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## **Adoptees' Experiences with Direct-to-Consumer Genetic Testing: Emotions, Satisfaction, and Motivating Factors**

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Adoptees' Experiences with Direct-to-Consumer Genetic Testing: Emotions,  
Satisfaction, and Motivating Factors

by

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Bachelor of Science  
Wofford College, 2013

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Submitted in Partial Fulfillment of the Requirements

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## **Dedication**

I would like to dedicate this to my family and friends, who have been there for me throughout this process. They have been a constant source of support and guidance, not only while writing my thesis but throughout all of my triumphs and and many failures, and for this, I cannot thank them enough.

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## **Abstract**

Public awareness of the role of genetics in disease continues to expand along with the use of direct-to-consumer genetic testing (DTC-GT). One subset of customers taking advantage of the growing DTC-GT market is adoptees. Prior research has shown that adoptees appear to be more motivated than non-adoptees to learn about their genetic disease risk but have similar responses to health-related information acquired through DTC-GT. In this exploratory qualitative study, fourteen adoptees were asked about their motivations for pursuing DTC-GT; satisfaction with results; emotions throughout the process; and interest in meeting with a genetic counselor. Motivations for pursuing DTC-GT fell into three categories: 1) identity-seeking, 2) a desire for health information, and 3) general curiosity. Adoptees reported a variety of emotional responses to DTC-GT but had more profound emotional reactions to ancestral information, related to both ethnicity and biological familial connections. Finally, the majority of adoptees found value in meeting with a genetic counselor, either for themselves or for their family given certain circumstances. This study highlights adoptees' experiences in their pursuit of genetic information. By understanding this population's journey with DTC-GT, genetic counselors and genetics professionals can be better equipped to address the concerns and emotions of this population that is receptive to the idea of genetic counseling.

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## **Chapter 1. Background**

### **1.1 Overview**

Adoption is a familiar concept in the United States, and the majority of Americans have been exposed to adoption at some point in their lives (Dave Thomas Foundation for Adoption, 2002). Among adopted individuals, it is not uncommon to experience a lack of family health history, and for adult adoptees, this lack of family information may be even more prevalent (Corder, 2012; May, Strong, Khoury, & Evans, 2015; Moe, 1998). Currently, DTC-GT provides consumers with the opportunity to order genetic testing without the assistance of a medical professional (*What is Direct-to-Consumer Genetic Testing?*) The DTC-GT industry continues to expand, and many DTC-GT consumers are driven by a curiosity about genes and genetic disease risk (Sanderson et al., 2015; Gollust et al., 2012; Su, Howard, & Borry, 2011; Baptista et al., 2016). Adoptees purchasing DTC-GT may be particularly motivated by this pursuit of genetic risk information, and for this subset of customers, DTC-GT may be viewed as the only available source of family history information (Corder, 2012; Crouch, Shankar, & Tabor, 2014; Hill & Edwards, 2009).

This background will explore several factors: adoption in the United States; the DTC-GT market and its development; risk perception and factors affecting its development; and where adoptees and genetic professionals fit into the DTC-GT market. The goal is that this will help to gain a better understanding of the unique situation of adoptees navigating this newfound source of genetic information.

## **1.2 Adoption in the United States**

Adoption can be described as a “legal process in which a child is raised by someone other than his or her biological parents” (Kavanaugh & Fiorini, 2016; Corder, 2012). The concept of adoption is not new, and written laws regarding adoption have been uncovered throughout several major parts of history (Moe, 1998; DellaCava, Phillips, & Engel, 2016); for example, laws concerning adoption can be found in the Babylonian Code of Hammurabi, in Hindu law, and in the Old and New Testament. The idea of adoption continues to become increasingly familiar in the world today. A joint study performed by the Dave Thomas Foundation and the Evan B. Donaldson Institute estimated that, in 2002, 64% of Americans had been exposed to adoption, either through their own families or through the experience of friends. With the increasing prevalence of adoption and favorable public perception of adoption, this number can be expected to increase (Dave Thomas Foundation for Adoption, 2002).

According to the 2010 United States Census, two percent of the 64.8 million children under the age of eighteen in the United States are adopted, totaling 1.5 million adopted children (Kreider & Lofquist, 2010). However, this represents only a small portion of the adoptees living in the United States today, with many more over the age of 18. Within the adoption process, several categories of adoptions exist: closed, open, and semi-open adoptions (Corder, 2012). In a closed adoption, the adoptee does not have contact with his or her birth family. Only through a search initiated by the adoptee can contact be achieved. Open adoptions allow the adoptee and the birth family to maintain contact using various methods such as letters. However, the amount of information exchanged can vary. Finally, semi-open adoptions permit the exchange of

some information between the adoptive family and the birth family, but this excludes identifying information, such as names.

Overall, open adoptions are becoming increasingly common, but many current adult adoptees underwent closed adoptions (Kavanaugh & Fiorini, 2016; Corder, 2012). Even with open adoptions, however, a lack of information about biological family members can exist. For example, in one study performed by Hill and Edwards (2009) examining 57 adoptions, it was found that information was available for less than 50% of birth fathers, even when information about the birth mother was known (May et al., 2015). In addition, for almost two-thirds of international adoptees, no written medical records exist. Therefore, a lack of family health history information is not uncommon among the adopted population, and this lack of genetic knowledge can serve as a factor driving adoptees to pursue genetic testing (Corder, 2012; Crouch et al., 2014; Hill & Edwards, 2009).

### **1.3 Direct-to-Consumer Genetic Testing Overview**

Francis Collins, director of the National Human Genome Research Institute, stated in 2001 that “virtually every human illness has a hereditary component.” The U.S. Surgeon General initiated its Family History Public Health Initiative campaign in 2001 to promote conversation regarding family health history (Collins & McKusick, 2001; Rich, et al., 2004). Public knowledge and awareness of the role of genetics in health and disease continues to grow. In 2004, a survey performed by the Center for Disease Control (CDC) asked 4,000 participants about the role of family health history in personal health, and 96% of participants believed that family health history was important to one’s own health history (Centers for Disease Control and Prevention, 2005). This increased public

awareness of the contribution of genetics to health and disease, along with recent technological advances, could be one of the major driving forces for the growth and expansion for DTC-GT companies (Collins & McKusick, 2001). Several studies cite a desire to learn about personal disease risk and a curiosity about genes as major motivations for purchasing DTC-GT (Sanderson et al., 2015; Gollust et al., 2012; Su et al., 2011; Baptista et al., 2016).

Traditionally, genetic testing has been ordered through a healthcare provider such as a genetic counselor or physician (*What is Direct-to-Consumer Genetic Testing?*). The healthcare provider collects a DNA sample and interprets the test results. DTC-GT, however, is a growing field that provides an opportunity for consumers to independently order genetic tests. These tests are marketed directly to consumers and eliminate the need to interact with a medical professional. The customer receives a testing kit in the mail, collects a DNA sample, and mails this kit back to the laboratory. The results are sent directly to the customer, usually through an online report.

In 2008, Time magazine named such DTC-GT, or “The Retail DNA Test,” the Invention of the Year, and this market has continued to grow and develop over the past eight years (Hamilton, 2008). According to a meta-analysis by Phillips (2016), as of January 2016, approximately 246 companies provide some form of DNA testing that can be ordered online. The results of DTC-GT can offer a mixture of health information, carrier status for autosomal recessive conditions, ancestry composition, genetic relatedness, pharmacogenetic information, and much more. For example, 23andMe (Mountain View, CA), one of the leading companies in the DTC-GT field, now provides carrier status information for 41 conditions; ancestry reports; wellness reports for eight

characteristics; and reports for 22 traits that make individuals unique, such as sweet taste preference (www.23andme.com). The company celebrated its one-millionth customer in 2015 (Turrini & Prainsack, 2016).

Other companies choose to focus on one specific area. AncestryDNA, for example, provides its customers with information about their ethnicity and identifies possible relatives that have also used the site (dna.ancestry.com). The market for DTC-GT companies continues to expand. The 23andMe test is now offered in 56 countries, and AncestryDNA, which first offered a genealogical DNA test in five countries in 2015, has now expanded to 29 additional countries (Harper, Kennett, & Reisel, 2016).

In addition to sites such as 23andMe and AncestryDNA that directly provide genetic risk or ancestry information, DTC-GT customers have the opportunity to access and download their raw genetic data from these sites and then use third-party tools to further analyze the data (Kirkpatrick & Rashkin, 2016). These third-party tools include companies such as Promethease, GEDMatch, and Strategene, which utilize the raw data provided by DTC-GT companies to further extrapolate information that has the potential to impact medical management and provide more in-depth ancestry information (Kirkpatrick & Rashkin, 2016; <http://seekinghealth.org/product/strategene>). These types of tools allow customers to learn even more from the genetic information originally obtained from DTC-GT.

#### **1.4 United States' Food and Drug Administration Crackdown on Direct-to-Consumer Genetic Testing**

In 2013, the DTC-GT company 23andMe failed to provide data supporting the analytical and clinical validity of its testing methodology to the United States Food and

Drug Administration (FDA) (Nelson, 2016; Chung & Yim, 2014), in response to FDA's concerns that consumers might be making medical decisions based on inaccurate information. Similar concerns were previously expressed by the American College of Medical Genetics (ACMG) in 2003, the American Society of Human Genetics (ASHG) in 2007, and other professionals in the field. FDA's warning letter sent to 23andMe in November of 2013 warned the company that the saliva-based mechanism used for genetic testing would be considered a medical device under regulation, and therefore, further marketing approval would be required.

On December 5, 2013, 23andMe ceased the production of all health-related genetic tests; after meeting FDA requirements, carrier status testing for 41 autosomal recessive conditions was resumed in October of 2015 (Nelson, 2016; Chung & Yim, 2014; Stoeklé, Mamzer-Bruneel, Vogt & Hervé, 2016). This action taken by FDA towards 23andMe also impacted the development of past and current DTC-GT in terms of the amount and type of information shared with consumers (Chung & Yim, 2014). FDA continues to keep tabs on companies providing information from DTC-GT tests. In November 2015, for example, three companies marketing genetic testing with supposed clinical utility received warning letters from FDA for the use of technologies that had not received approval (Brunstein, 2016).

### **1.5 Risks and Benefits of Direct-to-Consumer Genetic Testing**

Supporters of DTC-GT argue that it promotes patient autonomy and empowerment (Turrini & Prainsack, 2016; Bloss, Schork, & Topol, 2011). By supplying consumers with their genetic health information, DTC-GT can encourage healthier lifestyle choices (Bloss et al., 2011). Furthermore, proponents argue that this information

could also promote increased compliance with health screening practices. Patients can use of this form of more individualized genetic health information to adjust their health and lifestyle choices accordingly.

Several concerns also surround the DTC-GT market. In addition to worries about test validity, there is the potential for adverse psychological effects of DTC-GT results reports (and customers' interpretations of them). One reason for such a concern arose from the biased presentation of information on DTC-GT websites in which the listed benefits of such tests far outweighed the statements regarding risks and limitations (Singleton, Erby, Foisie, & Kaphingst, 2012). The worry is that consumers of DTC-GT are incapable of making a fully informed decision. If websites focus primarily on the advantages of DTC-GT, this results in a customer's biased opinion regarding the impacts of the test. The customer has a false impression of the test's benefits without being fully informed of its risks and constraints.

However, most of the literature to date demonstrates that these worries are not supported by research. Many studies have demonstrated a less significant psychological impact than expected (Bloss et al., 2011; Eggestone, Morris, & O'Brien, 2013; James, et al, 2011; Bloss, Wineinger, Darst, Schork, & Topol, 2013). In general, no significant difference in pre- and post-test level of anxiety was observed, even before FDA limited the genetic conditions for which this information could be reported. When participants did experience a change in anxiety level, anxiety was most often reduced. The majority of study participants experienced no rise in distress related to genetic testing after receiving results (Bloss et al., 2011; James et al., 2011). Overall, participants were likely to realize that health conditions are multifactorial in nature, and genetic testing results are not

deterministic. (James, et al., 2011). Therefore, regardless of marketing practices and the receipt of genetic test information that was anticipated to cause distress or anxiety, much of the research has shown that claims regarding the adverse psychological effects of DTC-GT are not supported.

### **1.6 Risk Perception and the Role of Family History**

Risk communication can be described as “the open two-way exchange of information and opinion about risk, leading to better understanding and better (clinical) decisions,” (Ahl et al., 1993; Sivell et al., 2008). The manner in which individuals construct and understand genetic risk is a complex, multi-faceted process unique to each individual (Sivell et al., 2008). Risk perception can be impacted by cultural beliefs, personal experience, stress level, genetic or family history factors, and many other facets of information. It has been observed that family history along with other factors can alter risk perception. For example, an individual’s experience with illness in his or her family greatly impacts the way risk is viewed. This holds true in terms of DTC-GT as well. An individual’s family history likely impacts both how one views the magnitude of disease risk as well as the clinical actions taken after learning testing results. In fact, family history of disease can be used to predict actions taken in response to receiving DTC-GT results, for example changing medication, pursuing follow-up testing and screening, and changing diet (Kaufman, Bollinger, Dvoskin, & Scott, 2012).

Furthermore, family history plays an important role in interpreting the results of such tests. Generally, a combination of genetic testing and family history is considered to be the optimal method of risk analysis when using DTC-GT (May et al., 2015). In a position statement on DTC-GT issued in February of 2016, the ACMG noted that

“medical interpretation of such results is often complex and includes patient specific information, such as prior medical and family history and other factors.” Ideally, genetic test results should be combined with family health history to provide to most effective and accurate risk assessment.

### **1.7 Adoptees and Direct-to-Consumer Genetic Testing**

In an ideal world, every individual has access to complete family health history. In the real world, however, this is not always the case, especially for adoptees who often have little or no family health history. This lack of family history that exists for many adoptees can also be a driving force for pursuing DTC-GT (Corder, 2012; Crouch et al., 2014; Hill & Edwards, 2009).

Previous research has shown that motivations for the use of DTC-GT include curiosity about genetics, a desire to learn more about disease risk for one’s self and one’s family, interest in novel technology, a desire to improve health, self-exploration, and professional use (Gollust et al., 2012; Su, Howard, & Borry, 2011; Sanderson et al., 2015; Baptista et al., 2016). Among these, a desire to learn more about disease risk and a curiosity about genes appear to be the most widespread motivations for customers of DTC-GT, and these are common among both adopted and non-adopted customers. However, adoptees are more strongly driven by a desire to learn about their genetic disease risk than non-adoptees, which may be due to the lack of family history that is prevalent in the adopted population (Corder, 2012; Crouch et al., 2014; Hill & Edwards, 2009). The question of the unknown family history may impact adoptees in several aspects of their lives including mental health, the management and prevention of disease, and a feeling of stigmatization in medical settings due to the embarrassment that arises

from an inability to directly answers health professionals' questions regarding family history.

DTC-GT offers a unique opportunity for adoptees to unearth some of this elusive genetic information. However, adoptees may also have unrealistic expectations for DTC-GT, and adoptees' disappointment with the DTC-GT testing experience may in some cases stem from a lack of definitive information surrounding genetic risk (Baptista et al., 2016). For some adoptees, DTC-GT may be the only avenue for obtaining family history information (May et al., 2015). This may lead to a higher set of expectations placed on testing results, and without access to a full family health history, the interpretation of such results may be complicated or unclear, resulting in frustration at the uncertainty (May et al., 2015; ACMG, 2003).

### **1.8 Study Purpose and Goals**

The use of genetic counseling services after the return of results of DTC-GT is perceived to be both beneficial and informative (Darst, Madlensky, Schork, Topol, & Bloss, 2014). It is also known that interest within the adoption community exists for genetic counseling services (Bartiomoli, 2008). However, in both of these populations, use of genetic counseling services is rare. The reasons for this have not been fully explored, but the lack of use of genetic counselors within the adopted community may be due to a lack of awareness, a fear of an inability to provide adequate genetic information, deterrence due to perceived medical stigmatization, or a combination of these factors (Baptista et al., 2016; Hill & Edwards, 2009).

Limited research has been done focusing on adoptees in the context of DTC-GT, and even less qualitative research has been done in this area. Through one-on-one

interviews with adult adoptees who have undergone the DTC-GT experience, this study aimed to evaluate adoptees' motivations for pursuing genetic information, their satisfaction with the test results from DTC-GT, their questions that remain unanswered, their emotions throughout the process, and their interest in discussing this information with genetic professionals, specifically genetic counselors. This was primarily an exploratory study. The goal of this study was to provide insight into a population that might benefit from meeting with genetic counselors and to highlight unique areas of concern or interest. By making an effort to understand the needs of this patient population, genetic professionals may be able to address specific concerns and clarify both the power and the limitations of DTC-GT. With the population of adult adoptees growing along with the use of DTC-GT, this presents a unique niche for genetic counselors in the future (Dave Thomas Foundation for Adoption, 2002; Harper et al., 2016).

## **Chapter 2: Manuscript**

### **Adoptees' Experience with Direct-to-Consumer Genetic Testing: Emotions, Satisfaction, and Motivating Factors**

## **2.1 Abstract**

Public awareness of the role of genetics in disease continues to expand, along with the use of DTC-GT. One subset of customers taking advantage of the growing DTC-GT market is adoptees. Prior research has shown that adoptees appear to be more motivated than non-adoptees to learn about their genetic disease risk but have similar responses to health-related information acquired through DTC-GT. In this exploratory qualitative study, fourteen adoptees were asked about their motivations for pursuing DTC-GT; satisfaction with results; emotions throughout the process; and interest in meeting with a genetic counselor. Motivations for pursuing DTC-GT fell into three categories: 1) identity-seeking, 2) a desire for health information, and 3) general curiosity. Adoptees reported a variety of emotional responses to DTC-GT but had more profound emotional reactions to ancestral information, related to both ethnicity and biological familial connections. Finally, the majority of adoptees found value in meeting with a genetic counselor, either for themselves or for their family given certain circumstances. Overall, this study highlights adoptees' experiences in their pursuit of genetic information. By understanding this population's journey with genetic testing, genetic counselors and genetics professionals can be better equipped to address the concerns and emotions of this population that is receptive to the idea of genetic counseling.

## **2.2 Introduction**

Adoption is considered to be a “legal process in which a child is raised by someone other than his or her biological parents,” and it is an idea that is familiar to the

majority of Americans (Kavanaugh & Fiorini, 2016; Corder, 2012; Dave Thomas Foundation for Adoption, 2002). Unfortunately, among adopted individuals, a lack of knowledge regarding family medical history is common (May et al., 2015; Hill & Edwards, 2009).

Additionally, DTC-GT is a growing market in which customers have the opportunity to order genetic testing without the involvement of a medical professional (Phillips, 2016; Harper et al., 2016). These genetic tests offer information regarding a variety of topics, including health information, carrier status for autosomal recessive conditions, ancestry, and genetic relationships (Phillips, 2016). Common motivations for pursuing DTC-GT include the desire to learn more about the risk of disease and an interest in genes; when compared to non-adoptees, adoptees that have undergone DTC-GT appear to be more strongly motivated by the possibility of learning about genetic disease risk (Gollust et al., 2012; Su, Howard, & Borry, 2011; Sanderson et al., 2015; Baptista et al., 2016). This could in part be due to the lack of family health history that is widespread in the adopted population (Corder, 2012; Crouch et al., 2014; Hill & Edwards, 2009).

The genetic contribution to disease is becoming increasingly recognized, and family medical history is known to be an important factor in the analysis of disease risk assessment (Collins & McKusick, 2001; Rich et al., 2004; Centers for Disease Control and Prevention, 2005). For adoptees with a lack of complete family medical history, genetic risk assessment, even with the use of DTC-GT results, can be unclear and uninformative (May et al., 2015; ACMG, 2016).

This study aimed to gain a more in-depth understanding of adoptees' experiences with DTC-GT. Through semi-structured interviews with adoptees that have gone through the DTC-GT experience, this study aimed to evaluate several key topics: 1) adoptees' motivations for pursuing genetic information, 2) adoptees' satisfaction with DTC-GT results, 3) adoptees' remaining questions after DTC-GT, 4) adoptees' emotions throughout the DTC-GT process, and 5) adoptees' interest in discussing this information with genetic professionals, specifically genetic counselors. Because little qualitative research exists analyzing adoptees' use of DTC-GT, this was primarily an exploratory study with the goal of providing insight into a specific population's experience with DTC-GT. The hope is that genetic professionals may use this information to better understand adoptees' areas of concern and interest when discussing genetic information and that the results may also be used to delineate a unique niche for genetic counselors within the world of DTC-GT (Dave Thomas Foundation for Adoption, 2002; Harper et al., 2016).

## **2.3 Materials & Methods**

**2.3.1 Participants and Recruitment.** This study targeted adult adoptees who have used DTC-GT. Eligible participants included adopted individuals over the age of 18 who had purchased DTC-GT and received testing results. Additionally, eligible participants were required to have used either a DTC-GT website that supplies health-related information (ex. 23andMe) or a third party tool that shares health-related information (ex. Promethease or StrateGene). Only English-speaking participants were included in this study. Interpretation from English to other languages was not available due to limited resources.

Individuals were invited to participate through a study advertisement, shown in Appendix A, posted on Facebook, Twitter, and the 23andMe online discussion forum for adoptees. This advertisement provided a link to a description of the study and a brief questionnaire (Appendix B) on SurveyMonkey. This study description also provided contact information for the investigators. Interested individuals answered questions regarding demographic information, expressed or declined interest in a telephone interview, and provided contact information that could be used to schedule the interview.

**2.3.2 Study Methods.** Ethical approval for this study was obtained from the University of South Carolina Institutional Review Board.

Semi-structured interviews were conducted with 15 adoptees' that purchased DTC-GT. Interested participants were first required to complete a short, web-based questionnaire on SurveyMonkey to acquire demographic information and determine eligibility. By beginning the questionnaire, participants gave their consent. Eligible participants who agreed to participate in the interview and provided contact information were then contacted by the principal investigator (AC) through telephone or email (whichever method of contact was listed as preferred) to schedule the interview. If a participant was not reached after two attempts, no further effort was made.

The interviews were conducted by AC over the telephone. Participants had the ability to choose not to respond to a question or to end their participation in the study at any time without penalty. The interviews were recorded, with permission of the interviewee, and transcribed verbatim. Audio files were stored on a password-protected computer. Aside from contact information used to schedule and perform the telephone interviews, no identifying information was obtained from study participants. This

information was also stored on a password-protected computer and destroyed after the completion of the study.

**2.3.3 Study Measures.** Demographic information was collected from each participant, including data regarding age, gender, race, level of education, age at adoption, DTC-GT companies used, and the date of genetic testing. The semi-structured interview consisted of 13 questions designed to explore the various goals of the study. These questions can be found in Appendix C. While on the phone, participants were also asked to confirm the DTC-GT companies or third-party tools used and the date of the testing.

**2.3.4 Data Analysis.** Descriptive statistics were used to analyze demographic information and to determine frequencies and averages. This study used a qualitative methodology to assess adoptees' motivations for pursuing DTC-GT, determine adoptees' satisfaction with DTC-GT results, provide insight into adoptees' emotional responses to DTC-GT, and assess adoptees' interest in sharing this information with genetic counselors. Grounded theory methodology was used to code and distinguish emergent themes (Hsieh & Shannon, 2005; Bradley, Curry, & Devers, 2007). Data was independently coded by AC and co-investigator, WD, with consistent inter-coder reliability checks and discussion of discrepancies.

## **2.4 Results**

**2.4.1 Participants.** A total of 37 individuals completed the web-based questionnaire. Of these, three were not eligible to participate in a telephone interview: one was not adopted; one had not received her DTC-GT results; and one was under the age of eighteen. Of the remaining 34 individuals, five specified that they were not

interested in participating in an interview over the phone. Therefore, 29 individuals were contacted in an attempt to schedule a telephone interview. Fifteen adoptees responded and were interviewed over the phone, yielding a response rate of 51.7%. However, due to a technical error, one interview was not recorded and not included in the results.

The age of participants ranged from 40-64 years old with an average age of 50.5 years. The majority of participants were Caucasian (71.43%) and female (85.71%). In addition, most had completed some level of college or university education (57.14%) or had received a bachelor's degree (35.71%). Although the age at the time of adoption ranged from birth to seven years, the majority of the adoptees were adopted before the age of one year (66.7%). Complete demographic details are in Table 2.1 (page 34).

**2.4.2 DTC-GT Tools Used.** A total of nine DTC-GT companies and tools were used, with 23andMe (85.71%) and AncestryDNA (78.57%) being the most frequently reported. The majority of participants used more than one website (85.71%), and half of the participants used three or more websites (Table 2.2, page 34).

**2.4.3 Motivations.** In exploring adoptees' motivations for pursuing DTC-GT, three main motivating factors emerged: 1) the search for some form of identity, 2) the desire for health-related information, and 3) general curiosity.

The idea of seeking some form of an identity surfaced throughout the majority (64.29%) of adoptees' stories. However, the method through which this self-actualization was achieved was further divided into two categories: the search for biological family and the search for ethnicity and nationality. Adoptees saw DTC-GT as a way to identify biological family that was previously unknown or unconfirmed, and for many, this was the first opportunity to learn such information. For example, one adoptee noted that “you

know nothing your whole life...your blood line starts and ends with you..." DTC-GT offered the possibility of becoming part of a larger, family unit. A different adoptee described this genetic testing as bringing "into perspective that you do have, like, blood relation out there that you belong to..."

For other adoptees, this feeling of completion was achieved through learning or confirming their ethnicity or nationality, and this was their means of creating an identity. Again, learning this information offered the potential to consider one's self as part of a group and form those connections with one's past. One adoptee described it as the opportunity to "learn" and "connect." She elaborated on this sentiment, saying the following:

*"People are proud of their heritage, and all your whole life you don't have one...You've had no family so a nice diverse one to me was being able to go 'oh gee I can associate with that, associate with that, associate with that, find out about all those different cultures...'"*

Five adoptees (35.71%) planned on using the DTC-GT results for their own medical care and saw it as a way to gain information about their own risk. An adoptee experiencing vision loss, for example, noted that "as you get older, you have more health concerns," and she "wanted to find out possibly if [she] could find out [her] biologic family in order to kind of come to terms with this vision issue." Another adoptee described this as a way to "look out for [her]self, to say hey, [I] might want to choose this diet or this habit."

Five other participants (35.71%) wanted to acquire this information for their family, whether it be children or grandchildren, in the hopes that it might improve the

care of their family members. One adoptee explained that “if it was just for me, I probably wouldn’t have done it, but I did it so my kids would have some kind of answer.” Another echoed this sentiment, saying that “[she] thought it would be nicer for [her] children and grandchildren maybe not to have to go through all of that,” in reference to the additional medical tests that she had to undergo due to her unknown family history. Finally, a third adoptee with a sick son described her desire for genetic information as “not a need to assess blame, but a need to figure it out.”

Three adoptees (21.43%) cited general curiosity as a major push for them pursuing DTC-GT. There were no clear goals in mind and there was nothing they were hoping to learn. Rather, any bit of knowledge was viewed as something of value simply because they started with such little information. For example, one adoptee stated that “you have so little information as an adoptee, really, that any shred of information, anything, is such a wonderful gift.”

**2.4.4 Satisfaction.** Adoptees expressed mixed levels of satisfaction with their DTC-GT. The majority of participants (57.14%) answered that they were satisfied with all the testing results that they received. Six adoptees (42.86%) made connections with their family or learned about various biological relationships. For example, one adoptee who was able to identify her birth father’s family expressed her happiness, saying, “So I count myself pretty lucky that without basically any information I was able to find my birth father’s family through DNA testing.” The few adoptees that were satisfied, but did not find immediate connections, were still pleased with any information, and in the words of one adoptee, felt that this information was helpful in “aiming [them] towards the right direction” in the search for more information.

However, five of the remaining participants (35.71%) had mixed feelings depending on the testing company and the information provided by the test. The reasons for dissatisfaction all stemmed from one major theme: a desire for more information. This need for more information was grouped into two categories: 1) frustration with the lack of familial information, in terms of matches and family history and 2) a desire for more specific medical and genetic risk information.

For two adoptees, frustration arose from a lack of response from biological family members. One described her anger with her biological family's silence, saying that this made her feel as though she was "still some family's dirty little secret that they don't want to talk about." Two other adoptees cited a lack of close familial matches that caused frustration. For example, one of these that planned to use her familial matches to acquire medical information said that "[she] was hoping to be able to get someone close enough to, at the very least, get that medical information." The other's lack of close matches resulted in feelings of "disappointment." Finally, two of the adoptees also noted that it would have been nice to know the origin (maternal or paternal) of the genetic information they received.

Five of the adoptees also noted that the health-related information that they received was not what they had hoped. Several desired more, and several also desired more actionable information. Specifically, one adoptee stated that "[she] wish[es] [the test] could be more definite" and "a little more clear." Another explained that "if [she] had been someone who wanted to use [the DTC-GT] information instead of going to a doctor, [she] probably would've been dissatisfied because it's pretty vague."

**2.4.5 Interest in Genetic Counseling.** When asked if they saw value in meeting with a genetic counselor, the majority of adoptees (85.71%) responded that they did see benefits to genetic counseling. Their reasoning and the circumstances under which they would pursue genetic counseling were grouped into four categories: 1) adoptees saw this access to genetic information as valuable, 2) adoptees believed that this would have been useful when they were younger, 3) adoptees saw merit in it for their family members, and 4) adoptees would have pursued genetic counseling if a medical concern arose.

Twelve of the adoptees saw genetic counseling as a useful and valuable tool. One adoptee expressed her interest in genetic counseling, saying “I feel strongly if there’s a way to test for things and if there’s a way to counsel people on how to deal with things, I think you should.” Another was thinking that the information provided by a genetic counselor could help to “ease some questions.”

Those who thought that this information could have been useful in the past (21.43%) acknowledged that they were no longer focused on genetic risk information, either because they were finished having children or had already faced several health concerns. One adoptee described her health situation:

*“I think I would have been very interested...about maybe about five years ago when all of my vision issues occurred. But at this point...I don’t want to because I’m dealing with this vision issue now. And whatever happens...I’ve been so fraught with worry about the vision issue that anything else I get, I’m not even worried about it.”*

Three adoptees (21.43%) noted that genetic counseling might be of use for their family members, especially their children or those that have children. For example, one

adoptee thought of her son, saying she would “definitely recommend it to him” if he decides to have children, and another thought that genetic counseling would have been useful for her sister who has children

Finally, six adoptees noted that in the event that their test results came back saying they were a carrier of a certain genetic condition or if a new medical concern arose, they would have been willing to meet with a genetic counselor to gain more information. Overall, adoptees were open and receptive towards the idea of meeting with a genetic counselor. However, for the two adoptees that did not see value in meeting with a genetic counselor, this was due to their own knowledge in the field. For example, one adoptee did not see any value in genetic counseling for herself because she has “a good enough basic understanding of all the components that cause and further a disease process.”

**2.4.6 Emotions.** Adoptees reported a variety of emotional responses to the process of undergoing DTC-GT (Figure 2.1 and Figure 2.2, page 35 and 36). In general, emotions experienced before receiving DTC-GT results fell into three categories: 1) excitement, 2) anxiety and a fear of the unknown, and 3) a fear of rejection.

Eleven adoptees (78.57%) were excited at the possibility of learning new information about their biological family, their ethnicity and nationality, and their various medical traits. A few adoptees were also excited at confirming the little information that they already had, whether it be information regarding familial relationships or information regarding ethnicity and nationality. One adoptee described her excitement at the possibility of matching with a close relative and said that she “kind of daydreamed

about maybe going and meeting people.” Another said that while waiting for the results, “[she] [was] almost like a kid on Christmas morning waiting for that day.”

Anxiety corresponded with a fear of the unknown for five of the adoptees (35.71%). These adoptees recognized that having no information on their background meant that they had no way of knowing what DTC-GT might reveal, and this created the feelings of anxiety. One adoptee compared this process to opening “Pandora’s box,” saying that it required “soul-searching” before sending off the testing kit. Another described feelings of excitement and fear before testing because “even though [she] desperately wanted the answers, [she] [didn’t] know what the answers [were].” She was worried that the DTC-GT results “might make [her] think of [her]self in a different way.”

Finally, a feeling experienced by three adoptees (21.42%) prior to undergoing DTC-GT was a fear of rejection on the part of their biological family. One adoptee recognized that DTC-GT offered the possibility of finding biological family, and this brought into question, “are they going to accept me, or are they going to reject me again?” Another adoptee elaborated on this sentiment:

*“One of the innate issues of being adopted is being rejected and having that glooming rejection over you for your whole life. So many adopted people, I think, don’t even bother to reach out and try because they’re just afraid that they’re going to be rejected again. So I think once they get to a point where they think the reward will be worth more to them than that fear is when they decide to try and seek those answers.”*

The emotions experienced after DTC-GT were grouped into four main categories: 1) obsession with new connections, 2) a feeling of a newfound direction in the search for more information, 3) frustration and disappointment, and 4) happiness.

Four adoptees (28.57%) experienced a compulsion to continuously check the familial matches portion of their test results, explaining that this was ever-changing as more and more people were doing these tests. They described this portion of their test as a newfound obsession, hoping to discover more and closer familial matches. One adoptee stated that after receiving close familial matches, she experienced this “obsession,” and she wanted “to just spend all of [her] time looking at these people and trying to figure out how [she] [was] related to them.”

However, five adoptees (35.71%) also noted that this obsession over checking for new connections, and this information in general, provided a new sense of direction in their search for familial information. One adoptee described this process as putting a “method to the madness.” Another described herself as being “positive and gung-ho” because she “knew what direction to look and then [she] started having things to work with that could get [her] further.” A third adoptee considered herself to be a “detective” saying that “everything from that point on, every single step [she] took on this path was more information.”

Three adoptees (21.43%) noted that they did not receive close familial matches or were not given much information from their biological family when they did attempt to make contact. These circumstances led to feelings of frustration and disappointment. For example, one adoptee said that she was both angry and disappointed because she had

been met with “complete silence” from her biological family after attempting to create connections.

Overall, the majority of adoptees (51.74%) were happy with the results that they received. Several viewed any information as more than what they knew originally. One adoptee stated she was “really grateful to finally know [her nationality] for sure rather than guessing.” Many adoptees were able to connect with their biological family. There were adoptees that learned valuable health information from the DTC-GT, such as an adoptee that stated that the “little \$99 probably saved [her] life.” Through DTC-GT, she was made aware of a rare form of hemophilia that she had and considered the genetic testing “the best thing that ever happened.” Others were put at ease after learning that they had no genetic susceptibility for the tested conditions. All of these circumstances led to overall feelings of happiness in adoptees regarding DTC-GT. For example, one adoptee described herself as being “just happy” after DTC-GT, saying that she felt like she had “a piece of the puzzle.”

**2.4.7 Adoptees Versus Non-Adoptees and DTC-GT.** When asked how adoptees might view the DTC-GT differently than non-adoptees, the main theme that adoptees highlighted was a difference in motivations for pursuing the testing. More specifically, adoptees emphasized that this form of testing was, for many, their only source of genetic information rather than a way to satisfy general curiosity about one’s family or background. One adoptee summarized this sentiment, saying, “I’m not looking because I’m curious about my family. I’m looking for my family, and that’s a huge difference.” Another described DTC-GT for adoptees saying that “for someone who’s adopted, there’s a whole other layer of it...I could find my biological family by doing this.”

Within this theme of different motivations, five adoptees (35.71%) also explained that for them, this information filled a void that those with knowledge of their family and genetic makeup might not have had. The potential of gaining biological family or a nationality changed their perspective of themselves. One adoptee stated that learning about biological connections “[made] you feel like you belong.” Even the health information offered some adoptees a feeling of comfort, knowing which conditions or traits should concern them.

**2.4.8 Adoptees’ Experiences in Medical Settings.** The majority of adoptees (71.43%) answered that they do believe that being adopted has affected their medical care and their interaction with medical professionals. The overarching themes of adoptees’ answers as to how their experiences in medical settings might be different fell into three categories: 1) changes in medical care, 2) feelings of marginalization and stigmatization, and 3) feelings of frustration.

Three adoptees (21.43%) acknowledged that not knowing their family history of certain conditions led to earlier screening and testing for many conditions, either for the purpose of having a baseline available or due to not knowing the actual genetic risk for a condition. These adoptees noted that this has a huge cost in time, effort, and money when in fact, this might not have been necessary. One adoptee described it as a lot of “time, effort, and unknown.” A statement from a second adoptee echoes this sentiment:

*"It's a thing where you kind of know what to expect if you have a family [history of] say breast cancer or heart disease. You can start looking early at those things so you can do preventative measures. You can't do any of*

*that when you have none of that information. Right? You're stuck doing it all.... The doctors have to assume you're high risk for everything."*

Five adoptees (35.71%) also described experiences that fit under the themes of marginalization and stigmatization. These were brought about by several factors. First, adoptees noted the medical paperwork that patients were required to fill out prior to a visit. In general, adoptees felt as though their status of being adopted was not viewed as a valid status for an individual. For example, one adoptee explained that the medical establishment does not “tend to take adoption as an equally weighted option,” and she has only encountered one intake form that has listed adopted as an option. In addition, adoptees described feelings of stigmatization brought about by the reactions of medical professionals upon learning that they were adopted. One adoptee, for example, described walking out of doctors’ offices because the doctor wrote “in big red letters across the folder ‘adopted.’” She described this as “horrific” and felt as though the doctor “acted like it was leprosy.” Another adoptee described the conversations that she has had with medical professionals that impacted her experience:

*"You know, and they backtrack like at a hundred miles per hour... because they really want to know does this run in your family, and they're talking to a patient that says I have no information. And they'll go like oh crap, okay, no it doesn't matter, and you know that's not the truth. So there's like this game playing even with your medical provider. It's weird."*

Finally, two adoptees (14.29%) noted that medical settings served as a constant reminder of their adoption. One adoptee compared going to the doctor to having “skinned knees, and every time you go in, they rip the scab off,” saying that she was “constantly

reminded that [she was] different.” Having to constantly specify that they were adopted, for some adoptees, brought about feelings of frustration. For example, the second adoptee described that “you grow up your whole life just saying don’t know, don’t know, don’t know, which is really frustrating.”

There were also four adoptees (28.57%) that did not believe that this changed their experience in medical settings, explaining that they saw it as very matter of fact. They did not know their family’s medical history, but they were indifferent to this. One adoptee said that “it’s not, never was, and still isn’t a sensitive subject to me.”

## **2.5 Discussion**

This study sought to explore adoptees’ experiences with DTC-GT. Adoptees’ use of DTC-GT was strongly motivated by the need to create an identity, based upon ethnicity or biological familial information, and a desire for health-related information. Adoptees were noted to have strong emotional responses to DTC-GT results, most often in regards to newfound ancestral information. This qualitative insight might help genetic counselors and other genetic professionals to better understand and anticipate adoptees’ needs and responses to DTC-GT. This is an important factor to consider because adoptees were also found to be receptive to the idea of genetic counseling, and most saw value in such services. Therefore, this information can be helpful in equipping genetic counselors with the skills necessary for interacting with a target population that is interested in the profession. With the increasing popularity of DTC-GT, this might offer a unique niche for genetic counselors in the future.

Prior research has attempted to describe the general population’s motivations for pursuing DTC-GT (Gollust et al., 2012; Su et al., 2011). Gollust et al. (2012) found that

the most frequently reported motivations for pursuing testing included a curiosity about genetics, a desire to learn about disease risk, and a desire to improve one's health. Su, Howard, & Borry (2011) conducted an exploratory study analyzing internet posts written DTC-GT customers and found that personal health was most often cited. Baptista et al. (2016) specifically explored the motivations of adoptees that have undergone DTC-GT. In this study, adoptees' motivations were similar to those in the general population, but adoptees were noted to be more strongly driven by a desire to learn about genetic disease risk. The majority found value in their results and were satisfied. However, a minority of adoptees were disappointed and expected more definitive genetic risk information, possibly due to unrealistic expectations for DTC-GT. The psychological impact of DTC-GT has also been studied in the general population. Studies found that the impact was less significant than expected. Anxiety was often reduced (Bloss et al., 2011; Egglestone et al., 2013), and test-related distress typically did not increase after receiving results (Bloss et al., 2011; James et al., 2011). Therefore, although studies have been done that analyzed the motivations, emotions, and satisfaction of those that have undergone DTC-GT, little research has been done exploring all of these factors specifically in adoptees, and furthermore, little qualitative insight is available for this population's experience with DTC-GT.

This study generally supported the findings of previous studies in regards to motivations for pursuing DTC-GT (curiosity about genetics, a desire to learn about disease risk, and a desire to improve one's health) but also highlighted another strong motivation for adoptees. Adoptees in this study most frequently cited three driving factors for purchasing DTC-GT: a desire to create some form of an identity, either

through ancestral or familial information; a desire to learn genetic health information; and general curiosity. Adoptees were strongly and almost equally driven by a need for health-related information and ancestral information, encompassing familial relationships and ethnicity, and considered both sets of information to be extremely valuable. Su et. al (2011) included genealogical interest as a driver for purchasing DTC-GT in the general population, but this was not the most frequently cited motivator for this group. In this study, this was the most popular response, highlighting a possible distinction between the motivations of adoptees using DTC-GT and the motivations of the non-adoptees using DTC-GT. Adoptees themselves also cited this difference in motivations for pursuing DTC-GT, recognizing the test as a starting point for adoptees in gathering information rather than a way to confirm previous knowledge or satisfy a curiosity to know more.

The emotional journeys of the adoptees interviewed in this study tend to support previous findings in the general population. For the minority of adoptees that did experience feelings similar to distress, however, these were related to ancestral information rather than the health portion of the test. This newfound information, whether it was discovering biological relationships or uncovering new information about ethnicity, was the most frequently discussed and seemed to have more of a profound impact than any health-related information. Therefore, although many adoptees' emotional responses to DTC-GT were similar to those of the general population, this study highlighted distress-related responses that were more unique to adoptees and, perhaps, to others with limited family history. With this information, we can anticipate that adoptees' response to ancestral information might be the most emotional rather than any information regarding carrier status. Much like Baptista et al. (2016), adoptees in this

study cited a desire for more clear-cut genetic risks and more medical information. In addition, adoptees described frustration with a lack of close familial matches and a lack of response from biological family members. Together, these factors support the idea that adoptees might have unrealistic expectations for DTC-GT, but it offers insight into the fact that these expectations encompass both health and ancestry information. Being aware of these expectations has the potential to aid genetic counselors and other genetic professionals in providing anticipatory guidance before DTC-GT or in addressing these feelings of frustration after testing.

This study found that, despite limited family history knowledge, the majority of adoptees saw value in genetic counseling services. This is promising for a field that is trained in addressing both the impact of genetic information on health care and the lack of genetic information on health care. This lack of information is not uncommon, and genetic counselors are trained to provide a detailed, yet sensitive, risk assessment. It is the hope that by understanding the desires, concerns, and expectations of this specific population, genetic counselors can shape their counseling to provide better care. Understanding adoptees' anxiety and fear of the unknown, for example, allows genetic counselors to address this before DTC-GT, and knowing that adoptees might have high expectations for DTC-GT gives genetic counselors the opportunity to explain fully the limitations of such testing. This study also offered insight into how adoptees think that being adopted has negatively impacted their experience in medical settings. This provides medical professionals, such as genetic counselors, with the opportunity to adjust their actions and ensure that adoptees will no longer have these feelings of stigmatization and marginalization. Also, the genetic professionals working for DTC-GT companies can use

this information to change marketing in an attempt to eliminate some of these concerns upfront. This will help to ensure that this population remains receptive towards the services offered by genetic counselors and other genetic professionals.

The findings of this study complemented the existing literature examining adoptees' experiences with DTC-GT but provided novel, qualitative insight into the emotional journey of adoptees going through this process. These findings provided insight into adoptees' frustration with DTC-GT and offer more general information regarding adoptees' experiences in medical settings. Future research could focus on the impact of genetic information on the family unit as a whole since adoptees' children and grandchildren are also affected by this lack of family history information.

There were several limitations to this study. First, the participants as a whole were relatively homogenous in terms of race, gender, and educational background, and these results are not generalizable to adoptees as a whole. Most of the participants completed, at minimum, some level of college or university, and this might also impact their understanding and their opinion of genetic information. Finally, the method of recruitment limits generalizability. By advertising on forums and social media pages directed at adoptees, this targeted adoptees actively pursuing information on adoptees and DTC-GT. These participants might have a greater interest in this information and might place greater value on such information as well.

<b>Table 2.1 Patient Demographics</b>			
	n (Total = 14)	%	Mean $\pm$ SD (Range) 50.5 $\pm$ 6.37 (40-64)
Age (years)			
18-29	0	0	
30-39	0	0	
40-49	7	50	
50-59	6	42.9	
60-69	1	7.1	
Gender			
Male	2	14.3	
Female	12	85.7	
Race			
Caucasian	10	71.4	
Native Hawaiian/Pacific Islander	1	7.1	
Mixed	2	14.3	
Other	1	7.1	
Educational Background			
Some high school	0	0	
High school diploma/GED	0	0	
Some college/university	8	57.1	
Bachelor's degree	5	35.7	
Master's/doctoral/professional degree	1	7.1	
Age at Adoption (years)			
$\leq$ 1	10	71.4	
$>$ 1	4	28.6	

<b>Table 2.2 Companies and Tools Used to Acquire Genetic Information</b>		
	n (Total sample = 14)	%*
23andMe	12	85.7
AncestryDNA	11	78.6
Promethease	5	35.7
GEDmatch	5	35.7
FamilyTreeDNA	5	35.7
StrataGene	1	7.1
Genetic Genie	1	7.1
MyHeritage	1	7.1
DNA.land	1	7.1

\*Proportions do not sum to 100% because participants could report using more than one DTC-GT company and/or tool

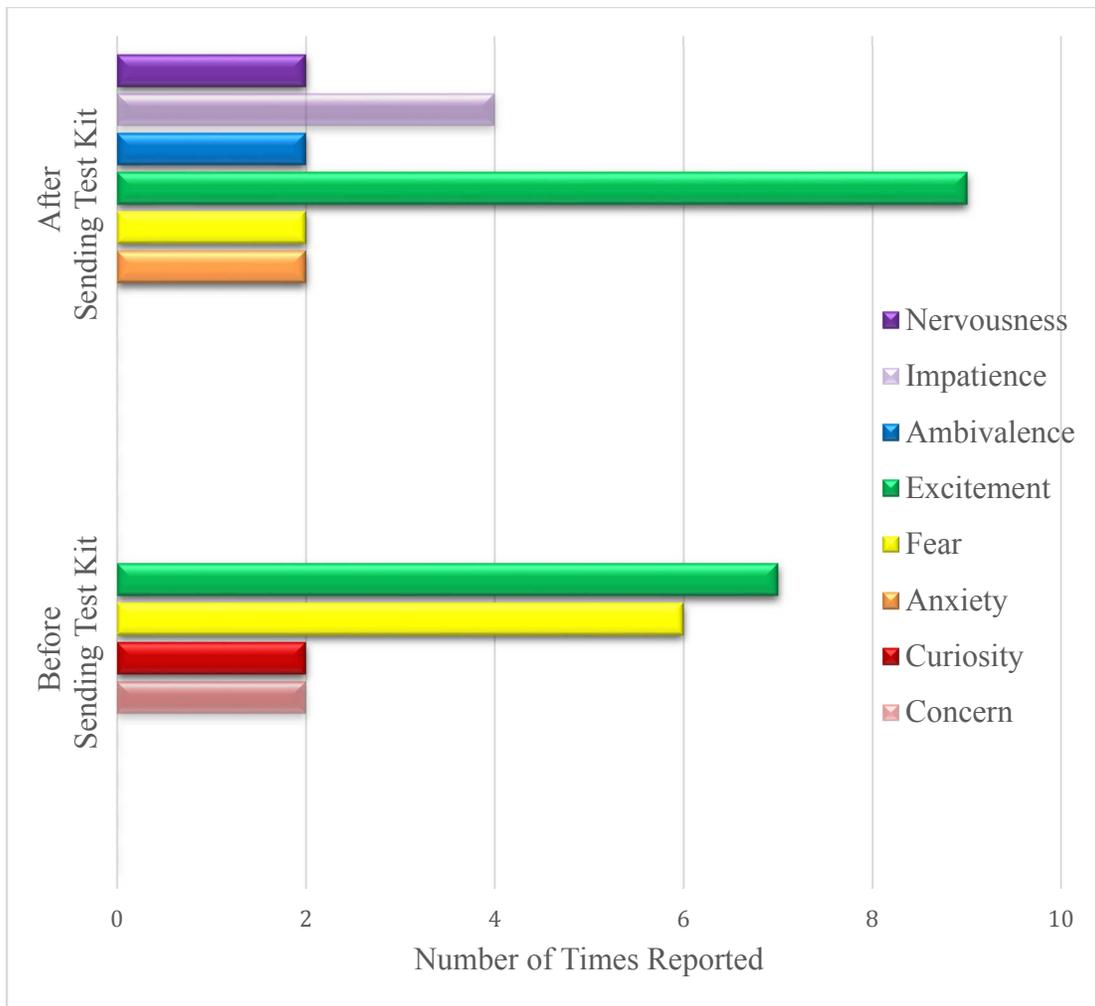


Figure 2.1: Frequency of Emotions Reported by Adoptees Before Receiving DTC-GT Results

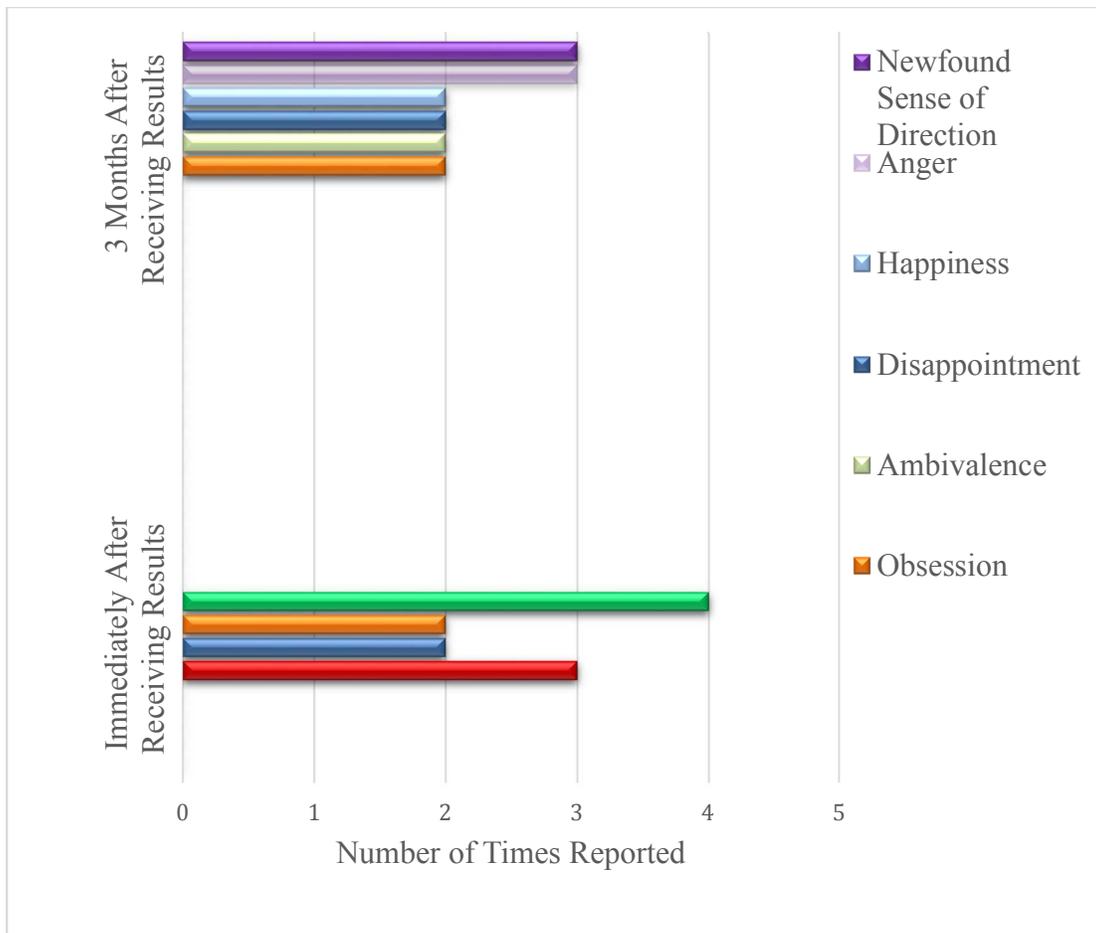


Figure 2.2: Frequency of Emotions Reported by Adoptees After Receiving DTC-GT Results

### **Chapter 3. Conclusion**

In this study, adoptees' experiences with DTC-GT mirrored those of the general population in certain aspects. Many of the adoptees were interested in learning more about their genetic disease risk, similar to non-adoptees. However, interest in ancestral information regarding both familial relationships and ethnicity served as the motivating factor for over half of the adoptees in this study. Adoptees experienced strong emotional reactions to this ancestral information, perhaps setting them apart from individuals that already know their family history. Knowing the value that adoptees place on this information and understanding the potential for strong emotional responses can aid genetic counselors in providing both anticipatory guidance and post-test counseling to adoptees using DTC-GT.

The overwhelming majority of adoptees in this study saw a potential benefit in speaking with a genetic counselor, either for themselves or their family members, but the majority had also experienced feelings of stigmatization or marginalization in medical settings and attributed these to their status as an adoptee. Understanding these negative experiences can help genetic counselors to ensure that adoptees remain open to the field and ensure that adoptees have positive experiences. Genetic counselors are well-equipped to deal with patients with limited family history knowledge and are capable of providing information on how this impacts healthcare in a detailed, thorough, and sensitive manner.

The DTC-GT market continues to grow and can serve as a primary source of information for many adoptees searching for both health and ancestral information. However, having an unknown family history can have an impact on how this information is interpreted and processed. Genetic counselors have the skills and training to help adoptees process the health-related genetic information and the reactions brought about by the ancestral information. Genetic counselors can provide adoptees with genetic risk information and tools to cope emotionally as well, providing a unique niche for genetic counselors in the future.

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## **Appendix A: Study Advertisement**

### **ADOPTees THAT HAVE USED DIRECT-TO-CONSUMER GENETIC TESTING:** Participants Needed!

You are invited to participate in a graduate research study. We are interested in discussing the emotions that you experienced both before and after your genetic testing, your satisfaction with the test, and the desired outcomes that you had or still have for the test.

Any person that is both legally adopted and over the age of eighteen qualifies for this study.

For more information or to share your thoughts, click on the link below:

## Appendix B: Web-based Questionnaire

Through interviews with adoptees that have used direct-to-consumer genetic testing sites (maybe insert specific site here instead of “DTC-GT”, ex. 23andMe), this study hopes to learn more about adoptees’ motivations for using this type of genetic test. Adoptees will be asked about their feelings after having their test results returned and what they think about using these results in the future. Overall, this study hopes to provide insight into adoptees’ feeling about genetic information and whether or not they hope to use this in future medical settings.

If at any point you do not wish to answer a question, please skip that question and continue to the next question. This is a graduate student project being completed by a genetic counseling student at the University of South Carolina. For any questions please contact:

Anna Childers  
childersak09@gmail.com

Whitney Dobek  
whiney.dobek@uscmed.sc.edu

- 1) Current Age: \_\_\_\_\_
- 2) Gender: \_\_\_\_\_
- 3) Race:
  - Alaska Native
  - American Indian
  - Asian
  - Black
  - Native American
  - Native Hawaiian/Pacific Islander
  - White
  - Unknown
  - Other
  - Do not wish to specify
- 4) Level of Education:
  - Some high school
  - High school diploma/GED
  - Some college/university
  - Bachelor’s degree
  - Master’s/Doctoral/professional degree
- 5) Age at adoption: \_\_\_\_\_

- 6) Genetic testing company used: \_\_\_\_\_
- 7) Date test results were received (MM/YYYY): \_\_\_\_\_
- 8) This study includes an interview conducted via phone call that may last up to one hour. Would you be willing to participate in this study?
- Yes
  - No
- 9) Please provide your preferred contact information so that we may contact you to set up the interview for this study. Your contact information will not way be linked to your responses. Participation is voluntary.
- Name
  - Email
  - Office Phone
  - Cell Phone
  - Home Phone

### **Appendix C: Semi-Structured Interview Questions**

- 1) How much do you know about your biological family?
- 2) Do you have any children? If so how many?
- 3) What was/were your main motivations for using DTC-GT?
- 4) How would you describe your satisfaction with your test results?
- 5) What information would you like to know more about?
- 6) As someone who is adopted, how do you think you view this genetic information differently than someone who is not adopted?
- 7) What kinds of feelings did you have before ordering this test?
- 8) What kinds of feelings did you have while you were waiting for your test results to come back?
- 9) How did these feelings change immediately after receiving your test results?
- 10) What kinds of changes did you experience in these feelings 3 months after receiving your results?
- 11) How does being adopted change your experience in medical settings?
- 12) Do you know what a genetic counselor does?
- 13) What value would you see in meeting with a genetic counselor either to discuss these results or discuss other family history concerns?

### Appendix D: Description of Adoptees' Emotions Over Time

Table 3: Adoptees' Emotions Throughout DTC-GT				
Participant Information	Before DTC-GT	After Sending DTC-GT Kit	Immediately After Receiving Results	3 Months After Receiving DTC-GT Results
#1, age 48 (AncestryDNA, 23andMe, Promethease, StrataGene)	Excitement, Terror, Fear of Rejection	Nervousness, Impatience	Overwhelmed, Obsession	Logic, Newfound Sense of Direction
#2, age 50 (AncestryDNA, 23andMe, FamilyTreeDNA, Promethease)	Anxiety, Fear of Rejection	Fear of the Unknown, Excitement	Denial (ancestry-related)	Anger (ancestry-related)
#3, age 64 (AncestryDNA, 23andMe, FamilyTreeDNA, GEDMatch, DNA.land)	Curiosity	Excitement, Impatience	Gratefulness, Comfort	Happiness, Newfound Sense of Direction
#4, age 55 (AncestryDNA, 23andMe)	Fear	Excitement, Impatience	Excitement, Obsession	Happiness, Completeness
#5, age 58 (AncestryDNA, 23andMe)	Concern	Ambivalence	Terror (ancestry-related), Confirmation (health-related)	Terror (ancestry-related), Interest (health-related)

#6, age 46 (AncestryDNA, 23andMe, FamilyTreeDNA)	Excitement	Excitement, Hopefulness	Excitement	Anger, Disappointment (ancestry- related), Confirmation (health- related)
#7, age 46 (23andMe)	Concern	Anxiety, Nervousness, Excitement	Shock (ancestry- related), Positivity	Ambivalence
#8, age 44 (AncestryDNA, 23andMe)	Excitement	Excitement	Excitement	Excitement, Obsession
#9, age 53 (AncestryDNA, 23andMe, FamilyTreeDNA, GEDMatch, Promethease)	Excitement, Fear of the Unknown	Relief, Excitement	Excitement, Happiness (ancestry- related), Disappointment (health- related)	Newfound Sense of Direction
#10, age 40 (AncestryDNA, Promethease)	Fear of the Unknown	Fear, Excitement	Disappointment (ancestry- related), Fear (health- related)	Obsession
#11, age 46 (23andMe, GEDMatch)	Excitement	Impatience	Curiosity	Ambivalence
#12, age 43 (AncestryDNA 23andMe)	Curiosity	Ambivalence	Newfound Sense of Direction	Self- Acceptance
#13, age 56 (AncestryDNA, Promethease)	Excitement, Fear of the Unknown (ancestry- related), Scientific Interest (health- related)	Anxiety	Happiness, Curiosity	Frustration (ancestry- related)

#14, age 48 (AncestryDNA, 23andMe, FamilyTreeDNA, GEDMatch)	Excitement	Excitement	Disappointm ent (ancestry- related), Curiosity (health- related)	Disappointm ent (ancestry- related)
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