product-moment correlation used to test this hypothesis was not statistically significant \((r(28) = .07, p = .72)\). Thus, Hypothesis 5 was not statistically supported.

**Hypothesis 6.** Hypothesis 6 stated that for individuals at risk for HD, the amount of talk within the family about HD and related genetic testing is positively associated with assessments of (a) overall efficacy, (b) coping efficacy, (c) communication efficacy, and (d) target efficacy.

The Pearson product-moment correlation that tested the relationship between the amount of talk within the family about HD-related topics and total efficacy yielded a non-significant correlation \((r(28) = .30, p = .11)\). Thus, Hypothesis 6a was not statistically supported.

The Pearson product-moment correlation that tested the relationship between the amount of talk within the family about HD-related topics and coping efficacy yielded a non-significant relationship \((r(28) = .07, p = .72)\). Thus, Hypothesis 6b was not statistically supported.
The Pearson product-moment correlation that tested the relationship between the amount of talk within the family about HD-related topics and communication efficacy was not statistically significant ($r (28) = -.02, p = .93$). Thus, Hypothesis 6c was not statistically supported.

Finally, the Pearson product-moment correlation that tested the relationship between family conversation orientation and target efficacy yielded a non-significant relationship ($r (28) = .02, p = .91$). Thus, Hypothesis 6d was not statistically supported.

**Hypothesis 7.** Hypothesis 7 stated that for individuals at risk for HD, outcome expectancies are positively associated with assessments of (a) overall efficacy, (b) coping efficacy, (c) communication efficacy, and (d) target efficacy.

The Pearson product-moment correlation that tested the relationship between outcome expectancies and total efficacy yielded statistically significant results ($r (28) = .41, p = .024$). This result is a moderate effect size, explaining 16.81% of the total variance (Cohen, 1988). Therefore, individuals at risk for HD in the present study who relatively rated their outcome expectancies higher also rated their assessments of total efficacy higher. Thus, Hypothesis 7a received statistical support. See Table 2.

The Pearson product-moment correlation that tested the relationship between outcome expectancies and coping efficacy also yielded significant results ($r (28) = .64, p < .01$). This is a medium effect size, explaining 40.96% of the total variance (Cohen, 1988). Therefore, individuals at risk for HD in the present study who relatively rated their outcome expectancies higher also rated their assessments of coping efficacy higher. Thus, Hypothesis 7b received statistical support. See Table 2.
The Pearson product-moment correlation that tested the relationship between outcome expectancies and communication efficacy yielded non-significant results ($r (28) = .01, p = .96$). Thus, Hypothesis 7c was not statistically supported.

Finally, the Pearson product-moment correlation that tested the relationship between outcome expectancies and target efficacy yielded non-significant results ($r (28) = .04, p = .84$). Thus, Hypothesis 7d was not statistically supported.

**Hypothesis 8.** Hypothesis 8 posited that for individuals at risk for HD, those who engage in an information management strategy (i.e., undergo genetic testing for HD) and those who do not differ in their assessments of overall efficacy. An independent samples $t$-test computed to test this hypothesis yielded non-significant results ($t (28) = -.79, p = .44$). Individuals who *had undergone the genetic test* ($n = 16, M = 2.16, SD = 1.07$) did not differ from individuals who *had not undergone the genetic test* for HD ($n = 14, M = 2.44, SD = .82$) in their assessment of overall efficacy. Thus, Hypothesis 8 was not statistically supported.

**Research question 1.** Research question 1 asked if individuals who have undergone genetic testing for HD, compared to those who have not, differ in their family conversation orientation. An independent samples $t$-test computed to address this research question yielded non-significant results ($t (28) = -.30, p = .77$). The family conversation orientation of individuals *who had undergone the genetic test* ($n = 16, M = 3.02, SD = 1.25$) did not differ statistically from individuals *who had not undergone the genetic test* for HD ($n = 14, M = 3.17, SD = 1.52$). Thus, the answer to research question 1 was “No;” the difference between these two groups was not statistically significant.
Table 2
Pearson Product-Moment Correlations among Variables

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<th>(3)</th>
<th>(4)</th>
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<th>(6)</th>
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Note: *p < .05, **p < .01
Chapter V

Discussion

The current exploratory study examined the role of family communication in individuals’ decision-making process regarding whether to undergo genetic testing for Huntington’s disease (HD). Past research has focused on the individuals’ decision-making process related to genetic testing for HD (i.e., Smith et al., 2002); however no research has focused on the role(s) that family communication plays in these contexts. The present study aimed to fill this gap by using Koerner and Fitzpatrick’s (2002a) family conversation orientation dimension from the Family Communication Patterns (FCP) framework in conjunction with Afifi and Weiner’s (2004) Theory of Motivated Information Management (TMIM) in a novel approach to examine the proposed relationship between individual and family communication for individuals considering genetic testing for HD. The current study lays a foundation for future research into this complex communication process which individuals at-risk for HD engage in while deciding whether to undergo genetic testing.

Summary of Results

The present study was designed to examine the role of family communication in individuals’ decision-making process regarding genetic testing for HD. Eight hypotheses were tested and one research question was addressed; these were derived from the proposed conceptual model. Results of hypothesis testing and answers to the research question revealed two significant positive relationships: (a) the higher the family conversation orientation, the greater the relative amount of talk within the family about HD-related issues, and (b) as outcome expectancies were rated relatively more positive, assessments of efficacy were rated relatively
more positive. These relationships garner some limited insight into these specific aspects of the decision-making process regarding whether to undergo genetic testing for HD.

Analyses addressing the remaining hypotheses and research question did not reveal any statistically significant relationships. The amount of talk within the family about HD-related issues was not associated with: (a) uncertainty discrepancy, (b) evaluations of anxiety related to uncertainty discrepancy, (c) outcome expectancies, or (d) assessments of efficacy. Thus, the influence of family communication on the various phases of the decision-making process, as posited by TMIM, was not supported in the current study (Afifi & Weiner, 2004). Further, the following hypothesized relationships within the decision-making process posited by TMIM were not supported: (a) uncertainty discrepancy and related anxiety, (b) anxiety and outcome expectancies and efficacy assessments, (c) outcome expectancies and target and communication efficacy, and (d) efficacy assessments and the information management strategy (i.e., undergoing the genetic test for HD). Thus, the decision-making process posited by TMIM generally was not supported in the current study.

**Family conversation orientation and the amount of talk about HD.** Hypothesis 1 predicted that the family conversation orientation was positively associated with the amount of talk within the family about HD-related issues. The results of hypothesis testing supported this assumption. Specifically, family conversation orientation and the amount of talk (i.e., information seeking) within the family about HD-related issues, including genetic testing, were significantly and positively correlated. Consistent with the tenets of FCP, individuals who rated their families as relatively more open in their conversation orientation also rated their families as relatively more likely to discuss HD issues, including genetic testing for HD (Koerner & Fitzpatrick, 2002a). Conversely, individuals who rated their families as relatively more closed in
their conversation orientation rated their family as relatively less likely to discuss issues related to HD. The relationship found in the present study illustrates that a family with an open conversation orientation may act as one source of in-depth information about HD related issues for individuals at risk for HD compared to families with a closed conversation orientation.

**TMIM, outcome expectancies and efficacy assessments.** The results of testing Hypothesis 7 partially supported the *evaluation phase* of TMIM (Afifi & Weiner, 2004). The *evaluation phase* of TMIM is characterized by outcome expectancies and efficacy assessments. Outcome expectancies consider the cost/benefit analysis related to the information management strategy and efficacy assessments are related to individuals’ perceptions of his or her ability to successfully engage in said information management strategy (Afifi & Weiner, 2004). Results in current study found a positive relationship between outcome expectancies and (a) assessments of overall efficacy and (b) assessments of coping efficacy. However, no relationship was found between outcome expectancies and (c) assessments of communication efficacy and (d) assessments of target efficacy.

The significant relationships found in the current study suggest that as individuals rated their outcome expectancies as relatively more positive, they tended to rate their assessments of overall efficacy and coping efficacy relatively higher. Conversely, individuals who rated their outcome expectancies as relatively more negative rated their assessments of overall efficacy and coping efficacy relatively lower. These relationships demonstrate some limited support in the context of decisions regarding genetic testing for HD for TMIM which theorizes that individuals who have a more positive cost/benefit analysis (i.e., the benefits of the information management strategy outweigh the costs of the strategy) feel more efficacious in their decision-making process (Afifi & Weiner, 2004).
These findings also indicate that individuals’ assessments of total and coping efficacy are linked to the cost/benefit analysis that is evaluated in the outcome expectancies, as theorized by TMIM (Afifi & Weiner, 2004). Positive assessments of efficacy are considered benefits; negative assessments of efficacy are considered costs. Thus, in the current study, individuals at risk for HD appear to have considered the cost/benefit analysis of undergoing the genetic test in relation to their perception of their ability to engage in the genetic test and cope with the results. The present study affirms the assumption that individuals' outcome expectancies are positively associated with efficacy assessments during the evaluation phase of their decision-making process regarding genetic testing for HD.

**Sampling technique implications.** The small sample size of the current study \(N = 30\) limited the ability to find statistical support for the tested hypotheses and the results related to the research question derived from the proposed conceptual model). As a result, Type II error may have occurred. That is, this study's small sample size limited the power of the analyses and thereby may limit interpretations of the results. Future research using the proposed model should overcome any possible type II error by expanding the sample size. However, results of the current study also may be interpreted as indicating the possibility that the model may not be applicable to the context of decision-making related to genetic testing for HD.

**Alternative Explanations for Results**

The findings of the present study revealed that that amount of family talk about HD-related issues was not significantly associated with the decision-making process related to genetic testing. That is, the family conversation orientation was not directly or indirectly predictive of the decision to undergo genetic testing for HD. Thus, influences other than family communication may be acting on individuals as they decide whether to undergo genetic testing.
for HD. Further, the decision-making process, as posited by TMIM, was only partially supported by hypothesis testing. Thus, in the present study, the concepts associated with TMIM were not useful in understanding individuals’ experience of deciding whether to undergo genetic testing for HD.

**Family communication and deciding to be tested for HD.** The current study hypothesized that family communication influences the decision-making process, however no significant relationships were found between family communication and the various phases of the decision-making process, as posited by TMIM. These results suggest the possibility that factors other than explicit family communication about HD may be acting to influence individuals who are at risk for HD. One potential factor that was not initially considered was the presence of a family member who had undergone the genetic test for HD. This presence of a family member who had been tested could independently influence the decision whether to undergo genetic testing. To explore the possibility of whether having a family member who had undergone genetic testing for HD makes a systematic difference in the decision-making process, as posited by TMIM, further statistical analyses were conducted.

**Further analyses.** One possible explanation for the results was that the presence of a family member who had undergone genetic testing for HD might act as a critical influence on decisions regarding being tested and the theoretically-related issues. That is, a family member who has undergone testing may play a role in the posited decision-making process by providing implicit and explicit influence based on their experience.

In order to explore that possibility, a series of independent samples *t*-tests was conducted to determine if individuals *with* family members who had undergone genetic testing differed in their family communication practices and in the specific processes of decision-making posited by
TMIM compared to individuals without family members who had undergone the genetic test. The groups were compared on the following variables considered in the current study’s proposed model: family conversation orientation, the amount of talk within the family about HD-related issues, uncertainty discrepancy, anxiety, outcome expectancies, and efficacy assessments. No statistically significant differences were found. Additionally, a chi-square analysis was conducted to assess the possible relationship between having been tested (yes or no) and the presence or absence of a family member who had undergone the genetic test for HD. The chi-square analysis was not statistically significant. Thus, individuals with family members who had undergone genetic testing for HD did not differ from individuals without family members who had undergone genetic testing in their family communication environment, as posited by FCP, or in the variables comprising individual decision-making and their ultimate decision whether to undergo testing, as theorized by TMIM.

**Limitations of the family conversation orientation.** The family conversation orientation dimension of FCP garnered some insight into the family communication practices surrounding HD-related issues, including the genetic test. As predicted, family conversation orientation and the amount of talk (i.e., information seeking) within the family about HD-related issues, including genetic testing, were significantly and positively correlated. However, as posited by Koerner and Fitzpatrick (2002a), FCP, including the family conversation orientation, does not provide insight into the varied nuances of family conversations; rather it provides a general, structural understanding of how much the family communicates. Thus, the family conversation orientation provides insight into the quantity of talk surrounding HD-related issues, but does not clarify the nature or the quality of the talk (e.g., the topics and tones of conversations, the amount of agreement, whether conversations are optimistic or pessimistic in orientation). Future
research should aim to understand the nuances of family communication surrounding HD-related issues, including genetic testing, and whether those nuances are associated with decisions regarding genetic testing.

Further, using the family conversation orientation dimension as a framework to understand the influence of these family communication practices on the decision to undergo said test was not informative. The results of both the original data analysis and the further exploratory analyses did not support the assumption of the current study that family communication is a primary influence on the decision-making process to undergo genetic testing for HD. However, one possibility is that communication influences outside of the family may act concurrently on individuals’ decision-making process related to genetic testing for HD (e.g., Wang, Gonzales, & Merajver, 2004; Coulson, Buchanan, & Aubeeluck, 2007; Case, Johnson, Andrews, Allard, & Kelly, 2004). These alternative sources of communication influence may include communication with: health care providers, members of individuals’ social support network, and additional informational and support sources beyond the family.

*Health care providers.* Health care providers (i.e., doctors, geneticists, and nurses) are a potentially important source of information for individuals making all types of medical decisions, including the decision to undergo genetic testing (Wang et al., 2004). Providers act as informational experts to whom patients turn when deciding to engage in complex health-related decisions, such as whether to undergo genetic testing. These health care providers can relay a nuanced understanding of complex medical procedures that may not be readily available outside of a medical setting. This understanding of complex medical procedures, such as genetic testing, may influence individuals’ assessments of target efficacy by instilling a greater sense of trust in the medical procedure to be accurate and reliable. These considerations are an important
assessment in the decision-making process as posited by TMIM (Afifi & Weiner, 2004). Health care providers may act as an important source of information and influence for individuals in the decision-making process regarding genetic testing for HD. This source is not examined in the current study, however past research has noted its influence (e.g., Wang et al., 2004) and future research should continue to examine the role of health care providers as an information source considered during the decision whether to undergo genetic testing for HD.

**Social support networks.** Social support networks beyond the family are a second potentially important source of information and influence on decisions to undergo genetic testing for HD. Social support networks can include both formal and informal sources of support for individuals making health-related decisions, such as undergoing genetic testing for HD (Goldsmith & Albrecht, 2011). Formal social support networks include structured support, such as HDSA support groups specific to individuals dealing with HD. Informal social support networks include less structured support, such as friends who offer information, advice, and support for decisions. Both formal and informal sources of social support networks may influence individuals’ decision whether to undergo genetic testing. These networks were not examined in the current study; however research has noted social support networks play an important role for those dealing with HD (e.g., Coulson et al., 2007). Future research should aim to further understand the role that social support plays in this decision-making process.

**Other informational and support sources.** In addition to social support networks, other sources of information and support outside of the family may influence individuals at risk for HD as they consider genetic testing. One channel for accessing information and support that has recently gained traction for individuals dealing with genetic testing decisions is the internet, which gives individuals access to thousands of possible information sources (Case et al., 2004).
Online resources, ranging from formal sources of information like the National Institutes of Health, to informal sources of information (e.g., personal blogs), have become a wide-spread means for accessing information and support for individuals dealing with a health issue, such as HD (Case et al., 2004). Thus, information gathering from online resources may act as a major influence on the individual at risk for HD. Online information and support seeking is a plausible source of information that individuals at risk for HD may consider when deciding whether to undergo genetic testing. Online information and support seeking was not examined in the current study, nor in extant research, as a potential influence on such decision-making, signaling a need for future research.

**TMIM and deciding to be tested for HD.** The current study hypothesized that individuals deciding whether to undergo genetic testing for HD would move through their decision-making process as theorized by Afifi and Weiner’s (2004) TMIM. This assumption was not supported in the current study. Specifically, the interpretation phase and the decision phase of TMIM did not receive support; partial insight was gained into two relationships in the evaluation phase. Thus, TMIM provided limited usefulness for understanding individuals’ decision-making process related to genetic testing for HD. As previously discussed, the relatively small sample size may have played a role in these findings; however, given the extremely small correlations and large p values of insignificant results, other explanations for the present study’s findings warrant consideration.

**Limitations of the interpretation phase.** The interpretation phase of TMIM is characterized by uncertainty discrepancy, the difference between how much uncertainty individuals possess and how much uncertainty they wish to have surrounding an issue (e.g., genetic testing for HD, as in the current study) and related anxiety. According to TMIM, these
interpretations motivate the individual to move through the decision-making process (Afifi & Weiner, 2004). In the current study, the hypothesized relationship between uncertainty discrepancy and related anxiety was not supported, nor was anxiety associated with participants moving through the posited decision-making process.

A possible explanation as to why the interpretation phase did not receive support is that the concept of the uncertainty discrepancy may not be useful in the current context. An uncertainty discrepancy occurs when an individual desires more or less uncertainty regarding an issue (Afifi & Weiner, 2004). The issue in the present study is genetic testing for HD. However, this evaluation of individuals’ uncertainty may not occur in the current context. Individuals may not think in a way that allows them to consider their current level of uncertainty and the amount of uncertainty they wish to have. To do so would involve a complex assessment of uncertainty, and these assessments may not occur in the experiences leading up to and during the decision-making process related to genetic testing for HD. Thus, uncertainty discrepancy may not be useful for understanding these decisions. Future research should aim to understand the parameters of uncertainty discrepancy, to discern which decision-making situations, if any, for which this concept is applicable for.

A second possible explanation why the interpretation phase failed to be supported is that the current study focused on anxiety as the sole emotion associated with the uncertainty discrepancy. Afifi and Morse (2009) propose that other emotions, beyond anxiety, may be associated with uncertainty discrepancies. These emotions may include: “anger, fear, disgust, jealous, envy, and hope” (Afifi & Morse, 2009, p. 94). Multiple additional emotions may be related to genetic testing for HD; however only anxiety was examined. Anxiety may be a critical emotion considered in the decision-making process, but other emotions likely also are at play in
this decision-making process. For example, individuals may experience hope that the genetic test will be negative or they may experience anger that other family members have been diagnosed with HD through a genetic test. The decision as to whether to undergo genetic testing is complex, so it is reasonable to assume that the emotions associated with this decision are also complex.

*Limitations of the evaluation phase.* The evaluation phase of TMIM was partially supported by results from the current study. The evaluation phase is characterized by outcome expectancies, the cost/benefit analysis related to the decision, and efficacy assessments, the individuals’ perceived ability to enact the decision (Afifi & Weiner, 2004). Hypothesis testing revealed that outcome expectancies were positively related to both assessments of overall efficacy and assessments of coping efficacy. However, no association was found between outcome expectancies and assessments of communication efficacy nor assessments of target efficacy. This may be because individuals deciding whether to undergo genetic testing for HD may not focus on communication efficacy or target efficacy as their primary efficacy concerns when they are considering the cost/benefit analysis associated with outcome expectancies. More likely, the primary factors relevant during the evaluation phase are related to coping efficacy, specifically to the uncertainties that individuals will face after making their decision regarding the genetic test. As discussed in the literature review, these uncertainties may include numerous changes in the practical, emotional, social, and health-related aspects of individuals’ lives.

Communication efficacy may not take priority in this decision-making process due to an already confirmed ability to discuss HD with others (e.g., family members) in an efficacious way at the time of the decision. Individuals who are at-risk for HD most likely have immediate and extended family members dealing with HD, thus individuals considering testing may feel able to
communicate effectively about HD and related issues based on their familial experiences. Target efficacy also may be a secondary assessment due to the general acceptance of the genetic test as the diagnostic tool for HD in health care and perhaps among individuals with or at-risk for HD. Therefore, questions related to the honesty and trustworthiness of the genetic test may not be critical efficacy considerations in this decision-making process. Thus, coping efficacy may take priority in the overall assessment of efficacy considered in relation to the outcome expectancies.

**Limitations of the decision phase.** The hypotheses associated with the decision phase of TMIM were not statistically supported in the current study. This phase is characterized by the individual deciding whether or not to engage in an information management strategy (Afifi & Weiner, 2004). In the current study, the information management strategy was undergoing the genetic test for HD. This phase is the final step of the decision-making process; it is the culmination of the interpretation phase and the evaluation phase. As previously noted, the interpretation phase did not receive support in the current study; however the evaluation phase did receive partial support. The limited support may be due to irrelevant aspects of the TMIM, such as uncertainty discrepancy, anxiety as the sole related emotion, and target and communication efficacy, which may not apply in the context of deciding whether to undergo the genetic test. Because of these limitations in the evaluation and interpretation phases, the cumulative effect of the first two phases of TMIM materializing in influencing the decision phase may be negligible.

In conclusion, TMIM was not useful for predicting individuals' decision-making process related to genetic testing for HD in the present study. One possible explanation is that TMIM may be better suited to less complex decision-making processes which are relatively easier to make. Past research has focused on less complex decisions, having less immediately significant
impact, such as college couples sharing sexual-health information and the decision to become an organ donor (Afifi et al., 2006; Afifi & Weiner, 2006). Although these past studies address important health-related decisions, these decisions do not have immediate, drastic, nor necessarily enduring impact on the life of the person making the decision: in contrast; a positive test for HD does have such impact. Thus, TMIM may be better suited to understanding less complex and less immediately significant decisions than examined in the current study.

Furthermore, some concepts of TMIM may not have been relevant to the current context. Specifically, individuals considering the genetic test for HD may not consider an uncertainty discrepancy; they may not have emotional interpretations limited to anxiety; and they may not have assessed communication and target efficacy as primary efficacy factors when making the decision whether to undergo genetic testing for HD. Perhaps, due to these limitations, TMIM did not provide a strong basis for providing insight into the decision-making process related to genetic testing for HD proposed in the present study.

Limitations

Several methodological factors may limit the current study. First, the small sample size was a methodological limitation. Although, only 30 people participated, their responses did provide insight into some significant relationships between general family conversation orientation and family discussions of HD and related issues, as well as in the evaluation phase of individuals’ decision-making process regarding genetic testing for HD. Although a larger sample size may have not made a difference in the results of the present study, future research should aim for larger sample sizes in order to limit the possibility of type II error and to be able to study this area more completely. Importantly, a substantially larger sample would allow
testing of the conceptual model as a whole (which this study did not propose to do), using statistical modeling techniques.

Second, the convenience sampling technique was a potential methodological limitation. HD is very rare, thus the current study used a convenience sample. This sampling technique may have provided the highest likelihood of participation for the current study; however, it may have limited the type(s) of individuals included in the sample. For instance, 25 participants self-identified as female and only 5 participants self-identified as male. Past research has found that, in general, women seek out support groups for health issues relatively more often than men (Tudiver & Talbot, 1999).

Further, individuals who are relatively more optimistic about their health issues are more likely to participate in support groups (Sochu, Ekeburg, Karensen, & Sorensen, 2008). This is potentially problematic in the present study. Individuals who are relatively more pessimistic about their disease status tend to be at higher risk for emotional distress related to their health issues. Thus, individuals who are at the highest risk for emotional distress are the least likely to seek out a support group; therefore these relatively more distressed individuals may have been less likely to be captured in the current sample. As a result, this sampling technique may inadvertently have eliminated individuals with the greatest anxiety related to the genetic test for HD and its potential outcomes. Future related studies should aim to balance the gender of participants, as well to enroll participants outside of the context of social support groups, in order to have a more representative sample of participants.

A third methodological limitation relates to the uncertainty discrepancy subscale from the TMIM measure used in the current study. Five items were proposed for this subscale. However, after considering the statistical and conceptual coherence of this subscale, only two of
the five items correlated at a level for acceptable reliability to be retained to measure \textit{uncertainty discrepancy}. As a result, this subscale may have been limited in its ability to capture the conceptual nuances of this complex uncertainty evaluation.

\textbf{Suggestions for Future Research}

Future research should examine the phenomenological experience associated with the decision-making process regarding genetic testing for HD. The concepts comprising TMIM did not prove to be useful for understanding the experience of engaging in the complex decision-making process regarding whether to undergo genetic testing for HD in the current study. However, identifying the important factors in the individuals’ experience as they decide whether to undergo testing \textit{could be achieved by using a qualitative approach}. A qualitative methodology may allow researchers to identify factors that are considered and experienced during the decision-making process, including more nuanced family communication factors (i.e., beyond the amount of talk). This qualitative approach could provide groundwork for future research into the influential factors related to this decision-making process.

A qualitative research approach also would identify the variety and relevance of information sources that may influence individuals who are dealing with HD and considering the genetic test. Moving forward, alternative sources of influence, such as health care providers, social support networks, and other information and support sources outside the family, in addition to family communication, should be examined. This may allow researchers to discern which information sources are pivotal in the decision whether to undergo genetic testing for HD, and if and how this decision-making process considers multiple informational and communicative influences.
Appendix A

Revised Family Communication Patterns Instrument

Adapted from Ritchie and Fitzpatrick (1990)
Conversation Orientation

1. In our family, we often talk about topics like politics and religion where some persons disagree with others.
2. My family members often say something like “Every member of the family should have some say in family decisions.”
3. My family members often ask my opinion when the family is talking about something.
4. My family members encourage me to challenge their ideas and beliefs.
5. My family members often say something like “You should always look at both sides of an issue.”
6. I usually tell my family members what I am thinking about.
7. I can tell my family members almost anything.
8. In our family we often talk about our feelings and emotions.
9. My family and I often have long, relaxed conversations about nothing in particular.
10. I really enjoy talking with my family members, even when we disagree.
11. My family members like to hear my opinions, even when they don’t agree with them.
12. My family members encourage me to express my feelings.
13. My family members tend to be very open about their emotions.
14. We often talk as a family about things we have done during the day.
15. In our family, we often talk about our plans and hopes for the future.

All items were retained for data analysis.
Appendix B

TMIM Items

Adapted from Afifi et al. (2006)
Uncertainty Discrepancy

1. I knew less than I would have liked to know about my own diagnosis of Huntington’s disease.
2. I did not know about my Huntington’s disease status and I wanted to know more.*
3. I was very uncertain about my own diagnosis for Huntington’s disease.
4. I wanted to know more than I did about Huntington’s disease itself.
5. I wanted to know my own Huntington’s disease status.*

Anxiety

1. Thinking about the difference between how much I knew, compared to how much I wanted to know, about my Huntington’s disease status made me anxious.*
2. I was nervous because of how little I knew about my diagnosis for Huntington’s disease.*
3. Not knowing how my family might react to the results of the genetic test for Huntington’s disease made me anxious.
4. Not having as much information as I would have liked about my own diagnosis of Huntington’s disease made me nervous.*
5. It made me anxious to think about how little I knew about my own diagnosis of Huntington’s disease.*
6. Not knowing how I might react to the results of the genetic test made me anxious.*
7. My family was nervous that I did not know my Huntington’s disease status.
**Issue Importance**

1. It was important to *me* to consider undergoing genetic testing for Huntington’s disease.*
2. It was critical to my future plans to consider undergoing genetic testing for Huntington’s disease.*
3. It was important to *my family* for me to consider undergoing genetic testing for Huntington’s disease.
4. Potentially knowing my Huntington’s disease status was important to me.*
5. I believe that knowing my diagnosis for Huntington’s disease is important.*
6. *My family* believes that undergoing genetic testing is important for anyone at risk for Huntington’s disease.

**Outcome Expectancies**

1. I assumed that knowing my diagnosis for Huntington’s disease, by having the genetic test, would be beneficial to me.*
2. I expected that the results of the genetic test would be beneficial to me.*
3. I thought that the benefits of undergoing genetic testing were big enough to outweigh the drawbacks.*
4. I expected that *my family* would have a beneficial (i.e., helpful) reaction to me having the genetic test.
5. I expected that the results of the genetic test for Huntington’s disease would have too many drawbacks. R
6. I thought that knowing my Huntington’s disease status would be more beneficial than harmful.*
**Communication Efficacy**

1. I believed that if I decided to undergo the genetic test for Huntington’s disease, I would be able to discuss the decision with my family.*

2. I knew that I would be able to talk to friends about the results of my genetic test.

3. I believed that I would be able to talk to strangers about the results of my potential genetic test.

4. I knew that I would be able to discuss the results of my genetic test with my friends.

5. I thought that I had the ability to discuss my decision to get a genetic test for HD with my immediate family.*

6. I knew that if I decided to undergo the genetic test for Huntington’s disease, I would be able to talk about the results with my family.*

**Coping Efficacy**

1. I knew that I would have no problem coping with the results of the genetic test, whatever they were.*

2. I believed that my family would help me cope with the results of the genetic test for Huntington’s disease, if I decided to get tested.

3. I was certain that I could handle the results of the genetic test for Huntington’s disease, whether they were positive or negative.*

4. I thought that I was able to fully cope with either positive or negative results of the genetic test.*

5. I believed that, if I decided to get tested, my family would be able to cope with the results of my genetic test for Huntington’s disease.
6. I believed that I could cope with a diagnosis of Huntington’s disease from the genetic test.*

**Target Efficacy**

1. I trusted the ability of the genetic test to provide an accurate diagnosis for Huntington’s disease.*

2. I believed that genetic testing for Huntington’s disease was final.*

3. I thought that the genetic test would provide me with accurate information about my diagnosis of Huntington’s disease.*

4. I thought that the genetic test would be completely correct about my diagnosis of Huntington’s disease.*

5. I knew that the genetic test would provide me with clear information about my Huntington’s disease status.*

**Information Seeking Behaviors: Amount of Family Talk**

1. While I was deciding whether to undergo genetic testing, my family discussed Huntington’s disease often.*

2. I did not consider my family member’s input while I was deciding whether to undergo genetic testing for Huntington’s disease.* R

3. My family talked about genetic testing often during my decision regarding whether to undergo genetic testing for Huntington’s disease.*

4. The conversations that I had with my family about Huntington’s disease influenced my decision regarding whether to undergo genetic testing.*
Outcome: Genetic Testing for HD

1. Have you undergone genetic testing for Huntington’s disease?

   - Asked in the demographic information section of the survey.

*Used in the final scale for data analysis.

R Reverse coded.
Appendix C

Demographic Information Items
1. What is your age in years? _________

2. What is your gender?
   ( ) Female ( ) Male

3. I consider myself:
   ( ) White
   ( ) Black or African American
   ( ) American Indian or Alaska Native
   ( ) Asian
   ( ) Native Hawaiian or Other Pacific Islander
   ( ) Other/please specify: ________________________

4. Are you of Hispanic or Latino origin?
   ( ) Yes
   ( ) No

5. What do you expect your family income for 2012 to be?
   ( ) Less than $10,000
   ( ) $10,000 - $19,000
   ( ) $20,000 - $29,000
   ( ) $30,000 - $39,000
   ( ) $40,000 - $59,000
   ( ) $60,000 - $100,000
   ( ) Greater than $100,000
6. What is the highest level of education that you have completed?
   ( ) Some high school
   ( ) High school diploma or GED
   ( ) Some college (no degree)
   ( ) Associate/2-year Technical Degree
   ( ) Bachelor’s Degree
   ( ) Graduate Degree

7. Have you been diagnosed with Huntington’s disease?
   ________

8. Have other individuals within your immediate biological family been diagnosed with Huntington’s disease?
   ( ) Yes  ( ) No

9. If you answered yes in question 8, please indicate who in your immediate biological family has been diagnosed with Huntington’s disease. Do not write down names; rather indicate how you are related to them (i.e., mother, two brothers, one child).

10. Have you undergone genetic testing for Huntington’s disease?
    ( ) Yes  ( ) No
11. Have other individuals within your immediate biological family undergone genetic testing for Huntington’s disease?

( ) Yes  ( ) No

12. If you answered yes in question 9, please indicate who in your immediate biological family has undergone genetic testing for Huntington’s disease. Do not write names; rather indicate how you are related to them (i.e., mother, two brothers, one child).
Dear Participant:

My name is Kaitlin Banduch. I am a graduate student at Kent State University. For my Master’s thesis, I am examining the decision-making processes related to genetic testing for Huntington’s disease. Because you personally are dealing with Huntington’s disease and possibly have undergone genetic testing for it, I am inviting you to participate in this research study by completing a questionnaire.

The following questionnaire will require no more than 30 minutes to complete. There is no known risk to you. In order to ensure that all information will remain confidential, please do not include your name on the survey instrument. If you choose to participate in the research, please answer all questions as honestly as possible. Please return the completed questionnaires promptly, sealed in the provided envelope. Participation is voluntary and you may refuse to participate at any time.

Thank you for taking the time to assist me in my educational endeavors. The data collected will provide useful information regarding how individuals decide to undergo genetic testing for Huntington’s disease. Completion and return of the survey will indicate your willingness to participate in the study. If you require additional information or have questions, please contact me using the information below.

Sincerely,

Kaitlin Banduch
Phone: (847) 970-1490
Email: kbanduch@kent.edu

Dr. Rebecca Cline (faculty advisor)
Phone: (330) 671-0286
Email: rcline14@kent.edu
Understanding the Decision Making Processes Related to
Genetic Testing for Huntington’s Disease

This questionnaire is about your decision making process related to undergoing genetic testing for Huntington’s disease. There are three sections, please complete all questions in each section. Make sure you read the instructions at the beginning of each section.

Section 1: Consider you immediate biological family (i.e., parents, siblings, spouse, and children) when indicating your degree of agreement with the following statements.

Please circle the number that indicates the extent to which you Agree or Disagree with each of the following statement: “1” means “Strongly Disagree” and “7” means “Strongly Agree.”

Select one answer for each question, unless otherwise indicated.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
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<tbody>
<tr>
<td>My family members often ask my opinion when the family is talking about something.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
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<tr>
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<td></td>
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<td></td>
</tr>
<tr>
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<td>1 2 3 4 5 6 7</td>
<td></td>
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<tr>
<td>Statement</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
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<td>--------------------------------------------------------------------------</td>
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<tr>
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<tr>
<td>In our family we often talk about our feelings and emotions</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>
Section 2: Now I would like you to think about your emotional/physical/psychological state while you were making your decision whether to undergo genetic testing for Huntington’s disease when indicating your agreement with the following statements.

Please circle the number that indicates the extent to which you Agree or Disagree with each of the following statement: “1” means “Strongly Disagree” and “7” means “Strongly Agree.”

Select one answer for each question, unless otherwise indicated.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I wanted to know my own Huntington’s disease status.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>It was important to my family for me to consider undergoing genetic testing for Huntington’s disease.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I expected that the results of the genetic test for Huntington’s disease would have many drawbacks.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>Not having as much information as I would have liked about my own diagnosis for Huntington’s disease made me nervous.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I believed that I would be able to talk to strangers about the results of my potential genetic test.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>While I was deciding whether to undergo genetic test, my family discussed Huntington’s disease often.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I knew that the genetic test would provide me with clear information about my Huntington’s disease status.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I believed that my family would help me cope with the results of the genetic test for Huntington’s disease, if I decided to get tested.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I believe that knowing my diagnosis for Huntington’s disease is important.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>Not knowing how I might react to the results of the genetic test made me anxious.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I wanted to know more than I did about Huntington’s disease itself...</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I thought that the benefits of undergoing genetic testing were big enough to outweigh the drawbacks.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I thought that I had the ability to discuss my decision to get a genetic test for Huntington’s disease with my immediate family</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>-----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>My family talked about genetic test often during my decision regarding whether to undergo genetic testing for Huntington’s disease</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I thought that I was able to fully cope with either positive of negative results of the genetic test</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I believed that genetic testing for Huntington’s disease was final</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>My family was nervous that I did not know my Huntington’s disease status</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I thought there were a lot more benefits than there were problems associated with possibly undergoing genetic testing for Huntington’s disease</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I was nervous because of how little I knew about my diagnosis for Huntington’s disease</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>It was important to me to consider undergoing genetic test for Huntington’s disease</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I believed that I could cope with a diagnosis of Huntington’s disease from the genetic test</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>Potentially know my Huntington’s disease status was important to me</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I expected that the results of the genetic test would be beneficial to me</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I knew less than I would have like to know about my own diagnosis of Huntington’s disease</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I knew that I would be able to talk to friends about the results of my genetic test</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>I thought that the genetic test would provide me with accurate information about my diagnosis of Huntington’s disease</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>
Not knowing how *my family* might react to the results of the genetic test for Huntington’s disease made me anxious........................................ 1 2 3 4 5 6 7

*My family* believed that undergoing genetic testing is important for anyone at risk for Huntington’s disease........................................ 1 2 3 4 5 6 7

I assumed that knowing my diagnosis for Huntington’s disease, by having the genetic test, would be beneficial to me................................. 1 2 3 4 5 6 7

I was very uncertain about my own diagnosis for Huntington’s disease................................................................................................. 1 2 3 4 5 6 7

I was certain that I could handle the results of the genetic test for Huntington’s disease, whether they were positive or negative............. 1 2 3 4 5 6 7

The conversation that I had with my family about Huntington’s disease influenced my decision regarding whether to undergo genetic testing................................................................. 1 2 3 4 5 6 7

I trusted the ability of the genetic test to provide an accurate diagnosis for Huntington’s disease............................................................ 1 2 3 4 5 6 7

It made me anxious to think about how little I knew about my own diagnosis of Huntington’s disease......................................................... 1 2 3 4 5 6 7

I thought that knowing my Huntington’s disease status would be more beneficial than harmful............................................................... 1 2 3 4 5 6 7

I knew that if I decided to undergo the genetic test for Huntington’s disease, I would be able to talk about the results with my family.... 1 2 3 4 5 6 7

I did not consider my family member’s input while I was deciding whether to undergo genetic testing for Huntington’s disease......... 1 2 3 4 5 6 7

I knew that I would be able to discuss the results of my genetic test with my friends................................................................. 1 2 3 4 5 6 7

It was critical to my future plans to consider undergoing genetic testing for Huntington’s disease.......................................................... 1 2 3 4 5 6 7

I did not know about my Huntington’s disease status and I wanted to know more.............................................................................. 1 2 3 4 5 6 7
I knew that I would have no problem coping with the results of the genetic test, whatever they were......................................................... 1 2 3 4 5 6 7

Thinking about the difference between how much I knew, compared to how much I wanted to know, about my Huntington’s disease status made me anxious............................................................. 1 2 3 4 5 6 7

I believed that if I decided to undergo the genetic test for Huntington’s disease, I would be able to discuss the decision with my family............................................................... 1 2 3 4 5 6 7

I thought that the genetic test would be completely correct about my diagnosis of Huntington’s disease..................................................... 1 2 3 4 5 6 7

I expected that my family would have a beneficial (i.e., helpful) reaction to me having the genetic test....................................................... 1 2 3 4 5 6 7

I believed that, if I decided to get tested, my family would be able to cope with the results of my genetic test for Huntington’s disease. 1 2 3 4 5 6 7
Section 3: Finally, we would like to get some general information about you. Once again, all of your answers are anonymous and there is no way you can be identified from your answers on the questionnaire.

1. What is your age in years? ________

2. What is your gender?
   ( ) Female  ( ) Male

3. I consider myself:
   ( ) White
   ( ) Black or African American
   ( ) American Indian or Alaska Native
   ( ) Asian
   ( ) Native Hawaiian or Other Pacific Islander
   ( ) Other/please specify: ________________________

4. Are you of Hispanic or Latino origin?
   ( ) Yes
   ( ) No

5. What do you expect your family income for 2012 to be?
   ( ) Less than $10,000
   ( ) $10,000 - $19,000
   ( ) $20,000 - $29,000
   ( ) $30,000 - $39,000
( ) $40,000 - $59,000
( ) $60,000 - $100,000
( ) Greater than $100,000

6. What is the highest level of education that you have completed?
   ( ) Some high school
   ( ) High school diploma or GED
   ( ) Some college (no degree)
   ( ) Associate/2-year Technical Degree
   ( ) Bachelor’s Degree
   ( ) Graduate Degree

13. Have you been diagnosed with Huntington’s disease?

   ________

14. Have other individuals within your immediate biological family been diagnosed with Huntington’s disease?
   ( ) Yes  ( ) No

15. If you answered yes in question 8, please indicate who in your immediate biological family has been diagnosed with Huntington’s disease. Do not write down names; rather indicate how you are related to them (i.e., mother, two brothers, one child).

16. Have you undergone genetic testing for Huntington’s disease?
   ( ) Yes  ( ) No
17. Have other individuals within your immediate biological family undergone genetic testing for Huntington’s disease?

( ) Yes  ( ) No

18. If you answered yes in question 9, please indicate who in your immediate biological family has undergone genetic testing for Huntington’s disease. Do not write names; rather indicate how you are related to them (i.e., mother, two brothers, one child).

PLEASE GO BACK THROUGH THE QUESTIONNAIRE
AND CHECK IF YOU HAVE MISSED ANY PAGES OR QUESTIONS
References


