

Family Secrets: Exploring Unexpected Paternity through Direct-to-Consumer DNA Ancestry

Tests

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## ABSTRACT OF THE DISSERTATION

Family Secrets: Exploring Unexpected Paternity through Direct-to-Consumer DNA

Ancestry Tests

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Increased interest in direct-to-consumer DNA ancestry tests in recent years lends importance to exploring the experiences of those who choose to complete them, particularly when the results provided are unexpected. The Human Genome Project (HGP) conducted from 1990-2003 contributed to the rapid advancement of cost effective direct-to-consumer DNA ancestry tests. Understanding motivations to complete these tests and what information is learned and understood from these tests are important areas to explore from the consumer's perspective. Social workers can provide leadership and education surrounding issues of clinical interventions and policy practices related to the growing field of consumer genetics. This study explored what happens to family relationships, individual identity, and support when adult children unexpectedly discover previously unknown paternity through a direct-to-consumer DNA ancestry test. The findings indicated that relationships are altered, identity is changed, and support is sought to cope with the new information.

Signature of Investigator \_\_\_\_\_ Gina Daniel \_\_\_\_\_ Date \_\_\_\_\_

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## TABLE OF CONTENTS

APPROVAL PAGE .....	ii
ABSTRACT OF THE DISSERTATION .....	iii
ACKNOWLEDGEMENTS .....	iv
LIST OF TABLES .....	viii
<b>CHAPTER 1: INTRODUCTION</b> .....	<b>9</b>
Problem Statement .....	10
Background .....	11
Family Defined .....	12
DNA for Paternity Testing.....	14
New Area for Research .....	14
Relevance to Social Work Advancement, Policy, and Practice.....	15
Theoretical Framework .....	19
Social Identity Theory.....	19
Family Systems Theory .....	21
Family Systems Theory and Social Work Practice.....	23
Research Questions .....	24
<b>CHAPTER 2: LITERATURE REVIEW</b> .....	<b>26</b>
Development of Direct-to-Consumer DNA Ancestry Tests.....	26
Early Development of Direct-to-Consumer DNA Ancestry Tests .....	28
Consumer Access .....	29
Concerns .....	32
Accuracy of Test Results .....	34
Understanding of Results.....	34
Informing Consumers .....	35
Privacy and Confidentiality .....	36
Regulation .....	39
Genetic Counseling and Disclosure of Misattributed Paternity.....	41
Secrets within Families .....	46

Recommended Further Study .....	51
<b>CHAPTER 3: METHODOLOGY .....</b>	<b>53</b>
Research Design and Rationale .....	53
Setting .....	55
Sample .....	55
Procedure .....	56
Confidentiality .....	58
Data Analysis .....	59
Researcher Statement of Reflexivity .....	62
Ethical Considerations .....	62
<b>CHAPTER 4: RESEARCH FINDINGS .....</b>	<b>64</b>
Participant Demographics .....	65
Response to the Research Questions .....	66
RQ 1: How Does the Unexpected Paternity Information Affect an Individual's Understanding of their Family? .....	66
Recreational Curiosity .....	67
Feeling Shocked about the Paternity Information .....	67
Family Secrets .....	69
Infidelity.....	70
Something was "off".....	70
RQ 2: How Does the Unexpected Paternity Information Affect an Individual's Relationship with their Family of Origin? .....	71
Relationship with Mother .....	71
Relationship with Birth Certificate Father .....	73
Relationship with Siblings .....	75
Anger .....	75
Now Things Make Sense .....	76
RQ 3: How does the Unexpected Paternity Information Affect an Individual's Identity ?.....	77
Change to Personal Identity .....	77
Ethnicity Shifts.....	79

Health Information.....	79
Resemblance to Family.....	80
Relationship with New Family .....	82
Rejection .....	83
RQ 4: How do Individuals Receive Support During this Experience? .....	85
Online Support Group .....	85
Navigating this Experience .....	86
Mental Health Counseling .....	87
Healing through Helping Others .....	87
Advising Others .....	88
Summary of Findings .....	89
<b>CHAPTER 5: DISCUSSION AND IMPLICATIONS .....</b>	<b>91</b>
Understanding of Family of Origin .....	91
Relationship with Family of Origin .....	92
Personal Identity Changes .....	93
Social Support .....	95
Limitations and Strengths .....	96
Implications for Social Work Practice and Future Research .....	98
Conclusion .....	103
Appendix A: Invitation to Participate in Study.....	104
Appendix B: Institutional Review Board Approval Letter .....	105
Appendix C: Demographics Survey Questions .....	106
Appendix D: Consent Form for Participants .....	108
Appendix E: Semi-Structured Interview Protocol Questions .....	110
Appendix F: Code Book .....	113
Appendix G: Interview Preparation Guide .....	117
REFERENCES .....	118

## List of Tables

Table 2.1. Summary of Direct-to-Consumer Ancestry Companies .....	31
Table 2.2. Consumer Contacts and Storage of Consumer DNA Material .....	33
Table 2.3. Genetic Counselor and Company Support .....	45
Table 4.1. Demographic Information of Participants .....	65
Table 4.2. Words and Phrases Used to Describe the Initial Discovery of Paternity.....	68
Table 4.3. Research Questions, Themes and Sub-themes .....	90

## Chapter 1: Introduction

Individual identity and the intricacies of family relationships are as unique as an individual's DNA. Studies have shown that positive family interaction is connected to healthy identity development (Acero, Cano-Prous, Castellanos, Martin-Lanas & Canga-Armayor, 2017; Bowles, Searight, Russo, Rogers, & Kleinman, 1997; Quatman, 1997). However, family secrets can negatively impact even the strongest of families (Imber-Black, 2014, 1998, 1993; North, Shadid, & Hertlein, 2018; Rober, Walravens, & Versteijnen, 2012). Secrets within families that can negatively disrupt may include those related to infidelity, criminal history of members, and adoption (Smart, 2011). This dissertation explored what happens to family relationships and an individual's identity when adult children unexpectedly discover previously unknown paternity through a direct-to-consumer DNA ancestry test.

Misattributed paternity occurs when the assumed father of a child is not the biological father of the child (Lowe, Pugh, Kahane, Corben, Lewis, Delatycki, & Savulescu, 2017). The International Society of Genetic Genealogy (ISOGG) defines a non-paternity event (NPE) as any event that interrupts the paternal, biological lineage (International Society of Genetic Genealogy, 2020). While the issue of misattributed paternity is not new, genetic counselors have long wrestled with the complicated decision of sharing or not sharing unexpected paternity information with family members in a clinical setting, (Christenhusz, Devriendt, & Dierickx, 2013; Hercher & Jamal, 2016; Lucast, 2007). Most recently, many individuals are discovering unexpected paternity through an at-home ancestry DNA test without the benefit of, and access to, individual and family counseling supports from the direct-to-consumer DNA ancestry companies (Kirkpatrick & Rashkin, 2017; Moray, Pink, Borry, & Larmuseau, 2017; Vrecar, Peterlin, Teran, & Lovrecic, 2015). Direct-to-consumer DNA ancestry tests are capturing media attention

through television, internet, and print ad advertisements (Hogarth & Saukko, 2017; Moray, et.al. 2017; Smart, Bolnick, & Tutton, 2017), and stories of paternity discoveries or non-paternity events through these tests have appeared on national television programs in the United States advertised as recreational fun. For the purposes of this dissertation, research will be limited to only those individuals who have discovered their misattributed paternity through direct-to-consumer DNA ancestry testing.

### **Problem Statement**

The genetic information and relationship indications provided by retail-purchased, mail-in, direct-to-consumer DNA ancestry kits has uncovered family secrets of paternity previously unknown or unexpected, (Hoglund-Shen, 2017; Kirkpatrick & Rashkin, 2017; Moray, et. al., 2017) potentially impacting personal and family relationships, (Berg & Fryer-Edwards, 2008) and creating distress for individuals who question the difference between genetic identity (the biological relationship) and familial identity (the social relationship) (Anderlik & Rothstein, 2002; Lord, 2018; Ravelingien & Pennings, 2013). This unexpected information is provided directly to the consumer via email or within the ancestry company website or mobile app (an application downloaded and designed for a mobile device). While discoveries of misattributed paternity are not new, receiving this information through direct-to-consumer DNA ancestry kits is (Hoglund-Shen, 2017; Kirkpatrick & Rashkin, 2017; Hercher & Jamal, 2016; Vrecar, et. al., 2015). When using direct-to-consumer DNA ancestry testing, biological connections that intentionally have not been disclosed due to adoption, third-party reproduction, assault, or infidelity have been discovered and exposed without warning (Barata, Starks, Kelley, Kuszler, & Burke, 2015; Hoglund-Shen, 2017). It is difficult to obtain exact numbers for the percentages of misattributed paternity in our society and across the globe because it is often unknown or

unreported (Hercher & Jamal, 2016). However, different researchers offer very different estimates. Several suggest a conservative estimate that 1-3% of the worldwide population may have misattributed paternity or paternal discrepancy (Anderson, 2006; Bellis, Hughes, Hughes, & Ashton, 2005). Turney (2005) estimates it to be 10-30% of the population. Lowe, et. al. (2017) found misattributed paternity may be as high as 30% of the population. As millions of individuals have purchased and submitted DNA through direct-to-consumer ancestry DNA kits, the findings by Turney (2005) and Lowe, et. al. (2017) suggest that it may be several hundred thousand individuals who have discovered paternity secrets or confirmations through these DNA ancestry test results to date.

## **Background**

The direct-to-consumer DNA ancestry market has grown considerably in the past decade, and it appears the growth trend will continue (Moray, et.al. 2017; Pearson & Liu-Thompkins, 2012). The academic literature is rather sparse related to paternity discoveries through direct-to-consumer DNA ancestry kits. Understanding if and how paternity discoveries made through these kits affect individual, family, and social identity was the goal of this research. While there is abundant literature about the intricacies of searching for biological identity for adopted individuals (Campbell, Silverman & Patti, 1991; Leckey, 2015; Lord, 2018), DNA ancestry kits are opening a new venue for discoveries of parentage that may breach confidentiality of closed adoptions (Casas, 2018) or identity disclosure of gamete material used for infertility interventions (Hoglund-Shen, 2017). Additionally, discovery of unexpected paternity may also result in unexpected new ethnic categorizations as direct-to-consumer databases provide individual genetic ancestral origin percentages based on the DNA history as it aligns with current

countries and continents within their database of consumers (Jobling, et.al, 2015; Phillips, 2016; Vayena, Ineichen, Stoupka, & Hafen, 2014).

### **Family Defined**

There are many definitions of family. Family can be biologically-based, socially-based, or situationally-based (Gavriel, Fried & Shilo, 2016; Girardin, Widmer, Connidis, Castrén, Gouveia, & Masotti, 2018; Powell, 2017). Families do not always live together in the same residence, yet, residing together is often a criterion for defining family (Powell, 2017). Initially, individuals are born into a family involuntarily and generally are connected for a lifetime, but due to many circumstances (divorce, adoption) may be unable or unwilling to remain in the original family for that lifetime (White, Martin & Adamsons, 2019). While relationships with family members may be voluntarily cutoff, enduring connections of parents, siblings, distant family members always exist on some level unlike other social groups. There are extensive definitions of what it means to live within a family unit that include biological relationships, family through adoption, close friends sharing residence, marriage, or cohabitating. Within family systems work, these relationships develop in an interdependent way, creating patterns of behavior and communications that are expected in order to maintain the stability of the family system (Morgaine, 2001).

American definitions of family have changed significantly in the past two decades extending beyond the traditional definition that a family encompasses a man, a woman and their children (Gavriel-Fried & Shilo, 2016; Powell, 2017). There are legal, situational, and emotional connections that create and maintain a family system. The biological relationships between individuals, especially between parents and their children, most often represent society's definition of what constitutes a family (Jacobsen, Fursman, Bryant, Claridge, & Jensen, 2004).

Families encompass personal networks and social capital as a type of support system designed to create a bond of care that is reciprocal. “Traditional families” (heterosexual married couples who have biological children) still exist but are being absorbed into a modern definition that reflects all types of families, with traditional now existing as only one type of family (Eftimie, 2015; Girardin, et. al., 2018; Tillman & Nam, 2008). One description of family can include family that is biological or by choice (Girardin, et. al., 2018). For the purposes of this dissertation, family of an individual encompasses a mother, father, and children. These roles may be considered social and not necessarily biological.

Within the United States, many families are culturally and ethnically diverse. Family definitions and family programs and policies often are not representative of this diversity (Hanson & Lynch, 1992; Parke, 2000). Even within the same ethnic and racial groups, there is much diversity inherent to family values, generational influences, traditions, geographic locations, and family/relationship primacy (Hanson & Lynch, 1992; Parke, 2000; Schwartz, Hurley, Park, Umana-Taylor, Brown, Wiesskirch, Zamboanga, Kim, Castillo, & Greene, 2010). Generalizations of the American family have often represented the White majority within the middle class (Parke, 2000). A study by Schwartz, et. al. (2010) found that the concept of collectivism (needs of the group are greater than the individual) was present within the four ethnic groups they studied in the United States (Blacks, Hispanics, Asians, and Whites) but is demonstrated differently within each culture. Ethnicity, culture, and class all contribute to how a family responds to stressors and how each member of the family develops their individual and social identity (Schwartz, et. al, 2010).

## **DNA for Paternity Testing**

DNA testing for paternity determination has been used for decades. This type of testing increased exponentially when government agencies wanted to require fathers of children to support them versus maintaining the mothers on financial assistance through federal welfare programs (Anderlik & Rothstein, 2002; Richards, 2010). These tests also may be requested when a parent raises the question of paternity. Individuals can seek paternity tests from medical offices or purchase a paternity test online or in retail stores. These tests have determined the paternity or non-paternity of men and, further, the financial responsibilities that are inherent with fathering a child (Richards, 2010; Turney, 2005). There are moral questions related to how justification of completing a paternity test by a father is determined (Draper & Ives, 2009). Draper and Ives (2009) take this further and state that understanding the difference between determining fatherhood and determining infidelity should not impact the child in question. They postulated that only the child should determine if a paternity test should ever be conducted (Draper & Ives, 2009). Consumer DNA ancestry kits have been, at times, used under the guise of ancestry testing to prove or disprove paternity (Moray, et. al., 2017). Consumer DNA companies do not currently have secure safety measures in place to ensure a minor child's ability to consent or to prohibit a minor child's attempt to prove or disprove paternity (Moray, et. al., 2017).

## **New Area for Research**

Although direct-to-consumer DNA ancestry test research studies are increasing, studies related to these tests and the potential disclosure of previously unknown paternity, are difficult to locate because the field is so new. The academic literature is rather sparse related to direct-to-consumer DNA ancestry tests and previously unknown, uncovered paternity as a result of testing, despite the estimated rate of misattributed paternity hovering around 1-30% of the human

population (Anderlik & Rothstein, 2002; Bellis, et. al., 2005; Lowe, Pugh, Kahane, Corben, Lewis, Delatycki, & Savulescu, 2017; Moray, et. al., 2017). Several scholars found the sensitive nature of the material that one can learn with the opening of an email, typically deeply embedded in the article, and often as an ancillary statement (Chow-White, MacAuley, Charters, & Chow, 2015; Phillips, 2016; Turrini & Prainsack, 2016). More often, there are several articles from popular media describing the unexpected discovery of misattributed paternity from consumer DNA ancestry tests (Farr, 2017; Hunt, 2018; Saey, 2018; Zhang, 2018).

Direct-to-consumer DNA ancestry tests are a new phenomenon gaining interest and attention. There are controversies aligned with many aspects of consumer DNA ancestry tests including the accuracy of results, the lack of policy and regulations regarding storage and sharing of DNA material, as well as privacy concerns for individuals who did not complete the testing but are uncovered as biological relations. Additionally, the unexpected information that may arise related to misattributed paternity is of concern. Discovering misattributed paternity potentially opens the door to being the product of rape, incest, or an extramarital affair, as well as infertility (in the case of donor eggs or sperm). This may require a re-writing of one's personal family narrative, as they grapple with this new, and perhaps unwanted, information. Mothers, as a result of their adult child's discovery, may experience shame, guilt, or unresolved trauma. Fathers may discover previously unknown biological children or conversely, discover for the first time that the children they had/are raising are not biologically related. What may begin as a fun, recreational ancestry activity may result in an unexpected significant familial discovery.

### **Relevance to Social Work Advocacy, Policy, and Practice**

The potential implication of and disruption to families and individuals' relationships, identities, and the emotional upheavals following unexpected paternity results from direct-to-

consumer DNA ancestry tests may benefit from further review and understanding how social work can have a role within this phenomenon. The National Association of Social Workers (NASW), one of the largest social work membership organizations worldwide, has created multiple Practice Standards and Guidelines, as best practice for social workers, employers, and consumers to understand the tasks and responsibilities of social workers in the field (NASW, 2021). The NASW Standards for Integrating Genetics into Social Work Practice (NASW, 2003) is one of these guidelines. Additionally, the NASW adopted an updated Code of Ethics (2017) that social workers are expected to adhere to in practice. Three key elements that the social work field addresses through the NASW Practice Standards and Guidelines (NASW, 2021) and the Code of Ethics (2017) include advocacy, policy, and practice.

Advocacy relates to how social workers support fairness and social change. Teaching others to advocate for themselves is an important tool that social workers want to develop with clients. The NASW Code of Ethics (2017) and the Standards for Integrating Genetics (2003) promote the role of social workers to support clients' health concerns, including genetic concerns. Standard 9 of the Standards for Integrating Genetics into Social Work Practice, advocacy, highlights the need for social workers to protect, ensure, and maintain privacy for clients' genetic information while addressing any larger issues related to social change that may need to occur due to prevent discrimination based on genetic data (NASW, 2003).

Confidentiality is a core component of the Code of Ethics (2017), as is social and/or political action to change policies.

Policy responsibilities for social workers are identified in the 2017 Code of Ethics addressing equal access for individuals to services, employment and opportunities, as well as equitable treatment for all cultures, races, ethnicities, classes, and/or genders (NASW, 2017).

Social workers must address concerns with discrimination and unfair practices as part of their ethical duties. The Standards for Integrating Genetics into Social Work Practice (NASW, 2003) also applies policy responsibilities to social workers in relation to equitable access to genetic testing and information about and access to pre- and post-counseling if needed. Further, the Standards also address the need for collaboration with other disciplines for policy and practice development as well as cross-cultural knowledge surrounding the field of genetics (NASW, 2021).

To practice as a social worker, the Code of Ethics (NASW, 2017) requires the social worker to have professional competence and to remain well-informed on research areas specific to one's specializations. The Standards for Integrating Genetics into Social Work Practice (NASW, 2003) requires practice skillsets that include theories and interventions specific to genetics when working with individuals. Gaining this skillset may require coursework in other disciplines to understand the nuances of genetics work (namely the medical field). However, social workers, using psychosocial and relational foundations with individuals and families, are in a strong position to develop a full picture of genetics intervention and assessment before and following genetic testing.

Sylvia Schild (1966) was the first author to discuss the value of the social worker's role in the field of genetics (Taylor-Brown & Johnson, 1998). At the time, considering the population explosion and the anticipated social problems associated with that, she wrote that social work has a place for program development, family planning access, the provision of genetic counseling, and for collaborating with other disciplines for the opportunity to reach a larger population affected by genetics research (Schild, 1966). Fifteen years later, the social worker's role in genetic counseling was again touted for support within the field of genetics due to social

workers' understanding of psychosocial needs, clinically understanding how to help individuals in crisis, and the provision of education for the family (Mealer, Singh, & Murray, 1981).

Predicting the impact of the Human Genome Project (HGP) information and understanding the additional influence of technology identifying disease risk through genetic tests, Taylor-Brown and Johnson (1998), expressed the important role that social workers can have within the genetics field as advocates for fair and appropriate family needs, education, and the policy creation that does not discriminate based on genetic information. While none of these researchers addressed genetic information specific to unexpected paternity results at the time, the advocacy, support, and education of social workers to assist individuals is clearly within the social work field to be further developed.

While the National Association of Social Workers (NASW) published the Standards for Integrating Genetics into Social Work Practice in 2003, to date, there has not been an updated version of the Standards for Integrating Genetics into Social Work Practice. Although direct-to-consumer DNA ancestry tests were just emerging at the time, the standards related to responsibilities of social workers within the field of genetics remain relevant today. The specific objectives that the NASW put forth in 2003 still support social work leadership responsibilities from the Council on Social Work Education (CSWE)'s 2015 Educational Policy and Accreditation Standards (EPAS) as they relate to advocacy, creation and evaluation of policy, ethical practices, genetic knowledge advancement, practical skills with clients, families and the larger community, development of continuing education opportunities, cross-cultural engagement, and genetic discrimination prevention (CSWE, 2015; NASW, 2003).

Considering the rapid advancement of direct-to-consumer DNA ancestry tests and the consumer market for these tests, the standards for integrating genetics into social work practice

may need to be revisited to ensure social work practice aligns with these advancements. While the field of genetics and DNA is generally associated with science, the human interaction, the necessary education about and delivery of sensitive genetic information, and the subsequent therapeutic needs or concerns of affected individuals explain why social work must have a voice within this field. Unexpected paternity surprises, as a result of completing a direct-to-consumer DNA ancestry test, are an additional potential consequence within the advancements of the genetics and technology fields. Social work may advocate for direct-to-consumer DNA ancestry companies to collaborate for responsible education and intervention with unexpected testing results. Social work can contribute to the field of genetics through policy development, community resource development, and research on the human impact of genetics advancements.

### **Theoretical Framework**

Family identity influences an individual's social identity development (Scabini & Manzi, 2011). To explore how the unexpected change to paternity knowledge may impact an individual and their family, this research project utilized the theoretical lenses of social identity theory and family systems theory. These theories together offer an understanding of the potential immediate emotions, behaviors and sudden disruption of one's familial and personal identity and relationships when unexpectedly discovering paternity through a direct-to-consumer DNA ancestry test.

### ***Social Identity Theory***

Social identity theory provides the foundation for the significance of belonging to and identifying oneself within a social system (Brown, 2000; Hogg, Abrams, Otten, & Hinkle, 2004; Stets & Burke, 2000). Based on the initial work of Tajfel and Turner (1979) in the field of social psychology, social identity theory describes the way in which people understand who they are

individually based on the groups to which they belong. These groups may include nation of origin, race, ethnicity, religion/spirituality, family, class, sexual orientation, ability, gender identity, and biological sex (Abrams & Hogg, 2010). The theoretical concepts of social identity and group belonging involved with understanding how an individual identifies themselves within the group can explain how social identity and individual identity are intertwined.

Social identity theory helps to explain how an individual's identity is constructed based on their membership and affiliation to the groups to which they belong (Brown & Capozza, 2000). Tajfel and Turner (1979) believe that determining social identity is a cognitive process that involves social categorization, social identification, and social comparison. These categorizations provide structure and meaning within group social categories and are determined by the social structure into which an individual is born (Hogg & Abrams, 1998). Individuals seek similarity in identities within family structures for cognitive and emotional connection (Spears, 2011).

Social categorization, social identification, and social comparison use individual and social identity terminology as a means to understand social identity theory and group belongingness. Individual identity may depend upon experiencing congruence and distinction within the social identity (Ashforth & Mael, 1989; Brown, 2000). When the individual is satisfied with the groups they belong to, they remain there and find ways to develop independently within that group (Ashforth & Mael, 1989). When and if the individual becomes dissatisfied with the group they belong to, they either leave or find ways to improve their association with it (Brown, 2000).

**Application to Study.** Social identity, and the meaning attached to an individual's sense of self through their social identity, may help explain why learning of previously unknown

paternity may cause a disruption to an individual's identity along with immediate coping behaviors initially. Secure belonging to a family, a lifelong, reinforced status, usually is a component of developing and maintaining a person's individual and social identity (Scabini & Mani, 2011). How an individual categorizes themselves within the group connects strongly with the roles the individual has within the group (i.e. daughter, mother, teacher, author, leader) (Stets & Burke, 2000). Stets and Burke (2000) also state that identity role, group membership, and individual identity are deeply intertwined. Learning that one is not the biological child of a member of the family (social group) or that there are multiple siblings previously unknown may give an individual pause, requiring the accommodation of the new information and how it informs the sense of self and influences social identity for an individual. Reassessing role and group membership may be compromised causing distress to the individual through the unexpected results of an ancestry test.

The sense of belonging within social groups provides stability and familiarity. Family narratives are often verbally passed down from previous generations. The results of completing a direct-to-consumer DNA ancestry test are expected to support the learned narrative of ethnicity, health, and familial genetic relationship for the majority of consumers (Kirkpatrick & Rashkin, 2017). For the individuals who complete the ancestry test and learn paternity information that was hidden, their previously understood family narrative and connections to family members may be disrupted. For the entire family systems on both sides of the paternity information, the impact of this unexpected information may disrupt many relationships.

### ***Family Systems Theory***

Family is defined as an emotionally connected, complex system of interactions between members generally engaging one another in order to influence their behaviors (Bowen, 1966;

Bowen, 1978; Day, 2010; Erdam & Safi, 2018; Kerr & Bowen, 1988; Knauth, 2003). Bowen's theory that one family member's emotional patterns within a family unit becomes absorbed by the rest of the family who then adapt their emotional responses was groundbreaking (Bowen, 1978). As a psychiatrist and founder of family systems theory, Bowen began his study with families of patients with schizophrenia in the mid-1950s. While the original study was conducted to learn about schizophrenia, Bowen began identifying similar patterns of behavior and interaction between these families, families whose members who had less intense mental illnesses, and within typical families without mental illness (Bowen, 1978). Based on these studied patterns and interactions, including those within his own family, he developed six original working family concepts to include triangles, differentiation of self, nuclear emotional family process, family projection process, multigenerational transmission processes, sibling position, emotional cutoff, and emotional processes in society (Bowen, 1978; Kerr & Bowen, 1988).

Over time, Bowen's theory has evolved and research has been expanded by others to include additional family systems concepts that include open and closed boundary systems, messaging and rules within a family, and family subsystems also referred to as coalitions or alliances (Charles, 2001; Day, 2010; Erdem & Safi, 2018; Morgaine, 2001). Boundaries within families are often complex, operate on an open or closed basis, and are personalized to individual family systems (Day, 2010; Morgaine, 2001). Open boundaries allow for outside influences, information, and people to impact the whole while closed boundaries work to keep outside influences, information, and people away (Morgaine, 2001). Closely related to boundary influences in family systems are the impact of messages or rules within a family. Rules determine how individuals within a family behave and emotionally respond through power, guilt,

and control (Morgaine, 2001). These rules are typically unspoken expectations in order to, again, maintain the stability of the system (Morgaine, 2001). Along with spoken and unspoken boundaries and rules, subsystems of family members (parent to parent, parent to child, sibling to sibling) also exist within each family (Morgaine, 2001). Subsystems in a family refer to smaller, often fluid, groups or pairs of individuals who provide roles and functions that influence one another and the other subsystems (Morgaine, 2001).

### ***Family Systems Theory and Social Work Practice***

Social work practice routinely utilizes family systems theory and its concepts when intervening with, supporting, and advocating for individuals and their family support systems. Families are often viewed as systems that may become dysfunctional, requiring interventions in order to balance communication and behavior patterns between members (Sutphin, McDonough, & Shrenkel, 2013). Within family systems work, relationships develop in an interdependent way creating patterns of behavior and communications that become expected in order to maintain the stability of the family system (Morgaine, 2001) and to reach what family systems' theorists believe are a family's often unspoken but crucial goals (Day, 2010). Noted frequently in the literature about family systems theory and family therapy is the notion that the individual must differentiate themselves as a separate entity from the emotional pull of the family while also considering how to make sense of themselves within the entire family system for the purpose of growth and healthy relationship development (Bitter & Carlson, 2017; Charles, 2001; Day, 2010).

**Application to Study.** Understanding the individual within the context of the family as a whole, may help explain family relationship difficulties within the family of origin when unexpected paternity secrets are discovered. Family interactions, differentiation, fusion,

boundaries, rules, and subsystems influence the emotions and behaviors of family members, particularly under stress. These concepts may provide an understanding for how individuals and family members struggle with the ability to differentiate cognitive processes (thoughts) from emotional processes (feelings) during this time of unexpected discovery (Bowen, 1978; Charles, 2001; Papero, Frost, Havstad, & Noone, 2018).

Family systems theory may help to explain the impact and fallout that learning of previously unknown paternity through a direct-to-consumer DNA ancestry test may have on an individual and family, particularly if this information was intended to remain secret. This theory may provide a better understanding about how boundaries and rules are challenged or are renegotiated between family members after unexpected paternity discoveries in order to maintain homeostasis. Change of one family member's behavior may have effects on the entire family unit including how a mother interacts with her child if she knows that child's paternity is a secret. Family systems theory may help explain what effect is there on the adult child once the secret of paternity is uncovered.

### **Research Questions**

The purpose of this research study was to explore the ways learning of unexpected paternity through direct-to-consumer DNA ancestry tests affects an individual's identity and their relationship with their family. The study considered the following research questions:

1. How does the unexpected paternity information affect an individual's understanding of their family of origin?
2. How does the unexpected paternity information affect an individual's relationship with their family of origin?
3. How does the unexpected paternity information affect an individual's identity?

4. In what ways do individuals who discover unexpected paternity seek support for this experience?

This chapter will synthesize key literature that is associated with direct-to-consumer DNA ancestry tests including the history and development of these tests. Public interest, consumer access, and concerns that include accuracy of test results, understanding of results, informing consumers, privacy and confidentiality, and regulation concerns with direct-to-consumer DNA ancestry tests will be highlighted. There is an abundance of literature about the impact of family secrets reviewed with a highlight specific to reproductive secrets. Further, genetic counseling as associated with misattributed paternity disclosure, is included as an area of study that has mixed opinions on when or how to disclose misattributed paternity in a professional setting. Unfortunately, research studies specific to unexpected misattributed paternity results received from direct-to-consumer tests, and the subsequent actions taken by individuals who receive this information is limited. The profession of social work, outside of the NASW Standards for Integrating Genetics into Social Work Practice in 2003, is not present in the professional literature as the field of direct-to-consumer DNA ancestry testing and the effects of unexpected paternity results is new and evolving.

### **Development of Direct-to-Consumer DNA Ancestry Tests**

Since the mid 1800's, scientists have been studying genetics and heredity (Bonduriansky, 2012). Advancements in this field led to the major scientific discovery of the double helix in 1953 which uncovered a brand-new understanding of the structure and replication of DNA (Klug, 2004) and, subsequently, human genetic code information. Since the discovery of the double helix, significant advances have been made to determine how genetic material is transferred between relatives within generations (Durmaz, Karaca, Demkow, Toruner, Schoumans, & Cogulu, 2015). The use of genetic information has primarily focused on disease markers within DNA for diagnosis, newborn screening, susceptibility to disease, and genetic

carrier risks (Allyse, Robinson, Ferber, & Sharp, 2018; Helgason & Stefansson, 2010; Meisel, Carere, Wardle, Kalia, Moreno, Mountain, Roberts, & Green, 2015). Because these concerns are medical in nature, genetic testing has historically been initiated and/or the results of genetic testing have been explained by a medical practitioner or genetic counselor for accurate risk assessments (Collins & McKusick, 2001; Cullen & Marshall, 2006; Wheelwright, 2014).

The Human Genome Project (HGP), an international effort by scientists to sequence the three billion base pairs of human DNA, conducted from 1990-2003, concluded with the discovery of over 30,000 human genes that contribute to disease and illness knowledge (Kingsmore & Saunders, 2011; Miller & Martin, 2008). Through the scientific work of the HGP and results of the HGP in 2003, the speed with which scientists have been able to develop testing and analysis of genetic material for consumer-accessible DNA tests has advanced rapidly (Anderlik & Rothstein, 2002; Galas, Patrinos, & Delisi, 2017; Hoglund-Shen, 2017). This work coupled with advancements in genetics knowledge and computer processing, along with a societal desire for immediate information and feedback, has contributed to the rapid advancement of the direct-to-consumer DNA ancestry testing market (Anderlik & Rothstein, 2002).

Although it was expected that the medical field, following the Human Genome Project (HGP), would promote the increased use of genetic science, for-profit companies have been on the forefront to establish the direct-to-consumer DNA ancestry testing market (Borry, Cornel, & Howard, 2010; Sweeney & Legg, 2011). Many companies initially interested in consumer genetics and ancestry did not see the consumer interest increasing quickly enough, nor the profit they expected, and withdrew from the market, sold to other genetics companies, or went out of business (Allyse, et. al., 2018).

### *Early Development of Consumer DNA Tests*

Direct-to-consumer DNA tests were commercially marketed to provide genetic information related to nutrition and health (Seward, 2018). From 2000-2009, a company called Sciona sold tests online and reported on health claims about genetics and nutrition and quickly came under attack for lacking scientific evidence (Saukko, 2017). In 2006, the Government Accountability Office (GAO) investigated the major direct-to-consumer DNA testing companies and reported on the unproven clinical validity of these DNA tests for health risk and disease predictions. Other companies, such as 23andMe and Navigenics, entered the market in the mid-2000s to promote online purchasing of their tests for consumer interest in genetic health information, while recognizing the value of collecting large databases of DNA data for more accurate DNA comparisons (Hogarth & Saukko, 2017). In 2013, the U.S. Food and Drug Administration (FDA), through numerous letters, asked 23andMe to remove consumer tests that provided disease prediction and intervention (Seward, 2018). In 2015, after working with the FDA, 23andMe re-entered the market with approval to screen consumer DNA for 10 health markers only (Seward 2018). Within the past decade, direct-to-consumer DNA companies have expanded to include ancestry testing (where ancestral family travelled over the past several generations) and personal trait information (determining similarities in physical traits of certain groups and family) along with developing minimal genetic health predictors (Hogarth & Saukko, 2017; Koeller, Uhlmann, Carere, Green, & Roberts, 2017).

Initially, DNA companies sought to collaborate with the medical field through attempts to utilize healthcare insurance and gain support from physicians. (Borry, et.al., 2010). Over time, the increased use of online marketing through social networking sites assisted in many companies' advancement developing consumer interest in personal genetic/ancestral information

(Koch, 2012). As direct-to-consumer DNA ancestry companies have grown and developed online, it is important to note that these companies have been using an opt-out consumer research approach and have yet to be universally held to the same legal health and privacy regulations, as well as for Institutional Review Board (IRB) approvals in research (Dent, Magoulas, Bamshad, Ramos, & Weissman, 2018; Koch, 2012; Laestadius, Rich, & Auer, 2017; Seward, 2018).

### ***Consumer Access***

Consumer accessibility for direct-to-consumer ancestry testing took off in 2007 when 23andMe developed the first saliva-based consumer test designed to uncover potential future disease markers, locate genetic relations within recent generational ancestry origins, and for simple entertainment value about personal traits like food preferences and reactions to alcohol consumption (23andMe, 2016). After registering a kit online and providing a sample of saliva or swabbing the inside of a cheek, consumers typically wait four to six weeks for a simple and general electronic report indicating their personal family geographic/ethnic origin from the past 200-500 years (or about six generations), physical traits, health markers, and/or family relationship connections depending upon which test a consumer chooses (Hoglund-Shen, 2017; Kirkpatrick & Rashkin, 2016; Phillips, 2016).

Consumer access to at-home DNA ancestry tests is a trend that has increasingly gained momentum in interest and sales (Brown, 2019; Phillips, 2016; Saey, 2018). In 2007, the cost for this experience was around \$1,000 (Allyse, et. al., 2018). By 2012, the competition in the market drove the price down significantly to approximately \$100-300 per test (Allyse, et.al., 2018). Current direct-to-consumer DNA health and ancestry tests are affordable, \$60-\$199, and aggressively marketed to consumers on television, print ads, and through social media sites (Allyse, et. al., 2018; Covolo, Rubinelli, Ceretti, & Gelatti, 2015).

Direct-to-consumer DNA ancestry tests utilize online and retail sales to grow their customer/consumer base (Phillips, 2016). Sales of these kits are profitable for the companies who make them and by early 2018, 12 million kits had been sold (Regalado, 2018), 7 million of them in 2017 alone (Saey, 2018). In early 2019, over 26 million direct-to-consumer DNA ancestry customers have provided their personal DNA through their ancestry tests to the five most popular DNA companies (Regalado, 2019). Predicted growth for direct-to-consumer DNA ancestry companies was expected to exceed \$340 million in sales by 2020 (Seward, 2018). Consumers, at their own expense, have the ability to order their test online, send it back to the company through the mail, and receive the results back via email within a few weeks, all without any medical personnel interaction (Allyse, et. al., 2018). Table 2.1 provides a comparison of some of the most popular direct-to-consumer DNA ancestry testing companies (23andMe, Ancestry DNA, Family Tree DNA, Geno 2.0, and My Heritage) marketing their DNA kits.

Table 2.1

*Summary of Direct-to-Consumer Ancestry Companies*

Company	Launch Date	Purpose	Collection Method	DNA Database Size
23 and Me	2007	Medical Genealogical Ancestry	Saliva Sample	10,000,000 tests sold
Ancestry DNA	2012	Genealogical Ancestry	Saliva sample	~15,000,000
Family Tree DNA	2012	Genealogical Ancestry	Cheek swab	~1,000,000
Geno 2.0	2012	Population genetics In-depth ancestry	Saliva sample	~230,000
My Heritage	2016	Genealogical Ancestry	Cheek swab	2,500,000

*Source:* International Society of Genetic Genealogy (ISOGG)

Each website from the above DNA ancestry testing companies explain, in similar terms, how their tests work. Once the test arrives at the lab, they describe removing the saliva sample from the mailed package, extracting DNA information using robotic technology, and creating hundreds of copies to apply to a DNA chip. Algorithms are then used with the information on the DNA chip to gather ethnicity estimates or ancestral histories. Ethnicity estimates compare DNA to reference populations within each ancestry database while also searching for additional DNA matches. The outlier in DNA ancestry testing is with 23andMe, which offers health, trait, and carrier information, along with ancestry, for additional cost.

Prior to the efficiency of direct-to-consumer DNA tests, blood tests were primarily used to determine relationship or exclusionary conditions for biological relationships between individuals. The 1990s brought forth Polymerase Chain Reaction (PCR) DNA testing (MacKnight, 2003). This type of testing no longer required a blood sample for evaluating DNA but used a buccal (cheek) swab to gather a small amount of DNA (Walker, Najarian, White,

Jaffe, Kanetsky, & Rebbeck, 1999). This type of DNA testing had a very quick turnaround in results compared to the previous decades of gathering and evaluating DNA (Walker, et.al., 1999). PCR DNA testing between parents and a child demonstrated that 50% of a child's DNA should come from the mother and 50% should come from the father (Ma, Zhu, Guan, & Cherng, 2006). Results of DNA tests used through this method are accurate 99.99% of the time (Ryan, Baner, Demko, Hill, Sigurjonsson, Baird, & Rabinowitz, 2013). By the 2000s, multiple Single Nucleotide Polymorphisms (SNP) in DNA were combined with DNA to identify significant additional information about individuals, including their recent ancestry and multiple types of disease markers (Patrinos, Baker, Al-Mulla, Vasiliou, & Cooper, 2013). Scientific advances within the field of direct-to-consumer genetics combines both PCR and SNP for individual relationship information, ancestry heritage, along with genetic health and disease information depending on the specific commercial test the consumer purchases (Durmaz, et. al, 2015; Kirkpatrick & Rashkin, 2017). Currently, 23andMe is the only U.S. Food and Drug Administration (FDA) supported direct-to-consumer DNA ancestry test company that offers the option of additional health, trait, and carrier information, along with ancestry results to the consumer, although other direct-to-consumer DNA companies are seeking the same approvals (Kirkpatrick & Mishkin, 2017).

### ***Concerns***

Direct-to-consumer DNA ancestry testing has come with numerous concerns related to accuracy of results (particularly between tests), interpretation of results without medical personnel (Meisel, et. al., 2015; Samuel, Jordens, & Kerridge, 2010; Seward, 2018) and the absence of pre-test and post-test counseling (Botkin, Belmont, Berg, Berkman, Bombard, Holm, Levy, Ormond, Saal, Spinner, Wilfond, & McInerney, 2015), along with significant privacy

concerns (Archarya & Gautam, 2015; GAO hearings, 2010; Huang & Bashir, 2015). Turrini and Prainsack (2016) discuss the complication that genomic information discovered by ancestry testing often affects more than the one individual who has submitted DNA. DNA is identifiable in its uniqueness and will identify any genetic connection to another person if that person has also completed DNA testing in the same database. The information determined from one's DNA can affect those biologically related to the individual identified. Additional concerns to consider revolve around results being delivered via email and website searches electronically without initial access to a human contact (Phillips, 2016) as well as the storage or sale of personal DNA information once collected (May, 2018). Table 2.2 provides comparison data of consumer contacts and storage between the most popular direct-to-consumer companies.

Table 2.2

*Consumer Contacts and Storage of Consumer DNA Material*

Company	Storage of DNA	Consumer Contact
23 and Me	Indefinitely	Email
Ancestry DNA	Indefinitely	Email
Family Tree DNA	Minimum of 25 years	Email
Geno 2.0	25 years with Family Tree	Email
My Heritage	Indefinitely	Email

*Source:* International Society of Genetic Genealogy (ISOGG)

**Accuracy of Test Results.** Completing multiple direct-to-consumer DNA ancestry tests can also result in multiple, at times, contradictory results (Saey, 2018; Sturm & Manickam, 2012). Empirical studies have shown that direct-to-consumer DNA ancestry testing reveals mixed results for consumer behavior changes (e.g. improve diet and exercise, seek professional

intervention or explanation) with most studies indicating a neutral stance on whether or not ancestry test results positively or negatively change consumer health behaviors (Carere, Kraft, Kaphingst, Roberts, & Green, 2016; Covolo, et. al., 2015; Kaufman, Bollinger, Dvoskin, & Scott, 2012; Nielsen, Carere, Wang, Roberts, & Green, 2017; Vayena, et. al., 2014).

A 2015 systematic review of 118 articles (Covolo, et. al.) concluded that there is developing concern about direct-to-consumer ancestry tests online due to confidentiality of information. They also found that these tests are neutral regarding health benefits or dangers for consumers (Covolo, et. al., 2015). Another study found that following the completion of ancestry testing, consumers' previously perceived knowledge of genetic information decreased due to the complexity of health risk disclosure and what it means to the individual (Carere, et. al., 2016). Additionally, a 2018 study of 49 consumer samples revealed elevated false-positive rates along with additional indicated health concerns that, once thoroughly studied, actually showed no consumer health risk concern (Tandy-Connor, Gultinan, Krempely, LaDuca, Reineke, Gutierrez, Gray, & Davis, 2018).

**Understanding of Results.** The direct-to-consumer DNA ancestry test market, providing genetic ancestry and health information, is accessible, inexpensive, easy to use, and has been considered a form of entertainment for consumers (Allyse, et. al., 2016; Loi, 2016; Smart, et. al., 2017). Today, consumers are increasingly concerned with knowing and accessing information to make decisions about their health and life choices (Kauffman, et. al., 2012; Ramos & Weissman, 2018). People increasingly use the internet to diagnose themselves and to inform themselves of treatment options (Ramos & Weissman, 2018). Additionally, individuals are increasingly using online platforms to connect with group supports, which, according to Hammond (2015), can have the same usefulness as in-person support groups. Online support groups can serve to

supplement or remove therapeutic interventions through traditional office-based counselors (Hammond, 2015). Online or in-store purchases of direct-to-consumer DNA ancestry tests bypass medical personnel interaction and deliver health and ancestry results to an email provided by the consumer. As a result, questions of consumers misinterpreting the health information provided is a significant concern (McGuire & Burke, 2011; Meisel, et. al., 2015; Tandy-Connor, et. al., 2018).

Carere, et. al. (2016) found that without health provider support, consumers did not understand the complexity of genetic results. There is also the concern that with false-positive results, unnecessary worry about disease indicators can harm consumers (Davis, 2007; Samuel, et. al., 2010). Turrini and Prainsack, (2016) and Meisel, et. al. (2015) share that unnecessary further medical intervention as a result of fear or a lack of understanding of consumer DNA testing could put an undue burden on the healthcare system. Consumers' understanding or interpretation of the results of testing has also been shown to increase levels of anxiety or stress (Laestadius, et. al., 2017; Meisel, et. al., 2015; Turrini & Prainsack, 2016; van der Wouden, Carere, Maitland-van der Zee, Ruffin, Roberts, & Green, 2016; Vayena, et. al., 2014).

**Informing Consumers.** Jobling, et. al., (2016), as geneticists, go further in expressing their concerns that consumer DNA ancestry testing does not properly inform consumers on how the tests work scientifically, how the information provided is a small portion of a consumer's actual health and ancestry background, and what databases consumers' information is compared with. However, after a recent review of the most well-known direct-to-consumer DNA ancestry company websites (23andMe, My Heritage, FamilyTree DNA, AncestryDNA, and Geno 2.0), each website in 2019 does include a brief, lay-person's explanation regarding the science behind DNA ancestry testing. Contradicting the lack of consumer value with direct-to-consumer DNA

ancestry tests, Helgason and Stefansson (2010) share their opinion that knowledge equals power for consumers and through the interest in ancestry tests for health information, consumers may increase their understanding or focus on their personal health.

**Privacy and Confidentiality.** Every living organism's cells contain specific genetic code. The DNA of humans is 99.5% the same in each one of us. The 0.5% variation is what makes each person's DNA identity unique to themselves. DNA is hereditary and half of each set of 23 chromosomes is passed down from each biological parent. This explains why children and parents have similar traits related to facial features, body build, hair color, eye color, and skin color. DNA provides the cellular blueprints for the development, reproduction and survival of a species. Ancestry tests are accurate in determining biological relationships (Davis, 2007; Moray, et. al., 2017; Phillips, 2016). As genetic information is uniquely identifiable and biologically connects to other individuals, consumers may unknowingly be disclosing information about others through testing (Chow-White, et. al., 2015; Kirkpatrick & Rashkin, 2017; Via, 2017).

Identification of others through consumer DNA databases has recently been in the media connecting DNA to criminals and solving previous cold cases (Taylor & Turner, 2019). As DNA databases grow, there is concern about individual anonymity, the release of DNA material once collected, and the transparency of direct-to-consumer DNA companies sharing how they store, share, and/or destroy genetic material after collection (Chow-White, et.al., 2015; Laestadius, et. al., 2017; May, 2018; Turrini & Prainsack, 2016; Via, 2017). The discovery of one's paternity through direct-to-consumer DNA ancestry results occurs using DNA matches within the specific company's database through the scientific measurement of DNA through centiMorgans (cM) (Kirkpatrick & Mishkin, 2017). The more centiMorgan's that match, the stronger the biological relationship. If a consumer's DNA matches any other consumer within their system, this match

shows up on both consumer profiles for viewing. From here, consumers can access the percent of the match, determined by the centiMorgan (cM) measurement to identify a reasonable and likely biological connection. For example, a fifty percent match indicates a parent, child, or full sibling connection, a twenty-five percent match indicates a half sibling, grandparent, grandchild, niece, nephew, aunt or uncle and a twelve percent match indicates a first cousin (Kirkpatrick & Rashkin, 2017). It is important to note that the direct-to-consumer companies do not know which relationship belongs to the percentage, just that there is a confirmed biological connection to that degree within that company's system matching a consumer's. It is then up to the consumer to piece the rest together and determine how the individual fits into their family tree.

Privacy concerns for the management, storage, and long-term use or sharing of consumer DNA genetic material are frequently mentioned in the literature (Borry, Bentzen, Budin-Ljosne, Cornel, Howard, Feeney, Jackson, Mascalzoni, Mendes, Peterlin, Riso, Shabani, Skirton, Sterckx, Vears, Wjst, & Felzmann, 2018; Huang & Bashir, 2015; Kirkpatrick & Rashkin, 2016; Laestadius et. al., 2017; May, 2018; Phillips, 2016; Samuel, et. al., 2010). A significant area of concern is the potential surreptitious testing of minors without their consent or the consent of one of their parents (Moray, et. al., 2017). Ancestry companies have no mechanism in place to prove that the genetic material sent in is that of an adult listed on the sample (Samuel, et. al., 2010; Vayena, et. al., 2014). A research study conducted by Laestadius, et. al. (2017) looked at the websites of health and ancestry companies to determine how transparent their privacy practices and use of the data was for consumers prior to purchasing the tests. Their research showed that the majority (of 30 company sites) disclosed how they handle confidentiality of and further storage and use of DNA material, but very few indicated the potential risk(s) of disclosing this information for consumers (Laestadius, et. al., 2017). Individuals who may want to remain

anonymous for a variety of reasons (i.e. reproductive donations, adoptions, misattributed paternity) will be unable to have their privacy respected if their DNA has not been stored safely or is shared for additional research (Kirkpatrick & Rashkin, 2016; May, 2018; Richards, 2010).

Ultimately, when using DNA testing, biological connections that are present but have not been disclosed due to family secrets, infidelity, donor conceptions, community rejection, or persecution, have been discovered and exposed (Barata, et. al., 2015; Saey, 2018; Vayena, 2015). Ethical issues arise when considering the arguments for and against a child's right to know their biological parents, in particular when the child is a product of donor eggs or donor sperm (Ravelingien & Pennings, 2013). Ravelingien and Pennings (2013) argue for universal paternity testing at birth in order to provide equal access for children and families to understand their biologic information. However, Mandava, Millum, and Berkman (2015), argue against the sharing of misattributed paternity by genome researchers when it is discovered. As social structures exist about the raising of children by parents, assumptions are made that mother and father are also biological contributors to their children (Richards, 2010). Oftentimes families who opt for reproductive assistance choose to maintain this information confidentially (Becker, Butler, & Nachtigall, 2005). With the increasing access to, commercialization of, and low cost of DNA ancestry tests, adult children may learn new, previously unknown information about their biological parentage. If, by chance, biological children of donors are in the same DNA ancestry system, the opportunity to maintain the donors' confidentiality is in question (Vayena, 2015). Because consumers are aware of this loophole, Moray, et. al.'s 2017 research indicated that direct-to-consumer DNA ancestry tests may be intentionally utilized to prove or disprove paternity in secret.

**Regulation.** Ancestry testing is typically used to determine an estimate of individuals' ethnic or geographical origins (Kirkpatrick & Rashkin, 2017). Searching for one's genealogical history is a common "hobby" in the United States (Shriver & Kittles, 2004, p. 611) and direct-to-consumer DNA ancestry testing has allowed for a new way to further develop the genetic family tree. These tests can also determine individual biological connections when individuals complete a test through the same company (Kirkpatrick & Rashkin, 2017). Genotyping is used to analyze DNA markers and, again, depending on the specific test a consumer opts to purchase, the types of genetic markers searched include the Y DNA (paternal lineage to ancestry), mitochondrial DNA (maternal lineage to ancestry), and/or autosomal DNA (both paternal and maternal lineage) (Kirkpatrick & Mishkin, 2017). What the consumer receives is a report on an estimate of geographical ancestry compared with the information that is stored in their databases. Oftentimes, these estimates vary when conducted between different ancestry tests due to the variance in database membership (Jobling, et. al., 2016; Saey, 2018; Sturm & Manickam, 2012). Jobling, et. al. (2016) takes this discussion further to state that direct-to-consumer ancestry testing fails consumers by withholding how small the comparison databases are for individual ancestry details. Direct-to-consumer DNA health/ancestry tests are fraught with ethical controversy related to regulation (Allyse, et. al., 2018; Phillips, 2016; Seward, 2017) clinical validity and utility (Helgason & Stefansson, 2010; Kaufman, et. al., 2012; Loi, 2016; Turrini & Prainsack, 2016), privacy (Kirkpatrick & Rashkin, 2017; May, 2018; Moray, et. al., 2017) as well as consumer understanding of information without the guidance of medical personnel or genetic counselors (Hogarth & Saukko, 2017; Koeller, et. al., 2017; Sweeney & Legg, 2011). However, it is clear that for now, direct-to-consumer DNA ancestry testing companies are using science for recreation and business (Saey, 2018; Seward, 2017).

Consumers of DNA ancestry tests are curious about information related to ancestry origins as well as information on health factors relative to individual genetic makeup (Wang, Cahill, Parlato, Wertz, Zhong, Cunningham, & Cummings, 2018). There is a gap with these ancestry tests as ancestry information is generally marketed and primarily perceived as entertainment, whereas learning more about genetic health markers is perceived as gaining medical knowledge or diagnosis (Smart, et. al., 2017). This connection between entertainment and health knowledge within the same test creates a nonmedical/medical category that has little consistency and very little regulatory oversight (Berg & Fryer-Edwards, 2008; Borry, et. al., 2018; Laestadius, et. al., 2017; May, 2018). However, a recent study by the PGen study group determined that consumers want more access to the direct-to-consumer DNA ancestry market and little to no government regulations interrupting this access (Gollust, Gray, Carere, Lehmann, McGuire, Sharp, Spector-Bagdady, Wang, Green, & Roberts, 2017). Without regulations in place for oversight, privacy risks for unsuspecting non-consumers of ancestry testing remain due to accidental or intentional disclosure of disease risk, heritability, or genetic relationships (Berg & Fryer-Edwards, 2008; Borry, et. al., 2018; Phillips, 2016; Turrini & Prainsack, 2016).

The lack of consistent, enforceable regulations within this online market provide additional worry, particularly considering the storage and use of consumers' DNA once provided to the DNA company (Berg & Fryer-Edwards, 2008; Chow-White, et. al., 2015; Phillips, 2016; Samuel, et. al., 2010). The U.S. Food and Drug Administration (FDA) has started the complicated process of regulating the privacy of health information within the genetic ancestry market in an effort to separate genetic health information and genetic ancestry information (Whaley & McGuire, 2018). The Genetic Information Nondiscrimination Act (GINA) was passed by the United States Congress in 2008 as a protection against genetic discrimination for

consumers who wanted to engage in genetic testing (Areheart & Roberts, 2019). GINA was designed to prevent employers and health care companies from using genetic data to discriminate against consumers and has had mixed reviews on its success (Huang, Huston, & Perri, 2013; Lee & Borget, 2014; May, 2018). Areheart and Roberts (2019) believe GINA to be successful in providing protections for privacy through employers, although GINA's original focus, to protect consumers' privacy upon completing genetic testing, is not clearly regarded as a known consumer safety net for genetic testing decision-making as predicted. However, it remains the consumer's responsibility to read through the privacy and DNA storage information before clicking through each and any agreement as failure to educate oneself could mean sharing one's DNA for additional third-party research (Huang & Bashir, 2015; Phillips, 2016; Phillips, 2017).

### **Genetic Counseling and Disclosure of Misattributed Paternity**

In 1983, a Presidential Commission report about the ethical, social and legal implications of genetic screening concluded that an incidental finding of misattributed paternity should err on the side of disclosure to the mother and biological father (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research). In 1994, the Institute of Medicine assessed risks in genetic medicine in a report which concluded that genetic counseling is a critical component of genetic testing services for all consumers and that only the mother needs to receive the paternity disclosure when it has been determined to be misattributed to the social (non-biological) father (Institute of Medicine [IOM], 1994).

However, according to Hercher and Jamal (2016), not all genetic counselors share results of misattributed paternity with patients if it is an incidental finding discovered in the course of genetic testing but is not why the individual sought genetic counseling. In fact, some genetic counselors admit that they "fudged" misattributed paternity results (Hercher & Jamal, 2016, p.

37). Despite federal law that supports the right of patients to access their entire medical records, some genetic counselors choose to share results while others do not (Hercher & Jamal, 2016). A 2015 position statement by the American Society of Human Genetics (ASHG) addressed concerns with the advancements in testing availability that there is not enough data to understand the psychosocial impact of genetic testing on children and families unless necessary. Their position remained clear that without necessary medical reasons for genetic testing, children should not have genetic tests until adulthood. While there are genetic counselors who support disclosing misattributed paternity as a patient's right to know, there are genetic counselors who support non-disclosure due to the potential disruption this could cause in the family (Botkin, et. al., 2015). In fact, ultimately the ASHG statement recommended that parents are provided with the information that misattributed paternity/parentage could be an outcome of genetic testing and that, "while honoring their broad responsibility to be truthful with patients and their families, we recommend that health-care providers avoid disclosure of misattributed parentage unless there is a clear medical benefit that outweighs the potential harms" (Botkin, et. al., 2015).

Their statement is opposite the Health Insurance Portability and Accountability Act (HIPAA) of 1996 that allows patients full access to all medical records. While HIPAA may not withhold medical records access, the ASHG encourages non-disclosure of genetic medical records if there are questions of parentage. A review of the National Society of Genetic Counselor (NSGC) code of ethics allows for genetic counselor judgement "to determine how best to respond to difficult situations" (National Society of Genetic Counselor [NSGC], 2017, p. 1). What complicates the decision for genetic counselors to disclose or not disclose information of misattributed paternity is contradicting opinions within genetic counselors' professional obligation. The decision to not disclose misattributed paternity as part of the consultation where

genetic counselors discuss the findings of genetic testing, “presumes that disclosure is reliably in the hands of the clinician. It is not. By federal law, patients (or their parents and guardians) have a right to all test results.” (Hercher & Jamal, 2016, p. 37).

With the advent of consumer DNA ancestry tests, Hercher and Jamal (2016) are clear in their position that genetic counselors share misattributed paternity even if it is an incidental finding. Kirkpatrick and Rashkin (2016) suggested that consumer DNA companies enlist the help of genetic counselors who understand the delicate nature of information that could be uncovered or misunderstood by consumers. A 2015 qualitative study about expert genetic counselors reveals that the traits of expert genetic counselors mirror those of expert psychotherapists in terms of empathy, self-awareness, self-reflection, and authenticity (Miranda, Veach, Martyr, & LeRoy, 2016). These authors, along with others, go a step further and suggest that pre- and/or post- counseling become a feature of direct-to-consumer DNA tests (Botkin, et. al., 2015; Kirkpatrick & Rashkin, 2016; Patrinos, et. al., 2013; Samuel, et. al., 2010; Tandy-Connor, et. al., 2018).

Historically, individuals who have concerns related to genetics/health and genetics/family planning might be advised to seek out a genetic counselor or a third-party interpretation service for explanation of DNA raw data information. Counseling with an individual who has specialized understanding of genetics and skills to deliver information accurately, is expected to increase as direct-to-consumer DNA ancestry tests become more accurate in predicting health-related concerns (Kirkpatrick & Rashkin, 2016). In order to support individuals’ clear understanding about the results of direct-to-consumer DNA ancestry tests, several articles and studies suggest the provision of genetic counselor interventions (Borry, et. al., 2018; Berg &

Fryer-Edwards, 2008; Lynch, Parrott, Hopkin, & Myers, 2011; Sturm & Manickam, 2012; Vrekar, et. al., 2015).

The field of genetic counseling is a well-established practice used in clinical settings for the support and explanation of the science behind DNA results for patients. However, as consumers are accessing direct-to-consumer DNA ancestry tests, many genetic counselors are resistant to associate with the commercialization of genetic and ancestry tests purchased online (Harris, Kelly, & Wyatt, 2012). Genetic counselors are currently unsure how to provide support to consumers of these ancestry tests, en masse, and what this growing consumer-driven market means for their professionalization (Harris, et. al., 2013).

One area that direct-to-consumer ancestry DNA companies provide accurate results for, and that genetic counselors can assist with, is misattributed paternity results (Moray, et. al., 2017). While the results may not indicate exact genetic relationship, many make suggestions of relationship based on the degree of genetic match. Moray, et. al. (2017) share that, within the genetic testing and counseling field, misattributed paternity results are not a new phenomenon. In fact, a 2018 study of genetic research laboratories reported that 80% of genetic research laboratories discovered misattributed paternity in their work (Eno, Bayrak-Toydemir, Bean, Braxton, Chao, El-Khechen, Esplin, Friedman, Hagman, Hambuch, Hernandez, Juusola, Londre, Machado, Mao, Mighion, Rehm, Ward, & Deignan, 2018).

Because direct-to-consumer DNA ancestry tests are primarily purchased online, it is important to know what the current consumer DNA ancestry websites offer regarding genetic counseling. Du and Becher (2018) conducted research exploring telegenetics, using telehealth for interactive, online genetic counseling with patients, as well as access to this service within the direct-to-consumer DNA market. Their research ultimately determined that while telegenetics

may improve access to understanding and discussion related to genetic information that consumers receive, the direct-to-consumer market is not yet prepared with consistent informed consent procedures, protection of collected health data, and personal privacy related to sharing of DNA data (Du & Becher, 2018). Table 2.3 provides a list of the most common direct-to-consumer DNA ancestry companies and their provision of genetic counseling support along with company supports that are provided when a consumer searches the website.

Table 2.3

*Genetic Counselor and Company Support*

Company	In-house Genetic Counselor	Company Supports
23 and Me	No	Third-party website for consumer education, find a genetic counselor link
Ancestry DNA	No	No mention of support
Family Tree DNA	No	Community of citizen scientists and genealogists (blog), consumer information webinars
Geno 2.0	No	Email them for questions about test results
My Heritage	No	No mention of support, general contact center phone number provided

*Source:* International Society of Genetic Genealogy (ISOGG)

More recently, a study by Koeller, et. al. (2017) supports the use of genetic counseling subsequent to results that are concerning or confusing from consumer ancestry testing. There is a divide within the direct-to-consumer DNA companies providing consistently accurate results of DNA health and ancestry testing without offering medical supports and a lack of consultation, investment, and credibility that genetic counselors are willing to provide to these companies (Harris, et. al., 2012; Koeller, et. al., 2017; Tandy-Connor, et. al., 2018; Samuel, et. al., 2010). In

order to prevent consumer misinterpretation of results, a genetic counselor can provide the human interaction and discussion for accurate assessment of health risks that account for individual and family history and day-to-day risk factors (i.e. smoking or alcohol consumption) (McGuire & Burke, 2011; Sturm & Manickam, 2012).

Wang, et. al. (2018) found that consumers are often confused with the ancestral and health DNA information they receive. Their study recruited consumers to use third party services to learn more. Ultimately, consumers within this study paid for and used third party raw DNA data interpretation and upon seeking out medical expertise with their doctors, found that they gained little further knowledge about their DNA. Wang, et. al. (2018), also noted that the experiences consumers had sharing their direct-to-consumer DNA ancestry results with genetic counselors also provided little knowledge gain. With the accessibility and marketing of consumer DNA ancestry tests, Kirkpatrick and Rashkin (2016) suggest that consumer DNA companies enlist the help, expertise, and support of genetic counselors who understand the delicate nature of information that could be uncovered or misunderstood by consumers.

### **Secrets within Families**

Family members, and the family unit as a whole, influence our individual values, beliefs, attitudes, and behaviors (Gavriel-Fried & Shilo, 2016). Secrets within families may affect what is valued and what beliefs are held whether secrets are known or unknown (Imber-Black, 1998). Secrets within families are commonplace and can have powerful repercussions within the family if exposed (Smart, 2010, 2011). Considering the potential of family secrets, Smart writes, “reproductive secrets in families have the power to be disruptive and dangerous because, once revealed, they will always alter relationships” (2011, p. 550). The tension that secrets create may have lasting effects on several relationships within a family.

Uncovering secrets that are long held by family members may cause disruptions that are so deep, individuals do not ever fully recover from the effects attached to a sense of shame (DeLong & Kahn, 2014). The person holding the secret has the power, while the person who the secrets pertain to knowingly, or unknowingly, carries the effects of this shame (Imber-Black, 1998). Imber-Black (1998) also makes a distinction about secrets that are preventing another from information they may have a right to know. Connecting this to consumer DNA ancestry testing, if family members have not shared secret paternity information, information related to genetic health may be inaccurate and the lack of this information could be dangerous for the individual and the medical professionals caring for them (Bellis, et.al., 2005; Lowe, et. al., 2017; Mandava, et.al., 2015; Moray, et. al., 2017; Ravlinglien & Pennings, 2013; Wright, MacRae, Gordon, Elliot, Dixon, Abbey, & Richardson, 2002).

The information provided by consumer DNA ancestry tests has uncovered family secrets and discoveries of paternity previously unknown (Chow-White, et. al., 2015). Paternity is a secret that may be deeply held by mothers for many reasons (Ayers, 2017). Turney (2005) conducted a qualitative research study of women who found that women maintained the secret of their child's paternity for many reasons. The woman may have been sexually assaulted, engaged in marital infidelity, there may have been premarital sex resulting in pregnancy, or not knowing who the father may be due to numerous sexual partners in a short period of time. Some women fear public judgement and potentially experience shame due to these behaviors (Ayers, 2017; Turney 2005). Turney (2005) concluded that "moral panic" results in not sharing paternity for some women (p. 245). The use of donors for the conception of a child is another reason women/families keep paternity a secret (Heidt-Forsythe & McGowan, 2013).

When a person learns of their own misattributed paternity, they may feel the need to re-write their own family narrative and fill in the gaps with accurate information. Smart (2010, 2011) indicates that the effects of learning these secrets can be enormous for both the individual and the family. In times now past, this information could be kept confidential for the child's lifetime. With the advent of direct-to-consumer DNA ancestry tests, these types of secrets are being exposed when unexpected biological matching to someone they don't expect is a result. Nduma and Jewkes (2011) found in their study that when children were lied to, or that the truth went unspoken about who their father was, the children, even adult children, had significant emotional pain.

Families with secrets, particularly related to birth parents, have a heightened potential for conflict when those secrets are disclosed (Nduma & Jewkes, 2011; Sherr, Roberts, & Croome, 2018). Lowe, et. al. (2017) found that misattributed paternity secrets are best disclosed when discovered. Despite a father's right to know about misattributed paternity, when discovered by medical professionals, Lowe and colleagues (2017) believe this information should be shared with the mother privately. From this point, mothers may choose to keep the secret from all those involved for reasons of safety, shame, relationship debilitation, or maintenance of family cohesion. A case study conducted by Wright, et. al. (2002) concluded that while the information about paternity came to the participant as a shock, she (the case study participant) was happy to know this information. Wright, et. al. (2002) considered the pros and cons of not disclosing the information and how this could affect every member of the family involved. The discovery of new family identity may cause responses such as sadness, lack of motivation, replaying the event, isolation, and shame (Kimble, Sripad, Fowler, & Sobolewski, 2018). As we understand the negative impact that may be had on an individual or family system when discovering

previously unknown, or previously hidden, paternity through direct-to-consumer DNA ancestry tests, the context of learning more through consumers having this experience is currently missing in the literature and may be important to understand.

Imber-Black (1998) suggests four ways in which family secrets disrupt relationships: (a) they may divide members from one another, (b) they may interrupt communication within new relationships due to receiving the message to not share family business, (c) they can inhibit development of self-identity, and (d) they may contribute to unnecessary distrust and miscommunication between family members. Disclosure of family secrets is encouraged in therapy considering the range of potentially negative emotions that may initially occur (Imber-Black, 1993, 1998). However, when a secret is known by all family members, eliminating triangulation, there is opportunity for relationships to become more authentic (Imber-Black, 1998). This authenticity can lead to increased differentiation of members, which is what Bowen's family systems theory (1978) describes as a goal for healthy families.

Imber-Black (1993) explains that secrets and shame are often connected and affect relationships. Communication may become disingenuous, distant, or even non-existent because of the desire to maintain the secret. Imber-Black (2014) also astutely posits that those who choose to keep the secret from others, about others, are doing so by independently determining what is best for that person without their knowledge or input. Imber-Black (1998) writes that secrets can be healing or harmful, can cause lengthy stressors upon relationships, or can provide answers to longstanding wonderings. Secrets, while seemingly personal, have the potential to affect entire social systems based on the behaviors that keep the secret or by their disclosure (Barnwell, 2018). Secrets in families that are authentically told and secrets that are unexpectedly or accidentally uncovered may support a family's ability to heal from the secret or experience

emotional stress from the secret (Imber-Black, 1998). The nature of why the secret was kept is an important factor to consider when an individual learns of a deep family secret (Imber-Black, 2014). Direct-to-consumer DNA ancestry testing has removed the therapeutic interaction and care that is sought to disclose this type of information and, when results are delivered through email, may contribute to family stress by exposing paternity information to all biological parties who have submitted their DNA to ancestry companies for entertainment (Kirkpatrick & Rashkin, 2016).

Secure belonging to a family, a reinforced role, is a component of developing a person's individual and social identity (Scabini & Manzi, 2011). When this is lacking or is abruptly re-defined, a person's sense of self and identity may be questioned (Scabini & Manzi, 2011). The word identity describes the self in relation to how one defines and adds meaning to their roles in family, in groups, and within society (Pasley, Petren, & Fish, 2014). Sandhu, Singh, Tung, and Kundra (2012), found that maternal attitudes toward a child are a critical component to the positive or negative identity development of children. Nduma and Jewkes (2011) found in their study that determining paternal identity helps to establish individual identity. Furthermore, they emphasized that children who do not know who their father is may experience feelings of anger, confusion, and worthlessness. Undisclosed paternity (secretive paternity) and misattributed paternity (may be a secret, may be unknown to the mother) are different yet carry similar potential for identity questioning. Draper and Ives (2009) proffer that, "not knowing one's genetic parents, and consequently not knowing one's genetic history, is often regarded as a significant harm, which can impact negatively upon an individual's sense of identity and self-worth and can leave them feeling disconnected and alone" (p. 408).

### **Recommended Further Study**

Through research studies, recommendations have been suggested for direct-to-consumer DNA ancestry testing companies regarding standardizing policies for how the tests are marketed for entertainment, clinical validity, and prediction of disease, privacy, and secondary sharing of DNA material (Covolo, et. al., 2015; Helgason & Stefansson, 2010; Laestadius, et. al., 2017). Davis (2007) makes a strong argument about increased need for consumer awareness related to direct-to-consumer ancestry/genetic testing possibly resulting in misattributed paternity results.

Koeller, et. al. (2017) suggest that future research using the consumer's voice through qualitative research studies is an area of need for this field of study. Kaufman, et. al., (2012) also conducted a quantitative study on risk and use of medical personnel subsequent to completing a direct-to-consumer DNA ancestry test. They determined that more research needs completed quantitatively and qualitatively about consumers' thoughts on risks, experiences, and how they make decisions after receiving the results. With the advent of consumer DNA ancestry tests that are so affordable, and are increasingly marketed, large databases of personal identification are being created. The American Psychological Association (APA) is asking individuals to consider what genetics and identity mean to them prior to sending DNA to an ancestry testing company in case there are surprises that are uncovered (Pappas, 2018).

Research studies and scholarly journal articles specific to unexpected paternity results from direct-to-consumer DNA ancestry tests, if they exist, are exceptionally limited. The voice of social work appears absent in the literature. Social work leaders can help promote support for this population through advocacy, education, research, policy development, and potentially, therapeutic interventions as themes emerge through qualitative inquiry. Consideration of the potential implication and disruption of families and individuals' relationships when uncovering

unexpected consumer DNA ancestry information, as well as potential trauma inherent in identity shifts, will benefit from further review and understanding.

### **Chapter 3: Methodology**

The purpose of this study was to explore the lived experience of individuals who, after completing direct-to-consumer DNA ancestry tests, learned previously unknown paternity. This research explored how an individual's identity and family relationships are affected upon receiving unexpected paternity results from a direct-to-consumer DNA ancestry test. Research in this area is sparse, especially in the context of how social workers may understand, educate, intervene, and advocate for individuals and families affected by this new phenomenon. Direct-to-consumer DNA ancestry tests are a relatively new scientific/entertainment experience advertising retail access to genetic information outside of a medical office (Allyse, et. al., 2018; Lee, 2017). Most consumers have access to these tests due to cost reduction in recent years (Allyse, et. al., 2018; Regalado, 2018). As the objective of this research was to understand the consumer's perspective, behavior, and insight through their own words (Creswell & Poth, 2017; Denzin & Lincoln, 2018; Padgett, 2016), qualitative research methods were utilized.

### **Research Design and Rationale**

Research methodology is the way in which the world is understood through scientific research processes viewed through a particular paradigm (Creswell & Poth, 2017; Guba & Lincoln, 1994; Kivunja & Kuyini, 2017). Guba and Lincoln (1994) describe four paradigms in qualitative research applicable to social sciences. Specifically, social phenomena and social problems can be described as existing within positivist (objective truths), post-positivist (objective truths and subjective realities), constructionist/interpretivist (subjective truths) paradigms, or critical theory (change through transformational truths) (Guba & Lincoln, 1994; Tekin & Kotaman, 2013). Of these four paradigms, constructionism/interpretivism describes the way in which subjective experiences define the world while remaining open to alternate realities as new information is learned (Denzin & Lincoln, 2018; Guba & Lincoln, 1994). There is no one

fixed reality that appropriately describes the reality of all within a phenomenon (Tekin & Kotaman, 2013). Qualitative research's focus within the interpretivism paradigm, expressed by constructing meaning for individuals through a particular experience (Kivunja & Kuyini, 2017; Thanh & Thanh, 2015), is the best fit to explore the impact direct-to-consumer DNA ancestry tests have had on consumers who learn new paternity information unintentionally.

While the design for this research is qualitative, the approach combined aspects of both phenomenology and grounded theory. Phenomenology, as it originated as a philosophical concept through the work of Edmund Husserl and Martin Heidegger, describes studying an individual's experiences through their own interpretation and perception of the experience (Neubauer, Witkop, & Varpio, 2019). Neubauer, et. al. (2019) describes understanding a phenomenon through individuals' descriptive experiences with the phenomenon as well as understanding how individuals interpret meaning of the phenomenon into their life. Using a phenomenological approach was chosen in order to develop meaning and understanding (Padgett, 2016) directly from the consumers' experiences related to family and individual identity as well as to advance social work advocacy and social change measures for this population of consumers.

Grounded theory, as originated by Glaser and Strauss, describes how theory can be developed through interacting with data inductively particularly when there is little known about a phenomenon (Tie, Birks, & Francis, 2019). Grounded in the data, this theory uses an iterative approach to collect and analyze data as it is gathered (Charmaz, 2014; Tie, et. al., 2019).

Utilizing aspects of grounded theory was also appropriate to this study as little is known about the phenomenon related to learning paternity through direct-to-consumer DNA ancestry tests. For this research study, parts of both phenomenological approach and grounded theory methods

were blended. Neither approach was exclusively utilized for the collection, analysis, and reporting of data.

### **Setting**

Participants in this study are members of a private Facebook support group entitled NPE Only: After the Discovery. The criteria for membership within this group includes self-reported discoveries of previously unknown relatives through the completion of a direct-to-consumer DNA ancestry test. Since the formation of this NPE Only group (September 21, 2019), they report 757 members. Prior to acceptance into this private Facebook support group, each member of the group is vetted by an NPE Only administrator who reviews a self-reported three-question survey about an individual's DNA discovery along with an agreement for confidentiality and respectful behavior within group postings. For the purposes of recruitment, the researcher contacted the founder of this group privately to request a posting of this study on the Facebook site for members to voluntarily participate if interested.

### **Sample**

Purposive sampling was the chosen format for recruiting participants due to the nature of access to the exact population related to this study and for the goal of qualitative research rigor by developing saturation (Guest, Namey, & Chen, 2020; Hennick, Kaiser, & Marconi, 2017). Saturation is defined in qualitative research as the point at which no new codes or themes are discovered or the information provided becomes redundant (Boddy, 2017; Hennick, Kaiser, & Weber, 2019). While few qualitative research authors indicate best practice for exact numbers of participants for interviews beyond saturation of findings (Boddy, 2016; Guest, et. al., 2020; Mason, 2010), a recommended number of interviews within phenomenological research studies is generally lower than those within grounded theory studies. Mason (2010) conducted a content

analysis of qualitative research dissertations and their sample sizes and discovered that phenomenological research studies had no less than five participants, while the majority were within five to twenty-five participants. According to this same study by Mason (2010), most grounded theory qualitative research dissertations conducted between twenty to thirty interviews on average. The decision to interview between ten and twenty participants was determined using phenomenological methods and grounded theory methods but was guided by saturation.

The unit of analysis included individuals within the entire membership of the NPE Only: After the Discovery Facebook group. Twenty-six members of the Facebook group initially completed the informed consent and demographics form online within the first twenty-four hours of the posting. At this point, the researcher paused further collection of participant interest. All twenty-six participants received an email to set up an interview time. Ultimately, twenty-two participants were interviewed as four of the original twenty-six did not follow-up with the researcher. The demographics of the sample are provided in the following chapter.

### **Procedure**

The invitation to participate in this research study was shared with the administrator of the Facebook NPE Only group. The administrator of the NPE Only: After the Discovery Facebook group posted the invitation onto the Facebook page with the agreement to keep it posted on the Facebook group site for one week. Everyone who was interested in participating was directed to a link to read and electronically sign an informed consent form (See Appendix E). Upon receipt of the signed informed consent form, participants were directed to complete a demographic survey (See Appendix C) that took approximately five minutes to complete. The signed consent forms and demographics data were stored electronically within Qualtrics, an online survey tool utilized by Millersville University for research. In order to determine

eligibility for this study, the researcher reviewed each consent form and the demographic information to be sure inclusion criteria was present. Upon this review, the researcher contacted each participant via their provided email address on the demographics form. Participants were contacted via email within twenty-four hours by the researcher to set up the interview at a convenient time by the participant. All participants were provided with the researcher's Millersville University email address if they had any questions or concerns about the study at any point in the process.

Data were collected through semi-structured interviews, allowing for open-ended questions for further understanding or clarification of an answer when needed. The interview data were collected using the web-based conferencing platform called ZOOM (n.d). ZOOM is an audio and visual conferencing tool with recording capabilities that can be accessed by invitation through a computer or mobile application link. ZOOM interviews can also capture visual recordings when the participants use their camera function. ZOOM was utilized for every interview with participants. While the preference would have been to meet in person for any participant who lives within 150 miles of the researcher, the COVID-19 crisis and the safety issues inherent with the pandemic prevented the researcher from meeting with any local participants in person.

While planning for each interview, the researcher emailed an interview preparation guide (See Appendix G) that included the appointment date and time with considerations for time zones across North America. The interview preparation guide provided a list of instructions to prepare for each interview with considerations for working equipment and uninterrupted privacy. Participants were able to choose to interview via a one-time computer link with or without using the camera function or by a ZOOM-provided generic telephone number to call in. No participant

utilized the telephone option. One participant opted to not use their camera during the interview. The interviews averaged 31 minutes in length.

For the researcher, each interview was held in one of three private office locations without interruption and with privacy measures in place equal to what each participant received. The semi-structured interview guide used with the participants is attached (See Appendix D). One interview session was held with each of the twenty-two participants. A blank copy of the interview guide was present for note taking and observations by the researcher during each interview. Once the interview started, the researcher read a scripted communication that was shared with each participant reminding them that the interview was being recorded, what the process of the interview would entail, how the researcher would end the interview after the last question was answered, and that each participant could expect to receive a copy of the transcribed interview when completed for their review. At the end of each interview, the researcher ended the recorded interview session online for both parties. No follow-up sessions with participants were conducted.

### **Confidentiality**

All interviews through ZOOM were audio-recorded and saved to an online cloud storage location for later transcription. ZOOM offers encryption of data recorded to the cloud as an additional security feature. Every non-public ZOOM link sent to participants was enabled with a randomly selected password in order to enter the ZOOM meeting. A virtual waiting room was enabled for anyone waiting to enter the ZOOM meeting with a message to please wait until the host (the researcher) allowed them to enter the virtual room.

Participants' identities were renamed using names of First Ladies and former United States Presidents in order to protect their anonymity. Any names of additional family disclosed

during the interviews were removed to protect their identities as well. The primary researcher is the only individual who maintains the names of participants. The information obtained from the informed consent will be kept on Qualtrics and the recorded audio interviews will be kept on password protected secured servers at Millersville University. The transcribed non-identifying interviews were uploaded to NVivo and are kept on a password-protected computer in the primary researcher's office. The transcribed documents are saved on a flash drive and any handwritten notes or documentation provided are secured in a locked filing cabinet in the primary researcher's office. All transcribed audio recordings, written notes, and interview transcriptions will be destroyed after three years in accordance with Institutional Review Board (IRB) regulations.

### **Data Analysis**

In order to begin answering the research questions that guided this research, the researcher engaged with the interviews over multiple, organized reviews. ZOOM provided an automatic transcription of the interview that the researcher utilized. First, the researcher reviewed each of the twenty-two ZOOM-provided transcripts word-for-word for complete accuracy. Second, the researcher listened to the interviews again with the corrected transcript. Third, the researcher reviewed each interview a subsequent time while conducting a first cycle of initial coding. The researcher conducted the same process with all twenty-two interviews. After the initial round of coding, the researcher returned the interview transcript to each participant for member checking via their provided email account. Engaging in this type of member checking provided an opportunity for participants to review their narrative and engage with the researcher for corrections if needed to enhance trustworthiness of the data (Birt, Scott, Cavers, Campbell, & Walter, 2019).

The researcher transcribed the interview data onto a Word document before uploading to QSR's International's NVivo 12 software (2019). NVivo 12 is a Qualitative Data Analysis Software (QDAS) tool utilized for organizing large volumes of collected qualitative data. The transcription process offered the researcher an additional opportunity to review the data collected prior to uploading stored these transcriptions in NVivo. The organization of vast amounts of data assists the researcher in the analysis of the data (Leech & Onwuegbuzi, 2011). Leech and Onwuegbuzi (2011) state that the software used for organizing, storing, and sorting data, in this case NVivo12, only assists with managing the data. The data will be fully analyzed only by the researcher for further development of meaning (Leech & Onwuegbuzi, 2011). NVivo 12 software was used to store the researcher-created codes, analytic memos, and themes.

### ***Coding***

Codes within qualitative research are words or phrases that provide a summation or attribute describing an experience (Saldaña, 2016). The accumulation of meaningful codes in the research helps to guide the emergent patterns and themes within the data (Saldaña, 2016). Coding is also considered the link between the collection of data and the further development of meaning within the data conducted by the researcher (Charmaz, 2014; Tie, Birks, & Francis, 2019). Grounded theory's open, axial, and focused coding processes were utilized. Although most codes developed as they emerged from the data throughout the first and second cycles of coding, a few codes were developed a priori and aligned with the semi-structured interview guide questions. Participant responses to the interview questions determined the unit of meaning. Some of the responses were single words, phrases, or sentences while others were entire paragraphs in length. The inconsistency in the length is due to the researcher's decision to maintain the full intended meaning of the participants' response to each question asked or

statement(s) provided. A code book was developed and refined throughout the coding process (Appendix F).

An added component of establishing trustworthiness in qualitative research is inter-coder reliability (ICR). ICR is a percentage of agreement between different individuals coding the same data (O'Connor & Joffe, 2020). An IRB-approved independent party who used the same version of NVivo12 agreed to code six files (27% of the total files in this study) using the coding frame developed by the researcher. A norming session was conducted between the researcher and the independent party one time over ZOOM to review the codes used for this study. The literature suggests that a sample of 10-25% of the dataset is acceptable for conducting the intercoder reliability process (Campbell, Quincy, Osserman, & Pedersen, 2013). Agreements can vary from minimum 80% agreement (Wilson-Lopez, Minichiello, & Green, 2019) to within a range of 74-94% agreement in order to be considered acceptable (Campbell, et. al., 2013). The ICR was calculated at 98.1% agreement, well within either standard.

### ***Memos***

Analytic memo writing assists the researcher in the ongoing reflection of the content of the data during the coding process (Saldaña, 2016). Researchers use memo writing in qualitative research to note thoughts, questions, or ideas about the emerging data (Charmaz, 2014). Analytic memo writing also promotes researcher reflexivity (Saldaña, 2016). While reviewing the data over the multiple passes, the researcher utilized the annotation tool within NVivo 12 for frequent reflections about the data. These annotations were kept within NVivo 12 and were reviewed during data analysis for deeper understanding of content and context as the codes and themes emerged. Reflective memos encourage “critical thinking” to identify assumptions and potential bias (Rogers, 2018, p. 890). The memos and observation notes taken during the interviews were

reviewed for researcher reflection of thoughts, feelings, and potential biases throughout the analysis process.

### **Researcher's Statement of Reflexivity**

The role of the researcher is to accurately gather, and subsequently protect personal thoughts and emotions about a specific topic from participants (Sutton & Austin, 2015).

Reflexivity is used to ensure rigor and ethics in qualitative research (Berger, 2015). A researcher who is deliberately reflexive when collecting and analyzing data can use that awareness of self as an additional tool for understanding how meaning is developed from the process in addition to the collected data (Berger, 2015; Probst, 2015; Tracy, 2010). Patton (2015) posits that the researcher's observation of self within the data analysis process is obligatory. As a novice researcher, minimizing bias is essential for this study's validity. The researcher's knowledge of the Facebook support groups and personal experience with completing a DNA ancestry test is relevant for this research and it is acknowledged that my position as a Caucasian, middle-class, female aligns with the demographic of individuals who complete direct-to-consumer DNA ancestry tests.

### **Ethical Considerations**

This exploratory research study was approved by the Millersville University Institutional Review Board (IRB). The researcher followed all guidelines for approval through the Millersville University Institutional Review Board (IRB) for the maintenance of confidentiality procedures for all participants. The researcher completed training through the Collaborative Institutional Training Initiative (CITI Program) for research with human subjects as well as additional ethics training.

Because this research sought assistance from members of Facebook, the researcher reviewed the recommended ethical considerations provided by the Association of Internet Researchers (AoIR). Facebook was used only to provide invitational access to the private group of individuals who then voluntarily reached out to the researcher through the consent and demographics form link. Additional data provided by research participants on Facebook was not utilized, nor searched for by the researcher.

## **Chapter Four: Research Findings**

This chapter presents the research findings. Several themes emerged from the interviews.

The themes are discussed and organized by the four research questions:

1. How does the unexpected paternity information affect an individual's understanding of their family of origin?
2. How does the unexpected paternity information affect an individual's relationship with their family of origin?
3. How does the unexpected paternity information affect an individual's identity?
4. How do individuals receive support during this experience?

The purpose of this research study is to explore how learning of unexpected paternity through direct-to-consumer DNA ancestry tests affects an individual. As there is little research in this area to date, this study explores the impact on family relationships and personal identity on the individual. A semi-structured interview was conducted with twenty-two participants across North America who responded to an invitation to participate in the research through a private Facebook group entitled NPE Only: After the Discovery. Through data analysis, common themes emerged from the participants' descriptions of their experiences. The data were collected from the semi-structured interviews and analyzed into themes and sub-themes related to the experience of discovering paternity through direct-to-consumer DNA ancestry tests through the four research questions. The themes and sub-themes are presented in this chapter using the participants' own words to support the findings.

### **Participant Demographics**

Twenty-two interviews were conducted during the Fall of 2020. Each interview was conducted through audio and video-recorded ZOOM sessions due to the Covid-19 pandemic which prohibited in-person interviews. To protect participant and family member confidentiality, the research assigned pseudonyms using the names of United States First Ladies and Presidents. The length of the interviews varied from 13 minutes to 80 minutes with a mean interview time of 31 minutes. The participants were mostly female (n=20, 91%) and two were male. Participant ages ranged between 33 years and 63 years with a mean age of 50 years. All twenty-two participants discovered paternity through direct-to-consumer DNA ancestry tests. Of the twenty-two, two suspected their paternity may be in question prior to the test. One participant knew her birth certificate father was not her biological father, but the ancestry DNA test revealed new and unexpected paternity results.

Table 4.1 details the demographics of the study participants. It includes their current place of residence, their gender, age range, highest educational degree, ethnic identification, length of membership in NPE Only: After the Discovery Facebook group, and the direct-to-consumer ancestry test(s) used.

Table 4.1  
*Participant Demographics*

Characteristic	Category	N	%
Current Residence	Canada	2	9.1
	Connecticut	1	4.5
	Florida	1	4.5
	Georgia	1	4.5
	Indiana	1	4.5
	Iowa	1	4.5
	Louisiana	1	4.5
	Massachusetts	1	4.5
	Minnesota	1	4.5
	New Jersey	3	13.7
	New York	2	9.1
	North Carolina	1	4.5
	Oregon	1	4.5

	Texas	3	13.7
	Washington	1	4.5
Gender	Woman	20	91.0
	Man	2	9.0
Age Range	30-39 years	3	13.7
	40-49 years	7	31.9
	50-59 years	9	41.0
	60-69 years	3	13.7
Highest Educational Degree	High School	2	9.1
	Associate Degree	2	9.1
	Bachelor's degree	8	36.4
	Master's Degree	3	13.7
	Doctorate Degree	1	4.5
	Trade School	1	4.5
	Some college	5	22.8
Ethnic Identification	Caucasian	20	91.0
	Latino/Hispanic	2	9.0
Member NPE Only Group	Less than 1 month	2	9.0
	1 month to 6 months	5	22.8
	More than 6 months	15	68.3
Ancestry Test Used	Ancestry	9	41.0
	23andMe	1	4.5
	Both Ancestry and 23andMe	12	54.6

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### Response to the Research Questions

#### How Does the Unexpected Paternity Information Affect an Individual's Understanding of their Family of Origin?

This research question explores how unexpected paternity affects an individual's understanding of their family of origin. Participants were asked what they were expecting to learn when they received their ancestry results, to describe their immediate reactions to the paternity information and their experience with family secrets. The themes that emerged through

these questions included recreational curiosity, feeling shocked about the paternity information, and family secrets. There were two sub-themes of infidelity and something was “off.”

### ***Recreational Curiosity***

The majority (n=18, 81%) of the participants took the ancestry tests for recreational genealogical interest, one was looking solely for medical information, and three indicated interest in confirming paternity due to direct or indirect suspicions of paternity. For the majority above, they were interested in discovering, exploring or confirming their ethnicity with what family had shared in the past, or discovering the ethnic background of family members due to adoption or other family information gaps. The information that participants expected when the ancestry results arrived aligned with the original reasons for taking the test. Twenty-one participants indicated that learning about their ethnicity and genealogic background is primarily what they expected to discover. As Mary stated, “So, so when I say curiosity, curiosity of my heritage. Not curiosity of who my grandparents or parents were or anything like that. So just our, our, our makeup, you know, heritage makeup.” And Eliza similarly shared,

I thought I would learn just more about my heritage, like I'd always heard I was Irish and German and, but I'd hear about like Swedish too. So, I was wondering you know, how much of each of those I would be. I don't think I was really expecting too much beyond that.

### ***Feeling Shocked About the Paternity Information***

All twenty-two (100%) participants described a strong emotional response, twelve used the word “shock” to describe learning the unexpected paternity information. The participants also described feeling emotions of sadness, confusion, panic, denial, and disbelief after the paternity information is received. Some described trying to make sense of the new information without having any living family members with whom to share any their story. Table 4.2 illustrates each participant's adjectives and phrases that described their initial experience.

Table 4.2  
*Words and phrases used to describe the initial discovery of paternity*

Participant	Initial phrase of discovery experience
Abigail	“so I wasn’t a hundred percent <b>shocked</b> ”
Andrew	“and it was <b>shock</b> and happy surprise”
Angelica	“I had a physical effect. My heart started racing.”
Anna	“um, <b>shock</b> ”
Bess	“ <b>shock</b> , understanding”
Caroline	“it blew my mind. So that was a huge <b>shock</b> to me.”
Dolley	“ <b>shocked</b> and very sad about it”
Eliza	“my immediate reaction was intense <b>shock</b> ”
Elizabeth	“I was in <b>shock</b> and disbelief”
Ellen	“overwhelming”
Grace	“it was like a process”
Harriet	“my heart sank”
Helen	“this cannot seriously be happening”
Jane	“panic, the <b>shock</b> ”
Julia	“just crying, pretty much the whole day”
Letitia	“Denial, yeah, I, I, I couldn’t believe it.”
Louisa	“ <b>Shock</b> . Um, absolute <b>shock</b> .”
Lucy	“I’ll be a son of a bitch”
Martha	“I wasn’t fully surprised yet part of me was”
Mary	“surprise and confusion”
Rachel	“I, I was <b>shocked</b> I think.”
William	“So I kind of was <b>shocked</b> .”

*Family Secrets*

Several participants described their paternity as a family secret. Some discovered after the paternity information came out that others in the family knew or highly suspected but did not share. Bess shared about her experience with family secrets,

“Before this, I didn’t know there were any. Now I found out when, once I found out who my real father was, my biological father, I found out that my mother knew, my birth certificate father knew, my biological father knew, my mother’s parents knew, my father’s parents knew, my birth certificate father’s parents knew. Everybody knew but me.”

Andrew, who always suspected that his birth certificate father was not his biological father, described his mother keeping the secret to this day,

“I would say it’s kind of funny how people thought they’d be able to take some of these secrets to the grave with them in a pre-DNA world. And my mother held to this one steadfastly, she told everyone that the gentleman who raised me was, was my father and no one really believed it. But she told me that.”

While Andrew has not had contact with his long-divorced parents in many years, he described the family secret of his paternity as both worrisome and gratifying. He shared,

“So, there is a part of me, he knows now and, and my mother knows now and I was kind of worried that he was going to seek her out and rekindle this argument that ultimately broke them up. And so, there’s a little guilt inside of me about that, even though the two of them were terrible parents and largely terrible people bankrupt of anything that resembled a moral compass. And yet, I guess there’s, uh, I feel, I feel guilty a little bit about stirring this all up but I’m gratified they both know.”

Eight participants shared their experience with information they discovered about additional family members. The majority of these situations referenced family members or children placed for adoption as a previously kept secret. Several participants explained that part of the reason they chose to complete a DNA ancestry test had to do with learning about these types of family histories. As Harriet shared when prompted why she took the test,

My daughter actually took it about five or six years ago because her father was adopted and he hasn’t, he, he decided, he decided that he wasn’t going to pursue you know, finding that information out so she was badgering him for years. And the finally, she said, Mom, just please take the test, what the heck, so.

The current ancestry results also disclosed additional paternity secrets in Helen's family. While she grew up aware of one of her birth certificate father's estranged out-of-wedlock children, the ancestry results also uncovered this, "my dad (birth certificate father) had another woman pregnant at the same time, which we all knew about. Now we find out he had a third woman getting pregnant, exactly when I was being born."

### ***Infidelity***

Secrets regarding relationship infidelity were mentioned by participants throughout the interviews. Several participants learned that they were conceived while their mothers were married to or in a relationship with who would become the birth certificate father. As Letitia shared, "Um, yeah, I, I never imagined that my mom had an affair, that never entered my mind. Um, it was denial, yeah. I, I, I couldn't believe it." In Rachel's situation, she and her full, biological brother were conceived during a long-term affair her mother had. In her words,

I can't help but look back and think, hmmm. My mom was having an affair and it was a long-term affair and as a result of that affair, my birth certificate father has no biological children and he had to have suspected something and maybe that had some underlying cause of why they moved. Maybe my mother ran into her former lover and it worried my dad and he gave her an ultimatum, either you move away and separate completely, or we're done, or something like that. It just, just seems fishy now looking back in hindsight.

### ***Something was "Off"***

Eight (36%) participants always felt like something was "off" growing up but could not pinpoint it until the DNA ancestry test uncovered the unexpected paternity. Letitia said it directly, "I've always known something was off." Lucy's experience was similar growing up. She shared, "I had always, I always knew something was different growing up. Always." The paternity information helped the participants to understand why they grew up feeling like something was "off."

## **How Does the Unexpected Paternity Information Affect an Individual's Relationship with their Family of Origin?**

This research question explored how unexpected paternity information affected an individual's relationship with their family of origin. The family of origin is defined as the members of the family system that the individual grew up with (e.g. mother, birth certificate father, siblings). Participants were asked to describe their relationship with their family of origin before the DNA test and to describe how the relationships changed since the paternity information was learned. The themes within this section include relationship with mother, relationship with birth certificate father, relationship with siblings, anger, and now things make sense.

### ***Relationship with Mother***

Relationship with mothers was the most frequently noted reference in this study. Participants used many words to describe their mothers or the relationship with their mothers such as "narcissist," "loving," "difficult," "strained," "controlling," "great," "rocky," "close," "good," "not great," "rough," "no affection," "abusive," "clashed," and "superficial." Many describe having a better understanding of their mother since the discovery, but this understanding has not necessarily translated to having a better relationship.

Before the DNA ancestry test, participants described a range of relationships with their mothers. Two participants described having no contact with their mothers before the ancestry test as Darcy shared, "well, I hadn't talked to my biological, biological mother in ten years. She's not the easiest person to get along with." Seven reported having a good relationship as Angelica shared, "my mother I have a very loving relationship with." Four reported ambivalence growing up with mother. Jane shared her experience with her mom, "my relationship with my mom was

very rocky. I spent most of our relationship trying to figure out what she needed from me so that I could make her happy.” Nine reported having a difficult relationship with their mothers.

Louisa, as an only child, shared, “I never understood why she didn’t like me. I couldn’t, I couldn’t get it.” Five participants’ mothers were deceased at the time of the paternity discovery.

After the DNA ancestry test disclosed participants’ paternity, their relationship with their mother did not change for eight participants. For five participants, their relationship with their mother is better than before they took the ancestry test. Martha described her relationship like this, “I would say today, um, we’re probably better than we’ve ever been, and I bring it up whenever I want to bring it up.” Letitia said it like this, “I, I, not really anything different with my mom, really, we’re still close.” Two participants still have no contact with their mother by their choice. Seven participants reported that their relationship with their mother is worse now since the ancestry test. William had a very strong reaction from his mother when he shared the paternity information with her. In his words,

I said, oh, hey, you know, wanted to let you know I got my DNA results and what do you think it says? And she said, it probably says you’re a mutt, and I go, no, it says, I’m Irish. And I’m not Italian. And I go, what do you have to say about that? And her text response was, don’t ever fucking talk to me ever again.

The impact of any paternity lies told by mothers also negatively influenced relationships with their mother as some of the participants described. Angelica described her relationship with her mother since the discovery this way,

Um, a little unsettled at times with my mom, but we’ve come a long way. I mean, it’s been quite a number of years now. She’s still living. There was never like a total, like we, you know, cut our ties at all, but it was, it was really rough, yeah, for a while there. She, she lied, you know, she lied for a long time.

Helen remained close with her mother despite being sexually abused by her birth certificate father (her mother is aware of this and remains married to this man). However, the paternity discovery changed the relationship. As she shared,

When you realize that you literally have been lied to by one of the people that is the closest person to you in your whole life, my mother, my mother and I were the best of friends until this took place. Irregardless (sic) of the abuse, she was still, we were still very, very close.

Several participants described having compassion for their mothers as they navigate this discovery. Eliza shared:

So, that's kind of in some way like, gives me more compassion for her like, feels like I know her better because I always felt like there was just things that she didn't want to, that she was hiding. So, it feels like I know her a little bit more. We've gotten in the worst fight we've ever been in, since the discovery, which is really painful. Um, because she was being very defensive. But I think in some, some sense, I think there's more potential for the relationship now because we're being more honest with each other.

Two of the living mothers also were unaware of the paternity and found out when the participant shared it with them. Participants described difficulty in the relationship that occurred when mothers denied the information or refused to discuss it when asked by the participant. The relationships that have remained good were described as more open in communication and healthy since childhood for the participant as Elizabeth shared,

My mom was, has always been very, very honest with me and like I told you, I know, I knew that she was dating two men. When I told her I found this out, she was very supportive of me.

### ***Relationship with Birth Certificate Father***

Participants shared comments about family of origin, often including their dad, now referred to as birth certificate father. For eleven of the participants, their birth certificate father is deceased. Three participants shared that they were primarily raised by their birth certificate fathers. Five participants described having good relationships with their birth certificate fathers

using words like “close” and “connected.” For Letitia, whose birth certificate father is deceased, the strong connection to her birth certificate father, with the new paternity information, has affected her children. She shared,

The worst part was probably, um, telling my kids because they adored my dad who raised me. He was an amazing person. And they were so proud to be a part of him and it broke their hearts that they aren't and now those bloodlines are changed forever. That's probably the hardest part, not being a part of my dad who was so great.

However, seventeen of the participants described never being close with their birth certificate father or not having a good relationship despite trying. Eliza's commented

I always felt like we don't have a good relationship, we're not that close and maybe I should be doing something more to try to make it, make it work. Should I be putting in more effort? How come he's not putting in more effort? Like just thinking like maybe one day, if we do the right things, like it's going to click.

Rejection was a theme that emerged from participants' descriptions within family of origin.

When that code was examined, six participants shared feeling rejection directly from their parents in the family of origin. For four of these six participants, the rejection came from the birth certificate father. Bess shared that she could never understand why her birth certificate father never wanted to have a relationship with her despite her efforts,

When I got older and could drive, I would go to his house and try to spend time with him and try to make a relationship. And still we never became close. But I would still go for the, I would go for the holidays at his house by myself once I could drive and he never was, like he would hang out with all the rest of the family when we were at ga-, gatherings, but never really with me, like never really acted like a dad.

Bess shared that the paternity results helped her to understand that he knew he was not her biological father and took this secret to the grave. As she says, “he could have just walked away, but he didn't.”

### ***Relationship with Siblings***

Comments about siblings within the family of origin were less frequent than those about mother or birth certificate father. This could be because there was no specific prompt offered about siblings. Many participants separated brother and sister into stepsibling labels or half-sibling labels. One participant shared that she still has a full biological brother after the discovery because their mother had two children during her long-term affair with their biological father. Of the twenty-two participants, sixteen shared specific information related to their siblings. Fourteen of the sixteen participants shared that there has been no change to the sibling relationship since the paternity discovery. Two participants explained how “supportive” their family of origin siblings have been since the discovery. However, one participant shared that her siblings “avoid” her more now since the paternity information was revealed and another said the relationship with her half-sibling is “done” after they fought about the DNA results.

### *Anger*

Anger was identified by thirteen participants when describing their relationship with family after the paternity discovery. “Anger” was the second most common emotion shared when describing the unexpected paternity. Specific words used for anger descriptions included, “mad,” “hurt,” “pissed,” “resentment,” “furious,” “livid,” “rage,” “betrayal,” and “abandoned.” Anger was primarily used to describe feelings toward family of origin members (mother, birth certificate fathers and others in the family who may have known about the paternity). Elizabeth shared her anger:

And it’s, um, as people started coming to me and telling me, oh no, I knew that he was your dad, or I suspected that he was your dad. Then I was, I found myself really angry with them because then I felt like now the burden is on me to forgive you. If you are going to tell me this, why didn’t you tell me this, you know, 20 years ago? 30 years ago? Why are you telling me now? That just makes you feel better. You’re making me feel worse. You know, like, just to know that people all around me knew this and never told me. It was, it was frustrating. And I was so, I was so angry. There was a lot, a lot of anger. It took a toll on my marriage, my parenting.

For two participants, anger described feelings toward newly discovered family members who have thus far refused to have a relationship with them. For Ellen, she is angry that she is “stuck” with her ailing birth certificate father and wished that she had known prior to his illness. In her words,

I think, I think that’s probably the only thing that makes me angry about this whole thing is if I had known before he got sick, I could have, I could have jetted out of here you know, and, and here I am. That’s all I’ve ever done is take care of everybody else.

### *Now Things Make Sense*

The final theme that emerged within relationship with family of origin evolved around now things make sense. Participants described the connection between childhood experiences and memories after receiving the new paternity information. Ten participants described, retrospectively, that with the newly learned paternity information, now things from childhood make sense to them. William offered this description,

And so it just kind of like, all kind of came together and I go, you know, it just makes sense. And it makes sense for my mom’s violent outbursts sometimes toward me in the sense of, you know, she probably looked at me and she wanted a kid, but at the same time, I’m like, not any reflection of my dad and I look like the other guy, and that probably pisses her off that I look like him, and that is, causes grief.

In William’s circumstances, he shared that he now believes his parents’ marital conflicts were directly a result of his birth certificate father questioning his mother about William’s paternity.

Participants described how having the new paternity information made memories in their childhood make sense now. They described this as a better understanding of how they felt they fit in with their family of origin or why they were treated the way that they were growing up.

Harriet described her experience like this,

And my father who raised me when he would fight with my mother, he would indicate, he would, they would, they would fight and I would come up and multiple times he had said that I wasn’t his. So, it was something that was always in my head. My mother never

confirmed it. As I got older, I would ask her and she would say no, no, no. You know what I mean? But I was always different. And now when people find out this and they see me with my siblings growing up, they say, now it makes sense. Now it makes sense. And I wonder if everybody kind of was in that position where not his has come to light, now it makes sense.

### **How Does the Unexpected Paternity Information Affect an Individual's Identity?**

Participants were directly asked if they believe their identity has changed as a result of learning about their biological paternity results through a direct-to-consumer DNA ancestry test and if so, how. Additionally, participants were asked to describe their relationship with new family members, the best and most challenging parts of their experience, and if they resemble anyone in their new family members. The themes from this section include change to personal identity, resemblance to new family, and relationship with new family. Several sub-themes emerged related to ethnicity shifts, health information, and rejection.

#### ***Change to Personal Identity***

Seventeen participants stated that they believe their personal identity has changed, four said their identity did not change and one participant was unsure and answered yes and no to personal identity change. For the four who said their personal identity did not change, they described being the same person with the addition of knowing more information about themselves. Ellen shared,

I would say my personal identity, I think I'm the same person. Um, I think, like, I have a more interesting life story now and I have like new aspects of maybe like, why I am the way I am to explore that are interesting to me. But, like, who I am hasn't changed at all.

For those who said yes, that their identity has changed since the paternity information, they explained how in the follow-up question. Six participants said they feel more settled with who they are now. Jane explained it this way,

I definitely changed. I feel like I finally belong. I spent my whole life being so different. Yeah, I think I'm a lot more settled, obviously I'm crying because I'm talking about it,

but I feel my anxiety is a lot less. I don't spend so much time wondering why I'm so different and how can I change to fit in.

Andrew described his experience with personal identity like this,

My personal identity? I'd say, (pause) probably yes, but not in the way that I can describe. It, it's been comforting to know what my story is and where it began. It was a bit of a revelation to find out that I'm, in fact, half Italian where I was raised as, as Puerto Rican. You know, there's, there's an old saying that a tree can't stand without its roots and I just find comfort in the fact that I found mine.

Six others responded that they feel they are not the same person any longer. Helen's experience was shared like this,

Like, you feel like you're going crazy because you're like, I'm still the same person, but, but we all have that identity. And that identity that we think we know who we are is not the identity that we have anymore, if that makes sense.

Three shared that they felt like they lost a part of themselves. Dolley, when asked if her personal identity changed, shared,

Um, I would say yes. And I guess it's losing that one part of my family. I feel like I lost them a little bit. And I think it's probably maybe not as difficult for me because my dad [birth certificate father] isn't with us today, so I don't have to worry about am I going to tell him or not tell him and how he's going to react. But I feel like I've, I've lost a big chunk of that part of my, of myself, you know, and us, that's probably the biggest impact for me, so.

and the final two shared a change primarily within their ethnicity. William, who was raised in an Italian home and has an Italian name but learned through the test that he has zero Italian heritage, shared, "I was brought up with this whole Ital-, Italian identity that you know, I named my, my, my son and my daughter Italian names."

### ***Ethnicity Shifts***

A sub-theme that emerged from the participants was ethnicity shifts. Ethnicity shifts as a result of the unexpected paternity information were mentioned by just under half of the participants. Ten participants experienced shifts in their ethnicity due to their ancestry DNA

results. For two of these participants, the difficulties of continuing to live within the culture they were raised were shared. For example, William again shared, “I tell you, the first time I cooked an Italian meal after I found out was the hardest thing ever. I felt like, here I am cooking a meal of a culture that I no longer belong to.” And Lucy had a similar experience,

As I said, dad was Syrian. We grew up with much of that culture incorporated into our lives, especially when, when dad and mom were still together. So, a lot of the food and in that kind of stuff. Since the discovery, I’ve often felt like a fraud for continuing to like those foods, for continuing down that road.

And for Ellen, who was raised in a Hispanic household, speaks fluent Spanish, and through her ancestry results learned, “I don’t even have enough Native American or Hispanic, whatever it’s called to technically claim Hispanic.” She also shared that her ancestry results indicated that she is European, specifically English and Scottish. In her words, “I kind of feel like I don’t fit into those ethnicities, like that’s not, I don’t know, um, I don’t grasp them.” In addition to the new paternity information, another participant, Angelica, also had an unexpected ethnic shift. She shared,

We have to be so sensitive to the needs of people whose ethnicity has changed. The cultural impact of that is so deep, you know, that, for me, I mean, I, I didn’t, you know, as Jewish, I came up 51% Jewish. I had no idea.

### ***Health Information***

Another sub-theme that emerged had to do with learning accurate health history because of the new DNA information. Nine participants discussed seeking out medical information, getting preventative care for newly discovered medical information, or learning new medical information that relieved them of previous health concerns. Andrew learned that on his paternal side, his biological father and a half-brother died from heart issues. “I went to get a scan, just to make sure everything was okay, and everything is fine but you know, I had very little, um, very little medical information to go on for half of my DNA.” Four others described having medical

diagnoses that were not present within their family of origin. Grace shared her experience although she is still working to determine her paternal family health history, “the health component, that’s really frustrating. So not having that identity.” Grace shared that she is working hard to understand the health concerns of her paternal side to explain some of her rare medical conditions of late.

### ***Resemblance to Family***

All twenty-two participants were asked if they resemble anyone in their new family. The experience of meeting new relatives, seeing photos of family, and receiving feedback on specific physical and personality features was shared by the majority of the participants when discussing resemblance to new family. Twenty participants described looking like their new biological paternal side using words like, “twin,” “unsettling yet comforting,” “uncanny,” “surreal,” “stunning,” “staggering,” “identical,” and “spitting image.” Many referenced their physical body shapes now explained due to the new paternity information and eight participants shared that their children also resemble the new paternal side of the family. Anna shared this about herself and her son,

It was, she brought out pictures of him when he was a baby and all the way up, and, and four cousins and one of them looks exactly like me, and that was the most emotional thing, that is finally having someone that I look like, and my son who’s 26 looks exactly like my, my father. And they all said even his mannerisms are him.

References to resemblance were the fourth highest coded theme after relationship with mother, relationship with new family, and birth certificate father. Resemblance was often mentioned by participants prior to this question being directly asked when describing their family of origin. In these cases, participants described that they lacked resemblance and/or lacked similar personality traits to the family of origin. Elizabeth, upon meeting her new family, explained it this way,

I don't know how to explain the feeling of, of seeing people with, people that look like me for the first time ever. I don't look like my maternal family. And I've never, I've always been the oddball. And that's because I look like my paternal family. And when I met them, just like to, it's like looking in a mirror. I just saw myself in my aunt, and I see pictures of my grandmother that I unfortunately never got to meet, but she's like my twin. It's crazy.

Andrew described his experience with resemblance in the family of origin (mother and birth certificate father) like this,

She was five foot two and the man that raised me was five foot three. And I'm six four. So as I got older, I began to resemble a great dane in a litter of chihuahuas. It was just, it was incredible. I didn't look like anybody there. And I was also a very different child.

Continuing his story through meeting his new paternal half-brothers,

I'm the spitting image of my father, my, my biological father, which is one of the reasons why they were, my half-brothers, were so convinced that, uh, I was, in fact, their half-brother. That I was a product from this union. Also, further biological matches on my father's side bear this out so it was easy for them to believe I was a brother because I so resemble their dad. Everyone says so.

Resemblance was also noted with personality similarities. Andrew's story described this as he described having different interests than his family of origin.

I, uh, I always had an aptitude for music, one that the family of origin I was raised with couldn't understand and every Wednesday night I play in a band with these guys [his new half-brothers] now and it's just, uh, it's just been an incredible blessing.

### ***Relationship with New Family***

At the time of the interviews, twenty-one of the twenty-two participants reported contact with their new paternal family. Six of the twenty-two participants had met their biological father. Two others have yet to meet but have spoken on the phone and hope to meet after the pandemic ends. One participant believes her father is alive and elderly but has no paternal familial

confirmation yet. Another participant has yet to locate her biological father's family, but her searching has gotten her very close to figuring out who it is. Twelve participants' fathers are deceased with Jane's biological father dying one week after Jane reached out to a paternal aunt. She was never able to meet him but has met several of her aunts who have shared many stories with her about her biological father who never had any other children and as the aunts described to her, he never knew she existed.

The impact of meeting new family has been positive for most of participants. Rachel and her full brother have spent a lot of time with their new half-sister. As she shared,

It's been worth all the hurt and the heartache and the pain and the bad stuff, just to be able to have the positive with her (new half-sister) and my cousin and getting to hear my father's voice has been amazing too. I still hope one day we can meet face to face that he still likes me then too.

Letitia described her meeting with her biological father like this,

It was literally like somebody took the final puzzle piece and put, put the puzzle together and put that last piece in the puzzle, that's how it felt meeting him I was like, this is my people. This is where my personality comes from.

Caroline's experienced growing up in a home with her mother and half-sisters and wondering why her father had no relationship with her. As it turned out, the man her mother thought was Caroline's biological father, was, in fact, not her father. The results of the ancestry DNA test provided another name. After years of feeling rejected by the wrong biological father, she shared the acceptance she has with her actual biological father,

Um, so we spoke on the phone that first night for two hours and it blew me away because I had spent pretty much the last twenty years of my life thinking that my biological father wanted nothing to do with me. And this man was so open and honest and welcoming, and he had me, come to find out he hasn't even logged into Ancestry to verify that what I was saying was, in fact, true...but the next day when, uh, he called and we spoke, he said, I just need you to know that had I known about you I would have done absolutely everything in my power to have been a part of your life.

While most participants described their new paternal contacts as the happy beginnings of new relationships and of increased self-understanding, not all participants described happy endings. For two participants, meeting new family has less positive. Abigail and Mary described not feeling connected to their new families and are considering pulling away from them. As Abigail shared,

I don't really have any feelings for him. You know, I wish I did. But I don't. I tried, but it's just not there. It's just and it's just so awkward. I mean, he had no idea I existed. It was the product of a one-night stand. But I try. I mean, he calls every week, but it's just so awkward. And you just can't, um, pretend. I know. I'm luckier than most that he accepted me. And I don't know what I was expecting. And at first, I was like, oh, you know, I haven't had a dad in so long and now I have a dad, but it hasn't worked out that way for me.

In Mary's case, she is only in contact with one half-sibling who is skeptical of Mary's intentions. Mary described that in all the ways she has tried to work with her new half-sibling to get more answers related to pictures, stories, and health information, the half-sibling's life circumstances are too much "drama" for what Mary wants in her life at this point.

### ***Rejection***

Rejection was discussed by participants within their family of origin and also with their new family. With new family, three participants shared their fear of rejection and five shared experiences with actual rejection. For Bess it was described as more complicated because new paternal cousins have accepted her, but her biological father and new half-siblings have not. In her words,

It's just nice that the cousins are so welcoming because my brother and my sister and my dad are not so. My biological father supposedly was told about me when I was a toddler. Who knows, who can believe what my mother says. And he has rejected me and that's pretty depressing.

Martha knew her paternal father growing up as a family friend, and rejection by him was direct as she described,

Like how can someone, you know, look at this little baby and he saw me until I was eight years old, and then just, you know, continually walk away and not, not care and not want, you know to know. The last communication I had with him when he discovered that I have emailed them (the half-siblings) was, I have no use for you and I probably never will.

For the three participants who described fear of rejection from the new family, they identified three different reasons. For Caroline, she expected it, as she was “used to” rejection by the father she believed she had growing up. For Eliza, her fear of rejection is a worry that the new family will not like her. She described it this way,

The other part is the fear of rejection with my new family members and the ups and downs around that. So like, at first, my new brothers were really nice to me and like, texting me and wanting to hang out and then I just felt like there was this huge switch and they haven’t been mean but I feel like they’re just always nice to meet you for a few weeks, that was cool. And now, maybe, I don’t know, maybe we’ll never talk again. Um, it feels like you’re dating ten people at once and you’re putting yourself out there and then it feels bad if they don’t reciprocate the way you want.

And for Grace who has yet to meet her biological family, her fear of rejection was described in these words:

I don’t know if it’s fear of rejection or, you know, fear of rejection maybe or feeling like I’m stuck with that family again [her family of origin].

### **How Do Individuals Receive Support During This Experience?**

Participants were asked how they sought support throughout this experience. Specifically, they were asked directly how they sought support, how they located the online support group, the best part of belonging to the online group. They were also asked what advice they would provide to others taking a DNA ancestry test and if participants would take the test again knowing what

they know now. The themes that emerged include online group support, navigating this experience, mental health counseling preparation, healing through helping, and advising others.

### ***Online Support Group***

Ten participants shared that they received emotional support from immediate family (significant others, half siblings, adult children, and a mother) upon the paternity discovery. However, several participants described that sharing their story in a private, members-only group has been their primary support on an ongoing basis. As Mary shared that her “normal support system is not sufficient” to provide her the emotional supports that she needs. Locating the NPE Only: After the Discovery group on Facebook was discovered most of the time by internet searching. Participants described joining one of several NPE Facebook groups and then having similar groups recommended to them. The majority of participants shared that they participate in several NPE groups.

Participants described the group using words and phrases like, “great,” “gratifying,” “comforting,” “helpful,” “lifeline,” “supportive,” “not alone,” “there when I need it,” “amazing support,” “found my tribe,” and “accepting.” Participants described that the groups strive to create community for NPEs while going through their experience. The online Facebook groups use administrators (who are also members) to monitor who is accepted into the groups as well as to monitor discussions within the group. Two participants shared concern that groups are not professional mental health organizations or therapy and as Angelica shared,

You have to understand if the groups aren’t run appropriately and people say and give advice that they shouldn’t be giving, that’s it’s dangerous and nobody should be doing that. Nobody.

The best part of being in the online Facebook group was reported as “other people get it” in a way that people who are not having this experience can understand. Participants specifically

mentioned not being alone because of the support and ability to relate to others who are experiencing similar emotions.

### *Navigating This Experience*

Participants described feeling unsure about how to navigate this experience. Some shared regret at how they handled things initially with family of origin or new family due to the emotionality of the experience. As William shared,

But I guess if I had it all over again, I would like to have known how I could have approached them differently, and maybe respectfully, without freaking them out and I might have been able to get answers, maybe not develop a relationship, I get that. But at least get some answers and have conclusion because ultimately, I think that's what I want.

Some wished for a guidebook to help get through the emotions of anger, sadness, shock, excitement, disappointment, loneliness, and healing. As Mary tearfully illuminated through her statement,

So, it was a very exhausting depression, um, that I, that I didn't know what to do with, with this discombobulation, this untethered-ness. I didn't feel tethered to anything.

And Rachel, who relied on her husband, also felt he was at a loss to help her said this, "he's like, I just don't know what to say. There's no, like, guidelines for husbands and the situation is difficult." Participants described feeling emotional about newly discovered paternity and not knowing the best ways to reach out to family made this experience more difficult.

### *Mental Health Counseling*

Eleven participants who engaged in mental health counseling as a result of the paternity information described experiences with mental health professionals who "don't know how to deal with this," "aren't prepared for this," "don't understand this," "don't know what they're doing," or "don't know how to address this." The sense that the therapist lacked knowledge, skills and resources for this experience was shared for eleven of the twelve participants who

reported having a therapist during this experience. While the reported lack of knowledge about NPEs and unexpected paternity results was expressed by the participants, four of the participants shared that they benefited from have a mental health professional help them process this experience. Others wished they had access to a mental health professional. As Louisa, who lives in a rural location described both access and mental health professional preparation,

We are isolated and there was no way I was going to seek mental health services here. Plus, I knew that this was such a new experience that I didn't feel confident that anyone was going to understand what this was about.

While several had or sought professional mental health counseling to assist with this experience, online group support was described as the most commonly utilized support participants accessed directly related to their experience.

### ***Healing Through Helping***

Ten participants shared the personal benefit they experienced by helping others who are new to the experience or who are struggling through this experience. Andrew shared that “being able to help someone else is really, really gratifying.” Angelica, Elizabeth, Grace and Martha have been very deliberate in starting online groups, advocating for legislative change for birth certificate changes, setting up routine supportive zoom calls, developing in-person retreats, and helping others find answers about their DNA connections. Louisa, who reported benefitting from the online support groups when she first learned about her discovery, described her role as she sees it now,

My role changed from trying to figure out and understand what was going on because of the support group, um, I think everyone su-, I think everyone supported each other and I thought I would disconnect from the group and then I realized my role is now to support others who are coming up with this. You know, I, I need to give back.

Participants described healing through helping others as a way to give and receive support.

### ***Advising Others***

Participants were asked what advice they would give to others who intend to complete a direct-to-consumer DNA ancestry test. Twelve participants offered words of caution or warning about what information could be uncovered with “be prepared.” Seven others shared “be aware” of what you could find out before you take the test. One shared a comment about being aware that this could harm others in the family and the final two said their advice is to “do it.” Many explained that they share their own stories of unexpectedly discovering different paternity as an example to anyone who asks about these tests.

Participants overwhelmingly stressed having a sense of caution and making sure the individual understands what information could be uncovered. Despite ancestry companies listing statements about the potential discovery of additional relatives, there were participants who shared that even with clear knowledge of that potential, they never would have expected the paternity outcome they received. Eliza described her experience like this,

I think like, I think ancestry and these other places should have some statistics to, clearly listed about like how many people will find out parental information they didn't expect. I think that would be helpful. Um, I think people should know how common it is because I think people think, like, oh, that will, I'm sure that it happens to other people, but it won't happen to me. That's what, I never thought this would happen to me. So just putting the statistics out there, I would let people know about that and, um, and that it, you know, there's, it's not just like a for fun, novelty kind of thing.

According to the participants in this study, preparation and awareness of what could be uncovered is the key advice they offer to others.

### **Summary of Findings**

This chapter presented the results of the findings from this study along with the participant demographics. Twenty-two participants were interviewed about their experience with unexpected paternity as a result of a consumer DNA ancestry test primarily completed “for fun.” The data contained responses from the participants that was aligned with answering the four

research questions this study sought to answer. Table 4.3 provides a summary of the research questions and the themes and sub-themes that emerged through the interview data. The following chapter will provide a discussion of the findings from this study, provide recommendations for social workers, address strengths and limitations, and discuss potential future research from this work.

Table 4.3  
*Research questions, Themes, and Sub-themes*

Research Question	Themes	Sub-themes
How does the unexpected paternity information affect an individual's understanding of their family of origin?	<ul style="list-style-type: none"> <li>• Recreational curiosity</li> <li>• Feeling shocked about the paternity information</li> <li>• Family secrets</li> </ul>	<ul style="list-style-type: none"> <li>• Infidelity</li> <li>• Something was "off"</li> </ul>
How does the unexpected paternity information affect an individual's relationship with their family of origin?	<ul style="list-style-type: none"> <li>• Relationship with mother</li> <li>• Relationship with birth certificate father</li> <li>• Relationship with siblings</li> <li>• Anger</li> <li>• Now things make sense</li> </ul>	
How does the unexpected paternity information affect an individual's identity?	<ul style="list-style-type: none"> <li>• Change to personal identity</li> <li>• Resemblance to family</li> <li>• Relationship with new family</li> </ul>	<ul style="list-style-type: none"> <li>• Ethnicity shifts</li> <li>• Health information</li> <li>• Rejection</li> </ul>

How do individuals receive support during this experience	<ul style="list-style-type: none"> <li>• Online group supports</li> <li>• Navigating this experience</li> <li>• Mental health counseling</li> <li>• Healing through helping</li> <li>• Advising others</li> </ul>	
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## **Chapter 5: Discussion**

This qualitative research study provides important perspectives from consumers of direct-to-consumer (DTC) ancestry tests who unexpectedly discover paternity. The focus of this research explored the impact of unexpected paternity discoveries on the understanding of family of origin, relationships with family of origin, personal identity change, and social supports for this experience. This chapter will connect the findings of the previous chapter to the literature and theory, discuss the strengths and limitations of the study, explore implications for social work practice, as well as discuss considerations for future research.

### **Understanding of Family of Origin**

Most of the study participants sought to utilize a direct-to-consumer DNA ancestry test for recreational curiosity related to personal genealogical interest (Allyse, et. al, 2018; Covolo, et. al., 2015; Loi, 2016; Smart, et. al., 2017) and not for paternity discovery. Participants described feelings such as confusion, shock, denial, anger, and sadness especially initially when the paternity discovery occurred. Similar to what Kirkpatrick & Rashkin (2017) suggested, this study found that discovering paternity through recreational ancestry tests can be a highly disruptive emotional experience. The impact of finding out a lifelong-held secret by the mothers through a recreational ancestry test appears to create a significant psychological blow to the participants, all adult children in this situation. Additionally, family secrets kept because of the paternity information, particularly those involving infidelity, also added to the difficult emotional response by participants.

Multiple participant descriptions of surprise along with relationship frustrations about this secret being kept from them supports Smart's (2011) work on reproductive secrets on the emotional damage that these types of secrets may cause. The range of negative emotions and family relationship difficulties that resulted for the majority of participants supports previous assertions that secrets in families can have a negative impact (Imber-Black, 2014, 1998, 1993; North, et. al., 2018; Rober, et. al., 2012). Participants described emotionally struggling with the previously unknown (secret) paternity information as they incorporated it into their existing life narrative. The findings suggest that the emotional upheaval for the individual to cope with the new information is significant as half of the participants reached out to mental health professionals to discuss the results.

### **Relationship with Family of Origin**

The findings of this study reveal that discovering paternity through a recreational DTC ancestry test altered relationships within the family of origin. Some relationships with siblings within the family of origin grew closer; others grew apart. Participants described complex feelings about birth certificate fathers; however, the relationship with mother was the most complicated disruption for participants to reconcile for a variety of reasons supports Palombi's (2016) assertion that all relationships within the family impact the functioning of one another, but particularly if there is a relationship disruption or stressful life event between mother and child. Participants described anger at mother (living or deceased) for determining what was best for them without the participant's knowledge or input pertaining to the secret, particularly when they believe mother had opportunities to share with her adult children. The findings of family of origin relationship complications discovered through DTC ancestry testing supports Imber-Black's (1998) assertions that secrets disrupt relationships in families. They may divide members from one another, interrupt communication within new relationships, inhibit self-identity development, and contribute to distrust between family members.

Many participants described creating an emotional distance between themselves and other members of their family in order to deal with this unexpected secret aligns with Bowen's concept of emotional cutoff in Family Systems Theory. Numerous participants describe this new paternity information as helping to explain childhood experiences and interactions with mother, birth certificate father, and siblings. Non-disclosure of the secret was interpreted by many participants as preventing the individual from having access to biological family earlier. In many cases, the paternal relatives had already died, therefore, eliminating any chance of relationship. This study reinforces that the information from these tests can have an impact on personal and family relationships (Berg & Fryer-Edwards, 2008) and can create distress for individuals who

question the difference between genetic (biologic) identity and familial (relationship) identity (Anderlik & Rothstein, 2002; Lord, 2018; Ravelingien & Pennings, 2013).

### **Personal Identity Changes**

Most participants described their personal identity as changed as a result of the paternity discovery. The described change to identity, as shared through the participants, supports the work of Scabini and Manzi (2011) who discuss that secure belonging to a family is reinforced by and affects the development of individual and social identity. This change in identity was characterized by the incorporation of new family into their life, the association of physical and character traits with new family members, and the discovery of previously unknown ethnicity and health information. Participants who learned of misattributed paternity searched for and wanted to know more about their new biological connections, supporting the work of Pappas (2018) who asserts that children of misattributed paternity seek to locate (identify with) biological family. Incorporating the new paternity information may create a re-defining and/or expansion of family that impacts the sense of self identity and group membership identity. The experiences described by participants support Njuma and Jewkes's (2011) assertion that determining paternal identity contributes to establishing individual identity.

Nineteen participants in this study shared identity concerns as they related to ethnicity shifts and a lack of health information. Ethnicity shifts were described by almost half of the participants as part of their identity change due to the DTC DNA ancestry test results. Some participants' ethnic associations are strongly ingrained despite the biological change according to the ancestry test. This supports the assertion by Schwartz, et. al. (2010) that ethnicity, culture, and class all contribute to how each member of the family develops their individual and social identity. Additionally, unknown paternity keeps half of an individual's health information

concealed, which adds another element that makes undisclosed paternity possibly a dangerous (toxic) secret (Imber-Black, 1998). The participant statements regarding previously missing health information supports standardized disclosure of misattributed paternity when it is known, so that individuals have access to accurate health information (Eno, et. al., 2018).

Resemblance to family growing up is an important way an individual feels connected to and identifies with their family. Many participants disclosed not resembling siblings or other family members in their family of origin growing up. This supports Becker, et. al.'s (2005) work that physical resemblance to family reinforces biological connection and identification to family members and "legitimizes the child as part of the family and is part of the process of constructing the child's identity within the family (p. 1301)." Supporting a study conducted by Isaksson, Sydsjo, Svanberg, and Lampic (2019), the value of resembling family begins early in a child's life and has significant meaning in families. The power of resemblance was a strong finding in this study, as it helped to highlight feelings of disconnection to family of origin, while allowing participants to feel a sense of connection with new biological family members.

Social identity theory informs the accommodation and reassessment of role and group membership (Ashforth & Mael, 1989; Brown, 2000; Tajfel & Turner, 1979). The unexpected paternity results removed the certainty of participants' personal, social, and familial identity as they learned that their birth certificate father was never of biological relation. The theoretical underpinnings of social identity describe how one seeks belonging and identification with a social system (Brown, 2000; Hogg, et. al., 2004; Stets & Burke, 2000). In this study, participants described this through seeking contact with new biological connections, discovering resemblance to new family, and accommodating ethnicity changes when they occurred. Resemblance was a strong indicator of newfound identity as participants described. This supported the assertion by

Scabini and Manzi (2011) that individuals seek similarity within family structures for connection.

### **Social Support**

All participants in this study sought support through the online Facebook group, NPE Only: After the Discovery. Additionally, half of the participants shared the need for mental health therapy intervention as a result of the paternity information. This level of intervention supports the assertion that professional genetic counselor interventions may be a helpful option for those who want help navigating this experience (Borry, et. al., 2018; Berg & Fryer-Edwards, 2008; Kirkpatrick & Rashkin, 2017; Lynch, et. al., 2011, Sturm & Manickam, 2012; Vrecar, et. al., 2015). The feelings of confusion about the information along with the mental health needs supports that consumers may understand DNA results better if they receive them along with access to medical or genetic personnel support initially (Hogarth & Saukko, 2017; Koeller, et. al., 2017; Sweeney & Legg, 2011).

Most participants reported that they would take the test again knowing what they know now. This finding supports earlier research conducted by Wright, et. al. (2002) indicating that having the truth about paternity, despite the emotional pain and, social and personal identity changes that may come with it, is preferred over not having the truth. Almost every participant suggests that anyone who is considering taking a DTC DNA ancestry test be prepared for unexpected results. Healing through helping others was an unexpected finding and indicates that providing support to others new in the journey is how many online group members find their own healing through this process. Engaging with others to sort out environmental supports during times of stress reinforces the need for individuals to adapt within their environment in order to recover (Bluteau, Couder, & Cureton, 2017).

## Limitations and Strengths

There are limitations and strengths to consider when reviewing the results of this study. The strengths of this research include rich, descriptive data from participants across North America adding new findings related to this experience where there are currently limited studies. The voice of the social work field in this new area is limited and these results have implications for social work practice development, further research for social workers, and social work education and leadership. The new knowledge from this study hopes to inform and inspire further social work practice and policy. The results support the assertion that there is a necessary role for social work within the rising industry of direct-to-consumer DNA ancestry tests (Siegel, 2019).

During the interviews, several participants described the emotional benefit they experienced sharing their story and their interest in contributing to research in this new area of study. They described a desire to help the community of individuals who have experienced surprise paternity discoveries, along with a desire to impact mental health service providers for greater understanding and therapeutic responses for individuals who experience this phenomenon. The research methodology used in this study can be utilized for future research studies within this population. A strength and a limitation of this study is the lack of previous research related to unexpected paternity discovered through the direct-to-consumer DNA ancestry tests in terms of comparison and validation.

Qualitative research considers the researcher's own biases and honest reflection of the material within the study (Merriam & Tisdell, 2015; Tracy, 2010). The first limitation in this study is the consideration of researcher bias. As the researcher engaged with participants in personal, sometimes emotional, interviews, efforts were made to remain neutral. However,

consideration must be given that the researcher's presence could impact participant responses as the researcher is engaged as the primary instrument for the collection and analysis of data (Merriam & Tisdell, 2015). Due to the limited information that exists on this topic and the seemingly absent voice in the literature, social work should remain invested in studying and contributing to the literature around this topic.

Participants were from various locations across North America. A limitation includes the inability to conduct interviews in person based on the Covid-19 pandemic guidelines for safety. In-person interviews would have also been limited due to the physical location, time constraints, and financial constraints of the researcher and the participants. While there is support for digital video recordings in qualitative research (Miller-Scarnato, 2019), in-person interviews would have been preferred.

The study's participants were limited in diversity in ethnicity and gender, adding another limitation to this study. Twenty females and two males were interviewed. Most of the participants reported their ethnicity as Caucasian/White. All participants in this study are members of a private Facebook support group specific to identifying with discovering paternity through direct-to-consumer ancestry testing. It is unknown if gender and ethnicity in this study is representative of the demographics of the Facebook support groups. However, other studies have determined that this is the primary demographic who access DTC ancestry tests (Graf, 2019; Roberts, Gornick, Carere, Uhlmann, Ruffin & Green, 2017).

A limitation is noted by the researcher regarding conducting more than one interview with each participant. Due to interviewing twenty-two participants, only one interview was conducted for each participant. If fewer participants were interviewed, a follow-up interview could have been utilized for more depth of questions about this topic.

## **Implications for Social Work Practice and Future Research**

This research adds new leadership and education implications for social work practice and research. The findings from this study provide valuable insight for social workers and for consumer DNA ancestry testing companies to understand the experience of individuals who uncover their Not Parent Expected (NPE) status through these recreational tests. This study found that there is a personal cost related to changes in family relationships and identity as well as personal gain to knowing the truth about biological paternity and connecting with those paternal relatives when paternity secrets are revealed through these tests. Anonymity is compromised with ancestry testing, as genetic material is compared within large databases of other genetic material.

### ***Social Work Practice Considerations***

There are five practice considerations provided as a result of this study to address supporting individuals who receive paternity results from recreational ancestry testing.

#### **1. Determine Appropriate Therapeutic Interventions for this Population.**

Affordable and accessible recreational DNA ancestry test kits have the power to expose paternity secrets and create stress within family relationships (Hoglund-Shen, 2016; Kirkpatrick & Rashkin, 2017; Moray, et. al., 2017). Concerns remain that a lack of medical personnel involvement with unexpected DNA results (Meisel, et. al., 2015; Samuel, et. al., 2010; Seward, 2018) and no pre- and post-test counseling (Botkin, et. al., 2015) can distress consumers. Some consumers are creating their own grassroots supports in order to cope with the emotional, identity, and relationship difficulties of recreational discovery of misattributed paternity. One of these supports is the creation of Facebook support groups, as there are no other widely known

supports reported in practice currently. A study by Crawshaw, Frith, van den Akker, & Blyth (2016) about parent discoveries of those who are donor-conceived described the benefit of peer connection upon their discovery. An important note to this study indicates that peer forums may cause distress to some when others in the forum have better outcomes with their parent discovery (Crawshaw, et. al., 2016). Many participants in this research study indicated a need to remove themselves at times from the Facebook support group, as there can be “overidentification” with the expressions of loss and grief, as well as “guilt” for finding happiness with their story. Social work, as a profession, has an opportunity to improve interventions through specialization of therapeutic work designed to understand the experience of consumers.

## 2. **Update the NASW Standards for Integrating Genetics into Social Work**

**Practice.** Half of the participants in this study sought additional professional mental health care directly related to the emotional upheaval and strain on family relationships caused by the paternity results. Social workers’ increased understanding about the impact of genetic information on families surrounding the consumer ancestry tests supports this new phenomenon as an area for education and leadership. NASW has standards for social workers and genetics. Within the NASW Code of Ethics, social workers are bound to principles and standards that support client self-determination, confidentiality, direct intervention, boundary setting, education, referral for services, and public welfare responsibility. NASW developed standards for integrating genetics into social work practice’s objectives of educating and informing social workers about the expanding field of genetics. These standards

include the development of continuing education materials and programs and addressing policy and practice related to genetics interventions for clients. As this was initially written in 2003, it would be appropriate to update the standards to incorporate technological advances and consumer access.

**3. Advocate for Direct-to-Consumer Ancestry Companies to Provide Therapeutic Options when Consumers Receive Unintended Results from Their Tests.**

Ethically, it appears that DTC ancestry companies have a responsibility to provide access or direction to consumers when unintended information is uncovered (Crawshaw, 2018). Privacy and confidentiality in the digital age is difficult to maintain, and DNA databases are rapidly growing through the increased sales of DTC ancestry test kits (Seward, 2018). Ancestry tests are accurate for determining biological relationships (Davis, 2007; Moray, et. al., 2017; Phillips, 2016). As genetic information is uniquely identifiable and biologically connects to other individuals, another area for therapeutic intervention may be for those consumers have unknowingly disclosed information about others through testing (Chow-White, et. al., 2015; Kirkpatrick & Rashkin, 2017; Via, 2017). Discovering paternity through a recreational ancestry test was determined in this study to cause distress for participants and their families. Social work can advocate for ancestry companies to collaborate about therapeutic options for consumers who want to seek additional mental health contact after unexpected paternity information is uncovered.

**4. Consider Social Work's Role with Private Facebook Groups.** Social work may have a role with self-help groups developed through social media platforms such as Facebook. As the participants in this study indicated positive regard for the private

support group, social work can also consider ways to use this platform as a tool for interventions, particularly when, geographically, participants cannot gather face to face.

5. **Consider the Creation of Professional Development about Social Work and Genetics for Clinical Social Workers and/or Social Work Education Programs.**

Aligned with the NASW Code of Ethics and the Council on Social Work Education, an ethical responsibility as a professional social worker is that of competence. As this study indicated, this is an emerging area of research. Participants shared concerns that the mental health community lacked knowledge and skills associated for awareness and support when they sought professional help after the paternity discovery. Social workers, social work students, and others in the mental health community may benefit from education about advancements in genetics and this new phenomenon affecting individuals and families often unexpectedly and often at mid-life.

***Future Social Work Research Considerations***

This exploratory study offers an entry point for studying the impact of paternity discoveries through commercial ancestry tests. Future research considerations include:

1. **Qualitative Studies with Biological Mothers.** The findings in this study suggest a need for studies with biological mothers for improved awareness and understanding of their experience with the exposure of their child's misattributed paternity. Navigating difficult relationships with mother was an outcome of this study. Understanding the experience of mothers may shed light on their decisions to keep the secret. If mothers understand the possible unintended consequences of

ancestry testing, further research may examine if mothers make the decision to share paternity secrets on their own terms.

2. **Longitudinal Studies.** A longitudinal study may be beneficial to determine how people fare over time once the initial surprise and disruption to family relationships settle. Reported identity changes and/or adaptations over time could also be viewed from a longitudinal perspective in order to determine if individual changes sustain. Additionally, understanding what supports remain in need for individuals who discover paternity over time could be studied.
3. **Consideration Future Research on If/How New Medical Information Changes Behavior Once Misattributed Paternity is Uncovered.** Ancestry tests that uncover paternity secrets also uncover half of an individual's medical information. For adult children in this study, the impact the paternity secret can have on health could be life or death. As learned through this study, some participants did not previously have important information about their health.

## **Conclusion**

This exploratory research study provides rich insights from participants about the impact on family relationships and personal identity after taking a direct-to-consumer DNA ancestry test and discovering unexpected paternity as a result. There is sparse professional and academic literature on this topic currently. This qualitative study provides valuable perspectives from the participants about the understanding of the family of origin, the relationships within the family of origin, the perceived change to identity, and the supports for this experience. Social work practice implications include further education for clinical social work professionals to understand and improve interventions, acknowledgement of the ethical responsibility for the

DNA ancestry companies to provide for pre- and post-counseling options if requested by consumers and reviewing or creating policy and practice related to the growing field of consumer genetics. Social work research could consider further qualitative studies from the view of the other players (mother, birth certificate father, biological father, siblings, new biological relatives) to understand more from their experiences. Additionally, longitudinal studies may be beneficial for understanding the long-term impact of unexpected paternity on family relationships, personal identity, and social support needs. Quantitative studies may also be beneficial for better generalization for the NPE experience. The findings from this research study add to the limited body of knowledge currently in the literature and hopes to inspire others to add more about this growing phenomenon.

## **Appendix A**

### **Invitation to Participate in Study**

Dear NPE Only: After the Discovery Facebook members,

I am contacting you to request your participation in a research study about unexpected paternity results received after completing direct-to-consumer DNA ancestry test. This research is being conducted as part of my dissertation for my Doctorate in Social Work degree through Millersville University in Pennsylvania. I believe there is a lot to learn about this experience that is not professionally documented yet. Your responses will provide information on family dynamics after learning DNA ancestry results. For benefits and risks, please see the consent form below.

If you are interested in participating in this study,

- Click on the linkXXX to access the informed consent.
- Read and electronically sign the informed consent.
- You will then be asked to complete a Demographics Survey that takes approximately 5 minutes to complete.

- Upon receipt of the informed consent form and the demographics survey, I will contact you to schedule an interview at a location of your convenience. The interviews will be recorded and may take an hour to two hours.

If you have any questions concerning this study, do not hesitate to contact me through email at [gidaniel@millersville.edu](mailto:gidaniel@millersville.edu).

Thank you for your consideration,

Gina Daniel, MSW, LCSW

Doctoral Candidate, Millersville University

[gidaniel@millersvile.edu](mailto:gidaniel@millersvile.edu)

(717) 991-3333

## Appendix B

### Institutional Review Board Approval Letter

(received via email 9/22/2020)

rene munoz <noreply+e6f9ee34dad47b17@formstack.com> Tue 9/22/2020 9:11 AM

To:

Gina Daniel

CAUTION: This email originated from outside of Millersville. Do not click links or open attachments unless you recognize the sender and know the content is safe.

Hello,

IRB Protocol No. Thanks 655403163 "Family Secrets: Exploring Unexpected Paternity through Direct-to-Consumer DNA Ancestry Tests" has been reviewed by members of the MU IRB Committee. You have received this email because you were listed as either a faculty mentor or co-PI on this protocol.

**Review Type:**Expedited

**Recommended Action:**Approved

**Summary Comments:** Well written protocol.

Please use the summary comments as the basis for any revisions requested. The link for submitting revisions was included in the email confirmation email received by the PI following the submission of the original protocol.

If you have questions, please contact Rene Munoz by phone at 717 871 4457 or by email at [//rene.munoz@millersville.edu]rene.munoz@millersville.edu.

## Appendix C

### Demographics Survey Questions

- What state or country do you reside in?
- What is your gender?
  - Man
  - Woman
  - Transgender
  - Non-binary/ third gender
  - Prefer to self-describe \_\_\_\_\_
  - Prefer not to say
- What is your age? \_\_\_\_\_
- What is your highest educational degree?
  - Some high school, no diploma
  - High school graduate, diploma or the equivalent (for example: GED)
  - Some college credit, no degree
  - Trade/technical/vocational training
  - Associate degree
  - Bachelor's degree
  - Master's degree
  - Professional degree
  - Doctorate degree
- What is your ethnic identification?
  - White
  - Hispanic, Latino, or Spanish origin
  - Black or African American
  - Asian
  - American Indian or Alaskan Native
  - Native Hawaiian or Other Pacific Islander
  - Other
- How long have you been a member of the NPE Only: After the Discovery group?
  - Less than 6 months
  - 6 months -1 year

- Over 1 year
- What ancestry test(s) did you use? (may check more than one)
  - Ancestry
  - 23andMe
  - Family Tree DNA
  - Geno 2.0
  - My Heritage
  - Other
- Please provide an email address for me to contact you.

## **Appendix D**

### **Semi-structured Interview Protocol Questions**

### **Ancestry Results Questions**

- How long ago did you take the DNA Ancestry test?
- What prompted you to take this test?
- What information were you expecting to learn about yourself when the results came back?
- Describe your immediate reactions when you learned about your paternity?

### **Family of Origin Questions**

- Before taking the DTC ancestry test, describe your relationship with your family of origin?
- What has been your experience with family secrets?
- Since the paternity discovery, in what ways has your relationship changed with members of your family of origin?

### **New Family Questions**

- Have you met any of the family members of the NEW unexpected family?
- If so, what was that like?
- Do you resemble anyone in the NEW family?

### **Identity Questions**

- Do you feel a change to your personal identity since the test?
- If so, how?
- What has been the most challenging part of receiving the DTC ancestry tests results?
- What has been the best part of this experience for you?

### **Support Questions**

- How have you sought support throughout this experience?
- How did you locate the NPE Only group?
- What is the best part of belonging to NPE Only on Facebook?

**Final Questions**

- Would you take the DTC ancestry test again knowing what you know now?
- What advice would you give to someone who wants to take a DTC ancestry test?
- What else would you like to tell me that I didn't ask?

## Appendix E

### Consent Form for Participants

You are invited to participate in a research study being conducted through Millersville University because you are a member of NPE Only: After the Discovery group through Facebook.

**Title of Research Study:** Family Secrets: Exploring Unexpected Paternity through Direct to-Consumer DNA Ancestry Tests

**Researcher:**

Gina Daniel, MSW, LCSW, Doctoral Candidate, Millersville University

**Purpose of the Study:**

The purpose of this study is to explore the experience of individuals who, after completing direct-to-consumer DNA ancestry tests, learned previously unknown information about their paternity. In particular, this exploratory research aims to understand how personal identity and family relationships are affected upon receiving results of the direct-to-consumer DNA ancestry test. There is little information about this topic and your input is expected to be valuable to understanding this experience and family dynamics.

**Procedures:** If you have agreed to this study, you will be asked to complete a demographics survey that will take approximately 5 minutes to complete. Afterward, a ZOOM (virtual) interview will be scheduled at a mutually agreed upon location and date and time. The interview will take approximately 30-90 minutes. All interviews will be audio recorded.

**Risks and Benefits of Participating in the Study:**

A risk of feeling uncomfortable discussing difficult family and personal information could occur by participating in this study. You retain the right to stop at any time within the interview if you should wish not to continue. The researcher will prepare local mental health supports within your community for you should you request them.

The benefits to participation in the study include the opportunity to share your thoughts and experiences about learning previously unknown paternity discovered through direct-to-consumer DNA ancestry tests. It is my hope that information from you will contribute to understanding of personal identity changes and family dynamics as a result of these test results.

**Confidentiality:**

All information will be handled in a confidential manner to the extent provided by the law, so that no one will be able to identify you when results are recorded. However, it is possible that University representatives may become aware of your participation in this study and may inspect and copy records pertaining to this research.

To help protect your confidentiality:

- All identifying information you provide will be extracted and assigned an alias. The main researcher will be the only person who knows your name. Only de-identified documents will be used by research team members for data storage, analysis, and final reporting.
- All recordings will be destroyed after the interviews have been transcribed.
- Final results from this study could be presented through future peer-reviewed publication and conference presentations. Since only anecdotal information and aliases will be referenced, not individual outcomes or names, minimal risk of confidentiality breach upon dissemination should occur.

**Data Storage:**

The information obtained from the informed consent will be kept on Qualtrics and the recorded audio and/or video interviews will be kept only until transcription has been completed. The recordings will then be removed and deleted. The transcribed interviews will be uploaded to NVivo and kept on a password-protected computer in the primary researcher's office. The transcribed documents will be saved on a flash drive and any handwritten notes or documentation provided will be secured in a locked filing cabinet in the primary researcher's office. At the conclusions of the study, all transcribed audio and/or video recordings, written notes, and interview transcriptions will be destroyed after three years in accordance with Institutional Review Board (IRB) regulations.

**Voluntary Participation:**

Your participation in this study is completely voluntary. There is no penalty for not participating. If you decide to participate in this study and later change your mind, you may discontinue your participation and withdraw from the study at any time without penalty.

**Contacts and Questions:**

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Gina Daniel (principal researcher), Doctoral Candidate, Millersville University at [gidaniel@millersville.edu](mailto:gidaniel@millersville.edu) or Dr. Laura Granruth (supervising faculty) at Millersville University at (717) 871-5956 or [laura.granruth@millersville.edu](mailto:laura.granruth@millersville.edu).

This study has been reviewed and approved by the Millersville University of Pennsylvania Institutional Review Board. If you have questions or would like to speak with someone other than the research team, contact René Muñoz, Director of Sponsored Projects and Research Administration, at either (717) 871-4457 or (717) 871-4146, or at [rene.munoz@millersville.edu](mailto:rene.munoz@millersville.edu).

**Statement of Consent:**

By continuing with this interview, I am indicating that:

- I am a member of the NPE Only: After the Discovery group through Facebook.
  - I have read and understand the information described above and have received an electronic copy of this information.
  - I have had the opportunity to ask any questions I have regarding the research study and have received answers to my satisfaction.
  - I agree to audio and/or video recording of this interview by the researcher.
  - I am 18 years of age or older and voluntarily consent to participate in this study.
- 

Participant's Signature and Date:

Researcher's Signature and Date:

**Appendix F**  
**Code book for Family Secrets**

Name	Description
INDIVIDUAL IDENTITY	
CHANGE TO PERSONAL IDENTITY	Described by participants as the personal change they feel to their sense of identity after the paternity information was discovered.
ETHNICITY SHIFT	Describing the information that is sought or discovered about an individual's maternal or paternal relatives/ethnic background based on the database information within each DTC ancestry company.
HEALTH INFORMATION	Describes participants who disclose the value of knowing accurate health information with the new biology connections.
PERSONAL GROWTH	Describes the words or phrases participants use when discussing their personal progress through the experience of learning their paternity information.
REJECTION	Describes participants who have felt left or abandoned by family before and after the paternity discovery.
RESEMBLANCE TO FAMILY	Describing physical and personality traits shared with members of the new family as well as shared or not shared with the family of origin.
SEEKING ANSWERS	Describes how participants were motivated to find answers or are still searching for information as a result of the paternity results.
SENSE OF BELONGING	Describing a sense of connection through a secure relationship or through connecting with a larger group of individuals.
SOMETHING WRONG WITH ME	Describes how some participants shared their experience feeling like something was wrong with them in their family of origin.
RELATIONSHIP WITH FAMILY OF ORIGIN	
ANGER	Describes angry feelings after the paternity results by the participant. This can relate to anger toward any family member about withholding information or the fact that there is no one alive to be actively angry with.
FORGIVENESS	Describes participant use of forgiving family members for the decisions, secrets, and/or lies regarding their paternity information.
MAINTAINING THE SECRET	Describes participants who are choosing to continue keeping their paternity secrets from family members.

Name	Description
MOTHER'S DENIAL OF PATERNITY RESULTS	Describes how participants cope with mothers who continue to deny the truth of the paternity results.
NOW THINGS MAKE SENSE	Describes how participants share the connection between childhood experiences/memories after receiving the new paternity information.
RELATIONSHIP WITH BIRTH CERTIFICATE FATHER (BCF)	Describes the positive or negative relationship with their birth certificate father in their family of origin.
RELATIONSHIP WITH MOTHER	Describes the participants' feelings or thoughts about their relationship with their mother before and/or after the paternity information was known.
RELATIONSHIP WITH NEW FAMILY	Describes participant's new family member interactions and what the relationship is like since the discovery of paternity.
RELATIONSHIP WITH SIBLINGS (FOO)	Describes participant's relationship after the discovery with their siblings in their family of origin.
SUPPORT THROUGH THIS EXPERIENCE	
ADVISING OTHERS	Describes the advice or suggestions that a participant would provide to anyone who asked about taking a direct-to-consumer ancestry DNA test.
GRIEF AND LOSS	Describes the feelings of loss and grief that include missed opportunities with family or a renewed sense of family losses. This can include birth certificate fathers, new family and/or time to discuss the paternity surprise with deceased family members.
HEALING THROUGH HELPING OTHERS	Describes participants who are at a stage in their journey where they feel that helping others in their process is helping them to heal too.
MH COUNSELING - UNPREPARED FOR THIS	Described by participants as the professional support they received and how they believe it was not helpful. Also includes participants' descriptions of what they believe mental health professionals are lacking with the NPE experience.
MH COUNSELING- HELPFUL	Described by participants as therapeutic counselling experiences that helped them while going through this experience.
NAVIGATING THIS EXPERIENCE	The words or terms used by participants that describe how they struggled to know what to do or how to handle the unexpected paternity information as they moved through the discovery.

Name	Description
ONLINE GROUP SUPPORT	Describes the online support groups that have been developed and joined by participants as a way to meet with others having learned the same information about their paternity. These online groups are all within the platform of Facebook.
PERSONAL SUPPORTS	These supports are those related to spouses and immediate family members who help(ed) the participant after the paternity discovery.
TRAUMATIC EXPERIENCE	Participant description of their experience specifically using a form of the word "trauma" to describe what learning about their paternity was like.
UNDERSTANDING FAMILY OF ORIGIN	
ALWAYS FELT SOMETHING WAS OFF	Describes participants' feelings about how they felt with aspects of their family of origin growing up.
DIFFICULT CHILDHOOD	Describes how participants refer to their childhood within their family of origin.
FAMILY SECRETS	Described by participants through their disclosure of experience with their family's secrets. Some pertain to paternity; others pertain to additional family secrets.
FEELING SHOCKED ABOUT INFORMATION	Described by participants how they feel once the paternity information is disclosed or discovered. Most often the word "shock" is their term prompted by their reaction to the paternity discovery.
FEELING UNDERSTOOD	Describes how participants share feelings related to finding people who they are comfortable sharing this surprise with.
INFIDELITY	Describes participants who share that their parent(s) were not faithful in their relationship(s).
RECREATIONAL CURIOSITY	Describing the reason for taking the test. Curiosity about ethnic background, confirmation of ethnicity and/or seeking additional relatives for recreational genealogical interests.
SUSPECTED MY FATHER WAS NOT MY FATHER	Described by participants as their sense or suspicion that their birth certificate father was not their biological father.

## **Appendix G**

### **Interview Preparation Guide**

Scheduled interview date and time: **Sunday, October 4, 2020 at 4:00PM EST.**

I will email a ZOOM link to you the morning of the day we are meeting. This email will have a password that you will need in order to get into the room. I will highlight (in yellow) this password. The password for this meeting is unique only to the date and time we are scheduled to meet.

Thank you for agreeing to participate in this study. Your input is very valuable. In order for us to have an optimal interview experience, below are a few suggestions to consider prior to our meeting time. I will also be checking the list below prior to our meeting to be sure we have an uninterrupted, private interview.

- Please charge your device fully.
- Please check your video and audio function to be sure this is operating properly prior to our meeting time.
- Plan to meet in a private space, preferably with a door that closes, in order for optimal privacy during our meeting time.
- Also, ask that others do not interrupt unless necessary so that we can have uninterrupted time to talk.
- If possible, turn your phone off or place it on silent to limit interruptions.

Thank you for your time and I look forward to our interview!

## References

- 23andMe. 2016. The new 23andMe experience: a look at our trait reports. *23andMe Blog*, Jan. 5.  
<https://blog.23andme.com/23andme-and-you/23andme-how-to/the-new>.
- 23andMe. <https://www.23andme.com/genetic-science/23andme-experience-a-look-at-our-trait-reports/#Dg8JTj0gW09zewyd.99>.
- Abrams, D., & Hogg, M. A. (2010). Social identity and self-categorization. In Dovidio, J. F., Hewstone, M., Glick, P., & Esses, V.M. (Eds.). *The SAGE handbook of prejudice, stereotyping and discrimination* (179-193). London: SAGE Publications.
- Acero, A. R., Cano-Prous, A., Castellanos, G., Marting-Lanas, R., & Canga-Armayor, A. (2017). Family identity and severe mental illness: A thematic synthesis of qualitative studies. *European Journal of Social Psychology*, 47, 611-627.  
<http://dx.doi.org/10.1002/ejsp.2240>.
- Areheart, B. A., & Roberts, J. L. (2019). GINA, big data, and the future of employee privacy. *Yale Law Journal*, 128(3), 710-790.
- Allyse, M. A., Robinson, D. H., Ferber, M. J., & Sharp, R. R. (2018). Direct-to-consumer testing 2.0: Emerging models of direct-to-consumer genetic testing. *Mayo Foundation for Medical Education and Research*, 93(1), 113-120.  
<https://doi.org/10.1016/j.mayocp.2017.11.001>.
- American Society of Human Genetics. 2015, July 02). *ASHG issues position statement on genetic testing in children and adolescents*. American Society of Human Genetics.  
<https://www.ashg.org/publications-news/press-releases/201507-pediatric-testing/>
- AncestryDNA. <https://www.ancestry.com/dna/>.
- Anderlik, M. R. & Rothstein, M. A. (2002). DNA-based identity testing and the future of the family: A research agenda. *American Journal of Law & Medicine*, 28, 215-232.

- Anderson, K. G. (2006). How well does paternity confidence match actual paternity?: Evidence From worldwide nonpaternity rates. *Current Anthropology*, 47(3), 513. <https://doi.org/10/1086/504167>.
- Archarya, P. & Gautam, R. (2015). Ethical perspectives of direct-to-consumer genetic testing. *Online Journal of Health Ethics*, 11(1). <https://dx.doi.org/10.18785/ojhe.1101.07>.
- Ashforth, B. E. & Mael, F. (1989). Social identity theory and the organization. *Academy of Management Review*, 14(1), 20-39. <https://doi.org/10.5465/AMR.1989.4278999>.
- Association of Internet Researchers (AoIR). Retrieved from <https://www.aoir.org>.
- Ayers, S. (2017). Paternity un(certainty): How the law surrounding paternity challenges negatively impacts family relationships and women's sexuality. *Journal of Gender, Race, and Justice*, 2, 237-262.
- Barata, L. P., Starks, H., Kelley, M., Kuszler, P., & Burke, W. (2015). What DNA can and cannot say: Perspectives of immigrant families. *Stanford Law & Policy Review*, 26(2), 597-638.
- Barnwell, A. (2018). Hidden heirlooms: Keeping family secrets across generations. *Journal of Sociology*, 54(3), 446-460. <https://doi.org/10.1177/14407833177727878>.
- Becker, G., Butler, A., & Nachtigall, R. D. (2005). Resemblance talk: A challenge for parents whose children were conceived with donor gametes in the US. *Social Science & Medicine*, 61(6), 1300-1309. <https://doi.org/10.1016/j.socscimed.2005.01.018>.
- Bellis, M. A., Hughes, K., Hughes, S., & Ashton, J. R. (2005). Measuring paternal discrepancy and its public health consequences. *Journal of Epidemiol Community Health*, 59, 749-754.
- Berg, C. & Fryer-Edwards, K. (2008). The ethical challenges of direct-to-consumer genetic

- testing. *Journal of Business Ethics*, 77: 17-31. <https://doi:10.1007/s1055-006-9298-8>.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234.
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2019). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, 26(13): 1802-1811.
- Bitter, J. R. & Carlson, J. (2017). Adlerian thought and process in systems of family therapy. *Journal of Individual Psychology* 73(4), 307-327.
- Bluteau, P., Clouder, L., & Cureton, D. (2017). Developing interprofessional education online: An ecological systems theory analysis. *Journal of Interprofessional Care*, 31(4), 420-428. <https://doi.org/10.1080/13561820.2017.1307170>.
- Boddy, C. L. (2016). Sample size for qualitative research. *Qualitative Market Research Journal*, 19(4), 426-432.
- Bonduriansky, R. (2012). Rethinking heredity, again. *Trends in Ecology & Evolution*, 27(6), 330-336.
- Borry, P., Cornel, M., & Howard, H. (2010). Where are you going, where have you been: A recent history of the direct-to-consumer genetic testing market. *Journal of Community Genetics*, 1(3), 101.
- Borry, P., Bentzen, H. B., Budin-Ljosne, I., Cornel, M. C., Howard, H. C., Feeney, Jackson, L., Mascalzoni, D., Mendes, A., Peterlin, B., Riso, B., Shbani, M., Skirton, H., Sterckx, S., Vears, D., Wjst, M. & Felzmann, H. (2018). The challenges of the expanded availability of genomic information: An agenda-setting paper. *Journal of Community Genetics*, 9(2), 103-116. <https://doi.org.10.1007/s12687-017-0331-7>.

- Botkin, J. R., Belmont, J. W., Berg, J. S., Berkman, B. E., Bombard, Y., Holm, I. A., Levy, H. P., Ormond, K. E., Saal, H. M., Spinner, N.B., Wilford, B. S., & McInerney, J. D. (2015). ASHG position Statement, Points to consider: Ethical, Legal, and Psychosocial implications of genetic testing in children and adolescents. *The American Journal of Human Genetics*, *97*, 6-21.
- Bowles, C., Searight, H. R., Russo, J. R., Rogers, B. J., & Kleinman, K. M. (1997). Perceived family functioning, psychological adjustment, and parental marital status: Further validity support for the family-of-origin scale with adolescents. *Family Therapy: The Journal of the California Graduate School of Family Psychology*, *24*(3), 133-141.
- Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry*, *7*(5), 345-374.
- Bowen, M. (1978). *Family therapy in clinical practice*. New York, NY: Jason Aronson, Inc.
- Brown, K. V. (2019). Major DNA company sharing genetic data with the FBI. Retrieved 5 Feb 2019. <https://www.bloomber.com/new/articles/2019-02-01/mmajor-dna-testing-company-is-sharing-genetic-data-with-the-fbi>.
- Brown, R. & Capozza, D. (2000). *Social identity processes: Trends in theory and research*. London: SAGE Publications.
- Brown, R. (2000). Social identity theory: Past achievements, current problems and future challenges. *European Journal of Social Psychology*, *30*, 745-778.
- Campbell, J., Quincy, C., Osserman, J., & Pedersen, O. (2013). Coding in-depth semi-structured interviews: Problems of unitization and intercoder reliability and agreement. *Sociological Methods and Research*, *42*(3), 294-320.
- Campbell, L.H., Silverman, P. R., & Patti, P. B., (1991). Reunions between adoptees and birth

- parents: The adoptees' experience. *Social work*, 36(4), 329-335.
- <https://doi.org/10.1093/sw/36.4.329>.
- Carere, D. A., Kraft, P. K., Kaphingst, K. A., Roberts, J. S., & Green, R. C. (2016). Consumers report lower confidence in their genetics knowledge following direct-to-consumer personal genomic testing. *Genetics in Medicine*, 18(1), 65-72.
- Casas, K. A. (2018). Adoptees' pursuit of genomic testing to fill gaps in family health history and reduce healthcare disparity. *Narrative Inquiry in Bioethics*, 8(2), 131-135. Johns Hopkins University Press.
- Charles, R. (2001). Is there any empirical support for Bowen's concepts of differentiation of self, triangulation, and fusion? *American Journal of Family Therapy*, 29(4), 279-292.
- Charmaz, K. (2014). *Constructing grounded theory* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Chow-White, P. A., MacAuley, M., Charters, A., & Chow, P. (2015). From the bench to bedside in the big data age: Ethics and practices of consent and privacy for clinical genomics and personalized medicine. *Journal of Ethics and Information Technology*, 17, 189-200.
- Christenhusz, G. M., Devriendt, K., & Dierickx, K. (2013). To tell or not to tell? A systematic review of ethical reflections on incidental findings arising in genetics contexts. *European Journal of Human Genetics*, 21, 248-255.
- Collins, F. S. & McKusick, V. A. (2001). Implications of the human genome project for medical science. *The Journal of the American Medical Association*, 285(5), 540-544.
- Council on Social Work Education (2015). Educational policy and accreditation standards.
- <https://www.cswe.org/Accreditation/Standards-and-Policies/2015-EPAS>.
- Covolo, L., Rubinelli, S., Ceretti, E., & Gelatti, U. (2015). Internet-based direct-to-consumer

- genetic testing: A systematic review. *Journal of Medical Internet Research*, 17(12).  
<https://www.jmir.org/2015/12/e279/>.
- Crawshaw, M. (2018). Direct-to-consumer DNA findings: The fallout for individuals and their families unexpectedly learning of their donor conception origins. *Human Fertility*, 21(4), 225-228. <https://doi.org/10.1080/14647273.2017.1339127>.
- Crawshaw, M., Frith, L., van den Akker, O., & Blyth, E. (2016). Voluntary DNA-based information exchange and contact services following donor conception: An analysis of service users' needs. *New Genetics and Society*, 35(4), 372-392.  
<https://dx.doi.org/10.1080.14636778.2016.1253462>.
- Creswell, J. & Poth, C. (2017). *Qualitative inquiry and research design: Choosing among five approaches (4th Ed.)*. Thousand Oaks, CA: Sage Publications.
- Cullen, R., & Marshall, S. (2006). Genetic research and genetic information: A health information professional's perspective on the benefits and risks. *Health Information and Libraries Journal*, 23, 275-282.2007
- Davis, D. S. (2007). The changing face of "misattributed paternity." *The Journal of Medicine and Philosophy*, 4, 359-373.
- Day, R. D. (2010). *Introduction to family process (5<sup>th</sup> ed.)*. Routledge: New York, NY.
- DeLong, L. B. & Kahn, J. H. (2014). Shameful secrets and shame-prone dispositions: How outcome expectations mediate the relation between shame and disclosure. *Counselling Psychology Quarterly*, 27(3), 290-307. <https://doi.org/1.1080/09515070.2014.908272>.
- Dent, K. M., Magoulas, P. L., Bamshad, M. J., Ramos, E., & Weissman, S. M. (2018). The dawn of consumer-directed testing. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 1, 89. <https://doi.org/10.1002/ajmg.c.31603>.

- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2018). *The SAGE handbook of qualitative research*. SAGE Publications.
- Draper, H. & Ives, J. (2009). Paternity testing: A poor test of fatherhood. *Journal of Social Welfare & Family Law*, 31(4), 407-418.
- Du, L. & Becher, S. I. (2018). Genetic and genomic consultation: Are we ready for direct-to-consumer telegenetics? *Frontiers in Genetics*. <https://doi.org/10.3389/fgene.2018.00550>.
- Durmaz, A. A., Karaca, E., Demkov, U., Toruner, G., Schoumans, J., & Cogulu, O. (2015). Evolution of genetic techniques: Past, present, and beyond. *BioMed Research International*, 1-7. <http://dx.doi.org/10.1155/2015/461524>.
- Eftimie, S. (2015). Social changes and family relationship. *Jus et Civitas, II LXVI*(2), 59-64.
- Eno, C., Bayrak-Toyemir, P., Bean, L., Braxton, A., Chao, E. C., El-Khechen, D., Esplin, E. D., Friedman, B., Hagman, K. D. F., Hambuch, T., Hernandez, A., Juusola, J., Londre, G., Machado, J., Mao, R., Mighion, L., Rehm, H. L., Ward, P., & Deignan, J. L. (2018). Misattributed parentage as an unanticipated finding during exome/genome sequencing: Current clinical laboratory practices and an opportunity or standardization. *Genetics in Medicine*, 1-6.
- Erdem, G. & Safi, O. A. (2018). The cultural lens approach to Bowen family systems theory: Contributions of family change theory. *Journal of Family Theory & Review*, 10(2), 469-483. <https://doi.org/10.1111/jftr.12258>.
- FamilytreeDNA. <https://www.familytreedna.com>.
- Farr, C. (December 2017). As at home DNA tests become more common, people must grapple with surprises about their parents. [www.cnbc.com/2017/12/10/dna-tests-can-reveal-paternity-surprises.html](http://www.cnbc.com/2017/12/10/dna-tests-can-reveal-paternity-surprises.html).

Fontana, A. & Frey, J.H. (2000). The interview. From structured questions to negotiated text.

In Y.S. Lincoln & N.K. Denzin (Eds.), *Handbook of qualitative research* (2<sup>nd</sup> ed, 645–672). Thousand Oaks, CA: Sage.

Galas, D. J., Patrinos, A., & Delisi, C. (2017). Notes from a revolution: Lessons from the human genome project. *Issues in Science & Technology*, 33(3), 57-62.

Gavriel-Fried, B. & Shilo, G. (2016). Defining the family: The role of personal value and personal acquaintance. *Journal of Family Studies*, 22(1), 43-62.

<https://dx.doi.org/10.1080/132290400.2015.1020991>.

Geno2.0. [www.genographical.nationalgeographic.com/for-scientists/](http://www.genographical.nationalgeographic.com/for-scientists/).

Girardin, K. M., Widmer, E., Connidis, I. A., Castrén, A. M., Gouveia, R., & Masoti, B. (2018).

Ambivalence in later-life family networks: Beyond intergenerational dyads. *Journal of Marriage and Family*, 3, 768-784.

Gollust, S. E., Gray, S. W., Carere, D. A., Koenig, B. A., Lehmann, L. S., McGuire, Sharp, R.

R., Spector-Bagdady, K., Wang, N., Green, R., & Roberts, J. S. (2017). Consumer perspectives on access to direct-to-consumer genetic testing: Role of demographic factors and the testing experience. *The Milbank Quarterly* 95(2), 291-318.

Government Accountability Office: *Testimony before the subcommittee on oversight and investigations, committee on energy and commerce, house of representatives: direct-to-consumer genetic tests (2010)*, 1-29.

Graf, N. (2019, August 9). *Mail-in DNA test results bring surprises about family history for*

*many users*. Pew Research Center. <https://www.pewresearch.org/fact-tank/2019/08/06/mail-in-dna-test-results-bring-surprises-about-family-history-for-many-users/>.

- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 105-117). Thousand Oaks, CA: Sage.
- Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLoS ONE*, *15*(5), 1-17.  
<https://doi.org/10.1371/journal.pone.0232076>.
- Hammond, H. (2015). Social interest, empathy, and online support groups. *Journal of Individual Psychology*, *71*(2), 174-184.
- Hanson, M. J. & Lynch, E. W. (1992). Family diversity: Implications for policy and practice. *Topics in Early Childhood Special Education* *12*(3), 283-306.
- Harris, A., Kelly, S. E., & Wyatt, S. (2013). Counseling customers: Emerging roles for genetic counselors in the direct-to-consumer genetic testing market. *Journal of Genetic Counseling*, *22*, 277-288.
- Heidt-Forsythe, E. & McGowan, M. (2013). Whose right to know? The subjectivity of mothers in mandatory paternity testing. *American Journal of Bioethics*, *13*(5), 42-44.
- Helgason, A. & Stefansson, K. (2010). The past, present, and future of direct-to-consumer genetics tests. *Dialogues in Clinical Neuroscience*, *12*(1), 61-68.
- Hennick, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code saturation versus meaning saturation: How many interviews are enough? *Qualitative Health Research*, *27*(4), 591-608.
- Hennick, M. M., Kaiser, B. N., & Weber, M. B. (2019). What influences saturation? Estimating sample sizes in focus group research. *Qualitative Health Research*, *29*(10), 1483-1496.
- Hercher, L. & Jamal, L. (2016). An old problem in a new age: Revisiting the clinical dilemma of

- misattributed paternity. *Applied and Translational Genomics*, 8(C), 36-39.  
<https://doi.org/10.1016/j.atg.2016.01.004>.
- Hogarth, S. & Saukko, P. (2017). A market in the making: The past, present and future of direct to-consumer genomics. *New Genetics and Society*, 36(3), 197-208.  
<https://doi.org/10.1080/14636778.2017.1354692>.
- Hogg, M. A., Abrams, D., Otten, S., & Hinkle, S. (2004). The social identity perspective: Intergroup relations, self-conception, and small groups. *Small Group Research*, 35(3), 246-276.
- Hoglund-Shen, A. (2017). Direct-to-consumer genetic testing, gamete donation, and the law. *Family Court Review*, 55(3), 472-484.
- Huang, H. Y., & Bashir, M. (2015). Direct-to-consumer genetic testing: Contextual privacy predicament. *Proceedings of the Association for Information Science and Technology*, 52(1). 1-10. <https://doi.org/10.1002/pra2.2015.145052010050>.
- Huang, M., Huston, S. A., & Perri, M. (2013). Awareness of the US genetic information nondiscrimination act of 2008: An online survey. *Journal of Pharmaceutical Health Services Research*, 4(4). 235-238.
- Hunt, E. (September 2018). 'Your father's not your father': When DNA tests reveal more than you bargained for. *The Guardian*. [www.theguardian.com/lifeandstyle/2018/sep/18/your-fathers-not-your-father-when-DNA-test-reveal-more-than-you-bargained-for](http://www.theguardian.com/lifeandstyle/2018/sep/18/your-fathers-not-your-father-when-DNA-test-reveal-more-than-you-bargained-for).
- Imber-Black, E. (2014). Will talking about it make it worse? Facilitating family conversations in the context of chronic and life-shortening illness. *Journal of Family Nursing*, 20(2), 151-163.
- Imber-Black, E. (1998). *The secret life of families*. New York, NY: Bantam Books.

- Imber-Black, E. (1993). *Secrets in families and family therapy*. New York, NY: W.W. Norton & Company, Inc.
- Institute of Medicine (1994). *Assessing genetic risks: Implications for health and social policy*. Andrews, L. B., Fullarton, J. E., Holtzman, N. A., Motulsky, A. G. (Eds.). Washington, D.C.: National Academy Press.
- International Society of Genetic Genealogy (ISOGG). <https://www.isogg.org>.
- Isaksson, S., Sydsjo, G., Svanberg, A. S., & Lampic, C. (2019). Managing absence and presence of child-parent resemblance: A challenge for heterosexual couples following sperm donation. *Reproductive Biomedicine & Society Online*, 8, 38-46.  
<https://doi.org/10.1016/j.rbms.2019.07.001>.
- Jacobsen, V., Fursman, L., Bryant, J., Claridge, M., & Benedikte, J. (2004). *Theories of the family and policy*. Treasury Working Paper Series.
- Jobling, M. A., Rasteiro, R., & Wetton, J. H. (2016). In the blood: The myth and reality of genetic markers of identity. *Ethnic and Racial Studies*, 39(2), 142-161.  
<http://dx.doi.org/10.1080/01419870.2016.1105990>.
- Kaufman, D. J., Bollinger, J. M., Dvoskin, R. L., & Scott, J. A. (2012). Risky business: Risk perception and the use of medical services among customers of DTC personal genetic testing. *Journal of Genetic Counseling*, 21, 413-422. <https://doi.10.1007/s10897-012-9483-0>.
- Kerr, M. E. & Bowen, M. (1988). *Family evaluation: An approach based on Bowen Theory*. New York, NY: Norton.
- Kimble, M., Sripad, A., Fowler, R., & Sobolewski, S. (2018). Negative world views after trauma:

- Neurophysiological evidence for negative expectancies. *Psychological Trauma: Theory, Research, Practice, and Policy*, 10(5), 576-584.
- Kingsmore, S. F. & Saunders, C. J. (2011). Deep sequencing of patient genomes for disease diagnosis: When will it become routine. *Science Translational Medicine*, 3(87).
- Kirkpatrick, B. E., & Rashkin, M.D. (2016). Ancestry testing and the practice of genetic counseling. *Journal of Genetic Counseling*, 26, 6-20.
- Kivunja, C., & Kuyini, A. B. (2017). Understanding and applying research paradigms in educational contexts. *The International Journal of Higher Education*, 6, 26-29.
- Klug, A. (2004). The discovery of the DNA double helix. In Torsten Krude (Ed.). *DNA: Changing science and society*. New York, NY: Cambridge University Press.

- Knauth, D. G. (2003). Family secrets: An illustrative clinical case study guided by Bowen family systems theory. *Journal of Family Nursing*, 9(3), 331-344.  
<https://doi.org/10.1177/1074840703255451>
- Koch, V. G. (2012). PGTandme: Social networking-based genetic testing and the evolving research model. *Health Matrix: Journal of Law-Medicine*, 22(1), 33-74.
- Koeller, D. R., Uhlmann, W. R., Carere, D. A., Green, R. C., & Roberts, J. S. (2017). Utilizations of genetic counseling after direct-to-consumer genetic testing: Findings from the impact of personal genomics (PGEN) study. *Journal of Genetic Counseling*, 26, 1270-1279.
- Laestadius, L. I., Rich, J. R., & Auer, P. L. (2017). All your data (effectively) belong to us: Data practices among direct-to-consumer genetic testing firms. *Genetics in Medicine*, 19(5), 513-520.
- Leckey, R. (2015). Identity, law, and the right to a dream? *Dalhousie Law Journal*, 38(2), 525-547.
- Lee, S. S.-J., & Borgelt, E. (2014). Protecting posted genes: Social networking and the limits of GINA. *American Journal of Bioethics*, 14(11), 32-44.  
<https://doi.org/10.1080/15265161.2014.957417>.
- Leech, N. L. & Onwuegubuzi, A. J. (2011). Beyond constant comparison qualitative data analysis: Using NVivo. *School Psychology Quarterly*, 1, 70-84.
- Loi, M. (2016). Direct to consumer genetic testing and the libertarian right to test. *Medical Ethics*, 42, 574-577. <https://doi10.1136/medethics2015-102827>.
- Lord, P. (2018). Family health history: Invaluable for adoptees' medical care and self-identity. *Narrative Inquiry in bioethics*, 8(2), 143-149.

- Lowe, G., Pugh, J., Kahane, G., Corben, L., Lewis, S., Delatycki, M., & Savulescu, J. (2017). How should we deal with misattributed paternity? A survey of lay public attitudes. *AJOB Empirical Bioethics*, 8(4), 234-242. <https://doi.org/10.1080/232945515.2017.1378751>.
- Lucast, E. K. (2007). Informed consent and the misattributed paternity problem in genetic counseling. *Bioethics*, 21(1), 41-50.
- Lynch, J., Parrott, A., Hopkin, R. J., & Myers, M. (2011). Media coverage of direct-to-consumer genetic testing. *Journal of Genetic Counseling*, 20, 486-494.
- Ma, H., Zhu, H., Guan, F., & Cherng, S. (2006). Paternity testing. *Journal of American Science*, 2(4), 76-92.
- MacKnight, K.T. (2003). The polymerase chain reaction (PCR): The second generation of DNA analysis methods takes the stand, 20 *Santa Clara Computer & High Tech. L.J.*, 95.
- Mandava, A., Millum, J., & Berkman, B. E. (2015). When should genome researchers disclose misattributed paternity? *Hastings Center Report*, 45(4), 28-36.
- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research*, 11(3).
- May, T. (2018). Sociogenetic risks – Ancestry DNA testing, third-party identity, and protection of privacy. *New England Journal of Medicine*, 379(5), 410-412.
- McGuire, A.L., & Burke, W. (2011). Health systems implications of direct-to-consumer personal genome testing. *Public Health Genomics* 14, 53-58. <https://doi:10.1159/000321962>.
- Mealer, W. F., Singh, D. N., & Murray, S. O. (1981). The social worker's role in genetic counseling. *Journal of the National Medical Association*, 73(12), 1159-1162.
- Meisel, S.F., Carere, D.A., Wardle, J., Kalia, S.S., Moreno, T.A., Mountain, J.L., Roberts, J.S., & Green, R.C., (2015). Explaining, not just predicting, drives interest in personal genomics. *Genome Medicine*, 7(74). <https://doi:10.1186/s13073-015-0188-5>.

- Merriam, S. B. & Tisdell, E. J. (2015). *Qualitative Research: A Guide to Design and Implementation (4<sup>th</sup> ed.)*. San Francisco, CA: Jossey-Bass.
- Miller, V. L. & Martin, A. M. (2008). The human genome project: Implications for families. *Health and Social Work, 33*(1), 73-76. <https://doi.org/10.1093/hsw/33.1.73>.
- Miller-Scarnato, J. (2019). The value of digital video data for qualitative social work research: A narrative review. *Qualitative Social Work, 18*(3), 382-396.
- Miranda, C., Veach, P. M., Martyr, M. A., & LeRoy, B. S. (2016). Portrait of the master genetic counselor clinician: A qualitative investigation of expertise in genetic counseling. *Journal of Genetic Counseling 25*, 767-785. <https://doi:10.1007/s10897-015-9863-3>.
- Moray, N., Pink, K. E., Borry, P., & Larmuseau, M. (2017). Paternity testing under the cloak of recreational genetics. *European Journal of Human Genetics, 25*, 768-770.
- Morgaine, C. (2001). *Family systems theory*. Unpublished manuscript, Department of Child and Family Services, Portland State University, Portland, Oregon.
- MyHeritage. Retrieved from: <https://www.myheritage.com/dna/dna-test-kit>.
- National Association of Social Workers. (2017). NASW code of ethics. <https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Highlighted-Revisions-to-the-Code-of-Ethics>.
- National Association of Social Workers. (2003). NASW standards for integrating genetics into social work practice, 2003. [www.socialworkers.org/practice/standards/genetics](http://www.socialworkers.org/practice/standards/genetics).
- National Human Genome Research Institute. <https://www.genome.gov/19516567/faq-about-genetic-testing/>
- National Society of Genetic Counselors. (n.d.). *NSGC code of ethics*. National Society of Genetic Counselors Policy & Publications. <https://www.nsgc.org/p/cm/ld/fid=12>.

- Nduma, M. & Jewkes, R. (2011). Undisclosed paternal identity in narratives of distress among young people in Eastern Cape, South Africa. *Journal of Child and Family Studies*, 20, 301-310. <https://doi.org.10.1007/s10826-010-9393-4>.
- Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experience of others. *Perspectives on Medical Education*, 8, 90-97. <https://doi.org/10.1007/s40037-019-0509-2>.
- Nielsen, D. E., Carere, D. A., Wang, C., Roberts, J. S., & Green, R. C. (2017). Diet and exercise changes following direct-to-consumer personal genomic testing. *BMC Medical Genomics*, 10, 24.
- North, J., Shadid, C., & Hertlein, K. M. (2018). Deception in family therapy: Recognition, implications and intervention. *Australian and New Zealand Journal of Family Therapy*, 39, 38-53.
- O'Connor, C. & Joffe, H. (2020). Intercoder reliability in qualitative research: Debates and practical guidelines. *International Journal of Qualitative Methods*, 19, 1-13.
- Padgett, D. K. (2016). *Qualitative methods in social work (3<sup>rd</sup> ed)*. Sage Publications.
- Palombi, M. (2016). Separations: A personal account of Bowen family systems theory. *Australian & New Zealand Journal of Family Therapy*, 37(3), 327-339. <https://doi.org/10.1002/anzf.1170>.
- Papero, D., Frost, R., Havstad, L., & Noone, R. (2018). Natural systems thinking and the human family. *Systems*, 6, 19. <https://doi:10.3390/systems6020019>.
- Pappas, S. (2018). Genetic testing and family secrets. *American Psychological Association*, 49(6), 44-50. [www.apa.org/monitor/2018/06/cover-genetic-testing](http://www.apa.org/monitor/2018/06/cover-genetic-testing).
- Parke, R. D. (2000). Beyond white and middle class: Cultural variations in families-assessments,

- processes, and policies. *Journal of Family Psychology*, 14(3), 331-333.
- Pasley, K., Petren, R. E., & Fish, J. N. (2014). Using identity theory to inform fathering scholarship. *Journal of Family Theory & Review*, 6, 298-318. doi:10.1111/jftr.12052.
- Patrinou, G. P., Baker, D.J., Al-Mulla, F., Vasiliou, V., & Cooper, D. N. (2013). Genetic tests obtainable through pharmacies: The good, the bad, and the ugly. *Human Genomics*, 7-17. <https://doi.org/10.1186/1479-7364-7-17>.
- Patton, M. Q. (2015). *Qualitative research and evaluation methods (4<sup>th</sup> ed.)*. Thousand Oaks, CA: SAGE Publications.
- Pearson, Y. E. & Liu-Thompkins, Y. (2012). Consuming direct-to-consumer genetic tests: The role of genetic literacy and knowledge calibration. *Journal of Public Policy & Marketing*, 31(1), 42-57. <https://doi.org/10.1509/jppm.10.066>.
- Phillips, A. M. (2016). 'Only a click away'-DTC genetics for ancestry, health, love...and more: A view of the business and regulatory landscape. *Applied and Translational Genomics*, 8, 16-22.
- Phillips, A. M. (2017). Reading the fine print when buying your genetic self online: Direct-to-consumer genetic testing and conditions. *New Genetics and Society*, 36(3), 273-295. <https://doi.org/10.1080/14636778.2017.1352468>.
- Powell, B. (2017). Changing counts, counting change: Toward a more inclusive definition of family. *Journal of the Indiana Academy of the Social Sciences*, 17(1), 1-5.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). *Screening and counseling for genetic conditions: A report on the ethical, social, and legal implications of genetic screening, counseling, and education programs*. Washington, D. C.: U.S. Government Printing Office [GPO], 1-137.

- Probst, B. (2015). The eye regards itself: Benefits and challenges of reflexivity in qualitative social work research. *National Association of Social Workers*, 39(1), 37-48.
- Quatman, T. (1997). High functioning families: Developing a prototype. *Family Therapy: The Journal of the California Graduate School of Family Psychology*, 24(3), 143-165.
- Ramos, E. & Weissman, S. M. (2018). The dawn of consumer-directed testing. *American Journal of Medical Genetics*, 178(C), 89-97.
- Ravelingien, A. & Pennings, G. (2013). The right to know your genetic parents: From open-identity gamete donation to routine paternity testing. *The American Journal of Bioethics*, 13(5), 33-44. <https://doi:10.1080/15265161.2013.776128>.
- Regalado, A. (2018, February). 2017 was the year consumer DNA testing blew up. *MIT Technology Review*. Retrieved from: <http://www.technologyreview.com/>.
- Regalado, A. (2019, February). More than 26 million people have taken an at-home ancestry test. *MIT Technology Review*. <https://www.technologyreview.com/>.
- Richards, M. (2010). DNA paternity testing, parentage and kinship. Reflections on some tendencies in the UK and in the US. *L'Homme*, 21(2), 101-106.
- Rober, P., Walravens, G. & Versteijnen, L. (2012). "In search of a tale they can live with": About loss, family secrets, and selective disclosure. *Journal of Marital Family Therapy*, 38(3), 529-541.
- Roberts, J.S., Gornick, M.C., Carere, D. A., Uhlmann, W. R., Ruffin, M. T., & Green, R. C. (2017). Direct-to-consumer genetic testing: User motivations, decision making, and perceived utility of results. *Public Health Genomics* 20, 36-45.
- Rogers, R. H. (2018). Coding and writing analytic memos on qualitative data: A review of

- Johnny Saldaña's *The Coding Manual for Qualitative Researchers*. *The Qualitative Report*, 23(4), 889-892.
- Ryan, A., Baner, J., Demko, Z., Sigurjonsson, S., Baird, M. L., & Rabinowitz, M. (2013). Informatics-based, highly accurate, noninvasive, prenatal paternity testing. *Genetics in Medicine*, 15(6), 473-477.
- Saey, T. H. (2018, May). An open book: The stories your DNA can tell are riddled with blank pages. *Science News*. <https://www.sciencenews.org>.
- Saey, T. H. (2018, June). DNA testing can bring families together, but gives mixed answers on ethnicity. *Science News*.  
<https://www.sciencenews.org/article/dna-testing-ancestry-family-tree>.
- Saldaña, J. (2016). *The coding manual for qualitative researchers*. Los Angeles: SAGE.
- Sandhu, D., Singh, B., Tung, S., Kundra, N. (2012). Adolescent identity formation, psychological well-being, and parental attitudes. *Pakistan Journal of Psychological Research*, 27(1), 89-105.
- Saukko, P. (2017). Shifting metaphors in direct-to-consumer genetic testing: From genes as information to genes as big data. *New Genetics and Society*, 36(3), 296-313.  
<https://doi.org/10.1080/14636778.2017.1354691>.
- Samuel, G.N., Jordens, C.F., & Kerridge, I. (2010). Direct-to-consumer personal genome testing: Ethical and regulatory issues that arise from wanting to 'know your DNA. *Internal Medicine Journal*, 40, 220-224.
- Scabini, E. & Manzi, C. (2011). Family processes and identity. In Schwartz, S. J., Luyckx, K., & Vignoles, V. L. (Eds.), *Handbook of Identity Theory and Research*, 569-588. Springer.
- Schild, S. (1966). The challenging opportunity for social workers in genetics. *Social Work*,

- 11(2), 22-28. <https://doi.org/10.1093/sw/11.2.22>.
- Schwartz, S. J., Hurly, E. A., Park, I. J. K., Umana-Taylor, A., Brown, E., Weisskirch, R. S., Zamboanga, B. L., Kim, S. Y., Castillo, L. G., Greene, A. D. (2010). Communalism, familism, and filial piety: Are they birds of a collectivist feather? *Cultural Diversity and Ethnic Minority Psychology, 16*(4), 548-560.
- Seward, B. (2018). Direct-to-consumer genetic testing: Finding a clear path forward. *Therapeutic Innovation & Regulatory Science, 52*(2), 482-488.
- Sherr, L., Roberts, K.J., & Croome, N. (2018). Disclosure and identity experiences of adults abandoned as babies: A qualitative study. *Cogent Psychology, 5*.  
<https://doi.org/10.1080/23311908.2018.1473744>.
- Shriver, M. D., & Kittles, R. A. (2004). Genetic ancestry and the search for personalized genetic histories. *Genetics, 5*(8), 611-618.
- Smart, A., Bolnick, D. A., & Tutton, R. (2017). Health and genetic ancestry testing: Time to bridge the gap. *BMC Medical Genomics, 10*(3), 1-9.
- Smart, C. (2011). Families, secrets and memories. *Sociology, 45*(4), 539-553.
- Smart, C. (2010). Law and the regulation of family secrets. *International Journal of Law, Policy and the Family, 24*(3), 397-413.
- Spears, R. (2011). Group identities: The social identity perspective. In Schwartz, S.J., Luyckx, K., & Vignoles, V. L. (Eds.), *Handbook of identity theory and research* (201–224). New York, NY: Springer.
- Stets, J.E. & Burke, P.J. (2000). Identity theory and social identity theory. *Social Psychology Quarterly, 63*(3), 224-237.
- Sturm, A. C. & Manickam, K. (2012). Direct-to-consumer personal genomic testing: A case

- study and practical recommendations for “genomic counseling.” *Journal of Genetic Counseling*, 21(3), 402-412.
- Sutphin, S., McDonough, S., & Schrenkel, A. (2013). The role of formal theory in social work research: Formalizing family systems theory. *Advances in social work*, 14, 501-517.
- Sutton, J. & Austin, Z. (2015). Qualitative research: Data collection, analysis, and management. *Canadian Journal of Hospital Pharmacy*, 26(3), 226-231.
- Sweeney, K. & Legg, A. M. (2011). Predictors of interest in direct-to-consumer genetic testing. *Psychology and Health*, 26(10), 1259-1272.  
<https://doi.org/10.1080/08870446.2010.514607>.
- Tajfel, H., & Turner, J. C. (1979). An integrative theory of inter-group conflict. In W. G. Austin & S. Worchel (Eds.), *The social psychology of inter-group relations*, 33-47. Monterey, CA: Brooks/Cole.
- Tandy-Connor, S., Gultinan, J., Krempely, K., LaDuca, H., Reineke, P., Gutierrez, S., Gray, P., & Davis, B.T. (2018). False-positive results released by direct-to-consumer genetic tests highlight the importance of clinical confirmation testing for appropriate patient care. *Genetics in Medicine*, 20(12), 1515-152.
- Taylor, D. & Turner, T. (2019, January 10). *How your at-home DNA test results could solve cold cases*. Washington Post. <https://www.washingtonpost.com/science/2019/01/10/how-your-at-home-dna-test-results-could-solve-cold-cases/>.
- Taylor-Brown, S., & Johnson, A. M. (1998). *Social work's role in genetic services*. Washington, DC: National Association of Social Workers.
- Tekin, A. K. & Kotaman, H. (2013). The epistemological perspectives on action research. *Journal of Educational and Social Research*, 3(1), 81-91.

- Thanh, N. C., & Thanh, T. T. L. (2015). The interconnection between interpretivist paradigm and qualitative methods in education. *American Journal of Education Science, 1*(2), 24-27.  
<http://www.aiscience.org/journal/ajes>.
- Tie, Y. C., Birks, M., & Francis, K. (2019). Grounded theory research: A design framework for novice researchers. *SAGE Open Medicine, 7*, 1-8.
- Tillman, K. H. & Nam, C. B. (2008). Family structure outcomes of alternative family definitions. *Population Research and Policy Review 27*(3), 367-384.
- Tracy, S. J. (2010). Qualitative quality: Eight big-tent criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10), 837-851.
- Turney, L. (2005). Paternity secrets: Why women don't tell. *Journal of Family Studies, 11*(2), 227-248.
- Turrini, M. & Prainsack, B. (2016). Beyond clinical utility: The multiple values of DTC genetics. *Applied & Translational Genomics, 8*, 4-8.
- Van der Wouden, C. H., Carere, D. A., Maitland-van der Zee, A. H., Ruffin, M. T., Roberts, J. S., & Green, R. C. (2016). Consumer perceptions of interactions with primary care providers after direct-to-consumer personal genomic testing. *Annals of Internal Medicine, 164*(8), 513-522.
- Vayena, E. (2015). Direct-to-consumer genomics on the scales of autonomy. *Journal of Medical Ethics, 41*, 310-314.
- Vayena, E., Ineichen, C., Stoupka, E., & Hafen, E. (2014). Playing a part in research? University students' attitudes to direct-to-consumer genomics. *Public Health Genomics, 17*(3), 158-168.
- Via, M. (2017). Big data in genomics: Ethical challenges and risks. *Revista de Bioética y*

*Derecho*, 41, 33-47.

- Vrecar, I., Peterlin, B., Teran, N., & Lovrecic, L. (2015). Direct-to-consumer genetic testing in Slovenia: Availability, ethical dilemmas and legislation. *Biochemia Medica*, 25(1), 84-89. <https://doi.org/10.11613/BM.2015.010>.
- Walker, A.H., Njarian, D., White, D.L., Jaffe, J.M., Kanetsky, P.A., & Rebbeck, T.R. (1999). Collection of genomic DNA by buccal swabs for polymerase chain reaction-based biomarker assays. *Environmental Health Perspectives*, 107(7), 517-520. <https://doi.org/10.1289/ehp.99107517>.
- Wang, C., Cahill, T. J., Parlato, A., Wertz, B., Zhong, Q., Cunningham, T. N., & Cummings, J. J. (2018). Consumer use and response to online third-party raw DNA interpretation services. *Molecular Genetics & Genomic Medicine*, 6, 35-43.
- Whaley, G., & McGuire, S. (2018). 23andMe: Future of personal genomics services business? *Journal of Case Studies*, 36(1), 78-96.
- Wheelwright, V. (2014). Adventures in personal genomics. *The Futurist*, 43-45. Retrieved from: [www.wfs.org](http://www.wfs.org).
- White, J. M., Martin, T. F., & Adamsons, K. (2019). *Family theories: An introduction* (5 ed.). Thousand Oaks, CA: Sage.
- Wilson-Lopez, A., Minichiello, P. E., & Green, T. (2019, July). An inquiry into the use of intercoder reliability measures in qualitative research. In *ASEE Annual Conference proceedings*. ASEE. <https://par.nsf.gov/servlets/purl/10089476>
- Wright, L., MacRae, S., Gordon, D., Eliot, E., Dixon, D., Abbey, S., & Richardson, R. (2002). Disclosure of misattributed paternity: Issues involved in the discovery of unsought information. *Seminars in Dialysis*, 15(3), 202-206.

Zhang, S. (July 2018). When a DNA test shatters your identity. *The Atlantic*.

[www.theatlantic.com/science/archive/2018/07/dna-test-misattributed-paternity/562928/](http://www.theatlantic.com/science/archive/2018/07/dna-test-misattributed-paternity/562928/).

ZOOM (n.d.). <https://www.zoom.us/meetings>.

[https://owl.purdue.edu/owl/research\\_and\\_citation/apa\\_style/apa\\_formatting\\_and\\_style\\_guide/reference\\_list\\_electronic\\_sources.html](https://owl.purdue.edu/owl/research_and_citation/apa_style/apa_formatting_and_style_guide/reference_list_electronic_sources.html)